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## Identified gaps and opportunities in perinatal healthcare delivery for women in treatment for opioid use disorder.


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1 *CLEAN VERSION*

2 Introduction

3           In the last two decades, the rate of pregnancies affected by opioid use disorder  
4 (OUD) in the United States has quadrupled<sup>1,2</sup>. Women with OUD often enter prenatal care  
5 later in pregnancy and stay longer in the hospital after birth compared to women without  
6 OUD<sup>3</sup>, and many also lack traditional support networks of family and friends<sup>4,5</sup>. In addition, a  
7 newborn exposed to intrauterine opioids may require medically supervised treatment for  
8 neonatal opioid withdrawal syndrome (NOWS) for several weeks after birth, a condition that  
9 is associated with significant neonatal morbidity and prolonged hospital stays<sup>6</sup>. The  
10 perinatal period, defined as the weeks immediately before, during and after the birth of a  
11 newborn, is therefore challenged by a structure of hospitalizations, multiple healthcare  
12 providers, and maintenance of OUD treatment.

13           The American College of Obstetrics and Gynecology (ACOG) recommends  
14 comprehensive perinatal healthcare delivery for women with OUD to ensure high-quality,  
15 safe care<sup>7</sup>, yet there is little documented in the literature as to the structure and components  
16 necessary to achieve this goal. In the general perinatal population, personalized  
17 approaches to perinatal care can improve delivery, contraception, and breastfeeding  
18 outcomes<sup>8-10</sup>, as well as increasing a woman's health literacy<sup>11,12</sup>. Perinatal engagement  
19 strategies incorporated into standard care are also associated with increased quality of  
20 patient-provider interactions through improved patient activation<sup>13</sup>. Women with OUD are  
21 known to benefit from personalized prenatal care, demonstrating increased adherence to  
22 prenatal visits through a model which tailors support and education to the individual needs of  
23 substance exposed pregnancies<sup>14</sup>. Furthermore, tailored breastfeeding support has resulted  
24 in higher breastfeeding rates among substance-exposed women and infants<sup>15</sup>.

25           Despite the importance of personalized care, especially among high-risk  
26 populations<sup>16</sup>, little is known about how women with OUD perceive perinatal healthcare,  
27 including any efforts to prepare them for the birth and newborn healthcare experiences.

1 However, pregnant women with OUD <sup>17</sup> and women with infants diagnosed with NOWS<sup>18</sup> do  
2 report barriers to effective communication with their healthcare providers. Gathering  
3 information on the perceptions of care could help inform a redesign of perinatal healthcare  
4 for women with OUD by identifying unmet needs. Therefore, the aim of this study was to  
5 identify and describe perceptions of the birth and newborn healthcare experiences among a  
6 population of women in treatment for OUD in order to improve the delivery of perinatal  
7 healthcare.

## 8 **Methods**

9 A qualitative study using focus groups with a convenience sample of participants  
10 recruited from a perinatal OUD treatment center was conducted. Qualitative thematic  
11 analysis methodology was used to sort and analyze the data through six steps:  
12 familiarization, generating initial codes, searching for themes, reviewing themes, defining  
13 and naming themes, and reporting themes <sup>19</sup>. The authors followed COnsolidated criteria for  
14 REporting Qualitative research (COREQ) principles to ensure comprehensive reporting of  
15 findings. This study was approved by the appropriate local institutional review boards.

### 16 ***Study population and Setting***

17 All study participants were receiving comprehensive behavioral and physical health  
18 support and care plus pharmacotherapy (methadone) for OUD from a single outpatient  
19 treatment center. Study inclusion criteria were (1) 18 years or older; (2) receiving treatment  
20 for OUD; and (3) English speaking. All participants had legal guardianship of a child younger  
21 than 2 years of age. Recruitment continued until thematic saturation occurred, when no new  
22 data emerged.

### 23 ***Recruitment and data collection***

24 In April 2019, counselors and front desk staff at the treatment center identified  
25 women who had a child less than 2 years of age. The identified women were given a brief

1 description of the study and directed to speak to the principal investigator in a private space  
2 if they were interested in participation. Those who expressed interest in participating were  
3 then scheduled, according to their stated availability, to attend one of four separate focus  
4 group sessions over the subsequent month. Participants provided written informed consent  
5 prior to the sessions. Focus groups were utilized due to the reported comfort level of  
6 participants in a group setting as compared to one on one interviews, as a result of prior  
7 experience with research of this type at the center.

8           The focus groups were facilitated by two or three Ph.D. level researchers who were  
9 not involved in the clinical care of study participants or the care of participants' children.  
10 Focus groups lasted on average 70 minutes and were audio-recorded. Focus groups were  
11 semi-structured and the discussion guide was based on the aims of the study, with open-  
12 ended questions and follow-up prompts to engage participants in a fluid discussion (Table  
13 1). A survey which assessed demographics and perceptions of social support in the  
14 perinatal period was also administered. After completion of the focus group, \$50.00 was  
15 provided to each participant in the form of a ClinCard, a standard payment mechanism for  
16 distributing incentives to research participants.

## 17 ***Data Analysis***

18           The audio recordings from each of the focus group sessions were transcribed  
19 verbatim. Following the last focus group session, the research team met to discuss data  
20 saturation and begin analysis. Saturation was determined after repetition had developed and  
21 no new information was obtained, which was agreed upon by both researchers (KA, VS).  
22 The transcripts were analyzed using qualitative thematic analysis methods<sup>19</sup> by a team of  
23 researchers with training in qualitative methods (KA, VS, MG) . The process included  
24 generating initial codes, searching, reviewing, defining and naming subthemes, and  
25 identifying basic and global themes. Transcripts were initially reviewed independently with  
26 each researcher individually coding the transcripts. Then the team of researchers (KA, VS)

1 met as a group to discuss the individually identified codes, merging similar ideas and  
2 separating out unrelated constructs into discrete codes. These codes were then grouped  
3 into two thematic patterns: 1) perceptions of preparation for the birth and newborn  
4 healthcare experiences, and 2) perceptions of support.

5 The themes which emerged regarding social support were analyzed using the  
6 conceptual framework of Leahy-Warren<sup>20-22</sup>. Leahy Warren extends social exchange  
7 theory<sup>23</sup> to maternal-child health and identifies four elements of social support: emotional  
8 concern, instrumental aid, informational support, and appraisal support. All types of support  
9 were discussed, and descriptions of the maternal perceptions were categorized based on  
10 the type of support. The final analysis was sent to the team and one additional researcher  
11 (NG) to ensure supporting data and themes were clear and distinct from each other.  
12 Participants did not comment or give feedback on the themes.

## 13 Results

14 A total of 22 individuals participated in one of four focus group sessions, with  
15 between 4 and 8 participants per group. Four individuals who consented to participate in the  
16 study did not attend their scheduled session due to childcare challenges, and one  
17 participant passed away prior to the start of the study. The mean age of participants was 31  
18 years of age, and the average age of participants' most recently delivered child was 11  
19 months of age. Participant demographics are displayed in Table 2. The two major themes,  
20 perceptions of preparation and perceptions of support, will be discussed below with their  
21 subthemes with representative quotes pertaining to each subtheme presented with a  
22 randomized participant number following the quote. Additional supporting quotations are  
23 available in Appendix A.

### 24 ***Perceptions of preparation for the birth and newborn healthcare experiences***

#### 25 *Birth: Sudden and Unexpected*

26 Women consistently mentioned the sudden and unexpected nature of their delivery.  
27 Many women stated that this was their first delivery or their first delivery in recovery, and that

1 they lacked emotional preparation for the delivery. Women described situations where they  
2 had to be emergently admitted to the hospital, or driven in someone's car when they were  
3 almost to the point of delivering the baby. Women expressed that they felt there was no  
4 way to prepare for the delivery, despite receiving prenatal care.

5 I wasn't prepared. Like I had her stuff or whatever, I was prepared as far as like her coming,  
6 but having her I was [emotionally], I was not prepared at all. (Participant 20)

7 Women recalled all types of deliveries, including emergency C-sections, and many  
8 reported being undertreated for the level of pain.

9 I know that one thing that I felt with the anesthesiologist- Like the level of pain that's normal,  
10 maybe there could be a conversation around that...And I don't know if it was because of my  
11 tolerance being high from, you know, using the opiates or whatever, but I felt like I felt everything.  
12 (Participant 11)

13 Women believed their opioid use disorder had contributed to their experience of pain,  
14 but they also felt that providers didn't listen to them. Many women felt it was important for  
15 healthcare providers to acknowledge their OUD and the steps they were taking in treatment.  
16 Women wished they had conversations about OUD treatment and how it may affect delivery,  
17 and attributed the lack of this discussion to the urgent nature of their birth.

### 18 *Birth: Connected to Recovery*

19 Some women reported that they entered treatment for OUD days before the delivery  
20 of their child. More than one women mentioned the need to defend their choice to be in  
21 treatment during pregnancy when they came to delivery (see Appendix A). Although they  
22 knew this was the best choice for them, they felt a need to justify and protect themselves  
23 among healthcare providers.

24 I said yes, my son was born with methadone in his system because I was on methadone when I was  
25 pregnant with him. The reasons why I was on it [are my] business and I'm not about to tell them.  
26 (Participant 6)

27

1 A pregnancy while in OUD treatment felt significant and positive. Women also spoke  
2 of birth as a tenuous and stressful time. Numerous stories were told of other women who  
3 had not been able to adhere to an OUD treatment program or maintain custody of their  
4 newborn because of re-initiating drug use.

5 Birth is traumatic for any woman, and so, some women, [treatment centers] push them so  
6 much they actually do relapse right after birth because they can't take it. (Participant 20)

7 OUD treatment was seen as a difficult journey, but a necessary positive step towards  
8 turning their life in a different direction. They understood the effects of OUD on their family  
9 connections, and they desired a different outcome for their recent child. Yet, women spoke  
10 of the drawbacks of methadone maintenance for OUD, including the side effects and general  
11 restrictions on their lives due to treatment structure. It was discussed that treatment centers  
12 had many rules to navigate, and medication caused concerns about the health of their baby.

13 Yes, if you are using, methadone is [a good option]. Methadone saved not only my life, but  
14 my baby's too. So regardless of how much pain and the side effects that it come with ... just  
15 imagine if we didn't have it. (Participant 18)

16 Women expressed guilt over prior choices related to drugs, and acknowledged the  
17 enormous effort it takes to enter treatment during pregnancy. It was stated that having a  
18 conversation with healthcare providers about the specifics of treatment and its unique effect  
19 on pregnancy would be welcomed, and may be useful to assuage fears about causing harm  
20 to the baby.

#### 21 *Newborn: Lack of information*

22 All women in the study were prescribed and actively taking methadone for OUD.  
23 Many women spoke of their methadone dosage as high or low, and thought it would indicate  
24 the severity of neonatal opioid withdrawal syndrome (NOWS). Women in the group would  
25 interrupt the others in the group, trying to correct the information.



1           But I was only on 160 milligrams. I know women who, I know one person, she was on 365, her  
2 daughter didn't go through anything. So like I was completely unprepared and I had to watch my  
3 daughter go through what she went through, really f\*\*ed me up because I knew nothing about that.  
4 (Participant 16)

5           Information about connections between dosages and length of stay circulated  
6 informally. Preparation came in the form of talking to other women in treatment and  
7 remembering their own previous experiences. Many women attended group therapy  
8 sessions and would hear stories about other babies going through withdrawal. These  
9 stories scared them without a context or framework for the bigger picture of Nows.

#### 10 *Newborn: Forming their identity as a mother*

11           Healthcare providers, mainly identified as nurses, were seen as the gatekeeper to  
12 forming an identity as a mother. It was discussed that some nurses allowed the women to  
13 perform caretaking behaviors that a typical mother would perform, but that some nurses  
14 would not. Women described nursing staff who would allow them privacy and the ability to  
15 be present with their child. In contrast, women also described nursing staff who would stand  
16 over them while they tried to hold their child, waiting for them to look like they may fall  
17 asleep.

18           I felt it even was like a power struggle between like me wanting to be a mother to my newborn  
19 and the nurses. (Participant 18)

21           The power struggle between nurses and women in treatment for OUD was  
22 perceived by the women as having a direct, negative effect on their newborn in  
23 treatment for Nows.

#### 24 ***Perceptions of social support during birth and newborn hospitalizations***

##### 25 *Birth: Emotional Concern*

26           Women expressed that emotional concern was not provided by all healthcare  
27 providers during birth, and instead, judgment was sometimes communicated during the

1 delivery. Women perceived that this was due to their history of drug use, and acknowledged  
2 that this interaction was expected, had occurred previously in healthcare settings. Most  
3 women had found providers for their prenatal care that they felt provided emotional concern,  
4 but they knew they couldn't control who was assigned during delivery.

5           One woman related that her birth occurred without any support person,  
6 without a partner or a family member. Some women had been labor support for each  
7 other in the delivery room, and others were able to have their mother or a sister with  
8 them. One woman mentioned having a doula present for her delivery as an emotional  
9 and instrumental support. A doula was able to teach ways of coping with pain, and  
10 explain procedures that were suggested by the healthcare providers. The doula was  
11 able to obtain a birthing ball, for example, or essential oils to provide holistic pain relief.  
12 It was perceived as a benefit to being in recovery that a doula could be involved in their  
13 care.

14           This was my first time having a doula. I was clean...I had a mid-wife, a doula, I had a lot of  
15 people to help me with my pregnancy but my other [son]... I was on drugs with my last son.  
16 (Participant 3)

17           The labor support person was seen as trusted and knowledgeable resource that  
18 could act as a liaison on their behalf to the healthcare team, and someone who could act as  
19 an advocate.

#### 20 *Newborn: Instrumental aid*

21           Nurses were seen as providers of instrumental support during the newborn  
22 hospitalization, teaching women how to care for their child in the context of medical needs.  
23 Nurses were identified as teaching feeding techniques, the scoring protocol for NOWS and  
24 techniques for soothing a newborn with withdrawal symptoms.

25           Women felt dependent on nurses in the neonatal intensive care unit (NICU) to  
26 teach them how to provide the best care for their child, since many of the children had

1 special needs in terms of feeding. The women also felt that the child did not score as  
2 well in their absence, and they appreciated any accommodations that could be made to  
3 improve their ability to be at the bedside. One woman mentioned that she was able to  
4 room-in during the NOWS stay with her newborn for the duration of the treatment. She  
5 felt as if that improved her child's feeding ability from a bottle instead of needing a naso-  
6 gastric tube, and that her newborn's scores improved if she was present. Most women  
7 who delivered at the affiliated hospital with the treatment center reported not being  
8 provided rooming-in accommodations.

### 9 *Newborn: Informational and appraisal support*

10 Maternal mothers (n=12) and the baby's doctor (n=6) were the most frequently  
11 identified sources of informational support in terms of newborn care as seen in Table 2.  
12 Although many women with substance use disorders are estranged from both the healthcare  
13 system and from family<sup>24</sup>, entry into OUD treatment during the perinatal period can prompt  
14 renewed communication with trusted sources of support. Maternal mothers were discussed  
15 as sources of information to explain newborn and medical care.

16 Sometimes I don't understand that, so like my mom is a nurse, so I brought her in, and I was like,  
17 "Can you explain to my mom and then she'll break it down?" (Participant 20)

18 Those that did not have maternal support felt they were on their own in figuring out  
19 information. Women expressed fear about acting on information that was not valid for their  
20 particular situation. Women felt that they were entering a system where the boundaries  
21 were not clear, and healthcare providers differed on the guidance they provided.

22 When emotional support was assessed, women mentioned again that their own  
23 mother (n=10) or their baby's father (n=4) were the most frequently identified support  
24 sources. Although discussed, appraisal support, which relates to positive feedback on  
25 behavior was not always present from healthcare providers or external support sources.  
26 Feedback took the form of judgment related to the women's recovery and opioid use

1 disorder and was directly communicated and indirectly perceived by the women during the  
2 newborn hospitalization. Women talked of responding to healthcare providers who treated  
3 them in a condescending manner:

4 I'd another experience with a nurse that was like talking down to me about my ... "Oh just don't  
5 use drugs again." Giving me like the whole speech like, that's not your job. That's not your job like,  
6 your job is my child not my, you know?

7 Women perceived a need to defend their recovery and felt as if they were on guard.  
8 Rather than feeling supported in their parenting journey, some healthcare providers  
9 communicated that their past governed their current ability to be a mother to the newborn.

## 10 Discussion

11 This study explored how women with OUD experience the birth and newborn  
12 healthcare experiences, the results of which identified gaps and strengths of existing  
13 perinatal healthcare delivery to women with OUD in one institution. Women with OUD saw  
14 birth while in recovery as a positive experience, although many felt unprepared for the many  
15 possible ways the delivery could unfold. Although all participants were receiving care in an  
16 academic medical center which specializes in the care of women with OUD, women lacked  
17 information and received misinformation regarding how OUD affects their pregnancy, birth  
18 and their newborn. The data highlight existing issues in the delivery of perinatal healthcare  
19 to women with OUD, and present challenges that need to be addressed in order to provide  
20 quality care for women with OUD<sup>25</sup>.

21 Comprehensive perinatal OUD treatment includes both medication, behavioral  
22 therapy and care coordination services. The women in our study had access to this type of  
23 treatment, and previous qualitative studies show that women with OUD in other contexts find  
24 this type of healthcare integration essential to quality care<sup>26,27</sup>. Yet, the majority of women in  
25 the United States do not have access to comprehensive perinatal health care tailored for the  
26 complexities of a pregnancy with OUD. In 2015, less than a fourth of OUD treatment  
27 centers in the United States provided gender-specific care<sup>28</sup>, despite the 50% increase in the

1 rate of women using opioids compared to men<sup>29,30</sup>. Although birth while in recovery was a  
2 positive experience for the women in the study, in some areas of the country, this is not  
3 possible or is inaccessible for the majority of women. A survey of Medicaid data in the  
4 United States revealed that among women in the southern United States admissions to  
5 medication-assisted treatment occurred at a rate of 30.6% compared to 54.2% in the  
6 northeastern United States where this study occurred<sup>31</sup>. Despite their access to  
7 comprehensive care, women in the study identified further areas of improvement  
8 surrounding their preparation and support in the birth and newborn healthcare experiences.

9 Many women reported misinformation from peers, and reported that their family or  
10 friends were the main sources of information regarding delivery and newborn care, despite  
11 consistent interaction with healthcare providers. The women desired more knowledge from  
12 trusted sources before delivery, and healthcare professionals were identified as trusted  
13 sources. Women stated that information provided by clinicians in real-time was perceived as  
14 emotionally supportive, and this is important as it is known that women with OUD report  
15 lower self-efficacy in their decisions to remain in recovery and maintain their health goals<sup>27</sup>.  
16 Appropriate support from healthcare providers independently impacts maternal confidence,  
17 self-efficacy and post-partum depression outcomes<sup>22,24,32,33</sup>. Reminding clinicians to engage  
18 in conversation with women, while offering them information and positive feedback  
19 specifically towards their choice for recovery creates a collaborative environment.  
20 Information from trusted sources can empower a woman and enable her to advocate for her  
21 own health, and operate as a full partner in her care<sup>13</sup>.

22 Women also reported inadequacy of pain coverage during birth, with women  
23 expressing fear that providers will not understand or may be biased in their treatment of their  
24 pain because of their OUD. There is limited current knowledge of intrapartum pain control  
25 management for women with OUD, but studies in the general population have demonstrated  
26 that individuals with OUD can experience heightened pain (hyperalgesia) due to chronic  
27 exposure to opioids<sup>34,35</sup>. Further research is needed to develop standardized protocols

1 which effectively management intrapartum and postpartum pain for women with OUD.  
2 Standardized education for obstetric healthcare providers is also needed to decrease bias  
3 and judgement and improve the quality of pain management delivered.

4 Women desired participation in their newborn's care as they formed their identity as  
5 mothers, but many healthcare providers (specifically identified as nurses) did not permit  
6 them to perform typical maternal care of their newborn. This is consistent with both prior  
7 qualitative work with women with infants diagnosed with NOWS<sup>5,18</sup>, and a study of nurses in  
8 the neonatal intensive care unit regarding their interaction with mothers of infants with  
9 NOWS<sup>36</sup>. The nurses reported moral distress while for women with OUD and their children,  
10 and nurses were capable of assigning blame to the mother<sup>36</sup> for the severity of withdrawal  
11 symptoms in the infant. An environment of judgement can be a barrier to effective  
12 communication with healthcare providers, and may effect teaching and learning of  
13 caregiving behavior.

14 All but one woman in this study reported visitation restrictions in caring for her  
15 newborn during hospitalization, and the women described those restrictions as an  
16 impediment to their caregiving, bonding and negatively affected withdrawal symptoms in  
17 their infant. One institution has demonstrated decreased lengths of stay for infants with  
18 NOWS<sup>37</sup> and decreased use of pharmacologic treatment for NOWS<sup>38</sup> through implementing  
19 a predictable schedule for infants with NOWS, coupled with rooming-in policies to increase  
20 maternal presence at the bedside. A focus on improving the preparation and support  
21 available to this population will require collaboration across teams of healthcare  
22 professionals and must include the perspectives of women with OUD.

23 There are several limitations to this study. First, the participants were recruited from  
24 a comprehensive OUD treatment center, affiliated with a large academic hospital OB-GYN  
25 department. Therefore, the perspectives of one context of delivery is most likely reflected in  
26 these results, potentially biasing the findings. In addition, we used a convenience sample of  
27 women who were willing to participate in focus groups during the day, potentially limiting

1 responses to women who were not employed. The perspectives of women who have  
2 experience with birth and neonatal hospitalizations outside our institution could also add  
3 valuable knowledge. As with any qualitative data collection, the possibility of social  
4 desirability is a potential concern, but the focus group format does increase comfort of some  
5 participants with sharing their stories. Women in this particular treatment center are very  
6 familiar with the other participants, their experiences, and feel largely comfortable revealing  
7 details of their journey.

8           Women with OUD shared valuable perspectives in this study which will inform the  
9 future delivery of perinatal healthcare. Comprehensive perinatal care for women with OUD  
10 should empower the mother to care for herself and her baby through emphasizing a  
11 partnership with the woman at the center of care. A focus on accessible, personalized care  
12 for women with OUD may also improve crucial maternal and infant outcomes.

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