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miyo-pimâtisiwin iyiniw-iskwênâhk (Good Health/Living Among Indigenous Women): Using Photovoice as a tool for Visioning Women-Centred Health Services of Indigenous Women Living with HIV

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INTRODUCTION

HIV in Indigenous Communities of Saskatchewan

The Saskatchewan Ministry of Health Report (2017) found that the national HIV rates in Canada declined from 7.9 cases per 100,000 in 2008 to 6.0 per 100,000 in 2012. Rates plateaued for four years before increasing to 6.4 per 100,000 in 2016. The rate of HIV in the province of Saskatchewan has been steadily increasing since the early 2000s (Saskatchewan Ministry of Health, 2014), and now are within the highest of the developed world, with 19 cases per 100,000 people (Saskatchewan Ministry of Health, 2014; Vogel, 2016). Indigenous Peoples, primarily women under the age of 50, are overrepresented in these statistics (Vogel, 2016). While statistics across the province show transmission of HIV is primarily through sexual intercourse, the primary method of transmission of HIV within Indigenous communities is through intravenous drug use (IDU) with 67% of new cases accounting for this (Government of Saskatchewan, 2017). The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) is committed to creating new knowledge that will be used to support women living with HIV in Canada to achieve optimal health and well-being. CHIWOS has brought together a national research team with expertise and experiences from various fields and areas across the country partnering with Morning Star Lodge. Researchers in Saskatchewan working out of Morning Star Lodge, an Indigenous community-based health research lab, have gathered stories from Indigenous women living with HIV. Using the Photovoice method, the lab is able to provide a unique experience for participating Indigenous women to tell their stories; the visual aids of the methods used assisted the women to dive deeper into their emotions, thus leaving the listener with a deeper appreciation and meaning to their lived experiences. As research is limited with regard to how women access and use HIV/AIDS health services and supports, Photovoice helped to explore lived experiences of women accessing HIV/AIDS care. In an effort to inform positive policy changes directly impacting the care provided to Indigenous women living with HIV/AIDS, we seek to discuss and identify the barriers experienced when accessing healthcare necessary for people living with HIV/AIDS. Systemic racism found within the healthcare system often leaves Indigenous women reluctant to access the care they require, or even acquire the medication that is needed to keep them healthy, highlighting the importance of this timely project (Rachlis, Burchell, Gardner, Light, Raboud, Antoniou, & Loutfy, 2017). Indigenous health research in the field of HIV is beginning to gain recognition as a specialized area that demands cultural responsiveness and distinct methodological skills to achieve results.

The CHIWOS study was developed to address issues of accessing appropriate and culturally relevant healthcare. This cohort study operates within community-based research and GIPA (greater involvement of people with HIV/AIDS) approaches, prioritizing the leadership, and valuing the experiences of the diverse women who are themselves living with HIV. CHIWOS is further guided by a critical feminist framework and a continuous analysis of the social determinants of health over a woman's lifespan and seeks to put its research into action in order to further social change and justice and to improve lives and care for women living with HIV in Canada (Mostafa Shokoohi, 2019).

MIYO-PIMÂTISIWIN IYINIW-ISKWÊNÂHK (GOOD HEALTH/LIVING AMONG INDIGENOUS WOMEN)

Years of oppression and trauma have been caused by a colonial system in Canada and discriminatory practices such as Residential Schools, Sixties Scoop, loss of land, and the loss of culture through forced assimilation. These experiences have contributed to poor health outcomes, increased violence, and addiction within Indigenous communities (Bourassa, C., & Peach, I. 2009). Despite this, Indigenous women are strong and resilient. The rates of HIV infection may be some of the highest among Indigenous women, but this does not deter the women from growing and caring for their families. Living with their diagnosis, these women are determined to not only survive but thrive as they care for their children and their home fire, work, and involve themselves in their communities. Many have found comfort in their children and families, while others balance time between family and ceremony, with ceremony being an active step in decolonizing their lives.

Women living with HIV have expressed their unique care needs through their involvement in the *miyo-pimâtisiwin iyiniw-iskwênâhk* research project. When accessing healthcare or other supports, co-researchers have expressed that they frequently face inattention to their specific social circumstances and health needs, particularly those of a sexual, reproductive and mental health nature. This indication can be seen clearly through the themes that emerged through this research—themes that include action-based reconciliation, access to culturally grounded services, and trauma informed care. In addition, co-researchers identified experiences of diverse challenges in accessing care. Research has suggested that women face not only biological susceptibility to HIV (Auger, Howell, & Gomes, 2016), they also face additional vulnerability due to social factors such as poverty, marginalization, violence, and gender inequity. While there is limited literature and research about how women access and use HIV/AIDS health and social services, these social factors affecting access to care indicate that many women could benefit from women-specific services.

Indigenous Research

Indigenous Peoples are reclaiming Knowledge through Indigenous Research Methodologies (IRM). This includes the sovereignty of research data produced in communities at the direction of Indigenous communities. They are at liberty to choose the research that meets their needs, and how the results will be used and shared in their communities. The language that is utilized within

IRM is vital to ensuring research is culturally safe and addresses any power imbalances that may arise between working research relationships. For example, the term *co-researchers* is used over *participants* as co-researchers hold valuable Knowledge to share within the research process. The purpose of Indigenous research labs such as Morning Star Lodge (MSL), is to initiate IRM by practicing Community-Based Research (CBR) built on a foundation of healthy and reciprocal relationships between Indigenous communities. It is also important for Indigenous communities to consider their worldviews, and how culture and ceremony will be intertwined within the research (Kovach, 2009). In particular, CBR has been a model of research that is popular within Indigenous communities because it utilizes traditional practices such as storytelling, ceremonies, prayer, song, and dance (Botha, 2012; Castleden, 2008; Kovach, 2009; Wilson, 2001). An example of an Indigenous-based research modality utilized by MSL is Photovoice (Wang, 2008). Photovoice is a participatory research methodology commonly implemented in health research as a mechanism for personal and communal change. It is a methodology that aligns with IRM and is commonly used in tandem with CBR. Photovoice centers on the lived experiences of people through the use of video and/or photographs (Community Tool Box, 2019). Photovoice is commonly used in the fields of community development, public health, and education (Wang, 2008). Co-researchers engaging in a Photovoice project are asked to represent their point of view or opinion by photographing scenes relevant to their examined community or peer group. The project begins with a carefully designed research question, which determines the direction of the outcome.

Photovoice empowers co-researchers by enabling them (1) to record and reflect their personal and community strengths and concerns, (2) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs, and (3) to reach policymakers (Wang, 2008). Photovoice has been utilized in many countries by professionals of various disciplines and education. An Indigenous-developed research method utilized in this project for qualitative data analysis is *Nanâtawihowin Âcimowina Kika-môsahkinikêhk Papiskîci-itascikêwin Astâcikowina* (NAKPA), meaning “Medicine/Healing Stories Picked, Sorted, Stored” in Cree. NAKPA is a data analysis method used to analyze qualitative data retrieved from focus groups and sharing circles. This method was derived from an earlier analysis method called the Collective Consensual Data Analytic Procedure (CCDAP) developed by Métis physician Dr. Judith Bartlett (Bartlett & Gottlieb, 2008; Starblanket, Lefebvre, Legare, Billan, Akan, Goodpipe, & Bourassa, 2019). NAKPA, while similar to CCDAP, is a streamlined and digitized version of the method for sorting, coding, and analysing qualitative data that is culturally safe and relevant to Indigenous communities. Alternatively, the CCDAP approach utilizes analog techniques such as cutting out shapes and using a whiteboard for the thematic organization. It has limitations for remote and digitized data analysis techniques, which NAKPA has accounted for and integrated into the methodology.

As IRM typically call for a collective approach to research, NAKPA invites the researchers and members of the research group to gather with community members (who are seen as experts in the field and co-researchers on the project), Elders, Knowledge Keepers and research advisory committee members to analyze the data that was collected. The data from the one-on-one interviews, sharing circles, or research circles were broken down into singular thoughts from the co-researchers. These are brought to the panel to discuss and collectively reach consensus on the multiple themes brought forth by the co-researchers during the interviews. When CBR is being

conducted in an Indigenous community, a level of negotiation must take place with community partners to ensure that the research and data regarding their community members is handled responsibly, and that all parties involved are empowered to all four of the principles within the framework of Ownership, Control, Accessibility and Possession (OCAP®) as defined by the First Nations Information Governance Centre (First Nations Information Governance Centre, 2020). NAKPA works to honour Indigenous worldviews and allows the community to have full access and control of the data and its interpretation, making it a suitable data analysis model for community-based research.

METHODS

The Photovoice and sharing circle was performed in Regina, SK over 2 days in March 2018. Eight Indigenous women, who were identified as HIV-positive, participated in the Photovoice workshop. The workshop was centred around a ceremony led by Elder Betty McKenna, Morning Star Lodge's resident Elder, and each morning started with a ceremony and smudge. In adherence to the Tri-Council Policy Statement 2 (TCPS2) - Chapter 9: Research Involving First Nation, Metis, and Inuit Peoples of Canada, MSL ensured that all employees have received their TCPS 2 training prior to engaging in research. Chapter 9 is particularly important for this research as it provides guidance on the ethical conduct of research involving Indigenous Peoples (Government of Canada, 2019).

During the Photovoice workshop, each woman was given a camera and asked to take 4 pictures that were related to the 4 questions that were asked:

1. How do you feel about your health status?
2. How do you feel about the healthcare you are receiving right now?
3. How do you envision your ideal healthcare?
4. How do you envision your ideal health?

The pictures were a means for the women to tell their stories by visually representing their feelings, thoughts and ideals. The co-researchers were transported to areas of strong cultural significance in Regina, allowing them to explore and take pictures of anything that resonated with them in relation to the 4 questions. These areas included local museums, the Mâdawêyatitân Centre, and the First Nations University of Canada. Once the pictures were gathered, the Photovoice protocol was utilized to facilitate the sharing circle where the women were able to answer each of the questions, while showing and discussing the pictures that they took. With the consent of the co-researchers, the sharing circles were recorded and transcribed so that the raw data may be analyzed.

Data analysis of the Photovoice interview was conducted via NAKPA (Starblanket, et al., 2019). Raw data collected by interviews were condensed into smaller quotes, or *nodes* (a term in NVivo that refers to a grouping of coded data). Nodes were then categorized with similar quotes, where a theme for the like-nodes could be established. Novel to this method is the aspect of bringing together researchers, community members, and co-researchers to mitigate the introduction of personal biases in the analysis of personal quotes and nodes. Together, the panel went through

each chunked quote, and separated them into like-quotes in order to determine a common theme between like-quotes.

The Photovoice interview was first imported into NVivo 12 qualitative analysis software where it was broken down into nodes. Nodes were then transferred to a PowerPoint presentation, where each node had its own slide. The PowerPoint presentation was divided into 4 sections, sorting each of the nodes with its associated interview question. A team of researchers and community members gathered at Morning Star Lodge and worked remotely through WebEx software to collectively go through all 123 nodes.

Using a Microsoft Excel spreadsheet, a symbol acted as a placement holder as the header for each column, which helped to avoid bias during data analysis. The NAKPA moderator displayed the PowerPoint and read through the text of first node and placed it in the first column of the Excel spreadsheet. The moderator then read the second node, and the panel discussed whether that node resembled the first node or not. When it did resemble the first node, it was placed in the same column, and if it did not, it was placed in a new column. All nodes for the first interview question were collectively analyzed by this process until all nodes had been placed in a column. Once the nodes were placed into their appropriate columns, the data analysis team evaluated the nodes within each respective column, ultimately establishing a theme. Upon agreement of a theme, the symbol in the header was replaced by the theme name. This process was repeated until there was an overarching theme for each column. The process was repeated until each interview question had been analyzed. Each question was analyzed on separate Microsoft Excel spreadsheets. Following NAKPA, overarching themes were placed in a table alongside the interview questions. Themes were placed in order of relevance, which was determined by the number of nodes per theme.

FINDINGS

Themes by Question

Using NAKPA, the themes discussed during each question were found. Up to 8 themes were found in each question.

Table 1: *Minor Themes of the Photovoice Workshop* (see Appendix 1).

Table 2: *Overall/Major Themes of the Photovoice Workshop* (see Appendix 2).

Largely, there were five overall/major themes that stood out during the Photovoice workshop as we explored the life and care of these eight resilient women living with HIV: *medical care and support, self-love and self-care, cultural responsibility and support, the challenges and stigma associated with HIV, and women's needs and parenting.*

DISCUSSION

When discussing the women's health status, the most important point the co-researchers brought up was learning and accepting their status, as well as taking care of themselves through self-care and self-love. Through acceptance, they were able to heal. As one co-researcher stated:

Yeah, you see the tears, but the tears are a medicine, it's a part of me, just having to really digest things and process things a whole lot throughout the years.

The women talked about their life prior to finding out their HIV status and following the discovery of their infection. Some of the women opened up and discussed their turbulent pasts, and how discovering that they were HIV-positive saved their lives. Because of the infection, they had to choose between life and death, and through their resilience, rose above to fulfilling lives.

I honestly felt my whole well-being was in a bunch of disarray, a bunch of pieces. And on my journey now, I'm finding the pieces that fit like my spirituality, my physical, everything, my whole wellbeing. I'm hoping that one of these days before I go home, like to heaven, I want to be a whole person again.

A universal symbol for change and metamorphosis is the butterfly. Caterpillars undergo a metamorphosis to transform into often quite majestic butterflies. It is no wonder people who have gone through such a level of change associated with them; this is what one of the co-researchers saw when she took a picture of a butterfly kaleidoscope.



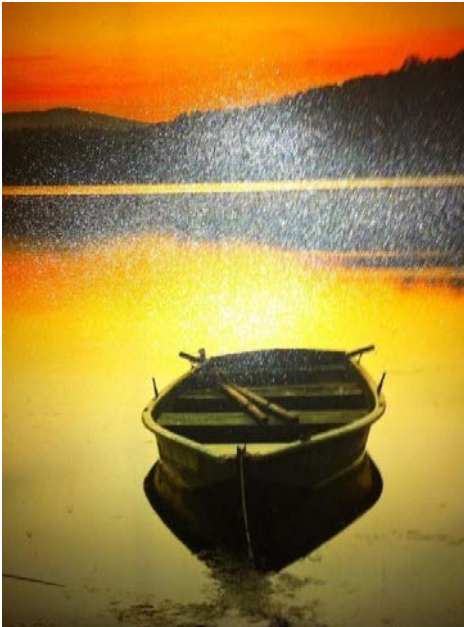
I have a picture of a butterfly that was taken in the museum, I believe. And that butterfly, to me, means that I went through a transformation. I was living in the dark for a long length of time in my life. I believe that I was lost, and I used drugs and alcohol throughout my life then I started to like myself, began to start to love myself, but I had to go through a lot of struggles to do that.

Because the women were able to accept their diagnosis, their resilience enabled them to build a better life for themselves through self-care and self-love, thus it is no wonder that they would be concerned about their relationships with the people that surround them. Many of the women pointed out that it wasn't always possible to build meaningful relationships when HIV-positive; many people don't have all the knowledge to understand the illness. This often leads to a breakdown of relationships, fear of transmission, and judgement. One co-researcher even

described a scenario where her significant other encouraged her to infect him, much to her dismay:

There was this one man, he was the first guy that I ever met, and I just told him that and he was like, really? And I was like, yeah. Well give it to me then, I'll have HIV, I'm okay, and stuff like that. I don't want to give it to him, I'm not his first and last and I don't want to ruin his life. He was willing to and I couldn't believe that, that's crazy.

This often left the women feeling alone. Dealing with an HIV infection can make it seem like the world is against you or has turned its back on you. Many of the co-researchers lost friends and family because of their infection. This was demonstrated by one of the co-researchers with a picture of a boat that she took:



When I first found out about my status, I felt alone. At first, when I found out about my status, and scared, I thought it was a death sentence. Now I have learned more about HIV, being a peer mentor, and my motto is no one has to go through this alone. And now I feel like I felt alone but I put the boat there because I felt like I had nobody, and I thought it was a death sentence and I felt all alone.

Medical care, support, and education were also very important to how the women felt about their health status. It was very important to them to adhere to their health plans, whether it be in terms of taking their medication, visiting their practitioners and support team, or being staunch advocates of their own health and health care.

I think my health is good at this point in my life because I'm choosing to take care of my health, I advocate for adherence to medication. I believe that if I feel ill or something bothers me that I want to get it fixed, I want to get it checked up, I don't let it go.

It is important to note that the co-researchers believed that Western medicine wasn't the only important aspect of their medical care, they also felt that cultural support systems were essential to their wellbeing. Cultural support systems can include Elders, ceremony, family, spiritual balance, and culturally safe spaces and all of these things were seen to aid in their spiritual, emotional, and mental health and are extremely important when dealing with HIV.

I really don't know what I would do without my belief in Creator and my strong belief in my ancestors and my blood memory and all those prayers my old kokum laid down for us to be living in a good way.

The lived experiences shared by the women told a story of hope and transformation. Many of the women expressed they were in very bad places when they were informed that they were HIV positive. Through their own resilience, however, they were able to build their lives back together, piece by piece.



I prayed a lot and now I feel like I have learned quite a bit about HIV, being a peer mentor, now I feel like a sunflower because I can bloom in the morning and be able to sleep at night without having to worry about my illness and worrying about what people think of me.

This resilience has helped them overcome many of the stigmas and negativity that surrounds people who have been infected with HIV. Some of the women told accounts of withholding their status from their family and friends out of fear of being alienated or abandoned.

Well, at first, I felt like withholding my status and not telling anybody because of all of the stigma and everything. And about what I'm hearing from my friends and family, how they talk about people with HIV and AIDS.

The quest for positive healthcare was on the mind of all the women participating in the Photovoice workshop. Some of the co-researchers had found a team of professionals that they could trust and rely on to provide them the proper care and support that they needed through their journey with HIV. These positive healthcare experiences made the women more apt to seek out help when they needed it, like when they are feeling unwell.

There's a doctor, I picked this because me and my doctor are actually on the same page. He gives me time to explain where I am, how I feel. He takes the time to explain everything and it's awesome because I like this doctor.



Everything is all good, but I think it should be every three to four months instead of, I think in Saskatchewan it's six months. Yeah, because we did in Vancouver, that was my only issue with that question, but other than that, yeah. That's why I had the clock up there because it represents more frequent testing, timewise.

That being said, it has not always been easy for the women to access the proper services. Many of them struggled for a very long time and had to fight to be heard and treated with dignity. Unfortunately, judgement and racism remain within the healthcare system in regard to Indigenous Peoples, and these women were further stigmatized because of their intravenous drug use—a disease that carries its own stigmas, and through which they may have contracted HIV. Culturally unsafe care and stigma can lead to a reluctance to seek the healthcare services they need.

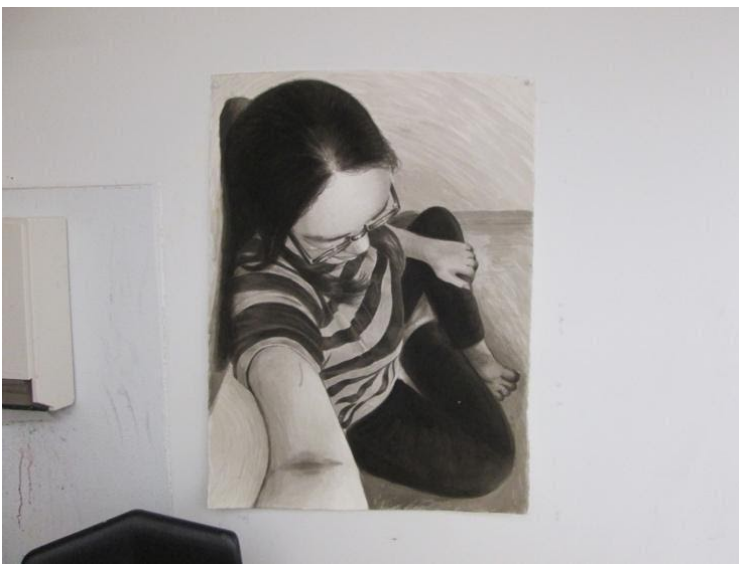


I feel like I have had to fight a battlefield and be in a war for my services being provided to me on the Western world, disciplinary or whatever, scale. I have had to fight to be where I'm at in my life. It has been a tedious, long, strong journey.

The reason why I picked the roses and the bible is because it was so rocky at first and I felt so in the dark and it was like I was drowning, and I didn't know what to do. And I was always raised to pray, that's the bible I had in my hospital room and I still have it up to this day and I have had it for so long, my nephew gave me.

However, positive healthcare experiences gave the women strength to take ownership of their healthcare. Self-advocacy is extremely important to these women who are dealing with a healthcare system that was not designed for them. In order to self-advocate, knowledge on HIV became crucial. Active learning of all aspects of the illness—including treatment, transmission, healthcare, supports, and lifestyle—have led them to seek out adequate care in all aspects of their health. With raised expectations, they have the power to demand more out of the healthcare system.

I know things have firmed up and my thread has gotten stronger, and I know that I deserve that space. So, when I feel the need to, I will go in and I will own that space, some people find it very threatening because they are not used to being told in a way from a strong woman. This is not something people are used to in this history, in this era right now, we're very feared. The doctor, they always want



blood work, right? I chose that one because with the arm out it looks like she is, again? Sometimes you get a technician that is very judgemental, criticizing because they see the track marks on your arms and they look at you like, oh. And I'm like, well you can get this vein really good. She looks strong, kind of hurt a bit but humbled, and that's how I felt and that's how sometimes I still do feel.

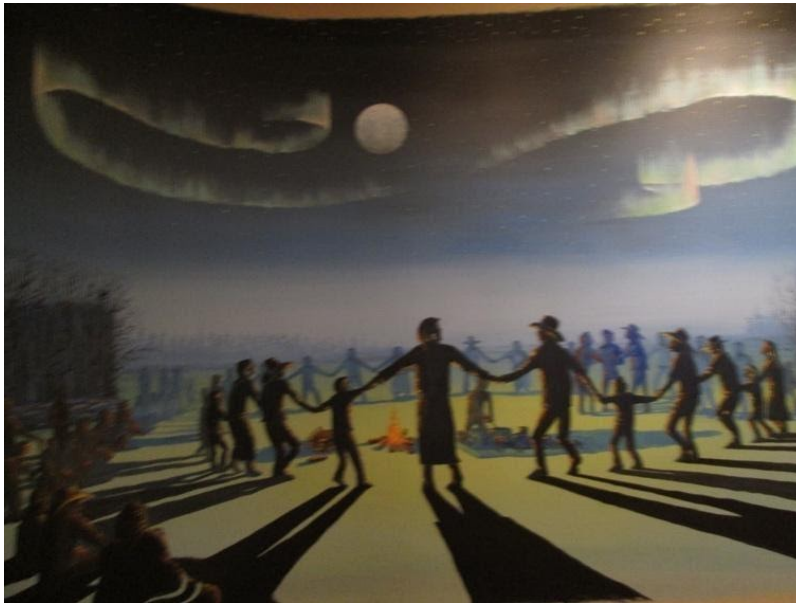
It was pointed out that an area severely lacking services was to the HIV-positive youth. One of the women was diagnosed as a youth, and she expressed that there were no services, no safe-space, and no support. Being so young, it made the whole experience vastly more traumatic. It was discussed that supporting youth in this situation is extremely important.

Youth have no space to be, youth, positive youth, there are no services in this community that exists that are for them, by them, and even the spaces, we lack all of that.

Again, it is very important for these women to have a cultural support system. Being connected to their roots helped them fight for the adequate care that they require on their journey. Having the support of family and Elders was essential to their healing and healthcare.

Good healthcare is around there, we are connected to the land, connected to the Creator, to the plants and animals, the stars, grandmother moon,

grandfather sun, all the medicines, the trees and the rocks, we are all connected.



During the workshop, the women painted a really positive and beautiful picture of what their ideal healthcare would look like. This came in three big overall themes: *medical care and support, cultural responsibility and safe spaces, and parenting.*

Within medical care and support, the women spoke of getting the appropriate support and services. This included medical staff such as doctors, specialists, and nurses, and support staff for things like mental health, detox, and pharmacists.

Support staff, specialists, multidisciplinary teams, women, health services, safe spaces, medicines on site and used in spaces on location, Wascapios [Elder's helper] on site.

Furthermore, the services would ideally be fast, reliable, and culturally safe. This would persuade these women, and likely more Indigenous women who are HIV-positive, to access these services. It was pointed out that often the services needed are in urban centres while they reside in rural areas, creating barriers in accessing appropriate healthcare.

I wish there were more clinics closer and more supporting and transportation for far away and hopefully some day for future care.

Systemic racism is well documented in the current healthcare system, and having a system that is free of racism and culturally safe would further persuade women with HIV to access these services. Moreover, having support staff that are more understanding, caring, and concerned about their patients would heighten the positive experience. Appropriate training in cultural safety for staff would be ideal in this case.

I envision my ideal healthcare is the nurses are more caring and concerned, some of them act snobby and everything. I'm not saying all of them are like that, but the majority of them are like that, racist and everything. They need to go through a really good course about not being that way.

Having culturally safe spaces and being culturally responsible was critical for women's ideal health care. Access to Elders and Wascapios, ceremonies, and access to lodges were discussed; a more pressing idea was brought forth; cultural translation. Many of the women talked about their doctors being caring and patient, carefully going through their care and medication with them. It was suggested that perhaps if Elders were trained about illnesses such as HIV, they could transmit the knowledge in a manner that is culturally understood. This cultural knowledge transmission would help the women make applicable decisions about their health, healthcare, and lifestyle.

I really wish there were more Elders where we could go and talk to them and how we feel or taught about the sickness, that they would be able to explain it to us in our way. Be able to explain it in our culture way, then the other ways of the doctors and that, if our Elders were taught that way, they would know how to speak to us about letting us know what to do.



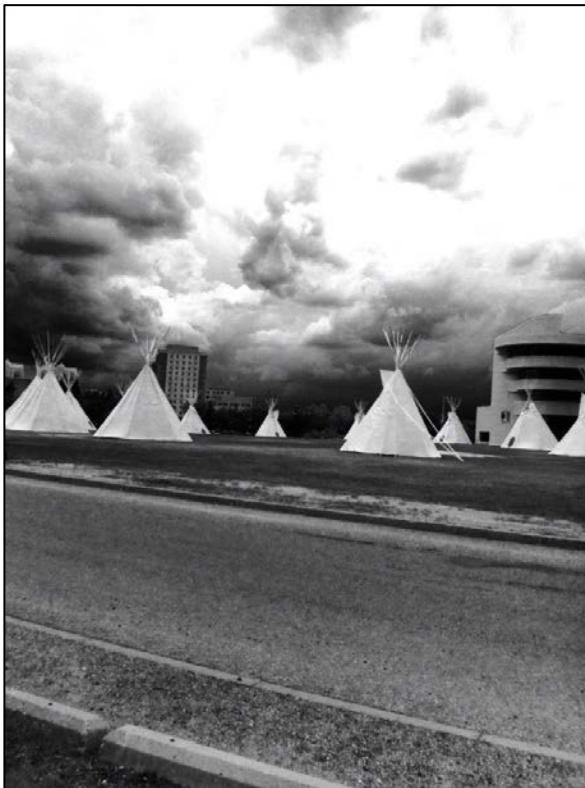
Right there, to me when I look at that picture, that looks like an old kokum, that looks like honouring our old kokum's prayers and our ways of being, that they have been in their roles and in that way of being since time immemorial. And that is going to allow us to be who we are, that's going to allow me to be who I am, when I go in there and I self-identify, I'm doing the self-identifying, they're not doing the labelling and sticking another label of attachment onto me, a label of judgement and discrimination on me.

A lot of the co-researchers were also mothers and grandmothers. As a part of their ideal healthcare, it was important to them that their children also be taken care of and welcomed along with them during appointments. Many were single mothers and could not always arrange for childcare while they were accessing healthcare; bringing their children along to their appointments was the only option. This was not always greeted with pleasure, leaving the

women feeling helpless. Because of this, it added reluctance to them seeking the care that they should have been getting or putting off important appointments.

I need places that are child friendly places that engage families. Quit telling me that I can't bring my kids, my kids are a piece of me, and this was years ago they would be right there along with me and nobody would say nothing about it.

Ultimately, the best-case scenario for an ideal healthcare would be a One-Site Health Lodge, where all these services are readily available. By being able to access all aspects of their medical care, in a culturally safe space, with Elders and ceremonies on-site, this Health Lodge could be visited with their family and personal support team without any hassle. The comfort this would add surely will help women heal in the best possible way.



My ideal healthcare is all the resources, so I picked the teepees and it's because it reminds me how it used to be in the olden days, the village. And you go see whoever has this and then you'll go seek guidance with our elders and whoever and ask them and tell them about your illness and whatever and they'll envision it. And the cloud looks like a little angel up there, to my eyes anyway, and it's like it's watching over the village. It's watching over the village and I feel at peace with this picture because I wish our culture was like that again, how we used to be as a whole, as a family in a village and everybody knew each other, and everybody helped each other.

The women discussed what they envisioned for their ideal health. This introspection on their own health spoke of the future these resilient women wished to live, and the world they wished to live in. Action-based reconciliation was a topic all the women agreed upon. Constantly having to face discrimination and battling all the health disparities Indigenous Peoples in Canada experience is something they strongly believed added to the high rates of morbidity and mortality.

I need people, even myself, to honour the treaties and respect the treaties so that we don't live in discrimination, because discrimination is another act of violence

which is another thing that you can uncover when you look at high rates of morbidity and death, mortality.

Having access to culturally grounded services and resources like Elders, ceremonies and safe spaces is also included in their plan for ideal health. Being rooted in culture helps the women find the resilience that they need to keep focused on their journey with HIV. Learning and honouring their Elders also helps keep them grounded.

It's because of our culture, how strong our people are, us Aboriginal people and how strong our prayers are. I remember what my grandfather always told; listen to the elders they have a lot to teach you. I have done that as I was growing up and I have learned so much and I'm thankful that I was able and blessed to have had that.



I thought it was a pretty good example, in my eyes. The elder doing her teachings with a lot of the women, showing them how to do their teaching, showing them how to burn and that, teaching them. So, that is why I picked that one, being able to have the teachings from the elders.

Practicing self-care, self-love, and living healthy lifestyles is also a priority when it comes to their ideal health. The idea of self-care and self-love for these women first started with accepting their status and forgiving themselves for the mistakes they had done in the past. This was the only way to move forward and build a better future. This helped to lay the foundation on which they were able to learn and grow, living with HIV.

Forgiving myself. I did a lot of bad stuff and I really felt guilty about it. I didn't feel good about myself until I learned how to forgive myself and forgive other people.



This picture, I chose because I feel like I missed out from having a mom, so I never got the teachings of how to be a woman, how to act. Like when I got my period, I was too scared to tell my stepmom, so I just kept it to myself and finally when I was done, she asked me, and I told her, and she got really mad at me for not telling her. But I was really terrified of her. So, that's pretty much why I took it because I want to be able to look in the mirror and maybe smile.

With forgiveness and practicing self-care, it also became important for the women to live healthy lifestyles and learn new healthier life skills to help them on their journey. Healing their mind, body, and soul was often key to achieving this healthier lifestyle. They learned how to eat better, rest, exercise, and take care of their body. Their status made them realize that this was the only life they had, and they had to make the most of it.

I need to feel good in my mind and my body and my spirit with living a balanced lifestyle, feeling my physical self by having my eight hours of sleep, eight hours of work, and eight hours of play.

Making a commitment to their health and adhering to all aspects of their medical care is part of their ideal health. Attending appointments and taking their medications as prescribed was also part of that commitment.



I believe medication adherence, my ARV is keeping me in good health, I am staying undetectable.

That's a picture of a medicine wheel and we are all made up of four, the physical, mental, spiritual, and emotional. And to be in balance, we have to look after each and every one of those in our lives.

Trauma informed care had not been discussed until the question of ideal health was brought up. Some of the women have lived traumatic experiences, and when certain boundaries are crossed, it can trigger a very strong negative response. It was expressed that having boundaries respected was important for their health.



I need my boundaries respected, I need my boundaries respected and I need sexually trauma informed care, I need life coaches and I will continue to need those for however many moments I need them.

You're looking at my bundle that I have created, and it has brought me nothing but good feelings, like smudging every day, and I have learned. And it taught me lots, how to properly use the stuff we use for smudging and I used to just try to burn them whole and then I finally watched an elder breaking them up and I'm learning. I was just so happy that I'm learning all this, and I smudge my house all the time, yeah, I'm liking it, it made me stronger.

CONCLUSION

While Indigenous research is as ancient as Indigenous Peoples, adapting novel research ideas to fit Indigenous worldviews has been at the forefront of IRM. Using several novel research methods, Indigenous women with HIV were able to discuss women-centred health services that would benefit them, and indeed, all Indigenous Peoples. The use of photography was able to inspire the co-researchers to dive deep within their emotions and trauma to reveal stories of resilience. While Photovoice itself was not originally intended for IRM, it aptly fits the model of Indigenous worldviews as it is a form of storytelling. Knowledge, including storytelling, is orally transmitted from generation to generation and is key to Indigenous traditions and ways of knowing.

Traditionally, our people viewed all diseases as a gift from which we can learn, from the nature of it, how we respond as a people to it, what supports do we gather to assist those afflicted with it. In our communities, we view disease not as belonging to one person but to the greater community. We didn't need to know about the disease, we relied on the ancestors to guide us through our Ceremonies.

This research project has also demonstrated NAKPA as a culturally appropriate method of qualitative data analysis to be used for research with Indigenous communities. As Indigenous

Peoples and communities are actively participating in the research that benefits them, data analysis has been an area which often leaves communities out of the process (Bartlett & Gottlieb, 2008; Starblanket, et al., 2019). Some data analysis methods lack the community's involvement, resulting in data leaving the communities and labs for researchers to analyse that data and assume conclusions without community input. The development of NAKPA resolves this issue and helps to foster Relationships, Reciprocal knowledge sharing, Respect, Relevance of research and results, and holds researchers Responsible and accountable for the research they conduct within communities (Kirkness, 1991).

Through the process of Photovoice and NAKPA, barriers in accessing adequate health services were identified, and positive solutions were reached on how to change policies and tackle the systemic racism that is found within the healthcare system. The co-researchers were able to discuss sensitive and traumatic experiences. Their resilience persisted throughout the research process; they learned to accept themselves, see their self-worth, and worked on self-love through self-care. Co-researchers advocated for positive health care experiences which are inclusive of culture and ceremony. Accessing services that focus on knowledge and cultural responsibility removes barriers and the stigma surrounding accessing HIV healthcare services. Ultimately, the women wanted to have healthcare services that supported their wants, and needs so they can be strong women for their children and families.

Through the Photovoice process, eight Indigenous women were able to share their experiences living with HIV. A positive HIV diagnosis is often seen as a grieving process; but to these women, it was rebirth. They were about to change their lives for the better through healthy and positive choices. The research explored the narratives of what contributes to the health needs of Indigenous women living with HIV through a Photovoice process. The study identifies strength-based factors such as reconciliation with family and friends; some co-researchers spoke of finding their culture and immersing themselves in it. Some even became mentors to people with newly discovered HIV-positive status. They have risen above the negativity and stigma surrounding HIV to lead full and meaningful lives through sheer resilience. These women have truly become role models for the communities that they serve.



So, why the picture was is because right there you see the tepees, that's all those beautiful cultural things that I shared about but do you see that sky and you see the light? So, that's why I picked that picture because I have hope and you can see that sun and that's where the ancestors shine down from. And it looked like a lady that's serving the clouds there, with a boat and hair.

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Ethics

Ethics was obtained through the University of Saskatchewan research ethics board.

Appendix 1

Table 1
Minor Themes of the Photovoice Workshop

Question	How do you feel about your health status?	How do you feel about the healthcare you are receiving right now?	How do you envision your ideal healthcare?	How do you envision your ideal health?
Theme 1	Learning and accepting	Positive healthcare experience	Support and services	Action-based reconciliation
Theme 2	Wellbeing, self-care, self-love	Search for positive healthcare experiences and adequate care	Cultural responsibility	Access to culturally grounded services and resources
Theme 3	Medical care, education, and support	Challenges of youth with HIV	Cultural and safe spaces	Women's health needs
Theme 4	Relationships	Worldview and cultural support system	Utilizing healthcare services	Healthy life skills and lifestyles
Theme 5	Overcoming stigma and negativity	Struggles accessing services	One-site health lodge	Self-love and self-care
Theme 6	Hope and transformation	Self-advocacy	Parenting	Trauma informed care
Theme 7	Cultural support systems	Knowledge of your own healthcare	Systemic Racism in HCS	Existing support systems
Theme 8		Negative healthcare experience, judgement, stigma		Medication adherence

Appendix 2

Table 2

Overall/Major Themes of the Photovoice Workshop

Overall Themes	Medical Care and Support	Self-love and care, (learning, accepting, relationships and lifestyles)	Cultural Responsibility and Support	Challenges and Stigma of HIV	Women's needs and parenting
Major Theme	Medical care, education, and support	Wellbeing, self-care, self-love	Cultural support systems	Overcoming stigma and negativity	Women's health needs
Major Theme	Positive healthcare experience	Relationships	Worldview and cultural support system	Challenges of youth with HIV	Parenting
Major Theme	Search for positive healthcare experiences and adequate care	Hope and transformation	Cultural and safe spaces	Struggles accessing services	
Major Theme	Knowledge of your own healthcare	Self-advocacy	Cultural responsibility	Negative healthcare experience, judgement, stigma	
Major Theme	Medication adherence	Self-love and self-care	Action-based reconciliation	Systemic Racism in HCS	
Major Theme	Existing support systems	Learning and accepting	Access to culturally grounded services and resources		
Major Theme	Trauma informed care	Healthy life skills and lifestyles			
Major Theme	Utilizing healthcare services				
Major Theme	Support and services				
Major Theme	One-site health lodge				