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ID 134. The perspective of European and North American parents on their involvement in shared end-of-life decision-making in neonatology: a meta-ethnography of qualitative studies

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Background: Medical societies recommend shared decision-making (SDM) for decisions to withhold or with aw life-sustaining therapy in neonatology. A uniform definition of SDM is ing. We aim to systematically examine and synthesize qualitative studies on the perspective of parents, to answer how SDM is realized in end-of-life decision-making in neonatology.

Methods: Qualitative Research Studies Synthesis. Systematic literature search in PubMed, PsycINFO and CINAHL, limited to qualitative interview studies since 1990 with parents who experienced conversations about end-of-life decision-making in neonatology. Quality appraisal was conducted according to Carroll et al.¹. Studies were translated and synthesized using Meta-ethnography².

Results: Seventeen studies from Europe and North America were identified. Eight studies reported on the perspective of parents on postnatal decisions to with aw life-sustaining therapy of NICU patients. We developed a model for the spectrum of parental involvement in shared end-of-life decision-making to translate the researchers' understanding of the parents' experiences and to explain heterogeneous theoretical frameworks and practical implementation of SDM. This model differentiates, if the values of the medical team, the values of the parents or if the shared values of both parties guide the process of SDM. The synthesis showed that SDM was used both as an umbrella term for nonspecific parental involvement in decision-making as well as a certain allocation of roles between the parents and the medical team. It revealed that European parents rather perceived parental-informed medical decision-making and North American parents mainly experienced medical-informed parental decision-making, at both ends of our spectrum. Parents seldomly perceived SDM, which is in the center of the spectrum.

Conclusion: This Meta-ethnography of qualitative studies shows that the recommendation of SDM for end-of-life decisions in neonatology is implemented differently in Europe and North America. The sociocultural context should be considered when interpreting different studies' results on the implementation of SDM.

1. Carroll, C. et al. Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qual. Health Res.* **22**, 1425–1434 (2012).

2. Cunningham, M. et al. Developing a reporting guideline to improve meta-ethnography in health research: the eMERGe mixed-methods study. *Heal. Serv. Deliv. Res.* **7**, 1–116 (2019).

No conflicts of interest.

ID 254. Nurses' attitudes and involvement in end-of-life decisions in Greek Neonatal Intensive Care Units: a national multicenter study

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Background: End-of-life (EoL) decision making for terminally ill neonates raises important legal and ethical issues. In Greece, no recent data are available on nurses' attitudes and participation in EoL decisions.

Objective: To investigate Greek neonatal nurses' attitudes and involvement in EoLs and the relation to their socio-demographic and work-related background data.

Material and Methods: The survey was carried out in 28 Neonatal Intensive Care Units (NICUs) in Greece between September 2018 and January 2019. A structured questionnaire was distributed by post, answered anonymously by 312 nurses (response rate, 71.1%), and returned to the investigators. The questionnaire included demographic and professional characteristics, involvement and opinions as well as an attitude question of 12 items measuring views on a scale 1 to 5, from value-of-life towards quality-of-life approach.

Results: Nurses more often reported involvement in various EoL decisions, such as continuation of treatment without adding further therapeutic interventions for terminally ill neonates, while less reported was mechanical ventilation with awal, and ug administration to end life. Nurses with a high attitude score, reflecting a more quality-of-life approach, were more likely to be involved in setting limits to intensive care. A low score was consistent with life preservation. Nurses' religiousness (p 0.097), parenthood (p 0.093), involvement in daily practice (p 0.03) and position on the existing legal framework (p<0.002) influenced their attitude score.

Conclusions: Variability in involvement in EoL decisions among nurses exists on a national level. The likelihood for nurses' views, supporting limiting interventions in neonates with poor prognosis in NICUs was strongly related to their attitudes. After adjusting for potential confounders, the most important predictors for nurses' attitudes were parenthood, involvement in daily practice and position supporting current legislation reform.

(ID 254) - Proportion of responses of nurses regarding involvement on EoLs

None

ID 275. Validation of DIGIROP decision support tool on a contemporary Swedish cohort

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Background: Retinopathy of prematurity (ROP) is a rare, sight-threatening disease diagnosed through repeated eye examinations. Recently we published a prediction model (DIGIROP-Birth) for ROP treatment based on ~7000 infants including only birth characteristics, and an extended model (DIGIROP-Screen) additionally incorporating ROP progression data. Based on the two models, a decision support tool was developed (www.digirob.com) to identify, at birth or during the screening process, low-risk infants not needing screening. The aim was to validate the decision support tool on a contemporary Swedish cohort.

Methods: This study includes 257 infants screened for ROP with gestational age (GA) <31 weeks (August 2018 to December 2020) from the Region Västra Götaland, Sweden. The predictors were GA at birth, sex, birth weight SDS, status and age when ROP was first diagnosed and important interactions. ROP treatment was the outcome. Sensitivity, specificity, and AUC with 95% CI were described.

Results: The mean GA was 27.5 (SD 2.2) weeks, birth weight 1044 (SD 366) g, 121 (47%) were girls, and 40 (16%) infants received ROP treatment. For DIGIROP-Birth, the AUC was 0.91 (95% CI 0.88–0.95); for DIGIROP-Screen, the AUC ranged between 0.91 and 0.96. The specificity was 46.1 (95% CI 39.3–53.0)%, and the sensitivity 95.0 (95% CI 83.1–99.4)% for the tool applied at birth, incorrectly flagging two severely ill babies, one with Bekk-Wiedemann syndrome, and one with intraventricular hemorrhage grade IV and hycocephalus treated with stage 3 zone III ROP. Applying the tool along the screening the achieved cumulative specificity ranged between 46.5% and 74.7% at week 6–14. Additionally two infants for whom the adequate ROP progression data was unavailable as a result of ing or incomplete examinations due to NEC or latrogen chylothorax were incorrectly flagged as not needing screening.

Conclusion: DIGIROP-Birth and DIGIROP-Screen showed high prediction ability in a Swedish contemporary validation cohort. The specificity corresponded to that obtained from the external validation in the original publication. All routinely screened infants requiring treatment, excluding those screened for clinical indication beside their immaturity, were correctly flagged as needing ROP screening. Further external validations of this decision support tool are recommended.

(ID 275) - Figure 1. Cumulative specificity (%) per gestational age (GA) at birth using a decision support tool based on DIGIROP-Birth and DIGIROP-Screen prediction models.

None declared.

ID 316. Assessing parental experience using emotional mapping following delivery room cuddle for babies born <30 weeks gestation

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Background: Imperial neonatal service has a strong culture of Family Integrated Care and supports parents to become partners in care from ad ion. Bonding is challenging for parents with a baby born prematurely. Visual and physical contact in the delivery room as a first cuddle potentially can help the bonding process and reduce the trauma of separation. Emotional mapping has been recognised as an effective tool to capture and share patient experience.

Methods: Our aim in this study was to assess parent experience by collecting qualitative feedback via emotional mapping following the delivery room cuddles for babies born <30 weeks' gestation. Semistructured interviews were performed with 6 mothers following consent via zoom or phone. AI Otter was used for transcription and interviewer checked correctness based on recordings.

Results: The positive and negative emotions and experiences were coded along the journey. This coding and in-depth analyses is currently undergoing via thematic analysis.

Conclusion: Mothers expressed different fears at the time of delivery, but all reported positive emotions about the cuddle with their baby, highlighting that the moments of this physical contact was the often the only positive and 'normal' birth experience they had from the time of delivery.

None declared.

ID 423. Parental experiences and staff views of visiting restrictions on a neonatal intensive care unit during COVID-19

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Background: The COVID-19 global pandemic posed significant implications for NICU parents and staff in terms of the visiting restrictions that were put in place during the first wave in March 2020. Therefore the NICU clinical psychology team in collaboration with the NICU nursing and medical team at the Rosie Hospital, Cambridge, endeavoured to explore the impact on parents, as well as the NICU staff's experiences of supporting parents throughout the visiting restrictions.

Methods: A bespoke survey was completed following the first COVID-19 lockdown to gather more information on the impact of change to visiting access on one level 3 NICU. One survey was completed by staff on NICU (N = 56). One survey was completed by parents of babies currently on NICU, or had a baby admitted to NICU whilst COVID-19 restrictions were in place (N = 50). One or both parents were offered to take part in the survey. Alongside relevant literature, the questions were developed in the context of initial observations of the impact of visiting access changes on families and staff.

Results: The findings of this study have illustrated the sheer extent of the restrictions on parental wellbeing and mood, with the restrictions having had an adverse effect on this. In addition, we show the extent of the adverse effect restricted visiting to NICU had on: babies' wellbeing, parent-infant bonding, partners wellbeing, parental confidence, the ability to breastfeed confidently and parents' access to the medical teams (see Table 1).

Conclusion: The findings of this study have a number of significant clinical implications for parents and staff on NICU. Namely, the data supported the decision not to close NICU again when cases of COVID-19 rose dramatically again over the winter of 2020–2021 and into the second and third waves. Furthermore, this study adds to a recent survey conducted by Fonfe et al. (2021), in which the authors argue that restricted visiting access in NICU could have harmful impacts on parents and babies (reference below).

Fonfe, A., Clements, D. & McKechnie, L. Parental access to neonatal units: inconsistency during the COVID-19 pandemic. *Infant 17* (2021).

Variable	Not at all % (n)	Not very much % (n)	Somewhat % (n)	Very Much % (n)	Extremely % (n)	Range between Somewhat, Very Much and Extremely (%)
Relationship with my baby	7 (2)	21 (6)	17 (5)	31** (9)	24 (7)	72
Partner meeting baby	31 (9)	3 (1)	21 (6)	10 (3)	34** (10)	65
Overall Wellbeing	7 (2)	3 (1)	17 (5)	28 (8)	45** (13)	90
Confidence in parenting reduced	7 (2)	17 (5)	31** (9)	21 (6)	24 (7)	76
Establishing breastfeeding	17 (4)	4 (1)	22 (5)	13 (3)	43** (10)	78
Impact on Mood	7 (2)	3 (1)	14 (4)	14 (4)	62** (18)	90
Anxiety	3 (1)	17 (5)	7 (2)	14 (4)	59** (17)	80
Wider Family's Emotional Wellbeing	3 (1)	10 (3)	17 (5)	24 (7)	45** (13)	86
Harder to communicate with NICU team	25 (7)	7 (2)	32** (9)	11 (3)	25 (7)	68
Harder to understand baby/ies health condition	10 (3)	10 (3)	33** (10)	20 (6)	27 (8)	80
Baby/ies wellbeing	10 (3)	30** (9)	23 (7)	20 (6)	17 (5)	60

** = Highest score in variable

(ID 423) - Table 1. Parent responses to survey

None declared.

ID 476. Identifying the extent of specific nursing developmental care interventions for preterm infants in the neonatal intensive care unit: a systematic scoping review

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Background: The concept of developmental care (DC) is a neuroprotective and family oriented care philosophy that ultimately intends to promote optimal health outcomes in preterm infants and their families in neonatal intensive care units (NICU). Nurses have a substantial contribution to the implementation of DC interventions in NICUs. However, the extent and the types of nursing interventions that are considered DC remain unclear. Thus, it appears important to scope the literature to identify key interventions implemented by neonatal nurses.

Aim: To scope the scientific literature to identify specific nursing interventions that have been associated with DC for preterm infants in the NICU.

Methods: A scoping review was conducted in accordance with The Joanna Briggs Institute methodology. Eight databases and grey literature sources were searched to scope the literature (i.e., research papers, literature reviews, text and opinion papers, practice guidelines and theoretical papers) on (1) DC interventions, (2) delivered by nurses, (3) targeting preterm infants and their families, (4) in a NICU setting, and (5) discussing at least one parental or infant clinical outcome. References were screened independently by two review authors using Covidence software. Data extracted from the included pieces of literature included the category of DC intervention and details as per the Description and Replication checklist (TIDieR).

Results: A total of 20,042 unique references were retrieved from the initial literature search and 789 were eligible for full-text review. After completing the screening process, 276 references were included. We were able to categorize the nursing interventions into eight DC categories including (1) sensory control, (2) sensory stimulation, (3) family-centered care, (4) positioning and handling; (5) sleep protection; (6) reduction and management of pain, (7) skin and routine care, and (8) feeding.

Conclusion: A gap in the literature remains as many nursing interventions that we identified (e.g., oral stimulation, live music) were not explicitly identified by authors as being DC, but still intended to some extent to promote neuroprotection and family involvement. Thus, results of this scoping review allow a better understanding of the specific interventions neonatal nurses can implement daily in order to optimize preterm infants' and families' outcomes.

None declared.

ID 481. Parental speech during neonatal intensive care: is it modified by skin-to-skin contact and holding?

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Background: Earlier research suggests that both parental speech and parent–infant skin-to-skin contact are important for the development of preterm infants. It has not been studied how skin-to-skin contact and holding modify parental speech in the context of neonatal intensive care unit. The aim of this study was to compare the amount of maternal and paternal speech in three distinct closeness conditions: (1) parent–infant skin-to-skin contact, (2) parent holding their infant, and (3) parent present in unit without skin-to-skin contact or holding.

Methods: The study included 85 very preterm infants born before 32 gestational weeks in Turku University Hospital, Finland, and in Tallinn Children's Hospital, Estonia, between 2017–2020. A total of 45 infants had Finnish-speaking parents, 38 infants had Estonian-speaking parents and 2 infants had both Finnish- and Estonian-speaking parents. Neonatal intensive care unit had single-family rooms in Turku and 2–4 infants per patient room in Tallinn. Sound environment of each preterm infant was recorded for 16 hours using LENA® audio recorder. During the recording, parents kept a closeness diary about their presence in unit, skin-to-skin contact and holding. Nurses marked their presence in infant's room. Adult speech was identified and quantified from the audio data using automatic tools. For each closeness condition, relative amount of maternal and paternal speech (%) was calculated as percentage of condition time.

Results: No statistically significant differences were observed in maternal or paternal speech between the closeness conditions in Turku (Fig. 1). In Tallinn, the relative amount of maternal speech was higher during skin-to-skin contact ($p < 0.001$) and holding ($p = 0.001$) in comparison to other presence in the unit, but no differences were found in paternal speech.

Conclusion: In general, skin-to-skin contact and holding do not seem to universally affect the amount of parental speech in the neonatal intensive care unit. The architecture in Tallinn could explain the finding of less maternal speech during presence without skin-to-skin contact or holding as mothers staying in the unit had an opportunity to rest outside the infant's room.

Alternatively, the intimacy of skin-to-skin contact and holding could encourage the mothers to talk more to their infants in the patient rooms for several patients.

(ID 481) - Fig. 1. Relative amount of maternal and paternal speech in distinct closeness conditions. Relative amount of speech is presented as speech per closeness time (%).

None declared.