ENGAGEMENT IN ONLINE COMMUNITIES BY NEW MOTHERS IN RECOVERY FROM OPIOID USE DISORDER

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Abstract

Purpose: The purpose of this study was to examine the role of engagement with online communities by women using medication-assisted treatment (MAT) to manage recovery from opioid use disorder (OUD) during pregnancy and the first year after birth.

Study Design and Methods: Ten participants were identified through purposive sampling for this secondary data analysis as part of a larger grounded theory study about ways women using MAT for recovery from OUD meet the needs of their mother–infant dyad. Inclusion criteria included: English-speaking, 18 years of age or older, living in the United States, within the first year after birth, using MAT to manage OUD, and identified engaging with online communities during pregnancy and/or postpartum. A categorical-content narrative approach was used.

Results: Three narratives were identified from the analysis, *belonging*, *collaboration*, and *expecting success*.

Clinical Implications: Engagement in online communities can be a meaningful adjunct or replacement for in-person support. Online spaces are available 24/7 and allow people to join a community where they will not experience stigma and can find support tailored to their needs. Health care providers could extend their care for mothers affected by OUD by referring them to online communities for support of recovery self-management efforts.

Key words: Opioid-related disorders; Postpartum period; Pregnancy; Self-help groups; Self-management; Social networking.

Opioid use disorder (OUD) during the perinatal period presents unique needs for the mother–infant dyad (American College of Obstetrics and Gynecology [ACOG], 2017). Rates of opioid overdose decrease during pregnancy and rebound to the highest rate between 7 and 12 months after birth (Schiff et al., 2018). Medication-assisted treatment (MAT), the use of a prescribed long-acting opioid agonist in combination with behavioral therapy, is the current recommended management of OUD during pregnancy due to high rates of relapse with medically supervised withdrawal (ACOG, 2017). Pregnant women affected by OUD rely on multiple forms of support, including social, emotional, material, informational, and recovery (Asta et al., 2021; Liu et al., 2020). During pregnancy, individuals' social network influences the forms of support they receive (Asta et al., 2021). Increases in social networking with individuals who are not currently using illicit substances or are in substance use disorder (SUD) treatment may lead to a decrease in substance use during pregnancy (Asta et al., 2021). Social support that matches needs of the pregnant woman can help women to manage the internalized stigma associated with OUD (Birtel et al., 2017).

The American Society of Addiction Medicine (ASAM) recognizes SUD, including OUD, as a chronic illness that can be managed with the same prevention and treatment efforts used by individuals with other chronic illnesses (ASAM, 2019) and recovery as an individualized process focusing on improved health and wellness (Substance Abuse and Mental Health Services Administration, 2018). For individuals with chronic illness, online peer support has led to positive outcomes like patient empowerment, identity development, receipt and provision of support, information sharing, and the sense of a collective voice (Barak et al., 2008; Kingod et al., 2017). Engagement with online peer groups is common for individuals at all stages of OUD (D'Agostino et al., 2017). Many pregnant women with OUD who engage in online health communities are self-managing their recovery without professional treatment (Liang et al., 2021), yet no studies have reported on engagement in online communities by pregnant or postpartum women in recovery from OUD who are using MAT as their recovery modality. The purpose of this study was to examine the role of engagement with online communities by women using MAT to manage recovery from OUD during pregnancy and the first year after birth.

Study Design and Methods

This qualitative study is a secondary data analysis from a larger grounded theory study about how women in recovery navigate pregnancy, postpartum, and early motherhood. Inclusion criteria for the main study were: English-speaking; 18 years of age or older; live in the United States; and are within the first year after birth who self-identify as using MAT to manage their OUD recovery through the course of their pregnancy. Individuals identified as actively using illicit substances were excluded. Recruitment took place from July 2020 to July 2021. Study flyers containing a URL and QR code linked to a confidential Qualtrics survey containing a brief study description and screening questions were distributed and displayed by local MAT facilities in a moderately sized midwestern city and on social media platforms, including Facebook and Twitter, by leaders of online forums for mothers in recovery. Interviews were arranged by the principal investigator (PI) using the participant contact information provided in the survey responses. Following a review of eligibility criteria and the consent form, all participants gave recorded verbal informed consent prior to the start of the interview. Pseudonyms were used for the interview; no identifying information was collected. The study was approved by the institutional review board at the PI academic institution. A Certificate of Confidentiality from the National Institutes of Health was obtained for the study to give participants additional confidence in the confidentiality of their data. For this secondary data analysis, 10 of the 16 participant interviews in the larger study were purposively selected based on their self-identified use of online resources for social support.

Interviews

Interviews were conducted virtually by the PI following tenets of intensive interviewing and constructivist grounded theory for the larger study (Charmaz, 2014). Single individual, semistructured audio interviews ranging from 47 to 83 minutes were conducted, audio-recorded, and transcribed via a secure online conferencing platform operated by the PI's university. Cameras were off during interviews. Transcripts were verified for accuracy and uploaded into NVivo v.12.6 for coding and analysis by the PI. Interviews began with a broad, open-ended question, *tell me about your recent pregnancy and birthing experience*. Prompts were used as needed to explore early identified themes more fully. Demographic data were collected at the end of each interview. Field notes were recorded by the PI during and following each interview. Data for this analysis consisted of the stories women told about their engagement in online communities.

Data Analysis

A categorical-content narrative approach was used to analyze data (Kim, 2016; Lieblich et al., 1998). Analysis began with initial line-by-line coding by the PI and focused on the content, context, and meaning conveyed by women's stories of support they received from online communities (Charmaz, 2014; Poirier & Ayres, 1997). Line-by-line coding continued until the PI identified categories and themes (Charmaz, 2014; Lieblich et al., 1998), which were then reviewed and discussed by the research team. An iterative process was used for within-case and across-case analysis of data comparing different views, experiences, situations, or actions between two or more narratives, across time within the same narrative, and between categories (Ayres et al., 2003).

The design and methods addressed four criteria for rigor of the research (Lincoln & Guba, 1986). Credibility was

TABLE 1. CHARACTERISTICS OF PARTICIPANTS

Participant Characteristic		*n*
Race and Ethnicity	Black	1
	White	7
	Hispanic/White	1
	Hispanic/Black/White	1
Pregnancy History	First pregnancy	3
	Second pregnancy	3
	Third pregnancy	3
	Fourth pregnancy	1
Level of Education	Partial college	3
	Associates degree	5
	College graduate	2
Time in Recovery on Medication-Assisted Treatment	Less than 1 year	2
	1–5 years	6
	Greater than 5 years	2
Sources of Support Identified	Partner or Spouse	8
	Family	10
	Friends	6
	Friend on social media	9
	Community programs	5
Neighborhood	Urban	1
	Suburban	6
	Rural	3
Relationship Status	Single	1
	In a relationship	1
	Living with partner	3
	Married	5
Employment	Unemployed	7
	Parttime	2
	Fulltime	1
Standard of Living	Getting by	3
	Living comfortably	7

addressed through rich interviews gathered from a diverse group of women and by expanding the interview guide as categories and themes were identified to validate that the thematic interpretation of data aligned with participant perspectives. The research team drew from personal experiences with motherhood and professional experiences as nurses to understand context to the participant narratives. Both authors have experience working as a registered nurse caring for patients throughout pregnancy, birth, and the postpartum period. The PI currently partners with local organizations focused on SUD in the surrounding community, including OUD during pregnancy and postpartum. The research team maintained an audit trail throughout data collection and analysis to address dependability. Memo writing was used to check personal biases and assumptions, examine developing categories, and maintain a timeline of how the PI thought about the data to demonstrate confirmability. Use of direct quotes and thick description of narratives were used to address transferability.

Results

Participants ranged in ages from 24 to 37 years and were, on average, 3.75 months postbirth (3 weeks to 6.5 months). Seven participants identified as white, and all reported some level of college education. The group included mothers who had been using MAT before their pregnancy and those who started on MAT during the pregnancy. See Table 1 for participant characteristics and demographic data.

Three narratives were identified during the analysis. The first story, *belonging*, highlighted the importance of acceptance, support, a place to be vulnerable, and a way of staying connected with others in recovery. The second story, *collaboration*, highlighted the reciprocal act of sharing and receiving knowledge through their engagement. The third story, *expecting success*, highlighted that group members had a strengths-based approach to mothering in recovery.

Story of Belonging

The story of belonging demonstrated importance of finding a community of women with a shared experience. For these women, specific shared experiences included being a parent or being on MAT while pregnant or parenting. Women told stories of having had challenges finding an in-person group with shared experiences due to transportation or distance. Face-to-face meetings or groups through their MAT clinic often had few participants, and most women lived in areas where they did not know many other mothers on MAT.

When women found that many women shared the experience of othering while using MAT for recovery in online groups, they felt it ameliorated the *othering* experience or stigma that they felt in many settings. Women who connected with other mothers at a similar gestation felt that they were going *through the same thing at the same time* (P3), finding a level of understanding that family and friends could not give. These online connections led to meeting over the phone and in person with women found to be geographically close. Having a large group of people with a shared experience made women comfortable asking questions to the group that they did not want to ask family or friends where they may experience feeling outside of the motherhood norm. The ability to ask questions at any time of day added to the approachability of the group, with one mother commenting how members of the group *have been there more than people in my actual life have been...you just share about what's on your mind...I would do that pretty often* (P10).

It was common for women to check out one or more groups before they found one where they felt this sense of belonging. Certain online groups stigmatized women for their choice to use MAT or identified one type of MAT as superior for their recovery; women saw this *debate about...[using] medication-assisted therapy and the difference between being addicted and being like dependent*

(P5) take place in the online setting. Having a place to talk openly about their use of MAT for recovery was necessary because many women will choose not to disclose their use of MAT to all individuals in their life. One participant expressed the importance of belonging when she stated, *That's why these groups are so important. And I mean on Facebook, because it shows these women that they're not alone, that they, you know, you are not a failure because you're on MAT medication and you're having a child* (P9).

Story of Collaboration

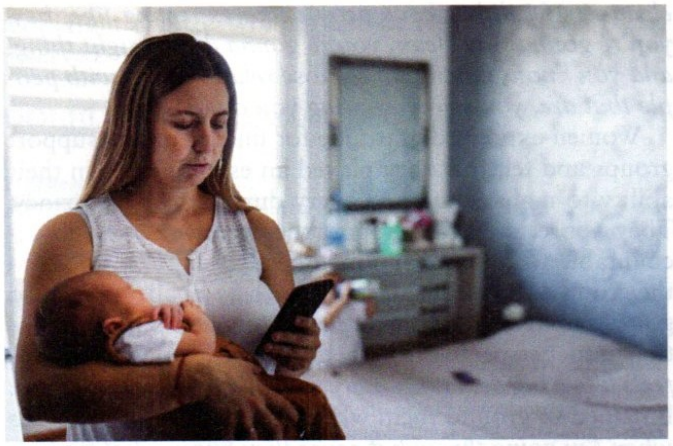
The story of collaboration revealed that women found online communities to be a place they could share and receive knowledge and wisdom. Women could not rely solely on general parenting support groups for parenting support or information because they felt unsafe sharing their recovery, *especially with moms, it's the stigma* (P9). Communities aimed explicitly at mothers using MAT were a safe space to find critical information and problem-solving issues of pregnancy and parenting through recovery.

They heard stories of management and developed a sense that they could plan to manage similar situations: *There's moms having babies left and right on MAT and I just basically went based on what they did, and I took their suggestions, and I had a birth plan...and I advocated for myself* (P3). One mother identified that she made sure to stay consistent with her medication and dosing after hearing from another mother who had a negative birthing experience and had not always been consistent with her medication dosing.

The knowledge from groups helped to calm fears by being prepared about things like drug testing while in the hospital, involvement of Child Protective Services, pain management plans for labor and postpartum, and neonatal abstinence syndrome (NAS), all of which would not be discussed in general parenting or pregnancy forums. The information gathered from the members of online communities was perceived as more meaningful and specific to the moms in the group than if they had just searched for information on their own online, feeling they received more honest information that fit their life context. One mother described an online group as a *treasure trove of information, support, [and] experiences. While I was in the NICU [and] while I was pregnant, anything I needed to know I could find it there or find out where to get information* (P6). Another mother stated, *you'll have moms in the group that will be like, hey this didn't work for me, this did work for me and why* (P1).

Armed with the knowledge and skills they needed for in-hospital stays, mothers felt able to advocate for themselves and their newborns. Women reported having made plans with online group members for postpartum pain management and for having discussions with nurses regarding their preferred in-hospital assessment for NAS.

Although most women reported that finding commonalities was helpful in creating self-management plans, others found that collaborative sharing still didn't meet their specific needs. One woman shared that she anticipated that her baby would not have any issues with NAS due to most group members sharing about how their child did not have severe signs of NAS. However, this same mother found that, though the dominant voices in the group had not had babies with NAS who had to be managed in the Neonatal Intensive Care Unit (NICU), she found connection with mothers whose babies had needed NICU care after she reached out during her postpartum period. From her experience, she now recommends that new members *learn as much as they can, about everything... don't just listen to [one experience], just in case, find out about the other [experiences]* (P6).



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Opioid use disorder is a chronic health condition responsive to interventions that support self-management across the lifespan.

Another barrier to effective collaboration was when members shared their *horror stories* with pregnant or postpartum mothers. These horror stories artificially heightened expecting mothers' concerns about stigma they would experience in the hospital or during appointments with providers. When women did not experience the kinds of stigmatizing experiences described, they felt grateful. Still, the impact of expecting the stigma was harmful to their recovery and mothering, causing women to be hesitant about *speaking openly* (P3) regarding their recovery or experiencing excess worry about the type of treatment they will receive from providers. One mother recalled being *"worried sick trying to advocate for myself...[and] my child" throughout her whole hospital stay* (P9).

Story of Expecting Success

Members of the group were optimistic and uplifting about the potential to succeed at being a mother on MAT. Mothers who were successful examples serving as role models to newly pregnant mothers or mothers new to recovery helped women focus on the possibility of maintaining recovery. *I would have a way harder time staying*

clean ... If I didn't have people like expecting like, hey, you're gonna stay clean, you're gonna do the right thing, and you know, having those close relationships with people that are, you know, rooting you on (P1).

Women expressed gratitude for finding online support groups and felt that they played an essential role in their ability to manage their recovery during their pregnancy. They appreciated the support they received and felt accountable to other group members. Being able to go to the group during difficult times, such as a baby needing to go to the NICU, and having other women put the situation into perspective for them let them know that *this feels like a big deal now, but it will all be behind you* (P6). It helped to ground them while also *[being] there for me when I'm going through it cause they know what it's like. Which my family can support me, but not in the same way* (P6).

Discussion

In this study, we found that women using MAT for recovery from OUD who engaged in online communities found a place of belonging, knowledge sharing, and expected success. Online communities played the vital role of social support that people in their daily lives could not provide because of a lack of experience with OUD or MAT. Members of their online communities were crucial because they assumed the woman seeking support could succeed in both motherhood and recovery. This expectation was not the default in any other sphere, including formal health care interactions.

Participation in mutual aid groups (also known as peer support groups) such as online communities is an integral part of SUD recovery (Hai et al., 2022). Our findings validate online communities for women using MAT during pregnancy as a source of support. The three identified narratives correspond with previous findings that information and emotional support are two main types of support sought in online group settings for SUD (D'Agostino et al., 2017; Liang et al., 2021; Liu et al., 2020). Perceived social support is associated with increased well-being for individuals in treatment for SUD, including those with OUD (Birtel et al., 2017). Encouraging the use of online communities as a place for social support may increase perceived social support, thereby reducing the effects of perceived stigma (Birtel et al., 2017). Nurses have an opportunity to talk with patients about their knowledge of and use of online communities for support. Allowing time to ask mothers if they have questions about advice or recommendations, they have seen in online discussions will validate the importance these online communities hold for this population.

Within the SUD population, peer support groups are more frequently attended by individuals with lower socioeconomic status and who are unemployed (Hai et al., 2022). Online communities specific to an individual's situation, such as mothers in recovery from OUD on MAT, can be a meaningful adjunct or replacement for in-person support and allow for 24/7 availability at no additional cost beyond having access to the internet. Online communities can have an impact for women who do not have close relationships with family or friends in real life or when family or friends are impediments to managing their recovery. Individuals living in areas with fewer MAT programs may benefit from the increased ability to connect with other mothers in similar situations. Online communities have become more relevant as in-person mental health therapies moved online in response to the COVID-19 pandemic (Hai et al., 2021).

Accuracy of information shared in online communities is debated, with studies identifying approximately 95% of peer-to-peer suggestions aligning with therapeutic practices and studies identifying unsafe suggestions, such as rapid self-led withdrawal protocols (D'Agostino et al., 2017; Liang et al., 2021). These studies have not examined online communities specific to women using MAT with provider oversight. An assessment of the appropriateness of therapeutic suggestions occurring in the online groups for this specific population is needed.

Limitations

Although the rigor of the study methods generated important insights, the findings are limited to this small group of women participating in online support groups who received MAT oversight by treatment providers during pregnancy and early parenting. This group of women was sampled from the larger study because they reported that they engaged in online communities as part of their self-management; therefore, the sample may be more homogenous than the larger population of mothers with OUD during pregnancy and postpartum using MAT.

Because this study used a purposively sampled set of data collected as part of a larger study, the team could not recruit in service of achieving saturation. The team engaged in dialogue throughout the analysis process to ensure that no new themes were being identified as later interviews were analyzed. Dialogue continued as themes were finalized to ensure that the themes represented the meaning expressed by participants, indicating that meaning saturation was achieved (Young & Casey, 2019).

It is important to acknowledge that this study was conducted during the most acute phase of social distancing during the COVID-19 pandemic, and recruitment for the larger study was done via online community outreach. This may have made online community engagement overrepresented compared with nonpandemic times or a sample recruited entirely in person.

Clinical Nursing Implications

When working with pregnant women or new parents in recovery, nurses, and other members of the health care team such as nurse practitioners, physicians, and therapists need to find ways to extend support beyond the walls of the clinic and hospital. Because women in recovery from OUD who use MAT during their pregnancy and the early parenting period are actively engaged in the care of their maternal–infant dyad, the added sense of belonging and expecting success is particularly important.

CLINICAL IMPLICATIONS

- Recognizing OUD as a chronic illness highlights the need for nurses to focus on self-management techniques during the perinatal period.
- Nurses should recognize that online communities can provide a meaningful adjunct or replacement for in-person support for mothers in recovery from OUD who use MAT.
- Through engagement in online communities, mothers in recovery from OUD who use MAT can find a place of belonging, a space for knowledge sharing, and an environment focused on the expectation of their success in recovery and parenting.
- Nurses can refer women to multiple online communities specific to the mother's needs as part of perinatal nursing care.
- Recognition of the level of engagement mothers have during their pregnancy and postpartum period may help to decrease stigma associated with being on MAT during pregnancy.

Encouraging engagement in online communities will provide an avenue to meet support and self-management needs, both for recovery and for the tasks of general self-care and motherhood in a way they cannot get in general mothering support groups.

Mothers in recovery from OUD who use MAT benefit from engaging in peer support. By engaging in online communities, they can experience a place of belonging, knowledge sharing, and expected success. Health care professionals need to recognize the value of these communities for individuals in recovery. An increased understanding of how women engage in online communities can guide future development of additional support services for women in recovery from OUD during childbearing. By highlighting the level of engagement mothers have during their pregnancy and postpartum period and hearing the narratives from women themselves, there is the potential to decrease the stigma associated with being on MAT during pregnancy. ✣

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