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# A qualitative study of parents' experiences with prematurity antenatal consultation

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## ABSTRACT

Objective: Antenatal consultations are an opportunity to provide anticipatory guidance about preterm birth to parents and facilitate their involvement in healthcare decisions. Literature shows that contextualization and eliciting family beliefs and values is essential, but there is limited discussion about *how* acknowledging those beliefs and values by clinicians is perceived by parents in antenatal consultations. The research question is: (How) does the integration of family context, beliefs and values shape patient experience of antenatal counselling?

Study Design: This is an exploratory secondary analysis of interviews with eleven parents. A flexible coding strategy was used with a thematic analysis that drew on some methods from grounded theory.

Results: Three themes comprising the parental experience of the prematurity antenatal consultation were identified. Parental experiences begin with a *whirlwind of unknown*, wherein parents feel caught in unanticipated, unknown frenzy of potentially delivering prematurely. Parents rationalized the need for this *overwhelming but necessary* discussion, but at times question how it was approached. Finally, they used two core methods to *cope with this uncertainty*; hope and human connection, both rooted in clinician integration of their family context, beliefs and values.

Conclusion: This study reinforces the necessity of acknowledging and addressing parental needs identified by understanding their context, beliefs and values, regardless of gestational age or perceived medical complexity by the healthcare professional.

## Introduction

Antenatal consultations by the neonatology team have become a standard of care for birthing parents admitted to hospital for risk of preterm birth[1–3]. They are an opportunity to provide anticipatory guidance about preterm birth to parents and ensure their involvement in healthcare decisions. The antenatal consult plays a pivotal role in shaping parental experience with the NICU team as it is the first introduction to the NICU and its clinicians[4].

Antenatal consultations are a critical moment for families to share information about their Family Context (FC), their beliefs and values. The FC includes everything that makes the family unique, such as their family structure, occupations and prior experiences[4]. There has been an increasing emphasis on developing personalized antenatal counselling approaches that focus on contextualizing the family[4–8]. Much of this work focuses on counselling at the edge of viability where the survival of the neonate is precarious; parents are given the option of a direction of care for their infant, treatment focused on survival or on palliation.

When a fetus passes beyond the edge of viability, parents may not face life and death decisions, but they still have conversations during the antenatal consultation that are life changing. The body of work that includes antenatal consults for prematurity, though not limited to periviability highlights the importance of building relationships to improve the consult. Research has demonstrated that this can be achieved through developing deeper understandings of the family and their unique context[5,6,8]. Von Hauff et al. conducted focus groups with parents and physicians to gather insights on what they feel is required in an antenatal consultations[9]. They identified three essential components to successful consultations 1) supporting the building of a caring relationship between families and clinicians, 2) sharing information in conversation between expectant families and the clinicians and 3) preparing for what is about to come for the newborn and their family. Gaucher et al. found that when physicians gain a better understanding of the family and their lived experiences during an antenatal consultation, they form a more trusting relationships with families[10].

While these studies discuss the importance of understanding the FC, beliefs and values, there is limited published data on *how* integrating the FC, beliefs and values affect the parental experience of the antenatal consult. A better understanding of their experience can facilitate the approach to antenatal consults and thus the approach to teaching trainees how to lead antenatal consults.

Our previous work focusing on the processes of communication around the FC allowed us to explore the intersection of contextualization and personalization and how these processes affect relationship building in the antenatal consult, both of parents who had infants born at the edge of viability and those who were not.

This exploratory secondary analysis seeks to better understand parents' perceptions of inpatient antenatal consultations regarding prematurity, in particular the impact of the physician's understanding of their FC, beliefs and values. The research question is: (How) does the integration of FC, beliefs and values shape patient experience of antenatal counselling about preterm birth in the inpatient setting? Gaining a better understanding of how the presence, or absence, of family contextualization is perceived by parents in antenatal consultations can inform *how* clinicians could approach capturing and incorporating the family context, beliefs and values in the antenatal consult. This in turn may help clinicians individualize and personalize consultations to the family's needs and preferences, irrespective of viability. This can also help shape how antenatal consultations are taught by adding the understanding of the FC, beliefs and values as a core skill required.

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## Methods:

This is an exploratory secondary analysis of a larger study that used interviews to evaluate the current state of communication around the FC as it applies to parental NICU experience in the NICU[5]. The project took place in a tertiary care neonatal unit, in a large academic hospital in Toronto, Canada. The site is a 42-bed unit that cares for inborn and outborn infants. Patients reflect the broad multicultural and multilingual diversity of city of Toronto.

During our previous study looking at the processes of communication in our NICU around the family context (FC) as it applies to parental experience in the NICU (both prenatally and postnatally), it was noted that antenatal consultations are a critical moment for families to share information about their FC. A second exploratory study was done to delve into this further.

The first study was a descriptive qualitative study that explores the experience of families and Neonatal Intensive Care Unit (NICU) clinicians with information sharing around the FC[5]. It used purposive sampling, families of varying cultural backgrounds and educational levels were recruited, representative of the heterogeneity of the population[11]. All interviews were held in English 3-14 weeks after the infant was born. Recruitment was stopped for each group when thematic saturation was reached for the primary analysis[12].

A total of eleven parents from eight families participated in the interviews. All patients had antenatal consultations to discuss the possibility of preterm birth prior to delivering their infant. One parent later recused themselves and therefore their data was removed from the analysis. Demographics are described in another paper and in Appendix 1[5]. Only two of the eleven participants had infants born in the periviable period as considered by our institution (22-23 weeks)[5].

It was reviewed and approved by the institution's Research Ethics Board. Each participant was consented individually and offered the opportunity to be interviewed individually or together if they were from the same family. Interviews occurred between August – December 2021. All interviews were recorded and transcribed. Semi-structured interview guides were used to lead the interviews and were modified in response to primary study findings[13]. Audio recorders were used to record the interviews with families. Interviews were transcribed using artificial intelligence (OtterAI) and corrected and anonymized by the lead researcher. The interview guide described in our previous paper used focused on the current state of communication around the FC as it applies to decision making processes for families, including but not exclusive to antenatal consultations[5]. The primary initial research question was broader, but given its inclusion of antenatal consultations, it allows this secondary analysis to capture an in-depth analysis of this more focused question.

### Analytic approach

The data collected through the larger study was analysed using a flexible coding strategy paired with a thematic analysis that drew on some methods from grounded theory. A flexible coding approach was opted for because of the existing literature on the subject, the previous related work done by the authors and the authors' knowledge of the literature that has informed this study.

The secondary analysis began with reading the interview transcripts were read and coding the text related to antenatal consults as "index parent codes" by the lead researcher (MD) using NVivo 12[13,14]. Next, MD used memos to identify themes, which were refined and applied as selective analytic codes drawing on modified grounded theory approach[15]. This process included initial open coding followed by axial coding. The constant comparison method was used to ensure that each iterative level of codes reflected the data [15]. This deductive and inductive approach facilitated the development of selective codes from which our theory was constructed and applied across interviews to ensure validity and rigor and

identify the conditions necessary for it to hold true[16].

### Positionality and reflexivity of lead researcher (lead interviews and completed initial analysis)[11]

MD was a senior neonatal fellow at the time of the interviews and an attending neonatologist at the time of this secondary analysis. As a neonatal physician, MD was familiar with the process of preterm birth and was able to describe in layman's terms the antenatal consults. During the time of the interviews, MD was not part of the regular clinical team, only covered occasional night calls, therefore mostly unknown in her clinical role to the participants. However, MD did have insight into their child's journey at the time which allowed her to ask informed questions. While she had knowledge of *what* the child had been through, she did not have implicit knowledge as to *how* parents had experienced each of these steps. At times, parental interpretations of medial occurrences were mistaken but MD focused on their experience of it given that an experience cannot be mistaken. She worked to leverage her positionality to understand why that misunderstanding took place by constantly reminding herself to ensure she approached each question with the humility one when faced with an unknown.

However, in her role as a physician, MD was conscious of the potential to have participants hesitate to share their experiences with her. To address this, she always started interviews by reinforcing that she was there to learn from them and their experiences. Throughout interviews, when participants shared stories, she did her best to validate their experiences and asked if they were comfortable telling her more about them. Parents did ask for her medical opinion at times, during which they were redirected to the clinical team. As a younger female however, she did not fit the stereotype of a physician and her role was often misidentified; when this occurred during interviews, was clarified.

## Results

Three themes that encompass parental understandings of the prematurity antenatal consultation were identified through the secondary analysis. Parental experiences begin with a *whirlwind of unknown*, wherein parents feel caught in unanticipated, unknown frenzy of potentially delivering prematurely. Parents rationalized the need for this *overwhelming but necessary* discussion, but at times question how it was approached. Finally, they used two core methods to *cope with this uncertainty*; hope and human connection. (Represented in Figure 1)

*1. Whirlwind of unknown preceding preterm deliveries*

All parents spoke to the sudden and dramatic fall into the unknown that preceded their deliveries in which their antenatal consultations took place. For some it lasted hours, days, or even weeks. During this time, many unknowns coexist: the unknown of their health, their pregnancy, their fetus, while in a new environment and with a constant influx of new people. A woman in labour before 24 weeks, described waiting in angst for the NICU doctor to come:

"I was terrified. I waited so long. And I see this woman come in. And, I was like who are you? I don't know what I thought. I thought it was gonna be like a big parade of doctors because that's what was happening quite often [referring to the large obstetrical group that rounded daily]."

Parents met the NICU team only after first being admitted under Obstetrics, and occasionally only after transfer to the study site. Whatever their prior experiences were, they served as a comparison in this vastly new environment.

In addition, parents describe being barraged with new information provided during the whirlwind of delivery (or anticipated delivery). A woman describes her experience of the antenatal consult that took place at the edge of viability:

"I tell you honestly, I think my husband was more alert. The only things I could focus on was [the physician] telling [us] this is the percentage…, this is the thing, this is… and then I just forgot what he was talking about. There were only lips moving."

Another patient who experienced her antenatal consult alone describes being overwhelmed: "*I just felt like I had so many questions and nothing could come out I couldn't think straight enough to write them down*." When her partner came after the consult, she struggled to relay the information. She shared that:

"It was very choppy, especially. Yeah, it was just it was too much. And I couldn't, I wasn't able, and I admit, I wasn't able to retain the information because [her partner] came in and he was like what did she say, and I was like, I don't know."

The pregnant people's partners described feeling equally overwhelmed, with their concern oscillating between their partner's health, and how to retain the information coming at them.

2. *Overwhelming but necessity of the antenatal consult*

Despite feeling overwhelmed and uncomfortable in an unanticipated new environment, parents described understanding the need for an antenatal consultation. One participant explained that there is a need for the doctors to get information about the patient "*So all that's for them to know me. What's going on, how to treat. How to handle the baby in case when the baby comes out early*." Families recognized the need for physicians to inform them about complications related to preterm birth so they can be prepared. One mother presumed it was legally necessary for the doctor to warn parents about all complications that could arise. The antenatal consult was perceived as a necessary and identifiable moment for them to meet the NICU team and learn about what is to come. One father described it as a crucial starting point to their NICU journey: "*In those sleep deprived moments, [being able to] name it or organize it or label it is helpful for the story that we tell about this experience down the road*."

Parents wanted to hear anticipatory information from physicians about what their child may go through. While there was a need for straightforwardness, they questioned the bluntness of the approach: "*information should be provided […] but should be so that the person does not feel too much traumatized in that situation*."

Other families noted the potential benefits of individualizing the approach to antenatal consultations. For example, some participants felt that the more information patients provided to the clinician, the easier it was for clinicians to support them through their time in the NICU. A mother wondered if "*they would even take in consideration what the parents are going through right now, what situation is, other than just coming and bluntly telling you everything?*" Another mother born and raised in community that did not accept preterm infants explained the crucial need for physicians to have context about her family. She had her antenatal consultation at about 27 weeks of gestation, a time where the consult had the unique goal of providing anticipatory information to parents to empower them when the baby is born prematurely:

"In my culture, if you have a Down syndrome baby, it is considered as a taboo. They feel like you did something wrong, and your God is punishing you or the God is not happy with your whatever. And sometimes, if you have preemie babies, they also feel that way, that something is not right. Sometimes they even say those preemie, they call them water babies, they are not supposed to live, you should just sign and let them die. And I've met some mothers here that have had that kind of conversation with me, that they are struggling with the husbands, because the family wants them to just give up on the child."

Without clinicians inviting families to express their prior beliefs, parent felt disempowered to discuss them. That mother continued by explaining:

"So imagine I'm coming from that background that believes preemies shouldn't survive. And you tell me all this information. It gets my head saying oh, maybe I shouldn't get this baby to survive, like I should just give up on this child."

The opposite held true as well; when clinician understood prior experiences, parents felt that their questions were better addressed which allowed them to feel calmer in the face of all this uncertainty.

3.*Hope and human connection to cope with uncertainty*

Parents spoke to two different methods coping with feelings elicited during and after the antenatal consultation; a search for hope for their baby and their family and/or solace in human connection with those caring for their children.

Even prior to the antenatal consultation and regardless of prior beliefs, parents looked for opportunities to cope with the unknown. They looked for signs of hope and connection from loved ones, the obstetrical staff, and from the internet. Several families spoke about knowing someone who had had a preterm infant that survived and looking for a commonality as a source of hope. "*I had a cousin that also had a premature baby and came home*". This mother wanted to go to the same hospital as her cousin.

Human connection with clinicians allowed space for hope to enter the consult. One parent described the clinicians who were *"warm and generous with their time*" as the ones they loved and felt more comfortable with. One mother spoke about the connection with a clinician built by sharing her beliefs that she felt lead to better care; "*because she was open and I was also open to her. She was able to help me. That was just amazing*."

The mother who had expressed the need for culturally informed antenatal consultations found solace and hope when bonding with a parent representative working in the unit who had a preterm infant several years prior. She wondered why the opportunity to bond with clinicians over what she viewed as potential positive outcomes was not provided during the antenatal consult, instead she found it solely focused on the negative aspects.

"Maybe you guys [the clinical team] should include that [discussion of potential positive outcomes] too in [the antenatal consult] it gives us so much hope."

Parental search for hope through the antenatal consultations was unanimous across study participants, but not felt to be universally provided. One mother acknowledged the physician's need to be straightforward but wondered why being straightforward could not include hope for some positive experiences and outcomes; "*it is a very scary part to be too much straightforward at that time*". Another participant, who was in threatened preterm labour well above the limit of viability, spoke about the negative impact of providing only pessimistic information. She explained: "*Daddy doesn't want anything to do with baby [because] baby won't be any good because of the prematurity*". She then saw pictures and heard stories of positive outcomes after delivering prematurely, which gave her "*so much hope, like he comes from zero to the roof*". However, she wondered if providing that hope during the antenatal consultation would have helped her partner allow himself to bond with his son, as he never came to the NICU and therefore did not see the pictures or hear the stories of hope. Another parent, also describing a consult devoid of hope, spoke about how things changed after their first time in the NICU "*I feel like when you come here you see pictures, you see hope.*" This potential for hope was a turning point in their journey and like others, wished they didn't have to wait so long for it.

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Figure 1: Graphic representation of the parental experience during the antenatal consultation

A birthing parent going through the three themes identified in this study: it begins with a whirlwind of unknown, they participate in an overwhelming but necessary discussion, and finally cope with this uncertainty through hope and human connection.

## Discussion

Three core intersecting themes of parental perception of antenatal consults are identified from the qualitative analysis of interviews with parents who had an inpatient antenatal consult for prematurity. For parents, antenatal consults begin with a *whirlwind of unknown*, but are rationalized to be an *overwhelming but necessary* discussion. Several parents questioned the physician's approach to the discussion. Finally, two core approaches were used to *cope with this uncertainty*; hope and human connection. Each phase is made easier for parents when clinicians have a better understanding of their family context, beliefs and values as it enables them to help generate hope and forge human connection.

Recognizing that parents start the antenatal consultation in a whirlwind of unknown demonstrates the importance of having a support person with the birthing parent to help recall what was said. This can easily be translated into an actionable item required in all antenatal consultations; before sharing information with parents, a physician needs to first, check in with the birthing parent if there is a support person they would like involved in the consult, in person or virtually. Offering this to all birthing parents is not currently overtly recommended in guidelines at the moment[3,17,18], but would be an easy improvement to better support parents.

Parents also value the information being provided but find it overwhelming. In our study, parents suggest that tailoring the information to the families' context would make the information more digestible, regardless of gestational age. A similar finding was focused on consults for babies born in at the edge of viability[8]. Clinicians can ask about parental context, beliefs and values before beginning to share information about what is about to come.

The parental feeling of being overwhelmed, and searching for hope and compassion through human connection is not new, however most studies that have investigated these relationships have focused on antenatal consultations at the edge of viability[1,6,7,19]. In our study, only two of the eleven participants had infants born at the edge of viability. Some clinicians question the ethicality of imbuing conversations with hope when a baby is at the edge of viability. However, hope may not always be for a long life. Hope can also be for time with their baby, knowing a child can be well cared for by a thoughtful team of clinicians that they may live comfortably and/or die without discomfort. Potential for hope and positivity is also seen as taking a more balanced approach to the consult without necessarily nudging parents towards one decision or another.

This study highlights that while hope and compassion are important considerations for antenatal consultations with goals of care decisions, these remain important for families regardless of the gestational age or prognosis. Having a baby born early is an unanticipated stressor on a family. Antenatal consults are described as moments of intense powerlessness where parents expect physicians to provide them with information to empower them[20]. Regardless of the physicians perceiving it as a more 'routine' admission, the parental need to cope with uncertainty remains. As highlighted in this work as well as that of others, building a strong relationship with families by exploring their FC, beliefs and values helps show compassion and facilitates parents to establish hope[6,8,21,22].

This study adds to the literature on essential components of a successful antenatal consultation for preterm infants, beyond targeting families counselled at the edge of viability. It maps out the interlocking and overlapping emotional stages parents go through during an antenatal consultation to reach empowerment. Three actionable items prompted by understanding the parental experience of the antenatal consult are 1) offering the presence of a support person during an antenatal consult, 2) asking about family context, beliefs and values before sharing information about what is to come and 3) providing hope and compassion in all consults regardless of the anticipated outcome. This literature can be used to inform guideline development of antenatal consults in general leaving room for specifiers such as the extremes of prematurity. A better understanding of *what* parents are experiencing facilitates a clinician's ability to anticipate their emotional needs; when combined with the practical needs as described by Von Hauff, a clinician can be better equipped to provide useful patient centered antenatal counselling[23]. The findings of this study have overlap to exploratory qualitative study done in the Netherlands with a similar population, demonstrating that these experiences cross cultures and borders[22]. This is particularly helpful to guide education of antenatal counselling skills, a critical gap in the current literature.

The limitations of this study include being a secondary analysis of a data set therefore thematic saturation was not assessed for this research question. However, all interviews included in the original study were included in this analysis therefore purposive sampling was appropriate. Another limitation is that only parents who had children who survived where interviewed, therefore the experience of those who choose palliation or whose babies died after birth were not captured. In addition, it was not designed to measure the differences between people with different demographics. Perhaps future research can address these gaps. Finally, this was a single center study.

## Conclusion

A better understanding of the parental experience of antenatal consults further emphasizes the importance of parental needs and the differing emotional waves they face. This study reinforces the necessity to establish an approach of meeting

these needs during antenatal counselling by understanding their context, beliefs and values, regardless of gestational age or perceived medical complexity by the healthcare professional. Future direction includes research to understand *how* best to contextualize families and elicit and integrate their beliefs and values into antenatal consultations.

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## Conflict of Interest:

The authors have no conflicts of interest to declare.

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Appendix 1: Demographics of participants[5]

| Gender | Marital Status | Other children | Self-identified Ethnicity | English as mother tongue | Highest level of education | Child's gestational age* |
|---|---|---|---|---|---|---|
| **Female** | Married | None | White | Yes | PhD | 26-27 weeks |
| **Male** | Married | None | White | Yes | PhD | 26-27 weeks |
| **Male** | Married | None | South Asian | No | University | 24-25 weeks |
| **Female** | Married | None | South Asian | No | University | 24-25 weeks |
| **Male** | Common law | None | Black | No | Trade certificate | 24-25 weeks |
| **Female** | Common law | None | Black | Yes | High school | 24-25 weeks |
| **Female** | Married | 2+ other children | Black | Yes | College | 28-29 weeks |
| **Female** | Single | None | Black | Yes | University diploma | 22-23 weeks |
| **Female** | Married | 1 other child | Arab, South Asian | Yes | University - above bachelor | 22-23 weeks |
| **Female** | Common law | None | Black | No | Bachelor's degree | 26-27 weeks |

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