Patient and Family Experiences of Adverse Pregnancy Events in Canada from a Multicultural Perspective

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Abstract

Background: Maternal morbidity can be conceptualized in multiple and unique ways by healthcare professionals, and patients. For pregnant persons and their families, adverse events in pregnancy can often extend beyond the scope of clinical diagnoses. This patient-led, peer-to-peer study aimed to understand how pregnant persons and their families described and understood adverse events in pregnancy in Canada using a multicultural perspective.

Methods: The Patient and Community Engagement Research (PaCER) program is program offered through the University of Calgary. Students are patient and community researchers trained in qualitative health research and committed to finding innovative ways of engaging patients in the health care research that matters to them. Focus groups and individual interviews were used to understand the experiences and perspectives of patient and community members who self-identified as experiencing adverse events in pregnancy. Data was collectively and iteratively analysed using thematic and narrative analysis.

Results: Thirteen participants from diverse backgrounds and with a range of pregnancy experiences participated in focus groups and individual semi-structured interviews. Five key themes emerged and were defined as: (1) access to appropriate, timely, coordinated care and follow up; (2) lack of transparent communication from healthcare providers and the ways power differentials and need for urgent action affected shared decision making; (3) cultural differences between participants’ traditions, and Canadian pregnancy care practices; (4) mental health impacts as participants struggled to access diagnosis for conditions that “didn't feel right” and to understand “why” adverse events happened (5) supports and resources participants felt were missing that would have been most helpful to managing the morbidity. Our team also identified five actionable recommendations for dissemination and implementation of study findings.

Conclusions: This study demonstrates that people with lived pregnancy experience may not perceive pregnancy-related morbidity as a list of adverse clinical conditions, but instead as negative consequences resulting from lack of transparent communication with pregnancy-care providers, and access to timely and culturally appropriate care, supports and resources. Our findings identify key research priorities and provide unique insights into designing best practices for more person-centred, culturally cognisant, and responsive maternal health policy and care going forward.

Background

Maternal morbidity is defined by the World Health Organization (WHO) as any health condition attributed to or aggravated by pregnancy that has negative outcomes to the pregnant person's well-being.\(^1\) Despite WHO's holistic approach to defining maternal morbidity, in both clinical practice and research environments maternal morbidity has come to refer to a set of clinical diagnoses and procedures that often discount mental, social, and functional implications. Through our literature review, we learned that few qualitative studies about the patient and family perspective of what constitutes an adverse event in pregnancy.

Pregnancy is not experienced in isolation and adverse pregnancy-related events can have far ranging implications beyond just the pregnant person. They can have lasting implications (physical, psychological, and relational) to the baby, partner or spouse, siblings, extended family members, and health care systems going forward. Canada continues to experience dramatic increases in immigration of persons from diverse cultural and ethnic background, particularly in those of childbearing years. Of the 259,000 immigrants who were admitted to Canada in 2013, 52% were female and nearly half of these were between 25 and 44 years old.\(^2\) In addition there continues to exist wide ranging disparities in rural and urban maternal health care access and experiences.\(^3\) To address these gaps and ensure positive and healthy outcomes, it is important to understand the unique socio-cultural and other challenges pregnant persons might face.

The Patient and Community Engagement Research (PaCER) program is offered through the University of Calgary, Continuing Education and supported by the Alberta Strategy for Patient-Oriented Research SUPPORT Unit (AbSPORU),
Patient Engagement Team. Together, PaCER is working to integrate patients and community members into the health research that impacts them, and to provide patient-centred research evidence that inform improvement to healthcare system design and care delivery.

As student researchers with lived experience of pregnancy and pregnancy-related adverse events, we aimed to conduct a peer-to-peer, qualitative study to explore and understand further, patients’ and family perspectives and experiences of maternal morbidity in Canada through a multicultural lens. More specifically, we aimed to understand the impacts of these life-changing experiences, and how these might range from a sense of inconvenience to significant distress. We wanted to identify factors that contribute to any negative experience during pregnancy and childbirth, including experiences related to coordination and follow-up care around pregnancy-related adverse events.

Methods

We conducted this qualitative study using a participatory action research approach as discussed in Qualitative Methods for Health Research and the PaCER process to integrate the patient and community voice, experience, and perspective throughout the research process. The PaCER process has 3 distinct phases: SET, COLLECT, and REFLECT as identified in Grey Matters. The study was conducted entirely online, and individuals with lived experience of adverse events in pregnancy in Canada (patients) were engaged through focus group discussions and individual semi-structured interviews.

SET

For the SET phase, we followed an iterative 9-step process to develop our research question and to inform the development of our study design. This included a review of previous PaCER projects, an academic and grey literature review, as well as team interviews and discussions. We then invited patient partners and PaCER graduates with lived experience of adverse events in pregnancy to a SET discussion group to get final feedback on the language and relevance of our research question, our participant inclusion criteria and recruitment strategies, and our project design including size and composition of the COLLECT focus groups. We included this feedback into our research protocol which was then submitted for institutional Research Ethics Board (REB) approval.

Participant Recruitment

Our PaCER student team of seven represented a diverse population base, including Asian, East African, and Latina communities, and offered us connections to unique participant populations whose voices and perspectives we aimed to capture and learn from. In addition, we shared the opportunity through the Alberta SPOR SUPPORT UNIT (AbSPORU) Albertans4HealthResearch network.

Our participant inclusion criteria were individuals or family members who self-identified as having experienced an adverse event during pregnancy; were 18 years or older; were currently pregnant and experiencing an adverse event or experienced an adverse pregnancy event after 2008; and the pregnancy occurred while they were living in Canada. To capture scope in diversity and perspective, the team intentionally recruited from community and newcomer organizations as well as those living in rural areas. All participants were offered, and accepted, a small token of appreciation for their time and valued contributions.

COLLECT

In the COLLECT phase, we conducted three focus group discussions with 2–4 individuals in each and seven semi-structured interviews. Team members each held unique roles for the approximate 1.5-hour long focus groups including Zoom host, facilitator, notetaker and process notetaker. The process notetaker was responsible for noting any details about challenges with network connections, Zoom, ambience, or conflicts or concerns. Semi-structured interviews were approximately 1 hour long and conducted by two team members; one team member led the discussion, and another was a notetaker. Both types
of discussion used the University of Calgary Zoom platform and were recorded for notetaking and transcription purposes only. Signed consent to participate in the research forms were received electronically in advance of the discussions from each participant. Participants were reminded at the onset of the discussions that their participation was voluntary and that they could withdraw at any time. Participants also consented verbally to be recorded. Audio recordings and interview transcripts were stored securely in a shared University of Calgary OneDrive team folder throughout the research. An anonymous online demographic survey was created using the University of Calgary Qualtrics platform and participants were encouraged to complete this.

Data Analysis

A thematic analysis approach \(^7,^8\) was used to analyze the focus group and semi-structured interview data. After collating and organizing the data into Excel sheets, team members each individually coded the data from the second focus group and then met to discuss and collectively, through consensus, create a codebook, which was then applied to the remaining data, with new codes added as they emerged. Narrative analysis was also applied to the interview data for further insights and context. The collective data was then synthesized and further analyzed, and we identified five emerging key themes and several subthemes of patient and family experiences of adverse pregnancy events in Canada, as well as several recommendations for improvement to maternal health care policy and practice going forward.

REFLECT

In the REFLECT phase, we invited COLLECT participants to join in one of 2 REFLECT focus group discussions to review our findings and key themes for accuracy and intent of words. There was agreement with the findings of the research and participants confirmed that their stories, perspectives, and insights were heard, visible and accurate in our findings. Additional suggestions and recommendations were also offered, and these were included in our results.

Results

SET

The SET phase involved six patient partners and previous PaCER students with lived experience of pregnancy. Our SET discussion group included two previous PaCER students, one with lived experience of pregnancy, and four patient partners from various places in Canada all who self-identified as having lived experience of adverse events in pregnancy. We presented the SET partners with our preliminary research question which was, and remained, “What are patient and family experiences of adverse events of pregnancy in Canada?”. The SET partners shared several suggestions to improve our research question and project design. The first was about being clearer in our definition of “pregnancy”, especially in terms of whether the study would include adverse events that occurred before (i.e., challenges with conception), during (including miscarriage) and after the pregnancy (in the post-partum period). Secondly, they suggested that we establish a timeframe for the adverse pregnancy experience (i.e., no more than fifteen years ago) to ensure that issues being raised are relevant to more current times and contexts. Third, they suggested clarity on whether the adverse events should include medical conditions only or whether they could include non-clinical issues such as socio-economic challenges, which may be perceived as ‘complicated’ even though they may result in a clinically uncomplicated pregnancy. They also suggested clarification on whether participants could include Canadians living abroad, a clear definition of the term ‘family’ and that we consider more gender-inclusive language instead of using the term ‘pregnant woman’. These suggestions helped us to better define our inclusion criteria, narrow down the research question and refine the wording and definitions around it. For the purposes of this study, we defined pregnancy as beginning from the time of conception to 6 weeks postpartum. About participant inclusion criteria, we decided to keep the definition of adverse events broad and not restricted to clinical events so that participants could self-identify with what they considered an adverse pregnancy event. Similarly, we chose not to define ‘family’ to better enable individuals to share their understanding of ‘family’. Finally, we decided to include only those who had experienced pregnancy in Canada in the past fifteen years, and that were current residents in Canada. The final
research question that emerged was, "What are the patient and family experiences of adverse events in pregnancy in Canada?"

Regarding the use of our SET recruitment poster, the partners suggested that if we were to use this for recruiting participants for our COLLECT focus groups and interviews, we needed to change the images. They suggested the images in our original (SET) poster (Appendix A) depicted only happy pregnant people and this didn't align well with adverse event experiences. They also provided formatting recommendations including using text hierarchy, higher contrast for visibility (colour and fonts) and to consider the accessibility and number of clicks that would be required to view information on different online platforms. Gender inclusivity was also mentioned as something to consider in the poster. These insights and input helped us to design a more appropriate COLLECT recruitment poster (Appendix B).

**COLLECT and REFLECT**

Nine of our 13 COLLECT participants completed our anonymous online demographic survey (Appendix C). Of these 9, all had lived experience of pregnancy in urban settings and described themselves as cis-gendered females. They represented three provinces [Alberta (n = 3), British Columbia (n = 1) and Ontario (n = 5)]. Four each were in the 28-37- and 38-47-year age group, while one was in the 18–27 age group. Three described their ethnicity as South Asian, two as Black African, two as Latin American and one as Filipino. A schematic representing recruitment and study conduct is described in Fig. 1.

Some participants joined the focus groups and interviews with a single pre-identified 'adverse event' however during discussions, they became aware of additional adverse events associated with either that specific pregnancy or another. This included one participant who was discussing her first pregnancy however during the discussion realized the miscarriage she had experienced earlier was in fact her ‘first pregnancy and with emotionally damaging outcomes.

Not surprisingly, participants described some of the medical and disease-related adverse events that are typically associated with maternal morbidity. They also identified socio-economic, relational, cultural, and mental issues that align better with the more expansive and person-centred WHO definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."¹

**Themes, subthemes, and exemplar quotes**

Our key themes and subthemes are summarized in Table 1 and details of exemplar quotes are provided in Appendix D.
<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td><strong>Theme 1: Access to care and continuity of care</strong></td>
<td>1a. Access to care. Challenges accessing appropriate care due to factors such as geography, clinic hours, transportation, availability of family doctor.</td>
</tr>
<tr>
<td>This describes the ability to access timely and appropriate health care, care that especially considers the unique and often urgent and unpredictable circumstances pregnancy can present.</td>
<td>1b. Timely care. Refers to the often-urgent care needs and timelines for tests unique to pregnancy.</td>
</tr>
<tr>
<td><strong>1c. Coordinated, comprehensive care.</strong></td>
<td>1c. Coordinated, comprehensive care. This includes for high-risk pregnancies, coordination between hospital units including transfers within hospitals from Emergency Departments to other units, and transfers between rural to urban hospitals, and possibly back.</td>
</tr>
<tr>
<td>This includes for high-risk pregnancies, coordination between hospital units including transfers within hospitals from Emergency Departments to other units, and transfers between rural to urban hospitals, and possibly back.</td>
<td>1d. Continuity of care. Describes the need for continuity and fluidity of care between health care professionals and across health systems to ensure follow-up and evaluation after adverse event.</td>
</tr>
<tr>
<td><strong>Theme 2: Communication</strong></td>
<td>2a. Power imbalances in patient-healthcare provider relationship. Describes the ways power imbalances including healthcare and health system knowledge and stigma obstructed informed, transparent, and respectful communication.</td>
</tr>
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<td>This describes the impact of communication between the healthcare providers, patients and family members (verbal and non-verbal) including the way participants felt their concerns went unheard; concerns about 'not normal' events being dismissed as normal or over-exaggerated; exclusion from decision-making conversations about their care; experiences of dismissal and disregard of participants including those with high health literacy; and disregard of the patient's right to make informed decisions about their health care even during crisis and the extra work of self-advocacy.</td>
<td>2b. Dismissal and disregard, even denigration of concerns and discrimination. Participant expertise and concerns about changes in their own body were not recognized; in fact, often ignored, dismissed, and/or disregarded including those with high health care literacy and training.</td>
</tr>
<tr>
<td><strong>2c. Removal of patient autonomy and agency.</strong></td>
<td>2c. Removal of patient autonomy and agency. Removal of patient autonomy and agency in informed decision making was a common experience both during critical high risk adverse events and otherwise.</td>
</tr>
<tr>
<td>This describes the additional work of making participants as patients responsible to self-advocate for attention and appropriate care and to learn more on their own about circumstances of adverse event(s) and find support and resources for follow up.</td>
<td>2d. Self-advocacy to obtain appropriate and person-centred care. This describes the additional work of making participants as patients responsible to self-advocate for attention and appropriate care and to learn more on their own about circumstances of adverse event(s) and find support and resources for follow up.</td>
</tr>
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### Themes

#### Theme 3: Need for cultural awareness and safety in delivery of care

This describes the necessity to recognize the cultural diversity of Canada’s maternal health population; to recognize and support the unique cultural and faith and value-based circumstances of each pregnant, birthing, and post-partum individual and look to ways divergent practices might be recognized together in care delivery when possible and the overall need for cultural competence to provide safety care.

3a. **Trying to balance between two cultures.**
This describes the physiological and emotional challenges participants experience with trying to reconcile between two maternal healthcare cultures, those of their home country and Canadian Western medical-centric institutions, policies, and practices. This also included stress and angst participants felt because of pressure from family members who were disappointed daughters didn’t follow traditional and cultural maternal health practices when in Canada.

3b. **Lack of cultural training and safety in health care professionals and professions.**
This describes the discrimination, stigma and inappropriate sometimes harmful care participants experienced because of lack of cultural sensitivity and training of health care professionals.

3c. **Western-centric medicine always automatically trumps traditional, cultural, and faith-based practices in high-risk events.**
Values, beliefs, and faith backgrounds of patients and their family members were often not considered or evaluated. Standardized practices and current western medical opinions always superseded, sometimes extremely detrimentally.

#### Theme 4: Mental health and well-being

This describes the way the participants worked to maintain mental health during their adverse pregnancy event(s) as well as the way the participants’ mental health was impacted by the adverse event. This includes ways participants experienced and managed emotional events, feelings, and trauma as well as pre-and-postpartum depression.

4a. **Psychological and emotional trauma associated with adverse event(s) experience.**
This includes feelings of sadness, anxiety, and regret things had not been managed differently.

4b. **Emotional impact of pressured decision-making.**
This refers to the influence participants’ emotions when their decision making capacity was compromised or pressurized.

4c. **Post-traumatic stress disorder (PTSD) as result of adverse event.**
This includes ways participants experienced and managed emotional events or trauma.

4d. **Pre-and-postpartum depression**
This refers to ways participants emotional experience or feelings of depression both pre and post partum.
### Theme 5: Supports and resources

**5a. Supports (social and community)**
This includes support from family and community.

**5b. Supports (from family members)**
This included positive experiences from participants appreciative of having their family members, especially mothers present postpartum as well as those who were negatively impacted because family members were not able to obtain visas to visit Canada and support. Some participants traveled with newborns to their home countries to be able to have this essential support.

**5c. Supports (for family members)**
Participants expressed concern for the mental well-being of partners, spouses, children, parents, and grandparents also affected by and experiencing the adverse event(s).

**5d. Supports (financial including income)**
Almost all participants worked during their pregnancy and intended to return to work after. This describes the impact of the adverse event on their income and ability to cover day-to-day living expenses and the additional expense of a newborn.

**5e. Supports (health system)**

**5f. Resources about pregnancy and postpartum**
This describes all the available resources for support during pregnancy and postpartum.

**5g. Supports (follow up to delivery and adverse event; impact of adverse event on family life)**

### Theme 1 - Access to care

Participants reported issues regarding access to care. This included more fundamental challenges such as clinic hours conflicting with participant work schedules to lack of care early in pregnancy due to shortages of family doctors, the latter causing significant angst to participants who were unable to access prenatal care until they were more advanced in their pregnancies. Many participants also experienced limited access to postpartum care, especially concerning their mental health. Participants recognized the benefits of access to multiple specialized providers, but they also felt this led to challenges navigating health systems and resulted in gaps in care. Unanticipated, adverse events often require immediate and urgent care. Participants felt strongly that the best possible care could be facilitated by having accurate patient information and histories on hand, especially when the patient is challenged to share these. Being asked repeatedly by multiple care providers for the same information resulted in some participants creating their own medical summaries they could more easily share with attending healthcare providers. Challenges in accessing their personal medical records, files, and reports regarding in-hospital experiences caused frustration in participants hoping to make sense of their adverse event(s) and inform their future reproductive planning.

### Communication

All participants expressed frustration and grief about not being listened to or heard. They shared a sense of being ignored when they tried to explain why things just didn’t feel right with their pregnancy or birth event. Disregarding and lack of empathy from healthcare professionals ranged from dismissive remarks to outright denigration of concerns and mockery.
Surprisingly, most participants did not seem to express anger or blame when describing their adverse event experience, but rather a profound sense of loss and sadness in the way things worked out and disappointment that reasonable changes still aren't being made.

Participants also reported a loss of agency and autonomy because of not being meaningfully included in information sharing and decision-making both during and after high-risk events. Several participants reported that self-advocacy and even being pushy were necessary to be listened to and yet still sometimes, despite this additional and taxing work, their concerns were still not acknowledged or addressed in a responsive way by providers. One participant, who was transferred from a small rural hospital to a large urban hospital spoke about how her husband was included in the decision-making during the high-risk event, however after the event, he was still the go-to person about their infant care even though she was extremely competent and wanting to be included in information receiving and decision-making as well.

**Cultural awareness and safety**

This is an essential piece of our results since participants represent the voices of people with different socio-cultural as well as urban and rural backgrounds. Newcomer participants mentioned that their own settlement and adaptation process influenced their pregnancy experience. In addition to the novelty of being pregnant, they were also facing a different culture, diet, climate, faith system, and language. Participants reported that they often struggled with family and personal conflict as they attempted to reconcile Canada’s more individualistic and Western medical centric approach. (i.e., vaccine programs, follow-up care, etc.) and the more holistic and community-centred cultures and traditions of their families and home countries.

Most participants reported that while they generally felt respected, their belief systems and personal wishes around their pregnancy and birth choices were not solicited or ever considered. Some participants experienced negative tangible and emotional outcomes because of being pushed to choices that conflicted with their faith or essential values. This includes one participant who travelled to another large city at the behest of healthcare professionals to terminate one of her two twins only to have the remaining twin born premature and with complications she felt could only be attributed to contravening the choice that was aligned with her own faith and values.

**Mental health**

Postpartum depression (PPD), postpartum anxiety (PPA) and post-traumatic stress disorder (PTSD) were identified in our research as adverse events that were commonly dismissed by our participants’ health providers which are concerning considering the prevalence of these conditions, however, we also feel that PPD and PPA could also be tangential to the adverse event experience.

Participants also reported significant impacts on their mental health because of their adverse event(s). This includes feelings of being traumatized however the trauma was more often associated with the way the adverse event was managed and follow up on in the healthcare setting versus the impact of the event itself. Many participants described distressing feelings about their experiences and diagnoses of pre-and postpartum depression, anxiety, and PTSD. Almost all participants shared that positive mental health was usually disregarded by their primary care providers and thought strategies around addressing maternal morbidity needed to be more conducive to addressing positive mental health during pregnancy. Participants described ways they became active agents in pursuing additional supports especially when it came to managing their mental health.

**Support and resources**

Various supports and resources were important to participants and helped them navigate their event experience and help to make sense of this and manage after. Participants were mostly satisfied with homecare nurses and the support offered at the time of discharge. All participants mentioned that they received literature or educational materials from providers about what to expect when expecting. All participants reviewed and considered all supports and resources made available to them...
and made further concerted efforts to seek and access information to help understand and manage their adverse event. The ways patients sought out and pursued resources to improve outcomes for themselves and their babies/children shows a great level of activation and empowerment among our sample. Peer-to-peer supports and resources such as social media, online trustworthy resources and sites, and peer support groups were mentioned by participants as being extremely useful and valuable.

**Recommendations**

Pregnancy is unique in that it is never an individually experienced nor end-point medical event. We believe these can be a start to assuring more equitable and appropriate, improved experience of all patients and their families experiencing adverse events in pregnancy going forward. Unanticipated or adverse outcomes of pregnancy can have devastating and long-lasting implications to pregnant persons and their families. Based on direct participant input as well as our collective interpretation of the results, we identified 5 recommendations (Table 2) for more person and family centred health research priority setting and maternal health care policy and practice going forward.
Table 2

Recommendations to improve maternal health care in Canada going forward

1. **Equitable access and coordination of care**
   - Ensure coordination and continuity of care across healthcare providers and regional health systems.
   - Enable access to primary care providers early in pregnancy to enable early diagnosis, treatment and follow-up for those impacted by adverse events. In-person visits should be an option whenever possible.
   - Support co-development of patient-centred tools (including smartphone applications) that patients can share with healthcare providers so don’t have to constantly re-tell their story.
   - Provide ongoing care and follow-up during and after adverse pregnancy event experiences, including regular check-ins upon discharge by utilizing accessible pools of healthcare providers such as community nurses.

2. **Communication, empathy, and power differentials**
   - Encourage communication between pregnant individuals and healthcare professionals and develop processes to identify those who might benefit from enhanced navigation through healthcare systems.
   - Train healthcare providers in the provision of more appropriate, comprehensive, and empathic care. This includes training that addresses social determinants of health, facilitates patient-centred communication, and improves cultural awareness and safety of diverse populations.
   - As much as possible, there should be shared decision-making about emergency procedures during high-risk events.
   - Provide patients access to health records and appropriate consultation after adverse events to help inform them of future reproductive health choices.

3. **More culturally informed and responsive care**
   - Carry out more qualitative research to understand to recognize and understand the diverse cultural maternal health perspectives, traditions and preferred practices of multicultural populations.
   - Ensure inclusive community member input and voice into maternal health research, health system design, policy, and practice.
   - Support greater integration of healthcare providers from diverse national, cultural and community backgrounds into the current health system i.e., increase licensing of International Medical Graduates and nurses.

4. **Mental health and depression**
   - Facilitate continual assessment of mental health and wellness before, during and after pregnancy, which could be integrated into regular and accessible postpartum follow up pathways.
   - Provide affordable, accessible, and appropriate pre-emptive and proactive pre and postpartum depression support.

5. **Supports and resources**
   - Develop more patient- and family-informed and evaluated holistic health supports which includes an emphasis on social, financial, and mental health in addition to physical health.
   - Provide and publicize centralized and coordinated resources to increase awareness and to various adverse pregnancy events available support. The information needs to be shared in formats and languages accessible to all persons.
   - Recognize that partners and family members may require unique and variable support both during and follow-up from adverse events.

**Table 2. Recommendations**

**Discussion**

This patient-led, peer-to-peer study helps to better understand patient and family perspectives on maternal morbidity in multi-cultural societies. It shows that people with lived experience of pregnancy often do not perceive morbidity or its implications the same way as clinicians. Further, pregnancy-related morbidity may not be perceived in similar ways by
individuals from different socio-cultural and ethnic backgrounds. Thus, the conceptions of patient-identified adverse events in pregnancy are complex and need to be approached in a more comprehensive way to fill the existing gaps in communication and care. The evidence generated through this study is integral to the development of more universally accessible and appropriate healthcare practices, improved outcomes for pregnant persons, their babies and family members, and the more judicious use of available resources.

Access to care has been defined as “the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use healthcare services and to have the need for services fulfilled.” 9 (p 8) In addition, for those living in rural and remote locations, evacuations due to pregnancy-related complications can be traumatic and complex for the pregnant person, partners, and families.

All participants felt health systems were fragmented and in need of greater centralization and coordination for delivery of maternal health care services and expressed frustration about having to share the same information and tell the same story to multiple health care professionals “over and over again”. Munch et al. 10 suggests that receiving conflicting information (different opinions from providers) caused not only confusion and frustration but also, led to difficulties in decision-making processes while having continuity in care generated confidence and more trust in the healthcare team.

Participants shared that lack of transparent and respectful communication around adverse events and the subsequent outcomes contributed significantly to the negative impact, angst, and trauma both during and after the adverse event confirming a gap in the way in which providers approach pregnant individuals experiencing unexpected situations and the ways these individuals would like to receive care. For those living in rural and remote locations, evacuations due to pregnancy-related complications can be traumatic and complex for the pregnant person, partners, and families. The emotional invalidation, lack of empathy, fragmented information, and poor communication skills our participants experienced reflects the need for improvements in both verbal and non-verbal elements of the patient-provider relationship where known benefits can extend beyond providing medical expertise.

When our participants were asked about opportunities and aspects of improvement, they highlighted the need for continuity of care and a humanistic approach. This concurs with the findings of Munch et al. 10 that suggested pregnant persons prefer a more empathetic approach from healthcare providers, where time is taken to connect and understand their situation instead of treating them as a number. Training in communication skills including emotional validation and active listening have been recommended frequently in recent years. 10, 11 In midwifery-related studies, it has been proven that patient satisfaction increases after healthcare providers receive training in empathy skills. 12 Enhancing interpersonal connections between those who give and receive medical care may offer an inexpensive and effective way to improve the health of our population. 13

Indeed, we also identified a wish for more patient autonomy which concurs with Vedam et al. 14 who reported that women expressed a strong desire for a model of maternity care that supports woman-led decision-making, however, they indicated that providers mostly led decisions around interventions. Shared decision-making models have also been promoted as a practice that ‘needs to start in the antenatal period, as part of developing a trusting relationship between the care provider and the woman, and to continue throughout labour and birth. 15 It is a matter of fact that patients are each day more aware and would like to feel more prepared to make informed decisions and be more involved in decision-making.

But how might this look? Person-centred care is defined as an approach to care where patients and health care providers work together to design and develop personalized, high-quality care that addresses individual needs and thus contributes to the overall improvement of both the efficiency and effectiveness of health care systems. 16 Literature and evidence have been recommending the application of a patient-centred care model in obstetrics based on the idea that “a paradigm shift in women's health as a concept is essential to deliver care that is more encompassing of the needs and priorities of women in different aspects of their health and over the course of their lifespan”. 17 (p 838)
But is this enough? According to our results, cultural differences and divergences in Canada’s growing newcomer population also need to be identified, understood, and addressed for more culturally responsive maternal health care going forward. Participants experienced angst and strife because of their engagement with novel-to-them Canadian postpartum practices. Disparities in maternal healthcare approaches caused angst and strife as participants tried to mitigate their personal challenges related to their settlement process such as adapting to the weather, tasting other food while craving traditional dishes from their home countries, encountering a different mindset because of migration and pregnancy, and their attempts to reconcile and explain their Canada-based pregnancy- and infant care choices to families still back home. In this sense, it is urgent to promote cultural responsiveness and competency among healthcare providers giving them training to increase their “understanding of the differences that exist in the maternity experiences of immigrant and non-immigrant women and provide a framework for improving clinical and community-based care of pregnant and postpartum immigrant women” (Kingston et al., 2011, p. 1114).

This also resonates with Higginbottom et al. who highlight the need to promote culturally congruent and culturally safe maternity care in Canada through the enhancement of multi-sectorial and multidisciplinary services. And Mumtaz et al. state that in Canada “for the most part, maternity services to a diverse group of newcomer women have been managed” our research found important gaps which aligned better with Higginbottom et al. that “although immigrant women in Canada are generally given the opportunity to obtain necessary services, they face barriers to accessing and using them. These barriers include not only the lack of availability or awareness of information and supports but also the presence of discordant expectations on the parts of the women and the service providers” (p. 28).

However, pregnancy-related resources and supports are especially harder for newcomer and immigrant families to source and utilize. Our study findings stress that supports and resources are key not only during pregnancy but also postpartum and are important to all populations to affect positive pregnancy outcomes. Access to prenatal courses, breastfeeding support, support groups, home care and knowledge translation materials to help pregnant individuals and their families navigate a pregnancy journey that might not always as expected, were also identified by Higginbottom et al. as the most appropriate multi-sectorial and multi-disciplinary response to ensure best maternal health outcomes.

Moreover, this could help to improve mental health which we found is heavily impacted, specifically for individuals who face adverse events. According to Gheorghe et al. (p247) one in four women who gave birth in Canada between January 1 and June 30, 2018, reported symptoms consistent with PPA or PPD five to thirteen months postpartum. Similarly, Saad illustrated that the literature reveals an increased prevalence of postpartum depression in immigrant women in Canada mediated by risk factors linked to social determinants of health such as social support, socioeconomic status, and life stressors. About this point, we cannot provide statistical data among our participants, but we can highlight that mental health was identified as a main theme for our project due to frequent mentions of related issues and experiences among our sample which underline the relevance of addressing mental health issues during pregnancy and postpartum. More awareness is needed and as suggested by Higginbottom et al. providers need to be “trained to understand the cultural manifestations and cultural context of postpartum depression” considering also that patients are the ones claiming better care in this sense since our participants were the ones to seek help instead of this being addressed and offered by healthcare providers. Once participants accessed appropriate mental health treatment and support, they all felt their mental health improved. This shows the importance of screening and intervention in pre- and post-pregnancy care.

**Strengths and Limitations**

This patient-led peer to peer study aimed to integrate diverse patient and community voice and perspective at every stage of the research process, from conceptualization to study design, data analysis and dissemination. Patient and community perspective were included at SET to refine the research question, participant inclusion criteria and data collection
approaches. As well, the REFLECT phase supported member checking and added additional rigour to the analysis of the findings and recommendations.

Established relationships of trust and community connectivity between researchers and those often missed in the health research that impacts them can support more effective and inclusive participant diversity, data collection, data analysis and dissemination and implementation strategies of more person-centred results. Our team was able to reach out to unique, often missing populations in health research as well as elicit data and narratives that might have been missed through surveys.

**Impact on Participants**

The benefits of qualitative, participatory research are the transformational aspects of the research but also the researchers and the participants. The conversational processes of focus groups and interviews can help participants make sense of their own experiences as well as gain additional insights and perspectives from others who share a similar health issue but experience this in different contexts, cultures and from diverse backgrounds. Participants expressed gratitude for being able to hear others experienced similar challenges to them as well there was an active exchange of information about supports and resources during the focus groups.

**Challenges and Limitations**

We faced a few challenges during our research. Some of the most significant ones to mention included the recruitment of genuine participants and identifying imposter participants, health literacy of participants, limited demography of participants, and pandemic protocols.

**Imposter participants:** While we did post recruitment posters in community locations as well as shared with our own networks, we also reached out on social media. Posting recruitment flyers on online social media forums facilitates and broadens the scope of participant recruitment but at the same time increases the possibility of non-eligible or illegitimate responses. The increase in language processing tools and global digital access make it easier for fraudulent participants to engage in online focus groups and interviews. Bulk spammed and fraudulent responses to participant recruitment, imposter participants during data collection activities such as focus groups and interviews, add significant work for research team members, and pose ethical challenges both to legitimate participants and the quality and validity of the research. Our initial focus group contained 4 imposter participants and we also carried out 2 interviews with imposter participants. As a result, we were able to identify some common characteristics of the imposter participants: they never contacted via phone, only responded over email using well-written detailed letters and although the grammar and spelling were impeccable they often asked for details about key points that were included on the recruitment poster; they had classic connectivity issues; always kept the cameras off during online interview; avoided providing verification address or location details, always had audio quality issues and preferred typing in chat box rather than speaking up. Another interesting fact we noticed was that somehow, they were very smart to use Artificial Intelligence (AI), google search or chat to answer the questions! This was easily figured out by pasting the exact Chat text sent by them on any of these search engines. As our study progressed, we responded by implementing additional participant screening features including obtaining oral consent as a pretense to meet with the participant online and confirm credibility and eligibility. We also created an online Qualtrics survey for participants to apply through as there are features on Qualtrics that can help with screening, including for IP addresses. A QR code was added to our recruitment poster to facilitate this.

**High health literacy of participants**

Many of our participants had medical and other advanced academic backgrounds. The high health literacy of the participants could be a limitation and yet, they still experienced disregard, and exclusion from respectful communication during their adverse event and follow-up experience. It is also important to note their motivations. They were very concerned about the experiences and outcomes of those who didn’t share similar circumstances to them and wanted their stories and
experiences to contribute to improving experiences and outcomes for everyone. All participants expressed gratitude for the work we were doing and the cathartic experience for them in joining the focus groups or interviews.

**COVID times**

Two of our participants shared pregnancy-related adverse event experiences that occurred while COVID-19 protocols were in place. While we agree COVID times might have had some impact, their experiences were also shared by participants who received care before and after COVID times. Also, the hospital one participant attended is still experiencing concerns about overcrowding and overuse concerns that directly emanate from the participants' COVID times experience.

**Participant population**

We tried to recruit partners and family members in our study to help capture and understand family members’ perspectives and experiences, but we were unsuccessful in recruiting other than cis-gendered female participants with current or previous experience of pregnancy. Additional populations we missed were those living with disabilities, Indigenous people, and those from traditionally marginalized or hard-to-reach communities including those who are incarcerated or unhoused. There was also a lack of scope for territorial and provincial representation. We only had one SET patient partner from the Northwest Territory but were unable to recruit COLLECT participants from the territories or any provinces other than Alberta, Ontario, and Quebec. Because of the diversity of socio-cultural background of our team, we were able to add valuable and essential cultural and linguistic context to data collection and analysis processes. Because of the sensitivity of the research topic and the vulnerability many newcomers feel in joining health research, we would suggest going forward that interviews will be offered in the participants’ own language if possible.

**Conclusion**

Participant narratives were accompanied by a unified feeling around the importance that communication (verbal and non-verbal) has for patients. All the participants highlighted the need for a more compassionate, culturally informed, and safe patient and family-centred approach. Canadian health systems need to understand how personal and cultural background impacts decision-making and patient preferences and need to recognize the diversity within and across Canadian populations. Our results identify future maternal health research priorities that may have scope beyond Canadian contexts and we share strategies for more inclusive evidence bases that can inform more universally appropriate maternal health care practices going forward.

**Declarations**

a. **Ethics approval and consent to participate:** Research Ethics Approval was obtained from the University of Calgary and details have been provided in the manuscript. Informed consent was obtained from all subjects and/or their legal guardian(s).

b. **Consent for Publication:** Not Applicable.

c. **Availability of data and materials:** The datasets generated and/or analyzed during the current study are not publicly available since we do not have consent from participants or the research ethics board to share the same. However, de-identified transcripts could be obtained from the corresponding author on reasonable request.

**Author Contribution**

All the authors (IN, KN, MS, WWOO, MCP, SB, LQ, QW, MS, RD) contributed to the conceptualization of the study, and writing, reviewing, and approval of the submitted version. All authors read and approved the final manuscript.
References


Figures
Figure 1

Legend not included with this version.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- AppendixASETRecruitmentPoster.jpg
- AppendixBCOLLECTRecruitmentPoster.jpg
- AppendixCDemographicsurveyQuestionnaire.pdf
- AppendixDThemensubthemesandexemplarquotes.docx
- LEGENDOFSUPPLEMENTARYMATERIALS.docx