

A Qualitative Study of Family Experience With Hospitalization for Neonatal Abstinence Syndrome

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BACKGROUND AND OBJECTIVES: Although the incidence of neonatal abstinence syndrome (NAS) in the United States quintupled between 2000 and 2012, little is known about the family perspective of the hospital stay. We interviewed families to understand their experiences during the newborn hospitalization for NAS and to improve family-centered care.

METHODS: A multidisciplinary team from 3 hospital units composed open-ended interview questions based on a literature review, clinical experience, and an internal iterative process. Trained investigators conducted semi-structured interviews with 20 families of newborns with NAS at hospital discharge. Interviews were recorded and transcribed verbatim. Two investigators independently analyzed each transcript, identified themes via an inductive qualitative approach, and reached a consensus on each code. The research team sorted the themes into broader domains through an iterative process that required consensus of 4 team members.

RESULTS: Five domains of family experience were identified: parents' desire for education about the course and treatment of NAS; parents valuing their role in the care team; quality of interactions with staff (supportive versus judgmental) and communication regarding clinical course; transfers between units and inconsistencies among providers; and external factors such as addiction recovery and economic limitations.

CONCLUSIONS: Families face many challenges during newborn hospitalization for NAS. Addressing parental needs through improved perinatal education, increased involvement in the care team, consistent care and communication, and minimized transitions in care could improve the NAS hospital experience. The results of this qualitative study may allow for improvements in family-centered care of infants with NAS.

ABSTRACT

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Neonatal abstinence syndrome (NAS) is a constellation of opioid withdrawal symptoms affecting the central and autonomic nervous systems and gastrointestinal tract that occurs in many newborns exposed to opioids in utero.¹ Withdrawal symptoms typically begin within 24 to 96 hours of birth and affect 49% to 94% of exposed newborns.²⁻⁴ Newborns with NAS can experience hospitalizations ranging from 2 to 12 weeks when pharmacologic treatment is required to control symptoms.⁵⁻⁷ Despite a 5-fold increase in incidence of NAS in the United States between 2000 and 2012, little is known about families' experiences with NAS during what is often a prolonged hospital stay.⁸

At our rural tertiary care center in northern New England, the regional rate of NAS is more than double the national average (13.7 vs 5.8 per 1000 hospital births), concordant with published data.^{9,9} In 2012, the average length of stay at our center for newborns with NAS requiring pharmacologic treatment was 17 days, and many families experienced multiple unit transfers (between mother–infant, NICU, and inpatient pediatrics) during the hospitalization. To determine whether families were dissatisfied with aspects of their care, and to use families' insights to guide quality improvement (QI) efforts, the aim of the present study was to better understand the family experience during the newborn hospitalization for NAS through a qualitative approach.

METHODS

Setting and Preparation

The Children's Hospital at Dartmouth–Hitchcock is a Children's Hospital Association member 63-bed/16-basinette hospital housed within a 396-bed academic medical center in rural northern New England. Approximately 5% of the 1200 newborns delivered annually have been exposed to opioids in utero. Affected newborns are observed for NAS for a minimum of 96 hours before discharge; morphine is used as pharmacologic treatment if infants demonstrate significant difficulties with NAS based on the modified Finnegan scoring system, a comprehensive tool commonly used to monitor NAS.¹⁰

During this study, newborns at risk for NAS initially roomed-in on the mother–infant unit. Newborns were transferred to the open-layout NICU if symptoms were severe enough to merit closer observation or initiation of pharmacotherapy. Once weaning on morphine therapy began, rooming-in could resume after a transfer to inpatient pediatrics. All morphine weaning occurred in the inpatient setting. The Dartmouth College Committee on the Protection of Human Subjects approved the study.

As part of the Vermont Oxford Network's NAS collaborative, which provided a QI curriculum for the nonprofit network's affiliated neonatal health professionals, we convened a work group in January 2013 to improve care of neonates and families affected by NAS. The team theorized that parents have unique insight into how hospital processes affect their infants (eg, variations in care that the medical team was unaware of or care routines that may worsen symptoms of NAS), which could then be used to design interventions in a QI project. A multidisciplinary team developed interview questions a priori through an iterative process informed by a literature review and team clinical experiences with NAS. The team modified and expanded questions further as interviews progressed. The final qualitative interview guide is illustrated in Table 1.

Data Collection

Between August 2013 and January 2014, families of newborns affected by NAS were identified through active surveillance by the unit charge nurses or social workers and were informed about the study. Families wishing to participate provided verbal informed consent to be interviewed by a research assistant. A team of research assistants, trained in qualitative interviewing techniques by 2 experts, conducted in-person or telephone semi-structured interviews with families shortly before or immediately after hospital discharge. The interviewers had not been part of the families' care team during the hospitalization. With parental permission, interviews were audio-recorded. Interviews began with general questions and covered many topics related to the hospital stay; the

interviews lasted 20 to 60 minutes. Parents were asked about staff interactions, breastfeeding, prenatal preparation, and unit routines. Without the use of leading questions, but employing probing queries, interviewers allowed for parents to elaborate their responses to any topic.

Data Analysis

Interviews were digitally recorded, transcribed verbatim, and reviewed for quality control. Interviews were analyzed through an inductive approach to qualitative analysis within the framework of phenomenology, as some of our analyses were based on literature in the field.^{11,12} However, also expecting that families' perceptions might include elements not readily discernible to investigators before the interview process, we did not develop a coding list a priori. The lead investigator (A.V.H.) coded all interviews by using qualitative analysis software (ATLAS.ti 7.1 (Scientific Software Development GmbH, Berlin, Germany)); each interview was also coded independently by 1 of 3 other members of the team. All investigators (A.V.H., E.C.A., E.H., and C.A.) used a constant comparative method as part of an iterative process. The pair of investigators who had independently coded each interview reviewed the transcript concurrently and reached consensus on each code. The team stopped recruiting families to participate when further themes no longer emerged (saturation of themes). We then analyzed frequency and co-occurrence of codes by using qualitative analysis software and determined emerging themes.^{13,14} Four members of the research team (A.V.H., E.C.A., E.H., and C.A.) sorted, collapsed, and split the identified themes and categorized them into domains via an iterative process requiring full team consensus.

RESULTS

Three families declined to be interviewed; 10 families were not interviewed because of scheduling conflicts before family discharge or lack of interviewer availability. Twenty families were interviewed before reaching saturation of themes; all families were white, English-speaking, and publically insured, which is representative of the NAS patient population at our institution. Eleven interviews were conducted

TABLE 1 Family Interview Guide

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- Did anything surprise you during your baby's time here at the hospital?
 - How did you learn about NAS before your baby's delivery?
 - Did you find any information about opiate treatment in pregnancy or NAS online?
 - How much did your family know about the diagnosis of NAS before your baby was born? Did this change during your baby's hospital stay? How about at your program?
 - What would you have liked to know about NAS before the delivery that you did not know?
 - What do you think would have been the best way to learn about NAS?
 - In what ways did you feel supported by our staff during your baby's time here in the hospital? Tell me about a specific story of feeling supported.
 - At what times, and in what ways, did you *not* feel supported during your baby's time in the hospital? Tell me about a specific story of not feeling supported.
 - In what ways did you feel like you were a part of your baby's care team? Tell me about a time when you felt you were treated as a part of the team.
 - In what ways did you feel like you were *not* a part of your baby's care team? Tell me about a time when you felt you were *not* treated as a part of the team.
 - What could we have done to make this a better experience for you and your family?
 - Did staff members ever say something in front of your family that they were not supposed to?
 - Was your baby cared for on different units? What was it like being transferred from 1 unit to another?
 - How was the clinical care different between the units?
 - How were you involved in your baby's scoring on the different units?
 - Tell me about how the different environments of these units might affect how you could provide comfort measures for your baby's NAS.
 - What were you told about breastfeeding? Did you receive any conflicting information?
 - Tell me something that you think would be helpful for our staff to know about caring for a baby and family like yours.
 - Tell me something that you think would be helpful for other families to know during the pregnancy or hospital stay.
 - Is there something that a staff member did or said that you will never forget? If yes, tell me what this was.
-

with mothers, 8 with both mothers and fathers, and 1 with grandparents. Other newborn and maternal demographic characteristics are listed in Table 2. Analysis of interview transcripts identified major factors affecting families' experiences during newborn hospitalization for NAS (Table 3). Domains of family experience that emerged from the data included parental education and preparation, the role of parents as partners in care, interpersonal interactions and communication with the health care team, hospital environment and transitions in care, and external factors. Table 3 includes select quotations from family interviews to illustrate the themes identified in each domain.

Domain 1: Education and Preparation

Many families desired improved prenatal and postnatal education about NAS. Families

wanted to learn more about the course of NAS, the scoring process, and the use of pharmacologic and nonpharmacologic treatment options before their delivery. Some families obtained an informational pamphlet before their delivery but stressed that this information was insufficient. Furthermore, few believed that their prenatal providers offered adequate education regarding NAS and what to expect during the hospital stay, although many voiced concern that nothing could have prepared them for the emotional process of seeing their newborn suffer withdrawal symptoms due to physical opioid dependence.

Families also felt unprepared for the long duration of the hospital stay. Given the rural nature of our tertiary care center, many families commuted long distances and were unprepared to make multiple round-trips

during their newborn's hospitalization. Other family and work commitments made it difficult for one or both parents to be present for the often-lengthy hospitalization. Mothers in particular also found it challenging to balance their own medical needs (eg, needing to leave for physician's appointments, group meetings, or maintenance treatments) with those of their child.

Domain 2: Partners in Care

Families emphasized the importance of parental involvement in newborn care and in the scoring of NAS symptoms. They addressed the utility of a "symptom diary" (which was introduced during the study) that allowed them to monitor their newborn's symptoms in interim periods between scoring checks by the nursing staff. During the course of our study, families were admitted to various units depending on bed availability and severity of infant NAS. Families highlighted the ability to room-in with their newborn (which was possible on the birthing unit and inpatient pediatrics ward) as having a major, positive impact on their hospital experience. Although families lacked the opportunity to room-in if their newborn was admitted to the NICU, several families appreciated the increased nursing support in that setting.

In addition, many families expressed disappointment regarding the impact of breastfeeding policies, particularly when such policies were unclear or inconsistent. Some mothers were unaware of hospital policies regarding breastfeeding when the mother's urine tested positive for illicit substances, including marijuana. When some mothers were instructed not to breastfeed given their substance use history, they were unsure how (and whether) to provide skin-to-skin contact with their newborn. Families also described a wide variety of emotions during their newborn's hospital stay, including guilt, disappointment, and fear, and reflected on the impact of these emotions when it came to forming trusting relationships with providers and to bonding with their newborn. Many families believed it was important for providers to understand these complex emotions to interact with and fully support them as partners in care.

TABLE 2 Maternal and Newborn Demographic Characteristics for Qualitative Sample

Maternal Demographic Characteristics		Newborn Demographic Characteristics	
Mean age (range), y	26 (19–32)	Received morphine treatment	13 (65%)
Documented compliance in maintenance treatment	11 (55%)	Discharged from the hospital with parent(s)	19 (95%)
Buprenorphine	8 (40%)	Report filed with child protective services	15 (75%)
Methadone	3 (15%)	Services before discharge	
Documented substance use in pregnancy while enrolled in maintenance treatment	5 (25%)	Mean LOS (range), d	15 (4–47)
Not currently in treatment, documented substance use in pregnancy/identified at delivery	4 (20%)	LOS, morphine treatment, d	18 (11–47)
		LOS, no morphine treatment, d	6 (4–12)

LOS, length of stay.

Domain 3: Interpersonal Interactions and Communication

Families attributed success in their hospital experience in part to good support by providers and staff members. Whether it was a physician taking time to address a concern during rounds, or a nurse listening and providing emotional support, families cited positive interactions as shaping their hospital experiences. Conversely, families' experiences were also influenced by staff behaviors that did not provide good support. Some families described feeling judged by staff members for their substance use, leading to negative interactions with care teams. Other families described breeches of confidentiality, in which staff unintentionally revealed maternal treatment of opioid dependence to other family members.

Families also voiced the need for clear, consistent communication regarding their newborn's clinical course. Unfamiliar medical jargon sometimes reduced clarity. In other examples, particularly if the newborn was admitted to the NICU where parents were not rooming-in full time, families simply felt left out of communication when it came to changes in treatment plan.

Domain 4: Hospital Environment and Transitions

The hospital environment itself, and the nature of transitions between units, also shaped families' experiences. Families discussed their difficulty with different routines on varying units, particularly with repeated transfers between units. Families also addressed the lack of continuity of both nursing staff and medical providers, which

led to discrepancies in caregiving approaches during the hospital stay. For example, families noted that some staff members woke the newborn every 2 to 4 hours to perform NAS scoring, which often resulted in a higher score and an increase in medication dosing. Alternatively, other staff members scored the newborn on his or her sleeping and feeding cycle, while skin-to-skin, and after a completed feeding, typically leading to lower scores and less pharmacotherapy.

Families also cited aspects of their hospital stay that were unique to the NICU environment. Some families appreciated the higher level of nursing care in the NICU, despite not being able to room-in with their newborn, while the majority preferred to stay with their newborn in a private room. Several families described feeling guilty that their newborn was in the NICU or that the level of care was not warranted given how healthy their newborn seemed compared with other neonates in the intensive care setting.

Domain 5: External Factors

Finally, families addressed external factors that played a role in their hospital experience. Parents were in varying levels of recovery during their newborn's stay. Some were stable in long-term buprenorphine or methadone maintenance programs, while others had been using illicit substances through the time of delivery. They wanted the medical and nursing staff to understand the disease of addiction and its treatment. The road to recovery was often limited by lack of access to community-based addiction treatment programs. For example, in at least 1 instance, the mother was able to access a treatment program once she

became pregnant, while the father remained on a wait list indefinitely; other pregnant women spent many months trying unsuccessfully to enroll in maintenance programs. Families also addressed a variety of economic limitations, such as the lack of transportation to and from the hospital and the maintenance program, and how this situation affected their hospital stay. Legal concerns were also of importance to families, including concerns about involvement with child protective services. Finally, the hospital experience was affected by the presence or lack of a supportive social network involving extended family or friends.

DISCUSSION

The goal of the present study was to understand the hospital experience for families of newborns affected by NAS. Our qualitative analysis of the interview transcripts identifies meaningful aspects of the hospital experience, including a need for education and preparation, a desire to partner with the newborn's care team, the impact of the hospital environment and transitions, and the role of external factors. Our analysis also highlights the impact of interactions and communication between staff and families, particularly the stigma surrounding substance use and how negative judgments can affect the parent-provider relationship. Conversely, positive interactions with staff make families feel valued and supported, and these interactions may have downstream effects on future health care encounters for their children.

Allowing the family perspective to inform subsequent QI efforts can enhance clinical ability to provide optimal family-centered

TABLE 3 Domains and Underlying Themes Identified in Family Interviews

Domain	Theme	Interview Excerpts
Education and preparation	<ul style="list-style-type: none"> • Prenatal/postnatal education on NAS, scoring, and pharmacologic and nonpharmacologic treatment 	<p>"I wish I had known a lot more about NAS before I gave birth...I didn't think about the consequences. I did [but I didn't know] they would affect the baby so much."</p>
	<ul style="list-style-type: none"> • Preparation for extended hospital stay • Prenatal care/maternal medical care 	<p>"I didn't really expect for it to be this long or for it to be honestly anything like this... I didn't expect her to go through so much, you know, pain and suffering through the whole thing. I didn't think any of that would happen."</p>
Partners in care	<ul style="list-style-type: none"> • Parental involvement in infant care 	<p>"I know my baby more than anybody else does. So they have to rely on that to help them out you know with scoring and knowing what she's going through."</p>
	<ul style="list-style-type: none"> • Role of parental emotions • Impact of breastfeeding and rooming-in 	<p>"And breastfeeding is way better in this situation. We have noticed that... when he gets that, he's more calm, aware, he's more awake...it just seems like it was more soothing to him and he did a lot better and I think that's why he got a lot lower scores."</p>
Interpersonal interactions and communication	<ul style="list-style-type: none"> • Good support from staff 	<p>"Well if they say captured, you don't really know what it means. Like what is she being captured with?"</p>
	<ul style="list-style-type: none"> • Poor support from staff (feeling judged, breeches of confidentiality) 	<p>"I just needed support... it's heartbreaking to see them sick and know that it's your doing... and [the RN] kind of came back at me with like 'it's your fault' type of feeling."</p>
	<ul style="list-style-type: none"> • Communication about infant's clinical course 	<p>"I'm a recovering heroin addict. I think overcoming something like that and then feeling like you are judged because of it, you end up building some resentment towards people... If you could tell people like us, hey, you are doing awesome, look what you made it through—don't think of this as in anyway judging you for doing that. You did everything right, and we are just making sure that your baby doesn't experience anything negative and that's all."</p>
Hospital environment and transitions	<ul style="list-style-type: none"> • Different unit routines/transfers between units 	<p>"One nurse on one shift would be okay with certain things ... then the next shift would come on and... we were told that we couldn't do certain things that we were just told that we could do. It was very, you know, difficult."</p>
	<ul style="list-style-type: none"> • Experiences unique to NICU • Lack of provider, staff, and care process continuity 	<p>"It wasn't <i>nice</i>, not being able to stay with him 24/7, stuff like that. You know, it's hard being a new mother and everything like that and have to leave him at night [in the NICU] and whatever—but I'd still prefer that over not being there. So the intensive care nursery was kind of hard for me."</p>
External factors	<ul style="list-style-type: none"> • Parental drug use and recovery 	<p>"A methadone clinic was not an option for us, because at the time, we didn't have a car, and it was, you need to show up daily at this specific time, and it was like, we can't always do that, and if you miss one, you're out."</p>
	<ul style="list-style-type: none"> • Economic limitations • Family and community supports 	<p>"Programs were completely full and the only thing I decided to do was wean myself off on my own until I could get a program, until I could get some kind of help."</p>

RN, registered nurse.

care; although qualitative studies have been used in adult populations to subsequently improve patient safety and inform practice

guidelines, this practice may be less common in pediatric research.^{15,16} Existing research on the hospital experience for

newborns and their families focuses almost exclusively on historically more common NICU diagnoses such as prematurity, with

many qualitative studies examining parental stress and promotion of family-centered care in the NICU.^{17–19} In terms of NAS specifically, previous qualitative research has focused on perspectives of the nursing staff and has shown that NICU nurses face moral challenges (eg, distress regarding newborn inconsolability, fear related to safe discharge planning) in treating newborns with NAS.^{20,21} Only 1 other study has examined parental experiences with NAS care, finding that mothers can feel judged by nursing staff and subsequently have difficulty establishing a trusting relationship with them.²² This previous study differs from the present one in that interviews occurred only with mothers and in an outpatient setting, sometimes occurring months to years after the newborn's NAS hospitalization. Given the increasing incidence of NAS, there is a need to understand the psychosocial dynamics involved in providing optimal family-centered care for newborns affected by NAS. The results of our qualitative study may be useful in guiding institutional improvement efforts regarding NAS care. These findings may inform policy changes regarding scoring consistency, staff training, or transitioning to a rooming-in model; full discussion of the institutional QI efforts that followed our qualitative analyses have been published elsewhere.²³ In general, families of newborns affected by NAS highlighted the importance of continuity and provided examples of discrepancies in care, which may be improved by implementing consistent scoring protocols and minimizing

unit transfers. Families emphasized the importance of patient-friendly language and the value of supportive, nonstigmatizing interactions with staff members. Institutions can act on this knowledge by enhancing staff education regarding opioid use disorders and maintenance treatment, as well as by promoting judgment-free language. Families also voiced the desire to be prepared for their newborn's clinical course, which may allow them to more fully partner with their newborn's care team.

There are several limitations of this study. First, interviews occurred in a single center with a homogeneous sample of white, low-income families from rural communities. Newborns treated with medications were oversampled ($n = 13$ [65%]) because these families had a longer hospital experience. Second, almost all newborns exposed to opioids in utero are discharged from the hospital with their families from our institution because New Hampshire and Vermont do not require mandatory foster care placement after illicit substance use during pregnancy. Policies aimed at improving family-centered care might be met with more resistance at institutions where this approach is not the case. Next, QI efforts began during the course of this study, and policy changes were being made in real-time in response to our qualitative data. As a result, parents' experiences may not have been uniform throughout the study's 6-month duration. Finally, although these qualitative results cannot necessarily be generalized across all centers, the approach itself can be generally applied;

taking time to understand the family perspective on content of care before initiating a QI project can be enormously beneficial to both families and institutions.

CONCLUSIONS

To our knowledge, this study is one of the first to examine family perspectives of newborn hospitalization for NAS. Families' hospital experiences are affected by a variety of factors, many of which are modifiable. This knowledge may be used to adjust hospital practices to improve families' experiences of the NAS hospitalization.^{2,24,25} More research is needed to better understand the complex social and emotional aspects of NAS to further improve family-centered NAS care, both in the hospital and in the community.

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Dr Atwood analyzed interview transcripts, led the research team consensus meeting, and drafted and revised the manuscript; Ms Sollender was involved in the initial planning phase of the project, conducted qualitative interviews with families, transcribed interviews, and contributed to drafting the manuscript; Ms Hsu assisted in developing the interview guide, conducted qualitative interviews with families, transcribed interviews, participated in the team consensus code meeting, and edited the manuscript; Dr Arsnow assisted with transcription and coding of interviews, participated in the team consensus code meeting, and helped edit the final manuscript as submitted; Ms Flanagan assisted in developing interview questions, conducted qualitative interviews, and edited the manuscript; Ms Celenza participated in developing interview questions and served as a family liaison in eliciting parental responses related to their care experience; Dr Whalen co-led development and revisions of the family interview guide, oversaw patient recruitment and student qualitative interviews, and revised the final manuscript; and Dr Holmes led the overall quality improvement project for the hospital, co-led the interdisciplinary team that developed the interview guide, oversaw the research design, performed the primary round of coding on all of the interview transcripts, participated in the team consensus code meeting, and edited and revised the final manuscript as submitted; all authors approved the final manuscript as submitted.

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Emily C. Atwood, Grace Sollender, Erica Hsu, Christine Arsnow, Victoria Flanagan,
Joanna Celenza, Bonny Whalen and Alison V. Holmes

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