Family Experience with Hospitalization for Neonatal Abstinence Syndrome

Dr. Bonny Whalen - Newborn Hospitalist; Cheri Bryer - Recovery Coach; Farrah Deselle, MSN, RN - Perinatal Educator
Feb 19, 2019
Rural tertiary care children’s hospital in NH:
- ~ 1200 births/year
- ~ 1 in 10 opioid-exposed

Majority of mothers receiving medication-assisted treatment (MAT)
- 63% Buprenorphine
- 22% Methadone
- 15% not in MAT

Now majority cared for in Newborn Nursery ± Inpatient Pediatrics, not NICU
Qualitative approaches used:

• When medical team perspective may be different from patient population
• To help understand family perspective in care
• To aid improvement efforts

Purpose of qualitative interview is to listen, reflect and capture accurate snapshot of patient and family experience

• Not to solve challenges
• Not to defend status quo
Qualitative interviews performed at Children’s Hospital at Dartmouth-Hitchcock (CHaD) in Lebanon NH with families of babies observed/treated for NAS

- 2018 - 2019: 17 families

Info gained from qualitative interviewing used to guide institutional QI activities
Family Perspective Sample Interviews ?s: 2013 - 2014

- Did anything surprise you during your baby’s time here?
- In what ways did you not feel like you were a part of your baby’s care team?
- What was it like being transferred from one unit to another?
- What could we have done to make this a better experience for you & your family?
Qualitative Interview Themes: 2013 - 2014

- Interactions/Communication
- Education/Preparation
- Partners in Care
- Environment/Transitions
- External Factors

Hospital Experience
Parents desire more prenatal and postnatal education

• Symptoms and course of illness
• Scoring
• Supportive care
• Treatment
Prenatal / Parent Education

“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 don’t know. I didn’t know they would so – they would affect the baby so much.”

“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.”

“I wasn’t aware exactly what it would be like. The midwives prepared me the best that they could, but it’s not the same as actually going through it every day.”

“I’ve been trying to learn everything I possibly can about NAS so that if there’s any problems when we go home I can be able to identify them right off the bat.”
Parents’ experience is strongly impacted by hospital environment

- Difficulty with different unit routines and transfers between units
- Experiences unique to ICN environment
- Lack of provider continuity
Hospital Environment / Transitions

“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.”

“The BP (Birthing Pavilion) was okay. That was more one-on-one. I could take my shirt off and skin-to-skin and try to keep him calm. In the ICN, you had parents in there ... not as private. The privacy makes it easier to tend to your child.”

“... sometimes the information was getting a little confused in the process. Like when she was getting transferred from the Birthing Pavilion to over here, and then from over here to ICN.”

“I think if we were able to stay in one area he might have been able to come home sooner.”

“The way the nurses were doing the scoring was a little different.”

“We were told she would only get scored for that once when it first happened unless it got worse. And then in a different department she was getting scored for it everyday even though it was getting better.”
Jan 2013: Formed Multi-D VON NAS QI team
April 2013 - Oct 2014: 11 PDSA cycles

1. RN scoring training/ reliability
2. Family interviews
3. Baby-centered scoring & care
4. Prenatal education
5. Parent symptom diary
6. Standardize score interpretation + modify Rx criteria
7. Rooming-in pilot
8. “Cuddlers”
9. Full rooming-in
10. Working with families with addiction training
11. Transfers
Parents value role as part of health care team

• Importance of involvement in care and NAS scoring
• Role of parental emotions (e.g., guilt, fear, disappointment)
• Non-pharmacologic treatment and rooming-in
• Impact of breastfeeding & related policies

“I don’t think I felt like I was too much a part of her care.”

“She said that even if we had been called and gone over there and comforted her that it probably wouldn’t have made a difference. But the only thing I could think to myself was well if you didn’t try it, you really don’t know for sure if it would have made a difference or not. And that was the only time she got scored for crying.”
Parent Insight → Baby-Led Scoring

Previously:
• Scoring at set 2 or 4 hour intervals
• Newborns woken up for scoring
• Scored before feeding
• Scored in bassinet

Now:
• Scoring on newborn’s natural sleep-wake cycle
• Scoring after skin-to-skin and feeding
• Scoring while skin-to-skin, if possible
• Parental input
Partners in Care

“In mornings when they’d do rounds, they would specifically ask me how I felt about her going down on her medication and they would listen to me... At first when I came here, I didn’t really think that the doctors would really care what I thought.”

“I think even the parent should have this piece of paper daily and so every 4 hours, what they feel, they have seen because [the nurses] come in and ask us ‘has there been sneezing, has there been yawning’ and I love the fact that they ask because they don’t see everything.”
Partners in Care / Rooming In

“I think they have the right idea with moving parents over to Pediatrics ‘cause they get to stay with their baby 24/7 and be there always to comfort the baby.”

“Yeah, I’m really glad that they’ve made it an opportunity to allow the mom’s to board-in because I think that we have so much going on – having to feel guilty about having addiction and that you have to be on medication and I think that it’s good that we are able to stay with the babies for the most part and um, and not stigmatize ‘you can’t be with your baby because your baby is on medication’ and stuff like that. It’s nice that we can still have the same opportunities as other parents.”
Interpersonal interactions and communication with staff members shape hospital experiences

• Good support vs poor support / feeling judged
• Value of communication about infant and clinical course
• Breeches of confidentiality
“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.”

“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.”

“They were on my side and they said that I was doing the best for him as a recovering addict going through this program. It was very nice--addicts just don't get enough praise for what they're really doing.”
Factors outside hospital have profound impact on the patient and family

• Effects of NAS on family dynamic or relationships
• Parental drug use history and stage of recovery
• Economic limitations and availability or lack of community and hospital supports (e.g., food costs, gasoline / transportation, pharmacy not carrying med/ mom has to leave hospital, childcare, missed work)

“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.”

“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.”
CHaD NAS Quality Improvement Activities

• **2013-2014:** Move to full rooming-in, baby- & family-centered model of care

• **2015:** Formal baby-centered non-pharm care bundle

• **2016:** Introduction to Eating, Sleeping, Consoling (ESC) function-based assessment concept

• **2017:** Move to full ESC-based model of care with standardized ESC assessments and non-pharm interventions optimized before considering pharm Rx
Follow-up Study Sample Interview Questions: 2018 - 2019

• Did anything surprise you during your baby’s time here at the hospital?

• How much did your family know about the diagnosis of NAS before your baby was born? How did you learn about NAS before your baby’s delivery?

• In what ways did you feel supported by our staff during your baby’s time here in the hospital? In what ways did you feel not supported?

• How were you involved in managing your baby’s withdrawal symptoms?

• Tell me about a time when you felt confused or frustrated by your baby’s management for neonatal abstinence syndrome.

• In what ways did you feel like you were a part of your baby’s care team?
Family Experience Domains: 2018 - 2019

- Parental Role in Care
- Education and Preparation
- Assessment Process and Care Focus
- Baby’s Withdrawal
- Care Environment
- Staff Interactions

Family Hospital Experience
Education and Preparation

• Appreciate comprehensive NAS education across care settings

• Desire improved prenatal preparation:
  • Hospital Stay Expectations
  • Importance of parental presence
  • Non-pharmacologic care
  • Clarity around breastfeeding
“My weekly meetings with them [Moms in Recovery Program] really prepared us for what they were going to do for testing the baby to see if they were healthy.”

“I knew a little as well as them telling me here...I see a counselor. It’s a one-on-one situation.”

“She (the mother) went to the classes and by being a father and being here, I don’t know anything about it or what’s going on.”

“My understanding has changed. About the skin-to-skin, the bright lights, keeping it quiet, what a big difference that makes.”
Assessment Process and Care Focus

- Parents want to be involved in assessment process
- Desire to be informed about assessments in real time
- Generally prefer function-based (ESC) over symptom-based (Finnegan) assessments
Assessment Process and Care Focus

“This time is easier than last time...They’re basically focused on how they’re feeding, sleeping and soothing. So, it’s a lot better.”

“I had a baby born 5 years ago and they were more rigid on their scoring at that time, following the protocol more. I was less fearful this time”

“I'm glad I was involved because I'm the one who is with him. And so them only seeing him for, like a few seconds to score is... They don't get the whole picture.”
Parental Role In Care

- Desire to be recognized as key team member
- Parents appreciate tools such as newborn care diaries that facilitate their participation
- Empowered to be primary caregiver and advocate
Parental Role In Care

“It’s really nice when it’s genuine you get asked your opinion...and that just made me feel like I had a part and say in how things went with her.”

“They’ve told us multiple times [mom’s] the best medication for him, skin to skin or milk and just being here in the room.”

“I am her symptom relief. Skin to skin and feeding. I am what she needs. I heard some parents don’t stay. The hardest part about this is [my son]. This is the longest time I’ve ever been away from him.”
Perceptions around Neonatal Withdrawal

- Parents expressed worry and guilt around withdrawal
- Symptoms distressing to parents
- Parents may identify with their infant’s withdrawal
Perceptions around Neonatal Withdrawal

“It was very upsetting when I found out he was going to through withdrawals and it was my fault...He’s just mild right now but still has shakes like I do and it reminds me of myself.”

“He's losing weight, which is part of the withdrawal.. But it is kinda, like, part of me feels like I'm a bad mother because I don't know how to feed him.”

“He’s very consolable... if you’re holding him and trying to breastfeed, which makes sense because when I went through withdrawal, I felt icky, I just wanted to be held and cuddled.”
Care Environment

- Most parents appreciate rooming-In setting
- Some mothers report fatigue, need for more breaks
- Need more support from staff and family/personal support
- Improved experience in current care model
Care Environment

“Since I’m with my baby all the time, I’ve been able to tell if something is caused by withdrawal or normal behavior.”

“He didn’t sleep through the night at all. I was kind of tired. I was kind of a shocked that they didn’t have a nursery where you could keep the babies.”

“They were also good about letting us get the rest we need. They would come in and take the baby for an hour or two so we could get some rest”

“It was a lot more comforting for me to be here with her and also for dad too. I think it made it a lot easier for her to transition from being a NAS baby to being able to go home today.”
Staff Interactions

• Most parents feel supported in a family-centered manner

• Still report incidents when parents felt judged, unheard or disempowered

• Improved experience for parents with prior NAS experience
Staff Interactions

“You can tell the difference between a nurse that has done this with other families and knows what questions we have and one that is just looking to do the scoring and be very by the book. “

“It was...not necessarily specific words that she said, but more of like the looks that she gave.”

“They were on my side and they said that I was doing the best for him as a recovering addict going through this program. It was very nice--addicts just don't get enough praise for what they're really doing.”

“For me, it’s been huge to be treated like every other patient, just a mom and a baby.”
Next Steps: Using themes to focus further QI efforts

- Improve prenatal education about NAS rooming-in care & hospital stay
- Validate role of family on care team
- Bolster use of cuddler program
- Improve consistency of staff communication & parental in-hospital education
- Reinforce environment of trauma-informed care & role of recovery coach
Working with Women/Families with Substance Use Disorder including those in Recovery

Cheri Bryer - Dartmouth-Hitchcock Recovery Coach
Farrah Deselle, MSN, RN - Perinatal Educator
Questions?