Understanding the Current Healthcare System Flaws Surrounding the Treatment of Mothers with Opioid Use Disorder

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Abstract

Background

The opioid epidemic has left countless mothers struggling with substance use disorders inside a health care system that is not trained, prepared, or resourced with the ability to help them on a stable path to recovery and successful parenting. Although in recent years, funding and resources have been better allocated to research surrounding substance use disorders, many physicians remain unaware how to best help these patients. Barriers and challenges these mothers face can be alleviated with better understanding from mothers about what they need, as well as increased training for physicians and nurses.

Objectives

We aimed to identify concerns and recommendations from mothers with substance use disorders who have experienced the healthcare system, as well as from current physicians helping these mothers about how to change the current system to better support patients and caregivers in their field.

Methods

We conducted interviews with four mothers and five healthcare clinicians using targeted questions to understand their current experiences and recommendations for improvement. Mother and clinician questions varied but both were aimed at getting a better understanding of where the flaws laid as well as gathering their personal insight about how flaws may be able to be improved.

Results

Every mother interviewed shared a variety of challenges and experiences within healthcare. Some of the findings include transportation issues, hospital and community resource access, judgement from clinicians, and personal trauma, fear, and shame. Overall, a general need for more support both in and out of the hospital setting shone through. While physicians were aware more support was needed, they noted a combination of factors stood in their way: insufficient access to resources for mothers,

insufficient knowledge post-medical school of routes of treatment, secrecy and fear from mothers, recent changes to practices for babies born with either Neonatal Opioid Withdrawal Symptom or Neonatal Abstinence Syndrome, and lack of care options, especially in rural areas, where the opioid epidemic is more prevalent. Mothers need clinicians to know more about opioid use disorder and how to best treat mother and baby, that is clear. However, healthcare clinicians also need training on internal bias, trauma informed care, and navigation of the Division of Children, Youth, and Families (DCYF) in order to provide effective long-term help. Mothers wish their story was understood, not judged, and they felt they could still effectively parent while also recovering from a substance use disorder.

Conclusions

With respect to the opioid epidemic and parenting/pregnant women, the current healthcare system leaves physicians untrained about best practices. As such, they must learn how to best help from the women they see as patients. While continual learning and patient input are a useful tool, training during medical school could better prepare future physicians on how to best approach treatment, stigma and bias to better serve these women. Moreover, long-term follow up and clear treatment plans for mother and baby is an essential aspect of healthcare for mothers with substance use disorders. By highlighting these findings, we hope to inform the development of new guidelines to the healthcare training curriculum and encourage a closer look at ways to reduce barriers for mothers seeking treatment.

Background

Opioid Use Disorder (OUD) is a subset of Substance Use Disorders (SUD). The opioid epidemic has continued to grow in recent years, leaving men and women in need of medical treatment (McHugh et al., 2018). While both men and women's rates of OUD are increasing, SUDs in women progress more rapidly and adverse psychological consequences are more severe (McHugh et al., 2018). Additionally, women face more barriers to receiving treatment for SUDs due to increased stigma, childcare responsibilities, and lack of care for the adverse psychological effects that women often experience (McHugh et al., 2018).

In 2020, 0.57% of women struggled with OUD during pregnancy or delivery (Shen, et al., 2020). Despite the number of women struggling, only 19 states have substance use treatment programs specifically designed for pregnant women, which does not include Vermont or New Hampshire (Sutter et al., 2019; Guttmacher Institute, 2021). Medication assisted treatment is the current standard practice, however, the evidence is overwhelming that further support, such as counselling, childcare, and privacy is needed for effective treatment (Sutter et al., 2019).

The opioid epidemic for mothers with OUD has not properly been addressed by the healthcare system. In 2007, 1 in 5 pregnant women were prescribed opioids, in 2010, 90% of opioids were prescribed to women, and from 1990 to 2010, there was a fivefold increase in overdose mortality in women (Lee & Saia, 2019). While the National Institutes of Health does allocate funding to OUD, only 10% goes towards maternal health (Lee & Saia, 2019). As of 2019, the current follow up time for mothers with OUD after birth was 42 days, while effective follow-up care, especially for mothers struggling with a SUD, is recommended for 2 years (Lee & Saia, 2019).

Pregnant mothers with OUD face many obstacles in accessing healthcare. Many women do not receive treatment due to fear of losing custody of their children upon admitting they need treatment (Frazer et al., 2019). Conversely, many finally decide to seek treatment to help retain custody of their children, as well as for concern for their baby's health and a need to escape unsafe home environments (Frazer et al., 2019).

Unfortunately, even after making the courageous decision to seek treatment, mothers with OUD continued to face countless barriers throughout their recovery. Healthcare clinicians carried negative attitudes towards the mothers seeking treatment, leading to more secrecy. Clinicians trained to help with pregnancy were not trained to help with SUDs. A general feeling by mothers with OUD of being misunderstood or ignored by clinicians, mandated reporting to the Department of Child, Youth, and Family Services (DCYF), and lack of resources offered when they finally were honest with their clinician are challenges they face (Paris et al., 2020). The public, including some clinicians, often

go ill-informed about the reality of OUD, thinking it is controlled by will, and not that it is a real disease that requires treatment (Paris et al., 2020).

Women are often most motivated to seek treatment once finding out they are pregnant; they want to protect and help their child (Paris et al., 2020). Babies born to mothers with OUD often experience either Neonatal Opioid Withdrawal Syndrome (NOWS) or Neonatal Abstinence Syndrome (NAS), both characterized by poor weight gain, irritability, inability to be consoled, gastrointestinal effects, and seizures (Schulman, 2019). Past research shows that, if treated, NOWS and NAS do not seem to have long term effects on babies, although more research in this area is needed, but without treatment, NAS and NOWS are almost always fatal (Oei, 2019). The diagnosis method for NAS and NOWS is currently changing in hospitals around the country. While previously the Finnegan method, a 21-point scoring system, was used (Oei, 2019), hospitals are slowly switching to the Eat, Sleep, Console method, which has reduced the number of babies having to receive morphine for treatment. There is no universally agreed upon best treatment for NAS or NOWS. In general, first line treatment involves swaddling and skin to skin contact with mother while second line treatment involves giving low doses of morphine to the baby, although generally this strategy is a last resort (Cleveland, 2020).

In addition to more funding for studies about OUD and pregnancy, public health needs greater access to contraceptives, universal addiction screening, and improved clinician training (Patrick & Schiff, 2017). A 2020 study showed the clinicians most effective at treatment were those who had the most experience with patients with OUD, not those with the most medical training (Coyne, 2020). While there is current and recurring training on child abuse, the lack of current training for OUD treatment, and the sensitivity of the subject, increased through stigma, has also provided challenges for treatment (Coyne, 2020).

While research has been done addressing barriers in the healthcare system for giving mothers and babies the most effective care and treatment, current research leaves gaps as to specifically where and how care needs to be improved. General negative experiences do not provide enough information as to where support is lacking for

clinicians and for patients. The goal of these research interviews was to narrow down on specific places within healthcare that mothers felt more support, what training and/or changes were needed to better understand their prenatal and delivery experience. Additionally, clinicians were also asked about where they felt changes were needed to improve their ability to care for these mothers struggling with OUD. By identifying specific changes needed for women and clinicians to feel best about treatment, we hope to alleviate barriers and challenges mothers with OUD face.

Methods

Conceptual Framework

Semi-structured interview guides were created for healthcare clinician and mother interviews. We drew from discussion about what themes we wanted to uncover to create targeted interview questions for both clinicians and patients. For clinicians, interview questions dove in-depth into training surrounding SUD, where they acquired most knowledge of SUD and treatment, suggested improvements to current curriculums, established current protocols for mothers and babies, and addressed the stigma and internal bias.

For mothers, questions focused on three sections: methods and critiques on prenatal care, labor and delivery care,, and postpartum care. The interview ended with three big idea questions: “How was your treatment for SUD and what changes do you suggest?”, “What messages do you want future physicians to know about treatment?”, and “What messages do you want to give about combating the stigma and negative clinician attitudes surrounding SUD?."

Participants

Participants were recruited via a larger study examining OUD among pregnant and parenting women. Interviews were conducted individually with five healthcare clinicians and four mothers via Zoom, each one lasting an average of 30 minutes. All questions were asked to each participant and natural discussion with the researchers continued. With interviewee consent, interviews were recorded for further analysis.

Clinician clinical background varied. Interviewees included a pediatric resident, pediatric doctor, family medicine doctor, nurse practitioner and certified nurse midwife, and a registered nurse from the labor and delivery floor. All currently practice in either the state of Vermont or New Hampshire, one additionally having clinical background in Maine. No interviewees have practiced outside of New England.

Mothers interviewed also currently reside within Vermont, New Hampshire, or Maine. One mother does bring prenatal experience with treatment from North Carolina, but now resides within New England. The first mother has two children, 18 months and 13 years, but only has custody of the 18-month-old. She has been in and out of recovery for 14 years, but has been consistent in recovery since the birth of her 18-month-old. The second mother has been in recovery for opioid use disorder since finding out she was pregnant with her daughter, who is now 15 months old. The third mother has had a similar journey as a mother of 2, and now has a 10-month-old child. Finally, the fourth mother has two children, 8 and 2 and has overcome multiple relapses since her first pregnancy, but has now been in recovery for over four years.

All mothers have received (or are currently receiving) medication assisted treatment during their recovery, one went to a recovery center, and all attend group and individual counselling. All have had at least one child who needed monitoring for symptoms of Neonatal Abstinence Syndrome or Neonatal Opioid Withdrawal Syndrome.

Data Analysis

Interviews were transcribed from recordings for thematic analysis. Overarching themes were found within clinician interviews, mother interviews, and all the interviews in general. After thematic analysis was complete, quotes were assigned to each theme as supporting evidence. Themes and quotes are shared below.

Results

The theme analysis of the interviews highlighted five main themes from healthcare clinicians and pregnant/parenting women with OUD. The five themes are as follows:

1. Clinicians are learning how to best treat OUD from the mothers themselves instead of through any formal training.
2. Clinicians with previous experience working within the OUD field are taking the initiative themselves to educate future physicians due to lack of formal training.
3. Both clinicians and mothers need to feel it is understood that OUD is a disease not a decision.
4. Recurring visits to the same supportive medical teams, allowing for a relationship and trust to build, leads to the best outcome for patients.
5. This population continues to face numerous barriers to quality care despite improvement in the field.

Theme 1. Clinicians are learning how to best treat OUD from the mothers themselves instead of through any formal training. One pediatric physician, who has been practicing since the early 2000s recounts in his interview that he currently “cares for 130 babies and infants who have parents in recovery for OUD." While he, like every other physician working with these moms, has had no training, he is “conscious to work with mothers to design the best system for them” and “is not afraid to ask mothers for their opinions on best practices." He is not unique in having to learn best treatment options from the mothers instead of in formal medical training. While this certainly needs to change, the increased level of patient/clinician communication that has come from having to make up for the extreme lack of training has helped practices develop better protocols. A nurse practitioner and certified nurse midwife says that her “patients taught [her]. Their stories inspired [her] to find ways to make life better for these people." While connections that lead to improved healthcare outcomes are essential, they do not compensate for the lack of training in medical and nursing schools and still leaves gaps in the medical field. A current pediatric resident and recent graduate of medical school says she “felt like [she] had to learn how to treat OUD on the fly as [she] came into residency” and “got no information about what treatment looks like, what recovery looks like, and how to best help these people." Over her three years of residency, she has learned “through conversation with patients, but it would have been beneficial to learn those things before having to just dive into it." Knowing what she learned from patients now, she knows she will ensure that the future residents she teaches will get “exposure to these families and understand they are people with a chronic illness."

Theme 2. Clinicians with previous experience working within the OUD field are taking the initiative to educate future physicians due to lack of formal training. As the pediatric resident mentioned above, clinicians, as they continue to learn more about OUD treatment, ensure they teach what they have learned to the students they currently have, hoping to end the cycle of blindly diving into helping people with OUD while being untrained. Fortunately, some mothers have been forthcoming with information that can help clinicians in training. For instance, in the interviews mothers were asked what kind of lessons they feel need to be taught to clinicians before the clinicians begin caring for them. Mother 2 addressed the problem of walking into a patient's room still carrying internal bias and a negative or judgmental attitude. She said she needed clinicians to not "be judgmental because it's not black and white. A lot of people think addiction is black and white, like you made the choice to use, and it's not that simple." She instead wants clinicians to "try to see inside a little deeper to understand the person's life. [OUD is] not what it seems when you just glance in." Mother 3 concurred with her, addressing the fact that clinicians can't walk in and pretend to understand something they haven't been through. She wants to remind physicians that they "don't know why [the patient] started using, [they can't] pretend like [they] do."

Two of the mothers interviewed also addressed women's health care, specifically pregnant women, as a whole. Mother 2 tells us that:

> "the number of women who are mistreated during prenatal care is very high. And then when you add addiction or opioid use disorder on top of that. And then add being a single parent. A lot of people in addiction have suffered a lot of abuse (parental and sexual) and that makes them more timid and so it's hard to go to those appointments by yourself and speak for yourself."

Prenatal health care involves women standing up for both their own needs and their baby's, especially as medical providers will not always know their needs as evidenced above. As mother 2 points out, women with OUD often have layers that make open and honest communication even harder, such as abuse or trauma, single parenting, or psychological effects from OUD. As mother 3 put it, clinicians have to "look beyond the surface. It's a real person and the individual experience is so different from the information you would get in books or literature."

Theme 3. Both clinicians and mothers need to feel it is understood that OUD is a disease not a decision. For years, stigma and lies about OUD have circulated and been perpetuated through society. Now, on top of trying to understand how to best treat OUD, clinicians and patients have to fight back against all the negative stigma regarding OUD and the most commonly circulated lie, which implies OUD is a decision people make, not a chronic disease they are fighting. The interviewed pediatrician says he always reminds every mother that what they are fighting "is a medical condition and not a moral failing." He explains in his interview that he thinks it's important to remind mothers of this because "so many women feel such a profound sense of shame and failing, we don't need to amplify that when they come in to get help." The family medicine physician interviewed resonated similar messages, explaining how "[clinicians] want to remain neutral and try to be on the patient's side. It is a disorder, like any other disorder." Getting these constant reminders from clinicians throughout a patient's treatment changes the patients outlook on what they are fighting. Mother 1 says the physicians helped her see that:

> "it's not that you don't love your kid enough to stop. Once you have SUD, your brain is wired differently from other people. So, once it's in your system, you can't do what's best for them, you can't make good choices. It's not that you don't love your kid or that your kid is not enough to keep you sober. It takes more than love of a child to keep someone sober."

The pediatric resident, who spends a great deal of time with mothers just after giving birth, understands that it "can be hard in conversations to make sure the mother isn't feeling guilt" but she always reminds the mothers that being in recovery for OUD and being a great parent are not mutually exclusive; "you are in recovery and you still can be a great mom." Encouraging this mindset, as well as consistent follow up care, can lead both mother and baby to lead successful lives in recovery.

Theme 4. Recurring visits to the same supportive medical teams, allowing for a relationship and trust to build, leads to the best outcome for patients. "There is very little determined about the kid from in-utero [drug] exposure. What is important is what happens after." This quote from the pediatrician is the mindset that has led him to be currently helping 130 children, some now years after they are born, who had drug

exposure in-utero. He knows that connecting mothers with the right resources and continuing to follow up with their care is what leads to the best results. Mother 4 tells the interviewer that she has "been clean and sober for over four years now and [she] thinks that is because of the support system given to [her] by [her] clinicians and by recommendations for other groups the clinicians gave [her]." Mother 1 has similar success with recovery, she says, due to the fact that the hospital was her "biggest cheerleader and they made [her] feel like [she] was doing such a good job. The nurses let [her] learn and prove to them [she] could take care of [her] baby which put [her] on a natural high and led to a great start to recovery." Conversely, hospitals where the patients are not supported from the beginning of motherhood have less successful results. Mother 4, who started at a less supportive health care clinic before finding her niche, said that her first maternity care team "constantly hid information from [her]" and that "they gave [her] a bad attitude towards recovery because [she] constantly felt judged and [they were] unsupportive of her recovery." Clinicians who continue to be judgmental towards these women seeking help are just one of the barriers that these mothers still face.

Theme 5. This population continues to face numerous barriers to quality care despite improvement in the field. Mothers feel overwhelmed and unclear about what path to take, clinicians are still facing law enforcement barriers that prevent them from helping the mothers as best they can, and many of these women have a history of trauma. Mother 4 says when she first decided to ask for help, she "had a lot of options and there were so many programs that run so differently, [she] didn't know where to start. If [the programs] were all on the same page and ran the same way, there might be more positive results." Indeed, many recovery programs are run drastically differently from one another that it can cause confusion and be overwhelming to the point that it can be difficult to find the appropriate one without proper guidance. A more standardized introduction to what options mothers have available may prevent mothers from being deterred and lead to more successful results.

Another substantial barrier is law enforcement regulations. Currently, the family medicine physician reminds the interviewer that clinicians "can prescribe very strong opioids but can't prescribe the treatment for it." By law, any licensed family provider

can provide opioids to patients, but without special licensing and further training, they cannot prescribe the drugs used to treat OUD, most commonly methadone. Furthermore, “[she] can prescribe methadone for pain but can’t prescribe it for addiction recovery." Clinicians struggle from regulations that prevent them from being able to help these mothers without a special license. In rural areas, clinicians with those licenses can be hard to find. In addition, clinicians need more training on trauma informed care. Mother 1 openly talks about how many women with OUD “unfortunately, didn’t have an ideal childhood." Mother 4’s interview covered similar topics. She speaks on how “a lot of [these women] didn’t have parents and lived in foster care [their] entire life and were drugging and homeless." Clinicians not only need to be given federal approval to prescribe medications to treat these women, but also need more training on how to best approach supporting these women through the trauma and psychological effects many of them have.

Discussion

The areas for improvement, while considerable, are specific to certain parts of the health care recovery and parenting process for pregnant/parenting mothers with OUD. The five thematic themes analyzed from the online interviews with clinicians and mothers with OUD narrowed down exactly where in the healthcare system improvements were needed to improve quality of care for this population. The five themes highlighted two necessary changes to the medical field, 1) we need to improve education and training on OUD and treatment for clinicians and the general public and 2) we need to knock down the barriers that lie in the way of these women seeking treatment.

Building up the education and training surrounding OUD has two parts; the clinicians and the general public. Clinicians need to be better trained on treatment options, adverse side effects of OUD, and learn about resource outreach centers for these mothers. The general public needs to be educated from a young age to learn that OUD is a disease not a decision. One of the largest barriers these women face is the negative stigma surrounding OUD, often stemming from false education. Public education, even starting in high school, about the reality of the chronic condition could lessen this stigma and make treatment for OUD normal and widely accessible.

Unfortunately, stigma is not the only barrier these mothers face and quality healthcare involves knocking down the other barriers as well. Strict regulations, limited access to care, history of trauma, and an overwhelming number of treatment options are just a few of the problems that keep these mothers from getting started with treatment. With more funding allocated towards reducing these barriers, such as determining a clear starting path to treatment, more mental health resources for this population, and transportation to and from appointments, treatment would be more accessible.

The current healthcare system lacks communication between mothers and clinicians, leaves the opioid use epidemic stigmatized by the public, and leaves physicians learning from mothers with OUD and mothers with OUD feeling unsupported. Funding towards better medical school education and towards eliminating barriers that stand in the way of treatment currently can lessen the state of the epidemic, better household environments and parenting, and reduce the stress on clinicians trying to treat OUD without adequate training.

Conclusion

With respect to the opioid epidemic and parenting/pregnant women, the current healthcare system leaves physicians untrained about best practices. As a result, they must learn how to best help from the women they see as patients. While continual learning and patient input are a useful tool, training prior to graduation could prepare future physicians on how to best approach treatment, stigma and bias to better serve and care for these women. Further, long-term follow up and clear treatment plans for mother and baby are essential aspects of healthcare for mothers with substance use disorders. By highlighting these findings, we hope to inform the development of new guidelines to the healthcare clinician training curriculum and encourage a closer look at ways to reduce barriers for mothers seeking treatment.

References

Cleveland, L. M. (2020). *Care of the Infant and Family Affected by Neonatal Abstinence Syndrome (NAS) Across Multiple Settings.* Advances in Neonatal Care, *20* (5), DOI:10.1097.

Coyne, K. (2020). *Nurses Caring for Pregnant Women with Substance Use Disorder: Exploring Emotional Intelligence and Attitude.* Carlow University, ProQuest Dissertations Publishing.

Frazer Z., McConnell K., Jansson, L. M. (2019). *Treatment for substance use disorders in pregnant women: Motivators and barriers.* Drug and Alcohol Dependence, *205*, ISSN 0376-8716. https://doi.org/10.1016/j.drugalcdep.2019.107652.

Guttmacher Institute. (2021, April 1). *Substance Use During Pregnancy.* https://www.guttmacher.org/state-policy/explore/substance-use-during-pregnancy#

Lee, Y. W., Saia, K. (2019). *Caring for Pregnant Women with Opioid Use Disorder.* Curr Obstet Gynecol Rep 8, 9–14. https://doi.org/10.1007/s13669-019-0255-9

McHugh R. K., Votaw, V. R., Sugarman, D. E., Greenfield, S. F. (2018). *Sex and gender differences in substance use disorders.* Clinical Psychology Review, *66*, ISSN 0272-7358. https://doi.org/10.1016/j.cpr.2017.10.012.

Oei, J. L. (2019). *After NAS*. Seminars in Fetal and Neonatal Medicine, *24* (2), Pages 161-165, ISSN 1744-165X, https://doi.org/10.1016/j.siny.2019.01.012.

Paris, R., Herriott, A.L., Maru, M. (2020). *Secrecy Versus Disclosure: Women with Substance Use Disorders Share Experiences in Help Seeking During Pregnancy.* Maternal Child Health J 24, 1396–1403. https://doi.org/10.1007/s10995-020-03006-1

Patrick S. W., Schiff D. M. (2017). *Committee on Substance Use and Prevention: A Public Health Response to Opioid Use in Pregnancy.* Pediatrics, *139* (3), https://pediatrics.aappublications.org/content/139/3/e20164070

Schulman, B. D. (2019). *The Opposite of Addiction Is Connection: Improving Clinical Outcomes by Implementing NICU Peer Recovery Coaches.* Biennial Convention.

Shen, Y., Lo-Ciganic, W., Segal, R., & Goodin, A. J. (2020). *Prevalence of substance use disorder and psychiatric comorbidity burden among pregnant women with opioid use disorder in a large administrative database 2009–2014*. Journal of Psychosomatic Obstetrics & Gynecology. DOI: 10.1080/0167482X.2020.1727882

Sutter M. B., Watson, H., Bauers, A., Johnson, K., Hatley, M., Yonke, N., Leeman, L. (2019. *Group Prenatal Care for Women Receiving Medication-Assisted Treatment for Opioid Use Disorder in Pregnancy: An Interprofessional Approach.* Journal of

Midwifery and Women's Health, *64* (2). https://doi.org/10.1111/jmwh.12960