

“Will My Baby Be OK?” A Qualitative Analysis of Pregnant Women’s Suboxone® Online Forum Posts

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Abstract

BACKGROUND: Intentional or accidental drug-overdose is a leading cause of mortality in U.S. women of child-bearing age. Opioid use during pregnancy is not only associated with maternal overdose, but with low birth weight at term and neonatal abstinence syndrome (NAS). Buprenorphine was approved as a medication for opioid use disorder (MOUD) in the United States in 2002 and is for many women, a preferred treatment option versus methadone. Buprenorphine is relatively safe during pregnancy and is associated with lower rates of NAS than methadone. Given the importance of MOUD during pregnancy, relatively little information exists regarding patients’ questions and concerns about buprenorphine treatment, including the psychological challenges they face. **AIMS:** The purpose of the study was to describe the perinatal concerns of women with opioid use disorder who posted to an online suboxone forum. **METHODS:** Qualitative descriptive design to analyze some 170 posts from mothers with OUD to an online Suboxone® support forum over the period 2016–2021. **RESULTS:** The analysis of the interview data revealed 4 important themes: (a) Stigma resulting in self-deprecation, low self-esteem, and low self-efficacy; (b) stigma from family members and loved ones; (c) stigma from the medical profession; and (d) stigma from the community at-large (social stigma). **CONCLUSIONS:** There is compelling evidence to emphasize the importance of open communication and support between medical personnel and patients to ensure optimal outcomes for mother and baby.

Keywords

opioid-related disorders, pregnant women, buprenorphine, naloxone drug combination, neonatal abstinence syndrome, social stigma

Introduction

Intentional or accidental drug-overdose is a leading cause of mortality in U.S. women of child-bearing age (Smid et al., 2020). Between 2007 and 2016, pregnancy-associated mortality involving opioids more than doubled from 4% to 10% (Gemmill et al., 2019). Opioid use during pregnancy is not only associated with maternal overdose, but with low birth weight at term and neonatal abstinence syndrome (NAS) (Krans et al., 2021).

The number of pregnant women with using opioids during pregnancy in the United States nearly quadrupled between 1999 and 2014, increasing from 1.5 women per 1000 delivery hospitalizations in 1999 to 6.5 per 1000 delivery hospitalizations in 2014 (Haight et al., 2018). These figures include both heroin and legally and illegally obtained prescription opiates.

In 2019 approximately 7% of surveyed women reported using prescription pain medication during their pregnancies (Ko et al., 2020). Of those women, one in five reported addictive behaviors: using opiates for a

reason other than to relieve pain or obtaining opiate pain medication from a source other than their health care provider.

Buprenorphine was approved as a medication for opioid use disorder (MOUD) in the United States in 2002 and is for many women, a preferred treatment option versus methadone. It is typically prescribed as a combination product, buprenorphine-naloxone, brand name Suboxone®. Buprenorphine can be prescribed from a medical office, or even a telehealth practice, a month at a time, as opposed to methadone treatment programs

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which require usually daily in-person visits and will often restrict patients to one day's worth of medication at a time. Since 2016 nurse practitioners (NPs) and physicians' assistants (PAs) have been able to obtain waivers to prescribe buprenorphine for opioid use disorder (Andrilla et al., 2020).

Buprenorphine is relatively safe during pregnancy and is associated with lower rates of NAS than methadone (Link et al., 2020). As the duration of MOUD increases (time taking buprenorphine or methadone), there is a significant decrease in maternal overdose rate, preterm births, low infant birth weight, and NAS. In fact, each additional week of treatment for mothers by using MOUD decreased the odds of overdose by 2% (Krans et al., 2021).

Given the importance of treatment using MOUD during pregnancy, relatively little information exists regarding patients' questions and concerns about buprenorphine treatment, including the psychological challenges they face. The purpose of the study was to describe the perinatal concerns of women with opioid use disorder who post to a public online Suboxone forum. It was hoped that through a close reading and analysis of these posts, investigators might discover information that patients are reluctant to disclose to their providers in a clinical setting. (Note that throughout this article we refer to buprenorphine generically to mean either buprenorphine-naloxone combination products, like Suboxone®, or Subutex® and other buprenorphine-only mono products).

Methods

Design

This study utilized a qualitative descriptive design to explore the concerns of women who use buprenorphine-naloxone for the treatment of opioid use disorder while pregnant. Qualitative inquiry aims to describe and interpret human phenomena (Speziale et al., 2011). Qualitative manifest content analysis was used from the online forum "Suboxone Talk Zone.com," an open-access moderated forum for persons with opioid use disorder.

At the time of data collection, posts were accessible to the public worldwide without registering for the forum and was easily found on the internet by searching for key words such as "Suboxone" and "forum." We believe that women located the site through word of mouth and by internet search.

Given the aims and objectives of our research study, we utilized a constructivist approach to focus on the social and cultural context as well as the structural issues that motivated the posts we read (Braun & Clarke, 2006; Burr, 2015). In that way, we looked not only at the

surface, but latent contextual meanings of the women's posts.

Data Collection

This study specifically examined the Suboxone Talk Forums' content related to pregnancy and childbirth, (<https://www.suboxforum.com/suboxone-and-pregnancy-6/>) which spanned the years 2010–2021; posts were from persons across the United States, as well as a few identified as being in Europe. After receiving approval from the University's Internal Review Board, posts were downloaded to a password protected folder and anonymized so that only the posting date and content remained. Data were saved as 2.2 MB of text files. From these data, all posts (approximately 170) from 2016 to 2021 were used to begin our analysis of posts from mothers with OUD to an online Suboxone® support forum. Investigators chose to look at these 5 years because the practical limitation of close analysis of such a massive amount of text, as well as the desire to capture data with the most recency. All posts from women who were pregnant or who had experience with pregnancy and opioid use disorder treatment were included. Posts by forum moderators or by persons who identified themselves as medical professionals were excluded from analysis.

Because of the sensitivity of this material, we took care to not to reveal any information that might somehow lead a reader to any of the 18 HIPAA identifiers that might identify one of the persons quoted. This would include the state or city the person posting lived in, any special nicknames, occupation, and so on. We also lightly edited quotes to remove any special spellings or unique phraseology that might be linked to a particular person. Participants used nicknames as identifiers in the forum.

Data Analysis

A recursive process was utilized to analyze and review the dataset. This methodology was modeled after a six-step process outlined by Braun and Clarke (2006) who provide a structured approach and guidelines for thematic analysis:

1. Data were transcribed and read at a high level for relevant content.
2. An initial set of codes was generated (Figure 1) from a list of frequent topics. We then coded data using standardized memo templates.
3. After, re-reading the data, codes were collated into potential large themes (Figure 2) and data organized by these potential themes.
4. Themes were applied to the coded extracts.

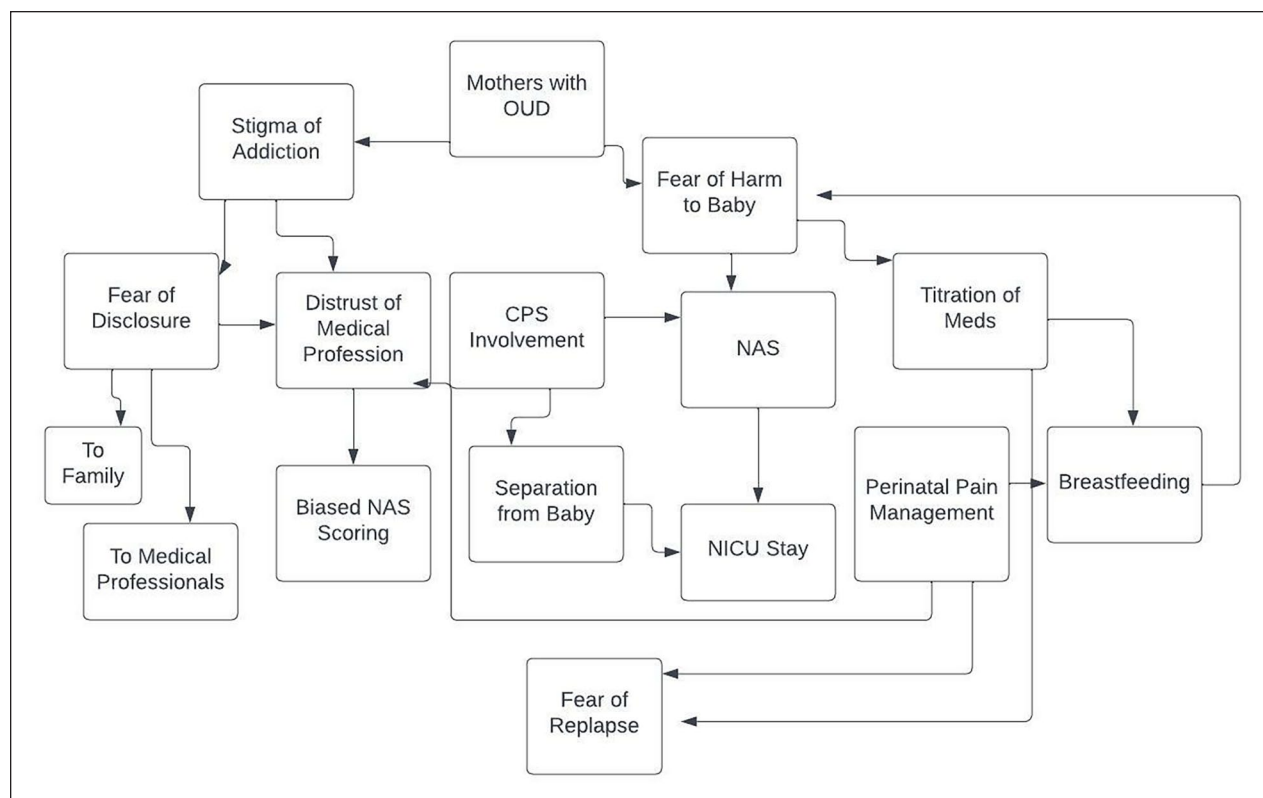


Figure 1. Initial Mind Mapping of Topics with Original Coding

Note. CPS = Child Protective Services; NAS = neonatal abstinence syndrome; NICU = neo-natal intensive care unit.

5. The specific meaning of themes and their narrative were discussed. Definitions of these themes were reviewed and finalized.
6. The data were re-analyzed to find the most illustrative thematic examples; we tied examples to the study's research question and to extant literature.

Data were reviewed inductively, that is do say without any preconception of what thematic content might exist. Hence, the analysis was data driven. In addition, the explicit meaning of the women's posts as well as the latent meaning of this content was examined, to analyze the deeper assumptions and meanings of the posts, as well as the social context in which they were written. Investigators looked for themes that capture important meaning as it related to our research question, and that represented some level of frequency or pattern in the posts. The stream of consciousness style of many of the posts enabled us to better understand the interior thoughts of pregnant mothers with opioid use disorder.

Multiple analytic discussions between the research partners allowed us to reorganize, link, and collapse

initial categories into subthemes under fewer main themes. LucidSpark®, a collaborative interactive whiteboard, was utilized to rename and rearrange virtual color-coded note cards through group consensus to form a holistic understanding of the dataset. Credibility in content analysis was enhanced by dialog and consensus, as well as inclusion of quotes by the participants (Graneheim & Lundman, 2004). Trustworthiness was ensured by keeping an audit trail of our analysis sessions. Ongoing dialog enabled the researchers, who are Suboxone prescribers, to examine their own biases and beliefs.

Results

Interpretive content analysis revealed that the pernicious effects of stigma was the over-arching theme of the women's posts. At the core of the posts were the negative consequences of stigma on the lives of the mothers. Effectively, stigma had driven mothers "underground" to seek medical advice and support from an online source where they felt safe to disclose their situation and vet their concerns. For purposes of this study, stigma was defined as the perception or reality by mothers that they were being adversely judged for their addictions and that

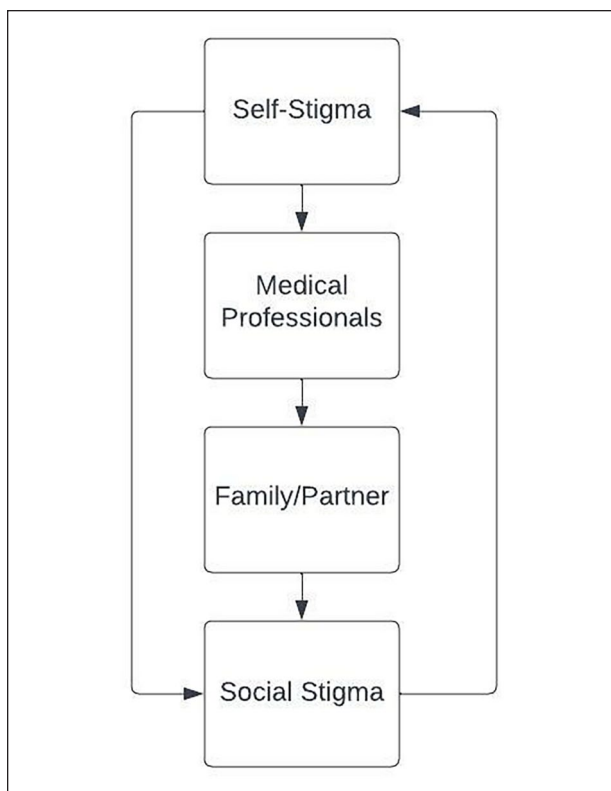


Figure 2. Final Themes: The Cycle of Stigma

they were resultantly deemed less trustworthy than other mothers. The mothers' experience of stigma could be broadly separated into these four subthemes:

- Stigma resulting in self-deprecation, low self-esteem and low self-efficacy
- Stigma from family members and loved ones
- Stigma from the medical profession
- Stigma from the community at-large (social stigma)

Self-Stigma

Most mother's felt tainted by their addiction. For these mothers, their addiction created a power imbalance between themselves, their medical providers, and society at large: "Pregnant mothers are already dealing with enough guilt and shame . . . without being told by medical professionals what's best for their growing baby," wrote one mother.

Self-stigma resulted in self-deprecation and self-devaluation by the women. Mothers internalized the feelings of others or society at large, leading to diminished self-esteem and self-efficacy. This was evident in the embarrassment and shame the mothers felt about talking about their addiction. One mother said, "I guess I don't know what I am asking for. I just felt I could talk and tell

more of the truth here (in the online forum) than I can even with my counselor."

Throughout the posts, mothers described a pressure to wean down or off buprenorphine and the fact that they sometimes titrated medication on their own, thinking this was best for their unborn child. This created internal conflict and intensified the mothers' shame that they somehow were not measuring up:

I started taking 4 to 6 mg a day . . . I do actually feel better mentally and physically at that dose . . . Now worried about the effect on the baby. But I wonder what is more harmful in the long-run? All this self-hate and misery I feel at a lower dose . . . or the higher dose of suboxone with a more mentally stable mom . . . when I did tell my subs doctor I had been taking more, he insisted on staying at 3mg, which I know is the right thing to do and I feel like a monster for wanting differently. I want to be at 4mg a day. Has anyone been at that dose at time of delivery?

Stigma From Family Members

Because of their fear of being judged adversely and not being supported, some of the women kept their addiction secret from family members, including their husbands and partners. They felt the pregnancy made them vulnerable to exposure about the truth of their addiction. The fear of being discovered as an addict caused the women to lead secret lives: "I have no one to talk about my suboxone use with due to a very judgmental family and it is hard keeping it a secret and never talking about it," wrote one expectant mother.

Another woman described that she was getting Suboxone® illicitly from a friend who had a prescription: "I don't abuse it. I take it to stay off opioids. My husband and my family don't know and I am really worried about what will happen after giving birth." Implicit in her comment is the fear that her baby will have NAS.

Stigma From Medical Professionals

The perceived need to hide their addiction from the medical establishment was the most frequent reason mothers posted. One mother wrote, "I have not told my OBGYN for fear of stigma, being judged and other people finding out. I REALLY do not want to tell ANYONE. I will lose everything if I do." This reluctance to talk directly with their obstetrics care team provoked a number of medical questions, ranging from safety of breastfeeding to perinatal pain management. However, by far the most frequent topic posted was NAS.

Mothers worried that once their addiction was exposed, they would be treated harshly and that their babies would be screened for NAS and then possibly either face a prolonged stay in the neo-natal intensive care unit (NICU) or

even be removed from the home by Child Protective Services (CPS). This potentially dire chain of events was a constant driver for women who wanted to taper down to the lowest possible dose of buprenorphine, or even quit treatment altogether:

I'm sure after birth they will test me and my baby for everything and I'm worried about CPS and how I will be treated at the hospital. I don't know how 2 mg affects the baby or if she'll be born addicted or not.

This need for secrecy based on stigmatization made for poor medical decision-making, driving women to try to taper off buprenorphine before their delivery date. Being on the lowest possible dose of buprenorphine was equated with a lower risk of having a baby with NAS. One woman wrote that she knew of other expectant mothers (not herself) who, to avoid being exposed as an addict by having a baby born with NAS, chose to terminate their pregnancies.

Many mothers said that it would have been better to wean off buprenorphine during pregnancy than to put their babies and themselves through extended ICU stays and CPS involvement. The motivation for preventing NAS was complex and nuanced for these mothers, ranging from not wishing harm to their child, to fear of being labeled as a bad mother, to a general distrust of the medical establishment. Here, one mother advised another to wean off buprenorphine *before* her baby is born:

... the doctors tell you opioid addicted babies are better off than a "safe" drug to prescribe during pregnancy! ... F*** what they say if you feel as if your able to stop with no withdrawal symptoms ... Otherwise you will witness the saddest thing when you see an innocent child go through hell just for big Pharm to get paid! Besides it's not their children in the hospital withdrawing ...

A frequent discussion topic was the perceived unfairness or biased application of the Finnegan Neonatal Abstinence Scoring System (FNAAS), a tool used to assess in-utero drug exposed infants. Mothers felt that many of the symptoms assessed by the tool would be typical for any neonate and that their babies were being held to a higher standard because the mother had taken buprenorphine during pregnancy. One mother wrote, "Yes, I 100% believe that while my daughter likely had some withdrawal symptoms she would've been able to come home had Finnegan not been used."

The use of opiates to manage neonate withdrawal was very difficult for the mothers who voiced powerlessness over this decision:

It broke my heart. We didn't want our son on morphine! But had no say ... hopefully only a few more days left. But seriously nothing prepares you for this, nothing. My taper

didn't matter. The OB has nothing to do with whether your baby stays or not ladies ... it's the pediatrician's call.

Stigma From the Community/Social Stigma

Mothers described the feeling of being an outsider and of being shamed by the community, one wrote: "I get being afraid of being judged or looked at differently, nobody wants to feel like that because it hurts!" The beliefs of the community-at-large, and the mothers' perceptions of those beliefs, marginalized these women and contributed to their feelings of shame and low self-esteem.

The ultimate worry of mothers who posted to the forum was that their children would be taken from them by CPS. The mothers felt that the breakup of their families was ultimately the lowest place community prejudice toward addiction would take them:

I am afraid of the judgment and them calling CPS. I don't want this baby taken away and I don't want my other children taken away either over a drug I desperately need [buprenorphine] that helps me get through day-to-day life.

Mothers found a lack of information available to them over what would trigger a CPS investigation: Would it be a positive drug test that showed buprenorphine? Would it be a referral by their obstetrician or a concerned nurse? This perceived lack of transparency drove patients underground.

One person posting to the forum and seeking information on what events would bring trigger a CPS investigation discussed getting a "burner phone" so that an inquiry call to their county's CPS office would not be traceable. Mothers found the idea of a CPS investigation to be stigmatizing noting that their prescription medicine (buprenorphine) carries a larger societal penalty than medications for other chronic conditions:

The thought of CPS opening a case against me simply because I take a prescription medication is just bogus in all honesty. I was told that they will more than likely come to my home & "inspect" our way of living, the cleanliness of our household, our lifestyle, etc. I find it to be quite insulting!

Discussion

For the women who posted to the forum, stigma had multiple levels: stigma from their family and partners, stigma from medical providers, and stigma from the community. Goffman (2009) defined stigma as a perception that is discrediting which disqualified individuals from full social acceptance. Link and Phelan (2001) described the act of being stigmatized through labeling, stereotyping, and loss of status is the act of discrimination.

Women who have addiction disease and who are pregnant face higher social penalty from stigma than males (Weber et al., 2021). The belief that women with addiction disease are unfit to parent is pervasive. As well, pregnant women are at heightened risk for being screened for drug abuse and being referred to CPS or for ultimately facing revocation of parental rights and having a baby removed from them by CPS and placed into foster care.

Women who posted to the suboxone forum self-internalized stigma and were in a great sense driven underground out of shame and fear of disclosure. Rather than speak directly to their medical providers or closest family members, women used the forum as a sounding board for all types of concerns surrounding the use of buprenorphine-naloxone during pregnancy. Overall, women were concerned that disclosure might result in the ultimate removal of the baby from their care.

Women did not want to expose themselves to criticism, discrimination, evaluation of their capabilities to be a mother. Ostracization and shaming created self-stigma and secrecy for the patient, leading to gaps in communication around medical care. This is supported by Weber et al. (2021) who found that stigma toward persons who abuse drugs negatively impacts care, both by characterizing addiction as a weakness, and undermining personal agency and self-efficacy for the patient. Moreover, mothers were concerned about interference from CPS.

Numerous researchers have examined the motivations for users turning to internet forums for medical advice (Gupta et al., 2022), including social interaction, peer support, and promotion, and engagement in services (Naslund et al., 2020). Posting to a forum may have great benefit to mothers with opioid use disorder to have a safe place to discuss medical concerns during pregnancy. However, the content of the forum posts revealed the depth of distrust patients felt toward their medical providers, as well as the many gaps in medical information being conveyed to patients.

Specifically, some of the mothers were given advice to taper down on buprenorphine during pregnancy. However, there is no relationship between maternal buprenorphine dose and NAS, Apgar scores, neonatal head circumference or several other key measures of neonatal well-being (Jones et al., 2014). The increased metabolic needs of a woman during pregnancy generally means pregnant women require a higher dose of buprenorphine with a more frequent dosing interval during pregnancy than non-pregnant women (Caritis et al., 2017; Zhang et al., 2020). Whereas, reducing buprenorphine during pregnancy can lead to increased maternal anxiety, greater risk for aberrant behavior and ultimately treatment failure (Jones et al., 2012). Furthermore, complete detoxification from buprenorphine during pregnancy results in low detoxification completion rates and high relapse rates

(Terplan et al., 2018), as well as risk of poor fetal outcomes (Link et al., 2020).

These apparent discrepancies in information conveyed to patients may be explained by the scarcity of obstetrics providers who have managed a patient on buprenorphine. In one study of the 31, 211 obstetrician-gynecologists who accept Medicaid, less than 2% were trained to prescribe buprenorphine (Tiako et al., 2020), indicating that buprenorphine providers should liaise with their pregnancy patient's obstetrics provider to create a common plan of care.

While the FNAST remains the most frequently used approach to evaluating neonates for NAS (Whalen et al., 2019), many researchers have called for a transition to Eat, Sleep, Console (ESC) model (Grossman et al., 2017), which focuses on maximizes nonpharmacological methods and increasing family involvement (Verklan, 2019). A repeated comment in the posts we reviewed was that mothers felt helpless and lacked agency in the care of their newborn infant while in the hospital. ESC encourages mother/baby bonding, reduce NICU admissions and may be most successful with early prenatal intervention and education through primary care and community nursing (Grossman et al., 2017).

Limitations and Strengths

This study's greatest strength is that it contributes to understanding the concerns of pregnant women who are also considering or using Suboxone® for opioid use disorder. It is rare to have an opportunity to review the thoughts, questions and anxieties of pregnant women with OUD in the way that the forum posts allow. (Practicing clinicians will recognize the limitation of 15-min appointments as being inadequate time to fully understand patients' worries and concerns about their treatment)

However, this study targeted a small cohort of pregnant women with opioid use disorder and is not generalizable to all persons with OUD, or even specifically to pregnant women with OUD who are being treated with buprenorphine-naloxone. As well, the women posting to the forum are self-selecting and may be more vocal or open about their experiences than other pregnant women with OUD.

Implications

Health care providers, including advanced practice nurses (APRNs) who prescribe buprenorphine-naloxone for opioid use disorder, need to increase their awareness when working with this population to include better assessment for psychosocial concerns. Women's experience of stigma can mean more anxiety, less self-efficacy as well as

reduced support from family, friends, medical professionals and society at large. In fact, the experience of stigma may lead to poor maternal and fetal outcomes.

Shame and lack of knowledge can drive women to secrecy, causing them to increase or decrease their medication dose without letting providers know, or even completely hide their pregnancy or addiction from those closest to them. Health care providers should openly and often discuss concerns with their clients and not assume that those who are silent do not have fears and concerns about their pregnancy. Open communication with clients will help reduce their anxiety, strengthen their self-efficacy, encourage supportive relationships in preparation for labor and delivery, and promote mother-baby bonding.

Conclusion

Findings revealed perinatal concerns of women with opioid use disorder who post to an online forum are influenced by perceived stigma. Analysis has determined the importance of open, non-judgmental communication between buprenorphine providers and opioid addiction patients who are pregnant. Patients feel stigmatized and ashamed of their addiction and will hide questions and concerns from their families and professionals involved in their care. This study reinforces the finding that stigma is an invisible but real force that creates shame for patients and that can adversely affect outcomes for mother and baby. Creating trusting relationships between mothers and those who care for them is vital. It is not sufficient to assume that silence from a patient means there are no questions about care.

Author Contributions

DJM conceived the study and both DJM and AB determined the methodology. Both analyzed the data. DJM took the lead in writing and organizing the manuscript. AB wrote the Limitations and Strengths and Implications section. Both authors reviewed the final manuscript before submitting for publication.

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