

# Bereaved Parents: Insights for the Antenatal Consultation

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## Abstract

**Objective** The study aimed to explore experiences of extremely preterm infant loss in the delivery room and perspectives about antenatal consultation.

**Study Design** Bereaved participants were interviewed, following a semi-structured protocol. Personal narratives were analyzed with a mixed-methods approach.

**Results** In total, 13 participants, reflecting on 17 pregnancies, shared positive, healing and negative, harmful interactions with clinicians and institutions: feeling cared for or abandoned, doubted or believed, being treated rigidly or flexibly, and feeling that infant's life was valued or not. Participants stressed their need for personalized information, individualized approaches, and affective support. Their decision processes varied; some wanted different things for themselves than what they recommended for others. These interactions shaped their immediate experiences, long-term well-being, healing, and regrets. All had successful subsequent pregnancies; few returned to institutions where they felt poorly treated.

**Conclusion** Antenatal consultations can be strengthened by personalizing them, within a strong caregiver relationship and supportive institutional practices.

## Keywords

- ▶ decision-making
- ▶ antenatal consultation
- ▶ extreme prematurity
- ▶ parents
- ▶ bereavement

## Key Points

- Personalized antenatal consultations should strive to balance cognitive and affective needs.
- Including perspectives from bereaved parents can strengthen antenatal consultations.
- Trusting provider-parent partnerships are pivotal for risk communication.

Parents who present in labor at extremes of prematurity often receive an antenatal consultation that follows the advice of academic societies in informing them about clinical

circumstances and care options as part of engaging them in shared decision-making.<sup>1-3</sup> At the time of these initial consultations, it is often not known whether delivery can be

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postponed. As a result, parents have different and unpredictable amounts of time to make difficult decisions about whether to withhold intervention and give comfort care or intervene for a life with uncertain outcomes.<sup>4–6</sup> As much as consultants try to prepare parents for the range of possible outcomes, some infants die during labor or shortly after delivery. Here, we report on in-depth interviews with individuals who have undergone the life-changing experience of such bereavement.<sup>7,8</sup>

Studies of antenatal consultations have typically focused on how best to prepare parents for the experience of neonatal intensive care, looking, for example, at what parents initially understand and later remember, as parents of sick neonates.<sup>5,9</sup> Only a few studies have examined how well these consultations prepare parents for very real possibility of loss.<sup>4,7,10–12</sup> Those few studies have found that physicians' language can have powerful effects and that social and affective factors drive decisions, along with clinical facts.<sup>10,12</sup> To the best of our knowledge, there are scarce investigations about parents who experienced a loss of preterm infants in the delivery room.

In this manuscript, we report on in-depth, semi-structured interviews with bereaved parents, reporting on the emotions and social dynamics of their experience,<sup>13</sup> making sense of tragic sudden perinatal loss at periviability. Bereaved parents often follow similar stages of grief after loss, whether it occurs earlier in pregnancy or after a prolonged neonatal intensive care stay.<sup>7,8</sup> However, those who experience a loss in the delivery room typically could have maintained hope of a viable birth when they arrived to the hospital. They are often asked to consider delivery room care options and have little or no time to bond with their infant. In this exploratory study, participants share insights that we hope will help both, clinicians seeking to improve these consultations and parents seeking other parents' experiences.

## Materials and Methods

Semi-structured, open-ended interviews with bereaved parents explored their perspectives on loss surrounding extremely premature birth, followed by their opinions regarding decision-making for a hypothetical vignette of a pending extremely premature birth. The interviews follow decision science methods for studying "mental models" and are structured around topics identified by expert clinicians as central to the consultation process.<sup>14,15</sup> The interviews allow participants to express their views on those topics, as well as others of their choosing, in their own words, allowing comparison with clinician perspectives.<sup>16</sup>

### Participants

We recruited participants who had experienced loss of extremely premature infants in the delivery room from among patients served by Valley Hospital and a perinatal loss support group. All were at least 18 years of age and English speaking.

Participants were told that the research sought to improve parent–physician communication and would discuss sensitive

topics, such as resuscitation and palliative care. Participants could choose to be interviewed either in a private office setting or by phone. Informed consent was obtained prior to the interview. The interviews were taped and transcribed. No identification information was collected other than demographics. Transcripts and participants were not linked. Participants received information about community counseling services after the interview. Participants received a \$50 Amazon gift card, funded by the Marron-Manginello Endowment of the Valley Hospital Foundation.

### Procedure

One author (M.H.) conducted all the interviews. Each of the 13 participants was encouraged to tell their story in as much detail as they felt comfortable. The interview sought a fluid conversational approach, following participants' direction. After participants finished sharing their personal stories, they were presented with a hypothetical scenario of a woman presenting in preterm labor at the extreme of prematurity. They were asked structured questions about the scenario based on themes from the expert interviews,<sup>16</sup> namely elements that the experts saw as influencing decisions, such as specific infant and parent outcomes, approaches to consultations and delivery room care options, and decision-making. Participants answered in their own words, allowing us to hear their thinking on a common set of topics, while also allowing new topics to emerge.

### Analysis

We used a mixed-methods approach, with qualitative identification of emergent themes followed by rigorous specification of themes for structured coding. Thematic analysis involved all authors independently reading a subset of transcripts, integrating their perceptions, and developing formal codes.<sup>17–19</sup> Two authors (M.H. and J.L.) then coded all interviews independently, resolving differences by consensus, with a goal of 95% agreement for each interview. Disagreements were resolved by those two investigators, involving a third when needed. The frequency with which themes arose was counted. When participants reported more than one experience in the same subtheme, each was coded separately. When participants provided multiple examples of the same experience, they were coded as one experience. As participants were not randomly sampled from a known population, statistics are descriptive for this sample alone. Responses to structured questions are reported as frequencies.

The research protocol was approved by the Western Institutional Review Board at Valley Hospital, Ridgewood, NJ.

## Results

In total, 13 participants shared a perinatal loss experience and agreed to participate, involving 17 pregnancies, with care given at sites ranging from academic institutions to community hospitals in the Greater New York area.

Interviews lasted 1 to 2 hours and were conducted either in person, in a private office setting ( $n = 11$ ), or by phone

( $n=2$ ). Of the 13 participants, four had more than one premature pregnancy experience, resulting in 17 experiences. Of these 17 pregnancies, 11 had twin gestations (for a total of 28 infants). For seven pregnancies, parents reported being asked explicitly for their preferences regarding delivery room management: six were between 21.5 and 25 weeks of gestation, and one was a complicated second pregnancy to bereaved parents. For nine pregnancies, physicians were described as having determined delivery room care without parental input, based on gestational age at birth ( $n=7$ ), mothers' critical condition ( $n=1$ ), or infants' condition at birth ( $n=1$ ). Some physician approaches were described as paternalistic, "...with (son's name), they didn't offer us the decision. They kind of said, 'We're going to inspect him if he looks okay, then we'll intervene'... when he was born they kind of assessed him... and determined no, it would be too severe," and value based, "'Why didn't you hook them up?' He said to me, 'there's no quality of life.'" It was unclear whose preferences drove intervention in one case involving 23-week twins. All parents recalled thinking about their options, regardless of whether options were offered explicitly. ▶ **Table 1** presents demographics and infant outcomes.

We examined themes for (1) overall experiences, (2) lessons learned, and (3) decision-making experiences; each divided into subthemes. As not every participant commented on each subtheme, the numbers of participants and pregnancies vary. All participants responded to the structured questions. We first report on the narrative themes, along with illustrative quotes.

### Overall Experiences

Many participants had an overall theme integrating their narrative. Typically, it focused on either positive, healing or negative, and harmful interactions with their clinicians or the institution. Nine participants went to another institution for subsequent pregnancies.

#### (1) *Feeling cared for or abandoned (13 participants)*

All parents explicitly mentioned whether they felt cared for or abandoned, typically described in terms of how well their medical, informational, and emotional needs were met, and whether specific caregiver(s) were available when needed. Medical needs were mentioned for nine pregnancies and met for seven, "The clinician said, 'let's slow things down, let's try, and prevent this from happening.' I wouldn't be sitting here right now if it wasn't for him." Emotional needs were met in three of the six pregnancies where they were mentioned, "I've said this all along, they made a horrific experience, I actually used the word magical once, it was as magical as it could be. They were wonderful to me." Information needs were met in only 7 of 14 pregnancies: "I don't even know what is going on, there was no explanation. It was never explained to me why or why not... there was a lot of, not miscommunication, or some of it was, but it was just no communication." A critical clinician was noted as absent in five of six cases where that topic arose: "She (social worker) never came back. Like, never came back. I was walking through the motions, but certain things stuck out and that was one of the things that she kind of made an empty promise."

<b>Table 1</b> Demographics	
Demographics	<i>n</i>
Participants	13
Pregnancies	17
Infants	
Infants delivered	28
Twin gestations	11
Total infants survived	4
Singleton delivered at older gestational	2
Surviving twin	2
Stillbirth: (fetus alive upon arrival to hospital, but died in utero without intervention)	4
Disabled survivor (surviving twin)	1
Gestational age at delivery 20–21.6 wk	5
Gestational age at delivery 22–25 wk	8
Gestational age at delivery 25.1–30 wk <sup>a,b</sup>	2
Gestational age at delivery >30.1 wk <sup>a,b</sup>	2
Participant	
Mother (ages = 29–45)	11
Father (ages = 35–41)	2
Education	
High school	1
Associates degree	2
College or bachelor degree	7
Masters	2
Postgraduate	1
Ethnicity	
Caucasian	8
Mixed	2
Hispanic	3
Income	
Below average <100K	3
Average ~100K	6
Above average >100 K	4
Significant other	
Yes	12
No (but FOB involved at time of birth)	1
Faith	
Religious and spiritual	7
Religious or spiritual	2
Neither	2
Became less religious after event	2

<sup>a</sup>Second pregnancy to bereaved parents.

<sup>b</sup>Pregnancy presented in extremely preterm labor.

#### (2) *Helpful or harmful clinician qualities (13 participants)*

Clinician attributes or behavior were mentioned for 14 pregnancies. Five clinicians were described as positive, "He

looked at us like parents devastated over the fact that we were going to lose our children... really very honest, but at the same time compassionate"; three as negative, "We didn't like her bedside manner at all. We wouldn't have been upset if she had brought up terminating at all, but the way she brought it up was terrible"; and six were described both positively and negatively. In five instances, parents remembered harsh language, leading one parent to remark, "It was very scary like 'your baby could be born and their skin will be see-through.' I wouldn't suggest saying anything like that." For eight pregnancies, clinicians' competence was mentioned, positively ( $n=3$ ), negatively ( $n=2$ ), or both ( $n=2$ ).

**(3) Favorable or unfavorable institutional interactions (12 participants)**

The institutions' competence was mentioned for nine pregnancies, as competent ( $n=2$ ), not competent ( $n=5$ ), or both ( $n=2$ ). One participant noted a price paid for the competence of an academic center, "... a huge crew of people (students) ... closing in on you ... made it really hard for us as parents to have them in the room." All six who commented on hospital practices regarding demise at birth were negative, "I didn't hold them until that evening around 11 P.M. at night. They were cold... I would have loved to have held them when they were warm."

**(4) Infant's life felt valued or not valued (8 participants)**

Eight participants recalled instances of clinicians or institutions not valuing their infant or treating the child as replaceable, "'You can always have another.' I'm like, I'm still in labor." and "The doctor said, 'Do you want to get rid of it because one baby is growing and the other is not.'"

**(5) Parents felt doubted or believed (2 participants)**

In two cases, participants felt doubted, "Sometimes they feel like, oh, it's a new mom so it's okay this is normal she may be overexaggerating. I don't think in my case it was taken very serious." One felt that staff was initially annoyed by her concerns, but was relieved when she was finally believed. No one explicitly mentioned being believed, as part of the experience.

**Lessons Learned**

When describing lessons learned, participants offered three main themes. **Table 2** summarizes specific reflections and recommendations on the experience.

**(1) Transformations: hindsight and new perspectives (11 participants)**

Eleven participants described their changed perspectives. One shared, "Emotionally the pregnancies are traumatic..., innocence is gone, you are never blissfully ignorant." Several

<b>Table 2</b> Parental recommendations
<p><b>Humanize</b></p> <p>"It helped when the doctors were real... he said, I know these are hard choices.... I never knew until I came here to study this that my mom had a loss at 25 wk."</p>
<p><b>Recalibrate</b></p> <p>"Help parents reframe their picture of what they hoped for because the second you find out what you're having, the second you go through a journey like you do where it's IVF and all these needles, and then you find out both eggs took and it's a boy and a girl and you are like picket fence, perfect life, life is super."</p> <p>"Say 'I want to be hopeful because there is hope, but I also want to manage your emotions and your expectations.'"</p>
<p><b>Personalize</b></p> <p>"'Okay, how are they going to react to the situation and what's going to be comforting to them?' You have to wear so many hats and it has to change depending upon who you're dealing with."</p> <p>"Let the parents take the lead, because some people want more information, like we've talked about, some people want less information. I think that the doctor just has to make sure the parents feel that they have all the information they need."</p> <p>"So, I think maybe there is a way that they could come in and say, 'Have you ever been through this before? Do you even want to talk to us right now? We want to give you as much information as we can.' Because when I was here the second time around, I needed only positive things to focus on. I didn't want to hear the NICU speech."</p>
<p><b>Attend to crisis and normalize emotions</b></p> <p>"Ask the parents what they feel and what they think because the parents, they want this baby."</p> <p>"I think that that's something that's important for doctors to know that this is obviously going to be the worst time of our lives. Nothing will ever even compare."</p>
<p><b>Allow special moments</b></p> <p>"Let them see the baby sooner rather than later, especially if you are not sure how long the baby is going to live."</p> <p>"I just remember they were working on them, and my little voice just went, "Is it a boy or a girl?" I just wanted to know so we could have that minute where, you know... That still gets to me because we just, we had no idea."</p> <p>"I would have loved for my family to meet the boys."</p> <p>"I wanted my babies' birth certificates. Because when it's a live birth, you can have a birth certificate issued."</p> <p>"These babies need to know in 20 min or however long we choose to be with them, they need to know what it's like to be held."</p>
<p><b>Facilitate other support structures</b></p> <p>"I think that having someone who can, not necessarily be the doctor, but someone who can be there to help look after the family as they're going through this, and help them navigate."</p> <p>"You want to talk to someone to see that they survived, that you woke up every day somehow and functioned."</p>

recalled the moment, “I remember so many little details, then part of me... it’s like I can picture the walls just spinning.” They reflected on their decisions: “I think about what their life might have been had they lived. We would have done it (resuscitate), but I don’t know if it’s selfish on my part” and their subsequent adjustments: “I don’t want closure because I don’t feel like there’s ever a feeling of closure.” Two described obsessive researching afterward.

### (2) Parents need preparation (10 participants)

Ten participants offered specific advice for hospital staff. It included providing education earlier in pregnancy ( $n=7$ ), using simple language ( $n=4$ ), preparing parents for the initial meeting with their baby ( $n=4$ ), and meeting the care team before delivery ( $n=3$ ). Specific suggestions included: “Let them know that they’re going to look like a regular baby, they’re going to look and potentially cry and everything else the same as a full-term baby. They’ll just be teeny teeny tiny”; “If the parent sees the neonatologist’s face, meet the person one time, it will click and they’ll be more open to listen and speak”; and “Just saying the odds are not in your favor, like simple things like that .... It wasn’t just doctor talk; it was like person to person.”

### (3) All parents are different (8 participants)

Eight participants emphasized the diversity of parents’ experiences, needs, and perspectives. “You (clinicians) are going to come across different families that have different religions, different beliefs... there’s no one shoe fits for each family” and “...I think that there are just so many different backgrounds that people will come from that will really impact how they interpret the information. That’s why I feel like there needs to be some level of, ‘here’s the information. Here’s what it means, and here’s what it means for the baby, and here’s what it means for you. But we want to help you make a decision.’”

## Decision-Making Experiences

Many participants’ narratives revealed the diversity of their decision-making processes.

### (1) How emotions influenced decision-making (13 participants)

Eleven participants described feeling too overwhelmed to process information: “You just can’t; it doesn’t sink in”; “I was in such a fog, but I don’t really remember meeting her and talking to her until after.” Thirteen mentioned other emotions (fear, anxiety or panic, shock, devastating grief, out of body experience, anger, and guilt): “I can’t do this, I kept closing my eyes, all within a 5-hour period, your life is just like, ‘what just happened?’... I’m making food to freeze, thinking that I was going to be big and pregnant like literally there were pots on the stove.”

### (2) How information influenced decision-making (13 participants)

The 12 participants who commented on the role of information expressed conflicting views. Six wanted information, “I might be a mess right now, but I’m not stupid.” Five were conflicted and one ambivalent. One said, “I was so sick I was like just get this baby out of me. ... I wouldn’t want someone to come in and be like, if your baby is born these are

the statistics.” Seven parents discussed statistics; three did not find them helpful; three saw good and bad aspects, “The percentages, they’re important, but a parent is always going to think well my baby is going to beat the odds.” One participant mentioned visual depictions of mortality and morbidity, saying that they were not helpful.

### (3) Participants preferences (13 participants)

All parents expressed preferences for their pregnancies ( $n=17$ ), including those who reported not having been offered them explicitly: resuscitation ( $n=13$ ) and comfort care ( $n=2$ ). One chose resuscitation at birth but redirected to comfort care due to the infant’s condition, and one wanted to wait and see the infant’s condition at birth. Eight parents believed choices should always be offered: “So, I think that it would have been very difficult for us if the doctors just said, ‘They’re only 22 weeks. We’re not going to do anything.’ It would have been one thing if we said, ‘Well, what do you think we should do?’ But they gave us the option and we’re so grateful for that”; “It felt like we were still being given a choice, which I think made our experience a lot better than a lot of other people I’ve met along the way”; and “If the parents aren’t given an opportunity (to choose), they’ll always have a regret they didn’t speak up.” Another valued making choices in advance, “...they go over everything and you have a total full understanding of what’s going to happen.” and one said that having a choice was difficult, “We definitely wanted all the choices; it still tears me up, but it tore me up so much at that time to think there was a choice.”

### (4) How external elements influenced decision-making (12 participants)

All six participants who mentioned physician recommendations described them as important: “When you’re in crisis, you kind of do whatever anyone tells you to do... I think they want your guidance” and “I think that the doctors need to guide. I do. I don’t think that they should be like, ‘this is what you should do.’ But I think they need to guide because we looked for that.”

Other influences included their faith ( $n=3$ ) and stories of other infants ( $n=3$ ). Four stressed the importance of clinician support in living with their decision, “When parents are overwhelmed with that decision to potentially have to let their child die, you need as much support, you need 100% of the staff to be supportive of that.”

### (5) How participants wanted information delivered during consultation (11 participants)

Nine participants wanted realistic information: “You don’t want to give them (the parents) false hope”; “...be realistic.” Six wanted hope, four of whom also wanted realism: “The pain is going to be there no matter what, so I didn’t mind trying to have hope.” One explicitly did not, “You hear those miracle stories of, ‘Oh, this baby was born at this age and went to Harvard...’ But that’s probably not the norm and an unusual case.”

### (6) How parents considered their partner when making decisions (7 participants)

Seven participants described considering their partner when making decisions. Some relied on their significant



other, “I had a very supportive husband who is very good at making decisions. I kind of leaned on him a lot and his rationale. He was emotional but he was able to help me with those decisions the best. So that’s a component, too, the relationship.” Others worried about their spouse: “On top of being devastated about what we were about to face, I felt like I was immediately trying to fix her. I was watching her knowing that she was falling apart, I knew I had to help take care of her.... I was thinking about the boys, but I also was in my mind like how do I keep her okay? Now before she delivers and forever?” One recommended, “If you see that the parents are together, always include the dad.”

*(7) How parents considered themselves as decision makers (5 participants)*

Five participants described their decision-making processes. Two mentioned being uncontrollably emotional: “Because you know, your emotions are running wild.” One mentioned striving to be rational, “The emotions were already off the charts so it was almost too, they were too

far gone. I needed to be pulled back with real data, real information, real future, and real picture.” Two described having both elements. One described the process as dynamic, “I think it is probably some combination of the two. Initially, it’s emotionally driven... I think after that amount of time I could make a more rational decision even though it was still very emotional.” One described trying to minimize anticipated regret “...do what, at the end of the day, you’ll look back and say you’ll regret the least. That doesn’t mean you’ll never wonder, but you won’t regret.”

**Structured Questions (13 Participants)**

–Table 3 summarizes responses to structured questions about the hypothetical scenario, reflecting issues raised in our previous study with clinician experts.<sup>16</sup> Some participants seemed to respond in ways consistent with their own reported experiences, while others seemed to recommend different things for others than they would have wanted for themselves. Most supported offering choice, agreed on the

Table 3 Structured questions and responses	
<b>Decision-making</b>	
Do parents have “gut feelings” about care?	Yes (6); no (0); unsure (6); did not answer (1)
Who should make the decision?	Parents (6); MD (0); both (6); inconsistent (1)
Whose interests?	Baby (8); parent (1); other children (1); did not understand (3)
Which elements, typically discussed, are most important for parental decisions? <sup>a</sup>	All (1); decision already made/none (1); survival (5); disability (1); infant’s quality of life (1); pain (1); survival, pain, and dying process (2); survival, disability, function, and infant’s quality of life (1)
Which elements, not typically discussed, but are most important for parental decisions? <sup>b</sup>	All (1); none (5); other children (2); family happiness (4); being a parent (1)
Would parents regret comfort care?	Yes (8); no (5)
Would parents regret resuscitation if the infant dies?	Yes (3); no (9); sometimes (1)
Would parents regret resuscitation if the infant is disabled?	Yes (1); no (12)
Should speaking with veteran parents be offered?	Yes (8); no (2); sometimes (1); yes, but not for self (2)
<b>Consultation</b>	
Model: MD-driven; parent driven; combination	MD (4); parent (0); combination (8); inconsistent (1)
Should infant’s day to day be discussed?	Yes (8); no (5)
Should short-term infant outcomes be discussed?	Yes (8); no (4); did not answer (1)
Should long-term infant outcomes be discussed?	Yes (11); no (2); unsure (0)
Should the parent’s NICU experience be discussed?	Yes (10); no (1); unsure (1); after decision (1)
Should parental adjustment with a disabled child be discussed?	Yes adjust (4); yes told may not adjust (1); no (5); offered personal experience of adjustment (1); did not answer (2)
<b>Choices</b>	
Should only resuscitation be offered, only comfort care or are both options reasonable?	Both (11); did not answer (1); MD decides what should be offered (1)
Should different hospitals offer different care to similar patients?	Same options should be offered (6); different options (4); did not answer (3)
<b>Opinions</b>	
Can severely disabled children be happy?	Yes (11); unsure (2)
Do parents adjust to a severely disabled child?	Yes (11); unsure (2)

<sup>a</sup>Themes typically discussed: survival, disability, function later on, quality of life, dying process, parent’s quality of life, pain.

<sup>b</sup>Themes not typically discussed: finances, relationship with significant other and/or other children, role as a parent, career, family happiness.

content of consultations, and prioritized the infant's best interests. However, they differed on consultative approaches and shared decision making.

## Discussion

The outcome of a threatened extremely premature delivery is generally unknown when antenatal consultation occurs. Informing parents about potential outcomes is considered the backbone of these consultations. It is explicitly recommended by professional societies as a prerequisite for informed decision-making.<sup>1-3</sup> However, little is known about how these communications affect parents' emotional responses, both when initial decisions are made and afterward.<sup>20,21</sup> Very few studies have considered the experience of parents who present suddenly at extreme prematurity and whose infants died during labor or shortly after birth<sup>4,11,12</sup> with regards to antenatal consultation and decision-making. The present study reports on 17 such experiences from 13 participants. Their narratives are poignant recollections of how social, medical, and emotional factors interacted in shaping their ability to process and manage their crisis.

The bereaved parents interviewed here described complex interactions between cognition and emotion during a crisis,<sup>22</sup> whose enormity and complexity can create a sense of helplessness.<sup>23,24</sup> As seen in other studies,<sup>5,25,26</sup> many participants reported intense emotions, limiting their ability to process information and leaving them potentially vulnerable to how information is communicated.<sup>27,28</sup> Recognizing this difficulty, the priorities of these bereaved participants included education remote from crisis, when they could better absorb it, and support for their emotional needs during crisis. We suspect that for some, educational efforts within the provider-parent relationship to build trust, and mitigate emotions would be preferable, while for others, technology, such as smartphone apps,<sup>29</sup> could improve knowledge without increasing anxiety.

The diversity in these reports shows the need to adapt consultations to parents' decision-making styles. Professional recommendations<sup>1-3</sup> currently embody a rational choice model that relies heavily on conveying clinical facts. That approach could fit parents like those of our participants who described data-driven processes, but not those who described relying on their emotions or on both rational and emotional processes. When faced with complicated decisions, people may not always act as "rational actors." Some may rely on cognitive and affective heuristics; some may focus on a few elements of complex decisions.<sup>30,31</sup> Our participants wanted different information and recognized that heterogeneity among parents, recommending that consultants, "...let the parents take the lead because some people want more information... some people want less information." Without addressing such heterogeneous demand, some parents may be overwhelmed by irrelevant information, while others lack relevant knowledge.

That recognition is also seen in the seeming contradictions between what some participants wanted for themselves, and what they recommended for the hypothetical

scenario (→ **Table 3**). Notably, most recommended discussing outcome statistics for the scenario, even when that was not the case when describing their own needs. One possible explanation for such discrepancies is that decisions seem different in the abstract than in the reality of a crisis, even for those who have experienced that reality. A second possible explanation is that our scenario, based on the expert interviews, did not resonate with parents' concerns.<sup>32</sup> For example, providers may feel the need to prepare parents for a child's disability,<sup>33</sup> whereas our participants typically said that they would not have regretted intensive care and would regret palliative care, even were their child disabled, a finding supported by comparisons between provider and parental opinions of disability.<sup>34</sup> A third possibility is that our scenario encouraged parents to express beliefs about what good parents should want. "Good parent beliefs" is a known coping strategy in pediatric end-of-life decision-making.<sup>35</sup>

Although this study was not designed to offer prescriptive advice on counseling, it highlights the importance of building trusting relationships during antenatal consultation, especially for parents whose infants do not survive. Bioethical norms require providers to communicate basic information needed to support shared decision making. Parents of surviving infants<sup>5,36</sup> have been found to agree about those information needs, as did our participants, when reflecting on hypothetical scenarios. However, our interviews suggest that such success may not address the needs of parents under the emotional duress of an emergency delivery and subsequent death. For our participants, during those acute moments of crisis, prognoses were less important than strong affective relationships with the provider and immediately relevant information.<sup>37,38</sup> That pattern is consistent with the finding that parents of children diagnosed with trisomy 13 or 18 prefer physicians who share knowledge in a personalized fashion that balances hope and realism, while guiding them with gentle recommendations.<sup>38</sup> Such consultations, which recognize parents as "rational, emotional, creative, and interdependent" moral agents and prioritize trust before information exchange,<sup>11,37</sup> may help bereaved parents more than traditional informed consent, using standardized scripts.

Balancing cognitive and affective support, within an intense, highly personal, and dynamic deliberation process, is a challenge for physicians and researchers.<sup>6,11,36,39,40</sup> Views like those expressed in these interviews suggest the tenor and content of those balancing acts. They show the diversity of interactions with providers and institutions, as seen in previous studies as well.<sup>4,5,41</sup> Indeed, those interactions appeared more important than information, in preparing our participants for the loss of their child. A common theme was whether their infant's life seemed to matter. Most went to other institutions for subsequent pregnancies. Studies of stillbirth or later infant losses have similarly found that strong caregiver relationships protect bereaved parents,<sup>8,42-44</sup> with key features including good bedside manner, feeling believed, feeling cared for, and positive attitudes.<sup>8,10,43,45</sup> Our participants described such providers

as sharing personal stories, placing information in context, and humanizing the experience. Conversely, they described negative language, hurtful behaviors, and absence at critical moments as undermining them. Grieving parents desperately wanted to feel like parents. They cited the great value of such simple behaviors as using the baby's name, reinforcing their parenthood, and recognizing their baby's "life," as seen in other studies.<sup>38,46</sup> Conversely, they were very sensitive to signs that caregivers or institutions devalued their infant's life, in terms of echoing the feelings of "ambiguous loss" and "disenfranchised grief" reported elsewhere in bereavement literature.<sup>47–49</sup>

As with any qualitative analysis, ours depends on our ability to capture the themes in these parents' mental models of their experience. Due to the fluid conversational tone of our interviews, not all participants provided reflections on each theme. Information such as method of conception was only known if the participant shared that information explicitly. As with any retrospective narrative, we cannot know how hindsight and subsequent experiences affected these accounts. Participants' responses may have been colored by their processing of their experience reflecting their religious, spiritual, ethnic, and cultural backgrounds. As neutral and supportive as the interview was designed to be, it may have inadvertently focused on a subset of experiences that became particularly salient. We cannot know how physician expertise in communication, which can vary<sup>37</sup> influenced parent's perceptions. Lastly, our sample is small and recruited largely, although not exclusively, from active members of support groups that shared similar demographics: mostly Caucasian and Hispanic, college educated and average incomes, limiting the generalizability of our findings. As mentioned, all participants had had a later successful pregnancy, which may have affected how they thought about the ones described here. Two-thirds of the pregnancies were twins, consistent with higher risk of twin gestations delivering prematurely. Although many extremely premature infants are singleton, this is reflective of higher prevalence of singleton gestations.<sup>50</sup> Views from parents of twin gestations have not been found to differ dramatically from singletons when making end of life decisions,<sup>51</sup> but we cannot know whether that would be the case with bereavement.

Our results add the views and experiences of parents whose extremely premature infants died in the delivery room to research on antenatal consultation and decision-making. Their stories challenge the medical community to consider how well those consultations prepare these parents, who may largely slip from view, compared with parents of infants who survive or die after prolonged hospitalizations and become part of "NICU life." They contribute to the mounting evidence regarding the pivotal role of trusting partnerships in risk communication.<sup>5,6,11</sup> Our parents expressed the need for both cognitive and emotional support, within a strong relationship with caregivers and institutions attuned to the dynamic changes in their circumstances. Further research is needed to help caregivers provide such support. The voices of bereaved parents, as captured in personal interviews, may help the medical community to serve them better.

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### Conflict of Interest

None declared.

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