

The Lived Experience of Postpartum Women Attending Outpatient Substance Treatment for Opioid or Heroin Use

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Introduction: The current opioid crisis and associated heroin epidemic have exhausted the limited community services that are available to substance users, with only about 12% of substance use treatment facilities offering special programs for pregnant women. Little information is known about the lived experience of postpartum women in outpatient substance use treatment programs, who are working toward abstinence and caring for a newborn. The purpose of this phenomenological study was to explore the lived experience of postpartum women attending outpatient substance use treatment for illicit opioid or heroin use.

Methods: Individual interviews were conducted between December 2017 and November 2018, with 10 postpartum women with opioid use disorder (OUD) engaged in outpatient substance use treatment programs. A 4-step conceptual framework as suggested by Moustakas was used to understand and synthesize the lived experiences shared by the women.

Results: Five themes emerged from the raw data: the presence of a stigma in providers of health care services, a fear of being reported to family services, children are primary motivators to remain engaged in treatment, concern for the welfare of the infant, and barriers to treatment.

Discussion: Postpartum women with OUD and their infants have complex needs that may best be served by treatment programs that offer comprehensive care. The fear of being reported to family services and possible loss of custody influenced all aspects of their decision-making.

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INTRODUCTION

Each day in the United States, 128 persons die from an opioid overdose.¹ As of 2017, nearly 10 million people had an opioid use disorder (OUD) associated with prescription pain relievers, with 808,000 cases being related to heroin use.² Among individuals who use heroin, 80% reported initial prescription opioid misuse.³ Substance use affects men and women differently, partially influenced by biologic differences and societal gender roles.⁴ According to researchers from the US Department of Health and Human Services Office of Women's Health, opioid overdose deaths have increased 218% in men and 471% in women over the last 15 years.⁵ This significant increase in the number of opioid-related deaths in women highlights the critical need for understanding the lived experiences of women with OUD.

The prevalence of OUD among pregnant women in the United States quadrupled between 1999 to 2014, increasing from 1.5 to 6.5 per 1,000 hospital births.⁶ For childbearing women with OUD, the postpartum period represents a time of increased vulnerabilities. In addition to the need for a woman's physical recovery, adaption to parenthood, and

learning how to breastfeed,⁷ postpartum women with OUD have an elevated risk of being diagnosed with a behavioral health disorder (depression, anxiety),⁸ intimate partner violence (IPV),^{9,10} social adversity (poverty, food insecurity),¹¹ or substance use relapse.¹² In fact, women with OUD overdose more frequently in the postpartum period when compared with pregnancy; the highest rate occurring at 7 to 12 months postpartum.¹³ This higher rate of opioid overdose in the postpartum period may be attributed to the loss of prenatal resources, a woman's sense of shame and stigma related to withdrawal symptoms in her opioid-exposed infant, and a lack of specialized services available to postpartum women with OUD.¹³ This vulnerability during the postpartum period underscores the need for access to comprehensive care, including behavioral health services, substance use treatment, and relapse prevention programs.

Local communities are challenged to find ways to meet the overwhelming demand for substance use treatment services, with only 23% of facilities offering specialized programs for pregnant and postpartum women.¹⁴ In addition to the lack of community resources, prescriber expertise to care for perinatal women with OUD can further restrict treatment options.^{15,16} Further exploration of the experience of postpartum women with OUD engaged in outpatient substance use treatment can lend insight to the lived experience of these vulnerable women. Understanding the experiences of postpartum women with OUD engage in treatment could further assist us in developing specialized services that best meets the needs of this population and retain more women in treatment.

METHODS

Transcendental phenomenology was the qualitative method used to guide this research.¹⁷ The phenomenological

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Quick Points

- ◆ The perception of being treated differently once a substance use history was disclosed was reported by 9 of the 10 women interviewed.
- ◆ The fear of being reported to child services and losing custody of their child or children guided all aspects of a new mother's decision-making.
- ◆ Children are the primary motivator to retain postpartum women in opioid use disorder (OUD) outpatient substance use treatment programs.
- ◆ Clinicians who serve this population should be familiar with institutional and local policy related to at-risk reporting.
- ◆ Provider education for new and existing clinicians should include OUD content and clinical competency training.

framework proposed by Moustakas was specifically chosen because it supports the critical value of “returning to self to discover the nature and meaning of things as they appear and in their essence.”^{17(p 26)} This specific phenomenological approach guided the exploration of the lived experiences shared by postpartum women in outpatient treatment for opioid and heroin use and allowed a deep exploration of some of the most marginalized women in the United States.^{18,19} Although a full description of this method is beyond the scope of this article, briefly, the Moustakas framework affords for the setting aside of biases, the deep evaluation of findings, the continuous analysis of participant statements, and the synthesis of meaning into unified statements.¹⁷

Participants were recruited from 2 outpatient substance treatment programs in the northeastern United States that offered comprehensive care to pregnant and postpartum women. Treatment included access to behavioral health prescribers and medication for OUDs (MOUD). One of the treatment centers offered no-cost on-site child care (during scheduled group sessions) and a food pantry to serve the intersecting needs of the new mothers. Participants were recruited by flyers posted at both facilities. One site allowed the researcher to introduce the study to potential participants with a brief in-person overview at the start of a group treatment session. Postpartum women who were interested in the study contacted the researcher directly.

Study approval was obtained from institutional review board of the study authors, and a Certificate of Confidentiality protecting participant statements was secured from the National Institutes of Health, National Institute on Drug Abuse. Study recruitment efforts took place between December 2017 and November 2018. Inclusion criteria were (1) ability to speak and read English, (2) postpartum within 6 months of birth, (3) age between 18 and 50 years, (4) currently enrolled in an outpatient substance use treatment program, and (5) have a self-reported use of opiates or heroin (in isolation or part of poly-drug use). A maximum of 6 months postpartum was selected to enhance the accuracy of participant recall. Women were eligible regardless of child custody or whether their treatment plan included MOUD. Women with a history of IPV or other abuse or mental health disorders were not excluded, as these are common co-occurring conditions with OUD. Data saturation was approached after 8 women were interviewed, and 2 additional interviews were conducted to validate no new in-

formation contributed to the phenomenon under exploration. The final sample included 10 women.

A study overview was provided by the principal investigator prior to obtaining written informed consent, including study purpose and the right to withdraw at any time or decline to answer questions without impact on their treatment. A brief demographic questionnaire was completed prior to each interview. At site 1, interviews took place in a private room located at the treatment facility, immediately before or after a group session. Interviews with women from site 2 were required to be off site and took place in a private room in a nearby church or, weather permitting, outside in a private location.

All participants agreed to be audio-tape recorded, and none of the participants asked to have the recording stopped or information omitted. An interview guide was used for all sessions and started with the general question: “Tell me about your experience as a mother receiving substance use treatment.” This broad question allowed women to direct the conversation toward their lived experience and provide rich description in their own words. Probing questions such as “tell me more” or “can you talk more about...” were used to more deeply explore experiences. All 10 of the women completed the entire interview, and 9 had their infant present. Participants were remunerated with a \$25 gift card as appreciation for their time.

Interviews were transcribed verbatim by a professional transcriptionist who signed a confidentiality statement. To protect privacy, participants were assigned a pseudonym using a list of retired female hurricane names. To further protect identity, participants are referred to as 1 to 10 in this report. Transcription and review of participant narratives were done immediately following each interview to promote immersion in the data and continual analysis of transcripts. All textual data were imported into NVivo 12 to assist with data management.²⁰ During data analysis, transcripts were reviewed, and raw data reflecting similar participant experiences were labeled as a node in the software. Individual statements within each node were reviewed for accuracy and completion, consistently referring back to the raw data. Themes were developed and continually contrasted with raw data to identify similarities and differences in participant lived experiences. Self-reported demographic data were entered into an Excel spreadsheet under the assigned pseudonym.

Table 1. Participant Demographic Characteristics of Postpartum Women (n = 10)

Characteristics	Value
Age, y	
Range (mean)	23-33 (26.4)
Race, n (%)	
White	10 (100)
American Indian	1 (10)
African American	1 (10)
Hispanic or Latino, n (%)	
Yes	1 (10)
No	9 (90)
Marital status, n (%)	
Married	1 (10)
Never married	5 (50)
In a relationship	4 (40)
Highest grade completed, n (%)	
Grade 9-11 (some HS)	1 (10)
Grade 12 or GED (HS graduate)	4 (40)
1-3 yr college (or tech school)	5 (50)
Employment status, n (%)	
Yes	2 (20)
No	8 (80)
Infant or newborn age, n (%), wk	
2-10	8 (80)
11-20	2 (20)
MOUD treatment, n (%)	
Methadone	1 (10)
Buprenorphine and naloxone (Suboxone)	9 (90)
Ever diagnosed with mental health condition or psychiatric condition,^a n (%)	
Yes ^b	5 (50)
No	5 (50)

Abbreviations: GED, General Educational Development; HS, high school; MOUD, medication for opioid use disorder.

^a Participants could include more than one diagnosis.

^b Depression 3, posttraumatic stress disorder 3, anxiety 4, attention-deficit/hyperactivity disorder 1, bipolar disease 3.

Multiple validation strategies were used to strengthen rigor and trustworthiness. The principal investigator used bracketing to set aside any preexisting personal beliefs or biases related to women with an OUD.²¹ Bracketing has been described as the process of actively suspending one's personal beliefs and experiences, so interpretation of the new data is not seen through the lens of a prior experience.²¹ This was accomplished by having the researcher dedicate time immediately before each participant interview to self-reflect and document any thoughts related to prior experiences, in an effort to partition previous experiences from any potential new data. Field notes were documented after each interview to ensure accurate recall and to note any preliminary thoughts or unexpected findings. Additionally, coding and final themes were verified by 2 PhD-prepared researchers with expertise in women's health and qualitative research. Member checking was not used because of the sensitive nature of the research topic. Any concerns about the meaning of participants'

statements were discussed and resolved with the research team prior to establishing the final themes.

RESULTS

The women ranged in age from 23 to 33 years (mean age, 26.4; Table 1). Most women identified as white and non-Hispanic, which is representative of the racial and ethnic characteristics of the geographical area where the study was conducted. Most of the women were unemployed, single, and had earned a high-school diploma or completed some college. All of the women were receiving MOUD as part of their care and half reported one or more mental health conditions. Nine of the 10 women cared for other children at home.

Five broad themes emerged as central to the lived experience of women who were postpartum, parenting, and receiving treatment for OUD. The themes represented the complex lives of these women as they worked through the process of recovery and included experiences of (1) stigma,

(2) fear of being reported, (3) children are the primary motivation for staying in treatment, (4) concern for the welfare of the infant, and (5) barriers to receiving treatment. The women reflected on their experiences while pregnant and in the hospital after birth. These experiences during and immediately after pregnancy framed how they viewed their lives as mothers.

Experience of Stigma

The experience of stigma from health care providers and the general public was a predominant focus for these women. The encounters they shared involved pharmacists, future employers, treatment counselors, nurses, and other members of the health care team. The women reported incidents of being judged or treated differently when filling MOUD prescriptions (especially when using public insurance), accusations of intentional harm to their unborn child, and being looked at differently by staff when MOUD treatment was disclosed. Other women were denied employment because of substance use or criminal records.

One participant stopped using heroin during her most recent pregnancy and continued with her previously prescribed MOUD to control cravings and minimize withdrawal symptoms. She shared her experience of stigma from the nursing staff:

I'm waiting to get induced and ... I started doing my makeup to kill time and I use like powder bronzer or whatever, and some of it spilled on the table. The nurse came in and was like freaking out, saying it was drugs. Security was called to rifle through all of my belongings and it was all over makeup. Like, it's supposed to be one of the most important days of my life and a kind of like ruined it.

Fear of Being Reported

The women shared their fear of being reported to the local family services agency despite being in a treatment program, and 3 women specifically shared they were given inconsistent information about required reporting to family services. The fear of being reported guided all decision-making for most of the women.

One participant discussed her experience of being reported to family services after the birth of her newborn and being labeled as an at-risk parent. She expressed her frustration that this contradicted the information she was given at time of treatment engagement when she was reassured that treatment would protect her from interaction with family services. She shared:

They told me since I was on methadone that they were going to report me to the authorities. I was like well, they told me that because I was here and on methadone, they won't report me to the authorities. Well, that's a crock of crap because they did report me. They reported me as an at-risk parent. I was doing my groups and everything I was supposed to, and I was still reported.

As a result of this continued fear of being reported, a few participants also described that this persistent level of anxiety

had exacerbated other preexisting mental health disorders. One participant reported 2 of her 3 medications used to manage her behavioral health conditions were discontinued by her prescriber at the discovery of her pregnancy, and needed to be swiftly resumed in the postpartum period, because of exacerbated anxiety related to the fear of being reported and a positive depression screening.

Children are Primary Motivator to Stay in Treatment

Nine of the 10 women identified their children as the motivation for continuing treatment. The women described personal hardships and sacrifices they had to overcome to regain custody of their children, with some efforts spanning several years. These included transitioning from homelessness to stable housing, obtaining a driver's license, and serial drug testing to demonstrate abstinence. One participant described a cascade of events including homelessness, loss of unemployment, health insurance, and loss of custody of her children, including one child born prematurely with multiple health issues. She expressed her motivation to remain in treatment:

My kids, definitely.....one-hundred percent the baby ... I am trying to get my son back ... if I got a place tomorrow I could go to the court and file the petition and I could get him right back. But just the apartment I am staying in isn't big enough.

Concern for Welfare of the Infant

Some of the participants were new to treatment and relied on the services of the treatment center to provide assistance with housing, clothes, and food. Other women described how they had reclaimed their independence and were working toward regaining child custody. The women voiced concerns regarding the effects of substance use on their neonate's health, meeting the newborn's needs, and learning to care for their newborn. Several of the women reported cutting back on the amount of heroin they used during pregnancy, whereas other women spoke about the conflicting nature of continuing to use heroin only when needed to relieve cravings and prevent withdrawal symptoms. One participant explained how she tried to decrease the amount and frequency of heroin use to minimize the effects on the fetus: "I was thinking I don't want to hurt my baby, but sometimes the cravings were too much. I would try and cut down the amount... so the baby is not born addicted. It's not fair to the baby." This participant also explained how she chose to take her daughter to medical specialist appointments over attending substance use treatment for herself, explaining the treatment center would not allow her to continue if she missed a session. Two participants also described their internal conflict of engaging in prescribed MOUD at the recommendation of their health care provider, against pressure from the baby's father not to continue, because of the potential in utero effects. Another participant shared she was thankful for the extended hospital stay required for neonates born with neonatal abstinence syndrome (NAS), allowing her extra time to learn how to bathe and care for her newborn.

Barriers to Attending Treatment

The participants in this study identified cost, lack of awareness of treatment facilities, lack of health care insurance, and prolonged wait times for treatment as barriers to treatment, which delayed treatment. One participant who lost employment and health insurance coverage alternated between purchasing the prescribed MOUD and using heroin, in an effort to avoid withdrawal. Another participant shared her struggle of locating treatment services for her heroin addiction, fearful she was going to relapse or attempt suicide.

I've tried to kill myself two times in the past ... I knew my head wasn't right and I didn't want to shoot up heroin anymore. I ended up having to say I felt like I was going to commit suicide so they would take me to the emergency room at the hospital and I could get treatment ... The problem is as soon as I tell them I have attempted to commit suicide before they no longer are willing to take you in a treatment program.

Participants who were currently receiving substance use treatment through an integrated delivery network shared they remained in treatment because of the combination of services in one location (obstetrics, behavioral health services, and MOUD prescribing). This allowed for streamlined appointments and the ability to balance other competing family duties and childcare. Participants who were unaware of their pregnancy prior to the birth were offered outpatient substance use treatment in the immediate postpartum period.

DISCUSSION

The postpartum women in this study shared their experiences as they were lived and provided first-hand accounts of their lives during the perinatal period. The experience of stigma was a main theme shared by the women, who were in varying stages of treatment. For some women, this was their first engagement in substance use treatment; other women had relapsed and returned to treatment. The women described feeling unequal, being judged or treated differently by members of the health care team once their history of opioid or heroin use was disclosed. The presence of stigma among health care providers when rendering care to perinatal women with substance use has been well documented.^{12,22–24} Renbarger et al²² and O'Rourke-Suchoff et al²³ both reported that women with OUD experienced disparaging comments or stigmatizing behaviors from members of the health care team while receiving care related to pregnancy. These findings suggest a common experience when women with OUD interact with members of the health care team during the perinatal period.

The fear of being reported to the authorities and potential for loss of child custody guided all decision-making. This influenced where and when to seek treatment and whether to use medication. These findings are consistent with the outcomes of previous research of women in the postpartum period, which identified fear of loss of custody of children if their substance use is discovered during pregnancy or postpartum²⁴ and the perception that child protective services case workers could hold a biased view of women they were assigned to work with.²⁵ One woman in this study reported the exacerbation of mental health issues, secondary to anx-

iety and fear of being reported to child protective services. The tandem presence of anxiety in postpartum women with OUD has been previously reported^{8,26}; however, the associated of mental health issues and fear of being reported to child protective services warrants further exploration. Previous research finding suggests that psychological distress induced by a modifiable risk factor in the first year postpartum can be lessened by providing targeted interventions designed to minimize the effects of a trigger and decrease the burden of a negative outcome.¹¹

The health and welfare of their children were of primary concern to the women, and their children served as the main motivator for almost all of the women to remain engaged in substance use treatment. The participants shared their concern of exposing their unborn child to the potential adverse effects of opioid and heroin use. This finding is similar to the findings of the study by Van Scoyoc and associates,²⁷ who noted concern related to the impact of substance use on a developing fetus among women attending substance use treatment. The women also shared their ambiguity about following the recommendation of their health care providers to continue with MOUD after pregnancy was discovered or refrain from engagement because of the contrasting opinion of the father. This sphere of influence should be further explored in postpartum women in treatment to determine the percentage of variance explained by these variables on such a critical decision.

The women shared experiences related to a deficit in knowledge on how to best care for their infant. National data suggest there is a gap in the availability of specialized services offered as part of comprehensive care to postpartum women with OUD.¹⁴ Offering new-mother education with other key services as part of a comprehensive care treatment program to postpartum women with OUD has the potential to fill a gap in care and improve infant outcomes.

The lived experiences shared by the women in this study have provided insight to the transition to motherhood while managing an OUD. Health care professionals who provide direct care to postpartum women with OUD should be knowledgeable about OUD and maintain competency in all skills required to best care for this population. Midwives and other health care professionals providing care to postpartum women with OUD have the potential to make a difference in the lives of these women. This requires an examination of personal biases and self-awareness related to OUD to provide care that is comprehensive and nonjudgmental. Implicit bias training may be one strategy, especially when used with additional approaches such as trauma-informed care. Although the women in this study did not discuss IPV or sexual violence, these are previous or co-occurring events for up to 70% of women with OUD.^{8–9,23} Health care providers should recognize that not all women will disclose violence, but this history could be considered when caring for women with OUD.

It is essential that health care providers also have current knowledge about mandatory reporting laws. These vary by state, and women need to understand how reporting laws may affect them. This is critical to ensure women are provided with accurate information to make informed decisions, and trust is not lost. Health policy related to mandatory

reporting laws for pregnant and postpartum women with OUD should be evidence-based and therapeutic in nature. States with punitive reporting policies have higher rates of NAS, possibly the consequence of women avoiding care out of fear of being reported.²⁸

Limitations

The results of this phenomenological research are limited to the experience of women who used opioid and heroin and were engaged in outpatient drug treatment after the birth of their newborn. Although saturation was reached, the sample was small and homogenous. The focus of this research was on opioid use, so women with other substance use disorders were not represented. Additionally, the results are limited to the lived experience of women in one geographical area and may not be transferrable to women in other parts of the United States, where the landscape of drug availability and treatment options may be different.

Despite these limitations, this study had notable strengths. A phenomenological approach allowed the women's voices to be heard and captured their experience with opioid recovery and transition to parenting in their own words. These first-hand accounts confirm the results of similar studies, add to our knowledge of women with OUD, and provide insight into areas for improvement of care for postpartum women engaged in outpatient treatment programs.

CONCLUSION

The results of this study provide valuable insight into the lived experiences of women who have an OUD and are also adjusting to motherhood. Many of the women reported experiencing judgment and stigma from health care providers, even when following all treatment guidelines and adhering to supervised MOUD. Several of the women who shared their hospital experiences were disheartened not only by the perception of being treated differently but the missed opportunity of the anticipated "best day of my life" to actually being the "worst day of my life." The fear of being reported to family services and possible loss of custody influenced all aspects of their decision-making. Health care providers should consider these first-hand accounts when interacting with women and use insights generated from this research to improve care for childbearing women with OUD.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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