Parental experiences of decision-making in the grey zones of neonatal intensive care: a multi-centre, mixed methodology, phenomenological study.

Turley J[1,2], Jewitt N[3,4], Foo G[5], Kates Rose J[6,7], Stoopler M[3,4], Bartholomew B[1], Tomlinson C[3,4], Greenberg RA[3], Moore GP[6,7] and Prentice TM[8,9,10]

[1]Monash Children's Hospital, Clayton, Victoria, Australia, [2]The Royal Women's Hospital, Melbourne, Victoria, Australia , [3]Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada, [4]The Hospital for Sick Children, Toronto, Ontario, Canada, [5]Joan Kirner Women's and Children's Hospital, St Albans, Victoria, Australia, [6]University of Ottawa, Ottawa, Ontario, Canada, [7]Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada, [8]The Royal Children's Hospital, Melbourne, Victoria, Australia, [9]Murdoch Children's Research Institute, Melbourne, Victoria, Australia, [10]University of Melbourne, Melbourne, Victoria, Australia.

Background:
Decision-making in the neonatal intensive care unit (NICU) is complex. Diagnostic information is often in evolution and outcomes are difficult to predict, while parents are often distressed and exhausted[1]. Shared decision making (SDM) is a method that aims to produce decisions that reflect a family's beliefs, values and preferences[2]. SDM is generally accepted as best practice for decision-making in paediatrics, including at the end of life[3]. In grey zones, where there are multiple morally acceptable pathways, families and clinicians may disagree about the best plan. Little has been reported on families' experiences of SDM in grey zones, especially when clinician-parent disagreement occurs. While negative moral phenomena (NMP) such as moral distress (MoD) are well recognised in clinicians[4], little is known about these phenomena in parents.

Aims:
We sought to understand parental experiences of making decisions for their critically unwell infants in the NICU, including decision making at the end of life. Particularly, we sought to determine if parents experienced negative moral phenomena, such as moral distress during this process.

Methods
This was a mixed-methodology phenomenological study, using surveys across four tertiary or quaternary NICUs in Australia and Canada. Included were both open-ended questions with free-text responses and closed-ended questions with Likert scale or yes-no responses. Statistical analysis was applied to categorical data. Thematic analysis, using an iterative grounded theory approach[5] was applied to free-text data via a process of line-by-line coding and theme generation. Included were parents of infants admitted to NICUs between July 2018–August 2022 who engaged in decision making in grey zones. We sought descriptions of the parental experience of decision-making, and to determine if NMP occurred in parents.

Results:
71 parents (80% mothers) completed the survey. 80% were bereaved. Half of included infants were male, half had a primary diagnosis of a major congenial anomaly or syndrome, while 15% had a primary diagnosis of a prematurity-related complication; 12% a severe brain injury; 5% had sepsis and 19% were undifferentiated.

Thematic analysis revealed 5 themes: (1) decision burdens, (2) internal tensions, (3) actualising beliefs and values through decision making, (4) inauthentic shared decision-making and (5) external factors that shaped decision-making.

Parents reported variable experiences of shared decision-making (SDM). Despite decisions being described as burdensome, 89% wanted to be very involved in SDM, while 63% felt included. Actualisation of beliefs and values was important to parents, as they enacted parenthood through making decisions. Time pressures, competing interests, and environmental factors influenced internal tensions experienced by parents. Despite framing as SDM, some parents reported feeling coerced and experiences consistent with NMP.

Conclusions:
Parental experiences of SDM in the grey zones of the NICU are highly varied. Some parents do experience significant NMP during this process. Clinician awareness of parental NMP and their antecedents may enhance communication and the SDM process in this challenging setting.

References:

1. Lasiuk GC, Comeau T, Newburn-Cook C. Unexpected: an interpretive description of parental traumas associated with preterm birth. *BMC Pregnancy and Childbirth*. 2013;13(1):S13. doi:10.1186/1471-2393-13-S1-S13

2. Lantos JD. Ethical Problems in Decision Making in the Neonatal ICU. *New England Journal of Medicine*. 2018;379(19):1851-1860. doi:10.1056/NEJMra1801063

3. Sullivan A, Cummings C. Historical Perspectives: Shared Decision Making in the NICU. *NeoReviews*. 2020;21(4):e217-e225. doi:10.1542/neo.21-4-e217

4. Prentice TM, Janvier A, Gillam L, Donath S, Davis PG. Moral Distress in Neonatology. *Pediatrics*. 2021;148(2):e2020031864. doi:10.1542/peds.2020-031864

5. Strauss A, Corbin JM. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Sage Publications, Inc; 1990:270.