

CLINICAL ARTICLE

Obstetrics

Disconnected perspectives: Patient and care provider's experiences of substance use in pregnancy

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Abstract

Objective: Generations of colonialism, abuse, racism, and systemic trauma have contributed to Indigenous women in Canada bearing the greatest burden of substance use in pregnancy. Stigma associated with substance use in pregnancy translates into multiple barriers to women engaging in care. Care providers have key interactions that can act as a bridge or a barrier to care.

Methods: Patient journey maps were created for women living with substance use ($n = 3$) and semi-structured interviews ($n = 20$) were performed to understand perceptions of maternity-care providers around women with substance use in pregnancy at a regional hospital in northern British Columbia.

Results: Patient journey maps showed overall emotions of hurt, loss, judgment, and anger at their interface with health care during pregnancy. Providers described gaps in knowledge of substance use in pregnancy and harm reduction. Although care providers overall perceived themselves to be providing compassionate care without bias, the patient journey maps suggested profound judgment on behalf of providers.

Conclusion: Ongoing cultural humility and trauma-informed care training along the continuum of care is critical to impacting discrepancies between perceived lack of bias and harm in patient interactions. Acknowledgment of systemic racism's impact on provision of maternity care is critical for health system change.

KEYWORDS

cultural safety, harm reduction, Indigenous health, substance use in pregnancy, systemic racism

1 | INTRODUCTION

I see you Ma'a (Mother), sharing your story.

Living in a world that needs information to make change.

Navigating the violent colonial structures only a whisper away from the theft of your k'abatgüütk (children),

your aunts and uncles, your grandparents, and Great Grand-Parents.

We ask for your journey so we no longer have to ask you to teach us. We are learning how to keep space in a good way and transform our practice to no longer need your tireless instruction.

I see you Ma'a, sharing your story ... once again.

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Walking beside you we privilege your story and keep the space.

Transformational change is needed in health structures and practice, we shift to a place of standing beside you in partnership and with compassion in this ethical space (Ermine).

Each day we learn more and each moment moves us closer to healing the collective soul wound. Our practice will improve because of you and your k'abat-güüt, we honor you. I hear you.

I see you Ma'a.

Jessie King, Hadiksm Gaax

Front-line care providers in maternity services are a critical link of engagement for women with substance use during pregnancy and postpartum. Stigma attached to substance use during pregnancy often compounds pre-existing experiences of trauma for women seeking care.^{1,2} The goal of this study was to increase understanding of care provider interactions with substance-using mothers throughout the prenatal and postnatal stages of pregnancy, and to draw lessons from these perspectives and experiences to improve care for substance-using mothers and their infants in northern British Columbia (BC).

Women with problematic substance use in pregnancy face multiple barriers to care in BC, including high rates of neonatal apprehension. Although there is clear evidence of effective harm-reduction strategies during pregnancy—including methadone, buprenorphine, and rooming in with neonates³—these options are not universally available. There is a growing body of literature that considers harm reduction and the continuum of care,^{2,4-6} but there exists minimal research based in northern and rural regions where patient care is delivered in both urban centers and rural and remote locations.

1.1 | Background

In northern BC, where this research took place, a higher proportion (18%) of the population are Indigenous than in many other parts of Canada. Indigenous women are disproportionately represented among women with substance-use issues and survival sex work during pregnancy; they are also more likely to be victims of violent crime, including sexual assault, and human trafficking, and to continue to have higher infant mortality rates.⁷⁻⁹ High rates of violence and substance use are lingering legacies of colonialism in Canada, where generations of Indigenous people have experienced systemic trauma, abuse, and racism, normalized within government health care, education, and social welfare systems.¹⁰ The Indian Act of 1876 was a direct assault on the value of women that remains today as a woman's status is still

determined by her proximity to men with status. The disproportionate apprehension and placement into the child welfare system of Indigenous neonates has been attributed to ongoing structural racism within Canadian health systems and society writ large.¹¹ Colonial systems continue to permeate health facilities through structural racism and willful ignorance. Resulting health inequities are exacerbated by a lack of culturally safe environments in mainstream healthcare systems, where too often Indigenous patients experience racism and stigmatization.^{4,12,13}

The publication of the *Truth and Reconciliation Commission Report* in 2015 included several specific calls to action around infant and maternal health and addictions.¹⁰ Additionally, the *Truth and Reconciliation Commission Report* calls pointedly on all care providers to engage in cultural safety training; this must involve ongoing critical self-reflection and humility. No current statistics exist on accessibility and facilitation of this training at the national level. More recently in BC, the *In Plain Sight* report¹¹ details systemic racism in the healthcare system and provides a framework for accountability, calling us to stand up and take note. Grand Chief Stuart Phillip describes racism as a malignant disease, spreading and impacting all levels of health care, and denial and ignorance around its impact on the provision of health services must be addressed.¹¹

Pregnant women living with substance use, are often medically complex, frequently with histories of trauma, who benefit from multidisciplinary care. However, the literature indicates that perceptions of healthcare professionals towards patients with substance addictions are often negative and disapproving, with these beliefs often going unchallenged.^{2,4} Pressure to improve the overall health of the fetus and a focus on abstinence has created a clinical culture of open negativity, sometimes hostility, and profound stigma associated with substance use in pregnancy; ignoring the fact that an abstinence-only approach results in higher rates of relapse.¹⁴ Healthcare discourse is conflicting in this context: the overwhelming historical promotion of abstinence within Canadian public health policy, the disease concept of substance abuse, and moral constructs that society has of pregnant women's bodies and their decisions to become mothers.²

Voiced desire from community stakeholders to address disparities in care for women struggling with substance use during pregnancy and postpartum highlights a growing recognition of the need for improved care. In response, this study aimed to describe the underlying perceptions of frontline care providers that may contribute to ongoing barriers to care for women struggling with substance use in the peripartum period; a holistic approach is informed by maps of these women's journeys at the interface with the healthcare system. Beyond barriers, our goal was to identify specific strategies to build bridges to care for women at this critical time in the life course.

1.2 | Theoretical framework

Our author team was intentionally composed of those with multidisciplinary backgrounds and both settlers and Indigenous

authors. Our roles include an obstetrician gynecologist/academic researcher (SMF), a health geographer (CE), a registered nurse (MB), an Indigenous Elder (LD), and an Indigenous academic with previous experience working with the Northern Health Authority (JK). Bringing all of these perspectives together, and an awareness of our positionality, has produced a description of some of the challenges faced in a somewhat complex environment to provide high-quality, trauma-informed, and culturally safe care.

2 | MATERIALS AND METHODS

In Phase 1, facilitated patient journey mapping was performed with three participants who had lived experience with substance use at different times in the peripartum period in previous pregnancies. This process mapped the health system, and more specifically their lived experience at the interface with health care (interactions with frontline workers from community primary care, acute care, and other community and government organizations) during pregnancy, delivery, and postpartum. Patient journey mapping is a holistic and analytical process based in storytelling in community incorporating patient advocates (MB), and an Indigenous Elder (LD) present to ensure that culturally safe process and ceremony were respected.^{15,16} Patient journey maps were reviewed with all participants, with participating care providers, then digitized.

Phase 2 comprised implementation of a survey and interviews with care providers involved in both community and acute care of pregnant and postpartum women and their infants. Data were collected in May and June 2015 using a structured survey followed by semi-structured interviews. The survey tool and interview guide were informed by priorities identified by project stakeholders and Phase 1 of the study (including front-line care providers and women with lived experience, the majority of whom were Indigenous women), incorporating themes from patient journey mapping as well as relevant peer-reviewed literature. These stakeholder priorities reflected trauma-informed approaches and culturally safe practices as all patient journey maps were completed together with Indigenous women.

Separate sessions were scheduled for interviews to include care-provider participants from maternity ward and neonatal intensive care units at a regional hospital in northern BC ($n = 15$); with an additional session at a community-based primary care center serving primarily Indigenous patients ($n = 5$). This facilitated incorporation of perspectives from both acute care and community healthcare providers. Semi-structured interviews were carried out by an interviewer, a practicing obstetrics and gynecology physician (SMF), and a research assistant (CE). Semi-structured interview methodology provided cohesiveness, while allowing for the exploration and elaboration of sensitive and complex subject material.¹⁷

All interviews were audio recorded and transcribed. Data were analyzed using inductive thematic coding, identifying themes and sub-themes using NVivo 12 software as data were being collected;

interviews continued until theme saturation was achieved. Two researchers (SMF and CE) reviewed themes independently to ensure validity. Ethics approval was received from the Institutional Review Board at University of Northern British Columbia (E2014.1014.081.00).

3 | RESULTS

Figures 1–3 show process maps with patient perspectives in red circles reflecting experiences from overt anti-Indigenous racism to fear, shame, guilt, anger, and helplessness. Women described overall emotions of hurt, loss, judgment, and anger at their interface with the healthcare system during pregnancy and deep mistrust of Ministry of Children and Family Development workers. Feelings of judgment and being stereotyped at the interface with acute care both antepartum and during delivery were voiced, “we are all people, it does not matter where you come from—do your job, don't judge, provide care.” Positive emotions were associated with connections at the community care level and care providers in acute care who were understanding and made them feel safe. Participants requested more understanding and culturally safe interactions at presentation for acute care and more information sharing between community and acute care providers; they highlighted the need for a change in how care is provided. One patient shared “I don't want any parent or kid to go through what I went through.” The need for culturally safe dedicated housing for women and families during the perinatal period to provide support and stability during pregnancy, and a highly supported environment postpartum to transition to independent living was highlighted.

For Phase 2, the majority of informants were registered nurses, including the maternity unit ($n = 8$), the neonatal intensive care unit ($n = 4$), a community-based clinic ($n = 4$), and a public health nurse ($n = 1$). Other fields represented were midwifery ($n = 1$), pediatrics ($n = 1$), and, social work ($n = 1$).

3.1 | Knowledge gaps around care

Specific nuances of care were addressed in the interviews, as participants expressed their uncertainty over the amount of pain medication to administer during labor and postpartum. This gap in knowledge limits the ability of a care provider to meet the needs of their patient. The following quote illustrates that different dose requirements may be required to ease discomfort for women with addiction:

I think people realize, but I don't think it's really taken into consideration a lot of times, that their pain med needs afterwards are much higher, [be]cause they just have this tolerance built up that they actually need higher amounts of pain medication and we don't often give that.

Overall Emotion: Hurt and lost, I don't want any parent or kid to go through what I went through; angry towards MCFD/hospital
Ideas for Improvement: Stop judging people; create a safe house for parents and their children; improve care to the patient in emergency department



FIGURE 1 Patient journey map: Patient 1; CINHS, Native health clinic; MCFD, Ministry of children and family development

Participants tended to be more cognizant of the impact of substance use on the fetus, not the mother, and considered this to be a determinant of what would constitute problematic substance use. Substance type was discussed by many participants, with the majority agreeing that alcohol consumption was most problematic and would have the greatest negative impact on fetal outcome, as illustrated in the following quote:

I feel like [alcohol], it's so harmful, right? Those babies that come out addicted to cocaine, methadone, whatever, they end up doing okay. The FAS [fetal alcohol syndrome] babies don't do okay ... I struggle with the moms that have been drinking throughout their pregnancy.

3.2 | Knowledge of available resources

Limited knowledge of resources was considered an impediment to patient care. One participant summed up the need for greater knowledge in all aspects of provision, stating that more needs to be learned "about drug use in pregnancy, where they can go for help, more of the harm reduction programs, what are out there, what can we access

to help [so we can] let them know where to go too." Nurses working in maternity stated that they have limited contact with new mothers impeding their ability to establish a rapport with the patient; fast turn-around times with neonates often being admitted to neonatal intensive care unit and not rooming in as main causes.

Lack of follow-up after mother and baby leave hospital was a point of concern for many participants. Participants identified that current services provided along the continuum of care act as a barrier because they tend to focus on the fetus and new baby, not the mother. Highlighting this apprehension one participant shared:

I think women do get kind of forgotten actually after baby is born. I don't even know if they always have follow-up appointments, like for their own medical care or medical needs really, you know, it's all around baby.

3.3 | Flexibility and harm reduction

Harm reduction takes many shapes and involves supporting mothers in a place where they are receptive to care, such as recognizing that she may not be able to abstain from using substances, but may

Overall Emotion: Glad I got better care and my baby was able to make it
Ideas for Improvement: We are all people, does not matter where you come from – do your job, don't judge, provide care; safe house for moms and babies

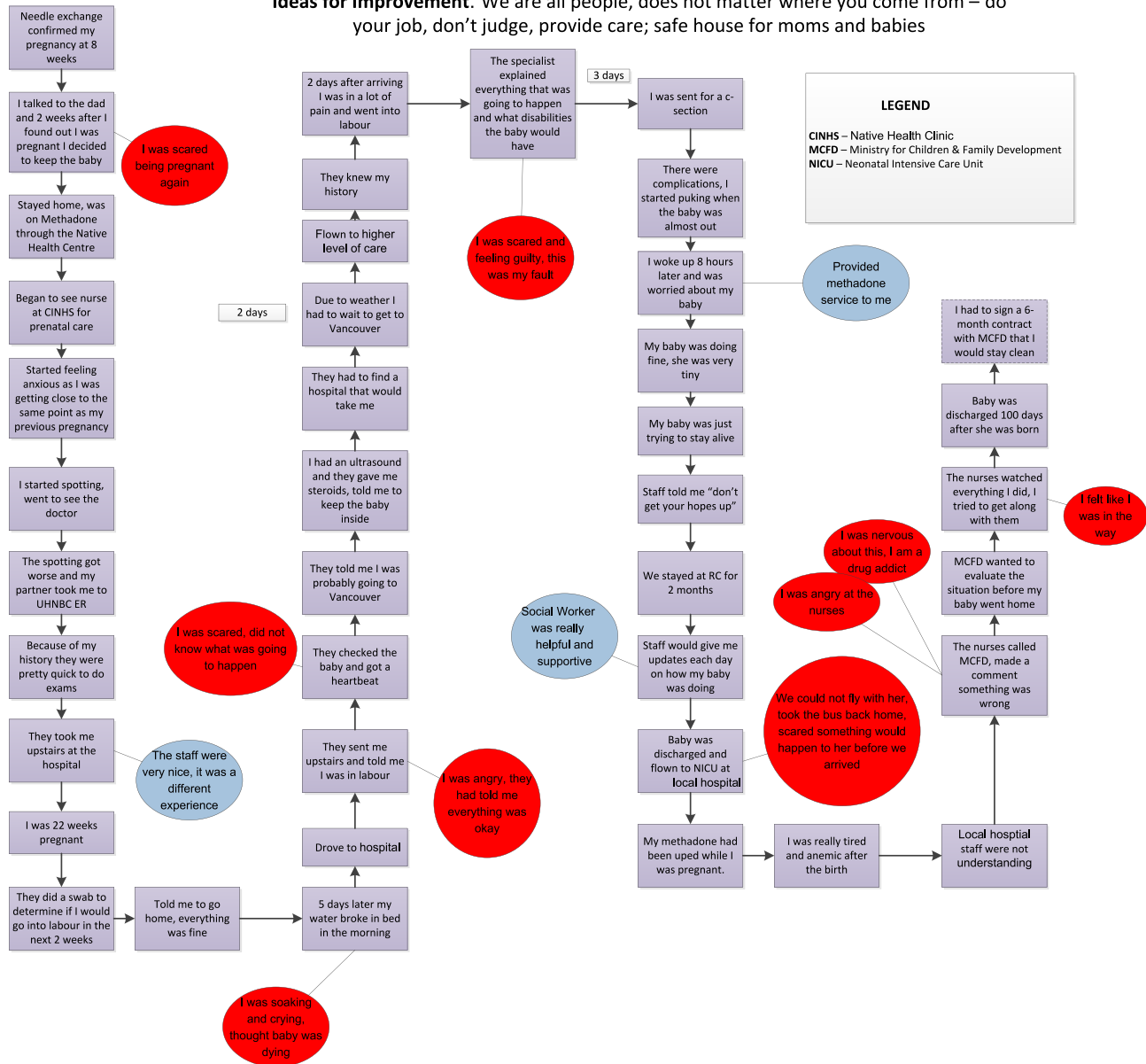


FIGURE 2 Patient journey map: Patient 2; CINHS, Native health clinic; MCFD, Ministry of children and family development; NICU, neonatal intensive care unit

be able to limit her use. As one community-based clinic participant stated:

I think the key thing is to get the engagement of the client, and so I think that means meeting them where they're at. So you know, maybe they're going to continue to use for a while but still within those supports ... [our] intention [is to] help them to be as safe as possible in that.

Participants commonly cited the need for flexible prenatal care, which is adaptable to the needs and practices of the client. Due to the chaotic environments in which women with substance use find

themselves, many participants identified that patients often miss appointments. Rooming-in was discussed as a positive method to continue care in the postpartum period, even in cases where the child is to be apprehended. As one participant stated, "it's been proven that skin to skin ... makes such a big difference and maybe it would make moms more attached to their babies and give them better incentive ... to try to beat their addictions."

3.4 | Culturally safe care

Including cultural practices in prenatal and postnatal care was cited often in the interview process. Participants felt that "getting

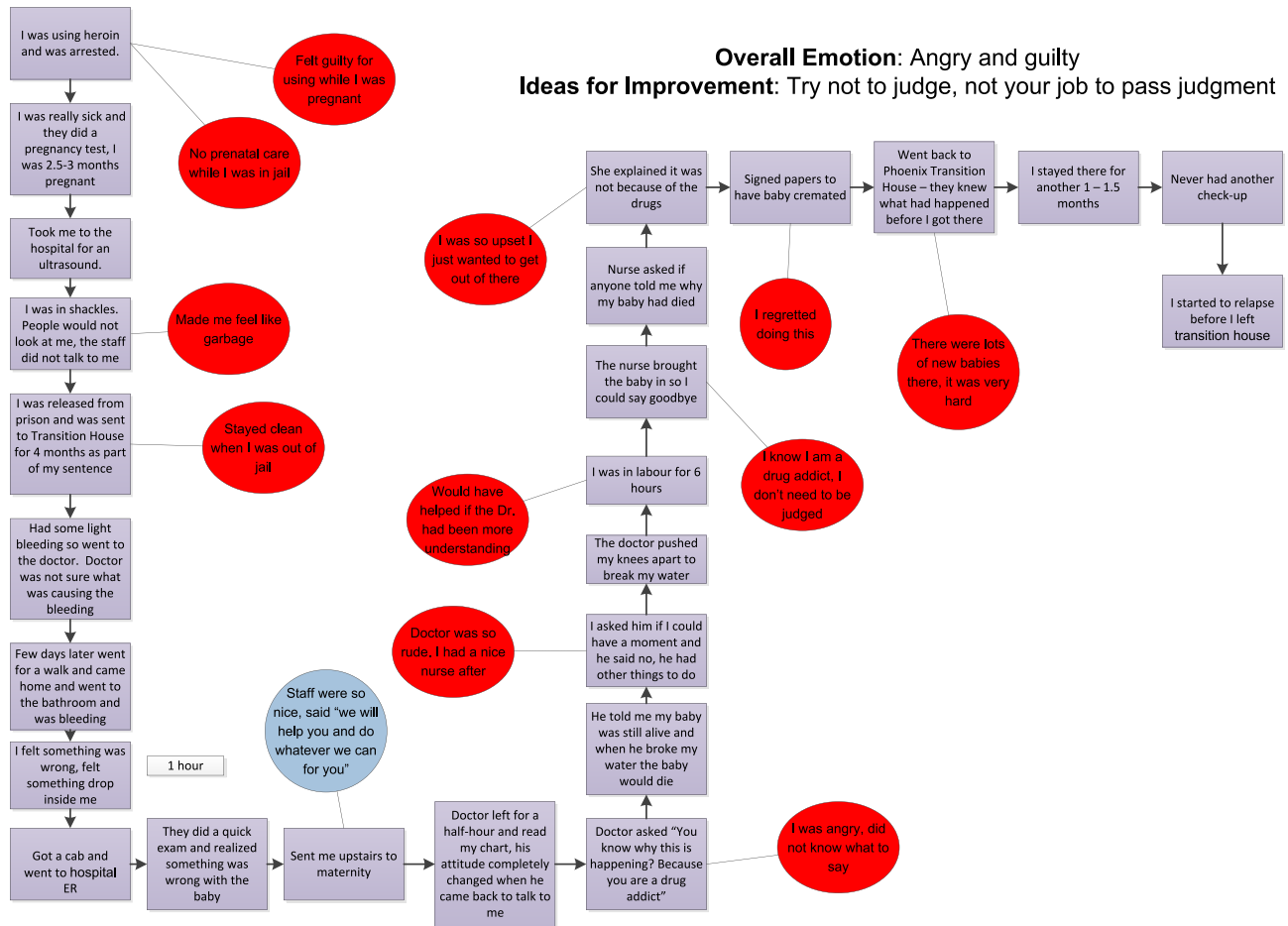


FIGURE 3 Patient journey map: Patient 3

[elders] involved a little bit earlier [is a positive step] because a lot of the women we see aren't connected really to their own traditions but everyone that we have talked with has been very receptive." Including non-conventional care providers in prenatal care may enhance the well-being of mothers with substance use because, as participants stated, they are in need of constant support, encouragement, and positive reinforcement. Education is a vital component to care and providers emphasized the need to prioritize cultural competency training.

Participants identified that they often provide care for prenatal patients with addictions. For this reason, self-awareness was considered an integral component to providing care for substance-using patients. As the majority of participants noted, it is important to acknowledge personal prejudices and put them aside in order to provide the best care for the patient. The following quote highlights the sentiments of the research participants when the care provider does not quell their own personal feelings:

I think it can if you approach [the patient] with attitude, you're just another stereotype, you're totally going to put up a barrier and ... I think, [the patient] senses you have a stereotype about them and they

usually feel super guilty already, so they're super sensitive to when you walk in the room.

Although participants recognized care provider stigma and judgments may be a barrier, the overall thought was "we are doing pretty well" in how patients are cared for and equitable care is provided to any patient that walks through the door. As one participant shared:

It's [maternity care] a full-on job, but a laboring woman is a laboring woman, regardless of what addictions issues or whatever race they are, we treat them the same way.

Participants identified the need for compassion when working with substance-using women, because "I don't think that any mother would choose to harm their little person out of choice. I think people need to understand that addiction is like an illness."

4 | DISCUSSION

The findings provide a glimpse into the beliefs and opinions of those caring for mothers with substance use at a regional center in

northern BC and map out individual patient journeys at this interface. Specifically, the illustration of the interface as disconnected in experience provides a platform to begin to understand the complex nature of care provision for this population, and the challenges faced in supporting both mother and child along the continuum of care. Importantly, the need to provide family-centered care that embraces both members of the dyad, rather than having a sole focus on fetal/neonatal health reflects this disconnect; honoring Indigenous motherhood and personhood must be at the center of prenatal and postnatal care. We struggled to find models specifically for rural Canadian settings when addressing the continuum of care during pregnancy and postpartum for women struggling with substance use, but we do find examples from urban work with a focus on culturally safe care that are highly relevant.¹⁸ Concerns were raised in the interviews about the need to increase knowledge with regards to multiple aspects of care when working with mothers who use substances. Increased awareness was considered to be a positive step forward in supporting the varying needs of this population and in addressing barriers to establishing a rapport with patients. In this context, care-provider participants spoke of the need to incorporate cultural components into the medical care of patients. Patient journey maps reveal that knowledge alone is not enough, dyad care must also focus on relational aspects and understanding hospitals as places of collective colonial trauma with the legacy of Indian Hospitals.¹⁹ This is further compounded with the long history of the removal of children from their families via the Indian Residential School System and the 60s Scoop; Indigenous mothers experience this collective colonial trauma as a strong undercurrent to receiving primary care.²⁰ Concerning beliefs of a “color blind” approach to care, these highlight the ongoing need for self-work, anti-racism training, awareness of implicit bias, and intrinsic racism in approaches to care. Cultural awareness and inclusion are important, as the rate of substance use in pregnancy is higher among Indigenous populations than non-Indigenous populations.²¹

Acknowledging personal bias is an important step for medical practitioners and care providers working with mothers with substance use addictions. A concerning finding is the disconnect between provider perceptions of their interactions as being free from bias in comparison to heart-wrenching narratives from the patient journey mapping of women who experienced profound judgment when accessing care. A sign that more focus needs to be placed on care providers' self-assessment in these settings and the provision of trauma-informed care to all women. Without the self-work of front-line care providers and acknowledgment that often a different level of care is currently being provided to Indigenous and substance-using mothers, there can only be limited change within the health system.

Historically, abstinence has been touted as the ideal treatment for substance use in pregnancy; however, this results in high rates of relapse and may also result in increased barriers for women attempting to engage in care. In recent years, there has been an initiative to improve the health of all pregnant women and neonatal outcomes

through the adoption of harm reduction models. Harm reduction is described as “an approach that helps to reduce the degenerative effects of alcohol and drug use at the same time as helping women meet their immediate health, social, and safety needs”.⁶ Striving for a positive approach to providing prenatal medical services, more clinics and treatment centers are adopting a harm reduction approach to care; however, rural and remote centers may lag in their uptake of these approaches because of sparse resources and understaffing concerns. Although, there appeared to be some awareness of harm reduction among participants, the definitions of problematic substance use suggested persistent expectations of abstinence as the ideal scenario for women struggling with substance use in pregnancy.

Pregnancy offers a unique and critical opportunity to support women in improving their health by introducing methods to reduce harm caused by illicit drug and alcohol use, due to both the additional motivators present in pregnancy and the potential for additional engagement in care for prenatal visits. There is wide agreement that a multidisciplinary approach to providing pregnancy and neonatal care to substance-using women has positive outcomes, as their needs are addressed by an array of care providers in a friendly and non-judgmental atmosphere.⁵ The patient journey mapping process highlighted significant gaps between community and acute care; the interface with acute care was laden with judgment, traumatic events, and lack of awareness in acute care providers of the women's stories or pregnancy care journeys. Our provincial guideline now strongly focuses on rooming-in with mother and infant to decrease the risk of neonatal abstinence syndrome and there is significant evidence supporting its impact.²² Wraparound care enables a seamless transfer of information throughout the prenatal and postnatal periods and has the potential to avoid some of the adverse experiences at the interface between community and acute care. Wraparound care, as well, embraces the dyad of mother and infant, facilitating a “stepping away” from solely focusing on the health and wellness of the infant. This one-sided care can be perceived through the lens of the long and ongoing history of colonial disruption of Indigenous motherhood in Canada; including the practice of apprehending Indigenous children on a large scale. Threat of child apprehension, which is always present to some degree for Indigenous women in colonial institutions, can prevent a mother from seeking care for herself, and can enlarge barriers to care.

Limitations of this study include challenges ensuring confidentiality in rural health regions, this contributes to fear of speaking out as it may have implications for access to care in future. Additional challenges arise in addressing ingrained racism in health research and the nuances of exposing something to an audience that cannot or will not integrate this experience. Although these data are limited to a small population of healthcare providers, they provide a glimpse into the varying attitudes and opinions in the care teams of substance-using mothers. Given that providers interact with women at a profoundly vulnerable time during the perinatal period, the role of both trauma-informed care and culturally safe care are central in building bridges to care and reducing harm. Our study reflects

similar findings of the Australian experience with nurses and midwives at the interface with acute care often feeling ill equipped when engaging with culturally diverse patient populations.²³ Birthing units across Canada continue to be “ground zero” of the ongoing apprehension of neonates from Indigenous families and being able to approach pregnancy, birth, and parenting support with cultural humility and trauma-informed practice must be an ongoing priority to address this. Training healthcare providers in culturally safe care involves both increased awareness of one's own cultural makeup and making steps towards non-judgmental and open-minded interactions, incorporating an understanding of historical contributions to their present social situation and ongoing critical self-reflection and understanding of the settler-clinician's role in acknowledging systemic racism.^{24,25}

In conclusion, the present study provides timely and highly relevant findings applicable not only to the northern BC setting but to rural and remote populations across Canada. Our study is unique in its use of patient journey mapping of women with lived experience informing our analysis of healthcare provider perceptions. The courage of the women who participated in patient journey mapping and the countless encounters that Indigenous women face on a daily basis with the healthcare system despite experiencing both explicit and systemic racism reflect the deep resilience of mothers. Key steps forward are the provision of trauma-informed and culturally safe training across the continuum of care and working towards integrating Indigenous advocates, at the interface with acute care to ensure women's voices are heard. There can be no forward movement without acknowledgement of the impacts of systemic racism at all levels of health care.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

SM-F is the lead author and designed the study approach, participated in data collection and analysis, and in manuscript writing and review. CE was responsible for data collection and analysis and wrote an initial first draft of the manuscript. MB guided the patient journey mapping and edited final drafts of the manuscript. ELD provided cultural insights and guidance throughout the process of patient journey mapping and supported patient participants throughout. JK provided extensive review and additions to later drafts, cultural insights, framing of methods and generous sharing of the blessing that starts the manuscript.

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