Improving family-centered care through greater understanding: A qualitative study of family experience with hospitalization for Neonatal Abstinence Syndrome

Dartmouth-Hitchcock, Children's Hospital at Dartmouth, Geisel School of Medicine at Dartmouth; Hanover and Lebanon, NH, USA

Emily Carson; Erica Hsu; Grace Sollender; Christine Arsnow, MD; Victoria Flanagan, RN, MS; Erin Swasey, MSW; Joanna Celenza, MA, MBA; Bonny Whalen, MD; Alison V. Holmes, MD, MPH

Primary author contact name: Bonny Whalen, MD bonny.l.whalen@hitchcock.org 603-653-6081

Background: The incidence of Neonatal Abstinence Syndrome (NAS) in the U.S. tripled between 2000 and 2009, yet little remains known about the family perspective on the often-lengthy newborn hospital stay.

Aim: To elucidate common experiences faced by families of newborns undergoing pharmacologic treatment for NAS through 20 semi-structured qualitative interviews, and to use this understanding to improve future family-centered care during the newborn hospitalization for NAS.

Setting: We conducted interviews in a 390-bed acute care hospital in rural northern New England, which also houses the state’s only full-service children’s hospital. Approximately 60 of the 1,200 newborns delivered annually are at risk for NAS, which represents a significant increase over the last decade.

Mechanisms: As preparatory work for our involvement in the VON iNICQ 2013-2014 NAS Quality Improvement Collaborative, we sought to further our understanding of the family perspective on NAS through qualitative interviews. Qualitative approaches are used when the medical team perspective is likely different from the population undergoing the intervention. We chose this method since a deeper, more nuanced understanding of family perspective was critical to any improvement effort; we felt all efforts to enhance family-centered care would fall short without first understanding families’ experiences in an honest, detailed way.

Methods: A multi-disciplinary team of physicians, nurse practitioners, nursing leaders, staff nurses, and social workers from three hospital units (mother-baby, ICN, and inpatient pediatrics), and a family representative, collaborated to write open-ended interview questions for families based on a literature review, clinical experiences with NAS, and an internal iterative process. Over a six-month period, a separate research team conducted in-person or telephone semi-structured interviews with 20 families of newborns with NAS just prior to or just after discharge from the hospital. The interviews were recorded and transcribed verbatim.

Measures: We identified and analyzed emergent themes with an inductive approach to qualitative analysis; two investigators coded each interview independently prior to arriving at consensus. We ceased recruiting for further interviews when we reached saturation of themes. The research team sorted the identified themes and categorized them into domains via an iterative process that required the consensus of four team members.

Results: We discovered 5 domains comprised of 15 themes that families identified as key:

1. Education and preparation: Families desire organized prenatal and postnatal education about the course of NAS, pharmacologic and non-pharmacologic therapies, and modified Finnegan scoring.
2. Partners in care: Parents value their role as part of the infant’s care team, such as involvement in scoring, rooming-in, and breastfeeding. Parents also recognize their own emotions, including guilt, disappointment, and fear, and the role these emotions have on their hospital experience.
3. Interpersonal interactions and communication: Support from staff, or lack thereof, plays a key role in the hospital experience, as does communication from staff regarding the newborn’s clinical course.
4. Hospital environment and transitions: Families’ experiences are greatly affected by transfers between units, transitions of care, and associated inconsistencies among providers.
5. External factors: Factors outside the hospital, such as parental drug use and recovery, economic limitations, and family and community supports influence family perspectives during the hospital stay.

Discussion: Families face myriad challenges during their infant’s hospitalization for NAS. Addressing parental concerns and needs by improving perinatal education, increasing involvement in the infant’s care team, providing consistent care and communication, and minimizing transitions in care could improve the family hospital experience. The results of this qualitative study have been used to develop PDSA cycles for quality improvement in our institution, including interventions to improve scoring consistency across units and providers, minimize interruption to babies and families, and maximize family participation in care through rooming-in and improved provider-family communication.