# Perinatal Mood and Anxiety Disorders: Focus Group Findings

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## Background & Significance

- PMAD are estimated to affect 11-21% of women in the U.S. and include depression, anxiety, post traumatic stress disorder, obsessivecompulsive disorder and postpartum psychosis (CDC, 2016; Fairbrother, Young, Antony, Tucker, 2015; Postpartum Support International, 2014).
- PMAD are known to have a profound negative impact on women, families and communities and can impair maternal behavioral response leading to long term behavioral problems among children (Sontag-Padilla, Lavelle, & Schultz, 2014; Goodman, Guarino & Prager, 2013; Glynn, Howland, & Sandman, 2017).
- Risk factors for developing PMAD include low socio-economic status, low educational attainment, history of mental illness, delivering a preterm baby, exposure to interpersonal violence and lack of social support (National Child and Maternal Health Education Center, 2016; American College of Obstetrician- Gynecologists, 2015; Knitzer, Theberge, & Johnson, 2008).

### Purpose

- Few studies have explored the experience of PMAD from the perspective of at risk groups. This critical gap must be closed if we seek to better understand PMAD, develop efficacious and culturally appropriate interventions, and engage at risk women in treatment.
- The purpose of this study was to explore knowledge and awareness of PMAD along with barriers to care among an at risk group of women during the perinatal period who reside in a low resource community. The perinatal period was defined as the time from establishing a diagnosis of pregnancy until the infant's 1<sup>st</sup> birthday. Data were collected from May – August 2017.

## Design/Methods

- Focus groups were convened at two community centers to provide a forum for participants to share what they knew about PMAD including risk factors, symptoms, treatment available after diagnosis, and barriers to care. This knowledge sharing included exploring perceptions, opinions and attitudes about PMAD.
- Foundation of CBPR: recommendations were sought about PMAD treatment, cultural nuances, barriers to care and other important issues not addressed in the current literature or by community and health care providers.
- The academic institutional review board approved the study prior to participant recruitment.

### Focus Group Questions & Prompts

- "Please tell us what you know about depression, anxiety and other mental health problems that a woman may experience during pregnancy or after the birth of her baby?"
- "Did you feel you were able to discuss any mental health problems that you might have experienced during your pregnancy or after the baby was born?"
- "What did you feel was a barrier to accessing mental health services and what facilitated accessing mental health services?"
- "What services should be offered to women in this community who might have depression, anxiety or another mental health problem?"

### Data Analysis

- Qualitative content analysis using Kreuger and Casey's (2015) framework provided structure for analyzing the data.
- Credibility, dependability and consistency were assured by verbatim transcription, review and collection of sufficient data that is clearly documented, and consultation with the author's research collective for external auditing (Lincoln & Guba, 1985).
- Descriptive statistics were used to describe the demographic characteristics of the 2 groups.

### Results: Participants

 The focus group participants ranged from ages 18- 42 with a mean age of 30.12 (standard deviation [SD] = 6.95). Nineteen participants reported a Hispanic/Latinix ethnicity (79%). Five reported a current pregnancy (20%) and the remaining 19 women had at minimum 1 child age 1 or younger. The groups were racially diverse with five self described as African-American (20%), five self described as White (20%) and the remaining 14 participants self described as mixed race (58%). All participants completed high school. Nineteen reported being bilingual (English/Spanish) but had sufficient fluency to participate in the focus group in English.

# Theme 1: Knowledge and Awareness of PMAD

- Most, if not all, could identify common signs and symptoms including sadness, fatigue, anhedonia, irritability, excessive worry and difficulty with regulating sleep and appetite.
- There was awareness about the gravity of PMAD "This is serious. People snap...everyone is not so strong that they can deal with the stress of the new baby."
- A few participants provided more extreme examples that they personally experienced or witnessed. "I had impulses I didn't act on, things in my head...thank God I never suffocated her or threw her out the window".

# Theme 2: Unmet Needs during the Perinatal Period

- According to the majority of the participants in this study the focus of perinatal care was the fetus/baby and not the mother or the mother/baby unit. For some participants this culminated in a lack of engagement with their healthcare provider and affected their ability to discuss mood instability, exposure to intrapersonal violence, and substance use.
- A participant disclosed, "I would want them [healthcare providers] to ask about me...to know me. Ask about how I am managing during this pregnancy. I have three kids. Five, three, and the baby. No one asked me if I was stressed. They asked once, in the beginning if I was sad or depressed. But I wasn't. I was stressed. How do I manage that? But it's all about getting in and out. I sometimes wait for an hour or two and then I am rushed out."
- Another participant stated, "It's like I am just carrying this baby. Like they need me to come in to test the baby but not me. You know? Ask me, 'how you doing?' But then really listen to me."

# Theme 3: Distrust of Services and Organizations

- The majority of participants in this study received prenatal care at hospital based prenatal clinics that offer many services including medical, midwifery, social work and nutrition. Most voiced concern about what they described as intrusive personal questions.
- One participant explained, "They ask very personal questions and expect me to answer although I don't really know them. Like am I smoking, drinking or using drugs? I get it. It hurts the baby but ask me a different way, like you're thinking of me too. Anyway if I said yes then they call ACS" [Administration for Children Services].
- Another participant recounted what transpired after she talked about feeling depressed, "They asked me a lot of questions and then told me to see the social worker. They gave me a slip of paper to bring to her. I just didn't go. I don't trust them. I don't want them to take my baby away from me".

# Theme 4: Recommendations to Improve Utilization of Care

- The majority of participants wanted a community based center where a pregnant woman or new mother could "drop in" for culturally appropriate counseling. Lack of transportation, lack of childcare and employment were cited as barriers to accessing and utilizing care. Participants believed a walk-in center that did not require an appointment would increase utilization in their community.
- A participant said, "I feel like if you're accommodated for, like if you're given support that gives the mom less distress. If there's a program that the mom wants to go but unfortunately, they don't have the means to get there that also discourages them."

### **Discussion**

- The women in this study were very knowledgeable and aware of the signs, symptoms and impact of PMAD. Many had experienced PMAD but reported avoiding disclosure due to fear of losing custody of their child and involvement of child protective services.
- As mandatory reporters HCPs may feel liable, both ethically and legally, if they do not report but women rarely act on their thoughts (Fairbrother & Woody, 2008). This may contribute to distrust between women and providers. The participants felt that prenatal care focused largely on the health of the developing fetus and that their healthcare needs were, at times, were unmet.
- The participants felt that prenatal care focused largely on the health of the developing fetus and that their healthcare needs were, at times, were unmet. When they were the focus of care, some reported that it could be intrusive and depersonalized. This perception contributed to feeling devalued as a person.

### **Discussion**

 Rollans, Schmied, Kemp & Meade (2013) found that women (n=20) reported depression screening was acceptable during the postpartum period but that questions were intrusive, uncomfortable and that they felt unprepared and distressed by the experience. Findings from this study recommend ongoing training and education to deliver care that is sensitive and empathic. Wadsworth, Degesie, Kothari & Moe recommended that developing a trusting relationship and providing a sense of safety if screenings are to be accepted by women in a study about interpersonal violence (2019).

#### **Discussion**

- The inability to access mental health services with the flexibility to meet the needs of a new mother was cited as a barrier by the participants of this study.
- Mental Health First Aid (MHFA) is gaining recognition as a health education program that can train community workers to respond to mental health problems and crises (Kitchener & Jorm, 2001). Educating women, families and communities in the Mental Health First Aid (MHFA) model may provide additional resources for prevention and early intervention.
- Recommendations to improve care include educating HCPs to recognize PMAD, screening protocols with a variety of well validated instruments and pharmacological and nonpharmacological treatment guidelines (Byrnes, 2018; Kendig, Kean, Hoffman et al. 2017; Byatt, Simas, Lundquist, Johnson & Ziedonis, 2012).

#### Limitations

 The participants were from the Northeast U.S. that has unique characteristics and therefore the results cannot be generalized to other populations. The participants were a convenience sample and self selected to participate in the study. This may indicate a selection bias, interest in the topic and affects the generalizability of the findings. Findings may not be representative of women who chose not to participate in this study.

#### Conclusion

- These findings contribute to what is known about an at risk group of women's knowledge about PMAD and barriers to treatment.
- HCPs have a duty to seek mechanisms to deliver culturally sensitive and accessible care to women while reducing risk.
- More data about the impact of harm OCD and how HCPs interpret intrusive harm thoughts are needed.
- Advocacy for mental health first aid training in high risk communities is essential for early identification of PMAD.
   Future studies should be conducted with larger sample groups are needed to establish and advance the science to improve outcomes.

# Thank you!

- Questions?
- Comments?