



September 15th, 2021 08:30 - 10:30

## PARALLEL SESSION 5 - ESPR nursing and health care prof section

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 withdraw life-sustaining therapy in neonatology. A uniform definition of SDM is missing. 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.<sup>1</sup>. Studies were translated and synthesized using Meta-ethnography<sup>2</sup>.

### Results:

Seventeen studies from Europe and North America were identified. Eight studies reported on the perspective of parents on postnatal decisions to withdraw 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 EoLDs and the relation to their socio-demographic and work-related background data.

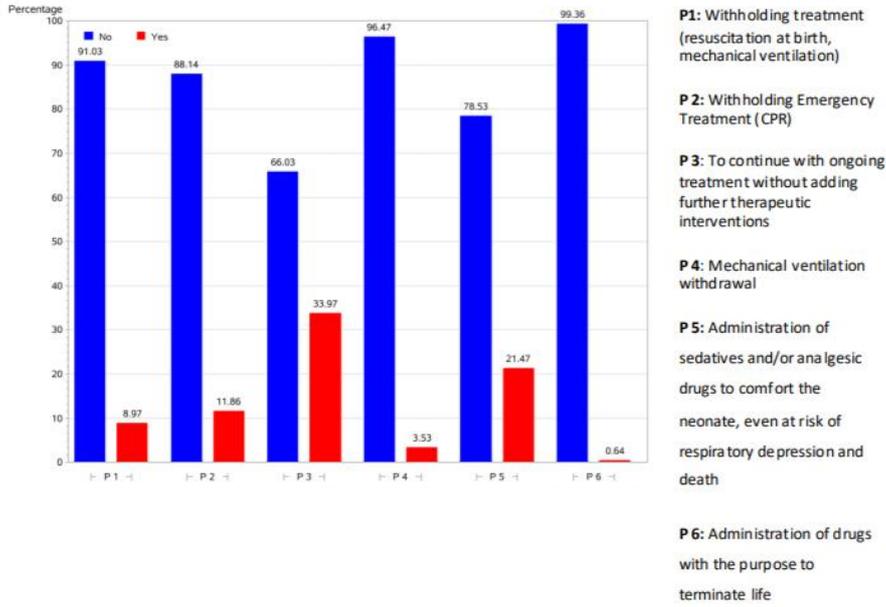
**Material and Methods:** The survey was carried out in 28 Neonatal Intensive Care Units (NICUs) in Greece between September 2018 and January 2019. A structured questionnaire was distributed by post, answered anonymously by 312 nurses (response rate, 71.1%), and returned to the investigators. The questionnaire 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 withdrawal, and drug 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.



**Figure 1:** Proportion of responses of nurses regarding involvement on EoLDs



Proportion of responses of nurses regarding involvement on EoLDs  
None



## 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.

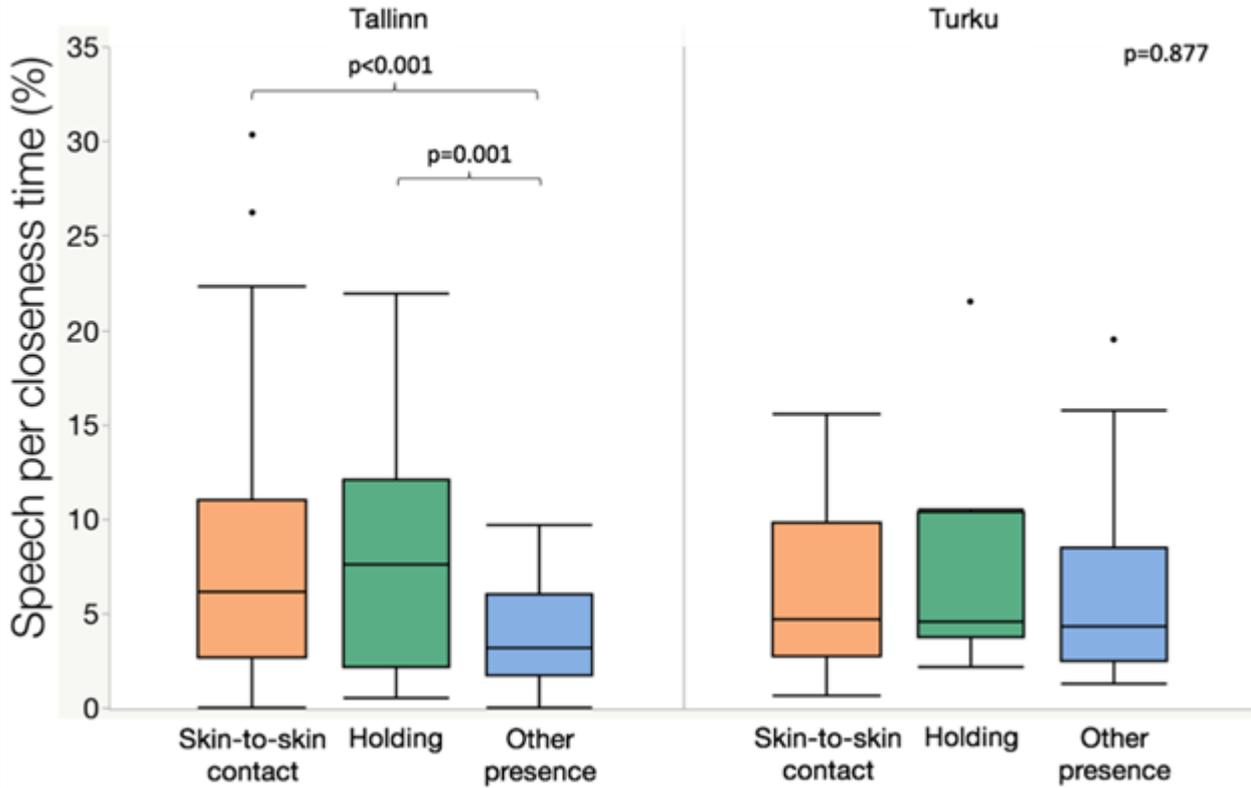
**METHODS:** The study included 85 very preterm infants born before 32 gestational weeks in Turku University Hospital, Finland, and in Tallinn Children's Hospital, Estonia, between 2017-2020. A total of 45 infants had Finnish-speaking parents, 38 infants had Estonian-speaking parents and 2 infants had 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<sup>®</sup> 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 (Figure 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.



### Maternal speech



### Paternal speech

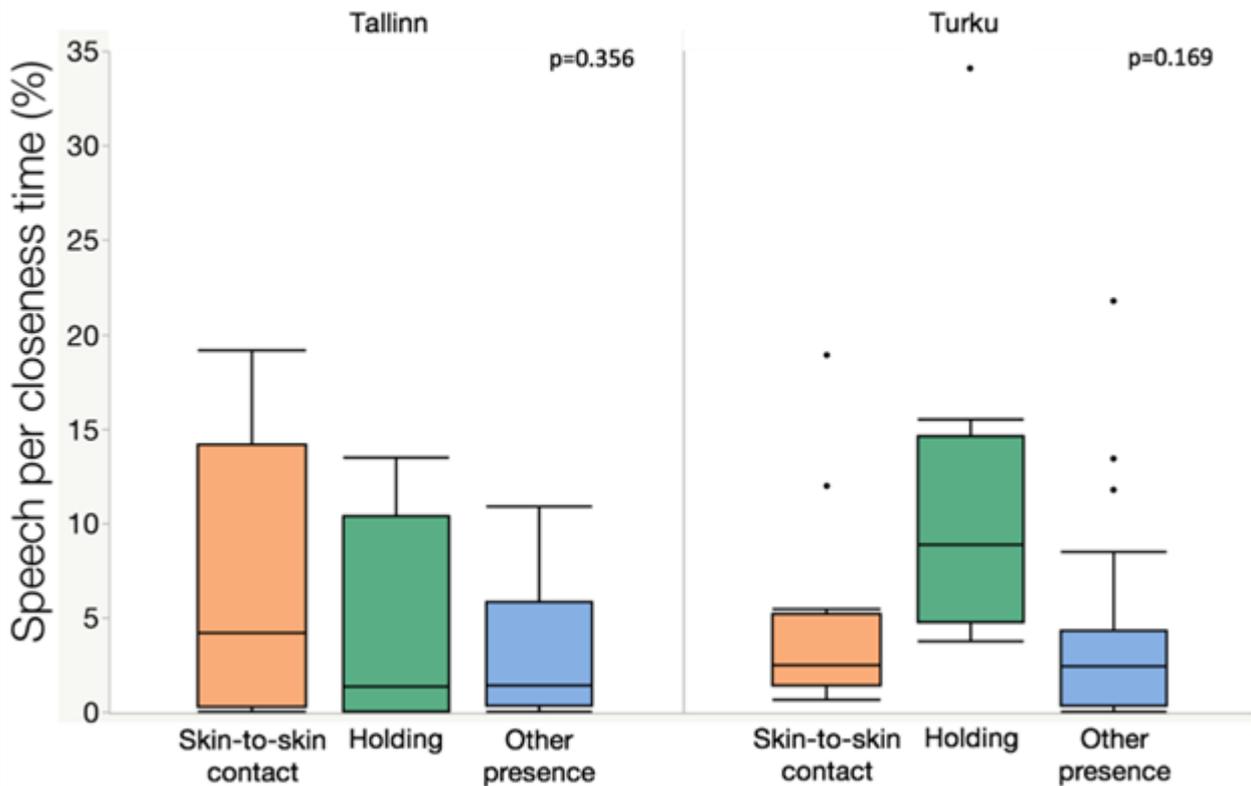




Figure 1. Relative amount of maternal and paternal speech in distinct closeness conditions. Relative amount of speech is presented as speech per closeness time (%).  
None declared



## 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 admission. 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. Semi structured 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