
Uncertainty in a Level IV NICU: The Parent Experience

Primary Author: Name: Erin Rholl, MD
Organization: Neonatology Fellow
Email: erholl@mcw.edu

Additional Authors: Krisjon Olson, PhD, MA; Joanne Lagatta, MD; Kathryn Malin, NNP-BC, APNP; Steven Leuthner, MD, MA

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Introduction: Parents of premature infants in a Neonatal Intensive Care Unit (NICU) experience feelings of uncertainty which have been described. The experience of uncertainty in the NICU has not been well defined for parents of infants in the NICU for reasons other than prematurity.

Hypothesis: The experience with medical uncertainty for parents of infants admitted to a NICU for reasons other than prematurity is multifactorial and not solely dependent on infant diagnosis.

Methods/design: Prospective qualitative study of parents of infants admitted to a NICU for >14 days, for reasons not exclusively related to prematurity. Purposeful sample was performed to include a range of diagnoses and demographics. Interviews occurred in person in private NICU rooms. Multi-investigator transcript coding and data collection continued until thematic saturation was reached.

Results: 49 Parents of 34 infants were interviewed from 06 – 12/2019. All 34 mothers participated, 15 fathers participated, 7 individually, resulting in 41 interviews with 44 hours of audio data. Parent demographics were diverse. 19 infants had prenatal diagnosis of which 78% were surgical conditions. Parents' expression of medical uncertainty fell within 5 areas: diagnosis, expected course, length of stay, long term outcome, and survival. The experience of medical uncertainty was mitigated by prenatal diagnosis, availability of surgical options, past experiences with financial and housing insecurity and strong social networks. Conversely, parents experiencing a postnatal diagnosis, perceived lack of care coordination, or whose infant had no surgical intervention expressed more medical uncertainty. Parents identified barriers to communication that might improve medical certainty including: complex rotating care teams and unclear leadership. Mothers, especially, then feel burdened with a perceived responsibility of care coordination. Parents' NICU experience was diverse and not solely driven by infant diagnosis/prognosis. Our qualitative data suggests that factors such as language, race, age, gender, and socioeconomic status may impact both parental goals and their experience of hospital treatment.

Conclusions: Parents' experience of medical uncertainty is not solely dependent on diagnosis/prognosis. Parents given prenatal diagnosis, a surgical intervention, social resource insecurities, or strong social network experience less medical uncertainty. Parents' experiences of uncertainty also reflect challenges of interdisciplinary collaboration.