



October 2018

## Challenges and Resources Available for Mothers in Opiate Recovery: A Qualitative Study

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### Recommended Citation

Suarez, M. A., Horton-Bierema, W., & Bodine, C. E. (2018). Challenges and Resources Available for Mothers in Opiate Recovery: A Qualitative Study. *The Open Journal of Occupational Therapy*, 6(4). <https://doi.org/10.15453/2168-6408.1483>

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# Challenges and Resources Available for Mothers in Opiate Recovery: A Qualitative Study

## Abstract

*Background:* Opiate abuse and addiction in women during childbearing years has led to a sharp increase in neonatal abstinence syndrome (NAS). Babies born with NAS are at risk for significant health and developmental deficits. Through understanding the challenges experienced by mothers in opiate recovery, and the resources available to this group, sensitive and effective treatment can be developed to ameliorate the impact of NAS on the child and the family.

*Method:* This qualitative interview study provides insight into the experience of becoming a mother for women in opiate recovery.

*Results:* Themes from the interviews include deep love for the baby, the baby as a motivation to stay sober, and the determination to make the relationship between mother and child different from the one the mother had experienced with her own mother.

*Discussion:* Occupational therapists have a distinct, important role in the treatment of mothers in opiate recovery and their babies. This study illustrates the need for the occupational therapy skill set in this population.

## Comments

The authors report grants from The Kellogg Foundation and Western Michigan University Internal Support for Faculty Scholars Award (SFSA) during the conduct of the study.

## Keywords

opiate, neonatal abstinence syndrome, motherhood, occupational therapy

## Cover Page Footnote

The authors would like to acknowledge the mothers who shared their experiences. They are a brave and inspirational group of women. In addition, thank you to the occupational therapy students who participated in data collection and analysis, including Elsie Bush, Lindsay Bennett, Michelle Dalton, Heather Fox, and McKensie Ward.

## Credentials Display

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DOI: 10.15453/2168-6408.1483

Opiate abuse and addiction is a serious and growing health problem in the United States. In 2016, 11.8 million people aged 12 years and older demonstrated opiate misuse (Substance Abuse and Mental Health Services Administration [SAMSA], 2017). Many opiate misusers begin with prescription drugs, like hydrocodone and oxycodone, before moving to heroin and cocaine. This trend has led to the doubling of heroin use among women between 18 to 25 years of age (Centers for Disease Control and Prevention [CDC], 2015).

The increase in opiate use among women during childbearing years has led to a sharp increase in infants born with neonatal abstinence syndrome (NAS). NAS is a postnatal opiate withdrawal syndrome that occurs in up to 94% of infants whose mothers were addicted to or treated with opiates while pregnant (McQueen & Murphy-Oikonen, 2016). This disorder is characterized by central nervous system hyperirritability, autonomic nervous system dysfunction, and gastrointestinal disturbances (Stover & Davis, 2015). From 2004 through 2013, the rate of neonatal intensive care unit (NICU) admissions for neonatal abstinence syndrome increased from seven babies per 1000 admissions to 27 babies per 1000 admissions. NAS has long-term negative implications not just for babies born addicted to opiates but for their families and the communities in which they live.

Babies born with NAS frequently demonstrate excessive crying, irritability, fitful sleep, increased muscle tone, tremors, loose stools, nasal stuffiness, yawning, sweating, and sneezing after birth (Stover & Davis, 2015). In addition, there is growing evidence that NAS has a detrimental impact on development. NAS is associated with a reduction in infant head circumference that may play a role in decreased early motor skill development (Bier, Finger, Bier, Johnson, & Coyle, 2015). Other studies have pointed to increased attention deficit hyperactivity disorder (ADHD) and other disruptive behavior disorders in this population (Ornoy, Segal, Bar-Hamburger, & Greenbaum, 2001). There is some evidence that the neurobehavioral dysregulation of NAS can impact early learning. For example, Beckwith and Burke (2015) found that children exposed to opiates prenatally had lower language and cognitive scores on the Bayley-III Scales of Infant Development.

Because of central and autonomic nervous system dysfunction and the potential for developmental delays, children with NAS can be hard to parent (Sundelin-Wahlsten & Sarman, 2013). Compounding this issue is the fact that caregivers with substance abuse disorders often do not possess a skill set conducive to meeting this challenge (Street, Whitlingum, Gibson, Cairns, & Ellis, 2008). A large number of individuals who abuse substances have had adverse childhood experiences, including abuse and neglect (Felitti et al., 1998). People who experience four or more categories of adverse experiences during childhood (e.g., physical abuse, sexual abuse, neglect, or parent mental illness) have a 4- to 12-fold health risk increase in alcoholism and drug abuse. In addition, substance abuse is highly correlated with poor parenting capacities, difficulty with the formation of relationships, and an increased need for child protective services involvement (Roussothe, Soderberg, & Sowell, 2010; Sarkola, Gissler, Kahila, Autti-Rämö, & Halmesmäki, 2011). Parents of children with NAS sometimes have difficulties regulating themselves and are unable to achieve the calm-alert state needed to respond successfully to their children's cues. These infants are very likely to have parents who are members of families that have struggled with substance abuse for generations (Ornoy et al., 1996).

Occupational therapists in pediatric practice strive to provide family-centered care (DeGrace, 2003). Our "client" is not just the child receiving services but the entire family in which the child functions. Therefore, we need to understand the experiences, strengths, and needs of the people in the child's wider social context. The mother, who provides nurturing and teaching, is at the center of this

context. To develop treatment to ameliorate the impact of NAS on the baby, it is necessary to understand the lived experiences of the mothers who are struggling to overcome opiate dependence and simultaneously mother their children.

Several studies have illustrated the treatment importance of noticing and honoring the mother in the mother-infant dyad. A qualitative study by Cleveland and Gill (2013) revealed that the mothers of children born with NAS had experiences that were marked by uncertainty, fear, shame, and stress. The stigma of substance use provided an additional burden for the mothers when the judgmental attitudes and behaviors of health care providers served to alienate and retraumatize mothers who had experienced prior trauma in their lives. A qualitative study by Olson and Esdaile (2000) examined the experience of mothering in a challenging urban environment for women who had children with disabilities. These mothers spoke of a lack of support for their mothering role due to living with violence and not feeling “seen” by occupational therapists who were treating their children. A review of the literature related to prenatal cocaine exposure and mother-child interaction stressed that mothers who have substance disorders needed support for exhibiting the responsiveness to their children that facilitated attachment (Miller, 1996). The author suggested that occupational therapists with knowledge of sensory integrative theory and child development could educate mothers about how to read their infants’ cues and needs. Finally, Graham, Rodger, and Ziviani (2013) highlight the need for occupation-centered practices that include guiding a caregiver to engage his or her child for better caregiver empowerment and competency. Family-centered care requires developing an understanding of the strengths and needs of the child’s entire family, and, in particular, the mother.

This qualitative study explored the experience of becoming a mother for women in an opiate recovery program who had babies born with NAS. In addition, the mothers who were interviewed shared their health care experiences after delivery of their babies. In light of the growing opiate epidemic, there is an urgent need to develop health care services that can match the unique needs of this population. Understanding the experiences and complex needs of mothers in opiate recovery will provide information that can be integrated into holistic and family-centered treatment.

### **Method**

This study used a narrative qualitative methodology (Barbour, 2008) to capture the voices of mothers in opiate recovery who have babies born with NAS. The study’s aim was to describe each participant’s lived experience while exploring common themes across the participants. The Western Michigan University Human Subjects Institutional Review Board approved this study and informed consent was obtained before each interview.

### **Participants**

Mothers in a larger scale study of the impact of combined occupational and music therapies were invited to complete interviews. All four participants were in an opiate substance abuse recovery program and had a baby born with NAS. At the time of the interviews, each baby was between the ages of 14 months and 20 months. Each mother had an established relationship with the researcher. This was important, as women in substance abuse recovery with complex histories often have difficulty with authentic sharing of personal information (Hooks, 2015; Woo et al., 2017). Therefore, although four constitutes a small sample, this population is typically difficult to reach. In addition, qualitative procedure was followed with evidence of data saturation across the interviews. Pseudonyms are used to protect the participants’ anonymity.

## Data Collection

Characteristics of the participants and their babies were gathered through the above mentioned larger scale intervention study. Semi-structured interviews were conducted in person or over the phone at the participant's request. Interviews ranged from 30 to 60 min. All of the mothers were interviewed once and each interview was audio recorded. The interviews consisted of a series of open-ended questions (see Table 1). In addition, the interviews allowed the mothers the opportunity to raise any other salient issues that were important to them (Barbour, 2008). All of the interviews were transcribed verbatim for analysis.

**Table 1**

### *Semi-Structured Interview Questions*

What are the best things about being a mother?
What are challenges or things that you did not expect related to your experience as a mother?
How is your relationship with your baby different from your relationship with your mom growing up? How is it the same?
What has your health care experience been like through your pregnancy, labor, and delivery?
Is there anything else you would like to share?

## Analysis

Analysis for this study was guided by the work of Barbour (2008). The coding frame was honed through the research team's reading (then rereading) of the transcripts and participation in discussion to develop agreement in relevant codes for the data. Then, constant comparison allowed for data patterns to be identified and themes to be revealed. All relevant statements were coded, clustered into themes, and then discussed among the authors until consensus was reached about the meaning of each statement and its fit with each theme. Verbatim examples were chosen to provide a rich textual description of the mothers' experiences in opiate recovery with infants with NAS (Moustakas, 1994). Data triangulation (Guion, Diehl, & McDonald, n.d.) was achieved through discussion of the data with the occupational therapist and music therapist (second and third authors) as each potential theme emerged. During this discussion, the occupational therapist and music therapist intentionally identified the ways in which these themes were validated during clinical practice with each mother.

**Table 2**

### *Demographic Information for Mothers and their Babies*

<b>Mom and Baby</b>	<b>Mom's age</b>	<b>Employment status</b>	<b>Family status</b>	<b>Mom's years of education</b>	<b>Baby's gender</b>	<b>Baby's race/ethnicity</b>	<b>Baby's birth order</b>
Natalie and Jordan	35	Working outside home	Divorced	Some High school	Male	No response	1
Ava and Megan	33	Not working outside the home	Single parent	High school diploma	Female	Caucasian Non-Hispanic	3
Bridgette and Reed	32	Not working outside the home	Single parent	Some college	Male	Caucasian Non-Hispanic	1
Allison and Landon	32	Not working outside the home	Single parent	Some college	Male	Caucasian Non-Hispanic	2

All of the mothers interviewed were single parents (although two lived with their partners, who were the babies' fathers) and all were in their early to mid-thirties. The participants shared similar views regarding the experience of motherhood and their interaction with health care professionals after the birth of a baby born with NAS. Themes that emerged from the interview transcripts included: (a) a deep love of being a mother, and the baby as a key motivator for sobriety; (b) the determination to make the relationship between mother and child different from the one the mother had experienced with her own mother; (c) difficulty with understanding child development as it unfolded; and (e) mixed reviews of the health care experience.

Quotes from the participants, such as, "There is no love like a mother and child's love," provide vivid illustrations of the concepts shared by the mothers in this study. It was clear that these mothers were in love with their babies and treasured the experience of motherhood. At the same time, these mothers were marshalling this love to serve as motivation to stay sober and to continue in substance abuse recovery. They spoke of their babies giving their lives meaning and purpose. The participants in these interviews were determined to stay sober so that their babies would have someone to nurture them and guide them through childhood.

**Natalie with Jordon.** "Let's see now. I have a purpose you know, before I didn't have too much to look forward to (chuckles). Now I do. You know I'm not . . . I'm not always trying to get better for me, I'm trying to get better for him, so he has a mother longer, you know."

**Ava with Megan.** "She has a mom and she has someone there for her, and that incentive is motivation to keep doing it [stay sober]."

**Bridgette with Reed.** "But you know recovery is. . . has been easy for me because that's what I focus on. I wanna be the best mother I can be for my child, and he's beyond more important than anything else."

**Allison with Landon.** "There's nothing like it. There is no love like a mother and child's love. You know he helps so much in my sobriety. I was like, 'he would be so confused and so hurt if something was to happen and he got taken from us.'"

### **This Relationship will be Different**

All of the mothers interviewed for this study described their relationship with their own mothers as difficult. They had either experienced abuse, had a mother with a substance abuse disorder, or felt like their mothers could not be there for them. The mothers interviewed were determined to make their babies' childhoods different from their own and to make the mother-child relationship different from the one they had experienced. In addition, two of the mothers that were interviewed spoke of losing custody of their other children. All of the mothers spoke of the intention and determination to make this relationship different.

**Natalie with Jordan.** "My mom was never really a mother, she used to beat on me and starve me. I had big fears that, you know, with her being as mean to me and as abusive and stuff that she was, that I would be maybe be . . . wrong to him and . . . and I . . . you know, now that he's come along I can't IMAGINE doing the things that happened to me to him. He'll go further in life than I ever did."

**Bridgette with Reed.** "Um, my mom had me at an older age, um, so I really don't remember a whole lot with playing with my mom or anything . . . Um, my mom also was an alcoholic, so I really . . . I really didn't feel like when I was younger I had much of a mother/daughter relationship."

**Ava with Megan.** "My other two kids, someone else cares for them. Raising the other two kids was interesting and difficult but it's different with this one."

**Allison with Landon.** “And you know, I have my older son Alex, he just turned 9 in January and he’s with family. You know, and I tried back then, but you know, and I didn’t lose my rights to him, I actually, I signed over my rights. He’s with his aunt and uncle. You know, I asked ‘cause I knew I wasn’t ready.”

### **Struggling to Understand their Children’s Development**

All of the mothers had some expectations of their children that did not match age expectations, or they held beliefs about behavior that did not reflect typical development. For example, Allison spoke of her 17-month-old engaging in acting out behavior.

Well, recently he’s acting out, like his behavior. If he hits, I don’t hit him back because I don’t believe that that’s gonna solve anything. So, you know I just try to get on his level, look him in the eyes, and explain to him, you know, ‘that hurt me’ . . . but I don’t hit. Um, that’s one of the biggest challenges right now, so . . . is him acting out in that way but . . . he sees it from the other kids.

Allison did not understand that her child was not yet ready to have the empathy needed to understand how hitting might make her feel, and that Landon was unlikely to stop with her explanation.

Bridgette shared her confusion about what constituted a “solid food,” and that she did not have anyone she trusted to ask.

I didn’t know . . . the health care provider tells you . . . they give you . . . you know, like a sheet of just stages of what they go through each month, and what they should be doing and for solid foods, you know, a lot of people were telling me that pureed foods were solid foods so I, you know, I thought that him taking pureed foods was okay at 9 months, but he should have been taking small pieces of foods like the puffs and everything.

In every interview, the mothers verbalized or demonstrated some confusion about what they should expect from their children. They struggled to understand and interpret their children’s behaviors and were unclear about how to respond. These mothers did not have reliable resources that they trusted to get their questions answered or to support their success in guiding and shaping their children’s behavior.

### **Mixed Reviews of Health Care Providers as a Caring Resource**

All of the mothers interviewed had mixed experiences with health care providers during and after their pregnancy, labor, and delivery. All four of the mothers experienced some stigma and judgement for their participation in substance abuse treatment that included a methadone maintenance program. However, all of the mothers had some positive and supportive experiences with health care professionals as well.

**Ava and Megan.** “Some of the nurses that were pretty rude. You know, they . . . there’s still all that stigma about people having babies born on methadone and . . . like one nurse was like, ‘I don’t know why you people keep having babies on that stuff, you know what it does.’ And I looked at her, I said, “Um, excuse me. This is my best, uh, choice, uh I didn’t want her to be born on heroin, is that what you would rather have me do? To be born on heroin or methadone? So that was my choice.”

**Allison and Landon.** “The [health center over by where I live] really shunned on me for it. Um, they . . . I felt like they looked down on me for it and they treated me differently once I started going to the methadone clinic. They were just short with me and they were rude.”

**Natalie and Jordan.** “But when it comes to my doctors . . . all they see is . . . they see the addiction . . . that’s all they see, you know, and it gets irritating.”

Two of the mothers spoke of the self-advocacy that was necessary in order to get their health care needs met. They spoke of the stigma that they experienced and how it impacted their care, even with a change in providers.

**Ava with Megan.** “I originally went to [Hospital A] where I had my other two kids, and as soon as they found out that I was in the methadone clinic they treated me like scum of the earth. Like I was a horrible person that didn’t deserve to be alive or pregnant. I ended up switching to [Hospital B], that was better. I still ran into some of the nurses that . . . there’s still all that stigma about people having babies on methadone. And I ended up telling her superiors about it and they ended up interviewing me for trying to get rid of the stigmas and all that. I was able to help . . . some of the nurses understand. This is a MUCH better choice.”

**Natalie and Jordan.** “We went to the other place and, um, I sat down and finally I just told them, ‘Listen, if this is what’s going on and if you can’t help us then, you know, I’ll take him to another . . . I’ll take him to another doctor.’”

Despite experiencing stigma and frustration in the health care system, all four of the mothers spoke of some health care experiences during pregnancy, labor, and delivery that were positive and supportive. They had some experiences that met their health care needs.

**Bridgette and Reed.** “Throughout the pregnancy, they were supportive. I went through a midwife and so I was with the same one every time. Then, they just told me to take care of my child and, um, I had a beautiful baby in front of me and that you know, I should really just . . . focus on that. They were really understanding and nice about everything.”

### Discussion

These interviews allowed a greater understanding of what challenges mothers in opiate recovery face when they have babies born with NAS. In addition, the perception of health care as a resource was explored. Not surprisingly, all of the mothers interviewed spoke of their deep love for their babies and of being a mother. They now felt like they had meaning and purpose in their lives. This is clearly no different from typical experiences of mothering for women without substance abuse disorders.

However, the mothers interviewed also spoke of their babies as a primary motivation to stay sober. Therefore, the stakes are high in this relationship. This makes the fact that they often had unrealistic expectations of their children or demonstrated misunderstandings about development dangerous for their own health and the well-being of their children. In addition, none of the mothers ever had a caregiving model, and they spoke of a lack of nurturing in their experiences as a daughter. It is difficult to put the needs of another above your own when you have never had this experience yourself. As the baby grows and enters childhood, if he or she does not meet their mother’s expectations, this could be a severe challenge to this relationship. Finally, the reviews of health care providers were mixed. From these mothers’ descriptions, they had all experienced stigma and isolation in health care due to their substance abuse histories. This finding supports the study by Cleveland and Gill (2013) that described the judgement that mothers experienced from health care professionals. The literature makes the importance of feeling “seen” and understood clear (Olson & Esdaile, 2000). The mothers in this study spoke of feeling like many in health care only saw their addiction. However, in addition, all of the mothers in this study spoke of some care providers that were sensitive and compassionate. It is clear that these mothers have few resources, and there is an important opportunity for health care professionals to provide needed nurturing and supportive care at a pivotal point in the lives of these mothers and babies.



Occupational therapists have a philosophy and skill set that is direly needed to improve the health and quality of life for mothers in opiate abuse recovery and their babies born with NAS. A central tenant in occupational therapy practice is holistic, non-judgmental, client-centered care (American Occupational Therapy Association, 2014). This perspective is necessary for building a trusting and nonthreatening therapeutic relationship, in particular with women in substance abuse recovery who frequently have traumatic histories (Felitti et al., 1998), have experienced health care stigma (Cleveland & Gill, 2013), and, as a result, are wary of people in positions of perceived authority. In addition, occupational therapists have in-depth knowledge of typical development, and through the therapeutic relationship they can convey this information to these mothers in a way that it can be accepted and integrated. Finally, occupational therapists are experts in facilitating coregulation (Miller, 1996), using relationship and sensory strategies to bolster the mother-baby connection and resilience in this dyad. In summary, occupational therapists are an ideal potential resource for this vulnerable population to set the mother and baby on a safe and productive path for future quality of life.

### Limitations

This study had several limitations. The first was the small sample. However, this is a population of women that is typically hard to reach (Hooks, 2015; Woo et al., 2017). This study can provide authentic insight into the experiences and needs of this population, which are key to providing effective and sensitive care to this group. Also, the sample included only White women. More information is needed about the experiences of a diverse group of women in opiate recovery. It is possible that institutional racism compounds stigma that minority women experience in health care (White & Stubblefield-Tave, 2017). Overall, there is more work to be done in this area. This study provides a foundation for future research.

### Conclusion

A rise in opiate use among women of childbearing years brings the needs of mothers with substance abuse disorders and their babies born with NAS forward in pediatric occupational therapy practice. Occupational therapists need to provide sensitive care to the infant that is equally attuned to the needs of the mother and fully supports her caregiving role. This study illustrates some of the challenges these women face as they strive to raise their children. Occupational therapists are poised to meet these challenges with family-centered focus and in-depth understanding of regulation and development.

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