

Barriers and Facilitators to Maternal Mental Health Care Access: A Qualitative Analysis

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A thesis

submitted in partial fulfillment of the

requirements for the degree of

Master of Public Health

University of Washington

2022

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Program Authorized to Offer Degree:

Health Systems and Population Health

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**Abstract**

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**Background:** Maternal mental health disorders (MMHDs) have adverse health outcomes on women in the United States. Previous studies investigate the burden of disease and describe unmet treatment and prevention needs, however, few studies investigate factors that shape care access from the perspective of perinatal populations.

**Research aim:** This study investigates the barriers and facilitators of accessing maternal mental health care through a qualitative analysis of 49 personal narratives submitted through an online survey.

**Methods:** Survey responses (N=49) were collected, reviewed, and qualitatively coded and analyzed for pertinent themes relating to barriers and facilitators of maternal mental health care access. Data was collected and provided by the organization 2020 Mom, and coding was performed using a hybrid inductive-deductive method.

**Results:** Facilitators of care access included partner advocacy, social support, and prior awareness and experience living with MMHDs. Barriers to care access included self-stigma and fear of judgment, provider lack of knowledge and non-specialized care for MMHDs, and lack of paid maternity leave.

**Conclusion:** Access to maternal mental health care for women in the U.S. can be improved with strong social and community support, increased education and awareness of MMHDs, and paid maternity leave policies.

## Background

Maternal mental health disorders (MMHDs)<sup>1</sup> are a range of conditions that affect individuals of reproductive age in the United States (U.S.). These conditions often manifest during the perinatal period (Yeaton-Massey & Herrero, 2019), which is defined as the time from one year before childbirth up to 24 months postpartum (Helfer, 1987). Currently, MMHDs are the number one cause of childbirth and pregnancy complications in the United States (U.S.), affecting up to 1 in 5 mothers, and approximately 800,000 women each year (CDC, 2021; Griffen et al., 2021).

The most common MMHDs include perinatal depression, which affect 11.9 percent of women (Woody et al., 2017), and perinatal anxiety, which affect 13 to 21 percent of prenatal women, and 11 to 17 percent of postpartum women (Fairbrother et al., 2015). Postpartum psychosis, obsessive-compulsive disorder (OCD), posttraumatic stress disorder (PTSD), as well as substance use disorders during the perinatal period are less common, but have severe adverse effects on both the mother and child (Kendig et al., 2017; Yeaton-Massey & Herrero, 2019).

Several social and environmental factors interact to create poor maternal mental health outcomes during the perinatal period. Individuals with a history of physical, emotional or sexual abuse (Hernandez et al. 2022), as well as trauma and previously diagnosed mental illness are at a higher risk for experiencing MMHDs (Griffen et al., 2021). Lack of support from partners, family members, and other social systems are strong predictors of poor mental and physical health throughout the perinatal period (O'Hara, 2014; Emmanuel, 2012; Milgrom, 2019).

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<sup>1</sup> The current thesis uses the term “maternal mental health disorders” (MMHDs) to align with current literature on maternal health, the experiences of the self-identified mothers in this study, and the terminology used by *2020 Mom*, whose data informs this study. This thesis does not use the term perinatal mood and anxiety disorder (PMAD) to avoid associating the psychological experiences of the perinatal population with the term "mad".

Importantly, the risk of developing an MMHD is shaped by an individual's social and environmental determinants of health, such as income, level of education, access to medical care, area of residence, and community resources (Griffen et al., 2021). Beginning in the year 2020, the impacts of the Covid-19 pandemic on physical and social isolation further exacerbated perinatal mental illness rates nation-wide. Studies show that 29 percent of perinatal women experienced moderate to high anxiety prior to the pandemic, compared to 72 percent during the pandemic (Davenport et al., 2020).

Adverse consequences of MMHD on health are more likely to affect communities living with racial and socioeconomic inequities. These groups face the greatest barriers to mental health care and treatment due to systemic racism and lack of culturally appropriate care (Griffen et al., 2021). Black women are at twice the risk of experiencing MMHDs and are less likely to be screened or receive mental health support throughout the perinatal period compared to Caucasian women (Hernandez et al., 2022). Living with untreated MMHDs can lead to worsening of existing medical conditions, inconsistent adherence to prescribed medical care and treatment, increased smoking and substance use, and in some tragic cases, suicide and infanticide (Kendig et al., 2017). What's more, children whose parents were not treated for MMHDS may experience poor fetal growth and delayed cognitive and emotional development (Griffen et al., 2021; Gelaye et al., 2016). The consequences of MMHDs are severe, and even more so for racially and socioeconomically marginalized communities. Understanding the maternal mental health experience is crucial for improving care access for all birth-giving individuals and their children.

Although perinatal mental health is a relatively new field of research, the growing burden of MMHDs is drawing attention from public health organizations and policymakers at national and international levels. Several national non-profit organizations and movements are working to

improve maternal mental health care through campaigning for public awareness, building strategic partnerships, advocating for policy change, and creating programmatic solutions in the name of maternal mental health. *2020 Mom* is one organization aggressively working toward “closing gaps in maternal mental health care” in the U.S., whose vision, leadership, and data inform the current study (2020 Mom, 2022). Other organizations, such as the Maternal Mental Health Leadership Alliance (MMHLA) and Postpartum Support International (PSI) lead policy research and analysis to better support MMHD service integration and care nation-wide (MMHLA, 2022).

On March 30, 2022, the World Health Organization (WHO) released a document with recommendations and guidelines to support postnatal maternal and newborn care. The report specifically recommends that health systems provide screening for individuals with postpartum depression and anxiety as well as psychosocial support during prenatal and postnatal periods (WHO, 2022). On May 6, 2022, the U.S. Department of Health and Human Services (HHS) launched a Maternal Mental Health Hotline that offers counseling, provider and support group referrals, as well as evidence-informed information and community resources (U.S. Department of Health & Human Services, 2022). Although global interest from public health organizations and lawmakers is promising, gaps in MMHD care access remain. The U.S. remains one of few countries in the world without paid parental leave and universal child care for pregnant individuals, where up to 23 percent of new mothers return to work within ten days postpartum (Jou et al., 2018; Van Niel et al., 2020). As the burden of MMHD continues to rise, factors that shape care access for perinatal populations in the U.S. remains poorly understood.

### *Study Aims*

The purpose of the current study is to determine facilitators and barriers to maternal mental health care access from a subset of survey responses submitted by women with MMHDs residing in the U.S. This study aims to qualitatively analyze maternal mental health experiences and identify common factors that enable or prevent mothers from accessing care in the U.S., with the hope to inform national research and policy on MMHD prevention, access, and treatment.

## **Methods**

### *Design*

This study uses a qualitative phenomenological design to examine facilitators and barriers to maternal mental health care access based on narrative accounts of personal experience. Qualitative research investigates factors that shape social or public health phenomena, and attempts to understand the meaning and causes behind them (Starks & Brown Trinidad, 2007), which align with the aims of this study. A phenomenological approach, which allows researchers to examine the meaning of one's lived experiences (Sokolowski, 2000), was chosen due to the personal nature of the data and the narrative format in which it is presented.

Data for this study was collected by *2020 Mom*, a maternal mental health and social change non-profit organization based in California. In 2019, *2020 Mom* created a Google survey with the open-ended prompt "Tell us your (maternal mental health) story" for the purpose of establishing a national database of MMHD data from individuals around the country. In addition to the open-ended prompt, the survey also asked for respondents' name and contact information, location by city and state, race or ethnicity, MMHD symptoms and diagnoses, and their baby's city and state. An open-access Google survey was the primary format of data collection. Anyone who accesses the survey link online was able to complete the survey. There was no specific research question established at the time of survey creation or dissemination, as such, the

preliminary phase of this study was exploratory. In November 2021, the University of Washington Institutional Review Board designated this study as one that does not require review.

### *Setting*

In 2019, the Google survey was disseminated to individuals who have signed up to receive emails from *2020 Mom*, which includes birthing people, partner organizations as well as supporters and stakeholders involved with MMHD care, policy, and advocacy around the country. The survey was primarily publicized via *TheBlueDotProject*, a sub-project of *2020 Mom* that aims to spread awareness of MMHDs and reduce stigma against individuals living with MMHDs nation-wide (TheBlueDotProject, 2022). *2020 Mom* publicized the survey on *TheBlueDotProject* website and its various social media channels. Responses were collected beginning May 2019. However, only survey responses received between May 2019 to October 9, 2021 were captured and reviewed for this study. At the time of study inception, 197 responses were collected.

### *Sample Selection*

In total, a convenience sample of 49 survey responses were included for review, coding, and analysis for the current study. All respondents were residents in the U.S. at the time of survey completion. Detailed participant demographics and characteristics are summarized in Table 5.

Because the survey was designed to be “opt-in”, all 197 submitted responses were included for preliminary review. All responses were exported into an Excel spreadsheet and duplicate or blank responses were removed. The first 10 responses received in chronological order (excluding duplicates and blank submissions) were selected for “preliminary coding”.

Identifying information such as name, contact information, location, and race/ethnicity were removed, and exported to a Google document for review. Responses submitted by participants who did not live in the U.S. were not considered.

The purpose of preliminary coding during this stage was threefold: To develop a preliminary codebook that is relevant and applicable to the remaining transcripts; to determine the approximate amount of time needed to produce in-depth, accurate, and relevant codes for the study; to enable adjustments of the codebook and coding process pending discussion and review with thesis committee members. Following an inductive-deductive approach, the first ten responses were qualitatively coded, and a codebook was developed based on consensus with committee members.

Following the preliminary coding phase, committee members established an approximate timeline for the study, and finalized the research question, which was: “What are the barriers and facilitators to MMHD care access?”. Any unused codes that were deemed irrelevant to the research question were removed from the codebook. Following these adjustments, the remaining participant responses were selected for official review, coding, and analysis. To ensure randomization of data, every fourth response from the database was selected (beyond the original 10 responses). Using this method, 39 additional responses were selected in addition to the original 10, and 49 total responses were included in the final study.

### *Code Application*

In total, 11 parent codes and 17 child codes were created. Four parent codes captured instances where the respondent mentioned facilitators of: (1) coverage, (2) access, (3) treatment, and the role of (4) positive relationships in their lived experience; another four parent codes captured the same elements from the perspective of barriers and negative relationships. The goal

of these parent codes were to capture factors that enable or prevent access to MMHD care, and serve as the umbrella for relevant child codes pertaining to the research question. Three remaining parent codes captured instances of MMHD risk factors, experiences of stigma, and notable quotes in relation to the research question. See Table 1 for full list of codes, and Table 2 for the codebook and detailed description of codes with example quotes.

Most child codes pertained to specific facilitators or barriers to MMHD treatment and care access, such as the role of the partner, employer, medications, continuity of care, screening procedures, and counseling and therapy. Other child codes capture the respondent's prior knowledge and awareness of MMHDs, their lack of knowledge, any facilitators or barriers to seeking care and treatment, any prior history of mental illness or lack of social support as a risk factor to MMHD development.

Two codes were not used. The code Facilitators to MMHD Care Coverage (F\_Coverage), was not applied, as there were no instances in the data that could be categorized under this code. However, its counterpart, Barriers to MMHD Care Coverage (B\_Coverage) was applied to the data. Therefore, F\_Coverage was included in the codebook to enable comparison between the two. The code Therapy as a Barrier to MMHD Treatment (B\_Treatment\_Therapy) was not applied, as no instances of such experiences were found in any responses.

### *Data Analysis*

All 49 transcripts were coded and analyzed using Dedoose qualitative research software. A combined inductive-deductive approach was used to conduct qualitative coding and analysis. In qualitative research, a deductive approach allows the researcher to draw upon existing knowledge to inform the coding process and generate hypotheses about the data, whereas an

inductive approach requires the researcher to put aside prior assumptions and allow themes to emerge from the data itself (Dew 2007).

In the preliminary coding phase, a deductive approach was used to predict codes and themes that may exist within the data. The author had conducted prior research on MMHDs and drew upon existing knowledge of the literature to inform her understanding of the study data. However, as coding continued, new themes emerged from the data. As a result, many codes were developed inductively during preliminary coding.

After preliminary coding of the first 10 responses, the researcher conducted a “first pass” review of all 49 responses to gain an overall understanding of the content as it pertains to the research question and the codebook. Codes and their definitions were reviewed and modified during thesis committee meetings. Potential themes of interest were noted and discussed between committee members. Following committee input on relevant themes, and updates and modifications to the codebook, official coding began. All 49 responses were reviewed and analyzed in Dedoose software, and any data relevant to the codes were highlighted and captured.

Following coding completion, the Dedoose “analyze” function was used to summarize data and develop themes. The “Code Application” table produced by Dedoose provided an overview of the number of times each code was applied in all 49 responses. The “Code Co-Occurrence” table showed instances in which two codes occurred together or close to each other. These tables allowed for analysis of the association between codes and the development of themes based on code frequency.

Code convergence was evaluated by identifying all individual responses with the top three highest-frequency codes, reviewing the codes directly preceding or following it (but not co-

occurring or on the same line), and noting similarities and differences between responses. Only the responses with two or more occurrences were evaluated. Codes were convergent if three or more responses revealed similar coding patterns.

## **Results**

### *Participant Characteristics*

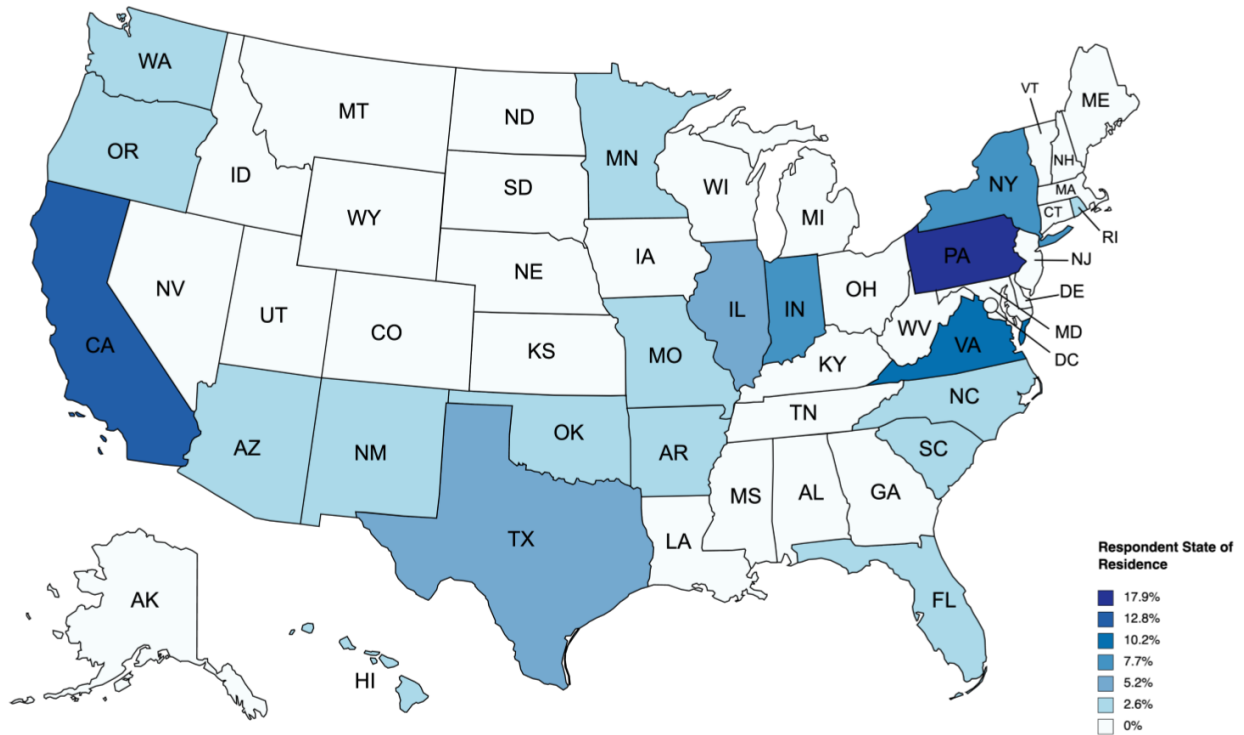
#### *Self-Reported Role*

Forty-nine total survey responses submitted by participants were randomly selected for qualitative coding and evaluation for the current study. Ten of the 49 responses were selected from the first ten responses from the list. The remaining 39 responses were randomly selected from the list of responses to ensure non-bias, as described in the methods section above.

From these responses, 48 participants identified with the role of “Survivor (Woman who suffered from a diagnosed/likely MMHD)”. No participants selected the two other options included in the survey, which were “Father” and “Other”. The “Other” option provided a space to include additional text. One participant did not select any of the three options.

#### *State of Residence*

Forty-nine total survey responses were randomly selected for qualitative coding and evaluation for the current study. Responses were submitted by participants residing in various states across the country, namely: Pennsylvania, California, Virginia, Indiana, New York, Illinois, Texas, New Jersey, Vermont, North Carolina, Alaska, Arizona, Arkansas, Florida, Hawaii, Michigan, Minnesota, Missouri, Nevada, Oklahoma, Oregon, Rhode Island, South Carolina and Washington. A detailed breakdown of demographics and places of residence are reported in Table 5.

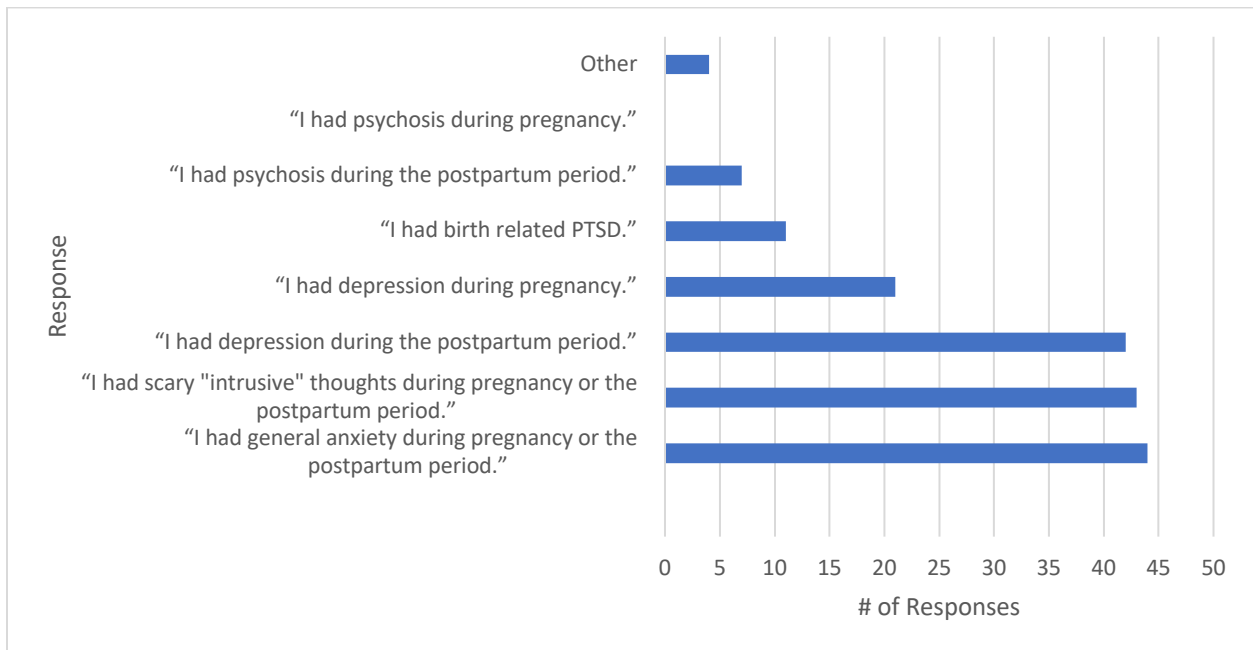


**Figure 1.** Respondents’ state of residence. Created with mapchart.net.

Self-Reported Symptoms and MMHD Diagnoses

Participants were given the option to self-report their symptoms and diagnoses from a list of multiple-choice options, and all participants identified with more than one option. Based on the survey, 44 selected “I had general anxiety during pregnancy or the postpartum period”; 43 selected “I had scary ‘intrusive’ thoughts during pregnancy or the postpartum period”; 42 selected “I had depression during the postpartum period”; 21 selected “I had depression during pregnancy”; 11 selected “I had birth-related post-traumatic stress disorder (PTSD)”; 7 selected “I had psychosis during the post-partum period”. No participants selected the option “I had psychosis during pregnancy”. See Table 5 for details.

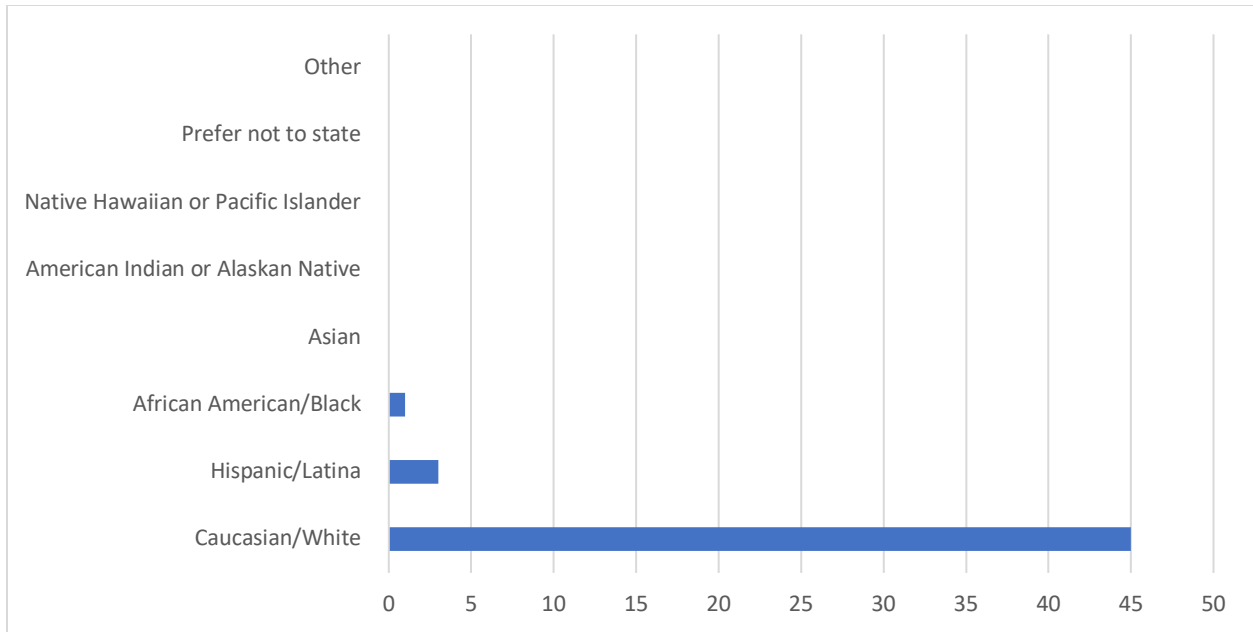
Four separate respondents provided additional responses on their mental health state in the “other” section. One respondent indicated: “Postpartum OCD” (obsessive-compulsive disorder). Another respondent indicated: “PTSD (post-traumatic stress disorder) from not knowing about our pregnancy and then from miscarriage”. A third respondent noted: “I experienced postpartum rage”. A fourth respondent added: “Codependency within a relationship with an alcoholic”.



**Figure 2.** Respondent self-reported MMHD Diagnoses

Self-Identified Race and Ethnicity

Participants selected their race and ethnicity from response categories: Caucasian/White, Hispanic/Latina, and African American/Black. Based on participants’ responses, 45 identified as Caucasian/White, three as Hispanic or Latina, and one as African American/Black. No participants selected the options: Asian, American Indian or Alaskan Native, Native Hawaiian or Pacific Islander, Prefer not to state, or Other. See Table 5 for details.

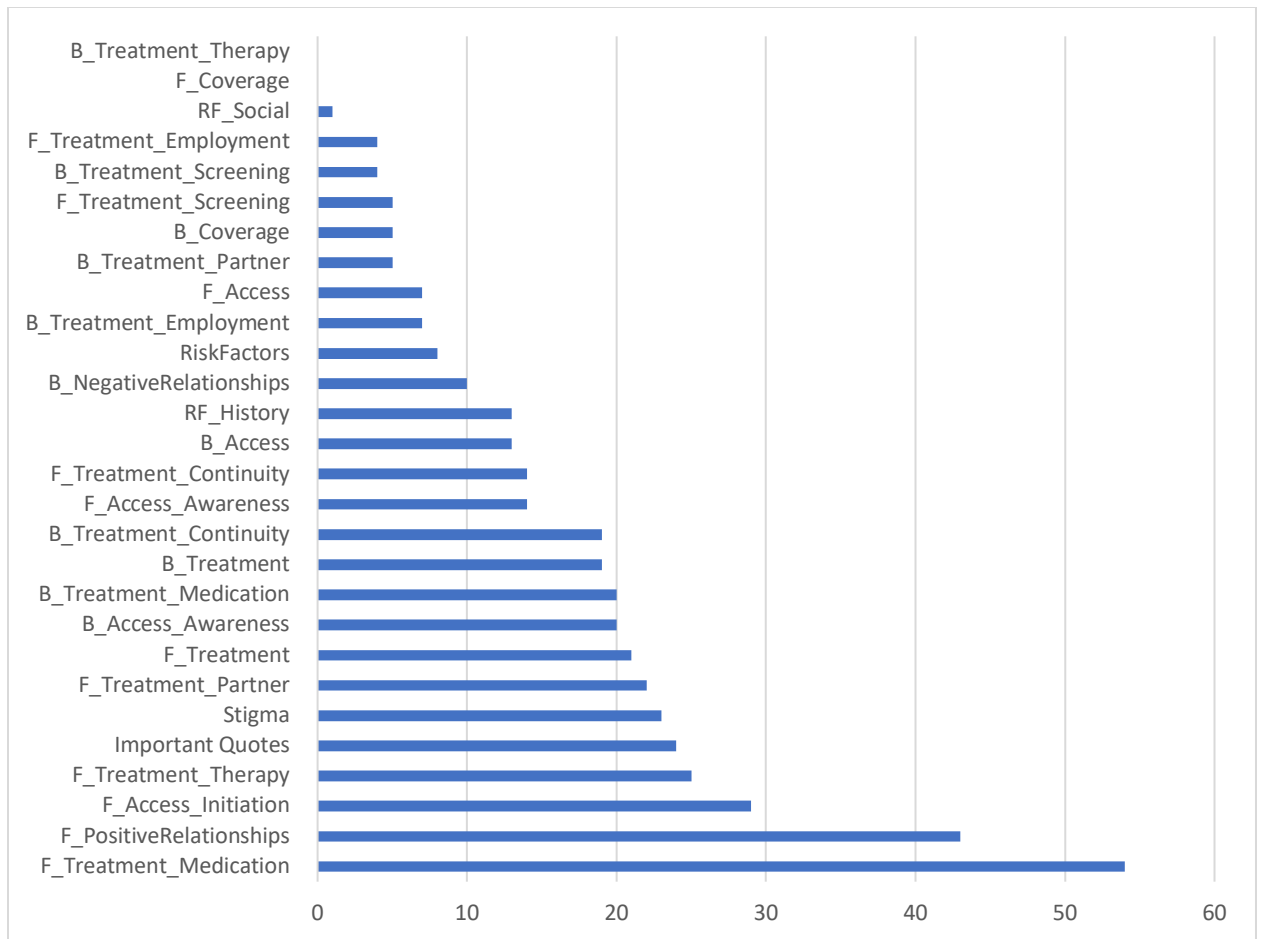


**Figure 3.** Respondent self-reported Race/Ethnicity.

*Qualitative Results*

Code Frequency

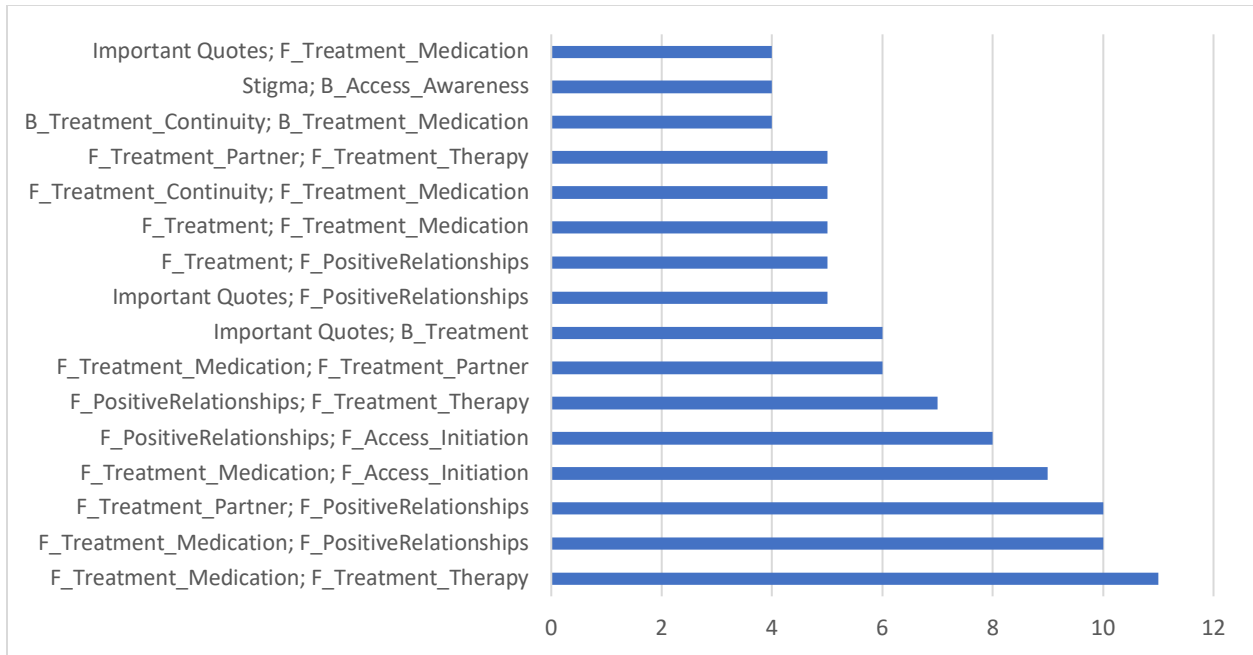
Overall, codes related to facilitators of MMHD care access and treatment were applied more frequently than codes related to barriers. The most frequently applied code across all 39 transcripts was Medication as a Facilitator for MMHD Treatment (F\_Treatment\_Medication), which was used 54 times; the least frequently applied code was Lack of Social Support as a Risk Factor for MMHD (RF\_Social), which was used once. The code Facilitators to Care Coverage (F\_Coverage), and Therapy as a Barrier to Treatment (B\_Treatment\_Therapy) were not used. See Table 3 for details.



**Figure 4.** Individual Code Application Frequency.

Code Co-Occurrence

In total, there were 16 pairs of codes that were “co-occurring”, or coded over the same region of text. The most frequent pair was coded together eleven times, whereas the least frequent three pairs were coded together four times. The two most common co-occurring codes were: Medication as a Facilitator for MMHD Treatment (F\_Treatment\_Medication), and Therapy as a Facilitator for MMHD Treatment (F\_Treatment\_Therapy). See Table 4 for details.



**Figure 5.** Frequency of Code Co-Occurrence.

Code Convergence

Code convergence reveals similar perspectives between different responses containing the same high frequency codes. First, all survey responses with the three highest-frequency codes were identified. The three highest frequency codes were F\_Treatment\_Medication, F\_PositiveRelationships, and F\_Access\_Initiation. Then, the text directly preceding or following any of the three codes were reviewed for similar coding patterns, and compared between responses. Co-occurring codes on the same lines were not considered.

The most common code across all responses was Medication as a Facilitator for MMHD Treatment (F\_Treatment\_Medication), which was coded two or more times in 11 responses total. The codes F\_PositiveRelationships and B\_Treatment\_Medication were highly convergent with F\_Treatment\_Medication, and each appeared five times either directly before or after it in text. There was some convergence with the codes F\_Treatment\_Partner, F\_Access\_Awareness, F\_Treatment\_Therapy, and Important Quotes.

The second most common code was Positive Relationships as a Facilitator (F\_PositiveRelationships), which was coded two or more times in 10 responses total. The code F\_Treatment\_Medication was highly convergent, appearing seven times directly before or after it. Codes F\_Access\_Initiation and Important Quotes were somewhat convergent appearing only.

The third most common code was Facilitators to Access Initiation (F\_Access\_Initiation), which was coded two or more times in six responses total. There were no highly convergent codes. However, the codes B\_Access\_Awareness, Stigma, and Important Quotes were somewhat convergent, occurring 2 times directly before or after.

#### *Facilitators to MMHD Care*

##### *Partner.*

The partner's role in facilitating access to mental health care was crucial to the woman's recovery. For many respondents, her partner was the first person she confided in when feeling unwell, and often the one who recommends that she seeks professional care. The partner serves as an advocate in cases where the respondent does not have access to suitable treatment options, or if she is hesitant or unwilling to utilize health services. Many respondents shared how grateful they were for the emotional support of their husband or wife, and credits them for their eventual improvement and recovery.

*“My husband was my biggest advocate and was relentless that I received the care I needed before and after returning home.” – ID 12*

*“I hit my low at six weeks postpartum. Standing in a dark room, un-showered, covered in tears and spit up, I called my wife to say I needed help.” – ID 40*

*“I was diagnosed with PPD a few weeks after giving birth to my first child. I am fortunate to have an attentive husband who pushed me to see my doctor for help.” – ID 136*

##### *Family, Friends, and Peers.*

Family members and friends were a major source of comfort for respondents, and played an important role in building a secure and supportive environment that enabled them to take the

first step in seeking care. Many respondents relied on loved ones to help with childcare, groceries, and household chores while they recovered. Family members were often the first to notice changes in respondents' mental health, and would encourage them to find professional help, or even contact health care providers on their behalf. Many women also pointed to postpartum peer support groups as a safe space for sharing their struggles with MMHD without feeling shamed or judged.

*“Aunt D came right out with it: ‘I think you have Postpartum Depression and you need to do something about it.’ ... someone was finally seeing that I was hurting. She thought that perhaps my PCP wasn't the right person to be treating my hormonal changes and encouraged me to talk to my OB about how I was feeling.” – ID 4*

*“I had family and friends visit me every day of my hospitalization and my newborn... We had several family members, friends, and neighbors help out with basic things like meals, chores, grocery shopping, and assisting with the kids. Everyone in my life was very supportive and understanding as I've recovered.” – ID 12*

*“My mom and husband called my doctor together and he called in an antidepressant. It took a few weeks to start working, but I started to feel better.” – ID 32*

*“...I had a couple of close friends and family members I trusted with this heavy burden. Their support, lack of judgment, and love at this time saved my life, as did my husband's.” – ID 52*

*“I am so thankful to my partner, to my mother-in-law, to my countless friends and family that listened to me. Who saw my white flag being waved and urged me to seek help.” – ID 84*

*“I started attending postpartum support groups (I went every week) and they gave me an outlet to be honest about my feelings and anxiety in a place where I did not feel judged or worried that I would be “mom shamed”.” – ID 76*

#### Awareness of MMHDs.

Respondents' prior experience with MMHDs and knowledge of psychological disorders allowed them to seek out treatment options before new onset or worsening of symptoms. Women were able to differentiate between normal pregnancy-related changes and MMHD symptoms, thus empowering them to contact health care providers and access appropriate care without delay or hesitation. As a result, many were able to recover faster from periods of feeling unwell.

*“Fast forward to my third pregnancy with Josie in 2019. I was prepared. At 34 weeks I was started on an antidepressant. I must say that it has helped tremendously this time around after giving birth.” – ID 88*

*“At two weeks postpartum I had another psychotic episode ... which led me to the hospital again. This time my stay was much shorter, 3 days, as we knew what medication worked.” – ID 12*

*“Since I had PPD before, I knew at 2.5 weeks postpartum that what I was feeling wasn't just the baby blues. I saw my OB and he prescribed the same antidepressant I was on with my daughter.” – ID 24*

*“I was definitely more laid back this time...I was about a month PP ... I didn't waste any time. Got right on the phone, called my doctor to increase my dose.” – ID 192*

*“Luckily, I was majoring in clinical mental health counseling. Through my strong desire to help others, I learned how to help myself. I understood what therapy was really all about, and I realized how badly I myself needed it. If it wasn't for school, I don't think I ever would have reached out.” – ID 140*

### *Barriers to MMHD Care*

#### *Self-stigma and Fear.*

Feelings of fear, shame, embarrassment, and guilt over being perceived as a “bad mom” were common among respondents experiencing MMHDs. This cycle of negative emotions led to worsening symptoms, delays in seeking care, and slower recovery even after care was accessed. Many respondents engaged in “self-stigmatization” by playing down their struggles during the perinatal and postpartum period, and as a result, did not share the extent of their difficulties even when connected to a health care provider. The fear of being judged by others, and the woman's own self-judgement is a significant barrier to a her care access and recovery from MMHDs.

*“I felt anxious, couldn't leave the house, always scared to be judged or that I was a bad mom.” – ID 28*

*“I was nervous and embarrassed to admit I needed help and that I couldn't do it myself.” – ID 116*

*“My six-week appointment with my OBGYN came. I lied when she asked me how I was feeling and how my moods were. I told her I was fine. I had felt so much guilt and shame around my feelings. I thought having those feelings would mean I was a bad mother and wife. Remember*

*that negative stigma surrounding mental health I mentioned earlier? That's a big reason I didn't want to admit to these feelings.” – ID 88*

*Non-Specialized Services and Provider Dismissal.*

Many respondents noted the lack of health care providers that were trained on maternal mental health. Women with MMHDs who were seeing their primary care provider, obstetrician, or gynecologist did not receive mental health services, and women referred to psychiatrists did not receive care relevant to the perinatal period. Respondents shared how providers failed to recognize signs of MMHDs, or dismissed their mental health concerns outright. As a result, many felt isolated during the care-seeking process and discouraged from further attempting to access services. Few providers are trained in screening and treating MMHDs, and will subsequently transfer patients out of their care, making patients feel unseen, embarrassed, and further stigmatized for living with a disorder perceived as “untreatable”. The unavailability of relevant and specialized services is a barrier and major deterrent for women accessing MMHD care.

*“In my experience, there are few places to turn for help and the lack of care creates a massive loss of hope in those that need it the most.” – ID 44*

*“The hospital didn't know how to treat me any longer and wanted to transfer me across the country to a facility that specialized in postpartum mental health.” – ID 12*

*“My PCP finally said that she couldn't help me anymore, I needed a psychiatrist. The embarrassment, the shame and humiliation that I felt that day is something that I will never forget. How can she say that I need a psychiatrist and therapy? I'm not crazy. For my family's sake and in desperation, I swallowed my pride and found a psychiatrist.” – ID 4*

*“I did get the courage to talk to my OB who swiftly and insensitively responded ‘you're fine, it's JUST hormones.’ Clearly, he was not willing to help so I returned to my PCP for medication management.” – ID 4*

*“Even the midwives expect you to be happy and didn't recognize what was going on.” – ID 52*

*“Through tears I said to the receptionist ‘I think I have postpartum depression’. She forwarded my call to the nurse where she asked if I was suicidal, too embarrassed to actually*

*admit I was, I said no ... She told me I 'just had the baby blues' and that was that... I cried so hard because I knew I needed help but I wasn't getting it." – ID 64*

### Lack of Paid Maternity Leave

A significant barrier to care access and subsequent recovery for women was the lack of paid time off work during the perinatal period. Many women were concerned about being laid off, or having no source of income while taking maternity leave, and were forced to return to work shortly after giving birth to maintain their employment. Most workplaces required women to resume work within a few weeks postpartum, and for women struggling with MMHDs, this led to worsening symptoms, delayed care-seeking behavior and poor recovery. Not having income or medical coverage during the perinatal period adds significant financial and psychological stress during a time where women must focus on their own health and that of their children.

*"I was told ... that I had to come back to work because I had no time to take off. So I went back to work while I was still very sick and recovering. Then I got severely depressed and had a difficult time functioning but forced myself to work because I had no other options..." – ID 13*

*"Mommas are returning to work with a bleeding wound the size of a dinner plate because they can't afford to stay home. Mommas are "missed" because their Medicaid ran out at eight weeks postpartum. And, Mommas are taking their own lives because they are not seen or heard." – ID 10*

*"On top of it, my employer told me I was ... 100 hours short of job protection ... I ended up going back to work after 8 weeks ... I wasn't ready. I ended up having a mental breakdown, and my doctor put me on disability for an additional six weeks... I shouldn't have to worry about money or if I'm going to lose my job. Period." – ID 156*

## **Discussion**

The findings of this thesis are highly convergent with current literature on barriers and facilitators to MMHD care access in the U.S and globally. In the current study, women relied heavily on their partners for emotional support. Studies show that partners are indeed a source of resilience and strength for women during the perinatal period (Farewell et al., 2020). Conversely,

lack of partner support is a risk factor for postpartum depression (Milgrom et al., 2008; Ogbo et al., 2018). Importantly, the partner also served as a champion or advocate for the mother's well-being. The importance of having an “advocate” supporting the woman’s health has been shown to improve access to care (Webb et al., 2021).

From the responses in this study, women shared that family and friends were instrumental to their care access and recovery. One article showed that women who have at least two or more friends or family members to support their needs during the postpartum period tested lower on the Center for Epidemiologic Studies of Depression Scale (CES-D) for depression (Surkan et al., 2006). Behaviors such as verbal reassurance, practical assistance (such as child care) were protective against perinatal depression (Milgrom et al., 2019). Women who did not have strong family support experienced barriers to care access, even when presented with appropriate and relevant care options (Webb et al., 2021).

Many responses revealed how previous exposure to MMHDs equipped women with the knowledge and confidence to seek out treatment without delay. One study found that having no awareness of the warning signs of MMHDs was an obstacle to care-seeking behavior for women (Webb et al., 2021). Furthermore, lack of awareness of MMHDs from family members and the general public delays initiation of mental health services as well (Selix et al., 2017).

Fear of stigma was one of the most important reasons why women hesitate to seek out much needed maternal mental health care. A systematic review of barriers to mental health service access found that negative attitudes from health care providers discouraged women from disclosing their struggles and utilizing services for fear of being judged (Smith et al., 2019). Such instances of external stigma only serve to perpetuate internalized feelings of guilt

and shame for the mother (Smith et al., 2019). These findings are highly consistent with the experiences of women in the current study.

Studies from the United Kingdom show that health care providers' poor knowledge of MMHD symptoms delayed referrals to care for their patients (Smith et al., 2019). Providers who showed disinterest in their patients prevented them from reaching out for further treatment (Webb et al., 2021). Researchers propose that the provider's ability to identify mental illness is a crucial step in the care access pathway (Webb et al., 2021). Similarly, respondents pointed to providers' lack of attention and sensitivity as detrimental to their mental state and overall well-being.

For many respondents in this study, being forced to return to work soon after childbirth while managing untreated MMHDs was stressful and often debilitating. Previous studies suggest that women residing in regions with paid maternity leave experience better mental health outcomes (Aitken et al., 2015). Conversely, women with less than eight weeks of paid time off were more likely to experience depression compared to women with eight or more weeks of paid time off (Chatterji and Markowitz, 2012). In the U.S., there are no federally legislated paid maternity leave laws that support working women during the perinatal period (International Labour Organization, 2014), which poses a significant barrier to care access and recovery for new mothers experiencing MMHDs.

### *Strengths and Limitations*

A major strength of this study is the diverse representation of perinatal women across 17 different states in the U.S. The in-depth, personal accounts from each respondent offered a rich landscape of data that greatly contributed to the qualitative value of the study.

The current study has several major limitations. First, respondents' race and ethnicity are heavily skewed toward White or Caucasian-identifying women, with very little data from women of color. As such, the conclusions made from this study may not be generalizable to perinatal individuals who identify as non-White. Second, respondents were not given the option to report their gender identity or sexual orientation. Almost all respondents identified as a "Woman who suffered from a diagnosed/likely MMHD" in the survey, however, no options were given to identify as a gender non-binary individual with MMHD. Therefore, the data from this study is limited to the experiences of female-identifying individuals. Third, all responses were typed out in a free-response format, and are therefore subject to recall bias. Fourth, survey questions were pre-established and were not tailored to meet the study aims of the current project. As such, data collected from the survey was broad in scope, but limited in relevancy. Regrettably, the scope of this project did not allow for analysis of associations between respondent demographic or geographical region and their MMHD experiences. Future studies should consider how race, MMHD diagnoses, location, and sexual orientation may be connected to barriers or facilitators to care. Finally, qualitative coding and analysis was conducted by one researcher. Despite establishing coding consensus with the thesis committee and best efforts to produce accurate and reliable codes, there were no other coders and therefore no validation of inter-rater reliability. The data in this study is subject to coding inaccuracies, confirmation bias, and potential selection bias, thus, results and conclusions should be appraised with such limitations in mind.

## **Conclusion**

Personal stories shared by 49 women across 17 U.S. states revealed various facilitators and barriers that shaped access to MMHD care and treatment. Partners, family members, and friends served as advocates for women and formed a trusting support system during times of

need. Prior experience and exposure to signs and symptoms of MMHDs facilitated treatment-seeking behavior and promoted recovery. Health care providers who were dismissive or unknowledgeable about MMHDs prevented care access for women, as did perceived stigma and fear of judgement for being a “bad mom”. Importantly, lack of access to paid maternity leave significantly hindered MMHD treatment and recovery for women, and further perpetuated symptoms. To best support perinatal populations, health care providers and the general public must be educated on MMHDs and stigma reduction, public health organizations must prioritize peer and social support programs, and policymakers must advocate for legislation of paid maternity leave.

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**Table 1.** List of codes.

<b>Parent Code</b>	<b>Child Code</b>
F_Coverage	
F_Access	F_Access_Awareness
	F_Access_Initiation
F_Treatment	F_Treatment_Partner
	F_Treatment_Employment
	F_Treatment_Medication
	F_Treatment_Continuity
	F_Treatment_Screening
	F_Treatment_Therapy
F_PositiveRelationships	
B_Coverage	
B_Access	B_Access_Awareness
B_Treatment	B_Treatment_Partner
	B_Treatment_Employment
	B_Treatment_Medication
	B_Treatment_Continuity
	B_Treatment_Screening
	B_Treatment_Therapy
B_NegativeRelationships	
RiskFactors	RF_History
	RF_Social
Stigma	
Important Quotes	

**Table 2.** Codebook.

<b>Parent Code</b>	<b>Child Code</b>	<b>Description</b>	<b>Example Quotes</b>
Care Coverage Facilitators (F_Coverage)	N/A	Refers to factors that enabled coverage of MMHD care and treatment. This code was not used.	None available.
Care Access Facilitators (F_Access)	Awareness of MMHD symptoms and risk factors (F_Access_Awareness)	Refers to factors that enabled improved MMHD care access, specifically prior knowledge and awareness of MMHD symptoms, and risk factors.	<i>“Since I had PPD before, I knew at 2.5 weeks postpartum that what I was feeling wasn't just the baby blues. I saw my OB and he prescribed the same antidepressant I was on with my daughter.” - ID 24</i>
	Initiation of MMHD care access (F_Access_Initiation)	Refers to factors that enabled improved MMHD care access, specifically factors that lead to the respondent's first instance of initiating care.	<i>“With the support of my family, I finally reached out to a therapist who helped me realize that I wasn't going crazy and what I was feeling was very common.” - ID 152</i>
Treatment Facilitators (F_Treatment)	Partner (F_Treatment_Partner)	Refers to instances where the respondent's partner facilitated their access to care, treatment or recovery from MMHDs.	<i>“I was diagnosed with PPD a few weeks after giving birth to my first child. I am fortunate to have an attentive husband who pushed me to see my doctor for help.” - ID 136</i>
	Employment (F_Treatment_Employment)	Refers to instances where the respondent's workplace or employer facilitated their access to care, treatment or recovery from MMHDs.	<i>“Taking time off of work has been helping me improve my mental health since I can see my therapist more and actually let things off of my chest and actually be assured that I'm not a horrible mom like I think I am.” - ID 16</i>
	Medication (F_Treatment_Employment)	Refers to instances where medication usage facilitated the respondent's treatment or recovery from MMHDs.	<i>“Once I did get back on my medication (Zoloft) I started to feel somewhat more “normal”. I would still find myself struggling with certain things, but I was a totally different person...for the better!” - ID 192</i>
	Continuity (F_Treatment_Continuity)	Refers to instances where continuous care facilitated the respondent's treatment or recovery from MMHDs.	<i>“It took time and baby steps to start to feel like I wasn't a complete failure. I still see an individual therapist and my psychiatrist on a regular basis</i>

			<i>and have officially been off the benzodiazepine that I felt dependent on for months.” - ID 24</i>
	Screening (F_Treatment_Screening)	Refers to instances where screening for MMHDs facilitated the respondent’s treatment or recovery from MMHDs.	<i>“I am incredibly thankful for ... our daughter's pediatrician's office who also did the postpartum depression screenings at our 1 month and 2 month well-child checkups, and my therapist who immediately started teaching me coping skills for depression.” - ID 144</i>
	Therapy (F_Treatment_Therapy)	Refers to instances where therapy and counselling facilitated the respondent’s treatment or recovery from MMHDs.	<i>“During one of my therapy sessions, I will always remember some of the first things my therapist said to me: Postpartum depression and anxiety are very real things; You are not alone; and We can help you get through this. I really needed to hear those statements. They gave me some strength and hope that I could start battling the postpartum depression and anxiety and I wouldn't have to do it alone.” - ID 116</i>
Positive Relationships as Facilitators (F_PositiveRelationships)	N/A	Refers to instances where positive support from personal relationships facilitated care access and recovery for the respondent.	<i>“I had family and friends visit every day and my newborn most days. When I returned home, I received a lot of help and support from family and friends as I recovered and learned to care for a newborn.” - ID 12</i>
Care Coverage Barriers (B_Coverage)	N/A	Refers to instances of lack of access to care due to poor coverage (e.g., health insurance, paid maternity leave).	<i>“The aftermath involved finding out that I was given less-than medical care, because the hospital staff thought I was a Medi-Cal patient.” - ID 156</i>
Care Access Barriers (B_Access)	Lack of awareness of MMHD symptoms and risk factors	Refers to factors that prevented care access, specifically lack of prior knowledge and awareness of	<i>“I didn't ever know I was experiencing postpartum depression and anxiety until maybe a year later.” - ID 28</i>

	(B_Access_Awareness)	MMHD symptoms and risk factors.	
Negative Relationships as Barriers (B_NegativeRelationships)	N/A	Refers to instances where negative or stressful relationships prevented the respondent from seeking care or recovering from MMHDs.	<i>“Then our apartment burned down and set me back 10 more steps, we had to move in with my mother and had to deal with the mental abuse from her which put me back even further.” - ID 16</i>
Treatment Barriers (B_Treatment)	Partner (B_Treatment_Partner)	Refers to instances where negative personal relationships prevented care access and recovery for the respondent.	<i>“My husband was working awards season (in entertainment), so he was gone 12-15 hours a day. Then also left me alone on weekends.” - ID 156</i>
	Employment (B_Treatment_Employment)	Refers to instances where the respondent’s workplace or employer prevented their access to care, treatment or recovery from MMHDs.	<i>“I was told by my school that I had to come back to work because I had no time to take off. So I went back to work while I was still very sick and recovering. Then I got severely depressed and had a difficult time functioning but forced myself to work because I had no other options or at least that is what I was told.” - ID 13</i>
	Medication (B_Treatment_Medication)	Refers to instances where medication prevented or delayed the respondent’s treatment or recovery from MMHDs.	<i>“I finally reached out and got help on my own, I started therapy and was put on medication that made me worse than what I was before.” - ID 16</i>
	Continuity (B_Treatment_Continuity)	Refers to instances where lack of continuous treatment prevented or delayed the respondent’s treatment or recovery from MMHDs.	<i>“Because I was on Medi-Cal, I had to go to a clinic, with a staff of rotating doctors, who would only know ME by my chart. Not by seeing me regularly.” - ID 156</i>
	Screening (B_Treatment_Screening)	Refers to instances where lack of screening or poor screening for MMHDs prevented or delayed the respondent’s treatment or recovery.	<i>“Three days later after a continued downward spiral, I went to the emergency room. I was evaluated by a man via video chat and he told me that it seemed that I wasn’t a threat to</i>

			<i>myself or my daughter so I had to go home.” - ID 76</i>
	Therapy (B_Treatment_Therapy)	Refers to instances where lack of therapy and counselling prevented or delayed the respondent’s treatment or recovery from MMHDs. This code was not used.	None available.
MMHD Risk Factors (RiskFactors)	History of Mental Illness (RF_History)	Refers to instances where respondent mentioned previous experience with mental illness or MMHDs.	<i>“I have suffered depression a majority of my adult life. I became pregnant with my second child October 2018 and delivered July 2019. The last few months of my pregnancy had me feeling extremely depressed, anxious, and a general feeling of hopelessness and loneliness.” - ID 68</i>
	Lack of Social Support (RF_Social)	Refers to instances where respondent points out weak or poor social support systems as a reason for worsened MMHD outcomes.	<i>“I stayed in the hospital for a week and had a blood transfusion, then was released and went home to figure it out on my own. I was married but didn't have a support system. I remember feeling disconnected and just going through the motions.” - ID 28</i>
Perceived Stigma (Stigma)	N/A	Refers to instances of stigma experienced or perceived by the respondent, including self-stigma.	<i>“I had felt so much guilt and shame around my feelings. I thought having those feelings would mean I was a bad mother and wife. Remember that negative stigma surrounding mental health I mentioned earlier? That’s a big reason I didn’t want to admit to these feelings.” - ID 88</i>
Important Quotes (Important Quotes)	N/A	Refers to quotes shared by respondents that are memorable or particularly relevant to the current study, such as elements that greatly facilitated or prevented access, treatment, or recovery.	<i>“I had a few bad days but I started seeing a counselor specifically trained in PPD and I saw a psychiatrist trained in PPD as well. Therapy, medication and my support system are what all got me through.” - ID 112</i>

**Table 3.** Individual Code Application Frequency.

<b>Code</b>	<b>Frequency of Application in 39 Transcripts (% compared to most frequent code)</b>
F_Treatment_Medication	54
F_PositiveRelationships	43
F_Access_Initiation	29
F_Treatment_Therapy	25
Important Quotes	24
Stigma	23
F_Treatment_Partner	22
F_Treatment	21
B_Access_Awareness	20
B_Treatment_Medication	20
B_Treatment	19
B_Treatment_Continuity	19
F_Access_Awareness	14
F_Treatment_Continuity	14
B_Access	13
RF_History	13
B_NegativeRelationships	10
RiskFactors	8
B_Treatment_Employment	7
F_Access	7
B_Treatment_Partner	5
B_Coverage	5
F_Treatment_Screening	5
B_Treatment_Screening	4
F_Treatment_Employment	4
RF_Social	1
B_Treatment_Therapy	0
F_Coverage	0

**Table 4.** Frequency of Code Co-Occurrence.

<b>Code 1</b>	<b>Code 2</b>	<b>Frequency of Co-Occurrence Within 39 Transcripts (# occurrences)</b>
F_Treatment_Medication	F_Treatment_Therapy	11
F_Treatment_Medication	F_PositiveRelationships	10
F_Treatment_Partner	F_PositiveRelationships	10
F_Treatment_Medication	F_Access_Initiation	9
F_PositiveRelationships	F_Access_Initiation	8
F_PositiveRelationships	F_Treatment_Therapy	7
F_Treatment_Medication	F_Treatment_Partner	6
Important Quotes	B_Treatment	6
Important Quotes	F_PositiveRelationships	5
F_Treatment	F_PositiveRelationships	5
F_Treatment	F_Treatment_Medication	5
F_Treatment_Continuity	F_Treatment_Medication	5
F_Treatment_Partner	F_Treatment_Therapy	5
B_Treatment_Continuity	B_Treatment_Medication	4
Stigma	B_Access_Awareness	4
Important Quotes	F_Treatment_Medication	4

**Table 5.** Participant Demographics (N = 49).

<i>Characteristic</i>	<i>n</i>
<b>Role</b>	
Survivor (Woman who suffered from a diagnosed/likely MMH Disorder)	48
Father	0
No Response	1
<b>State of Residence</b>	
Pennsylvania (PA)	9
California (CA)	5
Virginia (VA)	4
Indiana (IN)	3
New York (NY)	3
Illinois (IL)	2
Texas (TX)	2
New Jersey (NJ)	2
Vermont (VT)	2
North Carolina (NC)	2
Alaska (AK)	1
Arizona (AZ)	1
Arkansas (AR)	1
Florida (FL)	1
Hawaii (HI)	1
Michigan (MI)	1
Minnesota (MN)	1
Missouri (MO)	1
Nevada (NV)	1
New Mexico (NM)	1
Oklahoma (OK)	1
Oregon (OR)	1
Rhode Island (RI)	1
South Carolina (SC)	1
Washington (WA)	1
<b>Self-Reported MMHD Diagnoses</b>	
“I had general anxiety during pregnancy or the postpartum period.”	44
“I had depression during the postpartum period.”	43

“I had scary "intrusive" thoughts during pregnancy or the postpartum period.”	42
“I had depression during pregnancy.”	21
“I had birth related PTSD.”	11
“I had psychosis during the postpartum period.”	7
“I had psychosis during pregnancy.”	0
Other	4
<b>Race/Ethnicity</b>	
Caucasian/White	45
Hispanic/Latina	3
African American/Black	1
Asian	0
American Indian or Alaskan Native	0
Native Hawaiian or Pacific Islander	0
Prefer not to state	0
Other	0

## **Appendix A. The Blue Dot Project Survey Questionnaire “Share Your Maternal Mental Health Story”**

1. My Role (Multiple choice checkboxes)
  - a. Survivor (Woman who suffered from a diagnosed/likely MMHD)
  - b. Father
  - c. Other (Short answer text)
2. Your First and Last Name (Short answer text)
  - a. The City of MMH Baby’s Birth (Short answer text)
  - b. The State of MMH Baby’s Birth (Short answer text)
  - c. Your Current City (Short answer text)
  - d. Your Current State (Short answer text)
  - e. Tell Us Your Story (Long answer text)
3. Check all that apply (Multiple choice checkboxes)
  - a. I had depression during pregnancy
  - b. I had depression during the postpartum period
  - c. I had general anxiety during pregnancy or the postpartum period
  - d. I had scary "intrusive" thoughts during pregnancy or the postpartum period
  - e. I had psychosis during pregnancy
  - f. I had psychosis during the postpartum period
  - g. I had birth related PTSD
  - h. Other (Short answer text)
4. Race/Ethnicity (Multiple choice checkboxes)
  - a. Caucasian/White
  - b. African American/Black
  - c. Asian
  - d. American Indian or Alaskan Native
  - e. Hispanic or Latina
  - f. Native Hawaiian or Pacific Islander
  - g. Prefer not to state
  - h. Other (Short answer text)
5. E-mail address (short answer text)
6. Cell phone (Short answer text)
7. Anything Else We Should Know? (Long answer text)