

Barriers to Accessing Care and Services: Consequences for Indigenous Peoples living with HIV and AIDS in a settler colonial nation

Sean A. Hillier¹, Eliot J. Winkler², Meghan Young³, Keith McCrady⁴, Lynn Lavallée⁵

Abstract: Pervasive colonialism has resulted in dramatic health disparities unique to Indigenous Peoples, including the disproportionate burden of HIV and AIDS coupled with a scarcity of culturally competent care, particularly in remote or Northern communities. Twenty-nine First Nations participants partook in storytelling to share their experiences, which were re-crafted into a flowing story of their life's journey. As per Indigenous community partner request, storytelling transcripts were uploaded to NVivo 2017 and coded, uncovering 17 major themes. Ten have been condensed into eight and are reviewed in this work, including: HIV transmission and diagnosis, barriers to treatment & medication, access to services & culture, community, family, education, addictions, and trauma. Participants detailed their intergenerational trauma, the stigma surrounding their HIV status, discrimination from healthcare providers, absence of confidentiality within their community, and geographic and temporal barriers to care. This research confirms the merit of using qualitative Indigenous-based research methods to capture the importance of culturally competent, localized services that address the continuing trauma and negative health outcomes of settler colonialism.

Corresponding Author:

¹ Sean A. Hillier PhD, Associate Professor & York Research Chair in Indigenous Health Policy & One Health; Interim Director, Centre for Indigenous Knowledges & Languages School of Health Policy & Management, Faculty of Health, York University
348A Stong College, 4700 Keele Street, Toronto, ON M3J 1P3
Email: shillier@yorku.ca

Dr. Sean Hillier is a queer Mi'kmaw scholar and a registered member of the Qalipu First Nation. He is an associate professor and York Research Chair in Indigenous Health Policy & One Health the Faculty of Health of York University. He is also the Interim Director of the Centre for Indigenous Knowledges and Languages. Sean sits on the National Interagency Panel on Research Ethics. Additionally, Sean is a Board Member of the Native Canadian Centre of Toronto and the AIDS Committee of Toronto (ACT). His collaborative research program spans the topics of aging, living with HIV and other infectious diseases, and antimicrobial resistance, all with a concerted focus on policy affecting health care access for Indigenous Peoples in Canada. Dr. Hillier has been successful in receiving funding from each of the three federal granting agencies, with more than 10 external grants and is the current Inaugural Associate Director of Connected Minds: Neural and Machine Systems for a Healthy Just Society

² Eliot J. Winkler MSc, Medical Student
Temerty Faculty of Medicine, University of Toronto
Medical Sciences Building, 1 King's College Cir, Toronto, ON M5S 1A8
Email: eliot.winkler@mail.utoronto.ca

Network (OHTN), where he coordinated the OHTN Cohort Study, the largest prospective, longitudinal cohort study of people living with HIV in Ontario. He was a member of the HIV

Eliot Winkler (he/him) is a third-year medical student at The University of Toronto. Prior to entering medical school, Eliot worked as a Research Coordinator at the Ontario HIV Treatment Mental Health Network Steering Committee and was part of the Complex Mental Health and Substance Use Task Group for the Toronto to Zero Initiative. His ongoing research investigates health service use and barriers to care for people living with HIV in Ontario.

³Meghan Young
Executive Director, Ontario Aboriginal HIV/AIDS Strategy
Email: Meghan@oahas.org

Boozhoo Gagina Awiya! Waabishkaa miigwanabikwe nidizhinikaaz. Miskwaadesi nidoodem. Gichiwiikwedong nidoonjibaa. Orillia, ON indaa. My English name is Meghan Young and I am a citizen from the Métis Nation of Ontario, and grew up in Owen Sound, ON. I am from the miskwaadesi (painted turtle) clan, and my family has ties to communities in Lafontaine/Penetanguishene, Parry Sound, and Bawaating. I am currently living in Orillia, ON, which is home to Wawaseyaaguming (Lake Simcoe) and is the traditional territory of the Anishinaabeg.

I have been working in Indigenous social services for over 15 years, specifically in the area of Indigenous harm reduction and HIV/HCV prevention, life promotion (suicide prevention), and mental health and addictions. I have an educational background in Indigenous Studies (BA), and Social Work (BSW). In November 2020, I joined the Ontario Aboriginal HIV/AIDS Strategy (Oahas) team as the Executive Director.

⁴Keith McCrady
Executive Director, The 2-Spirited People of the 1st Nations

Keith McCrady, an Ojibway, Cree, and Two-Spirited individual from the Bear Clan and is Executive Director of The 2-Spirited People of the 1st Nations.

⁵Lynn Lavallée PhD, Professor, and Strategic Lead, Indigenous Resurgence School of Social Work, Faculty of Community Services, Ryerson University Room SHE-697 (6th Floor), 99 Gerrard Street East, Toronto, ON M5B 1G7
Email: lavallee@ryerson.ca

Lynn Lavallee is Anishinaabe registered with the Metis Nation of Ontario. Lynn uses she/her pronouns. She explicitly positions herself in the academy, identifying her family and ancestry because of the cultural fraud that is emerging given opportunities being afforded to people who self-identify as Indigenous. Lynn's maternal ancestry includes the last names of Godon, McIvor, Swain, Lillie, Larocque, Labelle, Lafond and Courchesne from the Red River and Anishinaabe territories of Swan Lake, Maniwaki, Timmins and Sudbury. Her paternal relations include the last names Lavallee, Gauthier, Pepin, Richard, Taylor, McKaye and Champagne from the Metis and Anishinaabe territories of Temiscaming, Mattawa, Sudbury and Algoma.

Lynn completed a Bachelor of Arts in Kinesiology and Psychology, Master of Science in Community Health and Doctorate in Social Work. She started her career as an assistant professor at Toronto Metropolitan University in the School of Social Work in 2005. She has taken on governance and administrative leadership roles including chair of the Research Ethics Board, associate director and acting director of the School of Social Work, senator, and many other service activities all with the focus of advancing Indigenous peoples and knowledges in the academy. Lynn served as University of Manitoba's first vice provost of Indigenous engagement in 2017.

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Introduction

Striking mental and physical health disparities exist amongst Indigenous Peoples because of persistent and unwavering colonial trauma (Mitchell & Arseneau, 2019). One such well-documented severity is the disproportionate burden of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) on Indigenous Peoples when compared to the settler population, particularly in Canada (Bourgeois et al., 2019). In 2021, Indigenous Peoples accounted for 5.0% of the total population in Canada or 1.8 million people (Statistics Canada, 2022). In 2020, Canada estimated there were 6,472 Indigenous People living with HIV (Public Health Agency of Canada, 2022). This represents 10.3% of all people living with HIV. Indigenous Peoples accounted for 10.8% of identified new HIV infections ($n = 1,639$) in 2020, comprising the largest demographic by race/ethnicity for infections in which race/ethnicity data was available (36.1% of cases) (Government of Canada, 2023). According to national HIV estimates, 276 new HIV infections in Canada were Indigenous Peoples, which accounts for 18.2% of all new infections (Public Health Agency of Canada, 2022). There were an estimated 15.2 new infections per 100,000 Indigenous People in Canada in 2020 compared with the estimated four new infections for every 100,000 Canadians. Furthermore, when compared to Indigenous populations in other colonial countries (United States, Australia, New Zealand), Indigenous Peoples in Canada experience the highest rates of HIV (Koehn et al., 2021). However, data is incomplete on the true impact of HIV and AIDS on this population, given significant issues with HIV data collection and reporting.

HIV management has changed from a terminal diagnosis to long-term management of a chronic illness. Of critical importance are widespread testing and diagnosis, swift linkage to care, and regular follow-up visits with sustained adherence to medical treatment. While treatment and supports for HIV/AIDS are widely available today, there remains a lack of culturally safe services for Indigenous Peoples living with HIV/AIDS outside of urban centres. This presents clear barriers for Indigenous Peoples living outside of those centres who will be required to travel for services and may experience discrimination, stigma, and an absence of culturally safe care. Additionally, there is an absence of specific policies in relation to Indigenous Peoples and HIV/AIDS in Canada. This absence is of importance to note due to the exceptionalism of HIV/AIDS as an illness that warrants specific policy creation at the federal level to assist in addressing the rising incidence of HIV within Indigenous Peoples in Canada. The heart of colonisation is policy (Jackson, 2009), a tool used to suppress Indigenous Peoples, whether it be through the creation of residential schools, removal of Indigenous children from their communities and placement in foster care or adoption, or through the forced assimilation and enfranchisement of tens of thousands of Indigenous Peoples (Truth and Reconciliation Commission of Canada, 2015). In the spirit of truth before reconciliation, strong evidence of the disproportionate burden of HIV in Indigenous Peoples (“the truth”) should prompt a federal policy that is developed by and with Indigenous voices to address the challenges to accessing culturally safe care (“the reconciliation”).

This research captures the stories of 29 First Nations people living with HIV and AIDS in Northern Ontario. These stories were used as a snapshot of how their lives in remote communities have been shaped by colonial trauma and HIV, and how the intersection of racism, discrimination, and stigma have contributed to violence, addiction, fear, and hopelessness that

represent significant barriers to culturally safe care for Indigenous Peoples. Amidst these negative outcomes, participants shared their resilience and how, for some, their connection to culture and community has provided them strength to adapt and thrive. Participants spoke of the evident power that came from actively participating in culture and reclaiming their Indigeneity, an undeniable source of inner strength that fuels their resilience and has allowed them to survive, grow, and succeed. This research emphasizes the need to refine existing health policies to address discrimination and intergenerational trauma, and affirms the demand for culturally competent, localized care that utilizes resilience-based models to support and strengthen clients' Indigeneity.

Methods

This research utilizes Indigenous ways of knowing and being as a methodological approach to examine the central question of how and to what extent does policy have an impact upon funding and/or programming, care, treatment, and service delivery for people living with HIV/AIDS in First Nations communities in Ontario, Canada?

This research was conducted alongside Indigenous Peoples living with HIV and was approved by the Ryerson University Research Ethics Board (REB 2015-343). Given the legacy of traumatic research conducted upon Indigenous Peoples, it was essential to give agency to the knowledge conveyed to researchers by participants. Accordingly, this research was developed, directed, and overseen by two community-based Indigenous HIV/AIDS service organisations, who entered into research agreements over ownership, control, access, and possession of the data. Their support included developing the research questions, study questionnaire, recruiting participants, reviewing and contributing to the analysis of the blinded data, and reviewing the findings.

Given ethical and logistical concerns about recruiting HIV-positive people directly from First Nations communities, participants who had been diagnosed with HIV/AIDS and had left their First Nations, now living in urban centres, were sought for participation. Data were obtained by an Indigenous method called storytelling, which places oral history and ceremony at its forefront. All participants sat with the same Indigenous team member and were asked six open-ended questions exploring the impact of HIV/AIDS on their lives, their access to services and treatment, and mitigating factors that may have forced them away from their remote community to urban centres. Twenty-nine diverse First Nations people living with HIV and AIDS participated (for a full breakdown of participant demographics, please see [Hillier, Winkler, & Lavallée, 2021]). All participants had come from a remote/rural northern First Nation in Ontario, Canada however at the time of participation had relocated (temporary or permanently) to an urban centre to access treatment and care.

Participants were offered tobacco as a form of consent, and a \$50 cash honorarium. Tobacco kept traditional medicines, a critical aspect of storytelling, central in the research process. Tobacco is a sacred medicine in many Indigenous communities and is “offered in every ceremony and in many other circumstances. Tobacco is used in funerals, weddings, for praying over and offering food, for picking medicines, for hunting, for thanking people, asking for help, praying for information, and sharing stories” (Struthers & Hodge, 2004, p. 217). Participants who were unaware of the teachings of tobacco were told what accepting tobacco meant and were

guided through the process. Storytelling meetings were conducted, and data were de-identified, with names/pseudonyms chosen by participants during the research process or assigned later by the researcher.

Completed transcripts were uploaded into the software program NVivo 2017 and coded. This process was chosen at the request of the community partners, to better understand (in a quantifiable way) the issues facing First Nations people living with HIV/AIDS. The data analysis process started by reading the transcripts and coding each statement, concept, or idea that emerged from the story, thereby highlighting and labelling them as a ‘node’ within NVivo. Carrying out the coding for this research allowed for the creation of analytical codes and categories from the data. This process uncovered 17 major themes, representing 143 individually coded nodes, the most significant of the themes are discussed below. This article is a portion of a larger research project seeking to understand the effects of policy on funding and/or service delivery for people living with HIV and AIDS in remote First Nations communities in Ontario, Canada. The stories and quotes appearing in this article have been edited only for length and grammar.

Results

Of the 17 major themes uncovered, ten have been collapsed into eight and are reviewed in this work, including: HIV transmission and diagnosis, barriers to treatment & medication, access to services & culture, community, family, education, addictions, and trauma & violence. Other major themes have been previously discussed in [Hillier, Winkler, & Lavallée, 2021] as well as 29 participant driven recommendations that are centered in a strengths-based approach [Hillier, Winkler, & Lavallée, 2020]. Many of the results found within this section were informed by the traumatic experiences of participants, however, the stories focus on promising practices as well as participant connection and re-connection to culture. Previously discussed themes have included the need for culture, resilience & family, and promising practices toward suicide prevention [Hillier, Winkler, & Lavallée, 2021], proving these Indigenous folks are surviving and thriving by strengthening and reclaiming their connection to their cultures and communities.

HIV Transmission & Diagnosis

Every story detailed mode of transmission and/or when participants were diagnosed with HIV, with diagnosis dates represented across four decades. Yvonne described the events around their diagnosis:

...when I first found out that I was HIV there was a big mix up with my status. The lab had screwed up the names and gave another woman my test results and it gave me hers. So, for 30 days I ran around not knowing I had the HIV virus or even what it was...Thought about my children. They didn't know – they still don't know today that I'm HIV...I still can't face the fact that one day I have to tell my children that I am HIV. Soon, I hope.

Eight participants shared the bleak prognoses they were given by physicians when informed of their HIV status. Skywalker states: “The doctor said: ‘you’ve got two years to live, tops. So that was about it’”. All eight participants initially believed they were going to die following their

negative counselling experience with physicians, resulting in persistent unease surrounding the medical system. Blessing Water detailed their reaction to what the doctor told them:

Get your affairs in order. They were speaking in a language of organisational speak that I didn't understand. Even though I was traumatized from some of the PTSD [post-traumatic stress disorder] of my life, I still knew what they were doing to us, it was wrong and could have been done way better.

Participants also spoke of circumstances surrounding their exposure to HIV, including: injection drug use (n=16), heterosexual sexual contact (n=7), men who had sex with other men (n=3), 'risky behaviour' (n=2), via a transplant (n=1), or needle prick (n=1). Three participants shared that sexual assault may have been a factor in acquiring HIV, detailing stories that were graphic and violent in nature. Singing Medicine Water details how abuse in early life sparked their relocation to the city, where they endured a struggle to be accepted for being two-spirited:

We were drunk and that was the first time I ever experienced GHB...I basically blacked out...the bouncer, big fellow, god bless him found me in the washroom being raped by six guys. And yeah, I wasn't even breathing. So pretty traumatic...Something I wouldn't wish on anybody. Because it took something.

Sexual assault for all participants was a traumatic experience that led to multiple coping mechanisms like substance use, further increasing their risk of HIV transmission.

Overall, participants described being shocked, traumatized, scared, depressed, lonely, and self-blaming, often experiencing many of these emotions at once. Six participants spoke of a desire to die upon finding out they were HIV-positive. Only three participants felt supported during the diagnosis process. Support came from outside agencies, friends, or family who helped them come to terms with their diagnosis and purported bleak prognosis.

Barriers to Treatment & Medication

Almost all participants (n=28) discussed barriers to treatment and medication access, including negative, culturally unsafe interactions with healthcare providers. Eight participants noted negative experiences with their doctors, as Nora shared: "He's rough. He's rough with some of us women". Sammy stated: "I don't like my doctor at all. A lot of people have a lot of complaints. . . He's no good, because he doesn't believe in homeopathic medicine". Three participants articulated that their doctors told them to not focus on having children because of their HIV status, with all three expressing discomfort and shock at this advice. Bee Dabum reflected: "I had a bit of an issue with him at first. . .when I was diagnosed and I still wanted to have children and when I brought it up to him, he said you should be focusing on your illness, not having more children. So, I found that was very negative". Eight participants noted a decreased likelihood of attending follow-up appointments or taking the advice of medical staff in response to their negative experiences.

All participants (n=29) noted issues getting access to HIV treatment and medication; including both Western and traditional medicine(s). Participants detailed their restricted choice of

medications, due to limitations on which drugs are funded by Non-Insured Health Benefits (the NIHB program provides eligible First Nations people with coverage for a range of health benefits that are not otherwise covered), resulting in significant side effects that they felt could have been otherwise avoided. Dominique described how it was difficult to access required medication:

My virus was starting to show immunity to the medications that they had and there were no new treatments. There was only this one treatment they have which is called fusion and I would have to inject myself twice a day but that was the only option I had. The problem with it is it wasn't covered [by Non-Insured Health benefits] so they asked me to see if my band will cover it, and they wouldn't cover it. I was on ODSP, so the province wouldn't cover it. I actually had to go to the Chiefs of Ontario and write a letter to them and go get them to lobby for me to get it covered. As a result of that, I did end up getting covered, but I can't say it was through my band.

Of importance, Dominique highlights how they were forced to 'out' themselves as HIV+ to their band, to the Chiefs of Ontario, and to ODSP to simply try and access medications. Others had trouble when they missed doctor appointments and their doctors were unresponsive, reporting periods of time with no access to necessary medications. Four participants discussed being non-adherent to their medications, all describing issues with accessing their doctor for refills or not wanting to be subjected to discriminatory or culturally unsafe care, raising concerns about complications, potential drug resistance, and medical mistrust.

Access to Services & Culture

Twenty-four participants reported currently or previously accessing HIV services. Seven participants discussed positive, supportive experiences in accessing HIV services, which felt like a reprieve from their daily lives. Rick said "I belong to an agency here in the city. So, you know it has a lot of open doors for me. A lot of support, meetings, group meetings and possibly outside training out of town. Just to get away". Bee Dabum shared: "They're an integral part of my life and I'm grateful they exist". Additionally, Brenda stated:

I've been very lucky being around here...there's a lot of agencies for HIV people for food and stuff like that. Some of the agencies they actually, not stigmatize, but some certain ones, they look for the gay men... and there's nothing wrong with that but it's not just always them and woman.

Rick, Bee Dabum, and Brenda all reported they found it easy to access services when they required them.

Culture was an important factor in access to services, with 15 participants having accessed Indigenous-specific services or care for their HIV-status. Participants noted that culturally based services and engaging in cultural activities helped them to heal. Sammy discussed access to a traditional healer and their connection to culture:

I also see a traditional healer which is a medicine man. We have to travel to see him and he gives me medicines and all like homeopathic medicines that I take. . .I go to a sweat lodge. And what that does is you don't necessarily need to sweat you can sit out and it's a sacred fire and you open up around that fire if you're comfortable you open up. Right now, I'm fully traditional, Aboriginal, I believe in the creator and a lot of these sweats and sacred circles. . .And I'm glad they're there because if they weren't there I'd be lost. I find they're important to me because the information I've learnt through them how to get through to where I am today.

Singing Medicine Water spoke of a two-spirited counselor, who helped them cope with their sexuality in addition to their HIV diagnosis:

. . .really gave me a sense of what an honour it is to be two-spirited and she gave me some information on how two-spirited people were and acknowledges medicine and healers. Back in the day, years ago. That our society had put being gay, two-spirited, as a negative thing. So, a lot of people that were two-spirited lost that identity. It's only been recently, the last 15 years that it's really overcome barriers and they've really made a movement. . .I'm Aboriginal, I can be proud to be Aboriginal, I can be proud of having HIV and now that's put it to better use.

While access to traditional services and programs is available to some, there remains a significant gap in the ability for others to access cultural programming. This was highlighted by 19 participants who were forced to leave their communities for care, due to a lack of local HIV services. Mukada Mukaa stated: "It's almost non-existent. Have to leave, even living rural, we have to go to Toronto. We have to drive three and a half hours there just for an appointment". Irene echoed: "Unfortunately there's not [any services]. There never was. And there's probably never going to be. And it's too bad that ya know that we can't have somebody there". Eight participants noted difficulties travelling to required services and treatment. Yvonne discussed going to an outlying city at least once a week for medication and to see a specialist.

We'd have to be like a day trip into town. Just to see the doctor and then drive back again. That's if you have a ride and they don't usually have a medical van that they can transport you. They used to have a bus that used to take people, but they stopped that bus route.

Four participants said that even when they were able to access services, they had negative experiences with providers, ranging from feeling unwelcome to staff being outright unfriendly. Five participants had confidentiality concerns, limiting them from accessing services at all; Irene explains how this prevented them from going back to their community:

I never went back. I haven't been back. I guess in a way it's, a lot of it has to do with ya know, you've got your gossip and all that. Not being able to access ya know our doctors and mentally. Like sure they have counselling but a lot of it's, a lot of confidentiality is broken and ya know like a lot of people don't like to say that but it's the truth. . .It's probably like that in many communities.

Twenty-five participants described 67 individual instances of HIV-related stigma, which led to rejection and violent threats, especially if people learned from others that a participant was HIV-positive. Four participants described violent acts committed against them because of their HIV status, with three stories including homophobia and the assumption equating HIV status with gay identity. Overall, participants felt as though they were second-class citizens in accessing care because of their race, which strongly affected whether they sought care at all.

Family

Twenty-one participants spoke about their family, often rooted in a negative context. Overarching issues of childhood trauma, stigma, rejection, and abuse were present in participants' stories about their families. Many discussed not having a supportive parent, like Charles Hill, whose mother was described as having an alcohol dependency:

My mother is still alive but she's a drunk. She has a job and stuff. She's not a very good mother. I don't know, I love her still. She's got a lot of her own issues. She grew up in CAS [Children's Aid Society]. I'm not sure if she was in a residential school or not.

Little Wolf highlighted their abuse experienced as a child, at the hands of their father who was a residential school survivor:

For me, I was a product of incest. My real father molested me from the time I was four 'till I was 14. I got pregnant by my real dad when I turned 14. My dad and his friends I should say, because my dad and his friends took turns on me all of the time. Me and my youngest brother. My youngest brother hung himself when he was 16. And that's what started me on the drugs anyways. I used to take them because they would take me away... My dad was getting me high on heroin. So ya know and in his eyes, he used to tell me that it wasn't happening. I was imagining it.

Substantially, participants said their parents, many of whom had attended residential schools or experienced some other legacy of colonial intergenerational trauma, led them to substance use. Alternatively, six participants spoke of supportive partners or spouses that helped them accept and handle their HIV diagnosis. Two participants discussed the loss of immediate family members from AIDS-related causes, which was especially challenging considering coping with their own HIV diagnosis.

Community

Many participants (n=24) discussed their community in some capacity. Fourteen participants left their communities due to their HIV-status and issues related to acceptance, fear, or access to treatment and services. Sammy stated: "I wasn't accepted. Nobody liked me. When they heard HIV it was like oh no. It's coming to our community, what do we do? We're all going to get it, we're all going to die". Ten participants, like Elizabeth, had no desire to return to their communities: "It's not remote but it's isolated. If you don't have a car because there's nothing there. So no, I would never go back there. Plus, they don't have the medical and the healthcare, they don't have it". Blessing Otter, like other participants (n=13), deemed their community unsafe due to a lack of healthcare: "The current state of, no it isn't safe. Until the First Nations

health catches up. . .I wouldn't consider moving back to a reservation. They're 25 years behind, minimum".

Four participants made the difficult decision to return home to their communities, which presented challenges. Ray of Sun noted the contrast between feeling safe at home and navigating their community's response to their diagnosis:

I feel safe in my community. Even though they struggle, some people struggle with HIV. It's still hard to face my community. I guess it's because I feel shame ya know but coming home was what I needed to do.

Education

Twenty-five participants stressed the need for greater HIV education, with 22 noting a lack of HIV education on modes of transmission, risk factors, general prognosis, and treatment. Twelve participants discussed this deficit of HIV education and the resulting stigma in their home communities. Ahiga highlighted the misperception that HIV status is equated with a gay identity:

I was talking about my friend in [city] to go do some, some help people over there on the reserve. Up north I'm talking about. To educate the people and tell them. A lot of people they don't know nothing about it... They just think about gay people, ya know. It would be nice if people know about HIV. Well I wasn't comfortable to live there because the people, some of them are pretty dangerous and for my safety ya know. Well my safety for me and my wife. I decided to come to [the city].

Gray Wolf discussed the lack of awareness around HIV transmission:

With my half-brother he tried at that time while he was using to bleach his needles and stuff and trying to keep clean, saying it won't spread or nothing but to this day I'm not really sure that did the trick. They say the clean needles is the safest way not cleaning them [needles that have been previously used].

Blessing Otter emphasized the need for culturally safe, peer HIV education:

Umm done properly? There's plenty of education out there by white middle-aged healthy women, right? Which was basically doing the education at the time I contacted it, so it was probably three layers away from the world I live in. and I'd say that still holds true.

Eight participants had taken part in speaking engagements or conferences to educate others by sharing their stories and lived experiences.

Addictions

Twenty-seven participants discussed personal drug use or drug use by those around them and the impact upon their lives. Brant shared:

I was on the right track, I found out I was HIV-positive, and everything was – I gave up. I was partying thinking I was gonna die right away. So I partied. I thought if I'm gonna die I'm gonna have fun before I die. Because I didn't know what HIV was. I come from a reserve and we don't talk – maybe we have like STDs and talk about it and school and everything, but I didn't know what HIV was.

Like Brant, these participants attributed their substance use as a coping mechanism for the trauma surrounding their HIV diagnosis.

Trauma & Violence

All participants (n=29) described various forms of trauma endured by themselves and their loved ones. Nine participants either directly attended a residential school, or had a parent who attended a residential school, which exposed them to abuse, trauma, and negative coping mechanisms. Singing Medicine Water experienced PTSD from watching violence between their father and mother:

I know my dad was a residential school survivor and was a very angry man. But now that I know that I can understand where he came from because my dad was very abusive to my mom. Even as a baby I have witnessed my dad beating my mom and all I remember is this curdling scream and blood everywhere. And to this day I still have PTSD from that.

Nora noted the personal toll of residential schools:

Right after residential school. I grew up in [city]. I was apprehended from my home after coming out from residential school. In [city] it was very easy for me to get pills. I was dead; valliums, pain pills, I was – at an early age. I even got into the huffing too. Because I ran out of pills, so I need something. And then the drinking came. So that was my way of forgetting. I wanted to forget everything. I – the way – the residential school they've done a lot of damage to me.

Eight participants, all of which described a struggle with addiction, were taken away from their families and communities while growing up.

Additionally, eight participants detailed experiences of violence, mainly domestic violence (n=6). Sammy noted how domestic violence contributed to their drug addiction and sex-work: “How I got into that was I was in a relationship and the relationship I got into with a gentleman who I thought loved me and I loved him, turned sour, turned into violence, like violence and physical.” Violence affected participants' drug use, relapses, and feelings of worthlessness.

Discussion

Colonial policies have enforced and perpetuated this health disparity from an individual-level to the systems-level. Structural violence and colonisation have resulted in rampant intergenerational trauma that has been substantiated by modern epigenetic studies and Indigenous Peoples' stories. This was affirmed by participants in our study, whereby attending residential schools, being taken from their communities, or experiencing violence in their lives robbed them of traditional

family and parental support. Many participants identified their parents as people who used drugs, neglected to take care of them, or abused them, both physically and sexually. Muir and Bohr (2014) argue that “Aboriginal child rearing practices may have been modified because of historical events such as colonialism, residential schools and foster care, and traditional parenting may have been corrupted by this history” (p. 76). As expressed by many participants, the normalization of negative coping mechanisms exhibited by their parents resulted in participants employing these same mechanisms in their lives.

In a national survey conducted between 2008 and 2010, 82% of First Nations respondents reported that alcohol and drug use were the number one challenge for community wellness faced on-reserve (Canadian Centre on Substance Use and Addiction, 2018). It is important to note that, while substance use may be seen as a significant challenge in communities, Indigenous Peoples abstain more from alcohol compared with the general Canadian population (43% vs 20%, respectively) (First Nations Information Governance Centre, 2018; Public Health Agency of Canada, 2016). Many of the participants had addictions to drugs and alcohol, resulting in homelessness and/or the need to perform sex work. Bingham et al. (2019) found that in two Canadian cities, homeless Indigenous participants were more likely to suffer post-traumatic stress disorder, have a lifetime duration of homelessness longer than three years, more severe substance use in the past month, and more infectious disease than non-Indigenous participants. As reflected in this research, these interconnected themes expose Indigenous Peoples to a variety of high-risk activities that dramatically increase the risk of acquiring HIV, most notably intravenous drug use. Many connected their negative experiences to a history of trauma and coping with the acknowledgement that life has been, and continues to be, difficult. Efforts are required to break the cycle of intergenerational trauma experienced by Indigenous Peoples and close the resulting psychosocial and health gaps. Only by eliminating these gaps can we create healthy relationships, reduce negative coping mechanisms, and attenuate the disproportionately high HIV transmission rates seen in Indigenous Peoples.

Participants experienced racism in healthcare settings and within society more broadly, an issue pervasive within the Canadian healthcare system that contributes to avoiding care and treatment (Allan & Smylie, 2015). Racism can be experienced at the structural level as well as at the patient care level (Juutilainen et al., 2014), both of which were experienced by participants in our study. Participants reported negative and rough interactions with physicians, treatment plans centred in Western medicine, a perceived lack of agency surrounding their own care, and a lack of transportation and access to services off-reserve, with the latter previously echoed by Indigenous Peoples living with HIV in Manitoba, Canada (Woodgate et al., 2017). Furthermore, the individuals in our research study reported enduring racism alongside HIV stigma when attempting to access services. Participants expressed the absence of confidentiality and anonymity within their communities, the negative perceptions from those closest to them, the need to ‘out’ themselves in the process of lobbying for medications not covered under NIHB, and the lack of culturally competent, proximally located services. Although participants reported discrimination and unattended health needs within their home communities, recent research stresses the insidious nature of this problem even in large urban centres, with discrimination by a healthcare provider reported by 28.5% of Indigenous adults in Toronto (Kitching et al., 2020). Similarly, Indigenous women in Canada have reported higher odds of a lack or delayed access to HIV care compared to non-Indigenous women (Kronfli et al., 2017). This leaves participants

unable to find the care they need whether at home or traveling to an urban centre. Previous research has documented barriers to HIV care for Indigenous Peoples centred around the social determinants of health, including expenses related to travel and care, transportation to urban communities, and homelessness (Jardine, Bourassa, & Kisikaw, 2021). Our research echoes these findings and underscores the crucial importance of dedicated funding for culturally competent services within and nearby remote communities, and increased competency for existing services in large, urban centres.

Fortunately, a source of strength for some participants was their connection or re-connection to cultural practices and services. Participants reported that meetings with a traditional healer or Two-Spirit counsellor, engagement in ceremonial practices (sweat lodges, fasting, drumming), and sharing their personal stories helped them come to terms with their HIV diagnosis and find strength in their Indigenous identity. Indeed, research shows that although Indigenous Peoples living with HIV in Ontario report more overall, ongoing, and early childhood stressors, their coping and mastery scores remain similar to non-Indigenous participants, suggesting undeniable resilience (Jaworsky et al., 2016). Although the existing policy has contributed to a scarcity of local services, as detailed by participants, there is a persistent need to re-establish a connection to culture wherever possible. Research projects like Stable Homes, Strong Families are finding solutions to provide culturally safe housing to Indigenous Peoples living with HIV, including creating cultural and ceremonial spaces and emphasizing community engagement to bridge existing gaps (Ion et al., 2018). By implementing Indigenous-led healthcare partnerships, we can improve holistic outcomes for those in healing lodges, remote clinics, and urban centres (Allen et al., 2020). This is essential for Indigenous Peoples living with HIV, where culturally competent care and service access will mitigate the discrimination they face and afford them the agency to make informed decisions about their care.

Conclusion

At the macro level today, continuing colonial policy, or the lack of any coherent policy succeeding it, allows for substandard healthcare to be delivered to Indigenous Peoples across Canada, particularly First Nations people living with HIV/AIDS. Canada has no direct policy to combat an HIV/AIDS crisis taking place within Indigenous communities (both urban and rural) in Ontario and beyond. While there are many general policies related to Indigenous health, they have neither the focus nor the funding to deal effectively with this exceptional health crisis. This lack of policy and direction has left First Nations communities with insufficient funds to support the high needs of their community members living with HIV/AIDS, forcing many Indigenous Peoples to have to leave their communities to seek out access to care, treatment, programming, and services in urban centres such as Thunder Bay, Sudbury, North Bay, Toronto, Ottawa, or Hamilton.

Participants discussed the impact of how violence, addictions, abuse and intergenerational trauma contributed to inconsistent access to healthcare services. Given the well-documented lack of funding, having a lack of access to care is unsurprising, especially across the north. Participants detailed a lack of essential services such as testing and follow-up care being available in their communities. Having people forced out of their community due to a lack of services only further strains the system across the rest of the province. Despite leaving their

communities to evade stigma and confidentiality issues, when traveling to urban centres to access care, participants were often met with stigma, discrimination, and culturally unsafe care from providers and support staff. Many participants spoke of their reconnection to culture and the importance of their Indigeneity to their physical, mental, emotional, and spiritual wellbeing and resilience.

This research has demonstrated how a lack of policy and funding is directly tied to treatment, care, services, and programming for Indigenous Peoples living with HIV/AIDS in the province of Ontario. Significantly, while the federal and provincial governments choose to recognize the exceptional nature of HIV/AIDS as an illness in other frameworks, the federal government refuses to address the exceptional nature of the illness for First Nations and Inuit people for which it has responsibility. This research highlights the importance of creating an Indigenous-led federal policy to ensure localized, culturally safe care and community education is created, implemented, and properly funded, to address the disproportionate burden of HIV within Indigenous communities in Canada.

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