

Abstract

Purpose: The purpose of this study was to describe the experience of individuals with opioid use disorder (OUD) during the perinatal period.

Study Design and Methods: We convened focus groups of patients with OUD who had been pregnant and were parenting. Participants who were 18 and older, English-speaking, self-identified as pregnant or parenting, and actively using opioids or in recovery from OUD were recruited using snowball and convenience sampling in resident treatment facilities and outpatient settings. Data were recorded, transcribed, and analyzed for themes.

Results: Twenty-four participants were recruited, 10 of whom were actively receiving residential recovery services. Most participants had been pregnant from 4 weeks to 2 years prior to our focus group session; none reported being currently pregnant. Nineteen participants had custody of some, or all, of their children. They identified four key themes related to their care: (1) *disrespectful care*, (2) *fear of accessing services*, (3) *inconsistencies in care received*, and (4) *limited health and social services*.

Clinical Implications: Participants reported overall negative interactions across different health care settings and lack of social resources to promote ongoing recovery and successful parenting. Nurses should be aware of the lasting impressions they have on their patients. Recognition of their own biases, person-first language, and partnership building skills with patients can help attenuate OUD stigma, promote positive nurse–patient relationships, and support new parents in recovery and infant bonding.

Key words: Opioid-related disorders; Parenting; Pregnancy; Qualitative analysis.

HEALTH CARE EXPERIENCES DURING PREGNANCY AND PARENTING WITH AN OPIOID USE DISORDER

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Background

Perinatal opioid use disorder (OUD) continues to increase dramatically in the United States, with 131% more patients having a diagnosis of OUD during birth hospitalization in 2017 compared with 2010 (Hirai et al., 2021). In 2018, the last year for which these data are available, the rate of neonatal abstinence syndrome was 6.8 per 1,000 newborn hospitalizations (Agency for Healthcare Research and Quality, 2021). Perinatal OUD is associated with negative neonatal health outcomes including preterm labor, low birthweight, stillbirth (Maeda et al., 2014), and neonatal opioid withdrawal syndrome (NOWS), a group of symptoms, such as irritability, sleep disturbance, vomiting and diarrhea, that can arise shortly after birth in newborns exposed to a variety of substances in utero, including opioids (Kelty & Preen, 2019). In one study, pregnant persons with OUD were five times more likely to die during hospitalization after labor and four times more likely to go into cardiac arrest compared with those without OUD (Maeda et al.). Perinatal OUD and its associated negative outcomes remain problematic and though not the leading cause of maternal death in the United States, a growing number of states have listed it as the leading cause of pregnancy-associated deaths during the postpartum period (Office of Women's Health and Family Services, 2019; Texas Health and Human Services, 2017).

The lived experience of affected communities can provide critical insight to existing gaps in care, allowing health care providers and policy makers to better tailor approaches to meet the needs of the community (Byrne & Wykes, 2020). Recent studies have largely explored the perspectives and

experiences of pregnant individuals with OUD as they relate to treatment adherence and retention in OUD care (Goodman et al., 2020; Wilder et al., 2015) or provided insight into a specific aspect of care during the perinatal period, such as the labor and birth experience (O'Rourke-Suchoff et al., 2020). The purpose of this study was to gain a broader understanding and identify most salient experiences of individuals with OUD throughout the perinatal and postnatal periods in Western Washington State.

Study Design and Methods

This study was an analysis of qualitative data collected from a larger study seeking to engage community members with OUD and health care workers to identify key priorities in research and care provision throughout pregnancy and parenting. We conducted the study between August and December 2019 to inform local agencies' funding allocation and agenda setting (Altman et al., 2021). Eligible participants were 18 or older, English-speaking, self-identified as pregnant or parenting with OUD or in recovery from OUD. Participants were recruited from outpatient and residential settings within the northwest region of Washington State via convenience and snowball sampling. We partnered with local community agencies providing services for pregnant and parenting individuals with OUD to assist with recruitment and participant engagement.

Participants were asked to join in two, 2-hour focus group sessions facilitated by the lead investigator. Three participant groups were convened across the state. Participants in two groups received outpatient services and participants in a third group received residential services. Verbal informed consent and demographic data were obtained prior to the start of the first session. In the residential and one of the outpatient groups, the two focus group sessions were separated by 4 to 6 weeks (Franck et al., 2020). Based on the recommendation of the community partners, sessions were condensed to fit into 1 day for the third outpatient participant group; each 2-hour session was separated by a 1-hour lunch (Altman et al., 2020).

In the first session, participants shared their health care and parenting experiences and were asked to identify and generate research and policy questions related to care provision during their current or previous pregnancy, birth, and parenting experience. The first session

With perinatal opioid use disorder (OUD) on the rise, maternal overdose is the leading pregnancy-associated cause of death during the postpartum period in a growing number of states.



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began with a grounding exercise and open-ended questions to allow participants to describe experiences most meaningful to them. Probing questions and reflective listening encouraged participants to further elaborate on their experiences and confirm mutual understanding among participants and researchers. In the second session, ranking and prioritizing exercises were used to set group priorities, with these methods described elsewhere (Franck et al., 2020).

Participants received \$150 (US) in gift cards for their participation. Coffee and breakfast items were available during the first session and hot food (typically lunch) was provided at the end of the first session. Onsite child care and transportation were also provided. Partnering agencies received \$1,000 honorarium for their support. The

Institutional Review Board of the University of Washington approved all study procedures.

Data Analysis

All sessions were audio recorded and professionally transcribed verbatim. We listened to the recording from the first session to review transcripts for accuracy and be familiar with the data. All authors were experienced in or received training in qualitative data analysis and participated in the thematic analysis using the following 6-phase guide outlined by Braun and Clarke (2006). The first and second authors independently conducted line-by-line coding on the first and second focus group transcripts. Initial codes were collated, and an iterative process was used within the team to identify themes. The first and second authors reviewed the candidate themes ensuring data were present to support the themes across all focus groups, capturing the data as a whole. Themes were finalized and defined through a second iterative team process and exemplars were agreed upon by all authors. Discrepancies were discussed as a group and resolved through consensus.

Results

There were 24 total participants, 10 of whom were engaged in inpatient recovery services (Table 1). They identified predominantly as White and ranged in age from 20 to 39 years. About two-thirds of the participants had received their high school degree or higher. All but two participants had one to three living children. Nineteen had custody of some, or all, of their children. The five participants who reported not having custody of any children were actively receiving inpatient services. The majority of participants had given birth from 4 weeks to 2 years prior to the focus group; seven participants had given birth more than 2 years prior. Participants reported primarily using heroin or oxycodone during their pregnancies.

Four key themes were identified from the shared experiences of pregnant and parenting people with OUD related to their care: *disrespectful care*, *fear of accessing services*, *inconsistencies in care received*, and *limited health and social services*.

Disrespectful Care

All participants described experiencing disrespect during their prenatal and postpartum care. They noted a shift in the nurses' attitude and being treated differently once the nurses became aware of their drug use. One participant recalled: *The nurse was so mean and so rough, because I was a drug addict because I went in there because I was going to detox. That was exactly how they treated me, like I was trash.* Participants described negative interactions with health care workers, feeling judged, neglected, dehumanized, and constantly monitored. During labor, many had their pain minimized and ignored. In one example, a nurse's lack of respect for a participant's reported pain nearly led to a precipitous birth: *I was in labor for two days before they admitted me, because the nurse that was there who was like, 'Oh, well. You're an addict so you have a really low pain tolerance. So, you're not in*

TABLE 1. CHARACTERISTICS OF PARTICIPANTS

Characteristics	N (%)
Total Participants	24 (100)
Setting	
Residential or Inpatient	10 (42)
Outpatient	14 (58)
Age (Years)	
20–24	7 (29)
25–29	9 (38)
30–34	6 (25)
35–39	2 (8)
Education	
Less than high school diploma	8 (33)
High school diploma	4 (17)
Some college	12 (50)
Ethnicity/Race	
Black	2 (8)
White	14 (58)
Hispanic	1 (4)
American Indian or Alaskan Native	1 (4)
Multiracial	6 (25)
Substance Used	
Heroin	21 (88)
Fentanyl	2 (8)
Oxycontin	5 (21)
Oxycodone	8 (33)
Other (methamphetamines)	5 (21)
Age of Youngest Child	
<6 months	7 (29)
6 months to <12 months	2 (8)
12 months to <18 months	1 (4)
18 months to <2 years	6 (25)
2 years or more	7 (29)

labor,' didn't check me. Didn't do anything. Gave me a sleeping pill and told me to go home and go to sleep. And by the time I finally got somebody, I was eight-and-a-half centimeters dilated. They barely had enough time to give me an epidural and stuff.

After the birth, many participants did not feel they were being supported as parents to connect to their newborn. They reported not being taught or encouraged to learn foundational parenting skills such as breastfeeding, diaper changes, and baths, but were intentionally excluded and had their parental rights violated. One participant shared: *...the nurse wouldn't even tell me — when I had him and he needed his diaper changed or something, she wouldn't even say 'Hey, do you want to come change the diaper, do you want to come down here?'* Similarly, another recounted: *We were in the middle of weaning my son down [from opioids] and behind my back [the nurse] went and told the on-staff doctor that I wanted to up his morphine dose. And so then the next day at rounds when I was like, 'No, I did not.' [...] And then the doctor's like, 'Oh, she said you wanted that.' And I was like, 'No.' and it ended up being a big deal and she was not allowed to — not care for me anymore.*

These interactions made participants feel discouraged about their ability to parent, leading some to be less motivated to maintain custody as described by one participant: *[the nurses] weren't being supportive, they weren't helping me try and connect with my baby or anything. And I hadn't 100 percent made my decision yet that if I was going to keep that baby or not, but then after I didn't really get to connect with it, I was like, 'Yeah, I am going to give it up for sure.'* Participants reported that judgment and lack of respect for them as parents persisted despite attending appropriate prenatal classes, engaging in intensive outpatient therapy, or having been in recovery for many years.

Fear of Accessing Health Care Services

There was a consensus among participants that they feared accessing services, largely attributed to Child Protective Service (CPS) involvement. Almost all were under the assumption that CPS would automatically separate them from their newborn due to their OUD. This was due to either their previous experience with CPS and loss of custody or having heard of someone who had been separated from their newborn. This fear of CPS persisted into parenting. Participants felt that they were held to an unfair standard compared with their peers without OUD. One participant felt there was no room for parental mistakes: *It's like, people actually miss doctor's appointments, things like that. But if you miss a doctor appointment and you're a drug addict, or recovering drug addict, it's the end of the world. It makes parents fear seeking health care [...] for their child.* Fear of CPS involvement made participants apprehensive to disclose their opioid use to their prenatal providers. Participants also feared criminalization and legal ramifications if they disclosed drug use.

Previous loss of custody also elicited fear in seeking prenatal care in their subsequent pregnancies as shared by one participant: *... being judged as a mother, because I don't have my other two children. I am scared to death of when*

I bring this child in there. What are people going to say and people are going to think because I don't have my other children.

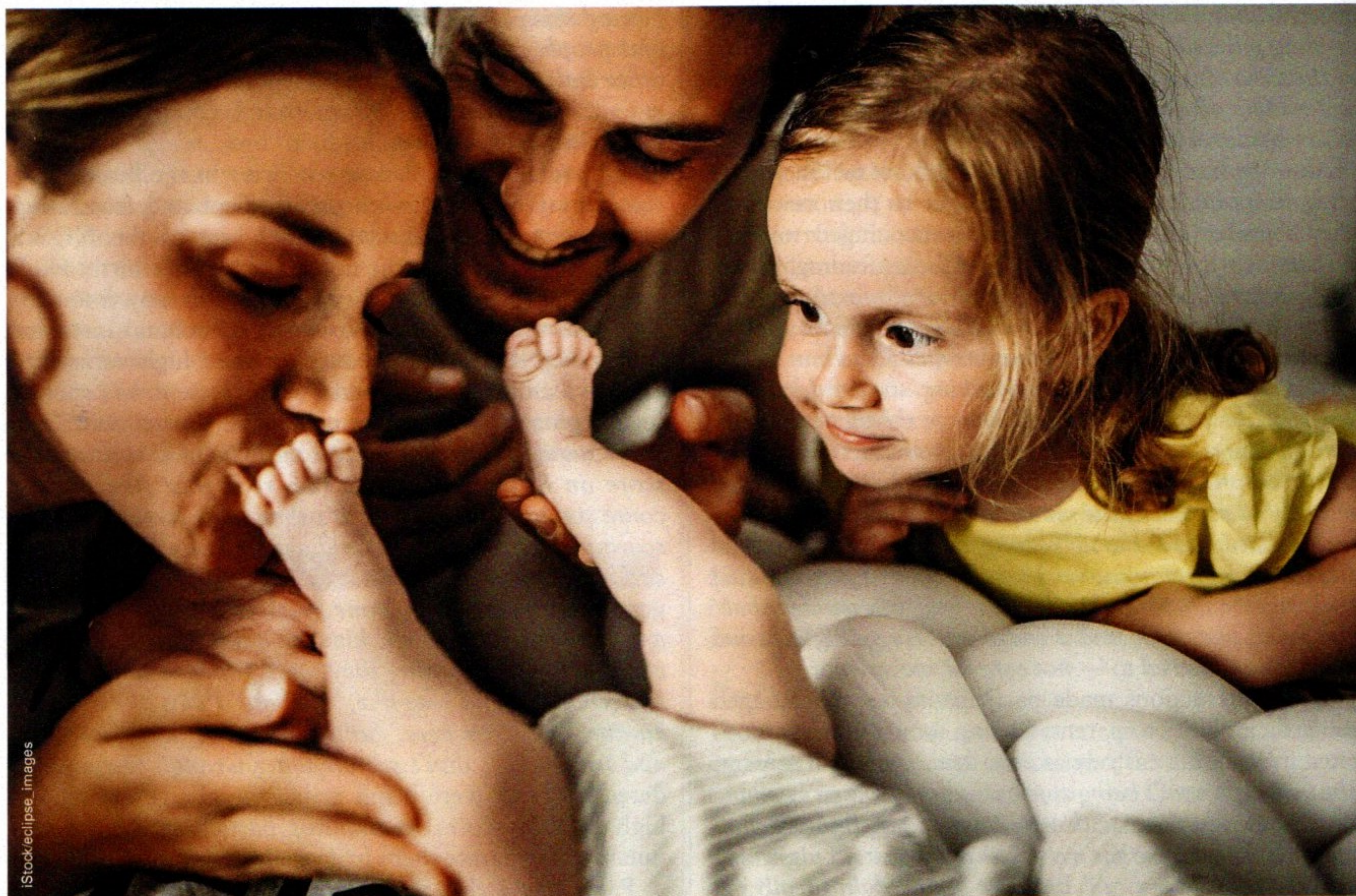
Inconsistencies in Care

Participants identified inconsistencies in the health care that they received. The most prevalent and frustrating inconsistency was associated with use of the NOWS scoring system during the hospital stay after birth. High scores could result in pharmacologic therapy intervention and transfer of a newborn to a neonatal intensive care unit (NICU). Participants reported high variability of scores among nurses, and felt the system was subject to inherent biases as reflected by one participant: *One nurse would score 4 or 5, and then the next shift would score an 8, and then once they're higher [the nurses] come sooner. And then, if it's that same nurse on shift, scoring higher than that could get my baby put on medication that maybe she didn't necessarily need.* Another participant shared: *...the one [nurse] kept scoring him 2s and the other one scored him the 8 and then 9 or whatever - the next morning they were going to take him to the NICU. Then I was like, 'Hell no.' I was like, 'I want another doctor in here.' So then another doctor came in and was like, 'I don't see anything wrong'.* Some wondered if nurses were being malicious, giving a newborn high NOWS scores to monitor participants more frequently or separate them from their newborn.

Participants also received conflicting information between care team members about various aspects of their care such as breastfeeding. One participant noted: *...the main nurse that was in there and helping me a lot, she was like, 'You should breastfeed.' She was like showing me and helping me and stuff. Then other nurses were coming and like, 'No, you can't breastfeed until you're negative [for opioids].* Others shared inconsistent recommendations regarding use of opioid replacement therapy, such as buprenorphine or methadone: *You've got your health care provider telling you, 'Yes, you need this. You need to take this.' You've got your counselors telling you, 'Oh, you've got to get off of that. Oh, you've got to taper down. Oh, you've got to do this.' So, here you are being ping-ponged back and forth. What do I do?* On a broader scale, there were no consistent practices or requirements for discharge across treatment facilities or drug courts. For example, some agencies viewed use of medically prescribed opiate replacement therapy as reasons to retain individuals in treatment and drug courts.

Limited Health and Social Services

Participants reported a limited number of quality inpatient treatment and outpatient medical services where people felt safe, supported, and could receive education related to their pregnancy. When services were available, the capacity to meet the needs of the population was insufficient. Inpatient facilities had a limited number of beds, and waitlists for providers in the community willing or able to treat OUD and pregnancy were as long as 2 years. Distance and transport exacerbated access for



Consistent person-first language and a patient-centered approach are urgently needed to support those who are parenting while in recovery.

those living in rural communities due to cost, time, and fear of traveling alone. Some participants were turned away outright from local providers unwilling to treat pregnant people with OUD. One participant shared: *I was turned away by [two community providers] saying that they didn't want to touch [opioid use disorder] while I was pregnant, [...]— and I was going to ask about the opiate replacement therapy. I left there on two different occasions with two different doctors crying the whole way home, just addicted to pills still.* When services were attained and opioid replacement therapy was prescribed, high co-pays ultimately made treatment unattainable.

Participants faced formidable social challenges in their personal lives and reported needing support beyond direct medical services. Existing social services did not adequately meet their needs. A significant concern affecting almost all participants was the difficulty in securing housing after discharge from treatment facilities or incarceration. A participant commented: *You get let out of treatment and then you have no clean and sober housing*

to go to. You're placed back into the same community you had just walked out of.

Participants were not confident about preventing relapse early in their recovery and expressed the need for ongoing support during transitions from treatment centers to the community. One participant noted: *This is a safe little recovery bubble where they watch your every move, and they plan out your whole day and stuff. So, I'm kind of worried that once I leave here I'll relapse, because I won't have that routine anymore.* Others acknowledged that to avoid opioids and sustain their recovery they may need to break their existing social network. One shared: *I pretty much had to start fresh. I have no old friends that I was friends with before.* Participants agreed there needed to be more opportunities, specifically tailored to those who are pregnant or parenting and in recovery, to rebuild these social networks.

Clinical Implications

In this study, we describe experience of pregnancy and parenting for those with OUD and the care they received. They primarily reported negative interactions with community and hospital clinicians and inadequate availability of health and social services. Fears of criminalization, CPS involvement, and separation from their newborn were cited as barriers to seeking care during the prenatal period and is consistent with previously reported literature (O'Rourke-Suchoff et al., 2020; Stone, 2015). The general public's perception of CPS is often viewed as punitive

(Falletta et al., 2018) and a report to CPS by a health care provider can elicit feelings of betrayal and provider mistrust. Negative patient-provider relationships have been attributed to patient care avoidance and earlier and higher rates of treatment drop-out for people with substance use disorders (Stone; van Boekel et al., 2013). When participants were able to access care, they faced refusal of care by some clinicians and perceived judgment, disrespect, and stigma from health care workers, particularly nurses, due to the participant's current or historical opioid use. Participants also did not feel supported in their new role as a parent. These experiences led to feelings of shame, disempowerment, and low self-efficacy both in their abilities to maintain recovery and parent after childbirth.

Pregnant women and new parents have complex psychosocial needs that can worsen stress during pregnancy, which has been attributed to increased risk of NOWS (Kelty & Preen, 2019) in newborns and increased mortality during pregnancy and postpartum associated with OUD (Schiff et al., 2018). In one study, 79% of postpartum parents with OUD and co-occurring homelessness were likely to experience an overdose within 1 year postpartum compared with 34% of those without co-occurring homelessness (Schiff et al.). Provision of social services early in pregnancy to reduce stress and its associated negative outcomes relies on early detection. However, stigma can motivate pregnant women with OUD to avoid seeking care, drive health care workers to deny prenatal services, or make people fearful of disclosing their substance use history (Stone, 2015).

Stigma creates barriers that reinforce health inequities and contribute to poor maternal and neonatal health outcomes. Nurses and other health care professionals must examine and acknowledge their own beliefs and attitudes to become aware of and alter inaccurate or negative perceptions they have of pregnant women with OUD. Nurses can begin by engaging in education and facilitated discussions to identify their own implicit biases that may influence their ability to establish patient rapport and trust. Nurses can practice person-first language, arranging words to place the individual in front of a diagnosis or behavior when speaking. For example, when discussing patient care, one might address someone as, "A pregnant person with substance use disorder" rather than "drug-using patient." This emphasizes the person rather than their diagnosis (Atayde et al., 2021). Nurses using person-first language reiterate to themselves, their peers, and to the patients they care for that OUD is a chronic disease often associated with a history of trauma and not a personal choice or moral failing. Research has shown that the words we use have the power to influence our conscious or subconscious biases and using positive language can create positive associations of stigmatized groups (Atayde et al.; Henderson et al., 2016).

Hospitals can help to address unconscious bias and its impact on patient care by examining current practices to ensure clinical approaches are consistent and reduce discretion in decision-making (FitzGerald et al., 2019). Currently, the Finnegan Neonatal Abstinence Scoring System

(FNASS) or an abbreviated, modified version of FNASS is widely used to assess 21 clinical symptoms of NOWS and determine necessity of pharmacological management. The FNASS is limited as a clinical tool due to its complexity, the necessity to disrupt the neonate for assessment and subjectivity in scoring severity of symptoms (Loyal et al., 2019; Timpson et al., 2018). The subjective nature inherent in FNASS has been highlighted by our participants and similarly by nurses elsewhere in literature (Loyal et al.).

Eat, Sleep, and Console (ESC) is an emerging, alternative approach to assessing NOWS based on three objective measurements: (1) the number of infant feeds, (2) hours of sleep, and (3) time to console (Grossman et al., 2017). ESC interventions, such as skin-to-skin and breastfeeding, emphasize parent involvement and caregiver skill training to optimize newborns' most basic functions (Grossman et al.). Our participants, like many parents with OUD, verbalized wanting to be included in their newborn's care (Holmes et al., 2016). Implementing ESC allows nurses the opportunity to directly interact with parents with OUD and develop collaborative patient-provider relationships to achieve common goals, a strategy that has been found to counteract negative associations.

Supportive, nonjudgmental relationships with service providers can be motivators for persons to make positive changes in their substance use during pregnancy (Ray-Griffith et al., 2021). Nurses who provide unbiased guidance and support, particularly during the critical postpartum period, can encourage positive nurse-patient rapport, strengthen parent-infant bonding, and promote continued substance use treatment beyond pregnancy.

This study should be viewed within the context of the following limitations. Snowball recruitment methodology lends itself to sample bias; however, we felt that this was the most effective way to recruit members of a population that have historically been marginalized and treated with disrespect. Our patient population was predominantly White; however, the racial and ethnic proportions were consistent with the population of the area.

The reiteration of negative interactions with clinicians from earlier studies reinforces the persistent, troublesome stigma associated with OUD and pregnancy. Stigma underlies participants' fears to access already limited services and contributes to the continued rise of the number of newborns with NOWS and opioid-associated maternal deaths in the United States. This study demonstrates the need to continuously include and involve affected communities and understand the contextual features that affect their OUD and proactively address challenges and improve patient outcomes. ✦

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SUGGESTIONS FOR CLINICAL IMPLICATIONS

- Participants with OUD highlight the negative experiences they had when receiving care during pregnancy and parenting. Negative interactions with nurses were described.
- Nurses can establish strong, positive relationships and attenuate OUD stigma by recognizing and examining their own internalized biases.
- Nurses can practice person-first language to create an environment of dignity and respect when caring for patients with OUD.
- Eat, Sleep, and Console focuses on enhancing parent-infant bond to alleviate NOWS through parent involvement and skill training and is an opportunity to bolster patient-nurse rapport.
- We must continue to engage those with experiences in research and policy agenda setting and intervention development to combat the continuing rise of OUD during pregnancy.

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The authors declare no conflicts of interest.

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