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Indigenous Resilience and Allyship in the Context of HIV Non-Disclosure Criminalization: Conversations with Indigenous People Living with HIV and Allies Working in Support of Community

Emily Snyder and Margaret Kîsikâw Piyêsîs¹

ABSTRACT

This article examines the strengths of Indigenous people living with HIV, and of the people working in support of this community, in the context of the criminalization of HIV non-disclosure. Although there are many challenging and difficult realities related to HIV criminalization, here we focus on Indigenous resilience to center Indigenous perspectives and to challenge settler colonialism. This discussion stems from 26 interviews that were part of a community-based case study on HIV criminalization. Participants included Indigenous people living with HIV, and Indigenous people (and one non-Indigenous person) not living with HIV, who we are referring to here as allies. Strengths were seen in both Indigenous people living with HIV and in the allies working to support the community. When brought together, their responses illustrate the importance of non-judgment and inclusion, community pedagogy as a practice of self-determination, honouring healing and supporting others, and centering Indigenous approaches to HIV. While it is crucial to center Indigenous people living with HIV, we argue that there is also value in including allies in Indigenous HIV research. Those allies, which included Elders, brought different perspectives to this research, and demonstrated a relational form of allyship or what we are referring to as allyship through kinship.

Keywords: Resilience, allyship, HIV non-disclosure, criminalization of HIV.

¹ This research was funded primarily through an Urban Aboriginal Knowledge Network grant, which was funded through the Social Sciences and Humanities Research Council of Canada. Funds from the University of Saskatchewan were also used to support this research.

INTRODUCTION

“Every person has a purpose on this Earth. We weren’t created to be down in the dumps, you know? We weren’t created - I’ll tell my kids, ‘We’re not created to be like a rug on the floor and be stepped on and people to wipe their feet off.’ I said, you know, ‘We are somebody.’ I said, ‘We’ve been created to be someone’”

– Old Lady Buffalo.²

People living with HIV and AIDS have long been subject to judgment, including unjustly facing dehumanization from a number of sources – the media (Mykhalovskiy et al., 2016; Kirkup, 2015), the legal system (Hastings et al., 2017; Adam et al., 2016; Dej & Kilty, 2012; Grant, 2008), social services, healthcare (Goodman et al., 2017; Logie et al., 2011), and also from family, friends, and people in one’s own community who misunderstand HIV. Although there have been important shifts in public understanding of HIV, and there have been significant medical advancements since the 1980s, criminalization of HIV persists. *Yet it does not go unchallenged.*

In Canada, criminal law is used to intervene in situations where not disclosing one’s HIV status prior to sex could create a “significant risk” for a sexual partner. The use of criminal law has become increasingly punitive with people most often being charged with aggravated sexual assault (Hastings et al., 2017; Dej & Kilty, 2012). Due to pressure from HIV advocates, in 2018, the Canadian Attorney General issued a directive to not use sexual offenses for non-disclosure (Canadian HIV/AIDS Legal Network, 2019). While this announcement was a positive step against HIV criminalization, concerns remain that further change is still needed, that it is up to each province to take up this federal directive (or not), and that there is still confusion about if and how this change will be implemented (Canadian HIV/AIDS Legal Network, 2019).

Overall, significant concerns remain that Indigenous people have been under-acknowledged in the Canadian government’s response, and, more generally, have been marginalized in policy responses and in research on HIV non-disclosure (for exceptions: Greene et al., 2019; Hatal et al., 2018). These are troubling omissions because Indigenous people have distinct experiences with the Canadian legal system (Monchalin, 2016; Richardson et al., 2009) and have distinct HIV experiences, including disproportionately high infection rates. These experiences are directly correlated to the social circumstances created and reproduced through settler colonialism, which directly undermines Indigenous well-being (Hatal et al., 2018, 1100; Prentice et al., 2018; Hawkins et al., 2009; Barlow, 2009; Pearce et al., 2008).

In 2017 (prior to the federal directive), we carried out a research project examining the impacts of Canada’s non-disclosure laws on Indigenous people living with HIV in Regina, Saskatchewan. Participants included Indigenous people living with HIV and HIV negative Indigenous allies (with the exception of one non-Indigenous ally). We wanted to understand the experiences of people who are HIV positive and wanted to examine how those working in support of Indigenous people living with HIV engaged with this legal context. As detailed in a policy report (Snyder, 2018), the findings from the research make clear that Indigenous people living with HIV have distinct experiences with the criminalization of non-disclosure and that

² This is the pseudonym used for one of the Elders in our research.

there is a need for more supports. There was a notable fear of unjust incarceration, negative impacts on sexual relationships, evidence of and concerns about gendered violence, evidence of and concern about discrimination from police, and an understanding that people will be criminalized for being both Indigenous and HIV positive. Yet Indigenous people living with HIV did not passively accept criminalization and neither they, nor the allies, accepted the impacts of this criminalization on the community.

Here we expand beyond the policy and legal aspects of the report and instead focus on strengths to demonstrate that, while people are profoundly impacted by the HIV criminalization reproduced by settler colonial institutions, they are not defined by this criminalization. Strengths are shown by Indigenous people living with HIV and by those working to support the community. When brought together, their responses illustrate the importance of non-judgment and inclusion, community pedagogy as a practice of self-determination, honouring healing and supporting others, and centering Indigenous approaches to HIV. While it is crucial that there be research focused exclusively on, and led by, Indigenous people living with HIV, we argue that there is also value in including allies in Indigenous HIV research. Those allies, which include Elders, brought different perspectives to this research and demonstrated a relational form of allyship or what we are referring to as allyship through kinship. There were sometimes tensions between the responses from those who are HIV positive and the HIV negative participants, but we hope that these points of tension are openings for reflection, and that we, as authors who are HIV negative, also engage in reflexivity when considering allyship as a relational approach.

These arguments are explored by first discussing some key concepts in this piece – resilience and allyship. We then explain the methodological approach taken in the research, which is followed by the key findings and a discussion of those findings. Lastly, we end with some reflections for ways forward.

RESILIENCE AND ALLYSHIP IN THE CONTEXT OF HIV CRIMINALIZATION AND SETTLER COLONIALISM

Resilience, as a term, suggests strengths. It has the potential to shift the focus away from deficit-based approaches and to challenge stereotypes about Indigenous people (Rolnick, 2018, p.1418). It is also possible for it to be used in ways that are harmful. Too often, resilience is deployed in ways that are individualized and pathologized. As Darren Thomas et al. (2015) explain, “[c]urrent conceptual approaches to understanding indigenous people as resilient consider resilience to be an individual trait, as a predisposition to succeed despite adversity” (p.1). Scholars working in the area of Indigenous well-being caution that such an approach to resilience is damaging, especially for Indigenous and other marginalized peoples, because it individualizes what are actually social problems (Thomas et al., 2015; Rolnick, 2018; de Finney, 2017).

In her work with Indigenous girls, Sandrina de Finney (2017) cautions that with resilience frameworks, “...the colonial violence girls experience is reduced to psychometric measurements and assessments [which] furthers a victim-blaming” approach (p.14). She observes, “[t]he lucky ones who survive and even thrive are called ‘resilient’ [...] Those who cannot ‘bounce back’ from abuse and violence are pathologised” (pp.14-15). She further explains, “[t]his approach

ignores a cruel irony: the fact that the traumas Indigenous girls experience and that the dominant system seeks to fix *are produced by the system itself*" (p.15, emphasis in original). In their research with Indigenous women living with HIV, Tracey Prentice et al. (2018) call for "a radical rethink" for HIV research and policy to be strengths-based, and they make clear that such rethinking cannot ignore the structural realities and impacts of settler colonialism (p.252). Using the concept of resilience in the context of HIV criminalization in Indigenous communities then, necessitates finding a balance wherein individuals and their strengths can be celebrated, and the focus can be on self-definition (Prentice et al., 2018, pp.243-244), while also being attentive to the structural realities and constraints produced by settler colonialism. Thomas et al. describe that *Indigenous* resilience in particular, "derives from indigenous knowledge and ways of knowing, and from cultural and ceremonial practices" (p.2). Similarly, de Finney explains Indigenous resilience as a "political act" that is intimately connected to Indigenous sovereignty and the revitalization of Indigenous traditions (p.15).

Allyship, arguably, has an important relationship with resilience, as people work to support one another in community. One of the Elders in the research clearly took up a reflexive approach to his own position of being HIV negative and noted that his prayer at the onset of the interview was about upholding respect and honesty in his interview. He, and the other HIV negative participants, expressed wanting to uphold the well-being of all Indigenous people, and took up practices of kinship and accountability to others. It is difficult when conducting research on "the Indigenous HIV community", to draw clear lines between one particular community and the broader Indigenous community, as they are embedded within one another. The well-being of Indigenous nations means that every individual within the nation as a whole, needs to be supported and safe. However, people also have different experiences.

We did not initially set out to label people as allies, rather our intent was to do research with Indigenous people living with HIV and with those working or volunteering in support of this community.³ We came to the language of allyship afterwards, when reflecting on the idea of allyship through kinship as a way of considering ethical actions toward one another in a community, and exploring the possibilities of allyship as an additional way for challenging HIV stigma and criminalization. While the term allyship is contested and has some troubling issues with people (especially white settlers) claiming to be allies, but then not practicing ethical relationships, we retain this language of allyship here as a tool for thinking about the strengths and potential for relationships between HIV positive and negative people working in and with Indigenous communities.

METHODS

This research used a qualitative approach and drew on decolonizing and Indigenous methodologies. As Randy Jackson (2019) describes, such an approach works "to interrupt colonialism in social science research by holding space that privileges Indigenous culture, voice, and knowing" (p.164). He emphasizes the importance of researchers reflecting on what shapes their own experiences and ideas (p.163), and so we want to begin by saying a bit about ourselves.

³ These participants had either informal and formal connections to various non-profit organizations in Regina. A few of these participants were also HIV positive, though we do not refer to them as allies here.

Emily Snyder is a white settler from Attawandaron, Haudenosaunee, and Anishinaabe territories in what is commonly referred to as southern Ontario. She now lives in Treaty 6 Territory and works as a professor in Indigenous studies and gender studies at the University of Saskatchewan. Her partner and extended family are Cree and Métis. Margaret Kîsikâw Piyêsîs is a First Nations Cree woman of the Moose Clan and Bear Clan with family ties to George Gordon First Nation in Treaty Four territory. She has worked in Indigenous HIV advocacy for twenty plus years. At the time of doing the research, she was the Chief Executive Officer of All Nations Hope Network. She is now the Chief Executive Officer of CAAN.

This research was a case study done in Treaty 4 Territory, in Regina, Saskatchewan, where All Nations Hope Network, the community partner, is located. The research was co-designed between Emily and Margaret and received ethics approval from the University of Saskatchewan Research Ethics Board.⁴ The research was not part of the services offered by All Nations Hope Network, however, the supports within the organization were available to participants if they were interested.

We aimed to create an approach that honoured the expertise of Indigenous people living with HIV and their allies and to learn from their perspectives and expertise. The method used was semi-structured interviews. A leader in Indigenous HIV advocacy, Krista Shore, was hired for the interview portion of the research. Krista was essential to the functioning of this research as she took the lead in arranging and conducting the interviews. Emily went through the details in the consent form at the onset of the meetings, including discussing the right to withdraw at any point and providing an opportunity for potential participants to ask questions, decline the interview, or to proceed if they were interested.⁵ Emily was also present for the interviews and provided explanations when needed about HIV non-disclosure in Canada. An Indigenous student research assistant was also hired to transcribe the surveys. A preliminary analysis of key findings for the policy report was discussed at a community presentation by Emily and Margaret. While we had a modest budget for this research, it is vital to reflect on how we could have structured the project differently to include more involvement from members of the community in the design and analysis components of this research. These reflections will be discussed later.

Semi-structured interviews were used so that people would be able to speak confidentially about HIV criminalization. Purposive and snowball sampling were used, and interviews took place at All Nations Hope Network so that there would be supports available to participants. Overall, 26 interviews are examined here. The interviews ranged from about ten minutes to an hour and people were compensated for their time. The interviews with allies tended to be longer, as there were additional questions about why they were interested in working in support of Indigenous people living with HIV. The broad range in interview times relate to some participants talking more in depth than others. Pseudonyms were assigned to protect the confidentiality of the participants. Seventeen (65%) of the participant are living with HIV. The remaining nine HIV

⁴ Although not formal boards, our approach was also shaped by the community partner's expectations for community-based research and by the funder's (the Urban Aboriginal Knowledge Network) guiding ethical principles which emphasize research that is community driven and values protection, ongoing consent, ownership and intellectual property rights, fairness, community relevance, and practicality

⁵ Signed consent forms were used.

negative participants included six Elders (one of whom was not Indigenous). Overall, 96% (all but one) of the participants were Indigenous and 81% (21 individuals) were women.

FINDINGS

The data was analyzed with NVivo qualitative software. The data analysis was approached in a way that allowed for all issues discussed by participants to emerge and be coded, however a focus on law was also maintained to understand how law was being discussed. When the data was initially analyzed in 2017, broad themes were assessed and identified by Emily and that analysis was then discussed with Margaret. Resilience was one of the initial codes we identified, however it was overshadowed by the focused examination of legal impacts. The entire data set was then analyzed a second time by Emily in 2020 for a closer look at a strengths-based analysis, including an analysis of allyship. Our discussion that follows is based on the themes that emerged from this second round of data analysis and while the following themes are discussed separately, it is noteworthy that there is significant overlap between them. The themes are: 1) non-judgment and inclusion; 2) community pedagogy; 3) healing and support; and 4) centering Indigenous approaches to HIV.

1. Non-judgment and Inclusion

Although participants talked about many profoundly hurtful situations in which they were labeled, judged, and harmed by others (including various “professionals” and often by family and friends), they also actively refused dehumanization in the discussions about HIV criminalization. Overwhelmingly, participants upheld principles of non-judgment and inclusion, and challenged HIV stigma. Participants living with HIV deconstructed harmful representations about Indigeneity and HIV. Mike remarked that “[p]eople are ignorant and say it’s a native disease.” Kisik, an Indigenous woman, spoke about the struggles that she faces in not internalizing stereotypes: “I just wanted to keep [it a] secret, you know, due to all the stigma going out there and, you know, all that cruelty towards it and, um, I just felt, you know, ashamed and- and embarrassed about me—about myself and, you know, because I was, like... the most popular girl that always was always there to help someone but nothing changed. I was still me.” Isqotew wanted to pass along a positive message to others – “keep your head up. Don’t let anybody tell you any different just because you’re HIV and they’re not and they think they’re better than you. They’re not. They’re just as ... same level as you.” Marie, also living with HIV, noted, “[j]ust because we’re Indigenous and we have it, it doesn’t mean that, you know, we don’t have feelings and that. We do.” She also condemned the labeling and stereotyping of people who are Two-Spirit, voicing that “[w]e’re all people. We’re all people of God and the Creator.”

Allies also actively worked to challenge stereotypes. For example, Musqua, an Indigenous woman, spoke about a family member living with HIV and talked about not wanting to use the word “disease” because of the negative connotations that such language carries. The Elders shared important knowledge about non-judgment and respect. Clement noted the importance of not calling down Indigenous kin and not labeling people who are HIV positive and said, “they’re no different than me.” Another Elder spoke about the importance of respecting others. He also expressed concern that Indigenous people are not respecting one another today. He emphasized

the importance of supporting others, rather than putting them down. Sarah also spoke out against lateral violence – “we can’t afford to just hate ourselves any more than people- people uh [pauses] being mean and talking mean and all that. I’ve- I’ve- I’ve heard people say, ‘oh did you know this person has HIV you know?’ and I think to myself ‘well so what?’” Many of the Elders came to this work because they too are resilient people who have faced many challenges, including residential schools, struggles with addictions, and gendered violence. Esikwew spoke of the role of helping in the community – “[w]e’re here to listen and, uh, we don’t shun people. We know what their, uh... their owies are and stuff like that, you know what I mean?” Both Old Lady Buffalo and Clement spoke about the importance of love, and about not-judgment and supporting people where they are at.

2. Community Pedagogy

We use the term community pedagogy to refer to practices in which people are learners and teachers. Both participants who are HIV positive and allies were active in myth busting, which is an important part of breaking down HIV stigma so that truths about HIV and non-disclosure can be understood. One similarity across the interviews was a need for more information about HIV non-disclosure and the law, and more useful resources about HIV in general. After learning more about HIV non-disclosure through the interview, Marie, who is HIV positive, commented, “How many other Indigenous women like me, you know, don’t even know that this exists? And, and if we don’t say anything we get charged with aggravated sexual assault?!” She insisted: “We’ve got to get out there. We’ve got to get the education out there on – on how it – the laws affect everyone, not just the Indigenous people but everyone. But more so Indigenous women and men [...] [b]ecause we are treated differently than men and women from Caucasian and other races. That I – I do know.”

Several of the participants living with HIV spoke passionately about learning and going to sessions and conferences. This learning was not only about personal growth, but also about gaining knowledge that could then be shared in the community. Meewasin expressed that “I would, you know, love to be a part of teaching” – a part of “[t]eaching the people [...] teaching the community.” Participating in the interviews was also an act of community pedagogy. Isqotew shared that she was at the interview to speak to her own experiences and said, “I hope it helps all the- the research out there.” Similarly, Rochelle commented, “It’s kinda good that there’s more research happening. I think that’s really good because it’ll help, help us.”

In addition to the enthusiasm for learning and teaching from most participants, concerns were also expressed that when there are educational events, it can be tough to get people to attend. During her interview, Old Lady Buffalo raised concerns that Indigenous people can sometimes be quiet because of the repressive and silencing impacts of settler colonialism. She talked about being strategic with one’s voice – using it when one feels they can and when it is worth their energy – and we want to acknowledge that while it took strength and made sense for some people to voice their ideas in the interviews, for others, it is also an act of agency to choose not to participate – be it for self-protection or for any number of other reasons.

For many participants, family was a key site for engaging in community pedagogy, including teaching younger people. Kisik, who is living with HIV and was learning and also teaching her

children to be strong allies, talked about how her “oldest, um, wants to be a doctor so she can help her dad. Because he has the virus and he, he gets sick quite often due to other health reasons. So, whenever I learn, my daughter likes to, you know, follow me around like she’s a journalist or something.” Community pedagogy is intergenerational.

This point was also raised by one of the Elders when he explained that young people can teach the Elders about HIV and that Elders can share their knowledge about the past. He talked about Elders’ knowledge not being above others and emphasized that different perspectives can be brought together on the same level to be shared with one another. His comment emphasizes that community pedagogy needs to involve reciprocity and we examine this issue more below when thinking about ways forward between Indigenous people living with HIV and allies working in support of the community.

3. Healing and Support

Many of the participants – those who are HIV positive and allies – talked about their own healing journeys and how they wanted to also support others. Participants were focused on HIV justice and well-being in addition to challenging other forms of injustice. Peyesis, who is living with HIV, was wanting to support others even while she was dealing with challenging housing issues. She had recently moved into a new place and said, “I feel safe there. Even though there’s users all around me, but it’s still... if I can help them in any way then that’s good you know... I’m trying to be uh [pauses] a bright light in a dark place.” Kisik, who is living with HIV and had struggled with addictions, talked about her experiences with healing and supporting others:

I don’t have no one in my family, anymore, that’s being judgmental and saying rude things [...] but I guess all I had to do was just open up, be honest and stop- stop keeping things to myself and just keep going, you know? Helping someone else, um, get by. I, um, can say I’m really happy and proud of myself for encouraging a couple of my friends [...] who were positive, you know, to go out and get the help they needed.

Speaking about HIV with family and friends, while a part of healing, was talked about by many as a challenging experience. Munson reflected on a conversation with his father – that it was tough to talk with him about being HIV positive, but that he felt a weight was lifted off his shoulders after doing so. The interviews show that there is a need for allyship from family members who are HIV negative.

Participants of all genders talked about the need for supports within the community. It was discussed that these supports need to be culturally relevant, accessible, and safe. Several participants also talked specifically about how Indigenous women living with HIV face distinct challenges and can have different experiences with healing and support (see also Prentice et al., 2018; Greene, et al., 2019). Rochelle commented that “It’s hard being an HIV positive woman” and reflected that “I’m starting to, um... like... I don’t know starting to... accept it I guess? [...] starting to be happy- more happy with myself now.” Meewasin, who is HIV positive, was also attentive to the specific challenges that Indigenous women living with HIV face, and she remarked, “I’m very proud of a lot of people, you now, that’s made it very far you know from

them living on the streets to having a child and now today they're living a straight and good life, you know, and I'm very proud of them."

Melissa talked about how she wanted to be a support person and share experiences with others. Joe also noted the importance of support networks. Having met other Indigenous women who are HIV positive, she reflected, "I figure out that, through my heart, that you don't have to rely on yourself. There's other people you can talk to about your disease. There's other people here, in the world, not only you that have it." Similarly, Marie commented that she felt comfort in "knowing that there was other women out there like me and being able to talk freely and openly about our HIV status." She had wanted to help others, "[e]specially, um, being Indigenous and, um, knowing what other women have to face." Further, Kisik talked about the importance of having role models who are Indigenous, women, and HIV positive.

The Elders also emphasized the importance of talking with people who are living with HIV and listening to them. Old Lady Buffalo reflected, "I think we should... use [pauses], as elderly people, our wisdom to help people to be able to talk and also know when to be quiet, you know?" She also called attention to the need for inclusive approaches to support and spoke of a challenging example where an Indigenous person living with HIV told her that they were excluded from a ceremony. She explained that he had been on morphine and was able to go to ceremony, but when he wanted to use medical marijuana instead, he could not participate. She reflected, "People have choices... let's be... at the level we can understand and recognize which is best for people, you know?" and cautioned that "[s]ometimes we put ourselves higher and say 'Oh, that's no good. Don't do that.' That doesn't do good for the one that's hurting, you know?"

4. Centering Indigenous Approaches to HIV

Although not the focus of this article, it is necessary to recognize that Indigenous people living with HIV have different ideas about HIV non-disclosure, and there needs to be ways to examine those differences while also speaking out against harmful assumptions. For example, Mike took a tough stance on the criminal approach to HIV non-disclosure, which supported the use of Canadian criminal law in Indigenous communities. He also stereotyped Indigenous women as those who are spreading HIV. Overall, participants had many ideas for change and support within the community. Phil, who is living with HIV and is a leader in the community, talked about the need for there to be specific supports for people to better understand the legal system in relation to HIV. Participants had ideas for gatherings, support groups, counselling, mentoring, educational sessions, educational tools, and continued support and growth for organizations working in the area of Indigenous HIV advocacy. These were all discussed as needing to be contextually relevant and useful for Indigenous people living with HIV. The only non-Indigenous participant in the research, Granny, showed that she was trying to learn at the same time that she spoke out against injustices against Indigenous people. She spoke about unfair treatment of Indigenous people through the justice system and was particularly interested in trying to find ways to support Indigenous youth. While non-Indigenous people might be involved in this work, participants expressed the need for Indigenous-led ways forward. One participant encouraged Indigenous leaders (such as those working at national Indigenous organizations) to learn more about HIV so that stronger alliances could be made.

A concern raised by a few participants living with HIV, and which is crucial when thinking about allyship, was that they wanted to see more Indigenous people living with HIV in leadership roles and shaping the organizations that are supporting their community. Sunshine commented that,

We should be the ones here doing a lot more work than a lot of others. Give us that opportunity. Let us grow! Give us the chance to grow. Let us heal. Help us. And if we fall and falter, bring us back up. Help - don't just let us stay there. Grab us back and – and if we're going to be using our stories and going out there and saying everything and then like don't just throw you away in there. Like, "Okay, there. Go! We got what you want," and then you know? Keep us involved.

While one could perhaps describe peers as allies to others within their community, we are using allies in this paper to refer to those not living with HIV, and there are additional unresolved questions here about the relationship between peers and allies.

DISCUSSION

It is noteworthy that those who we are referring to as allies did not necessarily label themselves as such in the interviews. The allies, for instance, included Elders who were working in support of Indigenous people, but who humbly spoke about their roles. Despite people not calling themselves allies, upon reflecting on the interviews, we found that allyship was present largely as a form of kinship and was intimately tied up with resilience, including a commitment to family and to upholding the well-being of all Indigenous people. The majority of those labelled as allies in the research either spoke of family members that they wanted to support, and/or talked about kinship in a much broader sense in terms of upholding well-being within Indigenous communities and nations. This form of allyship entailed a deep sense of relationality and accountability to others. Allies also challenged settler colonialism alongside Indigenous people living with HIV to encourage conditions of safety. We argue that there is value in including allies in Indigenous HIV research so that there is a collective of people working to challenge discrimination and to learn from/with Indigenous people living with HIV. The Elders in particular were purposeful in their intent to offer cultural and spiritual support to those who were HIV positive, but to also listen and learn as they strived for non-judgmental and accountable relationships with others.

For the most part, the participants – whether living with HIV or those who are allies – were contributing to building what de Finney (2017) refers to as “resilient circles of care and justice” (17) through practices of inclusion, community pedagogy, healing and supporting, and centering Indigenous approaches to HIV. Regarding community pedagogy, for example, the interviews made clear that there is a need for more information about HIV criminalization, so that Indigenous people living with HIV, and also the allies working in support of the community, have a better understanding of the implications of the current legal context. This problem of a lack of accessible information is echoed in Greene et al.'s (2019) research with HIV positive women where they note that, “[b]arriers to accessing information about the criminal law on HIV non-disclosure could be attributed to multiple and intersecting structural factors including

literacy, language, disability and other social determinants” (p.13). There is a clear need for more and better information. Participants in our research were taking significant ownership in educating themselves and others to support the overall well-being of Indigenous people who are HIV positive, and the broader community. Community pedagogy involves building capacity and drawing on knowledge from within the community, while also drawing on other knowledge, and using it in a way that supports self-determination. Allies can be a key part of this work by sharing what they know about the criminalization of HIV or by learning about it and sharing that information to support circles of care and justice. The strengths noted in the findings section (e.g., non-judgment, inclusion, community pedagogy, healing) work to challenge the stigma that fuels HIV criminalization and can work to challenge Canadian legal approaches to HIV that attempt to undermine Indigenous legal agency – that is, the ability of Indigenous people to address complex social and legal issues by drawing on community strengths, Indigenous knowledges, legal principles, and practices.

de Finney (2017) centers the revitalization of Indigenous cultural and political systems as core to Indigenous resilience, noting that “communities have always had their own conflict resolution and decision-making processes, customary laws and restorative practices, and spiritual, social and political traditions – all mechanisms that Indigenous nations have a right to utilise and implement” (p.16). Indigenous knowledge and traditions are invaluable for moving forward in Indigenous HIV advocacy, and Indigenous legal traditions could offer different ways for thinking about HIV disclosure and well-being, compared to the criminalization approach taken with settler laws. The interviews make clear that people are already doing this work of centering Indigenous knowledge systems and are wanting to increase community capacity to continue to strengthen such approaches. However, there are also some challenges and tensions, and they serve as important reminders for ongoing reflection.

One such tension relates to the very issue of disclosing one’s HIV status. In a case study examining Indigenous people’s experiences with HIV disclosure in Saskatoon, Saskatchewan, Andrew R. Hatal et al. (2018), not surprisingly, convey similar findings to ours. Their focus was broadly on HIV disclosure (rather than examining criminalization), and a key theme that emerged was that disclosing one’s HIV status could lead to “being and becoming a helper” (p.1099). They explain, “[t]his process involved the participants taking on more of an active role in not only disclosing their illness status with a wider contingent of individuals within their social networks, but also sharing their story and journey with others to potentially help them along their own illness journeys” (p.1106). They argue that becoming a helper “facilitated illness disclosure in a culturally sensitive and positive manner while also creating important opportunities for peer leadership and potential involvement of members of Indigenous communities in conducting health interventions of various kinds” (p.1101).

There is much that is insightful in Hatal et al.’s (2018) framing of Indigenous people living with HIV as helpers, but it is imperative to not conflate disclosure with empowerment and non-disclosure with disempowerment. It can be important to celebrate those who speak openly about HIV and who come to be seen as helpers, but it is also important to celebrate the strengths of others as well, including those who do not want to disclose or who feel that they cannot safely disclose. Participants in our research showed courage in disclosing to others and it is noteworthy that some relationships grew as a result, while others became harmful, and people distanced

themselves from those who had disclosed. HIV disclosure is not straightforward at a personal level, and it is also complicated in that the healthcare and legal systems are entangled in the issue of disclosure in ways that can be unsafe. Importantly, Hatal et al. (2018) acknowledge that “there are drawbacks to [HIV disclosure] in many situations and contexts and that individual responsibility, empowerment, and decision making should be emphasized over any kind of one-size-fits-all approach to illness disclosure” (p.1109).

There are many ways that people enact resilience, and in her writing on Indigenous girls, Rolnick (2018) raises a key point when she states that “an overly positive vision of resilience can have very real consequences for girls who cope with trauma in ways that are not clearly positive [...] too much emphasis on the survive-and-thrive version of resilience can lead decision makers to miss the importance of some young women’s coping strategies” (p.1422). It is important to not blame people when they do not ‘bounce back’ or flourish in the face of settler colonialism (Thomas et al., 2015, p.8). Settler colonialism creates systemic issues with criminalization, inadequate healthcare, an undermining of Indigenous self-determination, and is more broadly premised on Indigenous death than on Indigenous living (see Simpson, 2016; Wolfe, 2006). It is in these difficult spaces that people still exert agency in whatever ways that they can. This was evident from the participants in our research as they dealt with racism, sexism, HIV stigma and discrimination, violence, and isolation, at the same time that strengths in so many different forms were evident. Although not writing specifically about HIV, Napoleon (2020) writes about the importance of recognizing Indigenous agency (specifically Indigenous legal agency) and recognizing that people make the decisions that they can when working in and against the constraints of oppressive power relations (p.12). It is important to consider then what the role of allies might be in those contexts in which it is difficult for someone living with HIV to speak openly.

We have argued in this article that there is a need for allies to always be learners and to work alongside Indigenous people living with HIV. That relationship, however, is not straightforward, especially when thinking about non-Indigenous allies. As vital as it is to center Indigenous people living with HIV and to celebrate the strengths of practices such as community pedagogy, all of this work also cannot fall entirely on Indigenous people who are positive, nor on Indigenous allies working with the community. While resilience is a useful idea, people should not have to be so resilient and should not have to persevere against so many barriers and forms of oppression. Alongside these strengths then, settlers—particularly white settlers—need to learn more about settler colonialism and the attendant privileges they have falsely granted themselves in the name of others’ humanity, and they need to work to dismantle these systems, including challenging the stigma and harms perpetuated through the legal system.

When reflecting on our research, there are also complicated and unresolved issues about how Indigenous people living with HIV should have been included in this work (for a discussion about this issue, see McClelland et al., 2018). We appreciate the knowledge shared by participants, but we also know that it would be richer if Indigenous people living with HIV had been part of the entire research process, including design and analysis. The limitations in this research are openings for future reflection. These reflections include also considering how best to go about research on allyship. Although the interview guide included questions about why people who are HIV negative were interested in supporting Indigenous people living with HIV,

we did not directly ask Indigenous people who are HIV positive what they thought about HIV negative allies. While several participants spoke to this issue, the analysis would have been different had we asked questions beyond support programs and government funding, to ask specific questions designed to convey what ethical relationships look like to Indigenous people living with HIV in the context of HIV criminalization.

CONCLUSION

Several themes became apparent from the interviews. Non-judgment and inclusion were spoken about and matter because they attempt to recognize all Indigenous citizens within a nation, and they challenge the HIV stigma and discrimination that are at the core of HIV criminalization. Community pedagogy, healing, and centering the experiences of Indigenous people living with HIV also work to disrupt HIV criminalization wherein there has been a disregard of Indigenous people's humanity. Indigenous people have been impacted by the criminalization of HIV in distinct ways, and while this paper focuses on strengths, it is important to note that those strengths exist in tension with significant legal barriers which many participants navigate. This article has considered allyship through kinship as having potential for supporting Indigenous people living with HIV to negotiate the complexities of HIV criminalization – be it through Elders providing support, and/or other allies sharing knowledge and information about HIV non-disclosure and the law. Allies can also work to debunk misconceptions, extend their own learning by listening to those who are HIV positive, challenge harmful uses of law, and be a part of supporting community pedagogy and self-determination. Although our research was focused largely on those working with people that they considered their relations, it is worthwhile expanding these discussions to include thinking about how non-Indigenous people, such as lawyers, judges, and other legal practitioners, can work in a way that is focused on relational accountability to Indigenous people living with HIV in order to work against HIV criminalization.

REFERENCES

- Adam, B. D., Globerman, J., Elliott, R., Carriveau, P., English, K., & Rourke, S. (2016). HIV Positive People's Perspectives on Canadian Criminal Law and Non-Disclosure. *Canadian Journal of Law and Society*, 31(1), 1-23.
- Barlow, J.K. (2009). *Residential Schools, Prisons, and HIV/AIDS among Aboriginal People in Canada: Exploring the Connections*. Aboriginal Healing Foundation, <http://www.ahf.ca/downloads/hivaids-report.pdf>
- Canadian HIV/AIDS Legal Network (2019). *The criminalization of HIV non-disclosure in Canada: current status and the need for change*. <http://www.aidslaw.ca/site/wp-content/uploads/2019/05/HIV-criminalization-Info-Sheet-1.pdf>
- De Finney, S. (2017). Indigenous girls' resilience in settler states: Honouring body and land sovereignty. *Agenda*, 31(2), 10-21.
- Dej, E., & Kilty, J. M. (2012). "Criminalization Creep": A Brief Discussion of the Criminalization of HIV/AIDS Non-disclosure in Canada. *Canadian Journal of Law and Society*, 27(1), 55-66.
- Goodman, A., Fleming, K., Markwick, N., Morrison, T., Lagimodiere, L., Kerr, T., & Western Aboriginal Harm Reduction Society (2017). "They treated me like crap and I know it was because I was Native": The healthcare experiences of Aboriginal peoples living in Vancouver's inner city. *Social Science & Medicine*, 178, 87-94.
- Grant, I. (2008). The Boundaries of the Criminal Law: The Criminalization of the Non-Disclosure of HIV. *Dalhousie Law Journal* 31(1), 123-180.
- Greene, S., Odhiambo, A. J., Muchenje, M., Symington, A., Cotnam, J., Dunn, K., Frank, M., Glum, S., Gormley, R., Ion, A., Nicholson, V., Shore, K., & Kaida, A. (2019). How women living with HIV react and respond to learning about Canadian law that criminalises HIV non-disclosure: 'how do you prove that you told?' *Culture, Health & Sexuality*, 21(10), 1-16. <https://socialsciences.mcmaster.ca>
- Hastings, C., Kazatchkine, C., & Mykhalovskiy, E. (2017). *HIV Criminalization in Canada: Key Trends and Patterns*. Canadian HIV/AIDS Legal Network. <http://www.aidslaw.ca/site/hiv-criminalization-in-canada-key-trends-and-patterns/?lang=en>
- Hatal, A. R., Bird-Naytowhow, K., Pearl, T., Peterson, J., Del Canto, S., Rooke, E., Calvez, S., Meili, R., Schwandt, M., Mercredi, J., & Tait, P. (2018). Being and Becoming a Helper: Illness Disclosure and Identity Transformations among Indigenous People Living with HIV or AIDS in Saskatoon, Saskatchewan. *Qualitative Health Research*, 28(7), 1099-1111.
- Hawkins, K., Reading, C., & Barlow, K. (2009). Our Search for Safe Spaces: A Qualitative Study of the Role of Sexual Violence in the Lives of Aboriginal Women Living with

HIV/AIDS. Canadian Aboriginal AIDS Network. <http://www.caan.ca/wp-content/uploads/2012/05/Sexual-Violence-Document-ENGLISH1.pdf>

- Jackson, R. (2019). Indigenous Knowing in HIV Research in Canada: A Reflexive Dialogue. In E. Mykhalovskiy & V. Namaste (Eds.) *Thinking Differently about HIV/AIDS: Contributions from Critical Social Science* (161-185) UBC Press.
- Kirkup, K. (2015). Releasing Stigma: Police, Journalists and Crimes of HIV Non-Disclosure. *Ottawa Law Review*, 46(1), 127-160.
- Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, Gender, Race, Sexual Orientation, and Sex Work: A Qualitative Study of Intersectional Stigma Experienced by HIV-Positive Women in Ontario, Canada. *PLoS Medicine*, 8(11), e1001124, 1-12.
- McClelland, A., Guta, A., & Greenspan, N. R. (2018). Governing Participation: A Critical Analysis of International and Canadian Texts Promoting the Greater Involvement of People Living with HIV and AIDS. In S. Hindmarch, M. Orsini, & M. Gagnon (Eds.) *Seeing Red: HIV/AIDS and Public Policy in Canada* (195-214) University of Toronto Press.
- Monchalin, L. (2016). *The Colonial Problem: An Indigenous Perspective on Crime and Injustice in Canada*. University of Toronto Press.
- Mykhalovskiy, E., Hastings, C., Sanders, C., Hayman, M., & Bisailon, L. (2016). "Callous, Cold and Deliberately Duplicitous": Racialization, Immigration and the Representation of HIV Criminalization in Canadian Mainstream Newspapers. Report. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2874409
- Napoleon, V. (forthcoming). Gitxsan Legal Personhood: Gendered. In G. Pavlich (Ed.) *Legal Personhood Interrupted*.
- Pearce, M. E., Christian, W. M., Patterson, K., Norris, K., Moniruzzaman, A., Craib, K. J. P., Schechter, M. T., & Spittal, P. M. (2008). The Cedar Project: Historical Trauma, Sexual Abuse and HIV Risk Among Young Aboriginal People Who Use Injection and Non-Injection Drugs in Two Canadian Cities. *Social Science & Medicine*, 66(11), 2185-2194.
- Prentice, T., Peltier, D., Benson, E., Johnson, K., Larkin, K., Shore, K., & Masching, R. (2018) 'Good Medicine': Decolonizing HIV Policy for Indigenous Women in Canada. In S. Hindmarch, M. Orsini, & M. Gagnon (eds) *Seeing Red: HIV/AIDS and Public Policy in Canada* (235-256) University of Toronto Press.
- Richardson, B. J., Imai, S., & McNeil, K. (Eds.) (2009). *Indigenous People and the Law: Comparative and Critical Perspectives*. Hart.
- Rolnick, A. C. (2018). Resilience and Native Girls: A Critique. *BYU Law Review*, Spring 5-1 2019, 1407-1427.

Simpson, A. (2016) The State is a Man: Theresa Spence, Loretta Saunders and the Gender of Settler Sovereignty. *Theory & Event*, 19(4).

Snyder, E. (2018). *The Impacts of the Criminalization of HIV Non-Disclosure on Indigenous People: A Case Study of Regina*. Report.
<http://allnationshope.ca/userdata/files/187/HIV%20Non%20Disclosure%20Project/HIV%20Non-Disclosure%20Report%20-%20ESnyder.pdf>

Speakman, E. R. (2017). Constructing an “HIV-Killer”: HIV Non-Disclosure and the Techniques of Vilification. *Deviant Behavior*, 38(4), 392-405.

Thomas, D., Mitchell, T., & Arseneau, C. (2015). Re-evaluating resilience: from individual vulnerabilities to the strength of cultures and collectivities among indigenous communities. *Resilience: International Policies, Practices, and Discourses*, 4(2), 1-14.

Wolfe, P. (2006). Settler Colonialism and the Elimination of the Native. *Journal of Genocide Research*, 8(4), 387-409.