

**Prospective parents' perspectives on antenatal decision making for the anticipated birth of
a periviable infant**

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Abstract

Objective: To examine prospective parents' perceptions of management options and outcomes in the context of threatened periviable delivery, and the values they apply in making antenatal decisions during this period.

Study Design: Qualitative analysis of 46 antenatal interviews conducted at three tertiary-care hospitals with 54 prospective parents (40 pregnant women, 14 partners) who had received counseling for threatened periviable delivery (40 cases).

Results: Participants most often recalled being involved in resuscitation, cerclage and delivery mode decisions. Over half (63.0%) desired a shared decision-making role. Most (85.2%) recalled hearing about morbidity and mortality, with many reiterating terms like "brain damage," "disability," and "handicap." The potential for disability influenced decision making to variable degrees. In describing what mattered most, participant spoke of giving their child a "fighting chance;" others voiced concerns about "best interest," a "healthy baby," "pain and suffering," and religious faith.

Conclusion: Our findings underscore the importance of presenting clear information on disability and eliciting the factors that parents deem most important in making decisions about periviable birth.

Keywords: decision making, premature infants, parents, values, antenatal counseling

Introduction

Decisions regarding periviable delivery management are fraught with uncertainty about survival and long-term outcomes for the newborn. In light of this uncertainty and the potential severity of outcomes, parents may be given the choice to palliate or pursue resuscitative interventions for their child. There is substantial variation in how parental counseling actually unfolds and in the quality of the information conveyed to parents.¹⁻⁴

Studies to date have offered relatively little insight into the extent of expectant parents' understanding of the counseling they receive or the perceptions that shape their decision-making. Knowledge of these perceptions is vital to training obstetricians and neonatologists in effective methods of counseling, and to ensuring that parents are appropriately engaged in shared, informed decisions regarding management of the pregnancy, delivery, and neonate. Among the gaps in research on periviable birth noted in the Executive Summary of the 2014 Joint Workshop on Periviable Birth⁴ are studies that examine the effect of counseling on "family understanding, perception, decision-making and satisfaction" (p.8), as well as studies to "improve understanding of the effect of language and terminology used on family understanding and decision-making" (p. 340).⁴ Future efforts to develop decision support interventions for periviable birth will require greater understanding of how parents desire to be included in decision-making; their understanding of treatment options and associated outcomes; and the values and perceptions they apply to decision-making.

In response to this call and to aid in developing a decision tool, we set out to examine the antenatal decisions pregnant woman and their partners are involved in making; their preference for involvement in decision making; the language they utilize in describing their options and associated outcomes; and the values they apply in making decisions about periviable delivery

management. To do so, we utilized data from a larger, prospective, qualitative study that examined the decision making and decision support needs of parents concerning life-support decisions for extremely preterm infants from the prenatal to neonatal period.

Materials and Methods

The primary study was approved by the Institutional Review Boards of the three participating institutions. For the primary study, in addition to conducting 203 interviews across the perinatal period with parents, physicians and nurses, the study team extracted data regarding the hospital course and outcomes of both mothers and their newborns. Findings from the larger study are reported elsewhere.⁵⁻⁷ For this report, we focus on data obtained during the 46 prenatal interviews.

Participants

Participants were recruited at three tertiary care hospitals in the Midwestern United States. Eligibility criteria included being English speaking and at least 18 years of age. The pregnant woman had to be hospitalized at the time of the interview and to have been counseled about treatment decisions because of a threatened preterm delivery (22 0/7 to 25 6/7); partners of these women were also eligible to participate.

Data Collection

Using strategies to conduct the study in a sensitive manner,⁸ interviews were held in a private setting. Most of the parent interviews were conducted by the principal investigator and several by a co-investigator; both have extensive experience with interviewing on sensitive research. Consistency was maintained by using a semi-structured interview guide. Prenatal interviews were completed on the day of or after recruitment into the study. Thus, all prenatal

interviews were done at varying gestational ages but before the before the infant's birth. Couples were given the option to be interviewed together or separately, and several participants needed two sessions to complete the interview, resulting in a total of 46 interviews for 54 parents each lasting between 30 and 45 minutes. The interview was based on the Ottawa Decision Support Framework.⁹ For this analysis, we reviewed data related to the following targeted discussion points: treatment decisions made; decision roles of parents; parent knowledge of treatment decisions and infant outcome data; values that affected parents' decision making; and prior experiences with a preterm infant.

Data Management and Analysis

Interviews were transcribed verbatim and data were coded using Atlas.ti 5.7.1 software (2010). Forty-five percent of transcripts were double coded to establish inter-rater reliability. Recoding occurred until the investigators reached agreement. Conventional content analysis was used.¹⁰ Coded data related to the targeted areas in the interview guide were reviewed using a within and across case approach¹¹ to identify and describe patterns.

Results

We conducted 46 interviews among 54 prospective parents, representing 40 pregnancies. Details of the participants have been described.⁵ Briefly, most were pregnant women with gestational ages at recruitment of 21-21 6/7 (n = 1); 22 – 22 6/7 (n = 12); 23 – 23 6/7 (n = 12); 24 – 24 6/7 (n = 11); 25 – 25 6/7 (n = 4). Over half (57.4%) were black and 27.8% were Hispanic. Their mean age was 29 years (SD = 7. 3) and 35.2% reported incomes of less than \$30,000. 22 of these participants either had experienced a prior preterm birth (n=11), or knew someone else who had (n=11). Roughly two-thirds indicated that they preferred to share decision-making with

providers (Table 1). The majority of study participants reported that they agreed with their partner about the specific decision or that the mother should be the primary decision maker. More participants whose partner did not participate in the study reported disagreement about the actual decisions than couples who participated in the study. **Parental Involvement with**

Prenatal Life Support Decisions

Forty-two of the participants (33 pregnant women, 9 partners; 33 cases) reported that they were involved in making a decision for at least one of four different antenatal treatment decisions (Table 1). Maternal-fetal medicine physicians were involved in each case, and we were able to verify that neonatologists were involved in the counseling for at least 55% of the cases. Notably, the type of treatment decisions in which they were involved at a given gestational age varied across, and sometimes within, the three clinical sites. Some participants did not recall being asked to make certain decisions, such as resuscitation of the infant, but recalled being asked to make others, such as route of delivery. One woman explained:

At 24 weeks she told me that they do get very aggressive and the percentage of disability is like 20%, - that is what she told me. Yes, then all of that goes in the trash.....that is exactly, I am giving you verbatim. At 24 weeks our conversation, this conversation goes into the trash, and we start a whole new program, which we will aggressively try to resuscitate the baby. ... The cesarean was up to me, always up to me. They said at 23 weeks there would be no need to deliver a 23 week old fetus by cesarean unless it went into distress as it was coming vaginally.

However, at the same institution, another participant was allowed to make a decision regarding resuscitation of the infant before 24 weeks gestation. She said:

If you deliver early, um, they told me the options. Also, the option if I want to terminate the pregnancy knowing what I have to face. And the plan now, and they actually, I asked her to let me hold out as long as I could with the understanding that if I deliver in the 23rd (before 24 weeks) I would not resuscitate, that was my option. And that is, so right now I am just going to be at risk, being monitored with antibiotics and just see how long I can (pause) hold out.

Participants' Descriptions of Potential Infant Outcomes

Most (85.2%) of the participants reported that physicians provided infant mortality and/or morbidity data based on gestational age at birth. All but two were able to describe long term outcomes, using words such as “brain damage,” “disability,” and “handicap.” Specific conditions that participants recalled included cerebral palsy, cognitive impairment, developmental delay, and sensory impairment (blindness or deafness). One participant recalled hearing that, “The baby could be blind, retarded, handicapped.” Fathers were not typically present when the physicians provided this information to the mother. Among the 12 participants who were not involved in treatment decisions, only 2 recalled hearing about the potential long-term problems of extremely premature infants.

What Mattered to Parents during Decision Making

Several factors influenced how parents made decisions, including the importance of giving their infant a chance, doing what was best for their infant, concern about pain and suffering, attitude toward disability, and their faith. No patterns emerged that were related to socio demographic data, such as race, age, or educational level. Participants' prior experience

with perinatal loss, preterm birth, and disability influenced their decision making but in various ways.

Fighting Chance

Almost 30% of those who were involved in treatment decisions based their decision on the importance of giving their infant a chance--several used the words a "fighting chance." Some based it on their prior experiences with having a preterm infant. One of these mothers perceived that her prior infant died because of a lack of aggressive treatment. One couple reported that their 9-year-old son, born at 25 weeks gestation, is "doing wonderful;" others reported disability:

He (her partner) has another child that was premature, with severe cerebral palsy. Well, I don't know how severe it is...I don't know the name of it, the ones that has rigidity.... and I'm like well, I say no, because we'll still be giving him a fighting chance.

Other parents who either had another child born preterm (n=11) or knew others with a preterm infant (n=10) reported that these children were healthy, regardless of their gestational ages at birth, and were more likely to request resuscitation for their infant. *Best Interest, Pain, and Suffering*

Other participants explained that their decisions were based on wanting what they felt was "best for their infant," desiring a 'healthy infant' (without describing specifics), or concerns about infant suffering. They used words such as "pain," "suffering," and "hurt" when describing their concerns. One mother said:

Or if [I] wanted, you know, let him go, so he won't suffer that much because there was a lot of risks of, you know, brain damage, because he could be paralyzed, he could have a

variety of defects and stuff happening to the baby. So, they asked me whether I was sure if I wanted to put the baby through that or let it go.

Another mother explained her concern about the pain that the treatment in the neonatal intensive care unit might cause:

I had options that basically you know, if he, if he is viable, then you know they are, they can put him on the, on the machines... but they also let me know that if he was on a machine, he would have tubes and everything everywhere and it just sounds like that's painful. That sounds really painful.

Most of the participants who expressed concern about suffering were not involved in making resuscitation decisions. Those who were involved, however, still chose to have their infants resuscitated.

Disability

Views toward having a child with a disability also varied. For some participants, the possibility of a disability influenced their decision to not resuscitate. One woman, who had experienced three prior second trimester losses and was enrolled in the study at 22 2/7 weeks gestation explained:

If I deliver this early, knowing that, um, baby could have you know, um, disabilities is the reason why I said do not resuscitate. If I can hang in there until like the 26th week, where I know that I can have steroids, or whatever. I feel, I feel that I can, even though they tell me, I feel that the health things may not be, there may still be some burden, I don't think they'll be that severe even though they might. I'm not willing to take that

chance. I feel, I know that the longer I stay pregnant the better for the health of the baby will be.”

Others were emphatic that the potential for infant disability did not influence their treatment decisions. One woman who had experienced five prior perinatal losses indicated that her decisions were not based on the potential for disability but on her parental responsibility. Even those who had prior experience with or knowledge of disabilities explained that they did not base their decisions on the potential for disability despite being concerned about that possibility.

Faith in a Higher Power

The influence of a higher power was also important to several participants. One woman said, “I am religious, I mean, I just put it in God’s hands, and you can’t worry, pretty much, you have to put it in God’s hands, because nobody really knows, and that is that.” Another explained how a higher power had the final influence on his infant’s outcome: “They said cerebral palsy...blindness or deafness. You know, stuff like that. I did not really feed into that though. Like I said, God got the last word.”

Discussion

In this analysis of qualitative data from interviews with expectant parents, we identified several important themes related to how decisions are made in the context of periviable delivery. Many participants expressed a desire for a shared role in decision-making alongside their providers; most recalled hearing information about morbidity and mortality. In describing what mattered most to them in making their decisions, participants in our study spoke of giving their child a “fighting chance,” as well as notions about “best interest,” a “healthy baby,” “pain and

suffering,” and religious faith. The potential for disability in the infant had variable degrees of influence on decision making.

Although several studies have described provider's attitudes and practice patterns in caring for this population,¹²⁻¹⁴ insights from the perspective of parents making antenatal treatment decisions for periviable delivery is limited.^{5,15-18} In studies of simulated periviable counseling, obstetricians and neonatologists have tended to overemphasize informational content while failing to elicit parental values and preferences related to goals of care (resuscitative vs palliative).^{19,20} Similar to our findings, Boss et al reported that, beyond survival, parents also applied values related to pain and suffering, financial costs, religious faith, and hope to their decision making.¹⁵ Moreover, in another study, parents reported that physicians overemphasized morbidity and mortality,⁵ which is similar to what we found. Furthermore, we identified variability in parental perspectives regarding best interests and disability. This highlights the important role that values clarification and preference elicitation should play in periviable decision making. Knowledge of these perceptions is vital to efforts to train obstetricians and neonatologists in effective methods of counseling, and to ensure that parents are appropriately engaged in shared, informed decisions regarding the approach to their pregnancy and their infant's neonatal care. Our findings also underscore the importance of assessing parents' desired role in decision-making; their attitudes toward disability; and the factors that they deem most important in making decisions about periviable birth. These are essential elements of shared decision-making,^{21,22} and employing them will promote more patient-centered care.²³

More than half of our study participants recalled being told about the possibility of their child experiencing long-term neurodevelopmental impairment. A smaller number of participants

reported that they did not receive information on long-term outcome. However, we are unable to determine whether this reflects gaps in counseling on the part of physicians, or gaps in recall on the part of the parent. Because physicians tend to provide numeric estimates for survival, but not for long-term outcomes,² it is possible that survival estimates may be more salient. The vast majority of the participants who reported having been counseled on long-term outcomes were able to recount, in fairly consistent terms, the prospect of a range of neurodevelopmental impairments. These findings provide evidence that prospective parents are fully capable of engaging in such conversations in the context of threatened periviable delivery. Furthermore, some participants were able to articulate how the potential for disability and suffering impacted their decision making. Although providers have concerns that relaying information about impairment or disability will undermine efforts to promote hope and optimism, although there was variability in how much importance parents placed on this information in their ultimate decision making, none of the participants stated that it was detrimental or harmful to receive. We have argued that informed, shared decision-making is optimized when patients are presented with the full range of short and long-term outcomes that are *possible*, along with an indication of how *probable* those outcomes are to occur.²⁴

Our study is not without limitations. The parent study was conducted in a single state, among English-speaking women admitted to urban, academic medical systems and thus, the experiences of our participants may not be representative of, or generalizable to, other patient populations. Selection bias also may have been present because only patients who were medically stable and not imminently delivering could participate in the study. Therefore, caution should be applied when applying our findings, as they may not reflect the values and priorities of parents in other settings or clinical circumstances. Additionally, parental accounts were based on

self-report and subject to recall bias; their reflections may or may not provide a 'true' account of the content and quality of the physician counseling received. Nevertheless, parents ultimately make decisions based upon what was 'heard', not what was 'said' – making their recollection and perception of the information conveyed by the health team critically important to the decision-making process.

Despite these limitations, we believe our study makes an important contribution to the burgeoning literature examining counseling and decision making in the context of periviable birth by offering greater insights into parental perspectives. Furthermore, our findings provide key insights with implications for policy and practice. Previous studies have noted a discordance between physicians and parents regarding what they deem important in the following areas: decision making;^{5,7,15} critical components of the counselling exchange;¹⁷ and the parents' desired degree of involvement in decision making.¹⁶ As parents and professional organizations call for more shared decision making, interventions are needed to facilitate models of counseling that are both informed, deliberative, and attentive to parents' values. Our findings suggest that parents can retain basic concepts—if not specific statistics—about long-term morbidity. And importantly, parents place varying degrees of importance on the potential for disability in their decision-making. These findings should caution providers about making assumptions about parental values and preferences, and underscore the importance of eliciting values and preferences to clarify the factors that parents deem most important in their decision making. This highlights the need for skill development and decision support tools to assist providers and facilitate values clarification and preference elicitation.

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Table 1. Elements of Decision-Making Described in Prenatal Parent Interview

Element	N (%)
Preference for Decision Making*	
Shared decision making	34 (63.0)
Alone or with partner	7 (13.0)
Provider make decision	2 (3.7)
Uncertain	11 (20.4)
Reported Involvement with Life Support Decisions *	
Yes	42 (77.8)
No	12 (22.2)
Involvement in Antenatal Treatment Decisions †	
Infant resuscitation	17 (31.5)
Cerclage placement/removal	14 (25.9)
Mode of delivery	12 (22.2)
Termination of pregnancy	11 (20.4)
Factors that Influenced Decision Making †	
Giving infant a fighting chance	12 (28.6)
Best interest for the infant	7 (16.7)
Desires for a healthy infant	5 (11.9)
Concerns for infant suffering	6 (14.3)
Potential for disability	8 (19.0)
Communication of Infant Outcomes ‡	
Physician provided infant mortality/morbidity data*	46 (85.2)
Recalled discussion of long-term outcomes †	30 (71.4)

*Out of the total 54 participants

†Out of 42 participants involved in making treatment decisions

‡Categories are not mutually exclusive