

## ARTICLE



# Antenatal consultation and deliberation: adapting to parental preferences

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**OBJECTIVE:** To analyze and compare perspectives on antenatal consultation and decision-making from participants with varying degrees of prematurity experience and clinician-experts.

**STUDY DESIGN:** Open-ended interviews structured around topics previously identified by recognized clinician-experts were conducted with participants having different levels of prematurity experience. Analysis used mixed methods (thematic and mental models analysis). Secondary sub-group comparisons were performed, based on degree of experience.

**RESULTS:** Non-clinician participants' ( $n = 80$ ) perspectives differed regarding: amount and content of information desired, decision-making strategies, and who – parent or clinician – should direct consultations. Most wanted to retain decisional authority, all recognized their emotional limitations and many advocated for deliberation support. Participants worried parents' would regret choosing palliative care contrary to clinicians. Bereaved parents often saw issues differently.

**CONCLUSIONS:** Parents approach risk and decision-making for extremely premature infants in a personal fashion. They need personalized support tailored to their unique circumstances, decision-making preferences, and emotions.

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## INTRODUCTION

Before birth of an extremely premature infant, neonatologists and parents often must decide what care to offer the infant in the delivery room. Professional recommendations for antenatal consultation emphasize that these decisions should be informed, defined as ones where parents understand the medical information relevant to their choices. The recommendations assume that parents require similar facts. Yet with vast variability in parents' lived experience, values, resources, and tolerance for risk and uncertainty, the relevant facts vary. For consultants, tailoring information requires knowing what background knowledge parents have, how much information they want, and how much emotional fortitude they have for processing it. It also requires insight into how parents prefer to make decisions, recognizing that those who decide with their hearts [1] may rely less on specific information and more on trusted alliances [2].

Many clinicians assume 'more information is better' and conduct studies to maximize transfer and recall [3, 4]. Others focus on assisting parents in identifying and prioritizing their values and providing them with information most relevant to *them* in making this decision, in ways that address their cognitive and emotional needs [5–7]. Value awareness, a model of value driven-decision making, is achieved when there are no additional facts or emotional perspectives that would affect parents' choices, and the provision of irrelevant information is minimized [5, 8].

This research examines how lay persons perceive risk and decision-making regarding extreme prematurity. As experience influences opinions, we report perspectives of participants with varying degrees experience with prematurity and compare these with those of clinician-experts interviewed in a previous study [9].

## METHODS

We conducted qualitative semi-structured interviews, following the mental models methodology [10, 11] from behavioral sciences. The open-ended interviews sought to elicit participants' mental models, decisional influences, emotional states, and experiences, while allowing expression of individual variation on topics identified through clinician-expert interviews [9].

## Participants

Between 2017–2018, participants were recruited among groups served by Valley Hospital, Ridgewood, NJ, through flyers posted in the neonatal intensive care unit, a perinatal loss support group, a hospital newsletter targeting the community at large, and word of mouth. A total of 80 participants was determined as sufficient to allow diverse views and group differences to emerge based on previous mental model studies. Participants who were least 18 years of age and English speaking were informed that the research sought to improve parent–physician communication and would discuss sensitive topics. Those who agreed and gave consent could choose to be interviewed either in person in a private office setting or by phone.

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## Procedure

Participants were asked if they had experiences with prematurity. A description of antenatal consultation for an extremely premature birth was then presented (Supplementary Appendix A), after which all participants shared their thoughts. They were invited to expand on all topics raised, to be sure that we understood them and to evoke further associations. Participants were then asked structured questions (Supplementary Appendix B) based on the themes identified by clinician-experts [9] addressing: decision-making process (e.g., approach, responsibility, strategies, decisional regret), guiding considerations (e.g., survival, disability, best interests, family happiness, etc.), beliefs (e.g., options offered, disability, peer support, fears) and desired outcome information. Lastly, participants could share any remaining thoughts about antenatal consultation and deliberation.

## Analysis

Interviews were transcribed and analyzed using a mixed-method approach. We coded participants' answers into the clinicians' topics, following a mental models approach [10]. We identified additional themes, expressed by participants, using descriptive content analysis previously reported [12], in which themes were developed simultaneously and independently by all four authors. During the initial exploration of data, codes, sub-codes and coding definition and structure were developed gradually until consensus was reached. Then, systematic coding of all parental answers was done by two investigators with discrepancies resolved by a third coder when necessary. Codes of the qualitative content were introduced in the database as dichotomized variables (Yes/No). Structured questions were multiple-choice or open-ended, except for questions asking for considerations guiding decisions, where participants were asked to select and rank relevant options from a fixed list. We report response frequencies for all questions, except for these importance rankings, where a weighted score was created, as reported below.

Where direct comparisons are possible, we contrast clinician-experts' views [9] with those of our participants. We also provide comparisons between four subgroups: bereaved parents of peri-viability infants ('B'), parents of preterm infants with direct experience at later gestational ages/pre-viable stillbirth ('D'), participants with indirect knowledge of prematurity through a relative or friend ('I') and those with no experience with prematurity ('N'). Bereaved participants had lost an infant during labor, delivery or shortly after birth. Results are reported as descriptive statistics. As participants were not randomly sampled from a known population, no inferential statistics are used.

## Ethics

The research protocol was approved by the Western Institutional Review Board, Valley Hospital, Ridgewood, NJ. Consent was obtained verbally for telephone interviews or in writing for in-person interviews. No identifying information was collected other than demographics. Participants received information about community counseling services after the interview and a \$50 Amazon gift.

## RESULTS

In total, 80 individuals agreed to participate, among whom 13 were bereaved parents, 20 had direct prematurity experience, 27 had indirect prematurity experience and 20 had no prematurity experience. Table 1 reports demographics, including gestational age at delivery, where applicable. Interviews lasted 1–2 h; 1/4 were interviewed in person. Although all participants completed the interview, given the fluid conversational approach, not all participants addressed each mental-models topic and emerging theme. Table 2 reports results from structured opinion questions, analyzed with mental models coding. Where applicable, tables include results from the clinician-expert interviews [9].

## Information

**Locus of control.** Responses to structured questions pertaining to consultation showed variation within and between groups in who should determine what information is necessary: clinicians, parents, or both together (Table 2). Non-clinician participants expressed sentiments as, "...because I have never experienced

something like that ...I would want to know, quite frankly the scripted version of what they (clinicians) know" (I) and "...best if the parents led the discussion... allowing them to arrive at these points rather than kind of dispensing information in a fire hydrant kind of way and flooding their minds" (N). The bereaved group members never preferred consultations whose content was determined only by parents. They recommended that clinicians consider previous experiences to help guide their approach, suggesting clinicians ask, "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" justified by the following sentiment "...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". Bereaved parents also recommended clinicians consider whether delivery is imminent in guiding the consultation approach, expressed as "Okay, we [clinicians] kind of think you're not going to make it more than 12 hours. We need to give you these stats," as opposed to a more parent driven model (B). Clinician-experts were equally divided among the three approaches [9].

**Realism.** Our analysis of emerging themes revealed additional concerns regarding consultation. First, realistic information was considered central. Even though some bereaved parents were unsure whether information had helped them, they still favored offering it: "you want to know everything, but you don't want to mentally start preparing yourself and then this doesn't happen". In contrast, some clinician-experts tended towards pessimism, focusing on adverse health outcomes to 'protect' parents in case of poor outcomes [9].

**Emotions.** Next, nearly all participants recognized the emotional intensity of the situation with one describing "a panic attack" (D). Many feared emotions would limit their ability to absorb information: "If I'm confused or emotional or scared... you sound like Charlie Brown's parents in my head because I can't take it in" (D) and "(they) can present as much information as possible but parents are in shock." (B) Recommendations for reducing unnecessary emotions, included using "layman's terms" (D), providing information earlier in the pregnancy and having a supportive delivery style: "The most important thing for me to hear from a doctor is, 'We're going to do everything we can to help your child survive, to make it through this difficult time'" (D).

**Critical content.** More than half of parents and clinician-experts supported discussing routine care, conditions complicating NICU care (short-term outcomes) and long-term infant outcomes (Table 2). Most participants, but not most clinician-experts supported discussing short-term parent outcomes. Despite agreeing that parents adjust if their children are disabled, participants varied whether to discuss this prenatally.

In emerging themes, many participants raised the topic of statistics. Many used them to guide decisions, "Statistics really help because they are black and white" (D) and "Tell me the percentages... I prefer to go with where it's the safest bet" (N). Others, especially bereaved parents, were more skeptical: "[it] messes with your head" (B); "my child is not a number to me, my child is everything" (D); and "statistics could be manipulated to lay out whoever's presenting it wants to accomplish" (I). Clinician-experts opinions differed from each other, although many preferred less precision [9].

## Decision-making

**Integrative process.** Participants had differing views on how decisions were and should be made. Many, in all groups, believed that gut feelings dominated, as in "I think deep in your heart or your gut, you know kind of like well, this is what's best" (N). A common qualification was, "[gut feelings are important] but that doesn't necessarily mean that they [parents] know any of the information

**Table 1.** Demographics *N* (%).

<i>N</i>	All 80	Bereaved 13	Direct experience 20	Indirect experience 27	No experience 20
Reported themselves as					
Female	65 (81)	11 (85)	17 (85)	23 (85)	14 (70)
Male	15 (19)	2 (15)	3 (15)	4 (14)	6 (30)
Education					
- HS	1 (2)	1 (8)	0	0	0
- Some College	24 (30)	5 (38)	4 (20)	12 (44)	3 (15)
- College Degree	21 (26)	4 (21)	3 (15)	6 (22)	8 (40)
- Graduate School	34 (43)	3 (33)	13 (65)	9 (33)	9 (45)
Income					
- Below Average	5 (6)	3 (23)	0	1 (4)	1 (5)
- Average	34 (42)	6 (46)	9 (45)	12 (44)	7 (35)
- Above Average	38 (48)	4 (31)	10 (50)	12 (44)	12 (60)
- Defer	3 (4)	0	1 (5)	2 (8)	
Religion/ Spiritual					
- Religious	16 (20)	0	5 (25)	10 (37)	1 (5)
- Spiritual	7 (9)	2 (15)	2 (10)	2 (7)	1 (5)
- Both	48 (60)	9 (69)	11 (55)	14 (52)	14 (70)
- Neither	8 (10)	2 (15)	2 (10)	0	4 (20)
- Defer	1 (2)	0	0	1 (4)	0
Significant Other					
- Yes	72 (90)	11 (85)	20 (100)	24 (89)	17 (85)
Parent of living child					
- Yes	68 (85)	13 (100) <sup>b</sup>	19 (95)	20 (30)	16 (80)
Race					
- Asian	19 (24)	0	1 (5)	6 (22)	12 (60)
- Black	2 (3)	0	1 (5)	1 (4)	0
- White	41 (51)	8 (62)	13 (65)	14 (52)	6 (30)
- Hispanic	10 (13)	3 (23)	3 (15)	2 (7)	2 (10)
- Multi-ethnic	3 (4)	2 (15)	1 (5)	0	0
- Mediterranean	1 (2)	0	0	1 (4)	0
- Defer	4 (5)	0	1 (5)	3 (11)	0
Age					
- 18–30	6 (8)	1 (8)	0	2 (7)	3 (15)
- 31–40	49 (61)	9 (69)	14 (70)	14 (52)	12 (60)
- 41–50	18 (22)	3 (23)	6 (30)	5 (19)	4 (20)
- 51–60	3 (4)	0	0	2 (7)	1 (5)
- >61	4 (5)	0	0	4 (15)	0
Gestational age at delivery					
- <20		0	1 <sup>a</sup>		
- <23 weeks		7 (twins)	0		
- 23–25 weeks		6 (twins)	3		
- 26–34 weeks		3	4		
- 35–37 weeks		0	13		
- >38 weeks		1 (2 <sup>nd</sup> preg)	2		

<sup>a</sup>Stillbirth.<sup>b</sup>Subsequent pregnancy resulting in live birth.

that's out there" (*N*). Bereaved parents added "... they [parents] think they know [have gut feelings] but no I don't think they actually know [their decision]" (*B*). Some remarked on how deliberation styles vary within a couple, "I am more emotional, where my husband is more logical." (*D*). Many suggested clinicians should prepare for this diversity in decision-making.

**Deliberations.** In emerging themes, some reported how emotions impacted decisions, "panic can set in and fear...cloud a real fully

thought-about decision." (*I*) while others were guided by them, "Decisions are easy... I feel them" (*D*). The role of supportive relationships during deliberations was central to bereaved participants, expressed in terms such as "... there were very few people involved that were comfortable enough to handle being uncomfortable... He knew what he was getting into." They appreciated clinicians who could interpret their values to guide deliberations, as expressed in, "the doctor went back to that reaction... how did I get from there to there without ever mentioning

**Table 2.** Multiple-choice questions on consultation and decision-making process [N (%)].

Question	Clinicians [9] N = 18	All N = 80	Bereaved N = 13	Direct experience N = 20	Indirect experience N = 27	No experience N = 20
<b>Information- Locus of Control</b>						
MD should determine content	6 (33)	32 (40)	4 (30)	9 (45)	10 (37)	9 (45)
Parents should determine content	7 (39)	11 (14)	0 (0)	3 (15)	4 (15)	4 (20)
They should determine it jointly	5 (28)	31 (39)	8 (61)	7 (35)	9 (33)	7 (35)
Undecided			1 (8)			
<b>Information-Critical Content</b>						
Discuss routine care	8 (44)	70 (88)	8 (62)	19 (95)	26 (96)	17 (85)
Do not discuss routine care		10 (12)	5 (38)	1 (5)	1 (4)	3 (15)
Discuss short-term IO	12 (66)	70 (88)	8 (63)	17 (85)	26 (96)	19 (95)
Do not discuss short-term IO	6 (34)	10 (12)	5 (37)	3 (15)	1 (4)	1 (5)
Discuss long-term IO	17 (92)	71 (89)	11 (85)	17 (85)	24 (89)	19 (95)
Do not discuss long-term IO	1 (8)	9 (11)	2 (15)	3 (15)	3 (11)	1 (5)
Discuss short-term PO	8 (44)	69 (86)	10 (77)	16 (80)	25 (93)	18 (90)
Do not discuss short-term PO	10 (56)	11 (14)	3 (23)	4 (20)	2 (7)	2 (10)
Parents adjust to a child with disability	11 (85)	56 (70)	45 (66)	14 (70)	17 (63)	14 (70)
Parents do not adjust to a child with disability	0	3 (4)	3 (4)	1 (5)	1 (4)	1 (5)
Unsure if parents adjust to a child with disability	2 (15)	4 (5)	2 (3)	2 (10)	0	0
It depends if parents adjust to a child with disability	0	17 (21)	17 (25)	3 (15)	9 (33)	5 (25)
Clinicians should discuss parental adjustment (PA)	17 (92)	51 (64)	5 (38)	8 (40)	20 (74)	18 (90)
Clinicians should not discuss PA	1 (8)	29 (46)	8 (62)	12 (60)	7 (26)	2 (10)
<b>Decision- Integrative Process</b>						
People have gut feelings		40 (50)	7 (54)	13 (65)	10 (37)	10 (50)
People do not have gut feelings		25 (31)	4 (30)	5 (25)	12 (44)	4 (20)
Unsure if people have gut feelings		13 (16)	1 (8)	2 (10)	5 (19)	5 (25)
Not answered		1 (1)	0	0	0	1 (5)
<b>Decision- Critical Factors</b>						
Typical factors influencing decisions						
- Survival		426 (76)	75 (82)	118 (84)	111 (59)	122 (87)
- Disability		368 (66)	44 (48)	119 (85)	108 (57)	97 (69)
- Pain		296 (53)	40 (44)	77 (55)	82 (43)	97 (69)
- Best Death		248 (44)	26 (29)	70(50)	56 (30)	96 (69)
- Ability to function		341 (61)	38 (42)	94 (67)	109 (58)	100 (71)
- QOL infant		441 (79)	52 (57)	109 (78)	161 (85)	119 (85)
- QOL parent		274 (49)	28 (31)	73 (52)	69 (37)	104 (74)
Other factors influencing decisions						
- Finances		244 (51)	27 (35)	33 (28)	90 (56)	94 (78)
- Other kids		248 (52)	35 (45)	64 (53)	70 (43)	79 (66)
- Marriage		198 (41)	30 (38)	40 (33)	52 (32)	76 (63)
- Career		155 (32)	18 (23)	38 (32)	48(30)	51 (42)
- Parental role		189 (39)	21 (27)	47 (39)	59 (36)	62 (52)
- Family happiness		222 (46)	37 (47)	54 (45)	69 (43)	62 (52)
Whose interests guide decisions?						
- Baby		348 (88)	47 (78)	95 (95)	113 (84)	93 (93)
- Parent		266 (67)	20 (33)	65 (65)	103 (76)	78 (78)
- MD		56 (14)	8 (13)	17 (17)	14 (10)	17 (17)

Table 2. continued

Question	Clinicians [9] N = 18	All N = 80	Bereaved N = 13	Direct experience N = 20	Indirect experience N = 27	No experience N = 20
- Society		27 (7)	4 (7)	9 (23)	6 (4)	8 (8)
- Other kids		136 (34)	15 (25)	23 (23)	54 (40)	44 (44)
Which treatment options are reasonable to offer?						
- Only resuscitation is reasonable		1 (1)	0	1 (5)	0	0
- Only Comfort care is reasonable		2 (3)	0	0	1 (4)	1 (5)
- Both options are reasonable		71 (89)	11 (85)	18 (90)	26 (96)	16 (80)
- Unsure		2 (3)	0	0	0	2 (10)
- The MD should decide		1 (1)	1 (8)	0	0	0
- Did not answer		3 (4)	1 (8)	1 (1)	0	1 (5)
Should choices be standardized						
- Choices should be standardized		49 (61)	6 (46)	12 (60)	18 (67)	13 (65)
- Choices can vary		23 (29)	4 (31)	8 (40)	7 (26)	4 (20)
- Did not understand/answer		5 (6)	2 (15)	0	2 (7)	0
- Depends		3 (4)	1 (8)	0	0	3 (15)
Who should make the decision?						
- Physicians should make decisions		0 (0)	0	0	0	0
- Parents should make decisions		33 (41)	4 (30)	10 (50)	14 (52)	5 (25)
- They should decide together		44 (55)	7 (54)	10 (50)	12 (44)	15 (75)
- Inconsistent		2 (3)	1 (8)		1 (4)	
<b>Decisional Regret</b>						
Would parents regret IC if their infant dies						
- Regret IC if infant dies		20 (25)	3 (23)	6 (30)	7 (26)	4 (20)
- Not regret IC if infant dies		55 (69)	9 (69)	14 (70)	19 (70)	13 (65)
- Unsure if parents would regret IC if infant dies		3 (4)	0	0	1 (4)	2 (10)
- Depends on a variety of factors		1 (1)	1 (8)	0	0	0
- Not answered		1 (1)	0	0	0	1 (5)
Would parents regret IC if their infant is disabled						
- Regret IC if infant is disabled	12 (66)	18 (23)	1 (8)	4 (20)	8 (30)	5 (25)
- Not regret IC if infant is disabled		50 (63)	12 (92)	12 (60)	14 (52)	12 (60)
- Unsure if parents would regret IC if infant is disabled		11 (14)	0	3 (15)	5 (19)	3 (15)
- Not answered		1 (1)	0	1 (5)	0	0
Would parents regret PC						
- Regret PC		44 (55)	8 (61)	13 (65)	14 (52)	9 (45)
- Not regret PC		31 (39)	5 (38)	7 (35)	11 (41)	8 (40)
- Unsure		3 (4)	0	0	2 (7)	1 (5)
- Some do some don't		2 (3)	0	0	0	2 (10)
- Not answered		0	0	0	0	0
<b>Decision- Peer Support and Other Beliefs</b>						
- Speaking to other parents helps		64 (80)	8 (63)	16 (80)	22 (81)	18(90)
- It is not helpful to speak to other parents		2 (3)	1 (8)	0	1 (4)	0 (0)
- Maybe it is helpful to speak to other parents		9 (11)	2 (15)	3 (15)	3 (11)	1 (5)
- Didn't answer if it is helpful to speak to other parents		4 (5)	1 (8)	1 (5)	1 (4)	1 (5)

**Table 2.** continued

Question	Clinicians [9] N = 18	All N = 80	Bereaved N = 13	Direct experience N = 20	Indirect experience N = 27	No experience N = 20
- Disabled children are happy		68 (85)	57 (85)	14 (70)	24 (89)	19 (95)
- Disabled children are not happy		5 (6)	5 (7)	4 (20)	0	1 (5)
- Unsure if disabled children are happy		6 (8)	4 (6)	1 (5)	3 (11)	0

Clinician Data reported in Reference [9].

IO Infant outcomes, PO Parent outcomes, PC Palliative care, IC Intensive care, QOL Quality of life.

it [termination] in between. Did I do a lot of research? Absolutely. I could describe the process; I could describe where to go. But I never mentioned it. So, I think he knew that at that point that was almost a desperation, almost a 'What other choice do I have?' and he didn't want me to make a decision based on that." (B) Several suggested the importance of support with someone other than the physician during deliberations: "a therapist" (D) or "a religious person" (N). Faith emerged as an influence on decisions, "Some people don't feel like there is any spiritual or religious ceremony, some people feel the need to pray about every decision they make" (D). Many mentioned the importance of hope, "(E)very case is different, but to give the mother some hope, if there is at all hope, then maybe perhaps bringing the numbers in at that point, towards the end" (D).

**Critical factors.** Participants agreed on some factors as critical to making decisions, such as infant best interests and chances of survival and disability (Table 2). They disagreed on others, such as other children in the family, finances, and parental interests. Participants were torn whether clinicians should discuss these, "(It) is the elephant in the room because you don't want to be judged based on these decisions" (D) and "you are assuming that they are relevant if you talk about them and I do not know if they are" (I). No participant wanted to delegate decisional authority entirely to clinicians, although they appreciated their guidance.

**Decisional regret.** Participants typically saw decisional regret as more likely with palliative care than with intensive care, even if the infant was disabled or died. "I would just regret if I didn't try everything to save my child" (D). Some linked regret with guilt, "It's more about guilt, less guilt if I tried intensive care" (D); with fear, "I think it's the fear of when you're about to make that decision." (D); or as inevitable: "I think no matter what you choose you are going to regret it... I think it's human nature for that to cross your mind at some point" (D). Two thirds of the clinician-experts mentioned parents experiencing decisional regret when intensive care led to a disabled infant; none mentioned regret about death after choosing palliative care [9].

Bereaved participants feared the infant's death more than making the wrong decision expressed as, "Having to leave the hospital without a baby" and "... in the moment it's definitely losing the child." (B). Most other participants saw it the other way around, "My gut instinct would be do whatever you can to save him.... But then I'd probably be torn, like am I being selfish by wanting to go that route? Is that more for me, is it for the baby..." (I).

**Peer support.** Many participants valued speaking with peers, "You can also know that other people also second guessed themselves..." (I). Bereaved parents saw value in meeting others who "somehow woke up every day and functioned" but emphasized the need for training peer supporters for this role. Few recognized the complexities of providing such peer support [13, 14], e.g., "no one's ever experienced exactly what I'm going to experience" (D); "Rationally, my answer would be, 'I would love to speak to you,' but emotionally I would say, 'Get lost.' And it's not fair to anyone." (D);

and "...so many outside opinions, it would just make it harder for [parents]" (I). The clinician-experts did not mention peer support.

## DISCUSSION

We conducted 80 interviews regarding decision-making for extremely premature infants, with individuals representing a range of personal experiences with prematurity. The length of the interviews revealed the depth and complexity of their thoughts and feelings. Transcripts were analyzed using a mental models approach, with a coding template derived from earlier interviews with clinician-experts [9] and emerging themes from descriptive content analysis [12]. We compared participants' perspectives with those of the clinician-experts and, secondarily, between participant groups.

The content of the interviews revealed diverse perspectives on how to approach consultation and decision-making, what information to share, how to convey it, and how to support deliberation. These results reinforce calls for consultations sensitive to patients' cognitive and social needs, rather than standardized approaches focused on information content [5, 15, 16]. Such tailoring will require eliciting individual patients' preferences early in the consultation process. The views of bereaved parents were sometimes different from the other groups, and in particular emphasized the critical role of relationships [12], suggesting ways in which consultations could support parents for the possibility of death, especially when delivery is threatened at the earliest gestational ages.

Participants' views on the consultation content generally agreed among groups and with the clinician-experts. However, there were notable exceptions. Many participants wanted statistics, whereas many clinician-experts' preferred providing less precise information [9], believing that numbers were hard to grasp [17–19] or overstated the precision of expert knowledge. Statistics, as a measure of uncertainty, could be used differently by parents and clinicians: for parents, it may guide decisions as seen with our participants while for clinicians it may be used to communicate 'uncertainty' [20]. Another difference was that most participants preferred receiving realistic information, whereas many clinician-experts' provided more pessimistic accounts, seeking to prepare parents for difficult outcomes [9]. Other studies have also reported parents' desire for balanced consultations [21]. Lastly, two thirds of the clinician-experts were more concerned about parental regret regarding disability than parental regret after choosing palliative care, whereas only one third of participants were. In this respect, participant views were closer to the experiences reported in the research literature than the clinician-experts [22–24].

Participants, especially those bereaved, also stressed the importance of social and emotional support in order to absorb the clinical information, a desire supported by findings from interventions providing such support after birth [13, 23] and studies of parents' evolving feelings [24]. These perspectives provide evidence supporting mental health recommendations for parents of sick neonates [25]. Recognizing the intensity of these

consultations and their emotions, many participants suggested clinical information be provided earlier.

Most participants saw value in speaking with parents who had been there. The roles of resource parents have broadened with time, including involvement in administration, clinical care, education, and research [13, 14]. However, such peer-to-peer support has not, to our knowledge, been part of antenatal consultation with extremely premature infants. That extension would have to overcome challenges in logistics, coordination, training, and precautions to ensure the wellbeing of resource parents [13]. Few of our parents mentioned these difficulties and potential risks. Whatever the solution, the need for interpersonal decision support *during* consultation was a recurrent theme in our participant interviews, but not in our clinician-expert interviews.

The diversity in participants' views on some topics, even within subgroups, reinforce the need for clinician insight, sensitive to parents' cognitive and emotional status. Clinicians might anticipate some of these patterns as consistent with the diversity of opinion among their own colleagues. Others might surprise them, such as the fears about decisional regret and views about what issues are important. In some cases, individual parents' concerns might emerge readily from conversation (e.g., infants' wellbeing); in other cases, they might be hidden (e.g., finances).

Our sub-groups were too small to confirm any differences between them. However, they do suggest some themes worth examining in future research, especially regarding differences related to the intensity of experience with extreme prematurity. Notably, the sometimes diverging views of bereaved parents suggest the need to provide all parents with information and support that only few may most urgently need. That support includes strong, compassionate alliances [12] found to reduce long-term parental distress from loss [26] and end-of-life decision-making [27]. One challenging aspect is that the numbers most parents want when making decisions can seem impersonal after the fact, when a child is lost [26].

Such differences in perspective related to personal experience pose a challenge to clinicians, who should attempt to protect parents from that *hindsight bias* and *outcome bias* that can afflict even wise decisions. Hindsight bias leads people to second-guess how well they could have predicted what would happen in inherently unpredictable situations [28]. Outcome bias leads people to judge their decision-making by the quality of the outcome, rather than by the quality of the deliberations – an impossible standard in situations where even the most thoughtful decision-making process cannot guarantee a desirable outcome [29].

Participants' suggestions were often consistent with research on reducing such bias. They wanted clear, realistic estimates of expected outcomes and the chance to work through possible future scenarios, thereby reducing the chance that any critical considerations have been missed. They suggested that parents share concerns explicitly with clinicians and others, thereby legitimating different perspectives. These deliberations may enable them to accept the legitimacy of decisional conflict and reduce regret over things that could not be controlled.

Our research has several limitations. One is using convenience sample of individuals willing to discuss these sensitive topics. While participants were diverse in some ways (Table 1), they are not representative of all parents. Our references to the frequency of perspectives among participant groups are suggestive, awaiting future research. Second, the broad range of our interviews meant that they paid relatively little attention to the statistics and structured utility elicitation, central to some decision aids [30]. Third, all interviews started with the same hypothetical description. Although it was designed to be broadly evocative, neutral, and non-judgmental, we cannot know how differently participants would have responded to other scenarios or none at all. Lastly,

although our findings emphasize letting parents direct the consultative approach, we cannot assess whether parents have the insight or emotional fortitude in the moment to reflect on how to approach the consultation prospectively nor how this approach would affect their experience with the consultation.

## CONCLUSION

According to the American Academy of Pediatrics, effective communication addresses both cognitive and affective needs [31]. Yet, standardized consultation scripts suggest approaches that often work when deliberative processes follow rational models without much attention to affective needs. The tone and content of those scripts will not meet the needs of all parents. Our interviews show ways to tailor their consultations early, providing robust, personalized support for these fateful decisions, made under challenging conditions.

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## AUTHOR CONTRIBUTIONS

All authors participated equally in the following: 1- conceived and designed the work that led to the submission, acquired data, and played an important role in interpreting the results 2- Drafted or revised the manuscript. 3- Approved the final version. 4- Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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## COMPETING INTERESTS

The authors declare no competing interests.

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