

Navigating periviability: insights from experienced parents on guidelines and personalization

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Objective

To investigate the views of experienced parents regarding guidelines for managing births and personalization at the limits of viability, the study examined four scenarios: (1) no guideline, (2) a guideline based on gestational age, (3) a guideline based on gestational age plus other factors, and (4) a guideline based on a calculated prognosis.

Methods

A semi-structured qualitative interview study in the Netherlands with parents who experienced (threatening) extreme premature birth between 23 and 26 weeks gestation.

Results

19 interviews were conducted between September 2022 and April 2023. 4 of the interviews were with parents who had opted for palliative care. All participants recognized the necessity of a periviability guideline because it could (a) provide decision-making support, (b) protect against parental instincts of saving, and (c) aid in coping. Parents emphasized the need for a guideline that considers more prognostic factors than solely gestational age, while not overwhelming them with excessive information; they believed that including more information did not necessarily make the decision-making process easier. Parents defined personalization as 'being seen and heard' and, in this regard, valued small gestures that showed empathy and sensitivity. They linked personalization at the limit of viability mostly to relationship-building with healthcare professionals and sensible communication, which were both considered crucial by parents for optimal care at the limit of viability.

Conclusion

This study identified some common denominators among parents who have had diverse experiences with premature birth. It underscores the significance of having a periviability guideline to aid parents in making decisions at the limit of viability. It is essential to consider the perspective of parents in future guideline development.