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Indigenizing Scholarship to Examine Resilience Among HIV-positive Two-spirit Men: Lessons learned from the 2-Spirit HIV/AIDS Wellness and Longevity Study (2SHAWLS)

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ABSTRACT

This paper is a discussion of the process involved in developing and conducting a community-based academic partnership that privileged Indigenous knowledge and resources to ensure the study extended literature focused on resiliency among two-spirit Indigenous men living long-term with HIV/AIDS (IPHAs). In addition, we sought to describe the lessons the team learned by working through the process of prioritizing Indigenous knowledge and methods into the research study and its methods. Some of the challenging issues experienced and how the team attempted to address them in their work together are discussed. The team sought to ensure that the study focused on strengths and resilience among participants, as we explored Indigenous knowledge and ways of knowing throughout the entire process. Additionally, the team ensured Indigenous people were involved in all aspects of the study, from design, data collection, and data analysis to knowledge translation. Using an Indigenous framework crafted from the Medicine Wheel, the team worked in the context of research as “ceremony”. Employing principles of two-eyed seeing, the team worked to address the multiple challenges in conducting a study in an academic, Western context while ensuring that Indigenous people and knowledges were central to the project. Lessons learned included 1) how the team integrated Indigenous knowledge in a respectful and relevant manner to a study; 2) how to Indigenize the method of data collection; and 3) the challenges of data analysis from differing worldviews. The project provided an important opportunity for team members to appreciate the community-engaged two-eyed seeing process and to create findings that are relevant to both Indigenous and non-Indigenous researchers and communities.

BACKGROUND

Galvanized by a research policy environment that frames the meaningful involvement of Indigenous peoples in research that affect their lives as an ethical responsibility (Dockstator, et al., 2016), in Canada and elsewhere, community-based research (CBR) is now widely accepted as a wise practice approach in health research involving Indigenous peoples (Ritchie, et al., 2013; Ninomiya & Pollock, 2017). In addition to the potential to increase relevance and promote collective impact, community-based research also has the potential to: (1) help identify culturally grounded and innovative solutions to address health challenges; and (2) create space for the inclusion of previously excluded voices as central to guiding the research process (Ball & Janyst, 2008; Cahill, 2007; Israel, Schulz, Parker, & Becker, 2001).

These gains can multiply when CBR principles are combined in Indigenous health research with decolonizing and Indigenous methodologies. As Absolon and Dion (2017) powerfully observed, “CBR, using Indigenous methodologies, is healing and reconnects people to each other, their community’s story and journey” (p. 88). In using CBR along with decolonizing and Indigenous methodologies, this multi-methodological approach is also thought to: (1) address past negative Indigenous experiences of research through stakeholder engagement; (2) operationalize tribal self-determination in research through ownership and control of data and research findings; (3) adopt community-affirmed ideas of leadership rather than the colonial processes inherent in university-affiliated research; (4) appreciate cultural diversity and attend to its implications; (5) interpret data within the cultural context in which it was generated; and (6) utilize and operationalize Indigenous ways of knowing in research contexts (Absolon & Dion, 2017; Dockstator, et al., 2016; Ritchie, et al., 2013).

While there is clearly much to celebrate with respect to the promises made by CBR when used in conjunction with Indigenous and decolonizing methodologies, as Dockstator et al. (2016) caution, it is vital that we also learn to appreciate that, “Research with, in, and for, First Nations communities is often carried out in complex cultural and political environments” (p. 18). It is in these environments—cultural and political complexity—that complications in operationalizing a multi-methodological approach to making ‘Indigenous’ health research arise. Knowledge of principles that enable the participatory involvement of Indigenous communities is often not always enough (Ninomiya & Pollock, 2017; Mertens & Cram, 2016). Absolon & Dion (2017) and Dockstator et al. (2016) describe these challenges as related to differences in worldviews, language, place and protocols, political, academic and social pressures, and capacity issues. One example of an overarching challenge in the context of a research project are differences in worldviews—particularly where such difference is not acknowledged nor celebrated (Dockstator, et al., 2016). Absolon & Dion describe writing about these challenges as an “act of transgression,” with the potential for emancipatory knowledge to emerge out of team level critical reflection and analysis (Absolon & Dion, 2017, p. 92).

It is within this context where we situate our reflection of engaging in community-based, decolonizing, and Indigenous health research that is focused on exploring two-spirit male conceptualizations of and experiences with resilience living long-term with HIV. Not only is reflexivity and reflection a central epistemological and ontological goal of decolonizing and Indigenous methodologies (Krusz et al., 2020), it is also important towards improving research

practice. This paper describes several salient challenges that we, as a team, navigated through the research process, including: (1) differences in worldviews and how research should be approached; (2) questions on the synthesis of Indigenous knowledge in a scoping review; (3) questions related to using sharing circles in data collection; and (4) questions related to the centering of Indigenous knowledges in data analysis. As much as our challenges map onto the literature where other Indigenous scholars have also reflected on their own experiences operationalizing a multi-methodological research approach, we build and add to the dialogue by also describing the framework (i.e., research as ceremony; two-eyed seeing; and the Medicine Wheel) we used for responding to these challenges. Before we do this, however, it is important to first describe the processes we undertook to develop and conduct a CBR study focused on two-spirit resiliency living long term with HIV/AIDS. In this paper, we highlight a framework where we argue that Indigenous health research is best conceptualized using the Medicine Wheel and enacted through ceremony. It is in drawing on the teachings of the Medicine Wheel, alongside privileging research as ceremony, where we potentially and productively navigate (but not necessarily resolve) challenging research contexts.

COMMUNITY/ACADEMIC PARTNERSHIP: AN EXAMPLE FROM 2SHAWLS

The study under question—i.e., the 2-Spirit HIV/AIDS Wellness and Longevity Study (or 2SHAWLS) and as described elsewhere (see Jackson et al., 2021)—began as a conversation between an academic settler researcher (David J. Brennan), the Executive Director (Art Zoccole) of an agency supporting two-spirited people, an Indigenous academic researcher (Randy Jackson), and the Executive Director (Tony Nobis) of an Ontario-wide agency supporting Indigenous people living with, and at risk for HIV. All team members were aware through their knowledge of community work and academic literature, of the limited research focused on Indigenous People with HIV/AIDS (IPHAs). When the literature did describe IPHA experiences of HIV/AIDS, scholars often appraised the challenges Indigenous peoples confront through deficit models with little to no attention focused on the strengths of two-spirit IPHAs. Our review of the literature found that research in this area was paternalistic, relied almost exclusively on deficit-based understandings of two-spirit men's HIV/AIDS journeys, and overlooked the skills, tools, knowledge, and resources that two-spirit IPHAs employed in managing their health and well-being ((Bond, 2005; Reading & Nowgesic, 2002; Brennan et al., 2021).

Additionally, and at the outset, anecdotal community-grounded knowledge confirmed that many two-spirit long-term IPHAs, despite continuing challenges, were living vibrant and full lives. Indeed, our Indigenous team members felt strongly that it was important to share the stories of these two-spirit men whose voices were often silenced and lacking in the existing literature. From the onset of the study, and similar to approaches described by Absolon & Dion (2017) and Dockstator & et al (2016), our research team also committed to: (1) using a strengths-based lens and developing a more fulsome understanding of two-spirit men's strength and resilience; (2) engaging the representatives of two-spirit participants on the research team ("the Team") and as members of the community advisory board (CAB); (3) using decolonizing and Indigenizing research approaches—shaped by CBR processes—for data collection, analysis, and knowledge translation; and (4) making the results from our study accessible, culturally relevant, and useful to Indigenous Peoples through the design of a tool to share our findings in a way that

meaningfully engaged the Indigenous community broadly.

To consider the best ways to Indigenize the research process, the team reviewed the existing peer-reviewed Indigenous academic literature and discussed the variety of ways this could be accomplished. This included discussing all the possible ways in which we might work together to balance the variety of worldviews in the process. Previous researchers suggested ways to engage in research processes that are ethical and attentive to the worldviews of Indigenous populations (Ferreira & Gendron, 2003; Fisher & Ball, 2003; Lavallée, 2009). The methods in the 2SHAWLS study included: 1) A scoping review of the literature relevant to the topic of resiliency among two-spirit IPHA men (see Brennan et al., 2021); 2) a series of sharing circles used to gather data on the lived experiences of long-term two-spirit IPHA men; and 3) a symbolic and participatory analysis approach that embedded Indigenous knowledge throughout the entire process to reach the final results (see Jackson, et al., 2021). Below we describe the Indigenous research we used to guide our research process. It is within our model where we also discuss our challenges in conducting this research.

AN INDIGENOUS FRAMEWORK: AN EXAMPLE FROM 2SHAWLS

Grounded in emergent Indigenous scholarship focused on resiliency and using a community-based research (CBR) approach, our study sought to position Indigenous knowledge and voices at the forefront of our work and weave it throughout (Smith, 2013). Indigenous conceptualizations of resiliency recognize individual-level protective factors, as well as strengths emerging from connections to community, cultural assets, traditional teachings, and geography (Peltier et al., 2013). This shift towards recognizing resilience as rooted in the individual's relationships to self, family, community, and spirituality is captured in three guiding principles adopted by the team to ensure we were Indigenizing the research study and its protocols. First, the teachings of the Medicine Wheel (MW) were used to ground our methods, reflecting the Anishinaabe territory on which our study was conducted (as described in Jackson et al., 2021). We also employed ceremony (Wilson, 2008) to honor the work of the team and the contributions made by the CAB and the study participants. Finally, two-eyed seeing formed the broader framework for our research (Martin, 2012; Peltier, 2018). Elder Albert Marshall defined two-eyed seeing as “learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of mainstream knowledges and ways of knowing, and to use both these eyes together, for the benefit of all” (Bartlett et al., 2012). From this starting point, our research team sought to utilize the strengths of both Indigenous and Western science to help answer our research question. Throughout the paper we discuss how various strengths of Indigenous and Western methods were taken up and utilized.

We also discuss each component of our Indigenous research framework (MW, research as ceremony and two-eyed seeing) and how these components were used in the context of specific methodological challenges the Team faced in conducting the study. It is important to highlight that three of our four-member 2SHAWLS team identified as having an Anishinaabe tribal background. Early on in the project, it became clear that though this may limit the scope of our work, it was important to acknowledge that the Anishinaabe worldview operated as central to how the study team conceptualized the research process. Although not without challenges in

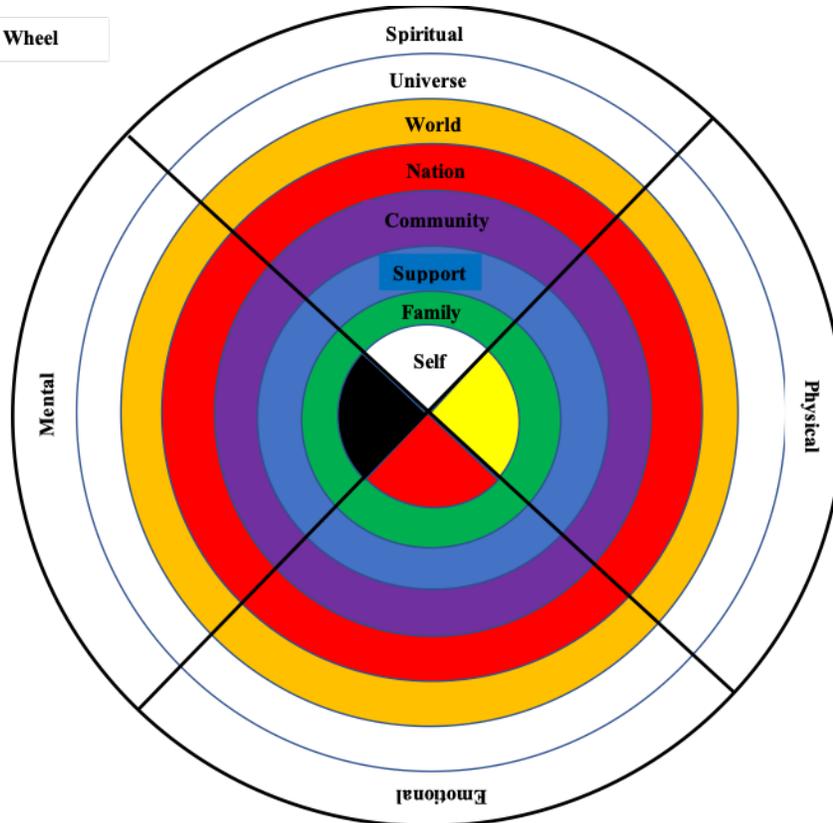
terms of limiting the potential bias that this might introduce, we were carried by the notion that across diverse Indigenous cultural orientations—even when we acknowledge important cultural difference as a way of avoiding pan-Indigeneity in our findings—there was still much shared across in terms of Indigenous values, perspectives, knowing, and doing (Loppie, 2007). Towards foregrounding Indigenous knowledge and worldviews, we presented our framework to members of our Advisory Committee (comprised of persons with Métis, Mi'kmaq, Cree, and Anishinaabe heritage) and also member-checked our preliminary findings with two-spirit IPHAs who come from diverse cultural backgrounds.

THE MEDICINE WHEEL (MW)

As described by Jackson & et al. (2021), the MW was used in 2SHAWLS as a framework because it is also how many Indigenous peoples understand their own physical, mental, emotional, and spiritual well-being (Martin Hill, 2009). Through the MW, well-being emerges from individual factors, but moreover, individuals experience well-being as a relational ethic that connects the self to the wider environment, to spiritual development, and to their cultural context (McGuire, 2010). For these reasons, the Team decided that the Anishinaabe MW consisting of the above-mentioned four dimensions (physical, mental, emotional, and spiritual) would be an effective framework to use in both our data collection and our analysis procedures. We felt the MW would help participants to be more comfortable in data collection—seeing themselves and their culture reflected—in discussing sensitive aspects of their lived experiences.

Though the MW is a common symbol across many Indigenous cultures, nations, and languages, it is not universal, nor is it used or applied consistently across Indigenous cultures (Education Canada, 2014). In addition to a focus on physical, mental, emotional, and spiritual dimensions, the Cree, for example, conceptualize the MW as having five parts, adding a fifth segment representing a social dimension. Inuit the Canadian Arctic, however, do not use medicine wheels. Nonetheless, and grounded in the decision to use the Anishinaabe MW as described above, the Community Advisory Board (CAB) whose membership included an Anishinaabe Elder, worked closely with one of our Indigenous Team members to design and develop the MW for use in the study (see Figure 1 below). This Elder and Indigenous team member provided additional training to the remaining members of the Team and CAB with the goal of achieving a shared understanding of how to apply its use in analysis. The theoretical concepts underlying the MW for this study are discussed by (Jackson et al., 2021) in a companion article. The meanings of the various components of this medicine wheel and its overall concept of “all my relations” (Wilson, 2008) were taught to members of the research team who had little or limited knowledge in this area.

Figure 1: Medicine Wheel



Our use of the Anishinaabe MW served as a tool to encourage dialogue from our participants of their lived experiences and served as an analytic tool for the data collected. Though social science research has only recently begun to frame the ways in which spirituality is an important component of resilience, health, and well-being (Barker & Floersch, 2010), one of the defining qualities of Indigenous research is the integration of spirituality. The inclusion of spirituality was critical to our research process through ceremony and use of the MW. Indigenous knowledge is grounded in the union of the spiritual with the mental, emotional, and physical dimensions of being. All of these dimensions are understood holistically, not compartmentalized or separated out (Fleming & Ledogar, 2008). It is through this worldview that our study, and its MW, were designed.

In the MW that was adapted for the study, the most inner circle represents the *Self*. The second ring represents *Family*, as that is the most immediate circle that one is exposed to after *Self*. Family is not considered to be solely relegated to biology. Individuals who travel away or have been pushed away from their biological family and/or community often find a new family; this may be even more common among two-spirit peoples. The next closest circle that plays a major role in an individual's life is their *Support* network. This may include professionals but may also include people with similar life experiences or identities such as people of the same gender, race, philosophical or political attitudes, values, and beliefs. Next, the *Community* represents the wider range of people that one engages with, but that may not be part of one's support network. The next ring is *Nation*. For each person, this may have different or multiple definitions. An Indigenous person, for example, may have government-issued identification that states they are

Canadian, yet they may align with their ancestral origins (e.g., Ojibway). The next ring is the *World* which represents worldview, or the way one sees the nature of things. The concept of ‘all my relations’ sits here. The final ring, *Universe*, draws upon the concepts of time and space and speaks to an even higher context of ‘all my relations’, evoking our ancestors who have gone to the Spirit World.

RESEARCH AS CEREMONY

Throughout the study, the Indigenous members of the team described engaging in the research process as being *in ceremony*. Based on the work of Wilson (2008), research as ceremony comes from the idea that all work is relational and that by engaging *in ceremony*, researchers seek to understand the connections between the sacred and scholarship (Wilson & Restoule, 2010). There are relationships between team members, participants, and ideas—just as there are relationships between humanity, environment, people, and higher beings (Mertens & Cram, 2016). This relationality and the processes to conduct these relationships are essential to developing strong, community-engaged Indigenous scholarship. Thus, to conduct this study and enter ceremony, certain protocols were observed. For instance, to ensure this research project respected and valued Indigenous worldviews and knowledges, a team of Indigenous community leaders, Elders, and researchers were brought together to form a CAB for the study. These included two Traditional Knowledge Keepers (i.e., Elders), as well as other community leaders who were familiar with the topics of the research (two-spirit men living long-term with HIV). The CAB helped to assert the value of Indigenous Knowledge. Through consultations with the CAB, a series of recommendations were brought forth that helped to ground the study in Indigenous knowledge and ceremony, including the use of our adapted MW, tobacco ties, and smudging throughout every step of the study’s planning and execution.

TWO-EYED SEEING

From the very beginning, there was a concerted effort to employ two-eyed seeing as a guiding principle to the planning and execution of our study. Born out of the work of Mi’kmaq Elder Albert Marshall, two-eyed seeing emphasizes balancing Indigenous ways of knowing with western science to eliminate inequities and improve the health of Indigenous peoples (CIHR, 2015; Martin, 2012). By engaging Indigenous peoples in every aspect of the research process and ensuring a balance between western and Indigenous methodologies, two-eyed seeing enables Indigenous peoples’ cultural connection, safety, and control of the research process. Moreover, balance is meant to suggest that research does not simply embed Indigenous notions into or onto Western research practices, but rather, both perspectives give different, but important views that produce an “integrative science... [that is] wider, deeper and more generative” (Iwama et al, 2009).

One of the more significant ways the research team and the CAB used a two-eyed seeing approach, was to host a two-day retreat where all team members (including the study coordinator and the research assistant) were invited to participate in team building activities, including ceremony. This retreat began with drumming, smudging, song, and a chance to clearly state our

intentions for the working time together. The retreat focused on the context and expectations written in our study proposal and how the team was going to engage two-eyed seeing and ensure that Indigenous knowledges were foregrounded. The team reviewed the Western academic research processes (i.e., research ethics, qualitative methods often used in academic research) and the context of Indigenous knowledges to explore how they might work together. Three of the more significant components of the Indigenous knowledge that were selected by the team for use as the study methods were: 1) the Medicine Wheel, 2) sharing circles, and 3) a participatory symbol-based analysis. (See Jackson et al., 2019).

Our Research Team included members of the two-spirit IPHA community who, while not actual study participants, represented the lived experiences of our participants and participated in the leadership of the CBR study. The Western knowledge components that were built into the study included data analysis that followed a grounded theory approach to first code the data. Data were then located in the Indigenous knowledge context for deeper analysis. The team was also required to respond to the Western Research Ethics Board's requests regarding recruitment and contact with participants (see more below). The team focused on the three areas described above as conceptual lenses and guiding Indigenous principles. As we conducted the study, we used these principles of two-eyed seeing, research as ceremony, and the MW to address the challenges we faced. Below, we discuss some of the ways the team employed these principles at various points during the process of conducting the study.

LESSONS LEARNED IN CONDUCTING THE STUDY

The Western Context of Research Funding

The study was supported by a federal funding body and even though the funding was directed to Indigenous research, there were inherent worldview conflicts that arose. For example, one of these tensions was on timelines and process. A Western notion of time and deadlines is often an important precedent in academic research. The funding is tied to an imposed start and finish date, a completion report, and other timeframes.

Striking a balance between the importance of timelines imposed by our funding agreement, versus the importance of carving out the time required to create a due, proper, and inclusive research process—essential if we were truly evoking Indigenous ways of understanding—proved to be a challenge in this study. Consistent with direction in the literature that highlights the importance of procedure in Indigenous research (Cochran et al, 2008), the team ultimately agreed that process was more important, and the timeline was managed as a secondary product to the complete and comprehensive nature of the study that foregrounded Indigenous knowledge.

The Scoping Review

The need to understand the strengths, assets, and resiliency of two-spirit men living long-term with HIV represents an important gap in the available academic literature. To understand how academic literature addressed resilience amongst this population, a scoping review of peer-reviewed social science and public health literature was undertaken, using Arksey and

O'Malley's (2005) well-established method. Scoping reviews represent a rapid gathering of literature in a given policy, knowledge, or clinical area where the aims are to accumulate as much evidence as possible and thematically map the results to find meaningful patterns in the existing literature. Further details on the scoping review methods, findings, and implications from the 2SHAWLS study can be found in (Jackson et al., 2021) and (Brennan et al., 2021).

The 2SHAWLS scoping review was undertaken as a means of developing an understanding of how two-spirit men's resilience is studied, and to identify gaps within this existing literature. The scoping review methodology, although well-articulated in Arskey and O'Malley (2005) and familiar to many of our research team members, presented unique challenges within this study. Throughout the scoping review process, the research team aimed to be particularly attentive to the ways existing literature described the use of decolonizing and Indigenous methodologies. However, both academic and community team members noted difficulty in determining when and how these methodologies were used in the research literature.

Academic writing often asserts limitations that do not provide room for Indigenous knowledge. For instance, although many of the studies identified their use of decolonizing and/or Indigenous methodologies, few articulated the ways in which ceremony was used in their research settings (Wilson, 2008). This trend illuminated an important challenge in conducting literature reviews of Indigenous-focused research. It also highlighted the difficulty of transmitting and translating diverse Indigenous knowledges within non-Indigenous research settings. Although conducting a scoping review of literature is a Western research method, it enabled us to identify places in the existing academic literature where Indigenous knowledge and methods could be further included and developed.

Indigenous scholars have suggested numerous pathways to ensure that Indigenous knowledge is valued and protected, but rarely have academic institutions taken up these suggestions (Battiste, 2005; Fisher & Ball, 2003; Lavalley, 2009). As mentioned above, this required non-Indigenous members of the research team and staff to put aside many assumptions about what is considered important knowledge based on their worldview in order to allow for the team's efforts to focus on Indigenous views and knowledge. Numerous conversations on these issues took time and space to allow for integrated learning to occur.

Additionally, conflicting approaches to defining community-based research within the articles examined made it difficult to identify these methods in the literature and raised important questions about ethical research with Indigenous communities (Brennan et al., 2021). Throughout our research process, members from two-spirit communities were actively engaged through the 2SHAWLS CAB and as members of our research team. The participatory and collaborative principles of community-based research were prioritized as an ethical imperative within our study (Castellano, 2000; Smith, 1999). However, in the scoping review analysis, our team found few studies that took the time to articulate and note the importance of these approaches to community-based research (Brennan et al., 2021). This has important ethical implications for community-based research with Indigenous communities. Although, as highlighted previously, this may reflect the limitations of academic writing, it is important to question with whom, why, and how community-based research is conducted among Indigenous communities. Active participation and collaboration, especially when coupled with prioritizing

Indigenous methodologies facilitates the unique opportunity of understanding phenomenon through the lenses of those who originally experience them (McLeod, 2007). The 2SHAWLS team developed its own methods to ensure Indigenous representation in as many of the components of the research process as possible.

Finally, our research team also came up against problems in translating our research question into searchable inclusion and exclusion criteria when it came to the literature search on academic databases. Our research question sought to understand the factors, skills, resources, knowledges, and practices that contribute to two-spirit men's health and well-being living long-term with HIV. To identify those articles that addressed our research question, inclusion criteria had to be developed that captured the various intersections of two-spirit men's identities, as well as a holistic and culturally attuned definition of well-being. In doing so, our team came across problems in identifying those articles that focused on Indigenous two-spirit men - especially with research articles that were published outside of Turtle Island (i.e., North America).

Indigenous communities across Canada, and globally, are incredibly diverse. To accommodate this diversity, the team ensured that our inclusion analyses involved active and continuous examination of various names of Indigenous nations and identities to ensure that articles met inclusion criteria. For further details please see, (Brennan et al., 2021).

Facilitation of the Sharing Circles

The team sought to employ decolonizing and Indigenous methods in our data collection as well. Collaborating with community agencies, sharing circles were conducted in three cities in (Jackson et al., 2021) with a total of 14 male participants who identified as Indigenous, gay, bisexual and/or two-spirit, and who had been living with HIV for 10 years or more. The sharing circles were facilitated by a two-spirit man living with HIV and a local Indigenous cultural resource person. Both men were experienced and knowledgeable of Indigenous HIV and AIDS issues, familiar with two-spirit people, and came from a place of not judging participants. The participants were asked: "what's allowing you to live well long-term with HIV?" and allowed to speak as long as they wanted to answer that question. After all participants had a chance to speak, a second round of responses to that same question was invited.

As mentioned above, the circles included a local Indigenous cultural resource person who helped to facilitate the circle. Additionally, a list of local Indigenous and mental health services was provided to participants in each city in the event that they were triggered by any context of the circle or after the circle disbanded. A counselor was also on hand at each circle's site should a participant need to excuse themselves and require support in that moment. Small honorariums were provided to participants to honour their stories, and food was provided to refuel the energy dispensed through engaging in such a draining process.

It was also important that any representative of the research team present in the sharing circle be Anishinaabe. This was critical as an Indigenous representative would be able to address instances if a participant briefly spoke in their Indigenous language. Traditional teachings, identifiers, and any other confidential information were redacted from the transcripts by Indigenous team members. While we were careful to make sure the facilitators of the circle did not influence what

participants shared, they, and the Indigenous team member could also work together to gently nudge the sharing back on point in a respectful way. Having an Indigenous two-spirit man living with HIV and a local cultural resource person as co-facilitators also served to ensure participants were able to openly share if one of the issues discussed involved experiences of anti-Indigenous racism.

The Medicine Wheel was used throughout this portion of the study. The Medicine Wheel developed to use in this project (Figure 1.) was made into a map that was painted onto canvas to be laid out on the floor. Participants were invited to walk onto the Medicine Wheel map, where topics of discussion that we anticipated they may explore were represented on laminated paper by words such as ‘Housing’, ‘Exercise’ and ‘Ceremony’, for example. Participants were invited to move around the Medicine Wheel as they needed, while answering the main question and telling their stories as they pertained to the topics the team had laid out for them. These words were used to prompt topics for consideration as participants told their stories. When participants struggled or began to cry, a smudge was available to help them release what was blocking them as the circle progressed.

Despite active participation, team members faced unique challenges in the participant recruitment and implementation of the sharing circles. For instance, based on REB recommendations, our community research team members were discouraged from having any direct involvement with the recruitment of participants. This REB recommendation, designed to ensure that participants’ privacy was protected and that they felt no pressure to participate, was a concern given the history of Western research exploiting Indigenous knowledge, stories, and people. We attempted to argue for a more nuanced approach, especially given the importance of community relationships, but were given this as a directive and decided as a team to work within the REB’s recommendations. We tried to mitigate issues that we anticipated by ensuring that a local cultural resource person conducted recruitment and was available at all sharing circles, in order to direct participants to local resources should the need arise. However, this also prevented our community research team members from being able to ascertain who was being overlooked for recruitment. Participants themselves also expressed their dismay, as they expected the 2Spirit community research team members to be involved throughout the recruitment process.

Data Analysis

Using a modified version of the participatory model (see Jackson et al., 2019 for further details on our data analysis; Flicker and Nixon, 2014), recordings of our sharing circles were transcribed, and data were deductively coded using NVIVO. Thematic codes were used to organize the transcript data to allow for analysis by the research team. To analyze transcript data as a team, transcript quotations that had been selected by the team for inclusion were then printed out and placed on flip-chart paper under the corresponding codes. This allowed multiple team members to analyze the same data, and for inclusion criteria to be negotiated fluidly throughout the analysis process. Each team member read through all the transcript quotations identified for each code and highlighted quotations that they felt were important to answering our study question: what’s allowing two-spirit men to live well long-term with HIV? A second member of the analysis team reviewed the highlighted quotations and any disagreements were resolved through discussion with the whole team. All members of the team walked around the room and

highlighted quotes that spoke to our research questions. When Teachings, words in Indigenous languages, or unfamiliar topics were brought forward, the Indigenous members of the team were able to provide clarification and advise on how these things related to our overarching theme of resilience.

The Medicine Wheel that we developed to facilitate the discussion/data collection sessions with participants was transferred onto flip-chart paper. Each highlighted quote was given a code in the form of a number and letter (A-11, for example) and that corresponding code was plotted onto the Medicine Wheel. Given the possibility that one quotation could hold multiple meanings, the quotes were coded on any and every space on the Medicine Wheel that it was drawn from or had impact on. Therefore, one quote could be placed on the Medicine Wheel up to twenty-eight times. This mapping process involved reflecting on the content of the quotations, the relationship of the content to our study focus, and the relationships between various quotations, thus creating a literal visual link between the data and the Medicine Wheel, demonstrating the interconnectedness of all things as evoked in the teaching of “all my relations.” All mapped quotations were reviewed and verified by a pair of reviewers (one Indigenous, one non-Indigenous) to ensure consistency and reliability in the review process. As well, this allowed for our analysis to ensure that the results were able to be understood by non-Indigenous audiences. Highlighted quotations, along with their locations on the Medicine Wheel, were then transcribed into a digital data base for ease-of-use in further analysis.

The next step in our analysis involved the identification of relationships between various codes and quotations. As in our previous analysis, relationships were considered by the entire team during an analysis meeting where decisions were reached through consensus. Relationships were identified by determining how codes related to one another, how they related to quadrants of the Medicine Wheel, and the intersections of these codes and their locations across the Medicine Wheel (Figure 2). Identification was inspired either by analyzing the meanings of codes and their relationships to the Medicine Wheel, or by specific quotations that were earmarked as highly pertinent to our study. After further debate and amalgamation of a few of the identified relationships, the team agreed upon seven relationships that answered our study question.



Figure 2. Analysis of relationships between codes.

Further to their identification, the relationships were named by considering their components, the dispersion of these components across the Medicine Wheel, and their relationship to our study question (see Figure 2). The relationships were identified as: Worldview, Finding One's Strength, Walking Towards Balance, Recognizing True Power, Mino-bimaadiziwin (the way of a good life), Self-Care, and Living our Truth. Through the process of naming the individual relationships, the team came to name the entire set as the Seven Paths to Resilience (Jackson et al., 2019).

One of the challenges in doing analysis in this way—employing active participation by research team members, coding and mapping and doing constant check-ins on the validity of the coding in the moment—is that the process necessitated more time than what we would have normally allocated to the analysis.

RECOMMENDATIONS

The 2SHAWLS study was a remarkable opportunity for Indigenous and non-Indigenous community and academic researchers to examine the lived experiences of two-spirit men living long-term with HIV in the context of resilience, health, and well-being. The lessons learned addressed in this paper represent the most challenging and visible team conflicts. Though discussion of the various issues addressed by the team are presented throughout the paper, there are a couple of important points to further address.

The methods employed by the team were meant to bring the knowledges of Indigenous and academic research together to enhance the rigour and usefulness of the study's findings. Based on the work of several other scholars (e.g., Bharadwaj, 2014; Castleden, Morgans, and Lamb, 2012; Lavallée, 2009), the research team and CAB members focused on employing an Indigenous framework (i.e., the Medicine Wheel) and Indigenous knowledges (Lavallée, 2009). Like previous researchers, the team found that adopting an Indigenous framework helped to keep the team on track and produced results that were community engaged and informed (Ball & Janyst, 2008; Lavallée, 2009). By adopting the Medicine Wheel throughout the study, the team was better able to conduct the research in a culturally safe way that allowed connections and relationships to resilience and wellness to be made more holistically (Evans, Hole, Berg, Hutchinson, and Sookraj, 2009; Jackson et al., 2019; Kyoon-Achan, Lavoie, Avery Kinew, Phillips-Beck, Ibrahim, Sinclair, and Katz, 2018).

Several of the issues faced by the team were related to REB recommendations. Given the high probability that research team members would know participants by nature of their community-engaged work, the ethics board was strong in their request to not allow team members to be involved in the recruitment process, for fear of breaches of confidentiality and potential impact on the voluntary engagement with the study. As recruitment numbers were small, Indigenous team members were not able to contact people they knew to ensure them that the study would be done in a culturally safe way, that engagement in the study would be completely confidential, and that participation would not affect their service delivery. Indigenous members of the team felt concern with this request and attempted to change the ethics board's decision, without success. As noted above, the research team saw this overly paternalistic direction as negatively

impacting the ability to connect with potential participants. As other researchers have reported, ethical concerns for research with Indigenous communities require important modifications to increase Indigenous participation and may be more suited to a two-phase review—one that involves an academic ethics board and one that also involves a community ethics board (Ball & Janyst, 2008). However, this may be onerous to academic researchers given that they must submit ethics reviews to more than one institution if the research team involves members of more than one University. Another recommendation would be to increase the number of Indigenous people serving on academic REBs.

Throughout the study, prioritizing Indigenous knowledge was a continuous, reflexive, and, at times, tense process. The ethical issues that arose during the implementation of the sharing circles are just one example of the tensions that can arise between colonial and Indigenous systems of knowledge. For the non-Indigenous team members on our study, discomfort using Indigenous knowledge was an opportunity to confront their positionality. Any tensions or discomforts that arose, however, were mitigated by a willingness to learn and, when negotiated in the presence of Indigenous team members, produced meaningful interactions and enriched the analytic process. For instance, non-Indigenous research team members frequently sought direction during the coding of participant data, especially sections where they felt the data did not directly answer the research questions, but focused rather on traditional teachings and/or cultural knowledge. Fear of misinterpreting the data often led non-Indigenous research team members to be hesitant to code sections such as these and required frequent feedback from Indigenous team members.

Indigenous research team members expressed their own struggles with the analysis process, particularly during coding. Coding the manuscripts involved categorizing key quotes by themes to facilitate a thematic analysis of these quotes. This process of taking the transcripts apart and looking at them independently of the whole conflicted with the holistic worldviews expressed in the sharing circles by participants. In this way, coding itself was, at times, a contentious process, as Indigenous team members had to negotiate their worldviews and those of participants against the priorities of the research methods. Through the meaningful interactions that were produced in negotiation of these tensions, the research team was able to work collaboratively and continuously towards prioritizing decolonizing and Indigenous knowledge throughout the research process. These processes were built on a cross-cultural vocabulary and versions of two-eyed seeing that allowed our Indigenous and non-Indigenous research team members to work together.

CONCLUSION

Through a collaborative partnership between Indigenous and non-Indigenous researchers and community leaders, our study sought to better understand the strength, resilience, and gifts of two-spirit men living long-term with HIV. Through the use of the Medicine Wheel, a CAB made up of Indigenous community leaders, Knowledge Keepers, and two-spirit IPHAs, the study foregrounded Indigenous knowledge and helped to establish a body of research that provides evidence for the development of strengths-based, culturally grounded research and community programs for two-spirit IPHAs.

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