

Enhancing Postpartum Psychosis Care With Qualitative Research: Current Findings and Future Directions

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Postpartum psychosis (PP) is considered the most severe of perinatal mental health disorders, particularly when unrecognized or untreated. While affecting a relatively small number of individuals, with estimates ranging from 0.89 to 2.6 per 1,000 births,¹ PP is regarded as a psychiatric emergency necessitating immediate treatment and possible hospitalization. Individuals with PP may present with acute mania, depression, cognitive impairment, disorganized behavior, or lack of insight, in addition to delusions and/or hallucinations.² Diagnosis is complicated by the absence of a *DSM* classification.³ As this disorder is associated with an increased risk for adverse consequences, including suicide and infanticide,² and is typically characterized by rapid onset and deterioration, increased research informing effective and acceptable treatment is essential.

There has been an increasing recognition of the value of qualitative research to inform patient-centered health research. Qualitative methodology offers a distinct path to synthesizing the contexts in which PP occurs, experiences of treatment, and recovery processes. Moreover, qualitative analysis allows for a richer understanding of the PP experience than quantitative studies can alone provide, and may include multiple stakeholder perspectives (eg, individuals with PP, partners, and providers). The past decade of research on PP has thus unsurprisingly been characterized by an increased qualitative focus, particularly seeking to describe the lived experiences of individuals with histories of PP.

Enough literature has accumulated to warrant the first (and to our knowledge, the only) systematic review of qualitative experiences of PP, specifically those related to recovery, from the perspective of both individuals with PP and family members.⁴ Synthesizing 15 studies of 103 women and 42 family members, this review described the experience of PP as “unspeakable,” resulting in a disruption of sense of self and a challenge to identity. Recovery was cited as a nonlinear process of integrating and realigning the “old self and new self.” Family relationships and interactions with health care professionals were seen as both barriers and facilitators to recovery.

While this review provides a much-needed synthesis of the current qualitative literature on PP, it both directly and indirectly points to significant gaps that remain in the field. To date, little qualitative literature has focused on treatment-related experiences for PP. Such information would be particularly valuable for improving existing interventions, enhancing treatment engagement, and developing new treatment programs for individuals with PP. Understanding the lived experiences of patients is critical to determining how health care professionals can best provide effective and acceptable treatment.

Additionally, there is sparse research describing the experiences of health care professionals with respect to identifying and treating PP, which is important in ensuring timely diagnosis and treatment of the disorder. Qualitative research has not yet explored providers’ knowledge of

PP and whether barriers to diagnosis and treatment exist at an institutional level; such studies have been conducted on postpartum depression and have shed light on important issues.^{5–7} Researchers in the future may also explore the context surrounding onset of PP from a qualitative perspective. Little is known about socioecological factors that could be involved in the precipitation of a PP episode, and qualitative research offers an avenue to begin to explore such contextual and contributing factors to elevated risk for PP.

Finally, the generalizability of existing qualitative literature on PP is limited. The vast majority of studies included in the previously described review (12 of the 15 included studies) were conducted in European countries with primarily white, well-educated participants. The remaining 3 studies were online and conducted in the United States and Canada. Compared to mental health care in the United States, treatment in European countries is qualitatively different, with different levels of access to care, types of health insurance coverage, and cultural considerations than are seen in the United States; comparative qualitative research offers an avenue by which future researchers may explore the impact of different health care systems on PP treatment experiences. Furthermore, the participants included in the review largely had access to and received some level of treatment during their episode.

Wide racial disparities exist in perinatal mental health with respect to diagnosis, treatment, and long-term

outcomes. For example, data suggest that ethnic minority, socioeconomically disadvantaged, and unpartnered childbearing individuals are less likely to report being asked about their mental health during the perinatal period.⁸ Even when accounting for demographic and clinical factors, Black and Latina individuals are less likely to initiate treatment, receive follow-up treatment, or continue care for postpartum depression.⁹ Given low base rates of PP, data on racial and ethnic differences are not yet available. However, broader psychosis literature suggests that Black and Latino individuals are diagnosed with psychotic disorders at rates 3 to 4 times higher than their white counterparts,¹⁰ indicating a potential for higher rates of PP among racial and ethnic minority individuals. Relatedly, PP researchers must recognize the ongoing deleterious effects of stigma, bias, and structural racism, which adversely impact mental health diagnosis and treatment among communities of color. This is an important avenue to explore with respect to improvement of PP care.

Qualitative studies of PP are challenging to conduct for a number of salient reasons. Broad societal stigma against the disorder and oft-sensationalized media coverage of select PP cases may discourage some individuals from wanting to participate in research or identify with the diagnosis. Additionally, PP is relatively uncommon compared to other perinatal mental health disorders, requiring unique and targeted recruitment approaches. Despite this, qualitative research has the potential to fill numerous gaps in current understandings of the disorder. Integration of such methodology with quantitative studies (eg, via explanatory sequential designs or exploratory sequential designs) will be critical to mitigating the suffering associated with PP. Understanding the

lived experiences of PP can provide researchers with explanations of treatment-seeking behaviors, treatment preferences, and values and priorities in decision-making, all of which have the potential to inform current intervention efforts, facilitate recovery, and improve long-term outcomes for mothers and families.

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