Voices of experience: what Dutch parents teach us about values and intuition in periviable decisions

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Voices of experience: what Dutch parents teach us about values and intuition in periviable decisions

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ABSTRACT

Objective When extremely premature birth at the limits of viability is imminent, shared decision-making with parents regarding the infant's treatment is widely recommended. Aligning decisions with parental values can be challenging. So, this study aims to get insight into (1) what values parents considered important in their decision, (2) whether their decision was based on intuition and/or rational analysis and (3) parental suggestions on how to help explore and articulate values during prenatal counselling.

Design A qualitative study was performed among Dutch parents who experienced (imminent) extremely premature birth. Diversity was aimed for through purposive sampling. Semistructured interviews were conducted until saturation was achieved. Transcripts were coded and themes were derived from the data.

Results Nineteen interviews were performed. Results show what parents considered important in their decision, such as the infants' future, family life and 'giving a chance'. Most parents made their decision more intuitively rather than rationally, for others both coexisted. Particularly fathers and parents who opted for palliative comfort care experienced the decision as rational. Parents would have liked to explore values, but found it challenging. They suggested strategies and conditions to help explore and articulate their values during counselling, such as a multidisciplinary approach.

Conclusions Various considerations and underlying values were found to be important. Parents recognise the influence of emotions and intuition in decision-making and struggle to articulate their values, emphasising the need for guidance. Healthcare providers should engage in open, personalised discussions to facilitate value exploration, enabling informed decisions aligned with parental values.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Parental preferences play a crucial role in decision-making about periviable care, but practical challenges, such as multi-interpretability and the influence of intuition, can complicate this process. Value clarification can facilitate aligning decisions with personal values. However, the clarification of values appears to be challenging for healthcare providers.

WHAT THIS STUDY ADDS

⇒ Parents considered various values, recognising a role for intuition in periviable decision-making. The importance of exploring values was emphasised and an active role for parents in this process is wanted. Some strategies to help parents formulate their values during counselling are suggested.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study describes a variety of values playing a role in decisions and shows how further exploration of values can help better understand what was meant by them. This may encourage healthcare professionals to further explore what is important to parents in the decision-making process at the limits of viability. Furthermore, our study shows that parents view periviable decisions as both rational and intuitive, recognising the importance and challenges of exploring their values, desiring an active role for themselves. Suggestions on how to help formulate their values are given and could be implemented in clinical practice. Further research could further explore the role of intuition in periviable decisions.

BACKGROUND

Complex prenatal decisions arise when extremely premature birth is imminent between 22+0 and 26+0 weeks of gestation.[1] In this period, of which the exact application varies between countries and institutions, roughly two treatment options exist: early intensive care (EIC) treatment or palliative comfort care (PCC).[2] Initiating EIC treatment results in great prognostic uncertainty; some infants will not survive and others will survive with or without morbidities.[3] Since there is no 'best decision', most guidelines recommend a shared decision-making (SDM) approach involving parental values.[4 5]

Within the context of SDM in case of extremely premature birth, value clarification can help in aligning a medical treatment decision with parental goals and circumstances.[6 7] It is essential to explore and incorporate the preferences and values of parents to guide their decision.[7] Studies have shown a variety of parental values playing a role in prenatal decision-making; values regarding quality of life (QoL), spirituality, religion or the perception of the infant's suffering are examples of values that could be essential to parents.[8 9] However, some of these values (eg, 'giving a chance') are multi-interpretable or require further exploration.[8] Additionally, parents commonly experience emotions such as

Table 1 Demographic information

Characteristics of interviewed parents	
Place of interview	
Home	11
Hospital	2
Online	6
Interview with	
Mother	12
Mother and father	7
Total parents interviewed	26
Highest education of the interviewed parents	
Secondary school	1
Secondary vocational education	10
Higher professional education	10
University education	5
Religion	
No religion	20
Christian	6
Experience with extreme premature birth between gestational age (GA) 24+0 and 26+0 weeks (n=21)	
>1 extremely premature birth between GA 24+0 and 26+0	
Yes	2
No	17
Year of experience with extreme premature birth(s)	
2009–2013	6
2014–2018	8
2019–2023	7
GA at which extremely premature birth first threatened	
<23+0	2
23+0 to 23+5	5
24+0 to 24+6	8
25+0 to 25+6	4
>26+0 to <28+0	2
Birth between GA 24+0 and 26+0	
Yes	14
No, beyond 26+0	6
Other (extremely premature birth at GA 23+6)	1
Multiple birth	
Yes (twin)	7
No, singleton birth	14
Initial treatment decision between GA 24+0 and 26+0	
Intensive care treatment	17
Palliative comfort care	4
Outcome of the premature birth*	
Survivor(s) (including gemelli)	10
Deceased	7
Both outcomes (twin)	4
Self-reported consequences of extremely premature birth	
None	10
Any (retinopathy of prematurity, bronchopulmonary dysplasia, hearing loss, short bowel (necrotising enterocolitis), complex sensory processing, social-emotional problems, language development problems, tube feeding, motor developmental delay)	4

*The outcome of premature births is categorised as survivor, deceased or both, accounting for both singleton and multiple births. For instance, the survivor(s) outcome encompasses singletons who survived or multiple births where both children survived.

anxiety and grief when extremely premature birth is imminent, which may affect their decision.[10–12]

Clarifying values appears to be challenging for healthcare providers (HCPs).[9 13 14] Understanding of values and the role of intuition in decision-making at the limit of viability is crucial for providing personalised counselling and further improving SDM.[15] This study aims to explore what parents considered important when faced with an imminent extremely premature birth, whether they relied on their intuition during this decision and how they think value clarification should be performed. With these insights, counselling may be improved contributing to more value-congruent decisions.

METHODS

Study setting and design

This qualitative research is part of the Dutch study called Toward INdividualized care for the Youngest (TINY), including qualitative research with extremely prematurely born adults (TINY-1) and experienced parents (TINY-2) to explore periviability guidelines, personalisation and parental values in the grey zone. In the Netherlands, the gestational age (GA) period of 24–26 weeks is considered the grey zone allowing both EIC treatment and PCC.[16] This article presents the TINY-2 results on parental values in prenatal decision-making. A more detailed description of the method with the Consolidated Criteria for Reporting Qualitative Research checklist is provided in online supplemental appendix I.

A Castor database was developed including parents who either had experienced an imminent extremely premature birth <26 weeks of GA but gave birth beyond 26 weeks, or if they were parents of an extremely prematurely born infant born between 23 and 26 weeks of GA. All parents in the database were invited to fill out a brief online questionnaire enabling purposive sampling to select a diverse group of participants (eg, both PCC and EIC decisions, parents of survivors and non-survivors).

Based on literature and the research team's expertise, an interview guide was developed.[8] Two researchers conducted the interviews and were performed until thematic saturation was reached. Interviews were recorded, transcribed verbatim and analysed independently by two researchers (AdB, LDP) using thematic content analysis. The codebook (online supplemental appendix II) and analysis underwent several rounds of discussion and revision until all authors reached consensus. Results are presented in themes with subthemes, supported by illustrative quotations along with the corresponding interview number and treatment decision.

RESULTS

Characteristics of participants

Nineteen out of 63 parents from the TINY database were selected to participate. Semistructured interviews were conducted between September 2022 and April 2023 with either the mother (n=12) or with two parents (n=7) (table 1). The participants experienced imminent extremely premature births between 23+6 and 26+2 weeks of GA. In four cases, PCC was chosen, while EIC was initiated in the remaining cases.

Results are represented in three sections corresponding with the interview questions.

Parental considerations and values at the limit of viability

Several considerations and underlying values were described related to parental decision-making. In general, parents struggled with the uncertainty of their infant's prognosis; '*one moment you decide to go left, two days later you decide to go right*' (19, PCC). Themes that emerged were 'the future of the infant', 'family life', 'everything done', 'to give a chance', 'trust', 'existing knowledge and experience', 'desire to have children' and 'hope'.

Future of the infant

An important theme was the infant's future, encompassing (1) statistics about chances, (2) the long-term consequences and (3) long-term QoL.

Some parents expressed the importance of the statistics on survival and the chance of a potential disability. They questioned how far they were willing to go for their infant to survive. As for other parents, the role of statistics about future chances was very limited, because at that moment '*that means nothing to you*'.

The infant's future QoL was also considered important by multiple parents, describing this as 'enjoyment', 'happiness' or the ability 'to be and act like others', such as 'play sports', 'have relationships' 'eat by yourself' and 'live independently'.

Quotes: 'Future of the infant'

'What you actually want to hear is if [your child] is going to make it or not? And, what [disabilities] she will have?'
Interview 16 (Early intensive care treatment)

'I imagined children in bed boxes and wheelchairs with tube feeding. And I thought: you would love them equally, but if you don't have to, you don't have to. She didn't have to survive at all costs.'
Interview 13 (Early intensive care treatment)

'He doesn't need to be the best at school, but he needs a place in society.'
Interview 14 (Early intensive care treatment)

Family life

The potential impact of an extremely premature birth on the family was also mentioned by parents. They thought about the implications for their own lives and their own happiness. In case of siblings in the family, they considered the impact of having an extremely premature infant on these siblings. As part of family life, practical factors like housing were discussed in terms of the possibility of adjustment to the house.

Quotes: 'Family life'

'There were two things that played a role: our child's happiness and our own happiness.'
Interview 7 (Early intensive care treatment)

'[When we heard all the chances], we also thought: we have a two-and-a-half year old child. (…) I want my baby, but I also have a family.'
Interview 17 (Palliative comfort care)

Everything done

Multiple parents were inclined to do everything possible to fight, often more driven by emotions than by rational arguments. However, one couple changed their reaction from 'do everything' to PCC after learning about the statistics.

Quotes: 'Everything done'

'We will do everything we can' changed to *'If we were to reach week 25+3, we would want to consider administering the lung maturation injections.'*
Interview 1 (Palliative comfort care)

To give a chance

Some parents wanted to give their child a chance and 'go for it', meaning a chance to have a normal life or the chance to survive. Parents found it acceptable to give their infant a chance when they were assured there would be no unnecessary suffering, but they indicated they might reconsider this if the treatment became disproportionate.

Quotes: 'To give a chance'

'I think that they really had a chance at a normal life, also because you heard about babies born at 25 weeks that did quite well. I would never forgive myself if I did not even try.'
Interview 3 (Early intensive care treatment)

'[We wanted to give] a chance for survival. That ultimately, you can bring one or two girls home alive.'
Interview 4 (Early intensive care treatment)

Trust

Parents also based their decision on trust in the doctor and in science. One father felt uncertain as the birth approached, but his uncertainty dissipated on the arrival of physicians with '*the expertise*'. Another couple mentioned they had trust in a good outcome.

Existing knowledge and experience

Some participants already had knowledge about extreme prematurity and its consequences, since they worked in healthcare (n=7) or had prior experience (n=3). The information about consequences was more concrete to them, which could make decision-making more difficult for parents, but also easier.

Quotes: 'Existing knowledge and experience'

'I work with children who have a disability, so I knew what could go wrong.'
Interview 8 (Early intensive care treatment)

'We already had a lot of information from our firstborn. That makes things more concrete, you know what can happen, what trajectory you're entering and about the daily fears during your stay [at the NICU]. That made things easier for us.'
Interview 17 (Palliative comfort care)

Desire to have children

The intrinsic desire to have children was discussed as important in the decision. Among our participants, some parents did not conceive naturally, or the pregnancy was unexpected, because they thought to be infertile. This history played a role in both decisions to initiate EIC or to opt for PCC.

Quotes: 'Desire to have children'

'Because we had a pretty tough time with the IVF process, (…) it was a real rollercoaster. And once you've come so far, we just felt like we wanted to take the chance even though that chance is so incredibly small.'
Interview 11 (Early intensive care treatment)

'We got pregnant through IVF. So, for the second pregnancy, we thought about how far we wanted to go, knowing the risk of premature birth. (…) Nobody can guarantee you that everything is going to be okay.'
Interview 17 (Palliative comfort care)

Hope

Lastly, hope that it would go well for their infant was mentioned by some parents. One father described it to be natural to draw hope from everything and to keep searching for some certainty that it would turn out well for your infant.

Intuition and rational

The majority of the parents experienced their decision-making as intuitive with a lot of feelings involved; '*You can provide statistics and chances, but I think most parents make the decision based on their feeling*' (4, EIC). Some parents experienced the decision as a combination of rational and intuition. They had some time to reflect on the information and balance their feelings and values. However, participants acknowledged that feelings and intuition might take over when there is no time to decide: '*You had to decide very quickly, so you could not turn your feelings off'* (7, EIC). Mainly the fathers indicated that they experienced the decision as rationally made: '*It was a risk, but a calculated risk*' (7, EIC), or mothers indicated that their partners approached the decision more rationally: '*I'm actually quite a sensitive person myself. My husband is a bit more rational*' (18, PCC). Furthermore, parents who opted for PCC often expressed their decision as rational. Participants mentioned that it is essential for HCPs to look at individual's needs; to explicitly clarify values or listen to intuition and feelings.

Value clarification experiences

Value clarification may help in aligning decisions with values that are important to parents. However, many participants could not recall whether they discussed their values and considerations during counselling with the physician: '*Perhaps [having no memories of those moments is] simply because you were truly overwhelmed*' (10, EIC). Although parents would have liked to discuss their values and considerations during counselling, they felt it would not have changed their decision as they believed they had all the necessary information. However, it may provide them with a sense of making a more informed and carefully considered decision.

To help parents formulate and discuss their values, they suggested to have a conversation with questions like: '*Let's see what you find important in life, or what you want for you child*' (1, PCC), and help them with their values: '*Ask the parents a couple of questions which will give parents an idea of values to consider/think about*' (5, EIC). Parents expressed concerns that this should not feel like '*an interview*' or '*the need to defend yourself*'. A more multidisciplinary approach was most frequently suggested. They suggested to include nurses, psychologists or social workers because parents thought physicians were

Box 1 What parents teach us about how to help them explore and formulate values

(1) Suggested strategies to explore and formulate values

(a) Personalisation: Personalise, address parents' needs and adapt the conversation to those needs. Take into account that there will be parents who do not feel the need to discuss their values or what they consider important in the decision at the limit of viability.
'*How can I help you to make this decision?*'

(b) Examine: Assess whether parents understood everything about what will happen and what is ahead of them when their child is born extremely premature.

(c) Questions: Ask parents questions after an introduction with information about considering values in this decision. Examples mentioned:
'*What are values that you consider important in life?*'
'*What do you consider important in life?*'
'*What do you consider important for your child?*'

(d) Examples: Discuss examples of values that parents could consider in their decision at the limit of viability.

(e) Decision aid: A decision aid designed to explore values or preferences for their infant's future should be designed and/or incorporated into existing decision aids. It should contain questions and examples to assist parents in exploring and articulating their values.

(f) Potential later decision moments: Inform parents that additional decision moments may follow later. Explain to parents that in case of future complications, intensive care treatment may not be in the best interest of their child anymore, and treatment can be withdrawn.

(g) Prepare during (high-risk) pregnancy: Preparation during regular checks by the midwife/gynaecologist, especially for the group of pregnant persons with a high-risk pregnancy. Not in an overwhelming manner but, for example, with a brochure. So, if you prefer not to read about the possibility of extremely premature birth and the decision at the limit of viability, that would be an option. The choice would be up to the person.

(2) Suggested conditions to facilitate the exploration and formulation of values

(a) Communication/give unbiased information
⇒ Create the environment for an open and honest conversation.
⇒ Take parents seriously.
⇒ Information provision in a friendly manner.
⇒ Information provision in clear, understandable language.

(b) Decision making
⇒ Ensure that the pregnant person is with another person to hear all the information.
⇒ Give the parent(s) some time to think about it, adjusted to each individual situation.
⇒ If possible, a second or third counselling session.

(c) Make it multidisciplinary with the right professionals
⇒ The presence of a neonatal intensive care unit (NICU) nurse.
⇒ The presence of a psychologist.
⇒ The presence of a social worker.

not necessarily trained to talk about values. Support should be offered for making a decision, without aiming in a certain direction. In box 1, all strategies suggested by parents are recorded.

DISCUSSION

This study aimed to explore parental values during treatment decisions at the limit of viability, the role of intuition and suggestions to help parents formulate values. Several notable findings emerged from our results.

Considerations and values of included parents mostly revolved around the infants' future and the impact on their family, consistent with prior studies.[17 18] Unlike international literature, religion and spirituality were not mentioned by our participants, potentially reflecting differing cultural values.[19] A recent review about common values considered important at the limit of viability showed the complexity and multilayered nature of values. Some values reflect on process preferences, such as the desire to do everything possible, while other values reflect on feelings or intuitions.[8] Our findings demonstrate that probing parents about their considerations could specify the meaning of underlying values and their impact on decisions. For example, by exploring various personal interpretations of QoL, we uncovered what parents aspired for their child's QoL, and how this can shape their decision. Additionally, values should be explored without assumptions or biases. Among our participants, the desire to have children supported both EIC and PCC decisions. This emphasises the variability in how a certain value can lead to different decisions, highlighting the importance of avoiding assumptions about an eventual decision. HCPs should explore parental values further to understand and align parental values into value-congruent decisions.

Participants acknowledged both the intuitive and rational aspects of decision-making, with more emphasis on intuition and gut feeling. This emphasis was even more pronounced when time was limited. However, particularly fathers and parents who opted for PCC emphasised the rational aspect of the decision-making process. Existing literature discusses that individuals can differ in their approach to decision-making, with some leaning towards a rational approach, analysing data and considering pros and cons, while others embrace an intuitive decision-making style, relying on gut feelings and instincts.[20] Intuitive and rational decisions at the limit of viability have not been described explicitly yet. Some research suggests that decisions are best made through analytical reasoning, and feelings interfere with good, rational decision-making.[21] Other research suggests that intuition may be surprisingly accurate by integrating existing values into decisions, because it can be based on an implicit integration of a large amount of information and may play a pivotal role in shaping preferences.[21 22] Our participants perceived their decision to opt for PCC as rational, a perception that may imply a sense of counterintuitiveness associated with palliative care decisions, because it goes against what parents instinctively want: a living child. Our results further underscore that intuition and rationality can coexist or even be intertwined and dependent on each other. Rationality can be used to gather and analyse information, while intuition helps with judgement and interpretation of this information.[23] Yet, gently challenging the initial preference to check whether it is stable or not may improve how parents feel about the decision in the long run.[14]

Lastly, our study offers beneficial suggestions to help explore values during prenatal decision-making. By exploring values, a treatment decision can be aligned with personal goals and circumstances.[23] Despite its acknowledged importance, several studies show this is not always practised.[13] Our results underscore this trend, with parents expressing a lack of recall regarding discussing their values during counselling. Generally, parents in this study acknowledged both the importance and challenges associated with exploring their values, expressing the wish for an active role for themselves in this process. They emphasised the need for HCPs to assist in articulating and constructing values for making decisions congruent with their values, as other experts suggested.[24 25] Although participants stressed the importance of an unbiased neutral approach, achieving this is challenging. Formulating values and preferences can be influenced by parents and HCPs' prior knowledge, bias and emotions.[24 26 27] HCPs might, inadvertently, influence the process by framing information due to their own values or bias.[24 28] Therefore, addressing those challenges is essential. Some of the participants' suggestions align with literature about VC strategies, including unbiased information, building a trustful patient–counsellor relationship, allowing extra time for parents to let them absorb information and promoting participation by empowering parents.[28–31] Newly suggested practical recommendations on how to initiate the conversation and conditions to facilitate the exploration of values are provided, such as adopting a multidisciplinary approach or preparing parents during pregnancy. Furthermore, literature suggests talking to a significant other or using value clarification exercises.[7 32] Not all parents may perceive the necessity of clarifying values in general, choosing not to engage in this process or do this independently. Therefore, HCPs should explore preferences in formulating values during SDM.

Strengths and limitations

This study has several strengths offering a unique perspective of experienced parents on the SDM process and explores beyond the existing literature in this topic area. Purposive sampling was used to select a diverse group of participants ensuring variations in experience with extremely premature birth and personal backgrounds. We achieved a broad selection of participants, increasing the external validity. Furthermore, the interdisciplinary nature of the research team contributes to the study's strength.

This study also has limitations. First, some findings of this study may be specific to the Dutch context and its societal values, which may limit their generalisability to other countries or healthcare systems. However, the overarching principles, such as the complexity of values, the need for probing deeper with follow-up questions and the role of intuition, derived from the study can still provide valuable guidance in diverse cultural contexts. Second, despite our efforts with purposive sampling, we faced challenges in recruiting parents with various religious and cultural backgrounds, members of the LGBTQIA+ community (Lesbian, Gay, Bi-sexual, Trans*, Queer, Inter*, Asexual and/or + indicating others within the community) and parents who opted for PCC. However, a described Dutch cohort shows the decision for PCC occurs much less frequently than active care (8% vs 92%).[33] Third, the results may be limited by recall bias worsened by the emotionally overwhelming situation that parents faced at that time.

CONCLUSION

Parents experienced a significant role of overwhelming emotions and a gut feeling in their decision, yet they acknowledge the importance of discussing values during counselling. However,

exploring and formulating these values is challenging for them, underscoring the need for assistance. Improving skills to help parents formulate their values and create conditions facilitating this process could lead to better understanding parental values.

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Contributors AdB took part in designing the study, collected the data through focus group interviews, carried out the initial analyses of the data and wrote the initial draft of the manuscript. LDP designed the study, collected the data, carried out the initial analyses together with AdB, and reviewed and revised the manuscript. MdV, MCdV and MH made a substantial contribution to the analyses and interpretation of the data by participating in the discussions about the data, and critically reviewed and revised the manuscript in multiple rounds of feedback. EJTV and RG conceptualised and designed the study, contributed to and supervised the analyses of the collected data, and critically reviewed and revised the manuscript. AdB was the guarantor of the overall content. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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