Primary Research

Indigenous Women Voicing Experiences of HIV Stigma and Criminalization Through Art

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ABSTRACT

Indigenous women living with HIV are disproportionately affected by the criminalization of HIV nondisclosure. The purpose of this paper is to better understand how the criminalization of HIV nondisclosure shapes the lived experiences of HIV-related stigma, disclosure, and health service among cis and transgender Indigenous women living with HIV (IWLWH). This study was developed based on a community roundtable on HIV criminalization with engagement of legal experts, HIV service organizations, and IWLWH on the unceded traditional territory of the Coast Salish Peoples, including the territories of the x^wməθk^wəyəm (Musqueam), Skwxwú7mesh (Squamish), and Səlilwətał (Tsleil-Waututh) Nations (Vancouver, British Columbia, Canada) in 2016 to 2018. Drawing on community-based participatory photovoice methodology, Indigenous Peer Researchers played a central role throughout this project, including planning, facilitation of photo-voice workshops, and analysis. This analysis includes 17 IWLWH. Through a peer-engaged analysis process, the photovoice images and narratives illustrated how the criminalization of HIV nondisclosure is intertwined with colonial violence to shape experiences of social isolation and exclusion, disclosure, access to safe health care, responsibility, fear, and resilience. The legal requirements of HIV nondisclosure are unattainable for many IWLWH who are not able to safely disclose their HIV status, negotiate condom use, and maintain a low viral load. In line with the Truth and Reconciliation Commission of Canada and National Inquiry into Missing and Murdered Indigenous Women and Girls, the justice system must be reoriented from punishment and oppression to healing and wellbeing for all Indigenous women living with HIV. Simultaneously, we call for culturally safe services that protect privacy and recognize strengths of IWLWH.

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Introduction

For generations, cis and trans Indigenous women living with HIV (IWLWH) have been speaking out, standing up, and taking action for their health and wellbeing. Through Indigenous worldviews, health is understood as holistic and interconnected: inseparable from identity, family, community, place, and spirituality (Bourassa et al., 2005). By means of community consultation including IWLWH, this project draws on community-based participatory research (CBPR) and photovoice methodology, aligned with Indigenous ways of knowing through storytelling. This process facilitates better understanding and space for listening to the experience of IWLWH in the context of stigma and the criminalization of HIV nondisclosure. We seek to inform policy and law reform toward improving health and wellness, and to redress the over-criminalization of IWLWH.

It is well established that stigma, colonialism, and structural factors, such as criminalization of HIV nondisclosure, are important factors propelling the HIV epidemic (Allan & Smylie, 2015; Canadian HIV/AIDS Legal Network, 2005; Reading & Wien, 2009; UNAIDS, 2018). These factors affect every stage of the HIV cascade of care (Jongbloed et al., 2019; Logie et al., 2018). UNAIDS advocates for a 90-90-90 goal, seeking to ensure 90% of people living

with HIV know their status, 90% of those who test positive access treatment, and 90% of those on treatment reach a suppressed viral load (UNAIDS, 2014). Indigenous leaders have questioned who the 10-10-10 represent in this goal and have asked us to pay attention to the acceptance of who is left out from this goal (Denise Lambert, personal communication, December 2017).

Colonialism and systemic racism are structural factors that underpin and validate harm and neglect of Indigenous people (Loppie, 2015). While colonization is often conceptualized as a phenomenon of the past, it is important to understand that it has “shape-shifted to fit the contemporary context” (Kovach, 2009, p. 76). Colonial state violence, such as residential schools and the Sixties Scoop, is replicated by modern colonial practices of child apprehension and foster care, with more Indigenous children in foster care today than at the height of the residential school era (Duff et al., 2014; Kassam, 2017; Martens, 2019). Colonialism is a paramount health indicator for Indigenous people globally, as mediated by structural racism (Czyzewski, 2011; Reading & Wien, 2009). The settler colonial project has created and continues to create poor health for Indigenous and racialized people through coordinated, imposed systems that privilege whiteness and Eurocentric belief systems, including but not limited to the criminal justice, health, education, and economic systems (Allan & Smylie, 2015; Reading & Wien, 2009).

The ongoing effects of colonial state violence and related health inequities are evident in the overrepresentation of Indigenous people¹ among those living with HIV in Canada (Public Health Agency of Canada, 2014). In the province of British Columbia (BC), Canada, between 8% and 17% of new HIV diagnoses are among Indigenous people, while only about 6% of the BC population identify as Indigenous (BC Centre for Disease Control, 2019). Between 2004 and 2008, Indigenous women were 19.7 times and Indigenous men 3.6 times as likely to be diagnosed with HIV as white women and men respectively (Public Health Agency of Canada, 2014). Problematically, there are no data on the number of Indigenous Two-Spirit people, trans women, and nonbinary people living with HIV (Anderson, 2014). Women living with HIV (WLWH) are disproportionately incarcerated, with 76% of participants in a study of 289 WLWH reporting incarceration at some point in their lives, and 17% have experienced incarceration within the past 6 months (Erickson et al., 2020). While the number of women charged with HIV nondisclosure in Canada is low, 42% of those charged identify as Indigenous (Hastings et al., 2017). Therefore, colonialism and white supremacy are root causes of health inequities, including the HIV epidemic among Indigenous and racialized people (Tuck & Yang, 2012).

In tandem with colonialism, stigma behaves by “producing and reproducing relations of power and control” (Parker & Aggleton, 2003, p. 16). Stigma is used to justify domination and systems of inequity (Parker & Aggleton, 2003). One way that structural stigma manifests is through the criminalization of HIV nondisclosure (Krüsi et al., 2018). Canada’s assertive approach to criminalizing HIV nondisclosure, which requires people living with HIV to disclose their status to sexual partners prior to any sexual activity that has a “realistic possibility” of HIV

¹ Note on language: We do not use epidemiological language of “risk,” “vulnerable,” or “target” when referring to Indigenous people in this paper, as this language is weakness-focused, militaristic, and unnecessary (Native Indigenous Youth Council on Sexual Health et al., 2017). Similarly, we do not refer to “our Indigenous Peoples” as this is inaccurate (Montreal Urban Aboriginal Community Strategy Network, 2019).

transmission, results in among the highest number of convictions globally (Canadian HIV/AIDS Legal Network, 2019; UNAIDS, 2012). Condom use or having a low or undetectable viral load does not remove criminal liability for HIV nondisclosure (Canadian HIV/AIDS Legal Network, 2014). This contradicts scientific evidence, which has shown that if either requirement is met, there is a negligible chance of HIV transmission (Barré-Sinoussi et al., 2018; Loutfy et al., 2014). The Canadian government recently issued a federal prosecutorial directive limiting HIV nondisclosure prosecutions if the person maintained a suppressed viral load, used a condom, engaged in oral sex only, or was taking antiretroviral medication as prescribed (Department of Justice Canada, 2018). However, this directive is only binding in territories under federal jurisdiction, including Yukon, Nunavut, and Northwest Territories. A parliamentary committee recently released a report that recommends limiting HIV prosecutions to actual transmission only (House of Commons Canada, 2019). If implemented, this measure would reduce the number of HIV prosecutions in Canada but does not go as far as criminalizing intention to transmit HIV, which is more narrow and aligns with UNAIDS (2013) recommendations.

Gendered structural factors disproportionately impact IWLWH through criminalization (Patterson et al., 2015). Gendered power dynamics, created by colonial destruction of traditional gender dynamics, complicate condom negotiation for IWLWH (Krüsi et al., 2018; Smith, 2012). Evidence indicates that the current approach to criminalization of HIV nondisclosure exacerbates gender-based violence and puts a disproportionate legal burden on IWLWH (Greene et al., 2019; Krüsi et al., 2016; Patterson et al., 2016). When a male partner refuses condom use, IWLWH may experience violence and rejection if they disclose their HIV status; or they face the possibility of prosecution for nondisclosure (Krüsi et al., 2018). The charge of HIV nondisclosure is categorized as aggravated sexual assault, resulting in mandatory listing on the National Sex Offender Registry, despite the intention of sexual assault laws to protect women (Patterson et al., 2015). These laws have been applied disproportionately to women who are Indigenous, or have a history of sex work, illicit drug use, or trauma (Hastings et al., 2017; Patterson et al., 2015).

Using a participatory photovoice approach, this study seeks to better understand the implications of criminalization of HIV nondisclosure for IWLWH, emphasizing structural factors, stigma, colonialism, and resilience.

Methods

This project is part of SHAWNA (Sexual Health and HIV/AIDS: Longitudinal Women's Needs Assessment), a longitudinal CBPR project including over 350 cis and trans WLWH, which focuses on examining the social, political, legal, gender, and geographic gaps in sexual health and HIV care in the unceded traditional territory of the Coast Salish Peoples, including the territories of the x^wməθk^wəyəm (Musqueam), Skwxwú7mesh (Squamish), and Səlilwətał (Tsleil-Waututh) Nations (Metro Vancouver, BC). In line with meaningful involvement of women living with HIV and AIDS (MIWA) and greater involvement of people living with HIV/AIDS (GIPA) principles, this photovoice project is based on a community roundtable with engagement of

IWLWH and HIV service and legal advocacy organizations (Global Network of People Living with HIV [GNP+], 2010; UNAIDS, 2007).

The colonial history of Western research has been largely exploitive and pathologizing, actively reinforcing inequalities between Indigenous and non-Indigenous people (Brant Castellano, 2004; Smith, 2012). Medical and nutritional experiments in First Nations, residential schools, and Indian hospitals are examples of harmful research (Geddes, 2017; Mosby, 2013; Elder Joan Morris, personal communication, 2015). In response to this and in alignment with community priorities, we used a peer-led CBPR arts-based approach to attend to inherent power imbalances of research (Greene et al., 2015). Respect, relevance, reciprocity, and responsibility (four Rs) are critical in Indigenous research, and arts-based methods can facilitate adherence to these principles (Kirkness & Barnhardt, 1991). In this project, the four Rs have been applied by *respecting* the knowledge and ways of knowing of participants who generously shared their experiences; designing the project to be *relevant* to community needs through the community roundtable; building *reciprocity* into the project by prioritizing ways that the community could benefit from the project, such as through advocating for policy change, and producing an exhibit and booklet (Centre for Gender and Sexual Health Equity [CGSHE], 2019); and lastly, fulfilling *responsibility* to the community by following ethical protocols and maintaining confidentiality of participants (Reciprocal Consulting, 2011).

Visual and arts-based methods create space for expression and discussion of difficult experiences. These methods are highly participatory and facilitate active engagement of participants, by allowing more control over how experiences and stories are expressed and giving room to develop counter-narratives (Melendez & Pinto, 2007). Arts-based methodologies are well aligned with Indigenous epistemologies, as they overlap with oral storytelling traditions, which complement Indigenous sciences (Blackstock, 2009; Flicker et al., 2020).

The research team and staff include both Indigenous and non-Indigenous people based on unceded Coast Salish territory. Indigenous Peer Researchers, SHAWNA Positive Women's Advisory Board members (PWAB), and Indigenous-led HIV advocacy organizations were critical in the development of the study protocol, data collection, analysis, and knowledge translation for this project. In 2016, PWAB engaged in a pilot photovoice series and provided feedback to inform the future structure of sessions. Participants were recruited through partner organizations that host support groups for WLWH to facilitate ongoing support for participants beyond the photovoice sessions, which were limited to five or six sessions. For trans participants, there was no existing support group, so participants were recruited through the SHAWNA research project, and the sessions were held one-on-one with the trans Peer Researcher to protect privacy. Overall, five groups participated in a 2-month process of self-reflection and art in 2016-2018. The curriculum was developed collaboratively with the Peer Researcher team, PWAB, and community partners. Workshops were conducted in partnership with support groups to create a safer environment for sharing. Unfortunately, most of these groups have ended due to funding cuts. An Indigenous Peer Researcher co-facilitated each session. Participants received an

honorarium for each workshop (CAD 30), stipend when returning cameras (CAD 20), and travel coverage.

In this paper, we focus specifically on the experiences of IWLWH. Seventeen IWLWH¹ participated across four groups: pilot (5), Indigenous (8), youth (1), and trans (3).² We focus this paper on the experiences of IWLWH to examine the intersections between colonialism and criminalization of HIV nondisclosure.

The lead facilitator (FR) of the pilot, Indigenous, and youth groups planned facilitation around a Medicine Wheel³ model, based on teachings from cultural teacher Robert Kakakaway; this involved attending to participants' mental, spiritual, physical, and emotional wellbeing. Mental wellbeing of the women was cared for through a peer mentoring approach, which included sharing personal experiences and receiving education on the criminal justice approach to HIV nondisclosure. The spiritual quadrant was supported through presence and support by an Elder, and ceremony including smudging, gifting, and sharing of food. While the presence and care of an Elder and the use of smudging is identified within the spiritual quadrant, these were critical to supporting all aspects of health for participants, including the physical, emotional, and mental. In line with Elders' teachings, providing food as sustenance for the participants nourishes a person both physically and spiritually. It recognizes the relationships between the people, the land, and Indigenous traditional food, and connects everyone in a good way. Sharing a meal nourishes relationships, connection, and healing (Robin, 2019). Relationship-building and the peer approach helped to develop trust and comfort with sharing and a supportive environment. Emotional and mental wellbeing was a priority for the facilitator and was supported by the presence of an Elder at the sessions, and peer-led facilitation that created space for emotional support and connection through listening and acknowledging experiences and emotions.

All participants provided written informed consent to participate, and facilitators drew on an "ethics of practice" in which research ethics is an ongoing process, taking into account colonial context, body language, and indications of uncertainty (Smylie, 2000). Recordings were transcribed and returned to the women for editing before inclusion in analysis, facilitating ongoing consent, and ownership and control of data. SHAWNA is the steward for the data. All participants provided written permission for use of their photographs in publications, presentations, and the photo exhibition. The study holds approval from UBC and Providence Health Care ethics boards. All names in this study are pseudonyms that were selected by participants.

Before the photography portion of the project, the facilitators invited participants to create a collage reflecting their experience of criminalization of HIV nondisclosure. Facilitators

¹ The term *Indigenous* spans a diversity of cultures, people, and experiences. While this project highlights the experiences of women who face many challenges, not all Indigenous women have parallel experiences, which an intersectional lens can help us to conceptualize (Crenshaw, 1989).

² The fifth group focused on the experiences of African im/migrant women living with HIV.

³ While the women access social and health services in Coast Salish territory, they identify with Indigenous communities across Turtle Island and draw on teachings from their cultures, such as Medicine Wheel teachings.

described photovoice methodology and HIV-related law, and provided photovoice guidance and tools. The participants selected their most significant photos and shared their meaning through a narrative, which was audio-recorded. The research team collected data through audio recordings, transcriptions of photo and collage narrations, and images of art (collages and photographs).

The analysis integrated both an iterative CBPR approach and an Indigenous analysis approach (Bird-Naytowhow et al., 2017; Castleden et al., 2008; Kovach, 2009; Tremblay et al., 2018). The broad analysis steps were as follows: (a) photo selection, in which participants identified photos that were most representative of experiences in relation to the research question; (b) contextualizing, in which participants provided a narrative describing the meaning of their selected photos; and (c) codifying, through an iterative process of participatory thematic analysis (Tremblay et al., 2018). Peer Researchers led the analysis, which drew on a structural determinants framework that centred on the influences of colonial violence and resilience. To facilitate the coding process, visual and narrative data were organized in NVivo (Version 12). Peer Researchers highlighted significant stories, themes, and images to shape the analysis; this process included conversations, discussion of analysis frameworks, and workshopping visual representations of the research findings.

Results

“An Inbred Kind of Fear”: Interlocking Experiences of Trauma, Loss, Fear, and Criminalization

To understand the impact of the criminalization of HIV nondisclosure on cis and trans IWLWH, it is necessary to contextualize participants’ experiences within ongoing colonialism. In giving voice to images depicting experiences of HIV-related stigma and criminalization, many of the participants described interlocking traumas rooted in Canada’s colonial past and present, including the following:

- being separated from their children
- fears of transmitting HIV to a child or partner
- historical trauma caused by systemic destruction of governance systems, culture, traditions, language, and healing practices
- dislocation from territory
- physical, emotional, and sexual violence
- HIV diagnosis
- HIV disclosure without consent
- social isolation because of HIV
- illicit substance use
- stigma
- criminal justice system involvement

Participants’ narratives highlighted that experiences of criminalization of HIV nondisclosure formed an additional layer of trauma and fear, building on, and for some

exceeding, existing traumas and fears. This was highlighted by Lyn (Indigenous group), who asserted, “I was more afraid of the law than having HIV.”

Several participants described their HIV diagnosis as a highly traumatizing experience; this was especially pronounced for IWLWH who were diagnosed before the advent of effective HIV treatments. Many recounted their diagnosis leading to suicidal ideation. For example, Ginew recounted, “I wanted to go and get hit by the first bus that went by,” and Lyn described wanting to jump out of a window, highlighting intense stigma and fear related to diagnosis.

Additionally, many participants voiced experiences of state violence through child apprehensions. Both HIV diagnosis and separation from children stood out in participants’ narratives as highly traumatic experiences and were intertwined with the threat of the criminalization of HIV nondisclosure, yet another form of state violence.

Having an Elder and peer support present created a supportive environment for participants to explore and reflect on difficult experiences and feelings. Anne reflected on her experience with the photovoice sessions:

A lot of emotions brought up a lot of fear, but I’ve dealt with things that I’ve been able to deal with because I’ve faced them. Which I can [now] put a name to what I was scared of—before it was just an inbred kind of fear of all-around stigmatization. (Anne, Indigenous group)

The theme of interlocking experiences of trauma, loss, and fear was interwoven with the crosscutting theme of colonialism, which constructs these experiences, in part through criminalization of HIV nondisclosure, but also through state intervention rooted in colonial violence, such as child apprehensions and the disproportionate criminalization and incarceration of Indigenous women (Allan & Smylie, 2015). Gracie (Figure 1) explains the metaphors in her images, which relate to themes of colonialism, trauma, and discrimination, but also resilience and liberation from colonial violence and governance.

Figure 1

Gracie’s Photo

Note. The bars represent jail. And on the other side, there's a big tree—that's me. But half of me is still here. So, for me that would be discrimination... I'm a First Nations woman, and I stand up for myself because we get discriminated against a lot—as a First Nations people and as people living with HIV. Once we're free and standing up for women, like it should be, we turn into butterflies. [They represent] freedom and beauty. To me [these pictures] are about my culture. When I look at my pictures I think about the Prairies, and about pow wows and fancy dancing. (Gracie, pilot group)

“I Was Just All Alone”: Social Isolation and Exclusion

HIV disclosure is complex and ongoing, situated within social location and relations. If and when to disclose HIV status is impacted by the nature of relationships and the likelihood of stigma, violence, or loss of reputation (Krüsi et al., 2018; Moyer, 2012). There was a strong link between participants' narratives of social isolation, stigma, and the criminalization of HIV nondisclosure; for example, several women described avoiding relationships so that they would not have to disclose their HIV status to a new partner. Many participants recounted being ostracized by their families once they disclosed their HIV status. In response to or in anticipation of fear and rejection, many participants chose to self-isolate. The narratives of CeeCee, Laura, and Ginew highlight the severity of social isolation:

The isolation is so real. I isolated myself, two, three years when I came here. Nobody knew I had it [HIV], so I'm safe here in BC. ... I'm not looking for anybody, so I don't have to ever share that secret. (CeeCee, Indigenous group)

And, like a puzzle, I don't know where I fit. (Laura, Indigenous group)

I was alone and nobody called. They didn't—nobody wanted to hug me or shake my hand or anything. (Ginew, Indigenous group)

These narratives highlight participants' struggle to find connection and acceptance. Linked to colonization and displacement, Betty Boop described having to leave her rural community and experiencing lateral violence after HIV diagnosis:

I had to leave my community, my family, everything behind, when I became positive. My family was being talked about very negatively, because of me being positive. To save them any more stigmatization from the community, I left. I left behind everybody. (Betty Boop, pilot group)

Participants' narratives further highlighted the link between gender-based violence and HIV disclosure. Many participants highlighted that staying in an abusive relationship was linked to fear of disclosing their status and feeling isolated from their support networks. For example, Ginew explained how the interconnection between social isolation and stigma contributed to her staying in an abusive relationship:

I told my sister [about my HIV status] and of course she went blabbing it all over to the family. And everybody denied me. They wouldn't come visit or anything. They wouldn't phone. ... It was like I was alone in a jar. No family, no help. I was just all alone and all I had was my baby and my abusive ex. (Ginew, Indigenous group)

Ginew's narrative demonstrates how social isolation can magnify experiences of gender-based violence and abusive relationships. For trans participants, stigma and social isolation were also closely linked to discrimination based on gender identity and presentation. Kaya described feeling traumatized and excluded after being invited to speak at a school event, but was later rejected based on her gender identity. Kaya's experience of rejection highlights how trans IWLWH live with additional layers of stigma, misgendering, and discrimination, which further exacerbate social isolation and exclusion.

While there were no existing support groups for trans WLWH, many IWLWH highlighted support groups as important spaces to release HIV-related shame and connect with others, countering social isolation with connection. Anne described what it was like to attend a support group:

I was able to talk and make new relationships. ... I found the key to unlock what I felt like a sentence you know, I felt like I found the key so that I could talk about it [HIV], and not be ashamed anymore. (Anne, Indigenous group)

“Our Safety Is Null and Void”: Disclosure, Violence, and Privacy

Disclosure of HIV status often led to social isolation, violence, possibility of criminalization, trauma, and emotional suffering. This is particularly challenging in instances when women's HIV status is disclosed without consent, which was the case for many participants, pointing to severe breaches of privacy. Several women shared experiences of being outed by social service and health care staff. Anne photographed the entrance of a health centre she had visited, and shared this story:

My lab results or the fact that I'm getting tested is getting yelled across [the health clinic] and my medications blatantly left on a table. People get nosy, want to know what's this and that. And I just feel like [privacy] wasn't being upheld. (Anne, Indigenous group)

Anne's abusive ex-partner confronted her when he found out that she was living in HIV-specific housing:

He said, “Oh, because I looked on the internet and [your address] is for people with HIV.” I just broke down because I wanted to deny it, but it's true. Of all people, it was somebody who ... in our previous relationship tried to kill me, and pulled a knife in front of the children. So our safety is null and void. ... He went and told everybody in my community. ... I just kind of fell into the shadows. (Anne, Indigenous group)

Parallel with many other women, Anne struggled with being outed by living in HIV-specific housing, and accessing HIV-specific services. This violated her privacy, severely compromised her safety given the history of abuse she and her family had endured, and could lead to prosecution. Anne's narrative highlights how HIV-related stigma and the potential for criminalization and abuse are closely connected and exacerbate the violence and injustice faced by IWLWH at the hands of the state, in the context of service access, and from intimate partners. Laura (Figure 2) felt stigmatized when her family members required that she use separate dishes, highlighting continued misinformation and HIV-related stigma.

When disclosing their HIV status, IWLWH face the possibility of rejection or violence. For example, AEM waits until emotional attachment is developed in a new relationship before disclosing that she is living with HIV:

I waited a month or two into the relationship and then I told, because then they were attached somewhat to me emotionally. ... I would bring a weapon and I'd make sure I wasn't inside my house. I'd talk to them outside. (AEM, Indigenous group)

Figure 2

Laura's Photo

Note. Okay, this is a photo of the dishes, part of the stigma that was against me. When I was at my youngest sister's place, her husband made me use my own dishes because they said I have a sickness, so I couldn't use the house dishes. I only had to use one set only. And so that didn't feel right, but I had nowhere else to live so I had to follow their rules. I had to wash my own dishes and put it by my bed. (Laura, Indigenous group)

Cee Cee fears violence, and possible death, when disclosing her status. These narratives emphasize the profound fear IWLWH face when disclosing their status and the immense burden placed on IWLWH through the criminalization of HIV nondisclosure.

Lily photographed a phone to represent disclosure and shared her experience as a trans woman who has struggled with disclosing her status. With both romantic and nonromantic

relationships, Lily feels obligated to share “everything that I’m carrying through my life,” and show “all the different cards,” including answering invasive questions about transitioning and living with HIV. Disclosure is an emotionally exhausting process, which she lacks support with (Figure 3). These narratives shed light on the complexity of disclosure and experiences of structural violence for IWLWH, which is exacerbated by the criminalization of HIV nondisclosure.

Figure 3

Lily’s Photo

Note. I took a picture of a phone, and what the phone represents to me is how I have to communicate my status every time I meet someone. I feel like that’s something that I’ve had to develop and learn along many years, because it was difficult for the first while ... and I really had a tough time, and I needed a lot of support. And a lot of times I didn’t have the support.
(Lily, pilot group)

“It’s Kinda Shady”: Knowledge and Education on HIV and the Law

Most of the women spoke of a lack of access to information on HIV and the law. Gaps in knowledge from health professionals, family members, the public, and the participants themselves led to many experiences of stigma, trauma, and fear. Many women described experiencing stigma and discrimination in health care settings when trying to access services, which are important for their health and wellbeing (Figure 4).

Participants’ narratives show that there is a lack of information for IWLWH about the evolving legal context around HIV nondisclosure. Many participants expressed gratitude for the opportunity to learn about HIV-related laws. Bambi’s picture represents how “murky” the definitions around the legal obligation to disclose her HIV status are (Figure 5). These narratives indicate that there is a critical need for culturally appropriate and accessible information about criminalization of HIV nondisclosure; this is desperately needed for social service and health professionals, families, people living with HIV, and the general public.

Figure 4*Lyn's Photo*

Note. It was so long ago I think, like 30 years ago. ... The people in emergency didn't know much about HIV. I think I was like—you know, touching you they'd—touching you would make them sick or whatever. And they made me feel so awful. That was the worst time I ever felt in my life that I can remember. And they didn't—I had pneumonia. I went in there. I didn't know I had HIV. I didn't even know what the hell it was until—I was wondering why they were treating me like that until I found out. And then when I took this picture, it brought that feeling back, just about. Like there was a knot in my stomach, you know, just remembering. (Lyn, Indigenous group)

Figure 5*Bambi's Photo*

Note. *All the blurriness represents how murky the definition of what exactly the law is or what specific grounds you can be criminalized. It's still very uncertain, very up in the air, it's kinda shady.* (Bambi, trans group)

“Learning the White Ways”: Responsibility

Responsibility formed a prominent theme in photographs and narratives; this involves taking care of oneself and others, through medications, regular checkups, healthy eating, condom use, and maintaining a low viral load. In addition to the biomedical responsibilities that come with living with HIV, the law contributes additional responsibility by requiring HIV disclosure in the context of sexual relationships when there is not both a condom used and a low viral load.

Participants' narratives indicated that women, at times, faced significant challenges in maintaining regular treatment and a low viral load in order to meet the legal requirements for nondisclosure. These challenges include a lack of culturally appropriate health care, stigma, and, as outlined above, potentially being outed by accessing HIV-specific support services.

Several participants photographed condoms and pills and described the legal responsibilities that come with living with HIV. Condom negotiation is a complex and gendered issue, which is not easily navigated to follow the law. Even if both partners agree to condom use, there is often little control for IWLWH on whether one is used. If a partner refuses condom use, it forces disclosure and often leads to violence. Additionally, for many participants the colonial sentiments and traumatic experiences associated with Western medicine constituted a barrier to maintaining a low viral load. Many participants had complex relationships with HIV treatment for this reason. Cee Cee and J reflected on their relationship with Western medicine:

I wish I had more time to learn the teachings, the proper teachings. That's the thing I miss the most is losing my culture. And then having this HIV, you have to learn the white ways and do all the things they ask you to do. (Cee Cee, Indigenous group)

This is a picture of me holding my pills. ... They are little but they have such a big control over my life. (J, youth group)

J has been living with HIV since birth. In addition to having a challenging relationship with antiretroviral drugs, she described feeling silenced and controlled by family and social workers, connected to colonial control of IWLWH: “[They] didn’t want me to tell people [that I am living with HIV]. ... I felt like I was silenced. Sometimes you’re unhappy but you still smile ... there’s little young me inside and, sometimes she’s sad.”

IWLWH commonly experience over-surveillance by health professionals, police, and the law. During this project, Lolita was questioned by police when photographing a police car and a pharmacy, both objects she chose to represent her experience with the criminalization of HIV nondisclosure. Similarly, when photographing a courthouse Lolita was questioned by sheriffs and security guards. This highlights the constant colonial surveillance and racism Lolita experiences as an IWLWH with a history of drug use.

Responsibility for IWLWH relates to colonialism, in that the responsibilities to meet the legal requirements of nondisclosure are forms of structural violence, control, and punishment by the colonial government on IWLWH and their bodies.

“It’s Like Magic”: Resilience

While the women face many challenges in their lives, there is also a great deal of resilience and strength. Kaya (trans group) described her relationship with HIV: “Becoming HIV positive has been one of those things I regret. Saying that, I also wouldn’t be where I am today if it wasn’t because of being HIV positive.”

The Elder told the women in the Indigenous group that they have gifts and they should be shared. The support and the photo sessions shifted how many participants viewed themselves, now as worthy, knowledgeable, and carrying gifts. Many women found the photovoice sessions to be uplifting, like Lyn (Indigenous group): “What I wanna leave here is the hurt and pain, and what I wanna take with me is the security I found here. These past couple hours, it just—it’s like magic.”

The resilience of the women was described by the lead facilitator (FR) as aligned with the Medicine Wheel understandings of emotional, spiritual, mental, and physical balance. The emotional was reflected in unconditional love sometimes received by family members, countering the social isolation described earlier, such as Anne’s (Indigenous group) description of her son’s response to learning her HIV status: “My son just said that he loved me ... for him to say that, meant a lot. It rubbed out all the negative phone calls that I got from people.”

For spiritual strength, support for many participants came from social connection through support groups, culture, prayer, and ceremony (Figure 6).

Many participants nourished their mental resilience through the process of sharing stories, creating art, and connecting with others. Lyn found the collaging to be difficult at first, but then validating:

It was upsetting because I was going through a lot of memories, a lot of stuff that’s to do with having HIV and the shame. And it was just scary. It brought back a lot of stuff, and I had to sit for a while and stop, and then I continued on and then I realized how far I’ve come. (Lyn, Indigenous group)

Lastly, physical resilience and strength came from effective treatment, feeling healthy, sweats, pow wows, and dance. Despite many barriers to accessing these supports, the IWLWH are strong and resilient, emotionally, spiritually, mentally, and physically (Figure 7).

Figure 6

Betty Boop’s Photo

Note. *I'm [from a Northern First Nation]. That's what the eagle symbolizes for me. And also in my photo are a bear and a salmon, and our culture is serving anybody. Everybody is welcome, to partake of a meal, and nobody is shunned, and that's what the salmon symbolizes.* (Betty Boop, Indigenous group)

Figure 7

Cee Cee's Photos

Note. *My pictures are a combo. The heart-shaped frame represents the hope of the sunlight and capturing the love in there. There are the lights of a fire truck, and that's the emergency—the call of the importance of the issue of HIV criminalization in our daily lives. ... And it's the story of us. And that's pretty powerful in itself, meaning all us people that deal with what we live with on a daily basis. All our stories need to be told. Then there is a picture of bars—incarceration,*

the law. This is where we potentially end up or will end up if we don't adhere to the law. And then the final picture brings us back to the balance of who we are as Indigenous women walking this earth, the path, our traditions that keep us bound together. And what all keeps us together is this little symbol of the HIV. (Cee Cee, Indigenous group)

Strengths and Limitations

The Medicine Wheel model brought balance and harmony to the sessions; it guided the lead facilitator (FR) with caring for the women in a good way, protecting them, and honouring their stories. This is reflected in the regular attendance, where the women were committed to gathering. Through the ceremony of storytelling, the lead facilitator shared with the participants that she brought 20 years of experience navigating nondisclosure and stigma, which was significant for participants. The presence of the Elder, arts-based approach, and sharing of food were also important components which created space for listening to the voices of IWLWH. In terms of limitations, these findings focus on a small group of IWLWH and do not represent experiences of all IWLWH. Further research on this topic would benefit from an increased emphasis on Indigenous research methodologies to strengthen cultural safety (Arsenault et al., 2018). Additionally, the inclusion of the resilience theme could be introduced earlier in the research to encourage IWLWH to share their reflections on strength.

Discussion

The findings of this participatory photovoice study highlight how HIV stigma and criminalization shape the experiences of IWLWH and demonstrate how the criminalization of HIV nondisclosure constitutes an additional layer of state-perpetrated colonial violence and control over the bodies, minds, and spirits of IWLWH. In addition to experiences of HIV-related stigma and criminalization, participants faced complex trauma rooted in Canada's colonial past and present, including child apprehension and displacement from their home communities and culture. This trauma parallels residential school experiences, where Indigenous people were separated from their families, cultures, and communities, and forced to assimilate to Western ways, with a high level of surveillance. In a finding resonating with previous work (Cain et al., 2013; Logie et al., 2011), social isolation was exacerbated by HIV-related stigma and linked to experiences of gender-based violence. Accessing culturally safe HIV support services was out of reach for most participants, and rather than having their privacy protected, many participants recounted experiences of having their HIV status disclosed without consent. Many IWLWH experience disclosure of their status without their consent, through social and health services, family, and partners, which has been linked to numerous negative impacts including increased risk of prosecution and violence (Barreto et al., 2018, Krüsi et al., 2016). This resonates with existing research that has highlighted the disproportionate experiences of violence, stigma, and breach of privacy WLWH experience (Kennedy et al., 2015; Krüsi et al., 2016).

Mirroring previous research that highlights the need for culturally safe services (Jongbloed et al., 2019) and culturally accessible information on HIV and criminalization of HIV nondisclosure (Patterson et al., 2017), participants' narratives indicate that there is a critical need for culturally appropriate and accessible information about criminalization of HIV nondisclosure. This information is urgently needed for social service and health professionals, families, people living with HIV, and the general public. While trauma, violence, and fear were prominent themes in this study, participants also used photographs and narratives to highlight finding strength through connection, culture, and community. It is important to note that these findings are not new knowledge, but a reflection of knowledge already held by IWLWH (Blackstock, 2009).

Conclusion

Participants shared experiences of complex traumas, social isolation, lack of access to culturally appropriate HIV services and information, and—despite all of this—significant strengths. The legal requirements of HIV nondisclosure are unattainable for many IWLWH who are not able to safely disclose their HIV status, negotiate condom use, and maintain a low viral load. The colonial responsibilities faced by IWLWH are focused on Western medicine, disregarding Indigenous healing practices, ceremony, and worldviews.

Our findings highlight the need for culturally safe services that protect privacy and recognize strengths of all Indigenous women. Furthermore, our results emphasize that criminal law is not well equipped to consider the gendered power dynamics of HIV disclosure and should not be used as a governing tool of HIV prevention. Indigenous systems of knowledge sharing, justice, and wellness continue to be disrupted by colonialism, which created intergenerational traumas and related shame around sexuality and bodies. The Canadian justice system must be reoriented from punishment and oppression of IWLWH to healing and wellbeing in alignment with Indigenous traditions, laws, and governance. This stance is in line with the Truth and Reconciliation Commission of Canada (TRC, 2015)¹ Calls to Action and the National Inquiry into Missing and Murdered Indigenous Women and Girls² (NIMMIWG, 2019) Calls for Justice. Specifically, our findings support the TRC Calls to Action to implement Aboriginal health care rights (18), value Aboriginal healing practices (22), and eliminate the overrepresentation of Aboriginal people in custody (30). Similarly, our findings echo NIMMIWG Calls to Justice that call for the removal of barriers to accessing culture (2.3), support rights to health and wellness (3.1), fund and support accessible, community-based, Indigenous-led health services (3.2), provide access to culturally grounded trauma-informed care (3.3), and address over-incarceration of Indigenous women (5.14). Further, the Calls to Justice stress that police and the courts system

¹ The TRC involved a multiyear process to listen to those impacted by the residential school system, where children were forced from their families and experienced extensive traumas, including neglect and physical and sexual abuse.

² The Calls for Justice were developed as one result of the NIMMIWG, which examined the systemic causes of all violence, including sexual violence, against Indigenous women, girls, and 2SLGBTQIA people. This involved building understanding of the social, economic, cultural, and institutional causes of the ongoing violence.

must acknowledge their roles in historical and ongoing colonialism (9.1) and ensure options for decarceration (14.1).

For more transformative responses to the health and justice needs of IWLWH, pathways forward include centering of Indigenous approaches to healing and justice, and providing space for collective healing and sharing. In alignment with the TRC and NIMMIWG, such responses involve community-based HIV and wellness education and supports, building connections to land and language, knowledge sharing, and traditional justice processes.

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