

“It is judgment by the people that have meant something to me that hurts the most”: Inter-discursive evidence synthesis incorporates the lived experience of adolescent mothers

Anna Dion (✉ anna.dion@mail.mcgill.ca)

McGill University Faculty of Medicine <https://orcid.org/0000-0003-2122-222X>

Aime Klevor

Peer Researcher

Amy Nakajima

Bruyere Centre for Continuing Care

Neil Andersson

McGill University

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Abstract

Background Evidence synthesis without meaningful stakeholder engagement can overlook factors considered relevant and influential by stakeholders. This paper presents an inter-discursive approach to grounding conventional mixed methods evidence synthesis in stakeholder views of adolescent perinatal health in Canada. Methods A parallel-results convergent mixed review identified studies reporting on perinatal outcomes and experiences of adolescents during pregnancy to 12 months post-partum, in French or English, published in Canada after 2000. We summarized findings using thematic synthesis and descriptive statistics. We then extracted data from a provincial database of maternal and newborn outcomes and calculated relative risks for common perinatal risk factors and outcomes for adolescents compared to adult population within a local health region and across Ontario from 2012-2017. Two trained peer researchers contributed to our evidence syntheses. We shared syntheses with four service providers and 13 marginalized adolescent mothers, who identified and prioritized their areas of concern. A second literature review refocused around the priority issues identified by the women and was then expanded through semi-structured interviews. Results Adolescent mothers face more poverty, higher rates of abuse, anxiety and depression than adult mothers. They also report experiencing negative judgments when accessing services, highlighting the need for more youth-friendly services. Adolescent women prioritized the experience of judgment in perinatal health and social services, and more specifically how they felt judgment contributed to them being identified as a child protection risk. Other priorities included inadequate housing, judgment around breastfeeding, loss of social support and inaccessibility of community resources. Judgment in the adolescent perinatal health literature was summarized around three themes: being invisible, incapable and at risk. Adolescent mothers adapted and added onto these categories, emphasizing organizational and social challenges, with important consequences for their mental health and accessing appropriate care. Conclusions Incorporating young women's voices changed the focus of our research. Women's priorities highlighted the way motherhood norms are embedded in social and institutional structures. Adolescent women's experiences of care have important implications for ensuring the effectiveness of more targeted interventions to maximize benefit to women and newborns.

Background

Despite Canada's investment in universal and accessible health services, stubborn health inequities continue and follow predictable social fault lines: people living in worse socioeconomic conditions have poorer health than those with greater access to resources and educational opportunities. (1–3) By international standards, Canada has a low maternal mortality rate (6.1/100 000 births). (4) Women living in lower socio-economic conditions, however, often face greater levels of chronic stress related to poverty, lack of social support, and violence. (5,6) Several studies show women living in low socio-economic conditions have worse perinatal outcomes and lower use of prenatal and postpartum care. (1,6–10)

Marginalized women are disproportionately affected by inequities in perinatal outcomes, yet their perspectives are rarely featured in efforts to address these inequities. (11) A disjointed Canadian surveillance system is unable to capture maternal health indicators among some of the country's most vulnerable citizens. (12) Those at the margins are rarely heard in institutional decision-making and, therefore, they have little influence over research and clinical practice. (11)

Adolescent women are among the populations in Canada that experience higher risk factors and poorer outcomes. Increased risks associated with adolescent pregnancies include preterm and very preterm delivery, low birth weight, small for gestational age infants, and neonatal and infant mortality. (13–15) Although socioeconomic and behavioural factors like smoking, alcohol and drug use, poor nutrition, and poor prenatal care are also risk factors,

young maternal age remains an independent risk factor for these outcomes after adjusting for potential confounders. (15) Significant resources are dedicated to reducing unplanned pregnancies in adolescence. The fertility rate among adolescents aged 15–19 has declined from 11.9 in 2012 to 8.4 in 2016. (16) This is primarily due to improved sexual education and increased access to contraception and abortion. (13)

We used modern participatory methods to ground available evidence in the lived experience of adolescent mothers to identify and better understand priority issues affecting their care as pregnant and parenting adolescents. As part of a larger initiative, this paper describes two meetings with young mothers, the first to determine the focus of the research project, and the second as an exploration of the chosen focus issue.

Methods

With the help of a health sciences librarian, we searched Medline, CINAHL and Web of Science for primary research describing perinatal (during pregnancy to 12 months post-partum) health outcomes and experiences of adolescent women (under 23 years of age) in Canada, including all articles published in French or English after the year 2000. The primary author screened all abstracts, read and extracted data from all eligible articles. We assessed the quality of qualitative studies using the Critical Appraisal Checklist for Qualitative Research. (17) We extracted findings as a standard parallel-results convergent synthesis mixed method review, using inductive thematic synthesis with NVivo to analyze qualitative data and descriptive statistics for quantitative data. (18–20)

We also analyzed data from the Better Outcomes Registry Network (BORN), a database on pregnancy, birth and childhood outcomes for the province of Ontario. We extracted data on common perinatal health indicators (such as pregnancy rates among adolescents, preterm births, access to antenatal care, labour and birth complications) as well as specific indicators commonly reported among adolescent pregnancies (substance use, sexually transmitted infections, mental health concerns, experience of abuse). We calculated relative risks for adolescents for each indicator by year and over the 5-year period for both the province and the relevant local health integration network from 2012–2017.

Engaging Peer-researchers

Ottawa-based staff from a social service organization for young pregnant and parenting women helped to identify two peer researchers with lived experience as young mothers. AK joined the project, along with another co-researcher, after 10 hours of peer researcher training, adapted and delivered by the primary author (AD). (21,22) Both peer-researchers were paid during their training and when contributing to the project.

Determining Priorities

The primary author and peer-researchers reviewed statistics of outcomes and risk factors from quantitative studies along with themes, quotes and images from qualitative studies. We discussed which findings might be most relevant to young mothers accessing services at our partner agency. AD summarized selected findings in an infographic, which was further refined by both peer researchers. The infographic was shared with four service providers from the fields of obstetrics, mental health, nursing and social work, all involved in providing front line services to pregnant and parenting young people in Ottawa. They individually identified what they felt were priority challenges in the perinatal health and well-being of their clients, and then grouped common themes between them. Each provider was given five stickers to allocate to the challenge they felt was most important to young mothers' well-being, specifying that they

could place more than one sticker per issue. Priority issues were summarized and included in the next step of sharing information with young mothers.

Using information postcards, short presentations and support from our partner agency, we invited young women to join an information and priority setting meeting at our partner agency. Following brief introductions and an informed consent process (detailed below), we shared and reviewed the evidence synthesized in the infographic and invited participants to tour a collection of nine pictures and quotes from published qualitative studies, selected by the peer researchers. We emphasized that this information represented how young motherhood was discussed in research literature, and that some aspects may be relevant to their own experiences, while others may not.

We asked each participant to identify areas or issues that were important to them where they faced challenges or barriers throughout their pregnancy and early postpartum experience. We prompted participants to draw from the literature, priority issues identified by service providers, as well as their own experiences. Participants wrote their ideas on post-it notes. Where comfortable, participants presented their issue, briefly describing why it was important and placed it on the wall. As each subsequent participant shared their issue, they determined whether their issue could be grouped with one already posted on the wall or if it addressed a separate issue. (21) Any participants who did not want to present their issue themselves could hand their post-it notes to the two facilitators (AD and AK) as we circulated around the room. Before moving on to the next step, we asked participants to adjust any grouping or descriptions of their own topics if they felt their idea had changed or was miscategorised. We also included priority themes identified by service providers if they were not already mentioned for women to include in their evaluation.

Each participant received five voting stickers to identify the most important challenges faced by young mothers, and they could place more than one sticker per issue. We then drew on sticker voting to re-organize issues according to importance. We gave participants an additional two stickers each, asking them to identify among those identified in the first round, their first (red) and second (yellow) priority concern.

We finalized the priority issues through group discussion, and participants were asked to write the answers to the following two questions with respect to the issue identified as the top priority: *Why is this important? What do we still need to know about this?* (22)

Grounding Evidence

Following the priority-setting meeting, we returned to our literature review to extract findings related to the priority issue. We compared themes identified in each of the papers together with the quantitative data to identify second-order themes around the priority issue. Second-order themes are grounded in evidence from the original studies but are the result of an interpretation across the collection of studies. (23) AD identified primary and second-order themes related to the priority issue, which were subsequently adapted by the peer researchers. We used these themes to guide an additional round of conversations with women. We carried out individual or small group meetings with 10 young mothers, where we asked participants to describe their own experiences related to the priority issue throughout pregnancy and early postpartum. We worked with participants to distil their main ideas and wrote them on small magnets.

We then presented the second-order themes identified in the literature on a magnetic whiteboard, emphasizing that these were concepts identified from the literature, but may not capture all their experiences. We asked participants to map out (using a small whiteboard) how their own ideas fit within (or not) the concepts identified in the literature. We also presented the primary themes identified from the individual papers and invited participants to incorporate into

their map where relevant. The lead author and peer researcher independently reviewed the conceptual maps and notes from each of the interviews and developed a list of common themes. These themes were compared and refined to reach a final set of themes identified by participating women.

Participatory inter-discursive evidence synthesis

We piloted all elements of the approach with peer researchers and adopted strategies to support meaningful engagement with young mothers including efforts to be youth friendly and build trust, and taking a scaffolded and iterative approach that included multiple opportunities for consent.

Youth-friendly and accessible information: We adapted our consent forms to ensure that language was understandable and accessible to potential participants. Together with peer-researchers, we prepared a general information sheet about the study and separate one-page consent checklists for each meeting in short question and answer formats. (24) This allowed people to understand the direction of the overall project, while deciding whether to participate in the one meeting without committing to the whole project. We opened each meeting with a discussion young people's rights when participation in research. Using a Charter of Rights for Children and Young People developed by Moore et al., we reviewed issues relating to participants' rights to be heard, to participate in the way they prefer, to be treated well and not be hurt or discriminated against, as well as to be fully informed and to benefit from the research. (25) Counseling staff from our partner organization was also available if anyone needed additional support.

Consent focussed: We relied on young women, all of whom were 16 years of age and older, to decide how and when to participate. Many clients of our partner organization have complicated or non-existent relationships with their parents or guardians, are already making important decisions for their children and engaging with many organizations as adults. While this often adds to their vulnerability as young parents, we felt it would be inappropriate and potentially harmful to ask potential research participants to seek parental consent to participate in this research project. (24) Given enough time and information, adolescents over the age of 15 years have the cognitive capacity to make informed decisions. (26)

Renegotiating consent: We incorporated multiple opportunities for participants to renegotiate consent, dissent or disengage at pivotal moments throughout this research. This included periodically checking in with participants to ensure they were comfortable continuing and encouraging people to step outside the room if they needed to. (27) Some women described experiences or events but were uncomfortable with representing them on the whiteboards. Facilitators supported the distilling of ideas, but women decided how their experiences were described, represented or even included on the whiteboard, emphasizing that they also had the right to have parts of their story not told. (28)

Scaffolded and iterative: Each activity built on a previous discussion. In a first meeting, young women decided what issues were most relevant to them. Subsequent discussions focused on issues identified by young women, bringing in relevant findings from research to inform the discussions. Each discussion served as an opportunity to ground research findings in the experience of young women. (27,29) Our approach sought to provide young women the same level of research evidence as other decision-makers, giving them the information that might be necessary to make evidence informed decisions around their care.

Compensation: We worked with our partner organization and peer-researchers to determine appropriate honoraria for participants. We provided child care, bus passes and snacks during each meeting to ensure that participants could engage comfortably in discussions. We also provided \$30 gift cards for each 2-hour meeting in recognition of their

knowledge and expertise. We chose to distribute these at the beginning of each meeting (after the consent process) as a sign of trust and so that participants did not feel obliged to stay if they were uncomfortable throughout the meeting. (30)

Building Trust: AD served as a volunteer birth companion in Ottawa for nine years, informing the overall research approach. Prior to engaging with young women as participants in this research project, AD was a respite volunteer for young mothers at our partner organization's shelter once a week for over a year before and throughout the project. Many women knew AK as a fellow client of our partner organization. This helped to build trust with participants and create familiarity with our partner organization's activities.

Results

Literature Review

Our search identified 771 publications. The lead author (AD) assessed all abstracts to determine eligibility and extracted data from 28 relevant articles (13 quantitative, 15 qualitative). All studies included women under the age of 23 who had a singleton pregnancy. Tables 1A and 2A show summary data from studies reporting risk factors and outcomes comparing adolescents with adult populations respectively, while Tables 1B and 2B show summary data from studies with adolescents accessing community and outreach services for marginalized and pregnant youth. Heterogeneity across studies precluded pooling of quantitative data. Full data tables can be found in Additional File 1.

Pregnant adolescents were 10–47% less likely to attend prenatal care in the first trimester, often citing financial barriers, long waiting times, lack of privacy, fear of judgment and not wanting to miss school. (13) Adolescent mothers were also more likely to have concurrent mental health issues and additional social and economic risk factors that may affect their pregnancy. Most young mothers were single (OR = 2.66 (1.69–4.18)) and were more likely to have a low income (less than \$40K a year). (31) Adolescent mothers were twice as likely to be at risk for postpartum depression compared to adult mothers. (32) Roughly 60% of young mothers accessing care at a youth pregnancy outreach clinic either completed or were in the process of completing high school. (33,34) Youth in foster care were four times more likely to become pregnant compared to other teens. (35)

Table 3 shows relative risks from the BORN database, comparing risks and outcomes in adolescent (under 23 years) and adult pregnancies in the Champlain Local Health Integration Network and across Ontario. Ontario adolescents were more likely than adults to have a mental health diagnosis of anxiety, depression as well as other mental health disorders, consistent with higher age-specific fertility rates among adolescents with major mental illness reported in the literature. (36) Pregnant and/or parenting adolescents were 2–4 times more likely to have ever experienced physical abuse (14,31) were more likely to have used drugs (RR = 5.63 (5.41–5.84)) or alcohol (RR = 2.33 (2.22–2.44)) during pregnancy and were more likely to be diagnosed with a sexually transmitted infection during pregnancy (RR = 2.77, 2.62–2.93). Adolescent mothers were roughly one half as likely to have a Caesarean section or breastfeed compared with adult women and were 16% more likely to deliver preterm. (13,15)

Themes identified in qualitative studies (Table 4) reflect the complexity of emotions surrounding pregnancy and motherhood. Women express deep gratitude for their experience of pregnancy and their children, while also feeling that an unfair burden of responsibility and social stigma surrounds their mothering experience. (37) They describe challenges in navigating education, employment, social services for themselves and their children while facing negative judgment. (37,38)

Determining Priorities

Peer researchers highlighted outcomes, themes and quotes they found relevant to the experiences of the women accessing services at our partner organization. After multiple rounds of feedback, we developed the evidence infographic in Figure 1. Peer researchers also chose nine quotes and photographs from the four qualitative studies that used PhotoVoice methodologies to include in the priority setting meeting. (38,39,41,42)

Table 5 presents priority concerns as identified by service providers, and by the women who participated in our priority setting meeting. Service providers identified concerns around mental health- both recognizing the need for and accessing services- as an important challenge for pregnant and parenting youth. They also discussed the influence of stigma and fear of the consequences of being vulnerable as a critical factor influencing perinatal well-being, highlighting the need for trauma-informed and culturally-informed programming. They saw young women's on-going precarity due to poverty, housing instability and the need for independent living skills as factors contributing to young women's overall vulnerability.

Thirteen women aged 17–25 participated in our priority-setting meeting. Participants' children ranged in age from one month to 4 years old, with women having between 1 and 4 children each, and varying levels of custody over their children. Women (almost universally) identified the experience of being judged or misunderstood as the most important challenge throughout their maternity and early motherhood experiences. Women experienced judgment in everyday experiences, such as riding the bus or grocery shopping, which was a source frustration that eroded their sense of confidence. Judgment was particularly challenging with respect to breastfeeding, as many reported having comments made to them or were asked to not breastfeed their infants in public.

“Young moms and moms in general are still constantly being shamed and ridiculed for breastfeeding in public. If a baby is hungry, feed the little one.....it makes me mad when I see women being shamed for it. If you don't like to see it, look the other way.”

After discussing women's experiences of judgment across multiple areas of their lives, we invited women to vote a second time, identifying their most important concerns with respect to judgment. Women identified the experience of judgment as it relates to being identified as a child protection risk as well as how judgment affects access to secure housing for themselves and their children. Several women mentioned that many of their interactions with child protection workers themselves have been positive, but women collectively explained that initial reports to the Children's Aid Society's were uninformed or made without adequate investigation. Women sought to be seen for their strengths as well as challenges, despite and not because of their age, and emphasized early and non-judgmental support to prevent the need for child protection involvement. This priority area was further explored with participants in subsequent meetings and described in forthcoming publications.

Unpacking judgment and its consequences

Following this priority setting meeting, we returned to the published literature to identify themes related to the experience of judgment and its consequences. We then met with 10 women in follow-up meetings either individually or in pairs, and worked with women to distil ideas, issues or themes from their own experiences of judgment throughout pregnancy and early motherhood. Table 6 shows the demographic characteristics of the women participating in these meetings. Several women reported using illicit drugs; cannabis was illegal at the time of these interviews, and therefore also included in this category.

Second-order themes identified in the literature included being regarded as a *risk*, *invisible* and *incapable*, shown in Table 7. Women arranged their ideas around these three second-order themes or created new ones when they felt other categories were needed. They subsequently incorporated the primary themes describing experiences judgment from the literature (Table 6) that they felt were relevant to their own experience.

Finally, we asked participants to describe the consequences or effects of each type of judgment listed and distilled these onto small magnets to be included on their map. We presented consequences of judgment identified from the literature and again, asked participants to incorporate themes relevant to their own experience.

Women described feeling discounted or quickly judged by service providers who didn't understand the broader context of women's lives and experiences around their pregnancy and/or postpartum concerns. Women were frustrated by experiences of surveillance and judgment rather than support when they disclosed needs around housing, low income, or other health and social concerns.

"They judge you for something you didn't even know you are doing. They make you feel like you are not capable of being a good mom....instead they should try to help you become the best mom you can be."

Several women also discussed the paradox of being a young mother, where they experienced administrative barriers in navigating health and social service systems. They were expected to manage the responsibilities of new motherhood as an adult, while simultaneously being a child and "not being taken seriously". In the words of one participant *"I am old enough to have a baby....but not old enough to consent?!?"*, describing the contradiction in being able to consent for medications for her infant, but not being recognized as an adult capable of consenting for her own medical needs.

Women linked experiences of negative judgment with their mental health concerns, including higher levels of stress, frustration and in some cases anger. They reported feeling as though they always second-guessed themselves, and that they were made to feel incompetent before being given a chance.

"When I had my first child in the hospital, people just took over, figured I had no idea what I was doing. They just took it upon themselves to take over with the assumption that I wasn't going to do it myself."

"I sneeze and it is judged; I go to the bathroom and I wonder if it is okay.....you cannot function as a human if you are always in doubt"

These experiences contributed to women feeling as if they had no voice in or control over their care, undermining their position as primary caregivers. Some women reported feeling that their consent in the care and handling of their child was not respected and reacted by becoming hyper-vigilant and protective in interactions with health and social service providers. One woman reported limiting her sleep in the hospital both ante and post-partum for fear that decisions about her newborn's care would be made without her.

Several women reported avoiding services or not fully disclosing needs for fear of judgment or being seen as incapable or a risk. This left them with unmet needs, particularly around mental health.

"I also had to balance not saying too much. I couldn't say what I really feel- like admitting feeling suicidal would be seen as a risk to my child, and would be reason to justify her removal or the removal of my rights."

"Even postpartum, it felt that it took excessively long to get a referral to perinatal mental health. I received great care for anything that directly affected baby's health, but my mental health didn't fall into that."

Women reported feeling let down or judged by those they thought could support them; in many cases, losing social support from friends, partners and sometimes family, upon learning they were pregnant. Women often spoke about isolation and harassment from friends at school or work, unsupportive teachers and/or family members who may disapprove of their pregnancy and/or their partners.

"It is judgment from the people that have meant something to me that hurts the most"

Women felt they did not have enough information about programs and services available to them, particularly those focused on the needs of pregnant and/or parenting adolescents. This left many women with a heavy burden of responsibility, while isolated from their previous support network.

Several women described unhealthy or dangerous family situations, stating that for them, isolation from these relationships was often difficult but necessary. Some women reported having to push back against conventional perceptions of sources of social support.

"Then she began to be really opinionated about me needing to get back together with my son's dad. Eventually, I told her that I didn't want to go back to being beaten every day and she backed off.....Isolation is seen as a bad thing, but when your support network isn't good for you, sometimes it is the best thing."

Women also described feeling permanently labeled based on their needs or events in their lives, over which they had little control. Examples included having had child protection involvement in their own childhood or by what were seen as choices to remain in abusive or violent relationships.

"They see you only for your risks.... when people look at me, nobody sees my future plans, just my present problems."

"We don't need to be hovered over-we aren't terrible or scary people, or that we have no idea what we are doing. Some of us are in bad situations or made some poor choices along the way, but it doesn't mean we don't know anything or how to do anything"

"I have a mild form of autism, so that brought additional judgment. They were telling me that I shouldn't be having kids because....neither of us will know what to do with it."

As a counter to these experiences, women highlighted how they resisted judgment and its consequences. For many women, this meant recognizing their own strengths and affirming their identity as mothers. Many women reported seeking out additional learning resources to support their decision-making around pregnancy and early parenting. Women invested considerable mental and emotional energy in controlling the narrative in how they were perceived, learning to advocate for themselves and their children early on:

"You can either deal with judgment and live your life, or hide away. I hid for a while but then I decided I just didn't care what other people think, but I had to grow up fast to get there."

"I feel I often have to fight to make myself heard over my pediatrician; I have to not back down. I had to go through multiple prescriptions for [my son's condition] because she assumed that I was doing it wrong. She didn't see that I understood, but that the medication just wasn't working."

Women also reported refusing support that did not meet their needs. Women's refusal often resulted in being labelled as non-compliant or seen as a potential risk.

"I wasn't interested in participating in an arts and crafts program but had to, as well as other programming that I didn't find helpful. I pushed back against the rules because I didn't feel they were helpful or what I needed."

"I am generally uncomfortable with males (particularly male authority figures) and didn't want a man examining my baby, so when the male resident came to examine my daughter, I refused the exam."

Women also emphasized the importance of supportive relationships as a counter to experiences of judgment that helped them benefit from health and social services and prevent difficult circumstances from evolving into more serious risks for themselves and their children. This often included family members and close friends, however, also included health and social service professionals, including ward and public health nurses, lactation consultants, physicians, early childhood educators and child protection workers. Many women highlighted adolescent-specific services as being particularly supportive, however they also cited several examples in mainstream services.

"What made a big difference for me was having someone speak to me - for me it was my mum and grandmother - telling me that I am a good person, that I can do this. They made me believe in myself."

"There were some good people at the hospital- they showed that they had faith in me and took the time to spend some time with me, and believed in my skills. One of these was a lactation consultant, who stood up for me within the hospital and with other professionals."

Discussion

Incorporating adolescent women's voices changed the focus of our research. While issues of negative judgment appear in qualitative literature on adolescent pregnancy, how young people experience this and its consequences are rarely explored. Our focus was to ensure meaningful participation of young people and our approach was driven by their experiences and concerns during pregnancy and early motherhood.

Rigidly gendered social norms around motherhood continue to play a large role in the experience of adolescent motherhood. (43–46) People who deviate from prevailing norms around motherhood are often seen as risky or unfit. In many cases, their perceived riskiness is seen as an individualized choice, with insufficient consideration of the context and structural influences. (37) Women described barriers to participation they found built into the architecture and organization of institutions. This affected their access to health, including being recognized as their child's guardian and parent, opportunities for education, financial support, housing and in navigating child protection issues. These systemic barriers exacerbate existing vulnerabilities, even in the absence of individual prejudice or discrimination on the part of care providers. (47)

Repeatedly being labelled often becomes internalized, and can influence people's willingness to seek care, as well as how care is delivered, received, what is shared, what is acted upon and what is refused. (28,47–50) Expecting and fearing rejection, women guarded or avoided potentially threatening interactions all together. All the women in our study mentioned the mental health consequences of repeatedly feeling judged, having their identity as mothers be undermined or questioned and the emotional work required to try to manage how they were perceived.

Women who are seen as outside of the conventional norms around motherhood also experience more frequent controls or access restrictions through both formal and informal interventions. (51) In our work, women described how they felt that judgment or a mischaracterization of their situation often led to restrictions on their activities and over-surveillance of their pregnancy and mothering.

The findings of this study have several implications for research and the provision of perinatal care for young people. Many women saw judgment and stigma associated with their positions as mothers as something they just have to live with. At a practical level, this is probably true. However, researchers, clinicians and care providers are in a position to change the extent to which judgement shapes all maternity and early parenthood experiences, and especially among those who may face high levels of stigma by changing their own practices as well as advocating for broader systems level changes.

One way of doing so is by centering the experience of people living with the everyday effects of being made vulnerable. They are the most relevant voices to speak about how this vulnerability intersects with perinatal care, and ultimately influences their own and their family's health and well-being. Services designed solely by those who identify with more privileged groups are unlikely to address the additional or different needs of less privileged groups, often leaving already marginalized groups underserved and further excluded. (52) Despite personal intentions to provide the best care possible, perinatal care providers may find themselves with limited ability to meet the needs of marginalized groups. (53,54) When policies and resource allocations do not match community needs, providers may lack the support of strong inter-professional collaborations, with patient follow-up falling through cracks between different organizations or care teams. (55–57) This can leave providers frustrated and feeling powerless while also leaving women feeling isolated and without adequate support. Women may find themselves labeled as “non-compliant” when they cannot access care in a system that does not adequately consider their needs. (52,58,59)

In a matched cohort study, Fleming et al. found that adolescents receiving specialized multidisciplinary community-based perinatal care had higher rates of prenatal visits, prenatal class attendance and group B streptococcus screening compared to adolescents across the province on Ontario. Although women accessing community-based perinatal care had higher levels of tobacco, alcohol and other substance use than the control group, those accessing community-based care had significantly lower risks of low birth weight and preterm delivery. (53)

The dynamic and multi-layered nature of young people's perinatal care needs requires a broad consideration of outcomes. While focused programs and interventions need continued support, interventions are also needed to shift deeply held attitudes and beliefs that lead to labelling, devaluing and discriminating. Alternatively, interventions must contribute to limiting the processes that make these perceptions the dominant ones. (47,50,60) While these are broader societal issues, ensuring the optimal health of families needs to be carried out in a context where compassion, understanding, encouragement and respect for parents are the foundational and enacted values.

Research also has an important role to play in shifting our understanding towards more people-centered health systems and services. Recognizing the value of lived experience can strengthen our understanding of the influence of social and organizational contexts in health interventions. (61) Considering people's experience as expertise recognizes that there is more than one piece to a puzzle and that putting the knowledge and experience of people who are living with vulnerabilities on equal footing with other types of knowledge is critical to challenging assumptions often implicit in clinical research and the provision of services. (62,63) This is particularly important in communities that are stigmatized, where incorrect assumptions or representations may reinforce negative or incorrect stereotypes. (64)

Conclusions

Young mothers have priorities in their perinatal care that might not be well understood without detailed consultation. An iterative process grounded conventional evidence syntheses in young women's experiences, deepening our understanding of the role of judgment in shaping perinatal care. Women explained how their experiences of judgment

around pregnancy and parenthood had important implications for their mental health, identity as mothers, and access to services. They emphasized the importance of supportive relationships and their role as advocates to counter experiences of judgment.

Service delivery and evaluation should take better account of service users' understanding of how determinants of health intersect with conventional biomedical evidence. This is particularly urgent in the context of health inequities, where perspectives of those who carry the greatest burden of inequities are often poorly reflected in published literature.

Declarations

Ethics Approval

Ethics approval was received from the McGill Faculty of Medicine Ethics Review Board (A09-B51–17A). An Advisory Board made of senior staff of our partner organization also refined and approved this research.

Informed consent was obtained from all participants prior to data collection.

Consent for Publication

Not applicable

Availability of Data and Materials

Not applicable

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

AD, AN and NA conceived of the study, AD and AK carried out the research, AD, AK and NA carried out the analysis. AD drafted the manuscript and AK, AN and NA made substantive revisions.

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Tables

Table 1A: Risk factors among adolescent compared to adult pregnancies in Canada

Author	Previous Mental Health Diagnosis*	Income (less than \$40K)	Experienced physical abuse	History of Substance Use	Any smoking during pregnancy	Alcohol during pregnancy	Not having age-appropriate education	Single
Al-Sahab, 2015		OR=6.66 (2.98-14.90)	OR=2.24 (1.53-3.29)		OR=1.12 (0.72-1.73)	OR=0.54 (0.27-1.08)		OR=2.66 (1.69-4.18)
Vigod, 2014	ASFR= 2.95 (2.84-3.07)	ASFR= 3.04 (2.95-3.15)						
Kingston, 2014			aOR= 4.87 (3.44-6.90)	aOR=3.7 (2.47-5.56)	aOR=4.9 (3.37-7.12)		OR= 1.92 (1.27-2.89)	OR=17.75 (13.49-23.35)

* Previous diagnosis of anxiety or depression; OR= odds ratio; aOR= adjusted odds ratio

Table 1B: Risk factors among adolescents accessing community and outreach services for marginalized and pregnant youth in Canada

	Previous Mental Health diagnosis	Low Income	Experienced physical abuse	Experienced sexual abuse	Experienced emotional neglect/abuse	History of Substance Use	Not having age-appropriate education	Child Protection Involvement in Own Childhood
Singh, 2015 (n=90)	58%					44%	60%	30%
Thompson, 2015 (n=116)			37.8%	29.7%	51.6%		57%	47%
Harrison, 2014 (n=36)	78% (n=28)	42% (n=15)				81% (n=29)		69% (n=25)
Fleming, 2012 (n=1037)	7.8% (int**) vs. 4.8% (con**)					19.6% (int) vs. 10.5% (con)		
Romano, 2006 (n=252)	33.30%	28.8%	21.10%	24.20%	26.60%			

* Previous diagnosis of anxiety or depression; ** int= intervention group, con=control group

Table 2A: Pregnancy outcomes among adolescents compared to adults in Canada

Author	Pre-eclampsia	Preterm Delivery	IUGR	C/S	Prenatal Visits in First Trimester	Exclusive b/f @ discharge	EPDS above 13	Admitted to NICU	Fetal Death
Fleming, 2013	aRR0.91 (0.83-1.00)	aRR1.16 (1.02-1.31)	aRR=1.00 (0.96-1.04)	aRR=0.57 (0.55-0.59)	aRR=0.53 (0.51-0.55)	aRR=0.73 (0.71-0.76))		aRR=1.08 (1.02-1.14)	aRR=1.02 (0.88-1.18)
Kingston, 2012				aOR=0.64 (0.46-0.9)			aOR=2.29 (1.48-3.54)		
Shrim, 2011		OR=2.3 (1.6-3.2)	OR=2.4 (1.6-3.5)	OR=0.3 (0.2-0.5))				OR=2.1 (1.5-3)	OR= 3.8 (1.9-7.5)

Table 2B: Pregnancy outcomes among adolescents accessing community and outreach services for marginalized and pregnant youth in Canada

	Pre-eclampsia	Preterm Delivery	LBW	IUGR	C/S	Intention to Breastfeed	Rate of Exclusive b/f @ discharge	Maternal hospitalization postpartum	Child Protection Involvement with the child
Singh, 2015 (n=90)									65%
Fleming, 2012 (n=1037)	2.9% (int) vs 4% (con)	aRR=0.47 (0.22-1.00)	aRR=0.41 (0.18-0.95)	11.2% (int) vs 3% (con)	9.2% (int) vs 13.7% (con)	82.8% (int) vs 83.1% (con)	40.7% (int) vs 45.6% (con)		
Thompson, 2015 (n=116)								19%	

Table 3: Pregnancy risks and outcomes in adolescent and adult pregnancies in the Champlain Local Health Integration Network and across Ontario, 2012-2017.

	2012-2017			
	Champlain LHIN		Ontario	
	RR	95% CI	RR	95% CI
Self-report drug and substance use in pregnancy	6.34	5.63-7.15	5.63	5.41-5.84
Self-report alcohol exposure in pregnancy	1.38	1.18-1.59	2.33	2.22-2.44
Reporting mental health anxiety*	1.76	1.62-1.9	1.77	1.72-1.81
Reporting mental health depression*	2.05	1.88-2.24	2.16	2.11-2.22
Reporting other mental health conditions* (bipolar disorder, schizophrenia, and others)	3.05	2.65-3.52	2.88	2.75-3.00
Disclose abuse during pregnancy	3.18	2.75-3.68	2.76	2.64-2.90
Did not attend prenatal care in 1st trimester**	1.11	1.10-1.12	1.10	1.094-1.098
Sexually transmitted infection during pregnancy*** (chlamydia, gonorrhea, syphilis, HSV, HIV, HPV)	1.98	1.59-2.46	2.77	2.62-2.92
Preterm Delivery (<37wks)	1.11	0.99-1.24	1.07	1.03-1.10
Labour and birth complications (Atypical or abnormal fetal surveillance)	0.99	0.93-1.06	1.00	0.982-1.024
Obstetrical Complications (IUGR/SGA, preterm delivery, UTI)	1.51	1.35-1.68	1.44	1.39-1.49

*Concerns during this pregnancy including those pre-existing, diagnosed during pregnancy or active during pregnancy. Both diagnosed or self reported;

**Before 13 weeks gestation

***Infection identified during pregnancy

Table 4: Themes Identified in Qualitative Literature

Theme	Illustrative Quote
Motherhood as Transformative	<i>"I was pregnant, and realized the path that I was going to bring another human being into. This was my choice - so there were two paths for me to go on. To continue going on this one and bring a child in that, not being in control of my life. And I knew that I couldn't do that to a child. So, making the choice to go the straight path and know what is coming."</i> (39)
Judgment	<i>"My social worker questioned my ability to mother properly."</i> (40) <i>"It bothers me what other people think. I am trying really hard not to think about what other people think about my mothering. Do you know what I mean? ... Because everyone is telling us that we can't."</i> (39)
Control	<i>"And actually I had a friend that took something for the birth and it showed [in a subsequent drug test] that she did drugs, when she's not that kind of person. And, they instantly took that baby ... So, I didn't take anything [during labour]. It was pretty crazy. I was scared."</i> (40)
Need for Comprehensive Support	<i>"I am not ashamed of being a teen mother. However I do feel that if someone had guided me when I was going through my eating disorder, addictions, and insecurities that my life could have been different."</i> (38)
Poverty and Meeting Basic Needs	<i>"Umm, just healthy foods. I find that they're really hard to access. That ties in really huge with women's health right?"</i> (38) <i>"if you don't have a safe place to call home, then you're not going to be able to get any other supports for yourself in place including anything for your sexual health."</i> (38)

Table 5: Priority Areas to Support the Well-being of Pregnant and Parenting Youth, Identified by Service Providers and Young Women

Priority Areas Identified by Service Providers	Priority Areas Identified by Young Women
<p>Mental Health</p> <ul style="list-style-type: none"> • Access to mental health services - Anxiety and Depression • Untreated or undiagnosed mental health needs <p>Judgment</p> <ul style="list-style-type: none"> • Fear of being vulnerable; fear of being flagged as a risk to Child Protection <p>Past Traumatic Experiences</p> <ul style="list-style-type: none"> • Impact of childhood trauma on parenting • Impact of domestic violence; unstable relationship with child's father (or mother) <p>Safe and Supported Living</p> <ul style="list-style-type: none"> • Unstable inadequate unaffordable housing • Access cultural perspectives towards parenting and perinatal care • Lack of life skills to support independent living • Poverty's impact on accessing care <p>Lack of coordinated services for youth</p>	<p>Judgment</p> <ul style="list-style-type: none"> • In being identified as a child protection risk • Accessing housing • Breastfeeding • Accessing health services <p>Lack of connection with supports</p> <ul style="list-style-type: none"> • Loss of social support network/Isolation • Not knowing options and resources <p>Navigating Care/Institutional Barriers</p> <ul style="list-style-type: none"> • Access to mental health services • Expectations • Permanently labeled <p>Influence of childhood trauma on parenting</p> <p>Intimate Partner Violence</p> <p>Poverty</p>

Table 6: Demographic characteristics of women participating in semi-structured interviews (N=10)

Demographic Characteristic	%	Demographic Characteristic	%
Completed High School	33%	CAS involvement in own childhood	67%
Ethnicity		Experienced IPV while pregnant or parenting	78%
Receives Public Income Assistance (OntarioWorks, ODSP)	77%	Experienced abuse of any kind from family	67%
CAS involvement in pregnancy or parenting	78%	Experienced anxiety or depression while pregnant or parenting	56%
Youngest Child is in their custody	89%	Accessed mental health services during pregnancy or post-partum	78%
No longer has custody of earlier child(ren)	33%	Used illegal substances while pregnant or parenting	44%

Table 7: Themes and Concepts Identified in the Literature and by Women around Judgment and Its Consequences in Perinatal Health

Experiences of Judgment	
<p>Seen as a Risk</p> <p><i>Primary themes identified in literature</i></p> <ul style="list-style-type: none"> · Blamed for things outside of control · Pressure to show “good motherhood” · Asking for help leads to blame · Always under microscope 	<p><i>Concepts added by women</i></p> <ul style="list-style-type: none"> · Using my past against me · Seen as dangerous if I stand up for myself
<p>Seen as Incapable</p> <p><i>Primary themes identified in literature</i></p> <ul style="list-style-type: none"> · Assumed incompetence · Consent not seen as necessary 	<p><i>Concepts added by women</i></p> <ul style="list-style-type: none"> · Loss of confidence of others; affects belief in oneself
<p>Invisible</p> <p><i>Primary themes identified in literature</i></p> <ul style="list-style-type: none"> · Own needs not recognized 	
Consequences of Judgment	
<p><i>Primary themes identified in literature</i></p> <ul style="list-style-type: none"> · Internalized blame · Self doubt · Unmet needs · No voice in decision-making 	<p><i>Concepts added by women</i></p> <ul style="list-style-type: none"> · Anger, Frustration · Contributes to anxiety and depression · Must fight to be heard · Makes me want to give up

Figures



Figure 1

Infographic of Mixed Methods Evidence Synthesis of Experiences and Outcomes of Adolescent Pregnancy in Canada

Supplementary Files

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