

BACKGROUND

- NICU parents experience stress and depression affecting their wellbeing
- Parent distress and wellbeing is associated with medical uncertainty
- The preterm parent experience with uncertainty has been described
- The experience with uncertainty for parents of infants admitted to a NICU for reasons other than prematurity has not been well described

OBJECTIVE

- Describe the uncertainty experience of parents to infants admitted to a level IV NICU for reasons other than prematurity

METHODS

- Prospective qualitative study of parents to infants admitted to a level IV NICU for > 2 weeks
- Purposive sampling for a range of infant and family demographics
- In-person, semi-structured interviews
- Enrollment occurred until thematic saturation reached which occurred after interviewing 49 parents of 35 infants
- Multi-investigator transcript coding
- Thematic analysis of interviews

RESULTS

Infant Characteristics		N
Gestational Age	>37 WGA	11
	34-36 WGA	20
	28-33 WGA	4
Prenatal Diagnosis	Yes	19
	No	16
Surgical Diagnosis	Yes	18
	No	17
Medically Complex	Yes	14
	No	21

Table 1. Infant Characteristics

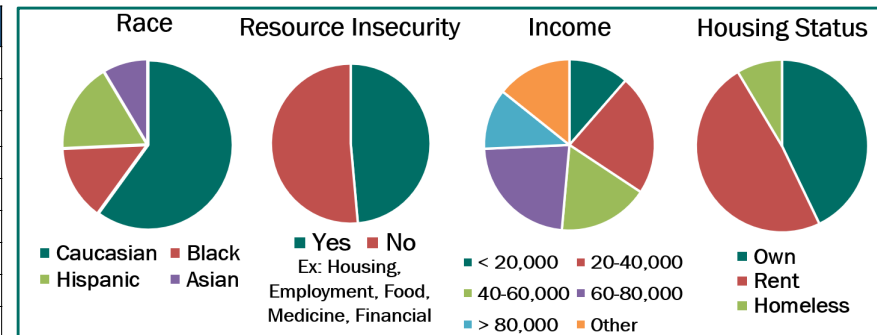


Figure 1. Family Demographics

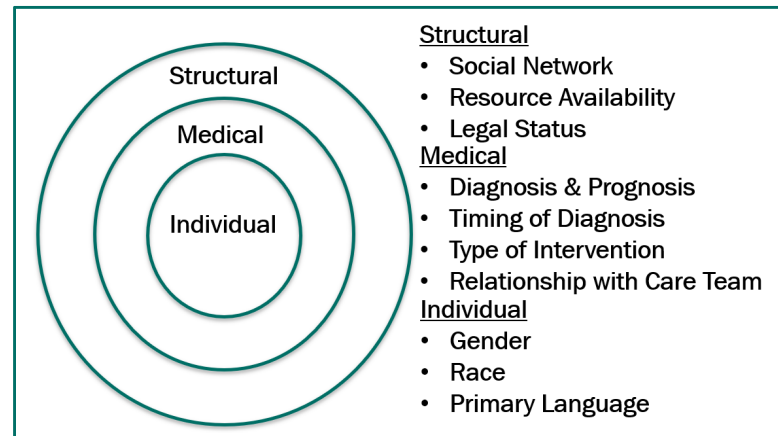


Figure 2. Structural Context of Parent Uncertainty

CONCLUSION

- Uncertainty experience was not driven solely by diagnosis and prognosis
- Structural, medical and individual factors shape parental perception of medical uncertainty

Example Uncertainty Aggravators:

- **Structural:** Temporary Legal Status
- **Medical:** Rotating Care Teams, Shifting Team Leadership
- **Individual:** Discrimination, Non-Native English Speaker

Example Uncertainty Buffers:

- **Structural:** Strong Social Network, Chronic Resource Insecurity
- **Medical:** Prenatal Diagnosis, Surgical Intervention
- **Individual:** Prior Parent Experience

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