

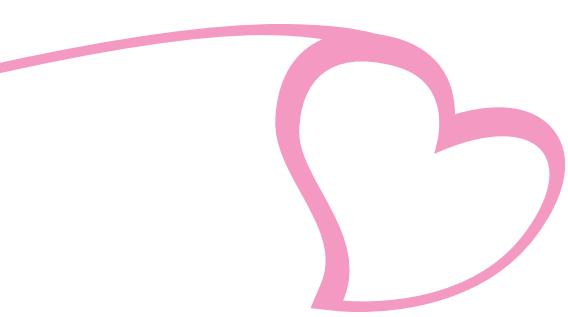


Resurgence of Our Relatives:

Centering Kinship and Storytelling in Indigenous HIV Doula Work

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LAND ACKNOWLEDGMENT

This project took place on the original lands of the Indigenous People of Turtle Island, including the ancestral territories of the Anishinaabeg, Cree, Oji-Cree, Ojibwe, Dakota and Dene peoples, and on the homeland of the Métis Nation. By acknowledging these lands, and by respecting the Treaties that were made on these territories, we are encouraged to continue honouring our relationships with Indigenous people as a part of ongoing reconciliation efforts, which will serve to educate the generations to come.

TABLE OF CONTENTS

Acknowledgments	4
Preface	5
Background	6
Methodology	8
Findings	9
Summary and Conclusion	28
Recommendations	29
References	30



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Ka Ni Kanichihk Inc.

"those who lead"

**Village
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ACKNOWLEDGEMENTS

The team would like to thank the members of the community who participated in this study and shared their stories, knowledge, experience, and wisdom with us. Your perspectives, experiences, and expertise have tremendous value. We hope to do justice to your voices and perspectives throughout this report.

FINANCIAL SUPPORT

We are grateful to the Gilead Sciences Canada, Inc. for their financial support of this initiative.



GILEAD

Creating Possible

PREFACE

The development of this project was based on feedback from community members who were already working in Manitoba and involved in doula work in a variety of capacities and indicated that the experiences of Indigenous women living with HIV or at risk of HIV were never adequately captured in formal research or community initiatives on doula work. These individuals also spoke of the importance of this research to identify unmet needs, promote tangible benefits for community, and to further enhance the sustainability of those benefits, including the creation of future culturally sensitive and innovative services, outreach, and interventions that focus on HIV doula work in Canada. As a result, Laverne Gervais and Rusty Souleymanov worked collaboratively and initiated the application to funders to develop and design the study within a framework that diligently accounted for systems of power and oppression that were in line with the reality of the lived experiences of Indigenous women and 2SLGBTQIA+ people living with HIV and participating in the study. Laverne Gervais through her work at an Indigenous-led organization called Ka Ni Kanichihk Inc. (www.kanikanichihk.ca) already supported the work of First Nations communities to help improve health outcomes for Indigenous people, including front-line sexual health outreach, HIV care and prevention, and doula work. Dr. Rusty Souleymanov's Village Lab (www.villagelab.ca) at University of Manitoba was also well-positioned to leverage its networks and research infrastructure to enable the implementation of this study. The result of this community-university collaboration included the formation of a research team and hiring of Candace Neumann who generously offered her personal and professional expertise and experiences to the success of this endeavor, including the implementation of participant recruitment, building relationships with communities, data collection, data analysis, and knowledge exchange. Through this collaboration, the project was carried out between May 2022 – March 2023.



BACKGROUND

Very little is currently known about the role of Indigenous doulas in HIV care and prevention with Indigenous (First Nations, Inuit, and Métis) women, particularly those that are living with, or at risk of HIV. Even less is known about impacts of Indigenous doulas on HIV prevention and care among these communities in Manitoba. While traditional roles of doulas have been documented in research, less is known about how Indigenous doulas can play a role in HIV care and prevention for Indigenous women. There is an urgent need to understand how Indigenous HIV doulas can support women (as well as Two-Spirit and non-binary people) when it comes to HIV care cascade.

PROJECT OBJECTIVES

This community-based research study responded to current and pressing knowledge gaps concerning the role of Indigenous doulas in the HIV care, prevention as well as health and wellbeing of Indigenous women and 2SLGBTQIA+ people living with, or at risk of HIV in Manitoba.

The specific study objectives were:

- To explore the role of Indigenous doulas in HIV care cascade in Manitoba, with a particular focus on how Indigenous doulas impact Indigenous women's and 2SLGBTQIA+ peoples' engagement and access to HIV care, treatment, prevention, and healthcare,
- To explore the role of Indigenous doulas in HIV health system navigation for Indigenous women and 2SLGBTQIA+ people in Manitoba, and ways Indigenous doulas can support these populations' linkage to HIV care, treatment, and prevention.

Finally, we also wanted to build capacity among Indigenous women and two-spirit people to engage in HIV community-based research and Indigenous-led sexual health initiatives.

THE ROLE OF DOULAS

Doula is a term that has its roots in the tradition of women supporting other women during pregnancy, labour, birth and postpartum (Campbell-Voytal et al., 2011). A doula provides continuous physical, emotional, and advocacy support during labour and birth, but does not provide medical or midwifery and nursing care (Campbell-Voytal et al., 2011). The role of doulas is documented as an important component of health management, pregnancy, childbirth, and critical cultural practices that are respected as essential to establishing and revitalizing the strong cultural connection and spiritual path for Indigenous children (Wiebe et al., 2015). In research conducted among First Nation communities, the role of doulas was identified as a central recommendation to addressing the health and wellbeing of First Nations women (Wiebe et al., 2015). While traditional roles of doulas have been documented in research, less is known about the role of Indigenous doulas in HIV care and prevention with Indigenous women and 2SLGBTQIA+ people living with, or at risk of HIV.

WHY THIS WORK IS IMPORTANT FOR MANITOBA

Manitoba has the second highest rate of HIV infections in Canada compared to other provinces (Haddad et al., 2019). In Manitoba, over fifty percent (n=59; 51.3%) of clients of the Manitoba HIV Program self-identified as First Nations, Inuit, and Métis in 2018 (Manitoba HIV Program, 2019). Indigenous women accounted for 81.4% of all women diagnosed with HIV in 2018 (Manitoba HIV Program, 2019). In addition, in 2018 among Indigenous People in Manitoba the co-infection rates for Hepatitis C, Chlamydia and Gonorrhoea have increased dramatically (Manitoba HIV Program, 2019). Many issues, including HIV facing this population stem from the long history of colonization and abuse (i.e., residential schools, the Sixties' Scoop), which can predispose people to sexual health disparities (Ristock, 2010). These same inequities may also increase HIV risks and a variety of other health disparities for this population, yet very little data is available about Indigenous women's health in Manitoba, particularly when it comes to HIV care cascade. This lack of data in Winnipeg is particularly perplexing, given that Winnipeg has the largest urban Indigenous population, compared to any other Canadian city (City of Winnipeg, 2018).

Research has identified the potentially devastating impact access barriers have on the health status, wellbeing, and quality of life of Indigenous People Living with HIV/AIDS (IPHAs) (Duran & Walters, 2004). Research also suggests that Indigenous people are more likely to have a later HIV diagnosis compared to non-Indigenous people (Stokes, Pennock, & Archibald, 2006; Manitoba HIV Program, 2019), have slower uptake of anti-retroviral treatments (Wood et al, 2006), and less access to experienced physicians (Miller et al, 2006). These care seeking behaviours, coupled with a lack of access to HIV testing have contributed to higher morbidity, shorter survival times, and a mortality rate for IPHAs that is three times higher than for non-Indigenous



persons (Lima, 2006). In Manitoba, negative social determinants of health and systemic racism faced by Indigenous women result in unfair inequities when accessing care, lack of HIV testing, PrEP awareness, and inequitable access to culturally safe treatment (Manitoba HIV Program, 2019). Little is currently known about how Indigenous doulas (who are peers in this community) can facilitate HIV care and prevention cascade for Indigenous women in Manitoba. The current lack of health data on Indigenous women in Manitoba is at odds with the Truth and Reconciliation Commission's calls to action, which highlighted the need to fulfill the right to health for Indigenous people, as well as at odds with the Calls for Justice outlined in the MMIWG report. We propose to supplement this gap in knowledge.

METHODOLOGY

Data were drawn from community-based participatory research conducted between November 2022 – January 2023 and that focused on the role of Indigenous doulas in HIV care continuum in Manitoba. Our approach was consistent with a decolonizing community-based research approach. Our approach has been developed to: 1) inspire social change and transformation for the benefit of Indigenous women in Manitoba, particularly those living with HIV; 2) be grounded in localized contexts; 3) build community capacity; and as a result, 4) make decolonizing CBR a valued and empowering approach for communities involved in this project.

Ten participants were recruited using word of mouth, peer networks, and a community agency serving Indigenous people (Ka Ni Kanichihk Inc). Data were analyzed using thematic analyses. Each transcript was double checked for accuracy in the translation. Analysis and interpretation of data involved all research team members (i.e., academic and community). For this qualitative component, this study utilized thematic analysis, which was appropriate because we are interested in an approach that focuses on generating themes surrounding HIV care and prevention.

FINDINGS

Sitting in conversation with the participants filled my heart. These conversations took place while the days got shorter and the nights longer, and the earth was covered under her winter blanket. Winter is the time for sharing stories. Each participant shared beautiful stories that ranged from happy and humorous to heartbreaking and tragic. One thread that wove through each sharing was the importance of kinship in all aspects of support for Indigenous people living with or impacted by HIV. This section looks at the ways that relationships could inform the role of an Indigenous HIV Doula. I honour the stories about kinship to loved ones, to ceremony, to land, to community, to each other, and to experiences, that each participant shared.

- Candace Neumann

Do you think people newly diagnosed, or living with HIV could benefit from there being HIV doulas?

A common thread among respondents was the benefit of having a doula role performed by peers. The sentiment was strongly expressed by one participant who stated, "Oh, definitely, 100%. The need is out there."

When thinking about a doula training and support, participants thoughtfully reflected on the range of beliefs that folks have:

"And showing them a doula way, it could actually comfort them, knowing that they're not alone... just having that training there, and other people connecting with the ceremonies that we have for doula training, because a lot of people don't understand it was lost with residential schools."

An important piece that was emphasized by participants was how doulas could provide support in both HIV education and testing processes for people. The following quotes exemplify this:

"Even with the self-test kits, it's very iffy to give a person that doesn't even have HIV, give them a self-test kit. Here, take a couple, keep on testing yourself. And then they test themselves by themselves. All of a sudden, they're positive and they're by themselves. So, I think these self-test kits need to be guided properly. They need to be done in front of somebody that is positive or knows stuff about HIV in order for them to understand and know that they're going to be okay, right?"

"What would have been helpful if I knew I was being tested, if I knew what HIV was, because back then people still, I'm sorry to say, but even in my own circle, people don't talk about it still? So, I think that should be talked about a little bit more and to give the youth education."



Some participants spoke about the benefits of the doula role during pregnancy, labour and birth. One participant talked about vertical HIV transmission, and the role of HIV doulas during pregnancy, and HIV viral load management:

"Because she's scared because she thinks she's going to transmit HIV to her baby, but really, as she took the antibiotics, the drugs, that thing they gave her, and then the baby can have it after. But she can have a perfectly normal labour if she is at a viral load of a certain percent. But after that, then there's going to have to be a Caesarean. Because I had my son Name-X. He was perfectly normal, but later on, I don't know about the drug because my friend too at the same time her son had the same effect as my son, so I don't know if that drug kind of helped us when we were pregnant because our kids are like ADHD and all that. But then when I had my two kids, Name-X and Name-X, I took the drug. One is smart. He graduated at 16. He got two valedictorians. And then my baby he is graduating next year too. So, I don't know, it's like mixed up. And then I had a Caesarean with my two smaller ones, my two babies. So, it's all depends on the woman. If their viral load is good and if they are taking the medication like the doctor says, but some women don't. My friend she died a couple of months ago of HIV and she died alone."

I was moved by a participant who reflected on the care she received from her own midwife throughout the process of diagnoses, pregnancy and postpartum. The following quote shows how she compares that care to the impacts that an HIV doula could have in someone's life:

"I'm being reminded of the midwife. Like, you know, I can't say if this woman didn't have HIV or she did, but I know that she was there for me when I was diagnosed and, like, my whole pregnancy, and then after, like, post-partum. Like, without her, you know ... Because I ended up slipping six months after I had my son, my oldest son, I fell back into drugs for a couple of years. But the first six months of my child's life, like, I wouldn't have gotten through that without her. You know. So, I can definitely relate to confidently saying that, yeah, having that doula, especially if that person is HIV-positive themselves, to help, you know, to be able to be relatable and be empathetic and sympathetic with the person, you know, at hand."

How do you think our community could benefit from having doulas that are specifically familiar with HIV and known as HIV doulas?

In listening to the responses from participants, I was reminded over again of the importance of relationships in community work. As Elder and community leader Leslie Spillett once shared, first and foremost, our culture is our kinship (personal communication). Kinship as the foundation of an HIV doula role is the most fundamental of teachings that was shared by the participants.

The reassurance that comes from connection was reflected beautifully by one participant who recognized how her own experience could be comforting to other young women:

“Well, yeah, like, it would be awesome. Like, even if I could become a support system for somebody, a young woman who, you know, that can just reassure them that it’s going to be okay. Because I remember, in my lowest point of my life, I remember begging someone to just tell me it’s going to be okay, whether or not they actually knew it or not, like lie to me even. So, I can confidently say those words, you know, it will be okay. But with everything to be okay, they got to work. Right? Whether that’s work to getting up early enough to go to that appointment to get that prescription refilled or possibly advocating for patients to have X-amount of refills, so they don’t have to navigate, you know, like, what if we go through another pandemic or some bullshit.”

Another participant shared the impact of simply being present for community:

“Just having that supportive person that can help you access medicines or invite you places and do things and just be supportive. And even just knowing that there’s somebody there, like in the case with the youth that I support, her just messaging me and saying hi, and knowing that she’s going to get a response.”

For one participant fierce love in the form of advocacy is rooted in stories of lived experience and personal knowledge:

“For people that don’t have the voice, for people that are in active use that aren’t able to stand up for themselves and say this is what I need. For people that are being held back their medication because of social workers that don’t know anything about it, but they think that it’s their role to play that they’re God because they are CFS workers. Things like that need to stop. If people knew that there was somebody out there that loved them for their HIV status regardless, they would be able to love themselves more. They’d be able to get out there and be able to allow their families to know that they’re positive. A lot of people are ashamed to go out and tell their family that they’re positive. I took my chance when I came back to my family after 13 years and told them all who was there that I was



HIV positive. I didn't know if they were going to love me or throw me away. Sure, it came with pros and cons, but if that family loves you enough, there are ways to work it out, right?"

Participants not only emphasised the importance of relationship building for doulas, but also for supporting the relationships of the people they work with. Kinship continued to weave through the stories shared as one participant spoke about ways she supports the relationships of the people she works with:

"Within my work, I was able to work with positive and non-positive folk. And then to have discussions with the relationship and educating that non-positive person and going through with the relationship and how things are going with sex and the transmission and the dos and don'ts kind of things. So, I have done that work as well. And I show nothing but respect for the folks there. I also reassure that it's okay for you to continue in this relationship."

The power of kinship and fierce love was further emphasized by the sharing of two participants who spoke about how an HIV doula could specifically support pregnancy:

"But then I can sit there and I can tell her, I know, I know, I've been through it, I've been through it. Yell at me. Get mad at me. I know you're scared. I know you're really upset and everything in your head. It's like you can't grab it right now. And then I'd calm her down and sit and talk to her, and say, we can do it together. Seriously, your pregnancy is going to be okay. The baby is going to be okay."

"If there was an HIV doula back when I was first pregnant, man, that would have been a life-changing scenario for me. Just to have another indigenous positive person in my life helping me out with this pregnancy, especially somebody that has had a pregnancy, that one time being HIV-negative, and then having another pregnancy HIV-positive. Because both of them, although different, and both beautiful, they are totally different experiences, and I have been able to be honoured to experience both...I think they kind of play into the death doula, too, an HIV doula. It has helped transitioning to that next cycle, that cycle living with HIV, and helps live positive with HIV in that you can be nourished and not malnourished) by having an HIV doula, and just the acceptance and support, supporting piece that as a peer giving another HIV peer that peace of mind."

What would an HIV doula look like to you? Who are they? What would they do? Where would they be? How would they connect?

Many of the participants had specific ideas about who, what and where an Indigenous HIV doula would do their work. When asked about who an Indigenous doula should be, most agreed that it should be someone with lived experience:

"It would be a positive person that is willing to put their all into that person, to make them understand that they're human and people love them for who they are and not what they have and allow them to know that they can live healthy long lives regardless of their HIV status. And that if they want, they can be pulled out of that water and walk with you on the road that you're walking and get their voices heard also."

"Yes, yes, definitely. Because I told you, you can do all the footwork, but if you're not positive, it is going in one ear, out the other. When you're first diagnosed, I don't want to hear your pity, I want to hear some positive messages from another positive peer. Hey, you're going to be okay, and that is the kind of (inaudible) when dealing with these women who were newly diagnosed. I didn't give them that pity party, like, I'm so sorry this happened to you. I'm like, no, you're living positive, these are ways to benefit yourself and how to live a good life while being positive. Here are some numbers for whatever you need, supports, if you need to go sit down in an HIV caring circle. When you're ready to start telling your story, here are some people who can make that happen."

"I don't ever remember being offered someone that could be so relatable with. You know. Like, everybody is the opposite of what I see in the mirror. Especially when you're dealing with healthcare, you know. Things are slowly changing, don't get me wrong, you know, but it's because of people like you and me."



One participant shared a powerful story that demonstrated the impact their experience had on someone else:

="Well, you know, I did some surveys. I had this one survey, this guy was newly diagnosed, because that was ... that's the people that we're aiming for in this research study. And my friend there went through the consent form. And then he goes, wouldn't you like, would you like me to introduce, I'd like to introduce Name-X to you. So, I said hi, and he was like, hi. And I told him, I said, I'm 16 years lived experience. His mouth and expression just dropped. It was ... he was just like, 16 years. I said, yes, I've been living with HIV now for 16 years. And then right then and there he got attached. Having an Indigenous doula, or having an HIV doula, there's going to be a connection right away. When you start speaking to him, when you start telling them the truth, you know? And they get attached right then and there. And they want to know more. Because he's like, how do you deal with the suicide park? Because I told him, I said, I ... me too, went suicidal. I wanted to give up. And I told him, I said, you know what? I said, the only thing that got me going is looking at the people I love. It's not time for me to go through that doorway. That doorway is locked, sealed, shut, for a different time. So, I think an HIV doula and somebody living with HIV ... if they can speak a little bit about their past, then that's where they built a trust."

Throughout the stories shared by participants, cultural safety was identified as necessary for the role of the doula. One participant recognized the importance of building relationships, access to ceremony and elders and community programs:

"A lot of the components that I just talked about, one-on-one support, connecting to culture, medicines, also with my youth I'm connected with their HIV nurse, so not necessarily their doctor but their nurse. And they don't reach out but that is the person that referred me to this person, so it was the nurse that said this person needs some extra care, can you take them under your wing? And it took me a while to get in there and the trust built, I think I probably messaged them about 20 times before I got a response. And the only reason why I got a response was because I told them more about me. And then all of the sudden we built a relationship."

"I could see them being connected to the sexual wellness lodge here or integrated into that whole care, because ultimately this would be a perfect place because you've got the elders. They can come in and talk to the elders, you're connecting them with a multitude, plus then you've got all the other programmes and services that you could direct people to as well. And that branches out, you just base it at one organisation, and we often refer to other organisations too."

Another participant highlighted the importance of language:

"I'm Aboriginal. It should be spoken in different languages as well."

One participant shared how her community work reflects the insightful connections she has made between cultural (re)connection and health:

"Yeah. And also that medicine. Like, if there was a traditional doula. Like, not just a doula who has the same status health-wise, but, like, having a traditional doula on hand. Like, because I know how important it is, like, I just advocated and spoke about how important it is to reconnect with your roots or to just acknowledge you have roots to reconnect with and all of that back-story. I think that's important to, you know, the longevity of someone's health."

For Indigenous peoples land and place are more than just where we live, work and are. Land and place are embedded in kinship systems and identity. All participants live in or around Winnipeg and have connections to community in this place. This place is flat, beautiful, fierce, cold, hot, and bright. When asked about places where the work of HIV doulas could be done, the answers ranged from community-based spaces to health care spaces. Despite the range in answers to this specific question, one thing was clear throughout all the interviews, community-based organizations such as Nine Circles and Ka Ni Kanichihk played a role in the care and support of every single participant.

"I'd probably go straight to Nine Circles."

"I just want to know what HSC and Nine Circles put our names up there and see if they're comfortable with it, like the pregnancy. For me, if somebody called me and say like, how did you experience that, how did you deal with HIV pregnancy, like talk to me about it, I can give my experience about it. And if they want me to be there like a doula, then I can help them out. But that's what I said. Nine Circles, HSC."

"My vision would be in the hospital you get diagnosed, and you're given a care package, and these are some peer networks, these are the AIDS service organisations, this is a personal



care. These are some of the indigenous organisations, these are some of the newcomer organisations, and these are some of the breakdowns through basic language, where we can get the supporting services and access to care, for HIV doulas, for support groups, for food and other things where you're like, hey, where do I start, where do I even go to begin getting help for myself?"

"Yeah, so like, Women's Health Clinic, Mount Carmel Clinic, wherever there is a team clinic."

I was continuously moved by the stories and connections shared by participants. In the following quote a participant demonstrates the connection of how kinship and place had a role in the support she provided for a neighbor, and how she was able to create those feelings in the community organizations she has worked in:

"Well, it depends with the area you would like to work in. You can go for an organization. You can go help in a drop-in. Or you can help your neighbours. Like, you can go next door and say, hey. Because I had to do that. A couple years ago, the grandmother ... there's a house right beside us, and they have about five or six kids, and the grandmother came out, and she goes, Name-X? And I said, yeah? She goes, I live up on Furby and Ellis. And she goes, you don't have any money, do you? And I said, no. And then she goes, she said, because the kids are out of juice. I said that I can help. I said, I have no money, but I do got lots of juice. So, I went inside, and she goes, just knock on the door and give it to them. I never met the mother before. I never met the father before. I just knew the grandmother. And I went knocking on their door, and they answered, and it was just like a big sigh of relief, that they had juice for the children. And that is what you see in those organizations when you're working drop-ins, when you're working at stations. You can feel the relief for them. You can feel happy, too, at the same time."

What are some things that are important to you as a community helper?

All of the participants had engaged in some form of community work. The following responses exemplify the knowledge and understanding of their experiences and community work and how it could be applied to the HIV doula role:

"Integrity, trust, accountability. I think trust is a big one and boundaries. Boundaries."

"What's important is awareness. I want the youth to know what they're getting into. They don't know what is going to be up coming. And it's just like, aah. I told my kids when they were younger what HIV is, what STD is and STIs. I told them when they were younger, so they're fully aware."

"I like sharing stories. Sharing stories is a big help because not all of us take meds and people that do take meds share in what are the side-effects on people that do take meds. When I first was diagnosed, I wasn't on any meds. Now I'm on meds, so it's a big difference, a big change for me. So, yeah, just talking with all the people that are dealing with HIV."

"I think the most important thing to me is that when I go out and speak my story, that at least one person hears me, one person gets me. And then maybe they go and tell somebody about what I said and it's a snowball that way. It's healing. By that one person, it's healing you and it's healing that person."

Cultural safety, in the form of spiritual practices, and non-judgemental spaces were identified as being important parts of meaningful community work:

"I like to try to say that I owe everything to Spirit and Creator because when I work with anyone in my life, I look at both sides. So, I'm looking at that non-infectious person and I'm looking at the infected person. When I'm dealing with these two people, these two individuals, I put myself in their shoes. I put myself there. So, how would I be feeling right now?...Whatever it is that they need, I make sure that they get the answer they're looking for. A lot of times they'll come to us outreach because we're easy going people, where they can express themselves and use their language and talk any way they want, and we can understand them. And it's non-judgemental!"

"Having the medicine on hand."



How could culture, traditions, spiritual practices be a part of this role?

Participants recognized that Indigenous people have different experiences of culture, traditions and spiritual practices while sharing their own connection to culture in both their healing, and in support of other people's healing journeys. The following quotes demonstrate the need for cultural sensitivity and respect:

"You know, everybody has their own beliefs. Everybody's raised their own different way. That's what you've got to be careful in ceremony, when you're doing ceremonies, because they're taught their way. And then when they don't see their way, they might give up, they might get mad. You know, they might just do something that normally they wouldn't do. But we've got to learn, all our ancestors came, came from different places. So, they did everything different. So just trying ... you know, we're not pushing anything on anybody."

"Just even having regular times to meet and do something that relates to culture if somebody's interested. Not everybody is going to be interested in culture and I've met a few people lately that haven't, and that's okay. But if they're interested to help grow on that and offer new experiences or even repeat experiences."

Incorporating culture into community work happens in so many ways. The bundles and teachings that each participant carry were only touched upon as part of these interviews, but the light that comes from their stories reflect upon a beautiful variety of ways that people make connections with each other in ceremony, on the land, around a beading table or drum group and more. The following stories demonstrate thoughtful and loving ways that participants have shared their experiences of culture:

"Getting out on the land and just being able to spend a few days out on the land. I'm an inner city girl, but my childhood was full of getting out on the land. And I think for a lot of our Indigenous people in the inner city, they probably have the same thing, but it's really challenging. It was challenging for me even to leave the city for the first time because of my medications, who's going to help me, and then I've got to make 6 million phone calls to get my medication changed. And still to this day, to travel, it's a bit of a conundrum, especially

with harm reduction meds. My doctors are really good at giving me what I need to go, but it's challenging to leave the city, there's a lot of anxiety with leaving the city."

"...like drumming. A lot of people I know, we have such beautiful voices where we can sing together, and that's part of healing."

"When you use medicines and practices of the people, it gives it a more structured and better understanding, because if you're dealing with Indigenous people, you want to bring them back into that kind of knowing where they lost. With me, I was lost because of my addictions and everything and I didn't know anything. And today, I am still learning. I learn each and every day. Sure, I don't smudge every day, but when I do, it lifts my spirit up. It takes away that negativity that's been festering in me until my next smudge. So, I think smudging and our way of life is a big huge part of what needs to be brought into Indigenous people living with HIV or even bringing it into the doula training and stuff like that."

"...another resource centre I was utilizing had little smudge kits. And I had this little smudge kit, it was just a little seashell, for the shell, and it had some medicine, and it had matches. So, I was sitting outside panhandling one day, and I don't know how many days I was up, but my teachings that I carry with me is, you can utilize medicine whether you're high or not, the Creator accepts you and acknowledges that you need to utilize medicine, so by all means. If you can connect to that teaching, then here's some medicine for your connection. So, I started smudging. And these two young girls were walking past me and one looked at me, but the other one just opened the door and was going to walk in. And when she walked past me, she smelled that sage, well, she came right back outside, she didn't even go do her order. She asked me, is that sage. And I said, it is. She says, wow, I haven't smelled that in a very long time. And this young lady must have been, shoot, I don't know, I'm going to say in between 12 and 15. And I said, well, did you want to smudge. And she said, sure. And she kneeled down with me at this coffee shop, we're outside the doors, and so she started smudging. And her friend is just looking at her. I said, did you want to, too. And she said, no. I said, well, do you mind if you just touch the shell. I said, just out of respect for your friend here, who's, you know, taking part in some smudging. And so, she did. And then she started asking me these questions. And I had these answers for her. And she started crying. And I couldn't believe that I was able to like, you know, because I felt like after she sees another person who may be down on their luck, as I was, whether or not it's self-induced or not, you know, because there's always a back-story (inaudible) things up."



“So, medicine. Having medicine on hand is major. Like, wherever you are. Like, I used to carry my bundle ... I don’t have a bundle anymore, but I used to carry a bundle and, you know, every time I see my daughter now, I give her sage. And I try asking her about her ... Because I’ve gifted her a drum and recently, I gifted her an eagle feather, just before Christmas. And I know that she’s not there yet to acknowledge how, you know, the importance of it, but there’s no amount of money that could ... You can’t buy these gifts. Like, I know that she’s not there yet, you know, and that’s partially my fault, in a sense, but, again, there’s back-story to that, you know, that I’m okay with now. And she’ll get there when she gets there. But I always offer my children smudge when I see them. So, medicine is a big one.”

“we need to have smudge kits. And there was a lot of requests. You know, alongside the harm reduction supplies that we’re handing out, you know, medicine was right in there, going in there with them. So, just, you know, being open-minded and allowing people to have the option to utilize the medicine is a huge one, I think, for our community. You know, there’s a church, like, I remember advocating before, when I was doing some sort of research, whatever I was doing before, you know, it came up that there’s a church on every corner, but there isn’t a sweat lodge, and the sweat lodges that are, they’re not as easy accessible as a lot of the churches. You know. So, smudge.”

The role that culture has played in the healing of participants and the community they live and work in is powerful. One participant highlighted the medicine wheel and understanding the life cycle is grounding and healing:

“Like I said, just with HIV and healing, I don’t see another way past that. Everything from your acceptance to you moving forward, it has a life cycle, and just to incorporate that medicine wheel, those traditional medicines. To really get grounded and knowledgeable, and being able to speak to Creator, and go to these ceremonies, and know that you’re accepted, positive or not, and that we’re all one.”

Culture is kinship, connection and so much more. The following story shared by one participant, a well-respected community worker, demonstrates how a beading circle fostered a moving relationship of trust and support for both the worker and community member:

“this one gal, she knew her lifestyle was rocky and she knew she was getting sick, and she just started coming to me in October/November and started to share with me. I did a beading workshop, so she was coming there. Very powerful moments when you’re beading and doing that kind of work and the topics that people and women speak of. And again, she was very vocal. No filters on this woman whatsoever. Still a rough life, still dabbling in using and she was saying that she was getting pains and feeling sick. And I was talking to her and she goes, the doctors won’t help, they won’t do nothing. And then she came again the next week. I said, well, maybe go to the hospital, just go. She goes, ah, no, I probably won’t get out of there. I said, well, you never know, but we need to check that out, right? So, she did go and she never got out of the hospital.... I was just reflecting on our last conversations and I was so grateful for her because when I’m reflecting on those conversations, I think for me and her as individuals, we both kind of talked about the process, the healing and that it was going to happen. And she was so brave, like it was nothing. You know what I mean? I try to put myself in her shoes and I’m like, I’d be crazy. I’d be devastated. She didn’t really have a good relationship with family. Her children weren’t very fond of her, but it went peacefully and suddenly. I had never seen that amount of courage from somebody that literally knew they’re going to die.”

What would you need to do this work?

Participants were clear on what they would need to do this work.

“Like a dedicated position, yeah. A paycheque. A little bit of money to take people out for lunches or make sure that they’re taken care of the best way that I can in the position that I’m in. So, maybe there’s an incentive, not an incentive but some way to make sure that they have mitts for the winter and stuff like that. A huge resource list of places to go and help them go to those places, yeah.

Food budget, for sure.”

“I just think if we can get a dedicated few positions or even one position would make a difference at this point. Because I know even with me, and my work is not dedicated to supporting people, I still try to support people in whatever time that I can. But having a dedicated position to doing that could help more than just a few people.”



“we need to be acknowledged that we’re out there. We need some place to call home. I think if you had a home, like Manitoba Moon Voices, a home. You know what I mean?”

“The doula trainers for HIV need a home, that way they’re stronger. Whereas if you’re just an individual doula trainer and nobody recognizes you, you’re stuck. You don’t go nowhere. If people knew that there is a home for doula trainers for HIV positive people and newly diagnosed, then they’ll be able to access that more likely and your name will be put out there. And it doesn’t mean that they have to come to you. You can go to them. And I think the biggest thing is that we need a home.”

“I would probably like a team behind me, ready to do that, too. Just to be prepared for it.”

“I would really like there be a link to care. Like I said, when somebody gets diagnosed, they go to clinic once they’re ready. Even if they’re not ready to start their medical regime or their healing journey, that they know there’s peers that can come to my appointments with me. There is somebody that can come sit at a sharing circle with me. There’s somebody that would come to my house and give me supplies or anything that I needed if I was too shy to get those services on my own because I’m uneducated right now. If I wanted to get educated, is there another peer I would feel comfortable with helping me navigate the system on where I could go for counselling. If there is a 24-hour emergency crisis line I could phone, if there was a support group for men, women, two-spirit, if I’m going through gender-based violence, where do I go. Healthy habits. Just education about why it is important to follow your medical regime, why it is important to have that balance with your spiritual journey and your healing journey, where can I get those supports if I need them so that I don’t have to walk alone.”

Alongside cultural supports, medicines, ceremony, and care packages for newly diagnosed folks, paycheques, resources for care, a place to work out of, a team of workers, and links to care were also identified as being needed to do the work. In fact, in the process of interviewing participants, many had expressed interest in being called to action when the time comes to carry on this work.

How has HIV or STBBI diagnosis impacted you or a loved one? How could this inform the HIV doula role?

Participants answers to this question reflect one drop of the ocean of knowledge held in their stories and experiences. Likewise, my understanding of these stories and the ways they impact my feelings and spirit, are limited by the brief time spent together sharing them. The following stories are powerful and hold a variety of teachings. I light a smudge as I write this to honour the words of every participant.

The following participant shared how after her diagnoses, she was forced to reflect on her relationships and her responsibility to her community and herself. The love she has is a huge part of who she is as a community worker:

“So, it was an eye-opener for me, for sure. It was a big, big eye-opener and after I was diagnosed, because I have a lot of empathy and I have a heart, so I couldn’t continue living the way that I was. Because most likely, I’m going to end up infecting somebody else or just dying of AIDS or an overdose or something. But it was a big eye-opener and when I told my parents, my mom, I just yelled it at her and she had just gone through my brother’s suicide, so it was hard. And she tried to provide me as much support as she could, but I feel like I was hatched from an egg a little bit, me and my mom are getting a lot closer. But for sure, it was a big eye-opener and led to steps to make me change the way that I was living and to live healthier. Now, my response is just take care of myself, make sure that I’m taken care of, and do the best that I can for myself.”

The following story shared by a participant left me speechless. The human experience of having the courage to face what is before you, taking the leap and landing in the warmth of a relative’s acceptance is beautiful:

“I think the thing that really made me strong in order for me to disclose my status to my family was one of my fellow mates that were living on the street with me, his name was Name-X. He was singing up, chanting to the ancestors in a park where I was going to sit to get rid of my dope sickness. I could hear this Indigenous chant song coming from a male. And when I saw him, his arms were stretched way up, like he was singing to the ancestors and everything. It was at night and you could see all the stars and everything around. I asked him politely if I could sit and join him, and he said, sure, so I started getting my medication ready so I could get well. And he continued singing his song. After he was done, I said, that was beautiful, what was that? And he said, I have to sing to the ancestors to see if they could guide me on what I need to do in order to allow my family to know that I’m HIV positive. As soon as he said that, I hung my head and I said, I am too. I said, you know what, your ancestors have answered because you just told your first family member,



me, your sister, that you're positive. And we hugged each other and I said, you shouldn't have any problem telling your extended family that you're positive. So, I think I'll end with that story."

The stories of familial and community kinship shared by this participant throughout our time together made me cry during our interview:

"It's really heart-breaking because I lost my kids five years ago. And I'm trying to make it up to all my kids. And then I see the ones that are running back and forth. They come to me and then they want to stay with me. Oh, you can be my mom. And then I'm like, I'm not your mom, you have a mom, and just go back. But then they tell me their stories and it's like, okay. So, it's kind of like a different story. But the thing is I tell them I'm HIV. I have a lot of issues. I have to work on myself. But I love them. Any resource I say get better parenting for people who are HIV, because some of them don't even know how to react to it. Some just give up and some people don't know how to deal with it. Seriously, when I first found out I thought I was going to give up, but later on, when I met other women and resources, I call them the grandmothers. They're my grandmothers and they taught me well. And a lot of them showed me how to respect myself. I try to do that with these ones like Sisters of Fire and all that. We're all learning you know. We're all learning...Well, my family. I can't even go anywhere. I'm stuck at home and everybody is really watching me. My brother will phone. See people are just calling me right now. My family is calling me non-stop. But I don't know. This is my family, but I don't know if people to have that support, And I'm sorry, but if you really need support, you should call me and I'll give you support too. Because I know how the feeling is being alone. You think you're alone but you're not alone. We're all fighting this disease together. We're all the same person."

Like the participant above, this participant really reflected on the impact her diagnoses had on her parenting, and the steps she took to ensure the well-being of her child:

"Okay. When I found out I was HIV positive, I just went in for a yearly check-up. I didn't know what my doctor ... my doctor just said, here, here's your blood work. Go take your blood work. And so, I went and did my blood work, and then he called me back. He goes, I can see you in the office. That's when he had ... that's when he told me I was HIV. I was just in shock at the time. He goes, I'm going to refer you to a specialist. So, I said, okay. And that was Dr. X. But during that time that I first found out, my daughter was only about nine years old at the time, and I booked an appointment with her pediatrician, because I didn't know

how long I had it for. And because I was still waiting for three months to see the specialist. But I took her in, and I spoke to the doctor, I said, I just found out I was HIV positive. I said can we test her too? And doctor said, sure, no problem. Thank you for telling me about that, because that's family history right there. So, they did a little blood test on her, and she came back negative. So, I was just like, okay. And she goes, we'll keep testing her for every six months for a while, though. And I said, okay. And so, I was just very happy and stuff like that, for that support that we got."

The next participant has an active and involved role in community work in Winnipeg. She is passionate in her role as a peer and uses her humour and intelligence to advocate for her community.

"It made me want to make my ... I have this saying, if you're 9 to 99 years old, get tested. It doesn't have to be scary. Walking with HIV is always going to be scary when you're first diagnosed, but it doesn't have to be. We've come so far in medical history that I said, it doesn't have to be a death sentence, you never have to get AIDS. I'm living my best life positive right now, that I ever was. HIV doesn't define me as a person....Yeah, we do testing events. I'm actually on the Go Ask Auntie campaign, and I'm also, because I'm a peer and I'm a positive peer, I'm also two-spirited, a lot of testing events I've been asked to in case somebody has a reactive, that they at least have somebody there immediately to talk to firsthand."


The next participant shared how her diagnoses made her relationships with her family and peers stronger:

"I think it wasn't really an impact but it got us closer to each other. I'm saying that as my children and my family we've gotten a little bit closer now that they know that I'm HIV. So, we've gotten close. I'm closer with my friends too that are living with HIV and people are more open and talkative towards each other."

Lastly, the following participants shared how their diagnoses challenged the relationships they had with partners and family. Their stories reflect experiences of stigma and emphasize the need for education. I was personally humbled by these stories, as they reveal nuanced, relationship dynamics of living with HIV:

"I just wish ...ex-boyfriend should have signed confidential paperwork, like don't disrespect the trust. But I told him what we experienced....I got into a fight with my family, and one of them reveals it, and then, yeah...it was just like a sneak attack"

"I guess, recently, I'm going to say, it impacted, you know, my relationship. If you're not with somebody when you, you know, because I was alone when I got diagnosed and then having to disclose my status, I think is a huge ... Which was kind of hard. You know. I actually didn't take my pills for a good two months recently and my HIV spiked right up."



If there was a training for this role what should it include? What would you like to see in a training?

The purpose of this study was to inform the role of an Indigenous HIV doula. The following answers both reflect the individual experiences and stories of the participants and set the foundation for the community work to come:

"I definitely have some ideas. I think for sure trauma-informed care, especially with Indigenous people. There are some good books out there and you probably know them, and then motivational interviewing and learning how to talk to somebody to keep them talking. And learning how to do it in a good way is a very big skill that I learned that helps me with communicating with people. And we like to think that everybody knows how to set boundaries, but I've learned in the professional world, not everybody does. So, some training on boundaries and how to hold boundaries in a good way."

"Definitely spending some time with elders, it should be grounded in culture but also having those basics like motivational interviewing and a lot of how do we work with others. And a lot of, what would you do if this happened? It helps with a lot of case studies, and I hate the word case study, but that's what they call them."

"I say get better parenting for people who are HIV, because some of them don't even know how to react to it. Some just give up and some people don't know how to deal with it."

"I would like to see ... well, obviously to make sure that there is cultural-safe aspects, so cultural safety while working in the workplace (inaudible) training, making sure that your personal health isn't jeopardised in any way. To do lateral kindness when working with other HIV doulas because of the sensitive material that is going on. Really just knowing your roles and responsibilities, and how delicate it is working in an area of expertise. I feel like I am a wisdom holder, and somebody with lived experience should work in those positions."

“When I think of that and I think about all the people that I worked with, and when I think of the colonization, when I think of the trauma that everybody that I worked with. So, again it’s marginalized people that I’m working with, right? Some of these people don’t even know their identity, no spirituality, no culture, and they want to be ... oh, god. Definitely, I would have to say culturally led for that and respect, high, high, high respect for the people that we would be working with, very high respect, and a lot of kindness. It’s not an easy job. It’s not for everyone. Certain folks will have that sort of gift. Not everybody can do this work and I can’t express that enough because when you’re working with us Indigenous people and stuff like that, without being racist or anything of the kind, I think our people would really prefer to work with our own people. And that’s huge. And that’s huge because that’s where we’re going to feel comfort. That’s where we’re going to feel strength. But at the same time, there is negativeness with that because of trauma at residential schools and then the abuses that people went through, sexual abuse and all that kind of stuff. But it’s a start. It’s a start for our people, right?... What has worked with me is non judgement and a lot of kindness and lots of respect, and just show them love, love, love, right? And validation of these people, listening to the people, letting their words be. Those are very powerful things.”

“One thing that I never brought up was the anger. There’s a lot of anger, lots of anger. So, that’s more hurt, right? Lots of anger from the folks, and lots of folks they feel that nobody is helping them. So, to translate nobody is helping into helping, I have to help the people see what the help is that they’re getting, because sometimes they’re undervalued by us. We don’t see significant change and stuff like that. Those things are relevant too. And then the anger is another thing. They’re mad. They’re mad at their life. They’re mad that they’re now HIV positive. They’re just resentful, and sometimes they’re dangerous too, right? I had to work with all kinds of folks like that too and it’s challenging, very, very challenging. I just learned, try not to take things personal, and that is really key, but sometimes it’s hard to do that, right?”

“Sensitivity class... Emotional, mentally, spiritually, and it depends which gender they are and what sexuality they prefer.”



SUMMARY AND CONCLUSION

For Indigenous people in what is currently known as Canada, relationships to land, community, ceremonies, stories, and each other have been disrupted by hundreds of years of colonial violence. This legacy continues to impact Indigenous women and 2SLGBTQIA+ people living with HIV. The recent resurgence of Indigenous birth work has led to the reclamation of the role of helper, or doula. Utilizing the power of stories and relationships, this study explored the role of Indigenous doulas in HIV care and prevention.

The findings of the research, in the form of conversational interviews and storytelling, reveal that Indigenous HIV doulas have the potential to impact the current landscape of HIV work in the Indigenous community of Winnipeg. Through kinship, storytelling, and culture the role of the Indigenous HIV doula is informed by relational ways of being and accountability to the community. The work is part of a community bundle that is held together with the love of the people who share it.

In summary, what participants identified as needed for this work to happen is proper compensation and training, dedicated positions, and resources for care. Participants also noted the need for commitment from agencies including integration of this work within community-based agencies and health care spaces alike, promotion of the work performed by HIV doulas, and links to care. Finally, participants emphasized the need for a home, a specific location that is designed for Indigenous HIV doula work. A space that is culturally safe, judgement free, and connected to community. This space would also include cultural supports, medicines, ceremony, and care packages for newly diagnosed folks.

Next, the recommendations for training of Indigenous HIV doulas were thoughtful, meaningful, and relevant to the community. Comprehensive training in trauma informed care, motivational interviewing, boundaries, and communication were indicated as being necessary to the professional practice of Indigenous HIV doulas. Training on cultural knowledge, ability to work with elders, cultural protocols, ceremonies, and knowledge of medicines were identified as necessary for meaningful and culturally safe work. Finally, knowledge of reproductive and sexual health, gender and sexual identity and HIV treatment and care were noted as being important in the work of Indigenous HIV doulas.

We continue our work and capacity strengthening with peers, Indigenous communities, and service providers whose work will be directly informed by the findings generated from this project, and who will implement HIV doula programs within their organizations. Our partner organizations can use these data to inform their services and traditional ceremonies with regards to sexual and physical health management for Indigenous women and 2SLGBTQIA+ people at risk of, living with HIV. This project can inform services, interventions, campaigns for Indigenous women and 2SLGBTQIA+ people living with HIV or at risk of HIV in Manitoba.

RECOMMENDATIONS

Service providers need to be aware of a variety of benefits that HIV doulas can bring to their agencies and communities, including advocacy, community support, and relationship building. Professionals who work in this field would particularly benefit from knowing more about: the nuances of HIV/STBBI doula work, the benefits of HIV/STBBI doulas, and referrals for people newly diagnosed and/or living with HIV to access HIV doulas in Manitoba.

It is recommended for organizations that do this work to include people with lived experiences, including people living with HIV in doula roles. Community organizations can advocate to funders to include people with lived experience in service and programming, highlighting the importance of centering the experiences of people living with HIV in doula work.

Creating platforms and spaces at community-based organizations and health clinics/healthcare settings for doula work is essential. Both community agencies and health clinics within community settings need to consider incorporating HIV doula positions within their workplaces.

Through consultations with community members this project established a variety of considerations that need to be taken into account to perform HIV doula work. These considerations include: 1) proper compensation for HIV doula work, 2) commitment from agencies to establish and apply for funding for these positions, 3) integration of HIV doulas within agencies team, 4) creating physical location/places to perform HIV doula work, 5) promotion of this work within communities, 5) inclusion of cultural supports, medicines, ceremony, resources for care, and care packages for newly diagnosed folks within the context of HIV doula work.

The interviews revealed a variety of recommendations for training HIV doulas. Participants spoke of the need to train doulas in trauma-informed care, motivational interviewing, boundary setting, communication, ability to work with Elders, as well as knowledge of reproductive and sexual health. In terms of other recommendations, knowledge of cultural protocols, ceremonies, as well as cultural safety, embeddedness in culture, and knowledge of specific Indigenous communities where this work is performed was reported by participants as essential knowledge and skills needed to perform HIV doula work.

Finally, service providers and professionals involved in the provision of doula services need to be informed about the unique health needs of Indigenous women and 2SLGBTQIA+ people at risk of, living with HIV in Manitoba and be able to identify resources to deal with a variety of sexual health outcomes through HIV doula work.



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