

AAP DISTRICT VIII SECTION ON NEONATAL PERINATAL MEDICINE

**2021 ANNUAL CONFERENCE ORIGINAL RESEARCH (BASIC SCIENCE or CLINICAL)
ABSTRACT SUBMISSION FORM**

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If yes, type and year of training _____

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Signature: Stephanie Bourque Date: 3/8/2021

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DEADLINE FOR RECEIPT OF ABSTRACT IS FEBRUARY 19, 2021. Submissions will be accepted for either poster or oral presentation. Authors will be notified of acceptance and format for presentation (poster or poster symposium) by **March 12, 2021.**

Title: Understanding the Parental Experience: Geographic Disparities and Prolonged NICU Hospitalization of VLBW Infants

Authors: Stephanie L Bourque, MD, MSCS, Venice N Williams, MPH, PhD, Jessica Scott, MA, Sunah S. Hwang, MD, MPH, PhD

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Background:

Prematurity affects over 10% of all births in the United States, often resulting in a prolonged birth hospitalization in the neonatal intensive care unit (NICU). Parents of preterm infants experience multiple stressors during this period, many of which act as barriers to parental engagement during the birth hospitalization. Little is known about the lived experience for families who live at great distance from the hospital, of specific relevance for regions in the U.S. where distance travelled from primary residence to the hospital is high. We sought to evaluate barriers and facilitators to engagement for parents who live ≥ 50 miles from the hospital and whose preterm infants was experiencing a prolonged birth hospitalization.

Methods:

This qualitative study used an adapted grounded theory approach to examine the impact of distance from home to hospital on a prolonged birth hospitalization via semi-structured interviews. Inclusion criteria included biologic or adoptive parents of infants born at ≤ 32 weeks gestation and admitted to the NICU whose primary residence was located ≥ 50 miles from the hospital. Participants were recruited from a single regional level IV NICU, which serves a broad multi-state catchment area for the Rocky Mountain region. The unit has a total of 84 beds and admits an average of 1350 infants each year. Recruitment for enrollment was conducted consecutively with each eligible family being approached for consent. We adapted a socio-ecological conceptual framework to inform a semi-structured interview guide and data analysis. 16 families were eligible for the study, of which 13 participated in a research interview. Recorded interviews were conducted by a qualitative researcher not involved in the infant's clinical care. Interviews were transcribed and validated. Multiple coders analyzed the data in NVivo 12 using thematic analysis consistent with grounded theory. We allowed themes to emerge from the data and wrote memos to synthesize findings into broader concepts within the adapted socio-ecological conceptual framework.

Results:

Among the 13 participants interviewed, the average distance from home to hospital was 284 miles (range 51-1643 miles), 77% (n=10) lived in state, 23% (n=3) lived in a rural county, 46% (n=6) had other dependents at home and 46% (n=6) had infants who were outborn. We identified the following themes within the socio-ecological conceptual framework. At the individual level, maternal mental health, preparedness for delivery, presence of other dependents and technical and emotional readiness for discharge were apparent. For environmental factors, relationships and communication with the medical team and ancillary staff, presence of in-hospital and community support, and access to technology impacted parental engagement. For societal factors, presence or absence of paid parental leave, accessibility of post-discharge early intervention services and the widespread impact of COVID-19 were noted.

Conclusion:

There is limited literature exploring the geographic disparities that parents of very preterm infants face during a prolonged birth hospitalization. This study contributes to the understanding of these lived experiences and identifies several contributing individual, hospital, and societal level factors. These findings may help to identify strategies to reduce geographic disparities and optimize parental engagement during a prolonged birth hospitalization for this population.