



Conversations about end-of-life decisions in neonatology: Do doctors and parents implement shared decision-making?

Shared decision-making in Neonatology

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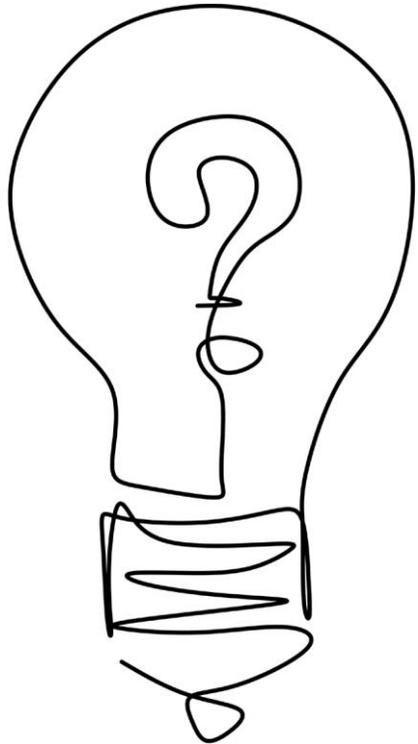
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Who should read the paper?



- Neonatologists
- Obstetricians
- NICU Nurses
- Psychologists
- Sociologists
- Medical Ethicists

What's it about?



To which extent is shared decision-making (SDM) implemented in the neonatal setting?

- Despite advances in perinatal medicine a number of newborns suffer acutely life-threatening illnesses
- A large proportion of these infants die following medical decision-making (MDM)
- International guidelines about end-of-life (EOL)-MDM for neonates recommend SDM
- SDM: joint deliberation and shared decision
- We do not know how SDM is realized in practice

Study design

Methodology: prospective qualitative study

Data acquisition: Parents-doctor conversations about EOL-MDM between 2018 and 2020

Setting: Level III neonatal intensive care unit from a German university hospital

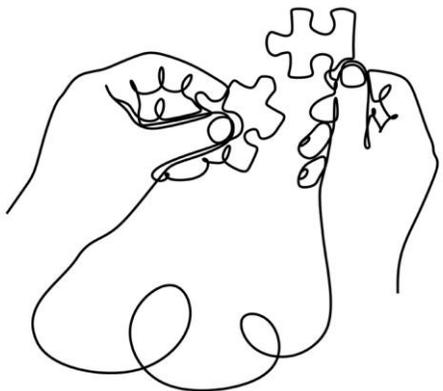
Participants: Parents of severely ill newborns and extremely premature infants

Data analysis: Qualitative content analysis according to a adapted SDM framework from de Vos et al.

What did the
researchers
do?



What did the researchers find out?

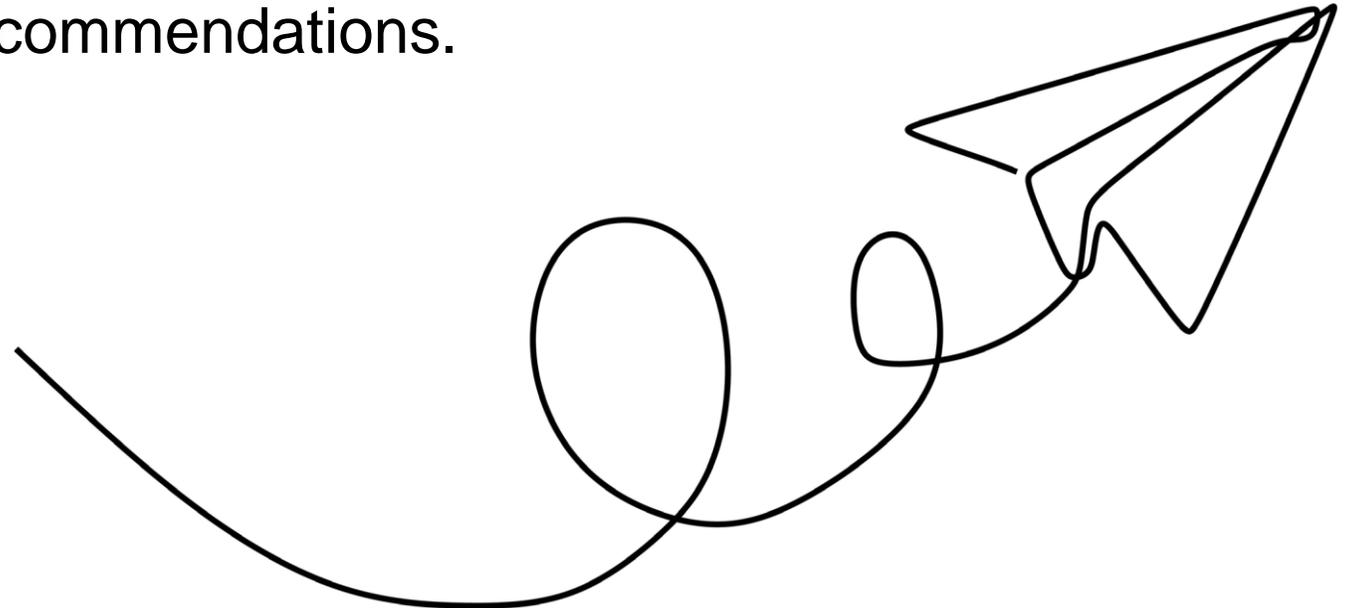


Results of the study

- SDM was adopted but only to a small extent in neonatal end-of-life decision-making conversations.
- The extent of sharing decreased considerably over the stages of SDM and among cases.
 - Low extend of shared deliberation and consented decision-making compared to high extend of information exchange
- Many neonatologists appeared to use a double bind communication in which they suggested to find a decision together with parents, while at the same time seeking parents' agreement to forgo life sustaining therapy.

How can the results be used?

- Different parents may prefer different roles in EOL-MDM, and the need for implementation of SDM to the full extent as suggested in the guidelines may need to be critically re-assessed.
- Specific research with the neonatal staff and parents could provide insights to understand why the approach in this NICU differs from the recommendations.



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