



Temporal Themes in Periviable Birth: A Qualitative Analysis of Patient Experiences

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Abstract

Objective Periviable birth accounts for a very small percentage of preterm deliveries but a large proportion of perinatal and neonatal morbidity. Understanding parental experiences during and after periviable deliveries may help healthcare providers determine how to best support women during these medically complex, emotionally charged clinical encounters. **Methods** This is a qualitative study with a voluntary sample of women who delivered between 22 and 25 weeks gestation at an academic medical center from 2014 to 2016. Women's narratives of each periviable birth experience were transcribed and analyzed using consensus coding and a grounded theory approach to identify key themes that describe parental experiences. **Results** A total of 10 women were interviewed. Four emergent temporal themes: (1) the time preceding admission: feeling dismissed; (2) transfer or admission to a tertiary care center: anxiety and doubt; (3) the birth itself: fear of the outcome; and (4) the postpartum period: reflection and communication. **Conclusions for practice** Women that experience a periviable birth may benefit from continuous support and clear communication. Overall, care for these patients should be expanded to address the specific psychosocial needs identified during the distinctive, periviable temporal themes that emerged during interviews. Continuous longitudinal support in the form of a designated person or team should be provided to women experiencing a potential periviable birth in order to help mitigate the fear and anxiety associated with these complex birth experiences.

Keywords Communication · Periviable birth · Parental experiences · Temporal themes

Significance

What is already known Studies in the NICU have demonstrated that families making end-of-life decisions following a premature birth have significant emotional and psychological consequences from these difficult choices. Other studies specific to preterm birth have demonstrated the importance of information provision and support. As periviable preterm

birth is extremely complex, a comprehensive understanding of this unique birth experience can further enhance provider counseling and support of these women and their families.

What this study adds Women move through a series of temporal experiences, each with unique psychosocial needs. Our findings demonstrate the need for consistent, empathic communication and support throughout the delivery and into the postpartum period.

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Introduction

In 2015, the rate of preterm birth in the United States was 9.63% (Martin et al. 2016). This includes a smaller subset of periviable deliveries, defined as birth between 20 weeks 0 days to 25 weeks 6 days. Although only 0.4–0.5% of births occur at less than 28 weeks gestation, these neonates have high rates of morbidity and mortality that result from the complications of severe prematurity (Lau et al. 2013). A 2017 National Institute of Child Health and Human Development Neonatal Research Network study of 11 centers across the United States reported

a survival rate of 3% at 22 weeks, 24% at 23 weeks and 55% at 24 weeks (Younge et al. 2017).

As periviable neonates have extremely low survival rates and a significant risk for profound neurodevelopmental delay, counseling prior to delivery must take into account complications that can result from interventions that may not benefit the neonate. When a pregnancy is threatened with a periviable birth, families have multiple critical and often time-sensitive decisions to make regarding management of the pregnancy. These choices range from comfort care to cesarean section for fetal indications. At an extremely early gestational age, some families and providers choose to intervene, whereas others do not.

Very few studies have analyzed antepartum and intrapartum patient experiences with periviable birth. Of the studies that have specifically focused on periviable delivery, parental support and clear communication of information regarding disabilities and outcomes is described as being most valued in the parental decision making process (Grobman et al. 2010; Tucker Edmonds et al. 2017). Other studies have identified several factors that influence perceptions of care such as staff professionalism, support, and the importance of the birth experience (Peters et al. 2016; Sawyer et al. 2013).

Despite the paucity of data regarding periviable birth experiences, studies have evaluated parental experiences in the neonatal intensive care unit (NICU) following a premature birth. These indicate that families have significant, and often long-term, emotional and psychological consequences when they are required to make extremely difficult choices about a child's care (Greene et al. 2015; Jubinville et al. 2012; Misund et al. 2013; Vigod et al. 2010). A high percentage of women who have a preterm delivery exhibit depressive symptoms, perinatal posttraumatic stress, clinically significant anxiety or acute stress disorder (Greene et al. 2015; Horwitz et al. 2015; Jubinville et al. 2012; Misund et al. 2013; Vigod et al. 2010).

Overall, parents have significant emotional and psychological burdens associated with periviable birth. Unfortunately, studies focused specifically on periviable pregnancies have been limited, even though these early deliveries require some of the most complicated decision-making. A more nuanced understanding of the periviable birth experience is thus, critical. The purpose of this project was to examine experiences of periviable birth in order to identify critical supports that may be employed to mitigate the significant psychosocial stress associated these complex birth experiences.

Methods

A qualitative study with consecutive women who gave birth between 22 weeks 0 days to 25 weeks 0 days gestation at an academic medical center between December 2014 and

December 2016. This gestational age range was selected because at our institution neonatal resuscitative efforts are not recommended at less than 22 weeks and universally recommended at greater than 25 weeks. Resuscitation at 22 weeks 0 days to 25 weeks 0 days has less consensus and as such we chose to evaluate this subset of periviable births. Women were invited to participate in person by a study team member during their hospital admission for an impending periviable birth. No relationship was established between the study investigators and the participants. In the instance where the investigator was directly involved in a patient's care, one of the other investigators conducted the interview. Participants were told during the consent process about the goal of the investigation, specifically to understand experiences with periviable birth. Open-ended, semi-structured interviews were then conducted one time as soon as possible following delivery in person or over the phone and audio-recorded for verbatim transcription. Women were asked to recount the events leading up to their birth, the delivery itself and the factors that impacted their decisions, including both positive and negative experiences. These questions were modelled after the study by Caeymaex et al. (2011). A description of the questions used are included in appendix 1. Interviewers initiated interviews using the questions provided and then allow the woman's responses to guide the conversation. In instances where the participant had difficulty in initially describing the events of their delivery without more interview structure. In these instances more directive questions including possible dichotomous answers or why statements were used to initiate a response and guide subsequent non-directive conversation. For example, "Do you regret anything about your decision?" would then be followed with a question such as, "Can you expand upon your answer?" or "Why do you think you feel this way?". The majority of the interviews did not require this more directive line of questioning and instead women were willing to relay their stories without prompts. No other persons were present for the interview other than the investigator and the participant. Each interview lasted for approximately 30 min to 1 h. The interviews were transcribed into Word documents, de-identified, and analyzed independently by the first, second, and fifth authors (first author: female, MD, resident; second author: female, PhD, associate professor; fifth author: male, MD PhD, associate professor) using a modified grounded theory approach (Charmaz 2014). All interviews were conducted by the first, third and fourth authors (all female, MD, residents). The second author is a PhD who has extensive experience with interviewing and qualitative methods research and was responsible for the training of the resident interviewers.

In grounded theory assessment, researchers ask a series of open-ended questions and look for common or recurring themes in interview narratives. These themes or key

topics are then translated into schema or models that map interviewee's responses and form the foundation for interpretations. During this process, interview transcripts were analyzed independently; researchers then met to discuss the themes identified, and any unique codes were debated until authors reached consensus on common and defensible themes (i.e., supported by the narrative data). Interviewing continued until concept saturation was reached and no new themes emerged, though the specific details and individual experiences continued to be unique to each woman (Burcher et al. 2016). The temporal schema that emerged was the result of careful analysis of the relationship between the obstetric researchers' perspectives and experiences of providing care and patients' experiences of receiving care for a periviable birth. Independent analysis of transcripts by multiple researchers helped to insure that a wider variety of themes were identified; this technique resulted in a high rate of subjective inter-rater correlation. A coding tree was not utilized. The participants did not provide feedback on the findings.

In addition, the authors used Lincoln and Guba's Evaluative Criteria to construct the study design, as well as to evaluate findings (Cohen 2006). Credibility was established through prolonged engagement, transferability through the elicitation of detailed narratives, and dependability and confirmability via the process of consensus coding described above (Holloway 1997). As a referral hospital, the first, third, fourth and fifth authors are integrally involved with the care of women with threatened previable birth and preterm labor and the postpartum care of women who have had a periviable delivery. Working clinically in the context from which these narratives emerged allows for some assessment of credibility. In addition, the use of multiple, independent coders, both researchers and clinicians, enabled assessment of dependability and confirmability. All of the themes presented here achieved consensus across coders. Finally, the richness of the stories shared and the ability of researchers to place those stories within the ethnographic context of one hospital (i.e.; thick description as described by Geertz) combined with the identification of some overlap in themes emerging from this and other studies enabled the assessment of transferability of findings. This study was approved by the Institutional Review Board prior to initiation. All women gave their informed consent prior to participation in the study. COREQ reporting for qualitative studies was referenced.

Results

Of 30 eligible women, a total of 10 women consented and were interviewed from 24 h to 12 days after giving birth. This variation in timing occurred because interviews were

scheduled at the convenience of the participant. Five women declined participation, 10 were unable to be reached after multiple attempts, and 5 were consented into the study but later declined to complete the interview citing time constraints. The demographics of the study sample are detailed in Table 1. The interventions and modes of delivery are outlined in Figs. 1 and 2. Women elected for antenatal fetal interventions in 8 of the 10 pregnancies.

Analysis of participants' narratives revealed some key commonalities, as well as differences in the ways women described progressing through a set of periviable birth experiences. These are described as temporal themes in order to highlight connections between experiential commonalities across participants and chronological aspects of experiences. As women progressed from the time preceding the delivery, to transfer or admission to the tertiary care center, the birth itself, and into the postpartum period, the needs, supports, stressors and decision-making processes also changed. Thus, women's experiences were categorized along a chronological continuum using the needs and concerns that women identified within each temporal theme. The four temporal themes identified were: (1) the time preceding admission: feeling dismissed; (2) transfer or admission to a tertiary care center: anxiety and doubt; (3) the birth: fear of the outcome; and (4) the postpartum period: reflection and communication. An overview of each temporal theme is provided in Fig. 3.

Time Preceding Admission: Feeling Dismissed

Participants identified several key experiences that influenced perceptions of the providers who cared for them and the events that occurred in the time leading up to the diagnoses. As the study hospital is a regional referral center, antenatal care frequently occurred at a different, primary care facility. Many believed that they had forewarnings leading up to the periviable delivery that went unaddressed. Women commonly reported feeling that they were ignored or that

Table 1 Demographic data for interviewed women

Maternal age	27.9 (22–35) ^a
Race/ethnicity	
Non-hispanic white	60%
Hispanic	10%
Unknown/declined	30%
Pregnancy number	2 (1–4) ^a
Prior preterm delivery	10%
Gestational age at presentation (weeks)	23.6 (22.2–24.3) ^a
Gestational age at delivery (weeks)	23.6 (22.2–24.5) ^a
Interval to delivery (days)	4.5 (0–18) ^a

^aMean (Range)

Fig. 1 Percentage of fetal interventions in the periviable study population. *PPROM* preterm prelabor rupture of membranes

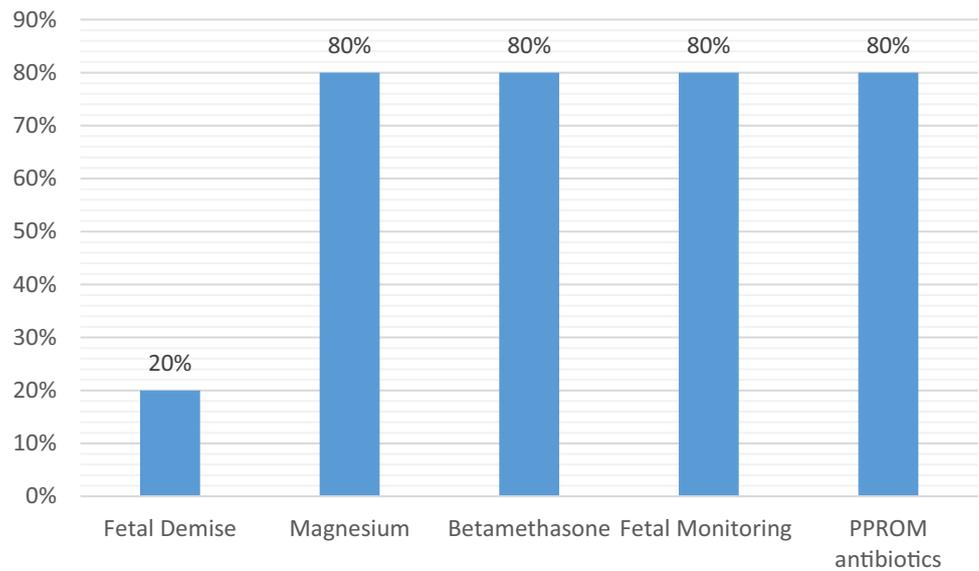
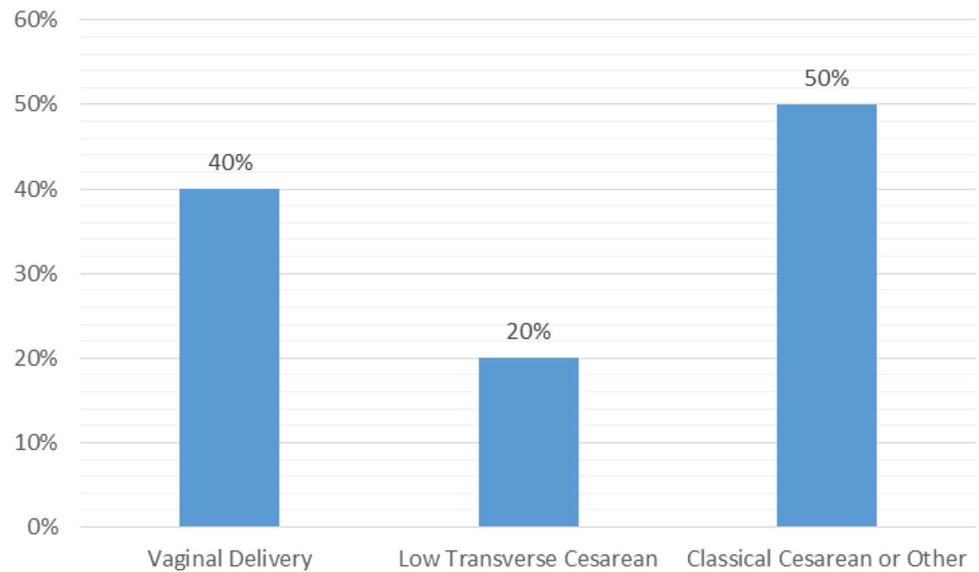


Fig. 2 Mode of delivery for the periviable study population



early warning signs were discounted by the referring obstetricians. One participant was distressed that her doctors,

Just kept giving me antibiotics for an infection that I never had... My doctor dismissed my complaints, I kept telling my doctor, I feel like I am going into labor. The OB did not seem concerned – I was very concerned.

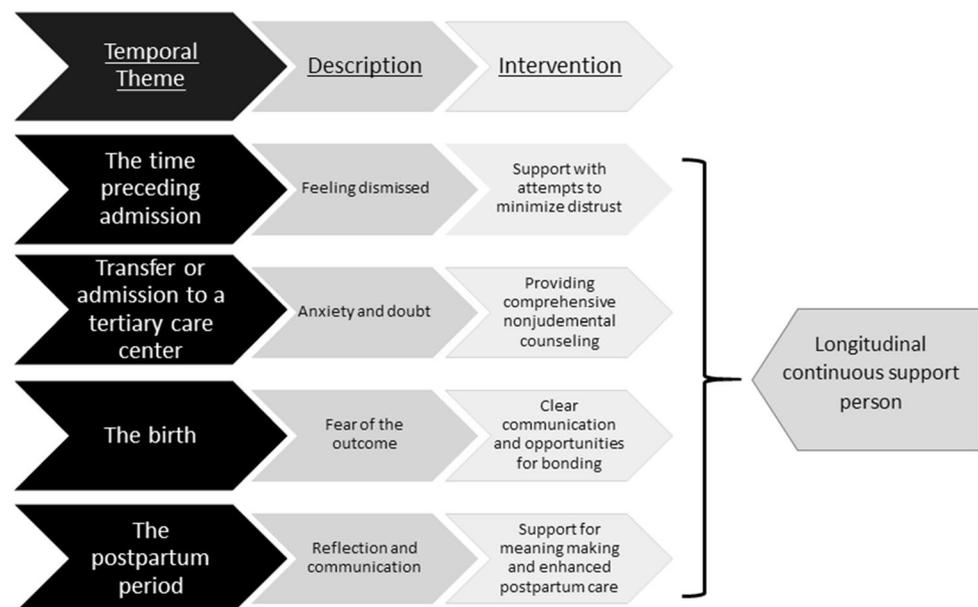
These experiences caused women to doubt the quality of the prenatal care they had been given, and these doubts lingered into the postpartum period. Another woman who questioned the quality of her prenatal care said:

Everything had been going fine, and then 2 weeks later I had an ultrasound and they had confirmed

that Baby A had no heartbeat. Maybe if they had been doing ultrasounds every week, they could have caught it earlier.

In addition to feeling dismissed and struggling with questions about the quality of care, all but one of the respondents also described this period of time with feelings of shock, disbelief and “why me?” questioning. The shock of realizing that something was wrong with the pregnancy left women reeling and with a sense of impending doom that was exacerbated by not knowing who to reach out to, especially when they felt the earliest signs and symptoms were ignored by providers.

Fig. 3 Overview of perivable temporal themes mapped to specific interventions by theme.
Source Authors



Transfer or Admission to a Tertiary Care Center: Anxiety and Doubt

Following the eventual identification of an obstetric complication and the transfer or admission to a tertiary care facility, participants describe a new level of anxiety. Women reported fearing the outcome, fearing what to tell family members (especially existing children), and fear for future pregnancies. Women recounted that it was,

Hard to be in the hospital every day, not knowing what could happen...hearing other stories puts more fear into you because of everything that can go wrong, which you don't think about when you are pregnant because you think everything is going to be fine.

As women grappled with a new level of risk and the possible range of complications, some described a desire to delay bonding until a more positive outcome might be expected. These narratives were permeated with descriptions of self-doubt, fear, uncertainty and second-guessing of choices made earlier in pregnancy. One woman recalled thinking:

Is it better to keep her alive or are we doing this for ourselves?

Some women also described a disruption of bonding secondary to feelings of uncertainty and fear. Whereas others referenced decision-making processes that indicated attachment had already occurred:

The whole thought process the whole time was ... just whatever is going to be the best outcome for her. We already loved her and just wanted her to survive. and

[the doctor] asked me, [if I] wanted to do everything we could to try to save [her]. And at that time... you hear a heartbeat, it's kind of hard [not] to.

Despite these uncertainties, participants also described the ways provider counseling helped to mitigate some aspects of fears and doubts. Specifically, participants felt supported when they were able to develop high levels of confidence in providers and when they believed the staff truly cared about them. In the tertiary care setting, participants felt as though concerns were being heard, and that the staff gave helpful information.

People sat down and asked how things are. No one was 'pushing you to the side' or 'just trying to get through the shift'.

This is a critical point; while women described an increase in stress when a diagnosis that would lead to perivable delivery was made, they also experienced greater support and a sense of relief as trust in providers made the situation easier. This trust revolved primarily around providers caring, listening, and attempting to provide factual information.

The Birth: Fear of the Outcome

With the birth, a new temporal theme emerged. Participants described the moment of the birth as terrifying, because they did not know what the immediate outcome was going to be.

[It was] scary to not know what was going to happen to the baby, and even worse because I had to wait to wake up to then find out what had happened.

Women feared the period immediately after delivery, but they also feared the long-term unknown. Participants commonly recounted a complete lack of concern for their own immediate status; they were consumed by fears for the newborn.

I wanted to try everything I could to save the baby. I knew there was more danger for me with a cesarean, but I didn't care at all about that. What concerned me the most was not knowing what was going to happen with her? She wanted physicians to do, whatever you have to do, whatever was going to be the best outcome for her survival because as a parent, you always want to try.

The birth was also commonly described as the scariest moment of a woman's life. One participant said:

I have never been in a situation that was so emergent.

Postpartum: Reflection and Communication

Following the immediate shock of the delivery, women described a period of time where they began to try to make sense of what happened to them. As women reflected on the choices and the medical decisions that had been made, they attempted to create a coherent narrative of the delivery events. Simultaneously, participants grappled with the birth's emergent and traumatic nature and the fact that no amount of preparation could have undone the experience of shock, fear and suffering:

Once you have had a regular baby and then you see how a premie looks, you are not ready for it no matter how much you try to prepare for it.

The postpartum portions of narratives reveal lingering concerns about physician dismissal and lack of communication throughout the pregnancy. Participants also describe wishing they had been more prepared even though all acknowledge that information itself cannot overcome the pain of losing or fearing you will lose a child. One participant said:

I wish doctors had talked to me more from the beginning to prepare me for what potentially could come with these types of twins...I wish that they had more information for me because I just wasn't prepared for what I now know is always a possibility with these kinds of twins.

Participants also emphasized the lack of emotional support and a lingering feeling of abandonment from obstetric providers, even after the delivery.

[There was] no follow up from the people that were taking care of me during my pregnancy.

Women did reflect positively on instances where they were offered empathetic support, specifically in the NICU and appreciated information from providers that was hopeful, yet factual. One woman stated:

So to come here and have people say 'This is what we can do, this is what we can't do, these are your options' and to have people actually sit [with you], and not only that, but seem like they care, because I didn't feel like they cared in the other place. They [tertiary care providers] cared about what was going to happen. So that makes things easier... its horrible. But it has been made easier by people that actually cared.

Conclusion

Analysis of the themes suggests that women who have periviable births progress through four temporal themes: (1) the time preceding admission: feeling dismissed; (2) transfer or admission to a tertiary care center: anxiety and doubt; (3) the birth: fear of the outcome; and (4) the postpartum period: reflection and communication. These are critical for thinking about the ways care is structured from diagnoses to debriefing. Although all of the women did not have the same experiences, these 4 temporal themes were consistent in aspects of each interview and shared some commonalities, such as the importance of patient support and empathic communication.

Very few studies have analyzed the unique antepartum, intrapartum, and postpartum experiences with periviable birth. Grobman and colleagues' qualitative analysis of pregnancies complicated by the potential for a periviable delivery yielded two main themes; patient needs for information and support. Furthermore, this study evaluated differences between the types of information that providers and patients desired and highlighted the need women expressed for straightforward information to use in decision-making (Grobman et al. 2010). This is consistent with the findings of this study: women desire unbiased factual counseling throughout each temporal theme. In fact, participants universally sought more information regarding options and prognosis, and in instances where adequate information was not provided, expressed a feeling of abandonment and distrust.

These findings are also consistent with Sawyer et al.'s analysis of women's experiences with a preterm delivery. The authors identified four aspects that influenced perceptions of care: staff professionalism, staff empathy, involvement of the father, and the importance of the birth experience (Peters et al. 2016; Sawyer et al. 2013). Staff support throughout the birth experience was essential to a woman's ability to navigate through each temporal theme. Periviable birth is characterized by concern, fear, and adjustment to

new statuses as women progressed from antepartum to intrapartum and postpartum care. Importantly, these fears seemed to be helped by transparent and inclusive counseling and care. Simple acts such as updates on the neonatal resuscitation, performing deliveries under regional anesthesia whenever possible, providing the opportunity for parents to visit the infant as soon as is feasible following the birth, and providing empathetic support that acknowledges fears may help to further support women during key temporal moments.

Analysis of the narratives also suggests that some women experience a disruption of bonding secondary to feelings of uncertainty and fear as they prepare themselves for the worst. Sociologist Barbara Katz Rothman describes a phenomenon she calls a tentative pregnancy (Rothman 1993) whereby women who engage in prenatal fetal diagnosis delay bonding and acceptance of a pregnancy until the risk of a genetic defect has been determined. In this study, participants described a similar tentativeness, characterized though, in this case, by a suspension of bonding while waiting for a feared outcome. In providing counseling and support to women experiencing a periviable birth and its sequelae, recognition of the struggle between simultaneous detachment and attachment may help providers better understand and support patients through the complex and shifting tensions that frame the decisions families are compelled to make. At the time of the birth, self-sacrifice continues to shape the struggle between this detachment and attachment. The willingness of some women to minimize or ignore potential risks that may impact their own health and future childbearing capacity can act as a central component of a woman's final decision, and as such may be crucial to recognize and discuss during counseling (Campo-Engelstein 2012; Lynch and Burcher 2016; Raymond 1990).

In the period of time immediately after delivery, women sought to make sense of the events that occurred, and through this exploration, sought to arrive at a more detailed understanding of the birth. This process of meaning making has been previously described in an analysis of women's birth narratives and identified as an important adjunct to birthing care. Multiple studies suggest that the act of sharing birth stories can allow for the integration and synthesis of the events that comprise this major life event (Callister 2004). Furthermore, evidence in studies of perinatal loss demonstrate that the integration of culturally sensitive meaning making can help families adjust to an unexpected outcome (Callister 2006).

For women in this study, fear and anxiety were mitigated when information was provided in a way that communicated genuine care. In contrast, feeling dismissed or as though concerns were not being taken seriously contributed to a greater sense of distress and distrust. With this in mind, women who have a periviable delivery may benefit from having longitudinal support during the birth experience. In

obstetrics continuous support in the form of doulas has been shown to improve labor experiences (Bohren et al. 2017). In addition, there may be a role for enhanced counseling after a complex delivery. Overall, a multi-disciplinary team consisting of professionals from obstetrics, maternal-fetal medicine, mental health, spiritual leaders if desired, family members, and nursing are essential for the necessary provision of support for families experiencing this type of complex and emotionally charged health care crisis.

Women in this study attempted to reflect back and assimilate the events that unfolded in order to identify reasons for why they delivered so prematurely often casting doubt on the care they had received prior to transfer. This is not to say that referring obstetric providers administered suboptimal care. Periviable birth complicates a small minority of pregnancies, therefore it is understandable that physicians do not initially or automatically assume an impending periviable birth. Furthermore, counseling of all women about the possibility of a periviable delivery would likely cause more harm than benefit by inducing unnecessary worry. Instead we believe that by understanding how women interpret their interactions prior to a periviable birth the provider-patient relationship may become less fractured. First, it is important to recognize that in the absence of adequate debriefing and support, distrust and anger with primary care providers may be unintentionally exacerbated at the tertiary care facility. Second, as communication is central to delivery experiences, coordination of follow up with primary providers may allow for longitudinal care even after discharge from the hospital. Postpartum support and guidance has been identified as a deficient area of care in the United States (Shaw et al. 2006). Women who have a periviable birth require support throughout, but perhaps especially following delivery. By expanding care to include support for the processing of periviable delivery experiences and the events leading up to them, providers can facilitate this vital process of meaning making.

This study has several limitations. As women were interviewed after the delivery, opinions may be impacted by recall bias and any neonatal complications that developed. Interviews were conducted at varying times after delivery to accommodate participant schedules. Therefore, women who were interviewed 24 h after delivery may differ in their recollection of their experiences as compared to women interviewed 12 days later. The investigators did make an effort to minimize this interval. However, long intervals may lead to more recall bias of the events, especially for those themes occurring prior to and during delivery. The study did not include how neonatal outcomes might have influenced the ways women made sense of the delivery, nor how the condition of the infants might have influenced the decision to participate in this study. As such, women that participated in interviews may represent those with either very positive or a very negative experiences. The study was also limited

in demographic variability, and therefore would not represent the experiences of minority women. Nonetheless, study findings help to illuminate the experiences and perspectives of women who have lived through periviable births and also suggest areas for improvements in care at the population level. Furthermore, the use of the grounded theory approach, specifically, open ended questions with subsequent mapping of the interviewees responses is a strength of the study. This technique minimizes investigator bias regarding outcomes and allowed for the unique perinatal experiences to develop the themes.

Women move through a series of temporal experiences, as they navigate the stresses associated with periviable birth. These findings suggest interventions such as expanding care to include continuous, longitudinal support may be of benefit. Additionally, enhancing the standard postpartum care to include support for the challenges facing women who have had periviable birth experiences, may help women adjust to a new, unanticipated role and identities post-periviable birth. Overall, by mapping a course forward along a potentially difficult road, providers can play a vital role in the process of meaning making and in so doing, help to mitigate suffering.

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Compliance with Ethical Standards

Conflict of interest The authors report no conflict of interest or financial support. This study was approved by the Institutional Review Board prior to initiation.

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