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Perinatal Mood and Anxiety Disorders: Findings From Focus Groups of At-Risk Women

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Purpose:

The purpose of this qualitative study, utilizing focus group data, was to explore awareness of signs and symptoms of perinatal mood and anxiety disorders (PMAD) and utilization of mental health services among pregnant and postpartum low-income minority women in an urban setting. The aim of the study was to elicit information from study participants to gain insight about how to increase awareness of PMAD and improve utilization of services to treat PMAD.

Methods:

Design: This qualitative study utilized 2 focus groups conducted with pregnant and postpartum women (n=25) on the topic of PMAD. **Sample/recruitment:** Participants were recruited using flyers posted in perinatal services offices in the catchment area and in community centers that served mothers and families in an urban setting. Inclusion criteria included fluency in English, ages 18-44, currently pregnant or in the 1st postpartum year and ability to participate in a focus group for approximately 1 hour. **Human subject approval:** The study was approved by the IRB prior to initiating recruitment. Participants were provided an incentive for participating in the focus group in the form of cash and reimbursement for travel to the study site. **Setting:** The study took place in the Northeast USA during the summer of 2017. **Data collection:**The PI has formal training in conducting focus groups and in community based participatory action research (CBPAR). The focus groups were moderated by the PI and the co-investigator of the study. A research assistant was present to assist with the consent process, to take notes, and to distribute the incentive. Each focus group was audio recorded and transcribed verbatim. Questions that guided the focus groups included: Please tell us what you know about perinatal depression? How would you describe what perinatal depression feels/looks like? Tell us what you know about perinatal anxiety? What signs and symptoms might a woman experience if they had PMAD? Is there a difference between PMAD and general depression or anxiety? Tell us about services (if any) in your community to diagnosis and/or treat PMAD. What would help women utilize these services? What are barriers to utilization? After each focus group the team met to debrief about what had transpired, initial impressions made during the focus groups and any concerns about commentary. These debriefings were recorded with notes by the PI. **Data analysis:** Data were analyzed using the framework outlined by Krueger and Casey including a systematic and sequential approach which is verifiable and continuous. Focus groups can help test assumptions of what we, as researchers, commonly think of as fact including the underpinnings of clinical practice and program development. Data from focus groups can be helpful to confirm or reject beliefs and acceptance about topics and can be useful to generate a deeper understanding of complex issues from different perspectives. This study was transcript based. The PI and the co-I both read through each transcript separately several times and wrote memos about thoughts and impressions of the content. The research team met to discuss study findings and to develop the study outcomes based on the analysis.

Results:

The study has limitations that must be acknowledged. These data do not reflect the views of non-participants and therefore may not be generalized to all populations. The study was conducted with low income minority women in the northeastern US who may have different perspectives and experiences about PMAD that again may not be generalizable. However the information that the women provided has important value and can impact how HCPs understand the experience of PMAD and utilization of mental

health services among at risk pregnant and postpartum women. In both focus groups the participants recognized the signs and symptoms of PMAD, which include sadness, anhedonia, hopelessness, hypersomnia, feeling isolated and irritability. They speculated that contributing factors to the development of PMAD included lack of social support, lack of economic resources including adequate nutrition, housing, transportation and increased exposure to community violence. They acknowledged the biological and genetic contribution but believed that social factors had a greater impact on the development of PMAD. Participants reported being screened for depression during the pregnancy at least once but not during the follow up postpartum visit. Participants were reluctant to report symptoms of depression or anxiety during the perinatal period due to the belief that reporting symptoms would result in a referral to Child Protective Services (CPS). Participants believed that CPS would place the child in foster care and they would lose parental rights if diagnosed with depression or anxiety. Utilization of mental health services was negligible due to this concern. Participants reported discussing feelings of depression or anxiety with their partner or another family member. These findings are critically important to inform best practices for helping women during the perinatal period who may be at risk for PMAD. Nursing and interprofessional interventions to improve the accessibility of services for PMAD are increasingly important. Developing outreach programs that can address concerns about family disruption/separation and social issues may impact both the rates of diagnosis and utilization of mental health services. Further studies should be conducted to evaluate the acceptance of mental health services among this community.

Conclusion:

This study provides needed insight into the beliefs and experiences of PMAD among urban low income minority women. Nursing and interprofessional interventions to improve the utilization of treatment for PMAD are increasingly important. These data provide a starting point to inform the development of programs and policies designed to address PMAD in these settings. Findings may be used to develop interventions that reduce unnecessary fears of family disruption, identify women at risk, and to develop services that assure maintaining the family unit while being treated. Further studies should be conducted to evaluate the acceptance of treating PMAD among this community.

Title:

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Keywords:

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Abstract Summary:

Perinatal mood and anxiety disorders (PMAD) have profound negative effects on women, infants and families. Little is known about awareness of PMAD among at risk women and their utilization of mental health services. Results from 2 focus groups (n=25) comprised of minority low-income women are presented.

Content Outline:

Introduction

Perinatal mood and anxiety disorders (PMAD) are increasingly being recognized as one of the most challenging issues women, families, communities and healthcare providers face today. It is estimated that PMAD affect 15 - 21% of women in the U.S. in any given year. Perinatal mood and anxiety disorders include depression, anxiety, panic disorder, obsessive-compulsive disorder, post-traumatic stress disorder and postpartum psychosis (Postpartum Support International, 2014). PMAD may pre-exist pregnancy or symptoms may develop during pregnancy or the postpartum period. 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). Perinatal mood and anxiety disorders have a profound, negative affect on women, neonates, families and communities. Women who are diagnosed with PMAD are less likely to bond with their baby, less likely to continue to breastfeed, and in cases of severe PMAD may commit suicide or infanticide (Glynn, Howland, & Sandman, 2017; Hoffman, Dunn & Njoroge, 2017; Galvin, Tabb, Melville, Guo, & Katon, 2011; Onah, Filed, Bantjes & Honikman, 2017). Infants born to mothers with PMAD are more likely to develop behavioral disorders (Center on the Developing Child at Harvard University, 2009).

Research Purpose and Hypothesis:

Perinatal mood and anxiety disorders (PMAD) impact communities that have few resources to screen, assess, diagnose and treat women during the perinatal period. The Council on Patient Safety introduced the Maternal Mental Health bundle in 2016 as an attempt to address this critical issue nationally (Kendig, Keats, Hoffman, Kay, Miller, Simas, et al., 2017). The bundle provides guidelines for delivering mental health services and offers valid and reliable instruments to screen women during the perinatal period for PMAD. These include the Edinburgh Postpartum Depression Scale (EPDS), the Postpartum Depression Screening Scale (PDSS), and the PDQ 9. However once a diagnosis of PMAD is made there are few interventions that have been developed to treat PMAD. The bundle guideline suggests referral to a psychiatric provider for further evaluation and treatment but, for complex reasons, there is often loss to follow up due to long wait times, childcare and transportation issues and a dearth of available providers. The purpose of this qualitative study, utilizing focus group data, was to explore awareness of signs and symptoms of perinatal mood and anxiety disorders (PMAD) and utilization of mental health services among pregnant and postpartum low-income minority women in an urban setting. The aim of the study

was to elicit information from study participants to develop educational programs to increase awareness of PMAD and improve utilization of services to treat PMAD.

Background/significance:

Women diagnosed with PMAD, including depression, anxiety and obsessive-compulsive disorder, are at greater risk for experiencing maladaptive thoughts and behaviors that can have a resounding and long lasting negative affect on the neonate and herself (Ford, Shakespeare, Elias, & Ayers, 2017). These include lack of interest in the well-being of the neonate, intrusive thoughts about harming the neonate, anxiety about the ability to provide care to the neonate, sadness, hopelessness and irritability. The severity, frequency and duration of maternal mood disorders vary and symptoms affect individuals differently. Signs and symptoms of PMAD include a sad or anxious mood, hopelessness, irritability, anhedonia, inability to focus or make decisions, hypersomnia or insomnia, appetite instability, physical symptoms including headaches, gastric upset, and lastly suicidal ideation and/or intent or infanticidal ideation and/or intent (Segre & Davis, 2016).

Design:

This qualitative study utilized 2 focus groups conducted with pregnant and early postpartum women (n=25) on the topic of PMAD. Data from focus groups can be helpful to confirm or reject beliefs and acceptance about topics and can be useful to generate a deeper understanding of complex issues from different perspectives. Findings can then be used to inform the development of programming to reach the target group. For this study, participants were recruited using flyers posted in perinatal services offices and in community centers that served mothers and families in an urban setting. Inclusion criteria included fluency in English, ages 18-44, currently pregnant or in the 1st postpartum year and ability to participate in a focus group for approximately 1 hour. The study was approved by the IRB prior to initiating recruitment. Participants were provided an incentive for participating in the focus group in the form of cash and reimbursement for travel. The study took place in the Northeast USA during the summer of 2017. The focus groups were moderated by the PI and a staff member of the perinatal services organization who served as the co-investigator of the study. Each focus group was audio recorded and transcribed verbatim. Questions that guided the focus groups included: Please tell us what you know about perinatal depression? How would you describe what perinatal depression feels/looks like? Tell us what you know about perinatal anxiety? What signs and symptoms might a woman experience if they had PMAD? Is there a difference between PMAD and general depression or anxiety? Tell us about services (if any) in your community to diagnosis and/or treat PMAD. What would help women utilize these services? What are barriers to utilization? Data were analyzed using the framework outlined by Krueger and Casey with the underlying assumption that focus groups can test the reality of assumptions that go into the development of programs.

Results:

In total, twenty-five women participated in 2 focus groups. The first focus group (n=14) was held in a conference room within the perinatal services network, was moderated by the PI and co-I and lasted approximately 75 minutes. The participants identified as Latina (n= 11) or other (n=5), ranged between ages 18-39 and the majority were within the first postpartum year (n=12). The second focus group (n=11) was held in a conference room of a housing unit for low income families, was moderated by the PI and co-I and lasted approximately 90 minutes. The participants identified as African-American (n=4), Latina (n=5), white (n=1) and other (n=1). One participant reported a current pregnancy with the remaining being < 1 year postpartum.

Conclusion:

In both focus groups the participants articulated the signs and symptoms of PMAD, which included sadness, anhedonia, hopelessness, hypersomnia, feeling isolated and irritable. They speculated that

contributing factors included lack of social support, lack of economic resources including adequate nutrition, housing and transportation. Participants reported being screened for depression during the pregnancy at least once but not during the follow up postpartum visit. Participants reported reluctance to report any symptoms of depression or anxiety due to the belief that Child Protective Services would become involved and they might lose custody of their child/children. Participants reported discussing their feelings with their partner or another family member. None of the participants sought professional help even when they knew they were depressed. These findings are critically important to inform best practices for reaching out to women during the perinatal period who may be at risk for PMAD. Nursing and interprofessional interventions to improve the accessibility of services for PMAD are increasingly important. Developing outreach programs that can address concerns about seeking assistance may impact both the rates of diagnosis and utilization of mental health services. Further studies should be conducted to evaluate the acceptance of mental health services among this community.

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