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Citation for final published version:

Vaiphei, Kimneihat, Yaresheemi, Shivanand, Yang, Jessica M. K. , Di Florio, Arianna , Chandra, Prabha S. and Thippeswamy, Harish 2023. Formation of a stakeholder group of women with a lived experience of Post-partum Psychoses (PP) – Experience from a perinatal psychiatry service in India. *Asian Journal of Psychiatry* 84 , 103592. 10.1016/j.ajp.2023.103592

Publishers page: <https://doi.org/10.1016/j.ajp.2023.103592>

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Formation of a Stakeholder Group of Women with a Lived Experience of Post-partum Psychoses (PP) – experience from a perinatal psychiatry service in India

1. Introduction:

Health-care systems worldwide are increasingly emphasizing the value of participatory approaches (Tambuyzer et al., 2011.) The involvement of patients and their caregivers in health system policy and planning, service monitoring and research can contribute to the strengthening of mental health system (Semrau et al., 2016). Engaging persons with mental illness and their families/ caregivers can lead to more accessible and acceptable health services, enhance service development and improve the responsiveness of mental health services. It may also lead to better therapeutic relationships, improved self-esteem and confidence among users, greater empowerment to recovery, and increased service satisfaction (Crawford et al., 2002.); (Lempp et al., 2017) compared to traditional models of care. (Lempp et al., 2017). Additionally, such an involvement would also guide research into areas that are of concern to the stakeholders. Further, a stakeholder group helps to understand the community concepts of mental health, plan interventions, and examine the acceptability of planned interventions. Women with low literacy and from low income groups are often not part of service user groups and their views do not get visibility.

One such group whose voices need to be heard are women with postpartum psychosis. The postpartum period is a high-risk period for new and recurrent episodes, particularly of severe mental illness (SMI) (Smith et al., 2011). Postpartum psychosis (PP) is a severe form of postnatal mental illness, affecting 1–2 mothers in every 1000 deliveries. PP episodes typically present soon after childbirth and can have a significant adverse impact on the mother, baby, and wider family (Perry et al., 2021).

It is important to involve women who have recovered from PP in service planning and research as 'experts by experience' in identifying areas that need attention and representation. Keeping this in mind, the Perinatal Psychiatry Services at National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru, India initiated the formation of a stakeholder group for PP. This was done as part of a multicountry study on cross cultural conceptualisation of Postpartum Psychosis involving three countries – UK, Malawi and India. This paper will focus on the

process of forming a stakeholder group for PP comprising of women with lived experiences of PP and their family caregivers in an Indian setting.

2. Methods

2.1 Procedures:

Women and family members who obtained inpatient or outpatient care for PP at the Perinatal psychiatry services during the period of 2016 to 2022 were contacted over phone and invited to participate in the stakeholder group. While 44 of 138 women initially agreed to participate in the group meetings, thirty-eight women and twenty family caregivers finally took part (Figure 1). The reasons for non-participation were an unavoidable emergency at home (2 participants), lack of support from family to reach the hospital-(1participant), geographical distance- (2 participants) and financial constraints.

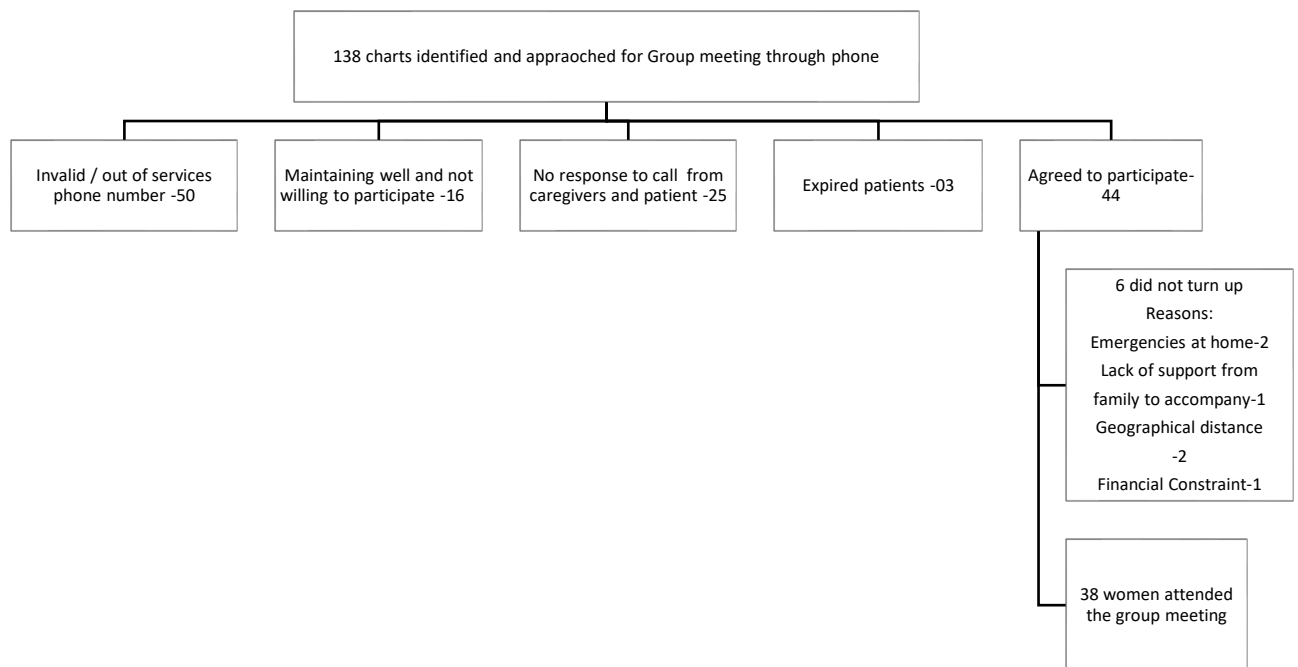


Fig: 1 Process of Involving the Participants

The Perinatal Psychiatric Service at NIMHANS, Bangalore is dedicated to helping the mother, the mother-infant dyad, husbands and families who need treatment, support and guidance for any mental health problem related to pregnancy or child birth. The stakeholder group meetings were held at the outpatient Perinatal Psychiatry Services, NIMHANS which functions every

Friday. The group meetings were held between September 2021 to January 2022. The participants joined group meetings on a date convenient to them and were provided with refreshments and the travel cost was reimbursed .

Written consent was obtained for both participation and audio recording of the meeting and the participants were free to withdraw from the group meeting at any point in time. The confidentiality aspect was discussed with the group members, and Institute Ethics Committee approval (IEC approval) was obtained. A total of 13 group meetings were conducted, in which 9 group meetings involved women with lived experiences of PP and 4 group meetings were with the family members involved in the care of woman during the PP episode. The meetings were held separately for women with PP and caregivers since women with PP expressed that they preferred to speak in the absence of relatives. The group meetings were conducted in the local languages and each meeting involved participation of 3-6 members depending on the language and logistics.

The group facilitator (SY- a psychiatric social worker trained in conducting groups) introduced the objectives of the group session to stakeholders, explained the need for involvement of stakeholders in terms of advice, sharing ideas on lived experiences, working together to design, evaluate or undertake research and services relevant to the needs of the stakeholders. Each group ran for approximately 90 minutes with breaks. The group members were encouraged to talk about their willingness to be involved in a PP stakeholder group and their thoughts related to the same.

2.2 Analysis

The discussion in the group meetings was transcribed and translated from the local language into English for analysis. KV, PC and HT analysed and coded the transcripts for emerging themes. Any differences were resolved by consensus.

3. Results

The mean age of women with PP was 28.9 years (SD=3.4), 22 (57.9%) women had less than 10 years of education. The family group consisted of spouses, mothers, mothers in law and siblings. Women with PP gave informed consent and identified the family member who needed to be contacted based on how much they knew about her illness. The mean age of

caregivers was 35.7 years (SD-4.4) and 13 (65%) had less than or equal to 10 years of education. Majority of the participants were from rural areas 28(73.7 %).

Of the 58 participants, 23 women and two family members expressed their willingness to participate in future stakeholder meetings. The reasons for non-willingness to participate for future stakeholder meeting included geographical distance (5 participants), a perception that one is not well-educated and hence may not be able to contribute to the stakeholder group (6 participants), and an inability to take time off from routine work (4 Participants).

Thematic analysis of the transcripts regarding views about stakeholder meetings found the following- nearly all the participants preferred in-person face to face group discussions rather than online meetings citing poor mobile network, lack of internet facilities and absence of privacy at residence. Some of the themes identified by the participants for future research and services included - treatment adherence, educating the community regarding perinatal mental health issues, and the need for caregiver’s support to the women with PP. Few excerpts of the group meetings are mentioned below.

Ms. A, 23 years age who had experienced an episode of postpartum psychosis 2 years ago said "I feel it is better to have in person session, I am uncomfortable speaking about my issues in front of my family members"

Ms K, 28-year-old who experienced postpartum psychosis 4 years back, said "I do not have internet access to my phone; I prefer to discuss in person".

Ms G, 27 years old who experienced postpartum psychosis 2 years ago said "Many (patients) are unaware of the illness and treatment; they would stop the medication without informing the doctor, which often leads to relapse".

Mr S, 32 years old spouse of woman with PP said "I think the focus should be on raising community awareness about perinatal mental health because, particularly in rural area people are unaware of mental health problems during pregnancy and childbirth, and many women face complications during pregnancy. There is a need for awareness campaign and provision of services. People should not undergo same suffering as experienced by us".

The Table 1 compiles the themes identified through group discussions with stakeholders.

Sl no	Theme
1.	Preference for in person group discussions
2.	Challenges to Treatment Adherence

3.	Community awareness and need for education regarding perinatal mental health issues
4.	Willingness to be part of the future activities of the stakeholder group

Table 1: Themes identified during the group sessions

Further, participants expressed their willingness to contribute to the early detection, treatment, and other promotional activities related to perinatal psychiatric illness in their respective communities. Participants mentioned that they were glad to share their views during the group meetings and were able to also learn more about PP from other group members. They found the concept of a stakeholder group worthwhile and reported that such meetings would contribute to promotion of the community's mental well-being in general and would be helpful for women with mental health problems during the perinatal period.

4. Discussion

Involvement of stakeholders and those with lived experience is being increasingly recognised as critical to service development and identifying research priorities (Grill, C., 2021, Stanley et al., 2021). This is particularly important in countries where marginalised groups such as women from rural areas and those with low literacy are usually not part of decision making in health services. In fact there are hardly any published examples from India of people with lived experience of mental illness being involved in service or research projects. While the response of this first attempt in the country of forming a stakeholder group of women with PP was quite encouraging, the team needs to find ways of handling differing language preferences by having more homogenous groups and also facilitating dialogue between people with different educational and income status using more than one facilitator or translations. There needs to be earmarked funding to support travel and refreshments for such stakeholder involvement to ensure adequate gender representation and persons from rural and urban areas as well as all educational and income strata. The urban and rural ratio of the group participants reflects the demography of inpatients who obtain services of the Mother Baby Unit at our hospital. (Chandra et al., 2015)

Women with PP have a difficult experience of becoming ill at a very critical period in their lives and suggestions stemming from their lived experience are very important to understand the unique service needs that they may have, which may not always be identified by

professionals. In addition to identifying service needs, such a stakeholder group may also help in refining research questions, advising on consent procedures and highlighting socio cultural issues in research including community engagement and sharing of research findings with study participants.

We could not make a direct comparison with other studies as there is a paucity of literature on women with lived experience of postpartum psychosis being involved, which highlights the need for further research.

Involvement of women with PP and their caregivers as stakeholders in mental health decision-making appears feasible in a LMIC setting. We hope that there would be a replication of our effort, and stakeholders would be proactively involved in various aspects of research and services for women with mental health problems during perinatal period.

Funding

This study was supported by a research fund- Global Challenges Research Fund, grant number: JA1130RD24.

Declaration of Competing Interest

All authors report no known conflicts of interest in regard to this study.

Acknowledgement

Cardiff University , GCRF and Wellcome Trust grant 217500/Z/19/Z.

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