Published in final edited form as:

Adv Neonatal Care. 2019 October ; 19(5): E3–E15. doi:10.1097/ANC.0000000000000616.

Trying to Do What Is Best: A Qualitative Study of Maternal-Infant Bonding and Neonatal Abstinence Syndrome

Katherin Rockefeller, MD[1], **Lynda C. Macken, RN, PhD**[2], **Alexa Craig, MD, MSc**[3]

[1]Center for Autism and Developmental Disorders, Maine Behavioral Healthcare, South Portland, Maine

[2]Center for Nursing Research and Quality Outcomes, Maine Medical Center, Portland, Maine

[3]Maine Medical Center, Department of Pediatric Neurology, Portland, Maine

Abstract

Background: The maternal experience of caring for and bonding with infants affected by neonatal abstinence syndrome (NAS) has not been adequately characterized.

Purpose: This study was designed to describe mothers' experiences of, supports for, and barriers to bonding with infants with NAS.

Methods: Semi-structured interviews were coded using computer-assisted thematic content analysis. A code co-occurrence model was used to visualize the relationships between themes.

Results: Thirteen mothers of infants with NAS participated. Trying to Do What Is Best emerged as the over-arching theme with which several sub-themes co-occurred. Sub-themes that captured mothers loving their infants and bonding, feeling supported by the infants' fathers, feeling supported in the community, and receiving information from hospital staff were associated with mothers' trying to do what is best. Barriers to trying to what is best included feeling unsupported in the community, guilt about taking medications or substances during pregnancy, feeling judged, and infant withdrawal.

Implications for Practice: Specific implications for practice may be derived from the mothers' criticisms of NAS assessment tools. Mothers highlighted the value of reassurance and education from providers and the uniquely non-judgmental support received from peers and male co-parents.

Implications for Research: There is a lack of information about maternal-infant bonding in dyads affected by NAS and factors that contribute to parental loss of custody. Qualitative, quantitative, and mixed-method studies in diverse populations might help researchers better understand the long-term outcomes of NAS and develop interventions that decrease family separation.

CORRESPONDING AUTHOR: Katherin Rockefeller, MD, Center for Autism and Developmental Disorders, Maine Behavioral Healthcare, 236 Gannett Drive, South Portland, Maine, 04106, krockefell@mainebehavioralhealthcare.org.

COMPETING INTERESTS

The authors do not have competing interests to disclose.

Keywords

neonatal abstinence syndrome; qualitative research; maternal-infant bonding; substance use disorder; opioids; mother; family and community support

BACKGROUND AND SIGNIFICANCE

Opioid use among pregnant women has increased dramatically over the past decade, corresponding with an almost fivefold increase in the number of infants experiencing opioid withdrawal at birth, or neonatal abstinence syndrome (NAS).[1–3] Hospital protocols for treating NAS have historically stressed automatic transfer to the Neonatal Intensive Care Unit (NICU), monitoring with the Finnegan Neonatal Abstinence Severity Score (FNASS),[4,5] and pharmacologic interventions that are time-intensive, costly, and minimize parental involvement in an infant care.[6,7] In recent years, more hospitals are recognizing non-pharmacologic interventions, including rooming-in of infants with mothers, human milk feeding, and skin-to-skin contact, as first-line treatments for NAS.[7,8] Non-pharmacologic interventions promote contact between a mother and her infant and thus maternal-infant bonding: a mother's connection to her infant.

Bonding may be observed in mothers holding, making eye contact with, and responding to behavioral cues from their infants and can influence how infants relate to and trust others throughout life.[9] Maternal psychosocial stressors and neonatal withdrawal symptoms can combine to make maternal-infant bonding more difficult for mothers of infants with NAS,[10–13] yet mothers with substance use disorders who score higher on bonding scales tend to be more motivated to stay in treatment, more invested in self-care, and better able to adapt to their maternal role.[11,14] Few studies have solicited mothers' perspectives of caring for an infant with NAS, and even fewer have focused on their experiences of bonding with their infants.[15]

In one qualitative study, 15 Mexican-American mothers of infants with NAS expressed guilt, shame, and a sense that they had been judged by nursing staff, all disrupting the formation of trusting alliances with hospital providers.[16] Although mothers expressed strong desires to be actively involved in the care of their infants,[17] they were reluctant to stay in the hospital during their infants' admissions when they felt judged by providers.[18] In another qualitative study, 20 white, rural New England families of infants with NAS appreciated opportunities to participate in their infants' care, prenatal and ongoing education about NAS, and consistent communication with providers.[19] Marcellus and colleagues conducted a grounded theory exploration through interviews with 18 mothers in British Columbia, finding that mothers exerted profound effort to "hold it together", regain credibility with loved ones, become a strong center for their families, and provide a sense of home.[20] Only one identified study specifically examined the mothers' experiences of bonding with their infants with NAS and found that mothers expressed a desire to connect with their infants, but faced barriers to spending time with their infants in the hospital.[21]

Hearing more from mothers of infants with NAS is warranted given the scope of the opioid epidemic in the U.S. and the benefit of non-pharmacologic interventions that require

maternal involvement. In this study, a qualitative approach was used with the goal of describing mothers' experiences of, supports for, and barriers to bonding with infants with NAS.

METHODS

Design:

This qualitative study was conducted at an urban tertiary care center in a predominantly rural, northeastern state heavily affected by the opioid epidemic.

Participants and Setting:

Participants were recruited from convenience samples of 1) mothers of hospitalized newborns with NAS and 2) mothers from an outpatient, medically supervised support group for women with substance use disorders whose infants had received care for NAS at the study hospital. Mothers were included if they were at least 18 years of age, English-speaking, and had given birth to infants who were exposed to opioids in utero and were under 12 months in chronological age at the time of the interview. No incentives were provided for participation. At the time the mothers and infants were hospitalized, the study hospital employed the FNASS scoring system to monitor the severity of infant withdrawal and inform decisions about pharmacologic treatment.

Procedures:

The study was introduced to mothers of infants with NAS by their clinicians. If mothers expressed an interest in participating and inclusion criteria were met, the consent process was completed verbally to provide the greatest protection from a potential breach of confidentiality.[22] The local institutional review board granted ethical approval for the study. The child psychiatry fellow conducted all interviews. No member of the research team provided direct care to the infants or mothers during their inpatient hospitalizations. Each face-to-face interview took place in the mother's or infant's hospital room or in a private outpatient office. Interviews were audio-recorded, de-identified, and transcribed verbatim by a paid, professional transcriptionist. Clinical characteristics about the mothers and infants were manually extracted from electronic medical records within 24 hours of the interview.

Instruments:

A semi-structured interview guide was developed to explore mothers' perinatal experiences of bonding with their infants with NAS (Supplemental Digital Content 1). Nine primary questions with probes were developed from a literature search, discussions with multiple authors of previous qualitative studies, feedback from staff on mother-infant units at the study hospital, and other published measures of maternal-infant bonding.[25–31] Questions were adapted and designed to be open-ended and not directive, with the aim of eliciting information about maternal-infant bonding and related supports without influencing the language or content of participant responses. For example, mothers were asked "How would you describe your feelings about your baby today?" and "What was it like for you when your baby was experiencing withdrawal symptoms?" with additional probing questions such

as “What could you do to care for your baby and yourself when your baby was having those symptoms?”

Data Analysis:

Thematic content analysis following a qualitative descriptive approach[32,33] was used to analyze the transcripts. MaxQDA Analytics Pro[34] software was used to organize the data. All research team members independently read the transcribed interviews. Two investigators collaboratively reviewed one transcript line-by-line, identifying initial principal themes and sub-themes. Then, both investigators independently coded each transcript as the interviews progressed. Through multiple meetings, codes were discussed, refined, and agreed upon through consensus. A third investigator provided feedback on the coding system throughout the analytic process. After the final coding was completed, the MaxMaps[34] function was used to create a visual representation of the relationships of themes and sub-themes through a co-occurrence model.

RESULTS

Between November 2017 and April 2018, 13 of the 18 mothers approached by a research team member chose to participate in the study. Reasons for non-participation included scheduling challenges (n=3), concern for potential loss of confidentiality (n=1), and emotional discomfort with the proposed discussion (n=1). Mothers ranged in age from 23 to 37 years. During pregnancy, all mothers were prescribed buprenorphine, and a minority used marijuana, heroin, or cocaine (Table 1). Six mothers were interviewed in the inpatient setting while their infants remained hospitalized. All but one mother had been discharged at the time of the interview. Their infants ranged in age from two to eight days. Seven mothers were interviewed in the outpatient setting; and their infants’ ages ranged from one to 11 months. Infants’ estimated gestational age at birth ranged from 36.4 to 40.3 weeks.

Interviews ranged from approximately 30 to 60 minutes. Thematic saturation, the point at which collecting additional data becomes redundant,[35] was achieved after 11 interviews; two subsequent interviews were completed for reassurance. Trying to do what is best emerged as the overarching theme of the interviews. The code co-occurrence figure is a visual display representing only codes/sub-codes that were associated with the overarching theme and the thickness of the lines represents the frequency of the code intersections (Figure 1). Three themes emerged indicating support or resources from family and friends, from the community, and from the hospital where the infants were hospitalized. Within those themes, sub-themes emerged that described the mothers’ perceptions of being supported or unsupported (Themes, Sub-Themes, and Definitions; Supplemental Digital Content 2). Themes associated with mothers trying to do what is best focused on loving their infant and bonding, support provided by the infant’s father, feeling supported in the community, and receiving information from the hospital staff. Barriers to mothers trying to do what is best included feeling unsupported in the community, feeling guilt, feeling judged, and infant withdrawal.

Trying To Do What Is Best:

Mothers described their efforts to support the wellbeing of their infants by doing what was "right" or "best" from the time they were aware of their pregnancies, through hospitalization, and after transitioning back to their communities. "*All my decisions, I think, are made just trying to do what's best.*"

Wanting To Be With Infant:

Mothers consistently expressed a desire to be physically present with their infants (Table 2). They described wanting to be with their infants during hospitalization, facing barriers to doing so, and fearing that they may be separated from their infants as a result of their history of substance use disorders. In observational notes taken immediately after each interview, the mothers were noted to be attentive to, at ease with, and affectionate with their babies; the infants were frequently soothed and held by their mothers. Two sub-themes, bonding and loving (her) infant, were associated with trying to do what is best. Mothers most often used the term bonding to depict their relationships with their infants when they discussed the decision to breastfeed.

> I talked about [breastfeeding] with my boyfriend, and I was just excited to have that bonding and be able to feed her anywhere and not have worry about formula and just have that bonding experience.

Most mothers elucidated the process of bonding with accounts of soothing, loving, wanting, protecting, and being with their infants. One mother summarized, "The best thing we can do for her is just love her."

Support:

Three sources of support (Family/Friends, Community, and Hospital) were explored with the mothers, who reported feeling both supported and unsupported at times (Table 3). For the purposes of this study, community includes healthcare practitioners outside of the study hospital; support at the hospital refers to the study hospital.

Support Family/Friends - Infant's Father:

The father of the infant was actively involved in nine (of 13) cases, and in one additional case, a male partner who was not the father of the infant was involved. The contributions made to infant care and reassurance provided to mothers by these male figures were described as inimitable and critical to the wellbeing of mothers and infants alike. Mothers frequently used the pronoun "we" rather than "I," seamlessly incorporating the infants' fathers into their narratives. Multiple mothers also pointed out the relief they experienced in knowing that these men were not blaming them for their infants' NAS.

> His dad has been really supportive through the whole thing. And to stay with us and I can tell how much he loves him. He's not like not blaming it you know, on me - what happened…He tries to comfort me."

Mothers also requested that more education and services be offered to fathers in the hospital.

Support/Resources Hospital:

Overall, mothers described feeling supported in the hospital; they wanted and generally received information about NAS from hospital staff (Table 3). They were eager to learn about NAS and valued consistent messages from clinicians. Furthermore, provider acknowledgment of maternal efforts to do what is best for her infant was meaningful and heartening for many mothers. When asked what *most* prepared her to care for her infant with NAS, one mother answered simply, "letting me know that I did the right thing [by taking buprenorphine] is huge." Mothers also wanted to be included in the care of their infants:

> [Hospital staff] encourage you to take care of your baby, which I super appreciate… I can take my baby's temperature, something as simple as that.

For some, transition periods at the hospital lacked clarity: mothers felt inconsistently informed about maternal and infant rooming-in opportunities and post-discharge plans. In addition, mothers received varying information about potential risks associated with taking medications and breastfeeding.

Support/Resources Community:

Several women especially felt supported from community providers or support persons who shared their own experiences with addiction or NAS.

> I have a counselor, and she's amazing…She's a recovering drug addict, and she had a child that was born that way [with NAS]… I feel like she actually knows what I'm going through.

In contrast, several mothers felt unsupported in the community, hindering their efforts to do what is best. Many of these mothers have long-standing histories of depression and other psychiatric conditions (Table 1). When one asked her psychiatrist to reevaluate her medications in pregnancy, "I don't have time" was the response she heard. Recalling a request to her prenatal primary care provider for more information about NAS, another mother commented, "at least [he] was honest enough to say, 'I don't really know.'"

Most mothers actively sought information from community resources as they tried to do what was best throughout the perinatal period. Mothers found peer support through community groups. They especially trusted information acquired from other mothers of infants with NAS who were frequently described as more accessible, accurate, and non-judgmental resources than community care providers. Overall, obtaining information outside of the study hospital was a challenge: it often impeded more than it aided mothers in trying to do what is best.

> I Googled a lot of stuff, reached out and talked to as many people or moms that I knew who maybe went through a similar situation. I think it would be huge if the OB clinic or prenatal care provided information more than just a packet that's one page. That's what they give you, and there's really not a lot of information.

Guilt:

Guilt about taking medications or substances in pregnancy (a sub-theme of Guilt) was the most frequently identified barrier to mothers' efforts to do what is best. Often mothers were

not aware that taking prescribed medications for opioid treatment increased a newborn's risk of NAS or withdrawal. One mother who had been discharged, but whose son remained hospitalized for NAS observation exemplified this sub-theme:

> It's just not worth it. I didn't need [buprenorphine]… I wish I could go back and fight through the anxious feelings rather than have that crutch of the [buprenorphine]… When I found out that it might have [hurt my baby], I had a hard time even looking at him. It was awful… I felt so bad. I literally didn't want to look at him. I didn't want to anything to do with him, and even that gave me guilt. I feel guilty for feeling guilty, basically.

Mothers expressed guilt about their use of prescribed medications for comorbidities such as depression, anxiety, and chronic pain, as well as other potentially harmful substances during pregnancy (Table 4).

Feeling Judged:

Three subthemes associated with feeling judged were linked to the overarching theme (Table 5). Ten of the 13 women in this study reported feeling judged, an experience reported more frequently in community than hospital settings. One mother recalled feeling judged at a prenatal visit:

> The doctor at the clinic was fairly new, and I'm not certain that he should have been working with addicts because he had an opinion formed and wasn't afraid to share it. But it wasn't kind. He said to me that I should consider aborting my child before I brought another whacked out drug addict in the world.

Mothers noted that friends had warned them to expect to be judged while in the hospital and reported feeling judged at times.

> I felt a little bit of it [in the hospital unit]. Like "judgy-ness". But I couldn't understand why because I didn't know at that point he was being looked at as a baby that's going through withdrawals. I had no idea. I was like, "What have I done to these women? Why don't they like me?" But then I realized that here they are thinking I'm just like any other junkie mom.

Seeking out prenatal care and treatment for substance use disorders required openness and trust, and mothers were vocal about the risks involved. Many women feared that they would not only be judged but also "turned in" for using substances prior to or during pregnancy; they worried that they would be separated from their infants as a consequence.

> I think that's why a lot of women don't go into treatment programs and try to do it on their own because they don't feel comfortable or safe going into treatment programs, feeling like DHHS [Department of Health and Human Services] will be called on them and they will have their kids taken away, when they're trying to do the right thing so that doesn't happen.

Several mothers in the outpatient setting continued to worry about, and lacked understanding of the role of child protective services in a state with mandatory reporting.

Infant Withdrawal:

Two sub-themes associated with infant withdrawal, the scoring system and takes a toll on parents, were barriers to trying to do what is best. Mothers felt frustrated with the use of the FNASS tool for monitoring their infants' withdrawal symptoms (Table 6).

> I'm imagining like Dancing with the Stars, like 8.5, like a whole bunch of doctors lined up like scoring my son. I didn't know why or what it was for, or what they were looking for.

They found it inconsistent and confusing and sometimes suspected higher scores reflected provider bias. They observed that the frequent and rigid scoring schedule disrupted their efforts to feed, soothe, nurture, and promote rest for their infants. Mothers concluded that these disruptions by hospital staff to obtain a score made their infants irritable, giving the appearance that they were experiencing more severe withdrawal symptoms and increasing the likelihood that they would need pharmacologic treatment. For some mothers, the impact of scoring persisted beyond hospitalization.

> Oh my God, at the very beginning she would jerk a lot, and twitch, during sleeping and stuff. I felt, yeah. It [withdrawal] must have been - I think that's all I seen [sic]. I'm not sure what they were scoring on. I know the sneezing. She didn't do much yawning but she still sneezes a lot to this day. Like I still wonder, I'm like is it [NAS]? I don't know if that could be possible nine months later. I don't believe so. But she still does sneeze a lot.

Mothers experienced psychological distress when witnessing their infants withdraw (Table 6). They wanted information about NAS to better understand and respond to their infants' symptoms.

> If a woman doesn't know what to expect, and she has a baby and the baby starts going through [withdrawal] and she doesn't know why the baby is crying all the time. 'Why can't I console them, what's going on here?'... It really does take a mental and emotional toll on a mom and a dad when they don't know.

DISCUSSION

In this study, mothers of infants with NAS consistently conveyed that they were trying to do what is best throughout the perinatal time period. This emerged as an overarching theme that has not been emphasized in previously published work. In addition, recognition of mothers' efforts to do what is best, especially by hospital providers, encourages maternal involvement in the care of infants with NAS.

Echoing the findings of previous qualitative studies, mothers wanted to be with their infants, despite facing some barriers,[19,21] and valued provider efforts to include them in infant care.[17,19] They used language to suggest that, with support, they embraced opportunities to bond with their infants, and they frequently acknowledged fears that they may be separated from their infants.[21] In this study, themes related to maternal-infant bonding supported a mother's efforts to do what is best. This finding is further supported by evidence in the literature that

mothers who score higher on quantitative bonding surveys are more likely to engage in substance use treatments programs, self-care strategies, and the mothering role.[11,14,20,36]

Unique to this study is the finding that the majority of mothers described the practical and emotional support provided by the fathers of their infants or male partners as critical to their own wellbeing and that of their infants. Paternal figures were described as engaging in the care of and bonding with infants as well as supporting mothers in feeling adequately rested and secure to bond with their infants.

In contrast to findings by Cleveland and colleagues[18], most mothers in this study reported that hospital providers respected them, and they were subsequently less focused on the need to assert themselves as the mothers of their infants. As expressed by families surveyed at a rural, tertiary care center in New England,[27] mothers in this study valued the provision of consistent education about NAS and provider efforts to make them an integral member of the care team. Still, mothers reported potential areas for improvement in the care they received in the hospital. As repeatedly documented in the literature, mothers were frustrated with the use of the FNASS tool for monitoring their infants' symptoms of withdrawal. [7,8,19,21] This instrument was described as "unfair" to the infant as it disrupted other soothing activities and gave higher scores for symptoms thought to be normal such as sneezing or yawning.

Most mothers described at least one encounter in which they felt judged by providers. This sentiment has been conveyed in previous studies[4,27,28] and could make mothers feel they did not belong in the place where they were most meant to be, their infants' bedsides. Fears, perceptions, and experiences of judgment made mothers hesitate to engage in prenatal care and substance abuse treatment, which suggests how judgment, particularly in community settings, served as a strong barrier to trying to do what is best. In contrast, participants strongly valued support from other mothers of infants with NAS;[21] these peer and community supports were trusted, consistent, non-judgmental, and influential sources of information about NAS, contributing significantly to engagement and retention in treatment for substance use disorders.

Most mothers described feelings of guilt, particularly when their infants were experiencing the symptoms of NAS even though most had followed medical advice to take buprenorphine during pregnancy. For many, the decision to take buprenorphine felt right in pregnancy, but when faced with an infant in withdrawal, several voiced concern that their outpatient buprenorphine prescribers had failed to fully inform them of the symptoms their infants might experience. While guilt is a consistent finding of qualitative work in this population, [12,16,18] this work uniquely illustrates the degree to which guilt impairs a mother's efforts to do what is best. This finding supports previous studies which suggest that mothers under stress, whether related to personal history of trauma, psychosocial stressors, or guilt[4,22,25] may emotionally or even physically withdraw from their infants, hindering maternal-infant bonding.[10,11,13]

One strength of this study was recruitment from both inpatient and outpatient settings, permitting the development of themes related to maternal-infant bonding throughout the first

year of mothering. However, because the study protocol necessitated that data on infant location (e.g. neonatal intensive care unit, continuing care unit, mother-baby floor, or outpatient clinic) only be recorded at the time of the interview, accurate data on infant location and illness course during hospitalization were not attained. In addition, protocol protections for participant anonymity prohibited the use of member checking after thematic development.

Enrolling participants from this population in research has been challenging in the context of widespread stigmatization of substance use disorders.[37] It is possible that the mothers who participated in this study were secure enough in their recovery to discuss their experiences with a researcher. Many mothers in this study had stable relationships with male partners, and this may also reflect a sample population with more established supports. Mothers in higher-risk situations may be less willing to speak with an interviewer who identifies as a mandated reporter and so their perspectives may not be included here. The maternal responses collected represent the experiences of a small group of mothers at a single institution in a rural state and may not be generalizable to other institutions or states.

Implications for Practice

Understanding the perspectives and experiences of mothers is critical to fully engaging providers in implementing non-pharmacologic strategies that treat the mother and infant as a dyad. This work illustrates the importance of non-judgmental approaches to support mothers' efforts to do what is best for their infants. Moreover, mothers want to be with their infants and informed about NAS, both of which make them better equipped to care for themselves and their infants. Guilt is a powerful deterrent to maternal efforts to engage in treatment and bonding, a finding that elevates the importance of training for hospital and community providers in the unique stressors faced by mothers with substance use disorders.[15,38]

Specific implications for practice may be derived from the mothers' criticisms of FNASS. This finding upholds efforts underway to implement "infant-centered scoring" of NAS based on not only provider, but also parental assessment of an infant's ability to eat, sleep, and be consoled.[7,8] In addition, the reassurance and education participants received from other mothers with similar experiences suggests the need for greater peer supports for mothers of infants with NAS. Equally pressing is the need for providers to learn and deliver consistent, accurate, and non-judgmental messages about NAS so that mothers are not driven to pursue pre- and post-natal care and education from alternative and perhaps less reliable sources. Fathers contributed to mothers' efforts to bond with and do what was best for their infants, indicating that interventions encouraging sustained paternal involvement in maternal and infant care may constitute an innovative and beneficial approach to NAS.

Implications for Research

Few studies have solicited the perspectives of mothers of infants with NAS, leaving them with relatively little voice in the literature.[15] Qualitative studies that examine the geographically, racially, and socioeconomically diverse populations affected by NAS remain warranted to enhance provider appreciation of the maternal experience. Specifically, there is

a lack of information about the health of their bonding over time and what factors contribute to parental loss of custody after discharge from the hospital. Quantitative and mixed-method studies may help researchers better understand the long-term outcomes of NAS for mothers, infants, and families and contribute to the development of interventions that minimize family separation.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

We want to express our sincere appreciation to the mothers who participated in interviews in support of this research.

FINANCIAL DISCLOSURE

This research was supported by funding for transcription costs from the Department of Pediatrics and the Neurosciences Service Line at Maine Medical Center. Dr. Craig was supported by the National Center for Advancing Translational Sciences, National Institutes of Health, Grant Number KL2TR001063.

LIST OF ACRONYMS

DHHS	Department of Health and Human Services
FNASS	Finnegan Neonatal Abstinence Severity Score
HPV	human papillomavirus
NAS	neonatal abstinence syndrome
NICU	neonatal intensive care unit
PTSD	post-traumatic stress disorder
SSRI	selective serotonin reuptake inhibitors
STD	sexually transmitted disease

References

1. Patrick SW, Dudley J, Martin PR, et al. Prescription opioid epidemic and infant outcomes. Pediatrics. 2015;135(5):842–850. [PubMed: 25869370]
2. Patrick SW, Schumacher RE, Benneyworth BD, Krans EE, McAllister JM, Davis MM. Neonatal abstinence syndrome and associated health care expenditures: United States, 2000–2009. Jama. 2012;307(18):1934–1940. [PubMed: 22546608]
3. Patrick SW, Schiff DM. A Public Health Response to Opioid Use in Pregnancy. Pediatrics. 2017;139(3).
4. Abrahams RR, Kelly SA, Payne S, Thiessen PN, Mackintosh J, Janssen PA. Rooming-in compared with standard care for newborns of mothers using methadone or heroin. Canadian family physician Medecin de famille canadien. 2007;53(10):1722–1730. [PubMed: 17934036]
5. Logan BA, Brown MS, Hayes MJ. Neonatal abstinence syndrome: treatment and pediatric outcomes. Clinical obstetrics and gynecology. 2013;56(1):186–192. [PubMed: 23314720]

6. McQueen K, Murphy-Oikonen J. Neonatal Abstinence Syndrome. The New England journal of medicine. 2016;375(25):2468–2479. [PubMed: 28002715]
7. Grossman MR, Berkwitt AK, Osborn RR, et al. An Initiative to Improve the Quality of Care of Infants With Neonatal Abstinence Syndrome. Pediatrics. 2017.
8. Holmes AV, Atwood EC, Whalen B, et al. Rooming-In to Treat Neonatal Abstinence Syndrome: Improved Family-Centered Care at Lower Cost. Pediatrics. 2016;137(6).
9. Bicking Kinsey C, Hupcey JE. State of the science of maternal-infant bonding: a principle-based concept analysis. Midwifery. 2013;29(12):1314–1320. [PubMed: 23452661]
10. French ED, Pituch M, Brandt J, Pohorecki S. Improving interactions between substance abusing mothers and their substance-exposed newborns. Journal of obstetric, gynecologic, and neonatal nursing : JOGNN. 1998;27(3):262–269.
11. Johnson HL, Rosen TS. Mother-infant interaction in a multirisk population. The American journal of orthopsychiatry. 1990;60(2):281–288. [PubMed: 2098001]
12. Fraser JA, Barnes M, Biggs HC, Kain VJ. Caring, chaos and the vulnerable family: experiences in caring for newborns of drug-dependent parents. International journal of nursing studies. 2007;44(8):1363–1370. [PubMed: 16938299]
13. Nardi DA. Parent-infant interaction during perinatal addiction treatment. Issues in comprehensive pediatric nursing. 1994;17(3):161–175. [PubMed: 7759321]
14. Alhusen JL, Gross D, Hayat MJ, Woods AB, Sharps PW. The influence of maternal-fetal attachment and health practices on neonatal outcomes in low-income, urban women. Research in nursing & health. 2012;35(2):112–120. [PubMed: 22262085]
15. Kramlich D, Kronk R. Relational Care for Perinatal Substance Use: A Systematic Review. MCN The American journal of maternal child nursing. 2015;40(5):320–326. [PubMed: 26295509]
16. Cleveland LM, Bonugli R. Experiences of mothers of infants with neonatal abstinence syndrome in the neonatal intensive care unit. Journal of obstetric, gynecologic, and neonatal nursing : JOGNN. 2014;43(3):318–329.
17. Cleveland LM, Bonugli RJ, McGlothen KS. The mothering experiences of women with substance use disorders. ANS Advances in nursing science. 2016;39(2):119–129. [PubMed: 27149226]
18. Cleveland LM, Gill SL. “Try not to judge”: mothers of substance exposed infants. MCN The American journal of maternal child nursing. 2013;38(4):200–205. [PubMed: 23812057]
19. Atwood EC, Sollender G, Hsu E, et al. A qualitative study of family experience with hospitalization for neonatal abstinence syndrome. Hosp Pediatr. 2016;6(10):626–632. [PubMed: 27647475]
20. Marcellus L A Grounded Theory of Mothering in the Early Years for Women Recovering From Substance Use. Journal of family nursing. 2017;23(3):341–365. [PubMed: 28795852]
21. Kramlich D, Kronk R, Marcellus L, Colbert A, Jakub K. Rural Postpartum Women With Substance Use Disorders. Qualitative health research. 2018:
22. 45 CFR 46.117. 2009.
23. Services DoHaH. Title 45; Documentation of Informed Consent. 2009.
24. Services DoHaH. Documentation of Informed Consent. 452009.
25. Amankwaa L, Pickler R. Measuring maternal responsiveness. The ABNF journal : official journal of the Association of Black Nursing Faculty in Higher Education, Inc. 2007;18(1):4–15.
26. Brockington IF, Fraser C, Wilson D. The Postpartum Bonding Questionnaire: a validation. Archives of women’s mental health. 2006;9(5):233–242.
27. Heermann JA, Wilson ME, Wilhelm PA. Mothers in the NICU: outsider to partner. Pediatric nursing. 2005;31(3):176–181, 200. [PubMed: 16060580]
28. Klier CM. Mother-infant bonding disorders in patients with postnatal depression: The Postpartum Bonding Questionnaire in clinical practice. Archives of women’s mental health. 2006;9(5):289–291.
29. Taylor A, Atkins R, Kumar R, Adams D, Glover V. A new Mother-to-Infant Bonding Scale: links with early maternal mood. Archives of women’s mental health. 2005;8(1):45–51.

30. Wittkowski A, Wieck A, Mann S. An evaluation of two bonding questionnaires: a comparison of the Mother-to-Infant Bonding Scale with the Postpartum Bonding Questionnaire in a sample of primiparous mothers. Archives of women's mental health. 2007;10(4):171–175.
31. Wittkowski A, Williams J, Wieck A. An examination of the psychometric properties and factor structure of the Post-partum Bonding Questionnaire in a clinical inpatient sample. The British journal of clinical psychology. 2010;49(Pt 2):163–172. [PubMed: 19460238]
32. Bengtsson M How to plan and perform a qualitative study using content analysis. Nursing Plus. 2016;2:8–14.
33. Mayring P Qualitative content analysis: theorestical foundation, basic procedures and software solution. 2014 http://nbn-resolving.de/urn:nbn:de:0168-ssoar-395173. Accessed July 14, 2018.
34. MAXQDA Analytics Pro [computer program]. Berlin, Germany: VERBI Software; 2018.
35. Polit DF, Beck CT. Nursing research : generating and assessing evidence for nursing practice. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins; 2017:491–505.
36. Nikoo N, Frank A, Nikoo MA, Jang K, Abrahams R, Krausz M. Health of Pregnant Women with Substance-related Disorder, A Neglected Global Health Issue Required Combined Maternity Care Units. Mental Health in Family Medicine. 2015;11(26):26–35.
37. Kramlich D, Kronk R, Jakub K. Challenges and Facilitators of Recruitment: Lessons Learned from Conducting a Focused Ethnography in a Vulnerable Rural Population. The Qualitative Report. 2017;22375000168302(3):818–830.
38. Marcellus L Supporting women with substance use issues: trauma-informed care as a foundation for practice in the NICU. Neonatal network : NN. 2014;33(6):307–314. [PubMed: 25391589]

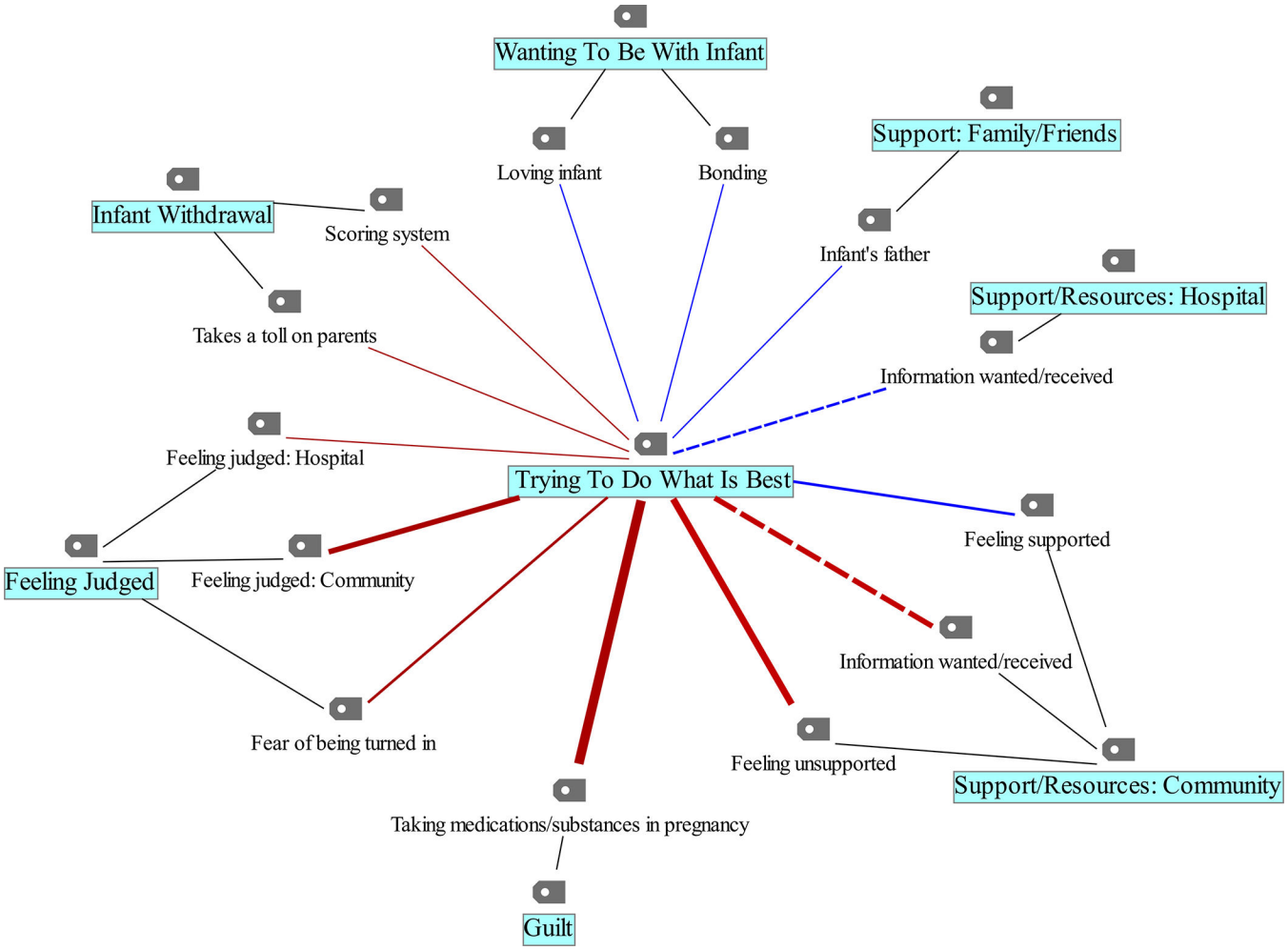

Figure 1.

Co-Occurrence of Codes Associated with the Overarching Theme: Trying to Do What Is Best.

Description: This figure provides a visual representation of the primary themes and sub-themes that co-occur, or are linked, with the overarching theme: Trying to Do What Is Best. The thickness of the lines indicates the frequency of the code intersections (co-occurrences). Blue lines indicate the code or sub-code linked with, and supportive of, the overarching theme.

Red lines indicate the code or sub-code linked with, and a barrier to, the overarching theme. Dashed lines indicate primarily supports (blue) or primarily barriers (red) linking codes or sub-codes to the overarching theme.

Table 1.

Maternal Characteristics

Maternal Characteristics	n (%)
Highest level of education	
Some high school	3 (23)
High school or equivalent	7 (54)
Some college	3 (23)
Living arrangements	
Lives with infant's father	9 (69)
Lives with other family/relatives	5 (39)[a]
Rural area	7 (54)
Ethnicity	
Hispanic	1 (8)
Native American	1 (8)
White	11 (84)
Comorbid conditions	
Anxiety	9 (69)
Bipolar disorder	2 (15)
Depression	10 (77)
Headaches, chronic pain	6 (46)
Hepatitis C virus	7 (54)
HPV and/or STD	7 (54)
Trauma, PTSD	4 (31)
Medications used during pregnancy	
Benzodiazepines	5 (35)
Buprenorphine	13 (100)
Gabapentin/muscle relaxants	3 (23)
SSRIs	3 (23)
Substances used during pregnancy	
Cocaine	2 (15)
Heroin	2 (15)
Marijuana	3 (23)
Tobacco	12 (92)

Abbreviations: HPV, human papillomavirus; PTSD, post-traumatic stress disorder; SSRIs, selective serotonin reuptake inhibitors; STD, sexually transmitted disease.

[a]One mother lived with infant's father, in home of her relatives

Table 2.

Quotes Illustrating Co-Occurring Themes Wanting to Be with Infant and Trying to Do What Is Best.

Theme	**Definition**	
Wanting To Be With Infant	Mother's desire to be physically present with infant	
Sub-Themes	**Definition**	**Supporting Quotes**
Bonding	Mother's connection to her infant Using the term "bond" in reference to relationship with infant	I can't put him to the breast because they want to know ounce-per-ounce, what he's eating. And that's just so that they can do a better assessment of how sick he may or may not be…Breastfeeding for any mom, even if they hate it, it's the extreme, it's the definition of bonding, you know? Especially if you can do it, to watch somebody else feed your child sometimes it's hard.
		So we kind of wanted to do what was healthier, because they say it's always best for immune systems and all of that, and the bonding also. So we kind of chose it [breastfeeding] for that reason.
Loving infant	Describing feelings of love for infant	So, I don't feel totally respected and totally like people have faith in me, but you know what, I don't care. I believe in myself now. Like, just looking at her, I know that I can at least give her my love and take care of her to the best I can. So, I don't really care what other people think. All I care about is that little girl.
		I don't know. It's hard to put in words. Holding her, I just love her so much.
		They can discharge me all they want. I ain't going nowhere until they say she can go. So they're stuck with me until they say she can leave… because I'm attached to her.

Table 3.

Quotes Illustrating Co-Occurring Themes Support and Trying to Do What Is Best.

Theme	**Definition**	
Support: Family/ Friends	Mother feeling, wanting, or lacking support from family members or friends	
Sub-Themes	**Definition**	**Supporting Quotes**
Infant's father	Describing involvement of infant's father, and/or perceived or actual types of support	His dad has been really supportive through the whole thing. And to stay with us and I can tell how much he loves him. He's not like not blaming it you know, on me - what happened…He tries to comfort me.
		The support of my boyfriend just assuring me that I did what I thought was right. That's all you can really do. So there's no manual. There's no instruction guide. I did what I thought was right.
		Out there I heard 'em all joking about, "Oh, fathers don't know anything…" I felt like saying, "Well, the father of my child does." You never see a post about a father's group or… a brochure [for fathers]…, but to me, she needs just as much bonding with him as she does [with] me.
Theme	**Definition**	
Support/ Resources: Hospital	Mother feeling, wanting, or lacking support from staff and/or providers at the (study) hospital.	
Sub-Themes	**Definition**	**Supporting Quotes**
Information wanted/ received	Expressing desire for or value of receiving information about pregnancy, motherhood, or NAS while at the (study) hospital, where newborn infant was hospitalized	Knowing the baby is - whatever it's called, when they go through coming off the medications. I guess some babies, their mother is on all kinds of meds, like high doses and the baby, it does alright and then some - it's a case to case thing. I've been asking and trying to research and figure out how it actually works, but I guess there's a lot of unknowns in that area, like it varies so much.
		So I'm like, "Well, what's this medication doing?" But nobody's even mentioned the fact that, is it - so then I was just like maybe the benefits of breast feeding outweigh anything bad from taking the medication. But nobody has really explained that.
		The first lactation consultant said "No, keep taking your meds." I absolutely recommend breast-feeding. The second one didn't agree. She thought that maybe I should come off a lot of them if I wanted to breastfeed. The third one was kind of like, "Well, it's up to your pediatrician." So I guess everyone has a different opinion. It's like who really, I mean, how do you tell what's best?
		The last couple days we were under the impression that [we] would both go home today. Then this morning we found out that wasn't the case. They kept on saying, "Oh you guys - go home tomorrow or - go home [in] two days."
		What would have been helpful was knowing the process. Like one person said we wouldn't be able to stay here. Then another nurse said we would. Another nurse, oh when you get discharged, I don't know if generally patients do go home and they're just being nice to us because she does better with us. Or I still don't really know how it technically worked. Then other people, if she goes to the NICU, yeah, you can stay on a cot with her. Oh no, you can't, you've gotta go. So there's a lot of confusion there.
		They have talked to us, which is also great, is to knowing what the treatment plan would be as far as medication and how much they might look to put her on, and how they would lower her down on it.
Theme	**Definition**	
Support/ Resources: Community	Mother feeling, wanting, or lacking support from community agencies and/or outside hospitals.	
Sub-Themes	**Definition**	**Supporting Quotes**
Feeling supported	Recalling or anticipating feeling	There's an outreach program, luckily in the town I live, which is too bad that it's the only town that has it. It's because it's a ritzy town. They're trying to clean their streets up so to speak. But it's just

Theme	Definition	
	supported in the community or outside hospitals	too bad other towns around don't have it. Just all the rich people pretty much donate money and they have this fund for people who are in recovery that need anything…they've paid my rent a few times.
		Being in a group with other women that are pregnant… and seeing them go through things and listening to how they would get over their fears and stuff like that… It would give me ideas.
Feeling unsupported	Recalling or anticipating feeling unsupported in community or outside hospitals	But the main reason was at [community clinic] I was high risk just basically because of the [buprenorphine] at that point. But, so I was being seen every two weeks and I called to reschedule because I couldn't make it one day, and they couldn't get me in for seven weeks. So I was like, I don't think so. So I transferred here. I do have to say I got really good care here as far as that went.
		I…found out I was pregnant and I went to a treatment program. I had been in a monthly program. There wasn't any - they'd say there was counseling, but there was never any counseling. This was for [buprenorphine].
		The doctor came in and was like, "Oh, the jitters are probably from the [antidepressant]." And I'm like, "What?" I guess I should have been asking or someone should have told me. No one seemed to care that all my prescribers, no one seemed to care. I mean, they'd give me anything under the sun, even pregnant.
Information wanted/ received	Expressing desire for, or value of, receiving information about pregnancy, motherhood, or NAS from resources in the community or outside hospitals	I switched to [community clinic] and I was not happy with her service. All she [community nurse] did was like come there and weigh the baby, and she could never give me an answer about advice on how to do things. I'm like, "This is not working".
		With the medication [buprenorphine] though, I did hear like, being on it and different. Like the doctor that I'm at, he was like yeah, dose definitely does matter. And then at the clinic they were like, "No, dose doesn't matter." So it's kind of like you have to get a feel of what you feel yourself.
		I just think the hospital, the prenatal, your prenatal stuff being more educated on the possibilities of NAS is huge for moms and I think it needs to be out there more. I think women, fathers, families, need to be educated before it happens so they know.

Table 4.

Quotes Illustrating Co-Occurring Themes Guilt and Trying to Do What Is Best.

Theme	**Definition**	
Guilt	Mother feeling guilt (i.e. remorse, regret, or shame)	
Sub-Themes	**Definition**	**Supporting Quotes**
Taking medications/ substances in pregnancy	Describing current or previous feelings of guilt about taking medications or substances during pregnancy	I love my son so much and when he's not with me, when he's not here, I hear his crying and I want to be with him and I feel bad that I did [buprenorphine] when I was pregnant, but yet again, I feel like I did [buprenorphine] because I was trying to do the right thing. So it's a torn feeling - torn between two different feelings.
		Because I know as a former addict how it feels to be sick. Then to have to think about her being to tiny, and I didn't even give her a chance… She's gonna have to go through that, and it's my fault.
		Like when she was born, just seeing her come out of me, I just started bawling, and it wasn't really happy tears, even though I love her to death… It was guilt… How could I smoke a pack of cigarettes a day…How could I do that to this innocent? I don't know if I thought it was a fake baby growing inside. I just didn't realize the consequences… I don't understand some women who [have] three, four, five kids [with NAS]. I couldn't do this again. No way. I couldn't.
		I smoked, actually when I found out I was pregnant I tried to cut back so I was smoking like two packs a day. I cut back to like a pack a day. Then I went right back up when I had my emotional thing, like two packs a day, which is ridiculous, I feel super guilty about it. I just sit here, that's what kills me. How could I just do that?

Table 5.

Quotes Illustrating Co-Occurring Themes Feeling Judged and Trying to Do What Is Best.

Theme	**Definition**	
Feeling Judged	Mother feeling judged by others; that others had formed a negative opinion (about her)	
Sub-Themes	**Definition**	**Supporting Quotes**
Feeling judged: Community	Feeling judged by agency staff and/or providers in the community	I went into the [community] hospital and told them I was in pain. Like something was wrong and I felt really weird. Then I went in there probably four times and they would assume that I was seeking for drugs because I would tell them I was straight but that I was on [buprenorphine]. Every time they would just assume that I was seeking for drugs. So they didn't really, I don't think really do much to try figure out what was wrong with me. Then finally, so by the time they figured it out I was almost in full blown kidney failure and ended up being in the [community] hospital two weeks.
		I feel really comfortable with the counselor I have. So it's like the other people, the receptionist, are the ones that are like judgmental and the counselor that's not a mother and…has never been a drug addict.
Feeling judged: Hospital	Feeling judged by providers in the hospital	I tried to do detox so she wouldn't have to [withdraw]. But that didn't work.., I felt like I was being judged. Maybe I wasn't being judged, but it just feels that way. And sometimes that's all - a look - just a certain look can really make you feel [judged].
		The only bad experience that the hospital brought me was some of the nurses were judgmental. That was really it. Besides that there was [sic] more nurses that we talked to. They apologized and said they'd do something about it.
Fear of being turned in	Fear of being reported to DHHS by providers; and/or subsequent separation from infant	I was really nervous, I think about the whole DHHS thing. I think that's what a lot of the women are concerned about here [in outpatient clinic], which is weird, because I never even had anybody come to my house or anything and I was told it was probably because I had the visiting nurses and I have the therapist still come to my house. But like someone in group had told me that DHHS went to her house and looked all around and had an open case or something.
		[Got help with substance use] knowing what was best for baby and make sure that she was as healthy as possible… thought about effects if I didn't get help when I had her at the hospital. They would know and the whole DHHS thing, you're worried about losing the baby.

Abbreviations: DHHS, Department of Health and Human Services

Table 6.

Quotes Illustrating Co-Occurring Themes Infant Withdrawal and Trying to Do What Is Best.

Theme	**Definition**	
Infant Withdrawal	Infant's signs/symptoms of drug withdrawal	
Sub-Themes	**Definition**	**Supporting Quotes**
Scoring system	Describing the experience of having an infant that is monitored with the FNASS	If the nurse would say, "Did she yawn? Has she yawned or sneezed?" It's like, my first instinct is to say, "No." But no, or because if I say yes, are they gonna mark her high and then you know, like if she needs medicine I want her to have it. I don't want her to suffer. I don't want her to be in pain. But at this point I don't really feel like she would need any type of medication. So sometimes I feel like their scoring thing is just - it makes me feel a little uneasy. Like you almost don't want her to do normal things because you think that she's gonna get scored for doing it.
		When they take the babies for scoring, I feel like it's just agitating them more. Of course they're going to be like fussy… I don't know how there could be other ways of really scoring them, or if they need to score them at all. It's just like, watch them and see... She sneezed, but babies do sneeze. You can tell if she's really going through withdrawals or not... I think they should just overall watch them, you know?"
		The whole scoring thing too, is that they should probably involve the parent a little bit in it.
		I don't know if the scoring system is absolutely fair because some of the [symptoms it monitors for] a regular baby would have, and it counts as points against her.
		This inconsistency with the nurses… like one would score her for being stiff, and another one wouldn't… that scoring system is kind of strange.
		Nobody's actually showed me a scoring sheet or how they score her or anything… I don't know if low is two, if low is four, if low is ten. I don't know."
Takes a toll on parents	Emphasizing the difficult emotions involved in witnessing infant having symptoms of NAS	As I started seeing the symptoms come on I knew what it was. I knew what to ask for. What kind of help to ask for. And it just made - it was still exhausting, but it made it just so much easier.
		[My daughter] was very shaky…She'd contract her arms and legs and just shake, and oh my God, it killed me.

Abbreviation: FNASS, Finnegan Neonatal Abstinence Severity Score