

**Original Research Brief:**  
***Experiences of perinatal substance use treatment in Western North Carolina***

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**Background**

Rates of opioid use disorder (OUD) in pregnancy diagnosis increased 127% from 1998 to 2011.<sup>1</sup> OUD poses significant health risks for pregnant women and their offspring including increasing long-term risks for the mother-infant dyad.<sup>1-4</sup> The value of comprehensive perinatal substance use treatment that includes medication-assisted treatment (MAT) is widely recognized; yet, women in the Southern U.S. have the least access to MAT despite being at highest risk for opioid use disorder during pregnancy.<sup>5,6</sup> Several factors contribute to lack of MAT access including a shortage of prescribers, less Medicaid coverage,<sup>5,7</sup> greater healthcare barriers overall, and stigma.<sup>5,7</sup>

**Methods**

We investigated patient experiences in a comprehensive perinatal substance use treatment program, integrated within an OB/Gyn practice serving a large rural region, to understand *how the program is working for participants, and overall experiences with perinatal substance use treatment.*

<b>Data Collection</b>	<b>Sampling</b>	<b>Semi-structured Interviews</b>
Oct. '17- Feb. '18	Opportunistic, convenience, purposive, & expert: n = 27 MAT patients (of ~40 active); n = 10 providers Total n = 37	18 prenatal; 11 postpartum*; 10 provider; 1 Focus Group; 4 mo. participant-observation (*some participants gave both prenatal and postpartum interviews)
<b>Data Analysis</b>	Descriptive statistics	modified Grounded Theory

**Results**

Dominant themes that emerged from qualitative interviews with patients were: the *supportive nature of care in the program, structural barriers that affect access to care, social support, and*

*experiences with judgment and stigma, and how patients responded.*

In interviews, providers, staff, and affiliates identified three main themes encompassing clinic-specific factors, outside-clinic factors, and the structural environment. Clinic-specific factors were: *supportive care, care coordination, wrap-arounds, and education.* Providers also focused on factors that directly impact patients and their experience with treatment outside the clinic including *stigma, duplicated efforts, postpartum transition, and transportation.* While not all providers explicitly mentioned the broader environment, they often alluded to structural obstacles to care: *Medicaid, Department of Social Services, rural barriers to care, and trauma.*

Patient theme: Supportive Care

*I never expected to have support like that from a doctor's office... they are arms wide open to support you and your child. As soon as [the doctor] gave me the contact information [for behavioral health] they found different psychiatrists and everything for me to go to in the area I'm from... [The clinic has] a good handle on it.*  
 - Billy<sup>1</sup>

19 out of 27 participants expressed appreciation for the supportive, non-judgmental care received in the program, which contrasted with less-supportive care they received elsewhere, earlier, or in a previous pregnancy.

*I didn't know who else to call because nobody wanted to take me [for treatment] in the first place... because of being pregnant... They didn't push a decision on me. I didn't want to be on M.A.T. [at first]. [The doctor] still found me [another facility] that was willing to try to treat me [for detox].*  
 - Morgan

Morgan talked about her ambivalence regarding MAT. This was an important finding - 9 of 27 participants shared this feeling. We argue it is closely linked to over-arching structures of substance use stigma and pregnancy surveillance in which women experience substance use treatment. In a societal context of criminalized and stigmatized substance use and closely monitored pregnancy behavior overall, pregnant women who disclose a history of substance use are doubly scrutinized and judged. Thus, they

<sup>1</sup>Pseudonym chosen by participant, as are all names listed with patient quotes.

internalize fears about the repercussions of seeking treatment.

#### Patient theme: Structural Barriers

*I've had a lot of people say, 'since you're in the [MAT] clinic, DSS is automatically going to come see you...' It's definitely nerve-wracking. [Not knowing] if they're going to be judgmental or understanding because being an addict has such a stigma anyways... Whenever somebody is in a program and they're doing this [MAT] and they're doing the things they need to do... I just don't understand why [the hospital] would have to call DSS anyway.* - Focus Group Participant

Eleven out of 27 participants mentioned concerns about potential or current DSS involvement. Such concerns affected many participants' feelings about being on or staying on MAT.

#### Patient theme: Social Support

*My goal was to take [buprenorphine] so I could build my fortress of support... I've just been building. Like, now we go to church four times a week... it's kinda been [me] getting ready because my goal was to come off [MAT] I'm getting myself ready, to be prepared to have all the resources that I need when it's time.* - Sarah

Sarah emphasized social support as a mechanism for transitioning off MAT, once again highlighting ambivalence about MAT as a key finding.

#### Patient theme: Judgment/Stigma

All 11 women interviewed postpartum reported experiencing judgmental treatment at the time of delivery at the hospital: e.g. arbitrary or inconsistent Finnegan scoring<sup>2</sup> of their infants or a nurse who questioned their MAT use while admitted. Six of 11 talked about “*that one nurse*” or otherwise described specific nursing staff members' judgmental treatment; four of 11 reported their buprenorphine dosing was delayed or disrupted, while in the hospital.

*One of the [NICU] nurses [scored my daughter] higher than the [others], eventually I got mad at her. I said, "She's not a junkie baby. She's a real baby. There's a real baby there..." Surely, not everything my child does [is] withdrawal.*

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<sup>2</sup> A scale for detecting symptoms of neonatal abstinence syndrome (NAS) among infants exposed to MAT, opioids, and other prescribed or illicit substances. Not all exposed infants experience NAS, and not all infants exhibiting symptoms require treatment.

*I told the doctor, "Let somebody else come and give her the [Finnegan] scale thing... If it's higher, then you can give her the medicine." And it wasn't higher... I was right! Not everybody was like that... there were a lot of good nurses... But that [nurse] saw me like that. For some people, that would make them relapse. I can see that being like, 'well, if you're gonna treat me like a junkie, I'm gonna be a junkie...' because I used to have that mentality. [Now] I had people that loved me and [told me] that it didn't matter. What if [someone] doesn't [have that]?! - Sarah*

Nine of 11 women who reported judgmental treatment also described ways they advocated for themselves and their babies – e.g., asking for a different nurse, asking to speak to a neonatologist or pediatrician, or otherwise taking an active role in resisting stigmatizing treatment. Five of 11 also said they felt good about the delivery care they received despite a particular nurse or judgmental incidents they experienced while there.

### **Patient Experiences: Discussion**

In a largely rural, underserved region, pregnant women with a history of substance use initiated pregnancy care within a dual context of criminalized substance use and pregnancy surveillance.<sup>8-11</sup> Healthcare providers and patients alike absorb and enact larger societal messages within structural environments that perpetuate stigmatizing and controlling messages. Public agencies and public spheres such as DSS, Medicaid, law enforcement, prenatal clinics, substance use treatment programs, and hospitals reproduce and reinforce messages about how perinatal substance use treatment patients should behave and can expect to be treated. Largely low-income pregnant women affected by substance use and stigma navigate care amid structural obstacles such as housing and food insecurity, unemployment, and intimate partner violence. Due to these larger forces, even receiving care in a comprehensive, supportive clinic does not shield women affected by substance use from pervasive judgment surrounding their pregnancies. As a result, our participants experienced comprehensive care in the context of larger structural forces that shaped how they understood their earlier care, expectations of current care, their feelings about MAT, and perceptions of support. The amount of support participants perceived also shaped how capable

they felt to respond to judgment, especially at the hospital.<sup>3</sup>

#### *Provider themes, Within Clinic*

##### Supportive Care

*I think [this program] is an opportunity for patients to trust... that they're gonna be in an OB clinic that is supportive of substance use [treatment]... team members all follow the same general philosophy: 'whether you last used five years ago or five days ago we're gonna treat you exactly the same.' Our team doctrine also is that all women who are pregnant are similar, whether you have a substance abuse disorder, if you have diabetes, or nothing, you just wanna make sure your baby's okay.*

- Betsy

Providers, staff, and affiliates in the comprehensive program are bound by a unified philosophy grounded in supportive and destigmatizing language, designed to allow patients to feel supported within the clinic. Their philosophy relies on a medicalization of substance use, intended to destigmatize addiction by framing it as a chronic relapsing brain disease<sup>8</sup> rather than a moral failing.

##### Care Coordination & Wrap-Arounds

*The clinic is geared so that the resources are available for clients at every visit. However... a couple weeks ago we had a new client - five people walked into her room. Though those all may be needed resources, there could have been a different way [to avoid] five people cycling through one room... It's foolish for us to think that she will remember the information that she needs from each [of] our entities and even understand what's the difference.*

- Betsy

Providers struggled with the dichotomy of helping patients with the many available resources within the clinic and the potential burden of overwhelming a patient.

#### *Provider theme, Within & Outside Clinic*

##### Education/ Stigma

*I think one of the ways we address that [substance use] stigma is by having a core team that is dedicated to serving this patient population and doing education within the group. We have fundamental knowledge that substance use is a*

*chronic relapsing disease and can look at it [through] that lens instead of [as] a moral failing, like how it is looked at in some parts of the community.*

- Jodeci

Providers mentioned education as a potential tool to push against, mitigate, and respond to stigma patients may have experienced from outside organizations, the community, or other treatment services. This provider also re-emphasizes the potentially destigmatizing nature of referring to addiction as a disease.

#### *Provider themes, Outside Clinic*

##### Duplicated Efforts

*In some ways, the danger of the opioid epidemic is that we are stumbling over ourselves. Everybody wants to do something.*

-Betsy

Providers mentioned difficulties associated with duplicating efforts between multiple entities outside of the clinic that aim to help these women. While resources are beneficial, overlapping ones can complicate who is going to do what for the patient, impeding how clearly and accessibly providers can deliver care.

##### Postpartum

*I think [the program] could have a more central role here in the pregnancy period and in the handoff postpartum... we could do better in preparing women for what services they're going to be asked to participate in after they deliver. We are focused here on the pregnancy piece, so we're doing a better job at having them anticipate what happens in the hospital. We have a lot of room for improvement on helping them anticipate what's gonna happen as they take this child home.*

-Jackie

Providers drew attention to challenges they face in caring for patients postpartum, a time of highest risk for relapse.<sup>9</sup> Jackie discussed the need for more education to seamlessly transition patients to postpartum services.

##### Transportation

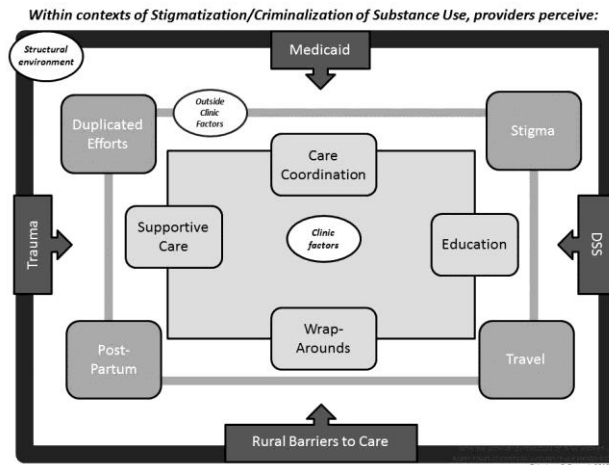
*Distance is a big thing. It would be great if we had a mobile way to do this or a way to access our patients in their community, because so many of them have issues with transportation, they don't have cars, they have to get rides from people...*

- Elizabeth

<sup>3</sup>Specific concerns about nursing care, raised by participants, have been shared and discussed with the nurse-education team at the hospital where all participants delivered.

All 10 providers, staff, and affiliates mentioned transportation as a major barrier for their patients to accessing perinatal substance use treatment.

## Provider themes: Discussion



Providers were aware their patients' attempts to access perinatal substance use treatment occur within a broader context of criminalization of substance use, in a rural Appalachian region with limited healthcare access overall. Providers described attempting to respond to these challenges on behalf of their patients, as well as to potential structural obstacles such as *Medicaid* coverage that ends 60 days after delivery, lack of Medicaid expansion, *DSS* notification requirements, *rural barriers to care*, and *trauma*, which all impact their patients. For example, providers described how the program works within bounds of what Medicaid will cover (including by seeking prior authorizations, noting how often patients need to be seen, which formulations of buprenorphine are covered, etc.), while providing support to navigate various stipulations for treatment. Providers described see supportive care and care coordination as vital to meeting such requirements for Medicaid coverage, and to supporting women covered by it. Providers discussed how they educate and support women in order to prepare them for potential *DSS* involvement postpartum, echoing many participants' concerns. The clinic responds to rural barriers to care, including transportation, by offering wrap-around services coordinated in one place. Finally, providers strive to provide trauma-informed care;<sup>10</sup> understanding that many patients use substances or seek treatment following abuse or other trauma. Providers

respond by providing supportive care. While providers did not always mention structural factors explicitly, they acknowledged their impacts when discussing how patients' larger needs were met or not, in direct clinical care. Providers were more explicit in descriptions of how they respond to factors immediately beyond the clinic: including *duplication of efforts*, *postpartum care*, *transportation*, and *stigma*. Such factors, while beyond the providers' control, affected the care patients receive and were described as negatively impacting care. Conversely, providers described aspects of care directly inside the comprehensive program positively. While several providers mentioned areas for improvement, *supportive care*, *wrap-around services*, *care coordination*, and *education* were highlighted as foundations of the program that work well for patients. Providers' awareness of and attention to multi-layered aspects of in-clinic, outside-of-clinic, and structural factors illustrate how they understand and respond to obstacles their patients face when accessing perinatal substance use treatment in the region.

## Recommendations

Based on our findings from this research about experiences of perinatal substance use treatment, conducted with patients and providers recruited in a comprehensive perinatal substance use treatment program in Western North Carolina, we recommend maintaining and expanding care and advocacy in several areas. First, we recommend providers continue to offer, and expand access to, supportive, non-judgmental comprehensive perinatal substance use treatment, including MAT for those who want it. However, there is a need to improve postpartum transition to community-based care, in rural areas. Next, by exploring patient attitudes about MAT and their goals for substance use treatment, providers can enhance the provision of patient-centered care. Finally, to the extent possible within clinical settings, providers and affiliates should address structural barriers by, for example, supporting and advocating for patients' Medicaid continued eligibility as well as supporting Medicaid expansion efforts. Identifying local and regional transportation resources, and making this information available to patients, is helpful. In future research better understanding of how both stigma and public policies are associated with substance use and treatment access, especially as related to attitudes toward MAT, is needed.

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