



## Perinatal mood and anxiety disorders: findings from focus groups of at risk women<sup>☆</sup>



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### Introduction

In recent years, much attention has been directed towards understanding and treating perinatal mood and anxiety disorders (PMAD). PMAD are estimated to affect 11–21% of women in the U.S. and include depression, anxiety, post traumatic stress disorder, obsessive-compulsive disorder and postpartum psychosis (Centers for Disease Control and Prevention, 2016; Fairbrother, Young, Janssen, 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 (Center on the Developing Child at Harvard University, 2009; Glynn et al., 2018; Goodman, 2009; Goodmann, Guarino, & Prager, 2013; Sontag-Padilla, Lavelle, & Schultz, 2014). Risk factors for developing PMAD include low socioeconomic status, low educational attainment, history of mental illness, delivering a preterm baby, exposure to interpersonal violence and lack of social support (American College of Obstetrician- Gynecologists, 2018; Knitzer, Theberge, & Johnson, 2008; National Child and Maternal Health Education Center, 2016). Few studies have explored the experience of PMAD from the perspective of at risk groups. This is a critical gap if we seek to better understand PMAD, develop efficacious and culturally appropriate interventions, and engage at risk women in treatment.

Data collected and analyzed by the New York City Department of Health and Mental Hygiene (NYCDOHMH, n.d.) highlights the issues faced by Bronx residents, the focus of this study. In the Bronx, between

17.8% and 33.1% of women report late entry or no prenatal care and approximately 8.9–10.9% of births occur prematurely (NYCDOHMH, 2015). In a review of the Community Health Profiles published by the NYCDOHMH, residents in the Bronx are exposed to more neighborhood violence (138/100,00 non-fatal assault hospitalizations), are less likely to have completed high school (30%) and are more likely to live in poverty (31%) when compared to other New York boroughs (NYCDOHMH, 2015a). Lastly, a study conducted by the New York City Department of Health and Mental Hygiene found that there are institutional and system barriers to screen and treat women for postpartum depression which results in fewer women having access to quality mental health services (Applewhite et al., 2009). These data underscore the adversity faced by residents of the Bronx and how this adversity might contribute to PMAD in this community.

The purpose of this study, based on these data, was to explore knowledge of PMAD and awareness of treatment for PMAD, along with barriers to care, among an at risk group of women during the perinatal period who reside in the Bronx. The perinatal period was defined as the time from establishing a diagnosis of pregnancy until the infant's 1<sup>st</sup> birthday. The aims of this study were to:

- 1). Develop an understanding of knowledge and awareness of PMAD among a group of at risk women during the perinatal period;
- 2). Identify barriers to access and utilization of mental health or social services for at risk women.

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## Methods

### Conceptual framework

Community based participatory research (CBPR) was chosen as the conceptual framework for the study. CBPR is defined as a collaborative research method in which community members engage with researchers as equal partners with a shared interest (Faridi, Grunbaum, Gray, Franks, & Simoes, 2007). CBPR also offers a philosophical foundation to planning, designing and implementing studies in which the involvement of the community is not only needed but is essential to the success of the study. The assumptions of CBPR include the following 1). Individuals and communities have rich knowledge of their lives and how they are experienced; 2). Individuals maintain responsibilities and connections to their communities; 3). We are complex organisms defined by social, political, and cultural systems in which power and privilege play a role; 4). CBPR is grounded in truth, awareness, integrity and commitment. (Torres, 2009). This partnership was essential if the system and institutional barriers to accessing care were to be explored within these groups. This study was the result of a discussion that occurred during a community engagement meeting hosted by the Weill Cornell Clinical Translational Science Center. A community member voiced concern over the lack of utilization of mental health services among pregnant and postpartum women and requested help to explore the issue.

### Design

Focus groups were convened to provide a forum for participants to share what they knew about PMAD including risk factors for PMAD, symptoms, how diagnosis occurs, treatment available after diagnosis, and barriers to care. This knowledge sharing included exploring perceptions, opinions and attitudes about PMAD. In keeping with the 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.

### Sample

Participants were recruited using flyers posted in 2 community centers serving women during the perinatal period in the Bronx. Women were eligible to participate if they were between the ages of 18–44, were either pregnant or had a live birth within the past year, and could participate in a focus group speaking English.

### Procedure

Women were screened by telephone for study eligibility by a research assistant who was fluent in English and Spanish. If eligible the woman was offered the opportunity to participate in one of two scheduled focus groups. The focus groups were held at 2 different but local community centers to reduce transportation burden. If a potential participant was ineligible an explanation was provided. The PI for this study co-moderated the focus groups with a community member who served as an outreach worker to women during the perinatal period in the Bronx. The research assistant attended the focus groups to assist participants with the consent process, setting up the recording equipment and distributing the incentive at the conclusion of the focus group. At the beginning of the focus group the PI discussed the importance of maintaining confidentiality for the ensuing discussion. The community member discussed having respectful consideration for what each participant brought to the group. A brief demographic survey was completed by each participant.

Group one had 12 participants and group 2 had 12 participants for a

total of 24 participants overall. Both groups were audio recorded using a digital recorder. A semi structured interview guide was developed to guide and prompt the participants. Each group began with the following question, “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.” Other prompts included, “Were you screened for depression or other problems during your pregnancy or after the baby was born?” “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?” The focus groups concluded when all at the table agreed that no new thoughts or comments would be forthcoming. The first group was approximately 90 min and the second group was approximately 120 min.

### Data analysis

Each focus group was audio recorded and transcribed verbatim. The transcripts were checked by the PI for accuracy. It should be noted that a few sentences were unintelligible in both groups but this ultimately did not impact the analysis. Qualitative content analysis using Krueger and Casey's (2015) framework provided structure for analyzing focus group data. As a qualitative research method, content analysis guides the researcher in the interpretation of text data by utilizing a process of coding leading to identification of themes (Hsieh & Shannon, 2005). Framework analysis occurs as the data is being collected and emphasizes the process as non-linear. There are 5 interconnected stages to conducting framework analysis. The first is to assure the collection of rich data by skillful planning, thorough note taking, and verbatim transcription. The researcher then must immerse in the data by reviewing the audiotapes and reading the transcripts multiple times. At this point themes will begin to emerge. Written notes in the margins of the transcripts help this process along as concepts form. This is followed by indexing and charting in which participants' quotes are placed together as themes emerge. Mapping and interpretation are only possible when the data has been reduced to this point. Dependability and consistency are assured by verbatim transcription and review and collection of sufficient data that is clearly documented (Lincoln & Guba, 1985). Descriptive statistics were used to describe the demographic characteristics of the 2 groups.

## Results

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/Latina? 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.

### Knowledge and awareness of PMAD

Participants in both focus groups had an expansive knowledge and awareness of perinatal mood disorders and anxiety. 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 a great deal of interaction as participants shared the following comments about PMAD: “not keeping up with your appearance”, “isolating yourself because you're sad or

overwhelmed and you think you should be happy about the new baby so you try to keep to yourself”, “everyone is telling you things and you begin to feel overwhelmed. If you weren't confident about the baby before now you feel like you can't do anything right. That made me really anxious.” 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.” The participants agreed with the individual speakers by nodding their heads or verbalizing.

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”. “She was premature and the father was always out. He gave me money for the baby but he wasn't there. She (the baby) couldn't sleep through the night and I yelled at her. I am not ashamed because I didn't snap and abuse her but I never told anyone. If I told they would have taken her away”. “You have a baby so that someone will love you but that doesn't happen for a long time. Some moms don't understand they [the baby] suck the life out of you. It's about what they [the baby] needs; not what you [the mother] needs. This can lead to feelings of depression.” “I used to get these feelings like I want to toss her out the window or I want to slam her into a wall. Can you imagine someone that couldn't stop?” None of the participants disagreed or appeared unduly distressed by this disclosure. They remained engaged with the group.

#### *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. Prenatal visits were brief and consisted of vital signs, fetal assessment and testing conducted on the mother but for the welfare of the fetus. Participant's reported few opportunities for exploration of the mother's socio-psychological concerns and behavioral practices unless they were deemed harmful to the fetus. This led the participants to feel that they had responsibility for fetal well-being, growth, and development but that their well-being was unimportant or ignored. For some participants this culminated in a lack of engagement with their healthcare provider and the ability to share concerns about 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.” One participant disclosed the following, “I had a history of using drugs. I told them that at my first visit. No one ever talked to me about it again. After the baby was born they gave me drugs in the hospital. That caused me to relapse. The monster was awake. Maybe if they knew that I wouldn't have relapsed”.

#### *Distrust of organizations and services*

The majority of participants in this study received prenatal care at hospital based prenatal clinics. These settings offer many services at one site including medical, midwifery, social work and WIC. Participants reported a lengthy first prenatal visit which included being seen by the doctor or midwife, a nurse, and nutritional services. Most reported what they described as personal and intrusive questions that they were expected to answer about their behaviors and most felt unwilling to respond due to distrust.

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]. Some of the participants shook their heads in agreement/show of support.

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”.

Health care staff often screen for domestic violence and depression at prenatal visits.

One participant discussed her reaction to this screening, “The nurse she asks questions like, ‘are you sad? Is the baby's daddy hurting you?’ Kicking, punching, things like that. No, that is not happening to me but why would I tell YOU? (emphasized by respondent). I don't want ACS coming to my home”.

Another participant described her experience, “No one asked me if I was depressed the first time. And I was...the father had gotten arrested the day before I went into labor. Nobody asked me any questions. I made like I was ok. I said I'm happy but, you know, I lied. I didn't want them to keep me in the hospital”.

One participant recounted her disappointment with her care, “I had a big issue...they refused to let me deliver in a certain hospital. I didn't have an ACS case when I got there but when I left I did. They labeled me an ‘insignificant mother’ meaning I couldn't provide for my baby. That hurts.” Participants expressed dismay and sadness when they heard this and a few kept quietly repeating insignificant mother and shaking their heads.

The final participant stated poignantly, “I also, I feel like one of the reasons, honestly, I feel the statistics number is low, I think more moms actually go through it but it's in private. I feel the reason of that is because post-partum depression is basically painted in a negative light. So, a mother hears about post-partum depression she thinks, ‘Oh my god, she's killing the baby’ or ‘I'm going to kill my baby.’ It's just painted in a negative way. So instantly if the mom is going through that she's not going to want to say anything because she might think that, people are going to call the cops or social services, so the mom feels she's not capable of taking care of her child.”

#### *Recommendations to improve utilization of care*

Participants in this study valued counseling as an intervention to treat PMAD. Most expressed a personal experience with counseling or therapy.

A participant stated, “I've had therapy and it has been so beneficial to me.”

When asked what would be the optimal way to treat PMAD in your community, 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.

One participant stated, “Motherhood isn't what I thought it was going to be, this stuff is hard. You know, and kind of removing that romantic idea of motherhood because sometimes it takes me three hours just to get dressed. It's more to be who we are and not shame ourselves for saying life is hard, this is not what I thought it was going to be and then knowing you have the support to help you get over that problem. But if I was already fifteen minutes late, that's it, I wouldn't go”.

Another 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 three times a week that also discourages them.”

One participant felt that access to care should begin during the pregnancy. “This support should begin during the pregnancy. We need to hear more about what can happen, how to prepare...you don't pay attention to yourself during the pregnancy because it is all about the baby. So we are not prepared for how we're going to feel.”

Because access to care was limited, many participants relayed that they addressed questions and concerns with their mother, the father of the baby or family and friends who were mothers.

One participant shared the following, “I don't like talking to people much, but in the end, I started talking to my mom. Before, during my teenage life, I didn't have conversations with my mom, but now I started talking to her and she started to help me and now I had a lot of something like depression.”

Another recounted, “When I had my kid three years ago I didn't expect to become depressed. It was not factored in. I didn't think of being depressed. However, when I had this baby and I went home—and I cried my eyes out thinking if I could go back to work, would that throw you off and then I realized this is hard. My mother and the baby's father, they really helped.”

## 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. Three of the participants disclosed the experience of obsessive-compulsive disorder (OCD) with harm features when they reported thoughts of harming their baby. Harm OCD is the experience of intrusive, unwanted thoughts of accidental or intentional harm to the baby with a behavioral component in which the mother avoids situations in which harm may occur. Harm OCD is not uncommon in the postpartum period but can be so distressing to new mothers that they may not disclose the experience (Fairbrother, Thordarson, Challacombe, & Sakaluk, 2018; Fairbrother & Woody, 2008). 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). 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. Rollans, Schmied, Kemp, and 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 (2018) 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.

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. Many reported discussing their feelings with family members and/or the father of the baby and did not seek professional help. Family members may feel unprepared to meet this need and when to seek professional help, if necessary. 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 (Jorm, Kitchner, O'Kearney, & Dear, 2004). 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 non-pharmacological treatment guidelines (Byatt, Simas, Lundquist, Johnson, & Ziedonis, 2012; Byrnes, 2018; Kendig, Keats, Hoffman, et al., 2017). It is well documented that

PMAD have a negative impact on women, children and families (Dunkel Schetter & Tanner, 2012; Hoffman, Dunn, & Njoroge, 2017). Therefore, prevention, screening and culturally appropriate treatment should be a priority in clinical settings that serve women during the perinatal period. New models of mental health care delivery are needed to improve access to mental health services for new mothers. Warm lines, MHFA, telehealth and walk in clinical hours are models to be explored for expansion of services. Community engagement will be critical in the ongoing effort to address PMAD.

## Limitations

There were limitations to this study. The participants were from an identified borough in the City of New York (the Bronx) 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

This study presents the perspective of PMAD from an at risk group. Although the study is specific to a regional area in the US and to a specific community, these findings contribute to what is known about an at risk group of women's knowledge about PMAD and barriers to treatment. We, as healthcare providers, 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.

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