

“Who is there to support our women?”: Positive Aboriginal Women (PAW) speak out about health and social care experiences and needs during pregnancy, birth and motherhood

ABSTRACT

Women living with HIV (WLWH) in Canada are increasingly planning to become pregnant and have children. This is due in part to the success of antiretroviral therapy and reduction in vertical transmission rates to less than 1% of babies born to WLWH, thereby emphasizing the need to focus attention to their perinatal experiences and needs. It is equally important in Canada to understand the unique context in which Positive Aboriginal Women (PAW) experience pregnancy, birth and motherhood especially given the overrepresentation of Aboriginal peoples in the HIV epidemic. It is essential to acknowledge PAW’s individual perinatal experiences within the broader context of colonization, the residential school system, poverty, experiences with child welfare, HIV-related stigma, systemic racism, and lack of culturally supportive health and social services. Drawing on the experiences of 29 PAW in Ontario, Saskatchewan and British Columbia, this paper highlights the challenges that PAW confront as they move through pregnancy, birth and motherhood including experiences of HIV testing, perinatal care, and challenging interactions with the child welfare system. Of critical importance however, is the resilience, that PAW embody through connecting to spirituality, family, Elders, ceremonial rituals, oral traditions, tribal identity, and support networks.¹ Hence, the PAW who shared their stories with us demonstrate practices of resistance to stigmatizing practices that are rooted within themselves, their communities, and their culture, providing key recommendations for how to support PAW during pregnancy, birth and motherhood in ways that work.

INTRODUCTION

Motherhood in Aboriginal Communities

Pre-contact, women have historically held a central social role in Aboriginal¹ societies (Halseth, 2013; National Collaborating Centre for Aboriginal Health, 2012). Although Aboriginal communities are diverse in terms of language, geography, culture and tradition, women held special roles in all communities as givers of life (National Collaborating Centre for Aboriginal Health, 2012; Canadian Aboriginal AIDS Network, 2010). Moreover, concepts of motherhood within Aboriginal communities transcend the biological to include culturally specific “individual and communally complex relational practices” (Halseth, 2013: 2) and recognize the many roles that community members play in ‘mothering’, such as the passing on of knowledge necessary for survival (Withlow, 2014). Hence, the entire spectrum of mothering, from pregnancy onward, involves a “multitude of roles and relationship across times, spaces and generations” (National Collaborating Centre for Aboriginal Health, 2012: 3). The implementation of the *Indian Act* in 1876 undermined the existing matriarchal structure of some Aboriginal communities and created systems of colonization, racism and oppression for Aboriginal peoples in Canada (Canadian Aboriginal AIDS Network, 2010; Peltier et. al. 2013; Canadian Aboriginal AIDS Network, 2004).

¹ The term “Aboriginal” is used throughout this paper and was explicitly chosen to reflect the language of the *Constitution Act, 1982*. The term “Aboriginal” refers to individuals who identify with at least one Aboriginal group, i.e. First Nation (North American Indian), Métis or Inuit (Eskimo), and/or those who report being a Treaty Indian or a Registered Indian as defined by the Indian Act of Canada and/or who are members of an Indian Band or First Nation (Statistics Canada, 2008). Aboriginal peoples includes those who live on and off-reserve and those who identify as Aboriginal but are “non-status.” We recognize that language pertaining to Aboriginal peoples in Canada continues to evolve and that the term “Indigenous” is increasingly being used in research and community-based initiatives.

Colonization in Canada has resulted in a shift away from pre-existing matriarchal systems and has undermined the cultural and linguistic traditions of Aboriginal women. Moreover, the imposition of a European patriarchal system has led to the diminished role of Aboriginal men as protectors and providers (Canadian Aboriginal AIDS Network, 2010; Bucharski, Reutter and Ogilvie, 2006) and highly valued role of women as mothers and keepers of cultural knowledge and tradition (National Collaborating Centre for Aboriginal Health, 2012; Andrew, Smith and Van Herk, 2010). Cumulatively, the impact of the residential school system and other discriminatory legal policies has resulted in a range of damaging consequences for Aboriginal peoples in Canada including intergenerational trauma and the breakdown of traditional child-bearing, birthing and child-rearing practices (Bennet, Blackstock, De La Ronde, 2005). Discrimination based on gender and the loss of social roles contributes to Aboriginal women being five times more likely to be the single parent in single parent homes (Halseth, 2013; National Collaborating Centre for Aboriginal Health, 2012).

The role of state child welfare systems in the lives of Aboriginal families entrenches the discriminatory practices that are aimed at “protecting” Aboriginal children (Downey, 1999; Trocmé, Knoke, Blackstock 2004; Greene, O’Brien-Teengs, Whitebird, Ion, 2014). The impact of colonization and the continuation of discriminatory policies and practices are in turn responsible for the increased risk of HIV facing Aboriginal peoples in Canada (Public Health Agency of Canada, 2010a; Public Health Agency, 2010b). Hence, “living with HIV” becomes yet another layer of stigma and oppression that presents real emotional, social and political consequences for Positive Aboriginal Women (PAW). PAW is a term coined by longtime First Nations HIV/AIDS advocate and activist Keisha Larkin that highlights the importance of

adopting a self-chosen empowering identity that gives dual and culturally relevant meaning to being “positive,” (Peltier et. al, 2013).

PAW and Pregnancy, Birth, and Motherhood

Research has demonstrated that WLWH are increasingly planning to become pregnant and have children due in part to the success of antiretroviral therapy and reduction in vertical transmission rates to less than 1% (Chen et. al., 2001; Cooper et. al., 2002; Forbes et. al. 2012; Loufty et. al., 2009). Women who are at risk for HIV are also at risk for unplanned pregnancies, which may also increase rates of pregnancy amongst WLWH (Miller, Pallant, Negri, 2006; St. Lawrence, Sondgrass, Robertson, Baird-Thomas, 2008). This may result in HIV testing during pregnancy for women who are accessing care during this time, however for women who continue to face barriers to care prior to and during pregnancy, there continues to be a potential for late diagnosis or diagnosis at the time of birth.

The last annual reporting by the Canadian Perinatal HIV Surveillance Program, an initiative of the Canadian Pediatric AIDS Research Group (CPARG) was in 2013 and in that year CPARG reported 201 children were born to WLWH across Canada (Public Health Agency of Canada, 2014). Two HIV transmissions were confirmed out of the 201 infants who were perinatally exposed to HIV in 2013 (PHAC, 2014). From 1984 to 2013, there were 184, 548, and 1407 infants born to women living with HIV in Saskatchewan, British Columbia and Ontario, respectively (PHAC, 2014). Out of the total infants born in these provinces who were exposed to HIV between 1984 and 2013, 17 were confirmed in Saskatchewan, 63 in British Columbia, and

243 in Ontario (PHAC, 2014). The total numbers have decreased over time due to access to cART.

Importantly, although there has been an exciting shift in the ways many WLWH think about and experience pregnancy including the decrease in vertical HIV transmission, it is equally important to understand the unique context in which PAW experience pregnancy, birth and motherhood. This is because the experiences of PAW during pregnancy, birth and motherhood must be understood within the context of poverty, the impact of colonization, the residential school system, experiences with child welfare system, HIV-related stigma and discrimination, and lack of culturally supportive health and social care. This is particularly relevant in the Canadian context due to the overrepresentation of Aboriginal peoples in the HIV epidemic. Aboriginal peoples are 3.5 times more likely to contract new HIV infections than non-Aboriginal people, and in particular Aboriginal women are being diagnosed later, many at the AIDS stage, and at a younger age than non-Aboriginal peoples (PHAC, 2011). Moreover, Aboriginal women account for nearly half of all cumulative HIV infections among all Aboriginal people and represent the highest proportion of HIV infection due to IDU exposure (CAAN, 2010; PHAC, 2011).

Despite this clear need, which has been articulated as far back as 2004 in the position statement on Aboriginal Women, Children and Families that recommended developing best practice guidelines for pregnant Aboriginal women (CAAN, 2007), this recommendation has yet to be realized more than ten years later. Consequently, there is still an urgent need for increased

attention to the particular perinatal needs and experiences of PAW that puts their voices at the center of the research, and that is grounded in Aboriginal history and cultures.

THEORETICAL FRAMEWORK

The lens through which we think and reflect on the experiences of PAW during pregnancy, birth and motherhood is informed by our critical approach to understanding the social determinants of women's health. Health differences among women both globally and in Canada result primarily from qualitatively different histories, experiences, and environments associated with the social determinants of health. In Canada, these social determinants include ethnicity, Aboriginal status, early life education, employment and working conditions, food security, health care services, housing, income and its distribution, and social safety net and support (Raphael, 2004). Social determinants also include culture and HIV-related stigma and discrimination, which have been found to contribute to HIV infection and disease progression (Ontario Advisory Committee on HIV/AIDS, 2002). However, the health and social inequities that PAW face must be understood within the context of the marginalization and oppression of Aboriginal peoples as a result of colonial policies and practices implemented by European colonizers, and the intersecting health determinants of poverty, racism, gender, and Aboriginal status (National Association of Friendship Centres, ND; Browne, McDonald, Elliot, 2009). Additionally, research indicates that Aboriginal women across Canada are born into structured systems of inequality through which they experience gendered violence, poverty, single motherhood, and low rates of education and employment, exacerbating existing barriers to health and wellness (Halseth, 2013). A consequence of this is increased vulnerability to child welfare involvement due to the high degree of surveillance that Aboriginal mothers are subject to (Greene et. al., 2014). Moreover,

these structured systems of inequality also increase women's vulnerability to HIV. HIV-related stigma exacerbates the multiple ways in which Aboriginal women experience discrimination and this is carried throughout their reproductive and child rearing years. This is in stark contrast to the historical roles as "the givers of life and keepers of the fire" (CAAN, 2010) that have been traditionally held by Aboriginal women as a result of "the imposition of Eurocentric governance systems and social values (Peltier et al., 2013)."

Social determinants of health greatly impact the well-being of PAW who become pregnant and give birth. Of particular relevance here is the impact of colonization on the physical and mental health of Aboriginal women in Canada coupled with HIV-related stigma that negatively impacts access to HIV prevention, treatment resources, including barriers to culturally appropriate perinatal care (CAAN, 2010). Consequently, the stories shared here and the analysis and recommendations that accompany them are grounded in our understanding of the impact of colonization and racism on PAW. This echoes other scholarship, which has explored access to and receipt of health and social care of Aboriginal women from a systemic perspective and called for systemic issues and service gaps to be addressed (Loppie-Reading, Wein, 2009; Wilson et. al. 2013). While understanding the systemic discrimination and stigma that PAW experience in pregnancy, birth and child rearing is very important, this research suggests that is also critical to acknowledge the leadership, resilience and resistance that PAW embody when they take on the responsibility of carrying and bringing forth life. This suggests that despite colonization and systemic racism, stigma and discrimination PAW seek to experience mothering in a traditional way, taking on the role of caregiver, life giver and protector of their children.

METHODOLOGY

This paper was written in partnership between PAW and academic researchers. PAW contributed to this study as co-investigators and as peer research associates (PRAs), and were integral to the development and facilitation of the narrative interviews and talk back sessions in Ontario and British Columbia. Talk back sessions in Saskatchewan were supported by front line service providers who work directly with PAW in clinical and community-based settings. The findings presented in this paper are based on the experiences of 29 PAW who participated in the HIV Mothering Study, a mixed methods study on the experiences of WLWH throughout pregnancy and motherhood in Ontario (N=5) and sharing circles that engaged PAW from BC (N=6) and SK (N=18) in a process of ‘talking back’ to the HIV Mothering Study data. We felt it was critical to bring together the stories of all PAW who participated in the HIV Mothering Study and sharing circles in order to provide a larger narrative about their perinatal needs and experiences. Ethics for this study was approved by the McMaster University Ethics Review Board, the University of Saskatchewan and the Regina Qu’appelle Health Region Research Ethics Board.

Recruitment

HIV Mothering Study participants including PAW were recruited through HIV and obstetrical care centres across Ontario where they were provided with details about the study and connected with the Research Coordinator. The ‘talk back’ sessions occurred at the end of the HIV Mothering Study as part of dissemination activities and efforts to share study findings with women living with HIV in Saskatchewan and British Columbia. Recruitment for the ‘talk back’ sessions was in partnership with local HIV/AIDS service organizations and health and social care professionals who worked in clinical and community-based settings. Posters, peer support

group announcements and word-of-mouth were the primary mode of providing information about the talk back sessions. It is important to note that although we did not intentionally seek to recruit only PAW for the talk back sessions in British Columbia and Saskatchewan, the participants who attended these sessions all identified as First Nations.

Data collection

Demographic data was collected in Ontario, SK and BC (see Table 1 for sociodemographic characteristics of study participants). Narrative interviews were conducted with HIV Mothering Study participants in pregnancy (3rd trimester) and 3 months postpartum by research associates including PAW. The sharing circle in BC was co-facilitated by a PAW peer researcher and the study coordinator. In SK, the sharing circles were co-facilitated by the principal researcher and study coordinator.

The talk back sessions in BC and SK consisted of a research dissemination process followed by a sharing circle through which the women could share their responses to HIV Mothering Study findings. The session began with a presentation of the HIV Mothering Study findings to include stories about the intersecting experience of living with HIV and being pregnant, giving birth and mothering. The second part of the session shifted the process from an information session to a sharing circle where women shared their thoughts about the stories presented, and the ways in which these stories resonated (or not) with their own experiences. Considering that all the women who participated in the talk back sessions identified as First Nations, we felt it was necessary to engage with the women in ways that respected Indigenous ways of sharing

experience. Consequently, we reflected on Shawn Wilson's (2008) articulation of the Indigenous research paradigm and his assertion that:

“An integral part of the Indigenous identity for many Indigenous people includes a distinct way of viewing the world and of ‘being’. Indigenous people have come to realize that beyond control over the topic chosen for study, the research methodology needs to incorporate their cosmology, worldview, epistemology and ethical beliefs,” (Wilson, 2008:15).

Consequently, each woman who attended the talk back sessions and participated in the sharing circle was given the time and space to tell her story respecting the communal nature of the research process and of Indigenous knowledge (Benham 2007; Brant Castellano, 2000). Through this process, the women chose to use this time to share their own experiences and ideas for how to support PAW throughout pregnancy, birth and motherhood.

Analysis

Corresponding with the narrative data collection process, a narrative analysis of the individual interview and sharing circle transcripts was conducted. Reflecting Riessman (2002), this included a process of unpacking, interpreting, re-reading and analyzing the stories, with close attention paid to the uniqueness of time and environment in which the story was told. In addition, reflexive conversations between Aboriginal and non-Aboriginal team members provided opportunities to culturally and regionally contextualize our understanding and interpretation of the stories. An integral aspect of our methodology was the participation of PAW researchers in the development of our data collection and analysis process in order to reflect our commitment to Indigenous methods, knowledge and experience. Two PAW researchers provided feedback on the analysis of interviews, sharing circles, recommendations for moving forward, and drafts of the manuscript. The PAW researchers also ensured that the participant's stories were accurately and honourably represented.

FINDINGS: THE STORIES THAT WERE SHARED

What follows are a selection of the stories that were shared by PAW in Ontario, Saskatchewan and British Columbia. Importantly, the stories presented here do not represent all of the stories that we heard; rather, these stories concentrate on the past and present day encounters with health and social care providers throughout the PAW's experiences of pregnancy, birth and motherhood; the resilience that PAW mothers embody and enact as they navigate their responses to these encounters; and recommendations for moving forward in a good way.

Part I: Stigmatizing Care and Practices

*There's supports that are not even there, there's supports for HIV, but they're not supporting the Person ... the individuality person for what my needs are, right?
(Saskatchewan Sharing Circle Participant)*

It has been well documented that WLWH experience HIV-related stigma in a range of health and social care settings (Riessman, 2002; Sandelowski, Lambe, and Barroso, 2004; Ion and Elston, 2015; deBruyn 2004). In the context of pregnancy and motherhood, fears related to the stigmatizing impact of disclosure are of particular concern (Sandelowski and Barroso, 2003; Greene et. al. 2010; Greene et. al., 2015) as the emergence of discriminatory practices when WLHV seeking pregnancy related support (Greene et. al., Forthcoming). However, as the stories below illustrate, PAW's experiences of HIV-related stigma must be understood in the context of the systemic acts of racism that permeates their experiences of pregnancy, birth and motherhood.

Testing Practices

PAW in all three provinces shared numerous stories about the challenges in accessing appropriate support. These stories can be traced back to the moment of HIV testing and the

emotional impact of the testing process. In Ontario, Tricia shared her story of going to get tested for HIV along with her partner:

I told him (partner) like when he went to get tested, that it's higher in Native women to have HIV and that he's best off just to leave me and to stay away from me...you know what my nurse said? I'm like, my nurse tells me that it's higher in black men that come from the islands and that I should stay away from them...when he asked them for condoms they wouldn't give him free condoms, they told him to go buy a box if he wanted to stay with me.

Although on the surface it may appear that the racism in this story was mainly directed at Tricia's partner, both Tricia and her partner were subjected to the impact of HIV-related stigma and racism. Tricia's belief that her partner would be better off staying away from her because "HIV is higher in Native women" demonstrates the internalized stigma that can accompany an HIV diagnosis. This raises important questions about the ways that Aboriginal women and PAW are portrayed as both receptors and vectors of HIV transmission and about the ways that Tricia was positioned in relation to her partner - as someone who does not have agency and who is not worth supporting vis-à-vis the denial of free condoms to her and her partner. Tricia's story also highlights the barriers to HIV testing among Aboriginal women, such as the fear of being rejected as a potential romantic and/or sexual partner in the event that the test comes back positive.

Stories about the challenges of accessing appropriate HIV services while in the midst of experiencing homelessness or housing instability also emerged as a significant barrier to care. This was reflected in stories about receiving HIV test results by a street outreach worker that did not include immediate support or a referral to an appropriate agency or program. As two women from Saskatchewan shared:

Ann: I didn't know I was positive when I found out I was pregnant. I found out all in one day. Who told me? The rig van came and found me and then sent me on my way with two pamphlets.

Betty: I found out from the rig van too. They didn't even tell me that I could get, I could go to a doctor and get medication for it. Like I thought I was done for, right? So I just started really drugging, you know, like I was an IV drug user so I really went to town on that and that's when I got pregnant...and I was like well I guess I'll have to get an abortion right?

In both these situations, a formal process of providing HIV testing information and support was completely absent from this service, suggesting a need for improved street outreach services that can support women who are at risk or diagnosed with HIV. Fortunately, Betty was able to find a supportive physician who was able to convince her that with appropriate care, she could have a healthy pregnancy and baby.

It is important to recognize that these experiences are current day realities for PAW and they occur, albeit in different ways, in a variety of urban contexts. For example, Nancy from Ontario shared her story about being tested for HIV during pregnancy:

It was upsetting because the doctor that told me, he calls me and goes you're HIV positive and walks out the room... and then he went and did a C section. He didn't even stay 2 minutes to talk to me, didn't give me a number or nothing to call right away. I had to wait, was it 3 hours for him to come back from the C section to get a number for to call someone at public health.

As Nancy continued to share her story, she also stated that she was tested for HIV without her knowledge and was not offered any pre or post-test counselling nor support with regard to learning about her diagnosis during her 2nd trimester of pregnancy.

The consequences of racism, HIV-related stigma and the multiple barriers to HIV testing and care that Aboriginal women encounter before and during pregnancy, result in the fact that some

women do not find out about their HIV status until the moment of or just after the birth of their baby. As Jocelyn from Saskatchewan shared:

Right after, not even five minutes after I gave birth, that's when they told me I was HIV positive in 2008. So I've been on meds since then.

These stories further highlight the continuing existence of HIV testing practices experienced by Aboriginal women that are at best damaging and at worst traumatizing.

Perinatal Practices

PAW were confronted with perinatal care tainted by HIV-related stigma and racism. These experiences occurred before, during and immediately after childbirth. As Kelly, Lisa and Shanae from Saskatchewan shared in their discussion about being a pregnant PAW:

Kelly: As soon as you're HIV positive and you go in around that time, they (the nurses) were like basically, so you're using so how did you get it?

Lisa: Shame, shame, shame, aren't you ashamed?

Shanae: Yeah, basically, yeah make you feel like a piece of shit when you're in there.

Lisa: Yeah, like you're pregnant? Like, that and you're HIV and you're pregnant?

And yet, rather than viewing these experiences as legitimate reasons to stop seeking inappropriate care, PAW in Saskatchewan talked about wanting to find appropriate support, which was challenging in its own right:

Yeah, I wanted help, I wanted support around what I was going through because I wasn't taking my meds and I just really needed, I really wanted to keep this baby...I didn't even know where to start to look. I wasn't even directed into any direction.

The shaming that PAW were subjected to when attempting to access perinatal care early in their pregnancy sometimes resulted in an attempt to develop a birth plan that would ensure access to appropriate care when the baby was due. Corrine from Ontario shared her story of attempting to

work through the limitations of living in a small town that did not have the experience or knowledge to support her during her time of delivery:

I had to have a back-up plan too because the small town where I am, they are super small and they don't deal with me...And then, there's kind of a middle town, medium town that they don't deal with people like me. They felt very, I don't know, against it...when I went to see him, he told me, he's like, well they're not going to want to touch you here. They're going to be scared of you, you know, and he told me not to come back to the clinic and I have to go to the hospital.

The intersection of HIV-related stigma and the racism that PAW experienced continued to emerge in the birthing stories we heard. For example as Shanae from Saskatchewan shared:

I had my C-Section and then at the same time the doctor and nurses were all like, oh, basically saying that the best thing for me is to get my tubes tied...well, this one nurse says to me do you really want, you know, like down the line there is a chance that you can get your baby, uh, you can transmit it to your baby? I was thinking okay, this woman wants the best for me, you know what I mean, and doesn't want me to go through this so I went and I did it because I thought okay, yeah you're right, do I really want that on my conscience, you know, do I want that?

Shanae's story raises critical concerns about the ways that PAW are communicated with regarding future pregnancy and/or HIV prevention efforts. Of particular concern here is the highly emotional context in which Shanae was provided with information about tubal ligation as an option to prevent vertical HIV transmission and the sneaky way in which racism and HIV-related stigma underpinned this suggestion.

Perhaps most striking was the lack of knowledge that women had, and how their perinatal care throughout pregnancy did not provide them with sufficient knowledge of vertical HIV transmission, cART medication during pregnancy and beyond, and the potential to be screened for drug use during pregnancy. Some of the questions that women asked us during the Saskatchewan discussion groups included:

Is it possible like if you're pregnant and you're HIV that shouldn't your baby get it like that too?

Why do they have to wait right at the four months to start putting the medication because I was pregnant and HIV positive, they told me I had to wait until I was four months pregnant? But I couldn't understand why I had to wait until I was four months pregnant?

The (doctor) didn't tell me about doing the urine screens, no one told me to do the urine screens while I was pregnant. I was like if I knew that I would have did that.

These questions were mainly asked by PAW who were unstably housed and/or who did not have a regular physician or access to other health and social support through which they could learn about what to expect throughout their pregnancy care. Hence, the overwhelming lack of knowledge that the women in Saskatchewan had about vertical HIV transmission, cART during pregnancy, and drug screening during pregnancy is incredibly concerning, particularly given the rates of HIV amongst Aboriginal women in Saskatchewan. This lack of knowledge increases anxiety about vertical transmission, barriers to taking control over one's health throughout the perinatal period, and sets women up to fail in situations when their drug use is being monitored. While these experiences may not be specific to PAW, it is only through the PAW narratives that these stories emerged signaling the social and health inequalities that continue to face PAW during the perinatal period.

Child Welfare Practices

A critical component of the perinatal experiences of PAW was their historical and present day relationship with the child welfare system. These experiences emerged for 21 out of the 29 PAW pointing to the ongoing experiences of racism and discrimination that Aboriginal women face who are involved in the Canadian child welfare system. For example, when talking about the historical impact of the Children's Aid Society (CAS) in BC, some of the women talked about the impact of not having culturally appropriate supports in place for themselves and their children:

Penny: What my children did was with Caucasians; they never practiced their culture, they never engaged them in their culture.

Irene: So they were losing all of their culture by where they were placed?

Penny: Yeah.

Irene: I suggested to the one, if you're going to have them at least have them in a Native environment... We're not church going, nothing against it, we just got our own ways.

These concerns were exacerbated for the mothers when their HIV status became an additional concern to the child protection worker, which often put them in the position of being forced to disclose their HIV status to their children. As Sheila from BC shared:

I got forced to tell my kids that I got HIV by Social Services. One sat there, one sat here and I sat there – I wanted to do it the traditional way... but the social worker and the other social worker, we're going to have a meeting, they came over to my house and he said tell them, tell them. What? What? That you have HIV.

While forced disclosure in this context is not a legitimate child welfare practice, mothers are rarely informed about their rights regarding disclosure. This highlights both the need for training of child protection workers and providing WLWH with information about their rights to privacy. Interestingly, the stories that the women shared in regard to their experiences with CAS ten to fifteen years ago mirrored the stories told by the women who were currently involved with the CAS in Ontario and Saskatchewan. As a result, the women who participated in our studies made clear choices not to disclose their status to their child protection worker. As Nancy stated:

I know myself like I would not expose my status to CAS because that's the last thing I'd want because CAS file stays with you longer than a friggin' criminal record does so I'd rather and to protect my children and their children because I know like after like when my kids get older, CAS finds out and then something happens with their kids they are going to use that against them, my status against my kids or their grandkids or whatever, like, you know?

Moreover, some of the women felt that the determining factor that resulted in the resurgence of CAS in their lives was connected to their HIV status. As Shanea from Saskatchewan stated:

Yeah but why are they even trying to be involved? You know, they didn't even care about your whole – your other two kids and all of a sudden they found out you're HIV, now you're pregnant, now they want to be involved. Where were they for the past seven months?

Shanae's narrative echoes findings from Greene and colleagues that highlight the lack of knowledge that child protection workers have about HIV that results in unnecessarily intrusive child welfare practices (Greene, O'Brien-Teengs, Whitebird and Ion, 2014).

Part II: Resistance, Resilience and Self-Empowerment Practices

You can't tell me I don't have a right to have a baby out of my body even though I have HIV, you know?

It is critical to recognize that even as PAW confront and experience the immediate and long-term consequences of HIV-related stigma, discrimination and racism, acts of resistance and resilience emerge as a central storyline. These stories were shared in connection to their experiences of pregnancy and motherhood and in relation to the systemic racism and supportive health and social care contexts that they encountered.

Education Practices

A significant act of resistance that emerged through the women's stories were instances where they attempted to educate themselves about pregnancy and HIV in order to move forward with their pregnancies and roles as mothers. For example, Candice from Saskatchewan stated:

“When I found out I was HIV, yes I took it pretty hard. But when I found out I was pregnant and HIV positive, that made me really want to change my life around for the better.”

Furthermore, with this desire to change one's life for the better, came a desire to learn more about being pregnant and living with HIV in order to make healthy decisions. For example, Lisa from Ontario shared her story of the feelings that emerged when she found out she was pregnant

and the process of researching pregnancy and HIV that followed. When she was asked how she went about her research she responded:

um on the internet actually I just kind of typed in pregnancy and HIV and everything popped up ya so I just go on all the different websites and everything...When I first found out I was pregnant I was thrilled and happy but then I'm like, oh wait...what about the HIV, you know? What am I going to do? What should I do...? That's when I started the research and thought about it and talked with my mom um did a lot of reading about it and asked the doctors... and even still I look on the internet every now and then.

Shelley from Ontario went online to “better educate” herself:

I went to public health, online, everywhere possible to find out more information 'cause I need to know for myself to better educate me cause I wasn't fully educated but I think I'm more than educated now...I had questions but you know what? I educated myself...bettered myself, bettered my child's life and now I can teach my son. A lot of things I didn't know so now I'm gonna pass it down to him.

Hence, in spite of both the gap in services and the limited information available to PAW about pregnancy and other perinatal information, the women we spoke to, both individually and in groups, sought out and found alternative ways to educate themselves. This enabled them to not only make educated decisions regarding their pregnancy, but also supported them in taking this information into their roles as mothers.

Self-Advocacy Practices

Educating oneself was particularly important for the women as they experienced discriminatory interactions with service providers. This theme emerged most prominently from PAW in Saskatchewan and rather than disempowering them from seeking care it had the opposite effect and appeared to arm them with a higher degree of confidence to self-advocate throughout their pregnancy. Sherri's story highlights her experience of engaging in this process of self-advocacy with her primary care physician:

But it wasn't Dr. (name) giving me my HIV hoedown or low down, you know, it wasn't. I actually had a standoff with him kind of one day because he assumed that I was actively using during my pregnancy and I was already three and some years clean sitting in front

of him. I planned my pregnancy. I didn't tell him that but you know it all worked out for my best benefit and I had to really send a strong message to him – hey, you know what, I deserve to be treated with respect and dignity.

Through this deep sense of dignity and pride in their identity as PAW, self-advocacy emerged as a critical factor in asking for what they needed in terms of health-based support. As Terri stated:

They (the doctors) need to be reminded that, you know, we don't come from cookie-cutter houses or a perfect little place. We do the best that we can. We're resilient people and support us where we're at really, give us the time of day, you know, and be there when we need you whether that's a phone call for a check-up or whether that's taking you to your check-up, you know.

This demand for recognition of one's history, culture and resilience was echoed by Michelle who spoke about what needs to change in the child welfare system in Ontario:

They (CAS) need to get off their high horse and quit being discriminating towards Aboriginal women and our belief system about pregnancy and childbearing and the honour of all that. We have kids because this is our way of life and this is our culture.

Importantly, acts of self-advocacy were also demonstrated within the context of one's own reserve community. As Rachel from Ontario shared:

I moved onto the reserve so I can get help with like my son and stuff like that...I actually went and told the chief at the band office of my status because I was getting a rental unit and I heard about the rental unit having a bad mold problem...I went to the chief and I'm like listen, I'm like, I am HIV positive and I'm not gonna move into a dive. I'd like my house needs to be fixed properly because I don't want to get sick. I don't want my kids to get sick...They re-did like the whole inside of house. The walls, the floors.

Self-advocacy, therefore, not only occurred in the context of women's experiences accessing care in mainstream health and social services, but also within their own communities.

Cultural Practices

A critical theme that emerged from the women's narratives and talk back sessions were their recommendations for developing more effective ways of working with PAW throughout the entire perinatal period and supporting their important role as mothers. Importantly, these recommendations highlight the connection between culture, community and resilience through

PAW's insistence that health and social care practices be grounded in a culturally-based practice framework. As Lori from British Columbia articulated:

I believe the roots of any culture is the grounding; the foundation of who they are, what they practice like whether it's Muslim, whether it's Buddha, all cultures have a grounding of some sort of spiritual ceremonies that they do. It's in their DNA.

It is therefore not surprising that PAW in all three provinces often talked about the need for “cultural training” or “cultural sensitivity” for health and social care providers in order to access culturally safe care that was free of racism and stigma. In addition, PAW also require their own spaces and resources that address their specific cultural and health needs. Hence, a critical aspect of cultural support was understood as being connected to a community of PAW that incorporated Aboriginal cultural traditions into the provision of support.

Women with long histories of child welfare involvement made recommendations for how to work more effectively with PAW mothers based on their past experiences and as a way to envision the future. For example, when asked about the role of tradition and ceremony in their children's and grandchildren's lives, PAW mothers and grandmothers in British Columbia highlighted the need to:

Introduce them to it (ceremony), bring it back to our grandchildren, our own kids that aren't practicing and all that, and actually participate in ceremony together.

Moreover, PAW also highlighted the importance of including the whole family in ceremony in the context of HIV-related support for PAW and their families. For example, in one talk back session, the women suggested developing cultural supports specific to children and families in order to heal themselves and their children:

Penny: You need some kind of camp, a camp for their HIV

Irene: Have a family reunion

Claudia: Yeah, let their guards down. Just let them be whoever they want to be.”

Irene: “So we can do the healing that needs to be done with our kids.”

Claudia: “I like that. We should all get together; we should all bring the tribes together.”

Penny: “And that it would be a good time to do something traditional too.”

PAW also acknowledged that an integral aspect of delivering culturally relevant support to pregnant PAW and PAW mothers, was the central and leading role that the PAW have in creating culturally relevant supports.

Peer Support Practices

The role of PAW mothers in the development and provision of support was a key factor in demonstrating and facilitating acts of personal and community-based resilience and acts of resistance. One example of this was a support group developed and lead by peers in Saskatchewan that is grounded in a “sharing circle model” to provide support. As Karri stated, “we’re trying to open up the doorway to invite them (PAW) in, to come walk with us.” This space highlights the importance of cultural and personal safety for PAW who are pregnant and/or mothering. As one woman shared:

You go in discouraged and you come out feeling better, you go in and you let go of everything and you go home, you know, in a peaceful mind. It’s good, it’s a really safe place, you know, you feel that there’s lots of confidentiality, like you know you feel safe, you feel that you can speak and speak of anything you want, you know, it’s a part of sharing and letting go. So it’s a really good group.

Of particular significance was both the valuing of lived experience within a culturally appropriate and safe space, and the impact that peer mentorship and leadership had on the PAW who attended this group. As Karri articulated:

I credit the people like my peers, I credit my peers for that, for that strength because I've always ran into people who were real strong in teaching me something and it rubbed off on me somehow, some way, you know.

Finally, the value of peer support was also articulated as integral to feelings of community “engagement” and “connection,” which were central to the perinatal experiences of PAW in Saskatchewan:

It's by that engagement and that involvement with other people like they teach you so much. That's my greatest thing that I can, you know, say that's been the best thing was having that connection to peers and people that actually were the front liners rolling out with HIV and pregnancy stuff. Like if I didn't have that connection, I don't know if I would have been that confident going through my pregnancy at all.

Consequently, a key factor in the accessibility and success of support geared toward PAW throughout the pregnancy, birth and motherhood, re the provision of services that support PAW in leading the way for other PAW as they enter into motherhood.

DISCUSSION

Moving forward “in a Good Way”: Working with PAW Mothers in Ways that Work

“Everybody has a story to tell, everybody comes from a place, sometimes they aren't the best places, but be a good person and be in a good way to be a light in people's darkness all the time. That's what I always tell people, especially nurses too that are dealing with our women that are HIV, you know. Like be a light in somebody's darkness.” (Saskatchewan Sharing Circle Participant)

The stories shared here echo findings from previous studies that highlight the multiple ways that the presence of racism and HIV-related stigma in health and social service settings continues to adversely affect the lives of PAW (CAAN 2010). Consequently, PAW continue to confront systemic discrimination, HIV-related stigma, a lack of culturally relevant services, and a lack of

knowledge or understanding of their personal circumstances and history (Benoit, Carroll, Chaudhry, 2003; Browne, Fiske, Thomas, 2000; Kurtz et. al., 2008; Tait, 1999). The individual narrative interviews and talk back sessions highlight the historical and present day challenges as well as the resilience and acts of resistance that PAW enact as they move through their experiences of pregnancy and motherhood. The challenges included encountering HIV testing, perinatal, and child welfare practices that were at times racist, stigmatizing, shaming, and life altering, particularly in cases of sterilization and/or forced separation from their children. And yet, in the face of stigmatizing practices, PAW engaged in significant acts of resistance demonstrating strength and resilience as individuals, and as part of a larger commitment to their families and communities.

Acts of resilience, resistance and self-empowerment were reflected through PAW's acts of self-education and self-advocacy as they took control of their pregnancy, birth, and mothering desires in ways that resonated with their identities as PAW. These acts are critical reminders of the importance of maintaining and creating culturally appropriate health and social care practices and policies that include the meaningful involvement of PAW in this process. Of equal importance was the leadership that currently exists amongst PAW mothers and the value of peer mentorship and support for PAW throughout pregnancy and motherhood. These particular stories highlighted the multiple spaces where PAW engaged in acts of resistance against HIV-related stigma, sexism, racism, and judgements related to histories of drug use and relationships with child welfare. It also demonstrates the importance of viewing their own communities as places of potential support and understanding.

Recommendations for Practice

Echoing McCall and colleagues (McCall, Browne, Reimer-Kirkham, 2009) it is important to highlight the acts of resilience and resistance that emerged throughout the narratives in order to acknowledge the resilience of PAW and Aboriginal communities more broadly (First Nations Health Council, 2009). Subsequently, we also learn about some of the key factors that must be considered when developing and supporting health and social care practices for PAW during pregnancy and motherhood. These include:

1. Increased attention to accessible and culturally relevant HIV-specific pre and post-natal education;
2. Self-advocacy skills building;
3. Culturally based health and social care services during pregnancy and beyond; and
4. Increased peer support programs during the perinatal period.

Equally, or perhaps even more importantly, is ensuring PAW leadership in the development and provision of a cascade of perinatal health and social care practices and policies that encompasses the entire pre-pregnancy to motherhood trajectory. These recommendations can be implemented in both hospital and community-based settings and integrated into the child welfare programs that are directed at Aboriginal mothers more broadly.

Conclusion

As argued by Carter et. al., (2014), the meaningful involvement of WLWH is a key feature of women-centred HIV care and is integral to ensuring that the needs and experiences of PAW during pregnancy, birth and motherhood are met. As highlighted above, this is also a critical component of the development and provision of care tailored and specifically designed by and for pregnant PAW and PAW mothers. PAW feel most supported when they are invited into peer-

led safe spaces that recognize their need for culture, connection and community. Consequently, advocating for increased attention to the specific perinatal and mothering needs of PAW also requires advocating for resources that are needed to support PAW leadership, growth and involvement in developing and improving appropriate services. This finding is consistent with the Canadian Aboriginal AIDS Network five year strategy on HIV and AIDS (CAAN, 2010) to increase the capacity of PAW to lead and partner in these processes, and it honours the historical and present day wisdom of Aboriginal mothers.

Table 1: Sociodemographic Characteristics of HIV Mothering Study participants from Ontario, Saskatchewan and British Columbia

N=29	Frequency (%)
Site of Data Collection	Vancouver (BC) = 6 (20.7%) Regina (SK) = 7 (24.1%) Saskatoon (SK) = 11 (37.9%) Ontario = 5 (17.3%)
Age	Median = 28.5, Range = 22 to 55
Race/Ethnicity	First Nations = 26 (89.7%) Metis = 2 (6.9%) Did not specify = 1 (3.4%)
Place of Origin	Canada = 28 (96.6%) United States = 1 (3.4%)
Sexual Orientation	Heterosexual = 25 (86.3%) Bisexual = 2 (6.9%) Lesbian = 1 (3.4%) Not specified = 1 (3.4%)
Relationship Status	Single = 13 (44.8%) Living Common-Law = 10 (34.5%) Separated/Divorced = 4 (13.8%) In a relationship, not living together = 2 (6.9%)
Educational Attainment	Elementary/Grade school= 5 (17.2%) High school/secondary= 11 (38%) Trade or technical training= 2 (6.9%) College= 1 (3.4%) University = 4 (13.8%) Other/unknown = 6 (20.7%)
Annual Income	Less than \$10,000= 15 (51.7%) \$10,000-19,999= 11 (37.9%) \$20,000-29,999= 1 (3.5%) \$30,000-39,999= 0 (0%) \$40,000-49,999= 1 (3.5%) Unknown/Prefer to estimate by month= 1 (3.4%)
Housing Status	House that you rent= 11 (37.9%) Apartment or condominium that you rent= 10 (34.5%) Shelter/ Transitional housing = 3 (10.3%) Other /Unknown = 5 (17.3%)
Number of children	No children = 3 (10.3%) 1 child = 2 (6.9%) 2 children = 9 (31.1%) More than 2 children: 15 (51.7%)

	Range: 0 to 6
Contact with child welfare system	Yes = 21 (72.5%) No = 7 (24.1%) Prefer not to answer = 1 (3.4%)

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