Perinatal mental ill health - the experiences of women from ethnic minority groups

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Abstract

Objectives **This study aimed to investigate ethnic minority women's experiences and opinions of perinatal mental health problems and the provision support services.**

Methods **An exploratory survey was undertaken using a questionnaire. Quantitative data were analysed using descriptive statistics and a simple thematic analysis was used for the qualitative data. A total of 51 responses from women of 14 different ethnic minority backgrounds were analysed.**

Findings **Women from minority ethnic groups face barriers to seeking help for perinatal mental ill health as a result of ongoing stigma, the poor attitudes and behaviours of health professionals and inappropriately designed services.**

Conclusions **Future interventions should focus on providing adequate cultural competency for health professionals and ensure that all women are able to access culturally appropriate spaces to talk and be listened to in community settings and wider services.**

Keywords

Perinatal mental health | Ethnic minority | Experiences | Women

Mental health disorders are among the most common morbidities experienced during the perinatal period (Megnin-Viggars et al, 2015). These disorders may be pre-existent or they may develop during the perinatal period. They include depression, anxiety, post-traumatic stress disorder, eating disorders, personality disorders, bipolar disorder, affective psychosis and schizophrenia (Howard et al, 2014; Jones et al, 2014).

Perinatal mental health is a significant risk factor for maternal mortality. Recent evidence suggests that 23% of women who died in the postnatal period suffered from mental health disorders, and suicide is now the second leading cause of maternal death in the UK (Knight et al, 2016). Adverse health and social experiences associated with perinatal mental health are not limited to mothers. They can also result in poor pregnancy outcomes including preterm birth, low birthweight and poor maternal-infant interaction, which is associated with child behavioural, emotional and cognitive problems and reduced educational attainment (Stein et al, 2014; Myers and Jones, 2018). Maternal mental ill health also has a devastating and long-lasting impact on families.' lives, as well as having considerable cost and resource implications for health services (Kingston et al, 2012; Howard et al, 2014; Prady et al, 2016; The Mental Health Taskforce, 2016).

Perinatal mental health has been recommended as a priority area for care providers and commissioners to pay specific attention to (NHS England, 2016a; 2016b). The Five Year Forward View for Mental Health report recommended further investment in services to ensure that at least 30 000 more women have access to evidence-based specialist mental health care by 2020/21, which should include access to psychological therapies and specialist community or inpatient care (The Mental Health Taskforce, 2016). However, fewer than 15% of localities in the UK provide specialist community perinatal services for women with complex or severe mental health conditions (The Mental Health Taskforce, 2016).

The Five Year Forward View for Mental Health report also highlighted ongoing racial inequalities in access to mental health services, unequal experience of this care and noted that these inequalities have persisted despite the end of the five-year Delivering Racial Equality programme (Department of Health, 2009; The Mental Health Taskforce, 2016). In the UK,

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ethnic minority groups have a higher burden of mental health disorders compared to the white population (Prady et al, 2016; Anderson et al, 2017). While the reasons for these disparities are not fully explained, for ethnic minorities, exposure to psychosocial triggers such as deprivation and social isolation (Bolton et al, 1998; Karlsen et al, 2005), discrimination (Wallace et al, 2016), being a migrant, refugee or asylum seeker (Onozawa et al, 2003; Howard et al, 2014), and inequity in healthcare access and support are being experienced (Latif, 2014; Prady et al, 2016; Anderson et al, 2017; Watson et al, 2019).

Therefore, it is of paramount importance to explore the experiences of women from minority ethnic and migrant backgrounds, to allow a better understanding of the experiences of these women regarding perinatal mental health and services. This can inform the development of future interventions to reduce inequalities in perinatal mental ill health, and to meet the needs of women from minority ethnic groups.

Objectives

This study aimed to investigate the experiences and views of ethnic minority women with perinatal mental health problems and support services.

Methods

An exploratory survey using a questionnaire was developed in consultation with maternity user group representatives. Our initial intention was to conduct focus groups with ethnic minority women; however, recruiting women to participate in group discussions was very difficult. Hence, we adapted the focus group questions into a survey questionnaire which was generated in both paper format and as an online version, using the cloud-based software, Survey Monkey. The survey was piloted by two women and was considered to be understandable and no amendments were suggested.

A convenience sampling strategy was applied and the questionnaire was distributed between 23 November 2017 and 21 December 2017 through a maternity service user and parenting Facebook group, which was moderated by the maternity user group representative member of the research team, RG. The survey was advertised in areas of high ethnic diversity in a large city in the north of England with the option to complete the survey face-to-face.

The questionnaire consisted of a mixture of question types, including free-text questions and fixed-response options. Demographic data was collected, including ethnicity, age, gender, participant's place of birth, length of time living in the UK and whether the participant had children. Survey questions covered the following topics: awareness of support for perinatal mental health problems, experience of support needs and accessing support and opinions about how support should be developed in the future.

Information was provided and consent was assumed inherent for the participants who completed the online questionnaire voluntarily. Participant information sheets were provided and a discussion about the study was undertaken with the women who preferred to undertake the survey face-to-face, before obtaining written informed consent.

Data analysis

The data were entered in Microsoft Excel and logical checks and data cleaning were carried out along with double-checking inconsistencies for clarification. The quantitative data were analysed in SPSS v.24.0, where simple descriptive statistics were calculated for the demographic data and for closed-answer questions. Qualitative data from the open-answer questions were managed using NVIVO v11. Simple thematic analysis was undertaken by coding the data after familiarisation, and deriving categories and themes inductively.

Results

There were a total of 60 responses to the survey; however, 9 women who responded were of white British ethnicity and the survey did not allow them to make further responses. Of the 51 included responses, 9 were completed face-to-face and 42 were completed through the online version of the survey. The characteristics of the participants can be seen in *Table 1*. The participants represented 14 different ethnic minority backgrounds, the largest groups being Pakistani and Indian, at 21.6% and 19.6% respectively. Of the 44 participants who reported their country of birth, 27 (61.4%) had been born outside the UK, and the majority of the participants, 25 (55.6%), had lived in the UK for less than 10 years. Most of the participants were aged between 25–31 years and 32–40 years, and only a small number were aged over 41 years or younger than 25 years.

Only 46 (90%) of the participants responded to the remaining survey questions about perinatal mental health and support services. These participants were all female and all had children, except one woman who reported that she was pregnant at the time of the survey. A total of 40 (87%) of these women reported that they had experienced poor perinatal mental health themselves, and the remaining 6 women (13%) reported their experiences with friends or relatives with poor perinatal mental health or preferred not to say whose experience their opinions were based on.

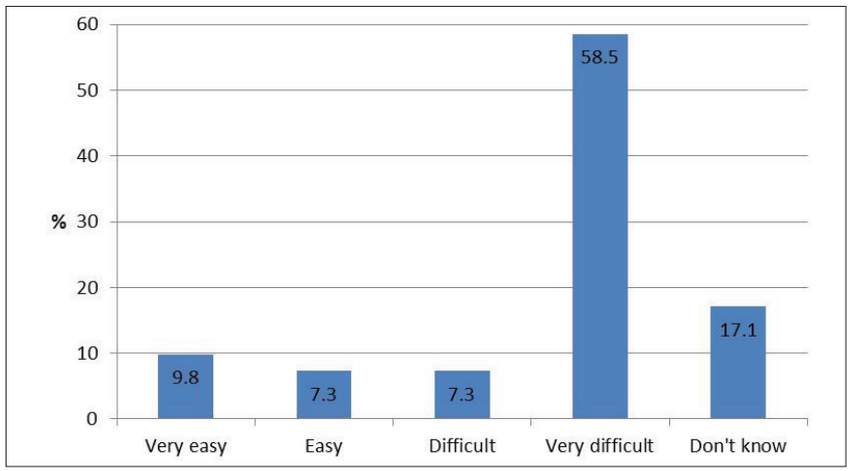

Figure 1. Women accessing support for mental health problems during pregnancy/shortly after birth

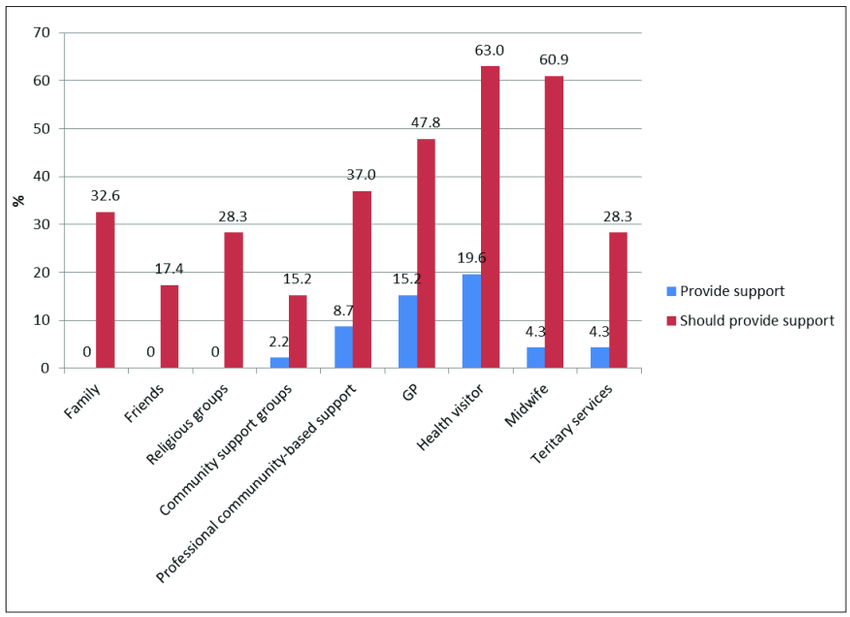

Figure 2. Improving Access to Psychological Therapies (IAPT) service and community support groups

Support for perinatal mental health problems

Most women (58.5%) reported that accessing support for mental health problems during pregnancy or shortly after birth was very difficult (*Figure 1*). The majority (67.4%, *n*=31) of the women were not able to identify any sources of support for women with perinatal mental health problems. Sources of support that were identified by the remaining women included their general practitioner, health visitor, midwife, tertiary perinatal mental health service, community-based professional support including Improving Access to Psychological Therapies (IAPT) service and community support groups (*Figure 2*). The sources of support that most women agreed should be available for women with perinatal mental health problems were the health visitor (63.0%, *n*=29), the midwife (60.9%, *n*=28) and their general practitioner (47.8%, *n*=22).

Experiences of support

Analysis of the qualitative data in the open-ended survey questions revealed three themes about women's experiences of perinatal mental health problems and support services: suffering in silence, the need for a safe space to talk and to be listened to, and what about women like me.

Suffering in silence

The women reported that they found it very difficult to talk about how they were feeling when they were suffering with perinatal mental health problems:

> ***'I felt bad but couldn't tell anyone, I felt bad for feeling bad.' (P14, Pakistani woman)***

Some of the women explained that cultural expectations and stigma associated with mental health problems resulted in them staying silent:

> ***'I couldn't tell anyone as they thought I should feel blessed.' (P42, mixed white and black Caribbean woman)***

> ***'My community hates discussing such things! It's seen as a weakness … or a complaint.' (P.50, black African woman)***

Some women who wanted to talk about their problems encountered a lack of support and found that no one was listening:

> ***'I asked for support but got none.' (P27, black African woman)***

The need for a safe space to talk and to be listened to

The women highlighted the need for support that enables women with perinatal mental health disorders to talk and feel listened to, so that someone knows about how they are feeling. Women who had the opportunity to talk about their feelings found this to be an important and positive experience:

> ***'…just talking … was really helpful.' (P18, black Caribbean woman)***

The women highlighted that health professionals should be alert, kind, caring, trained and willing to

talk about perinatal mental health issues with all women. Raising the topic of mental health during the earliest stages of pregnancy, or before problems start, was considered to be important. This would ensure that the women had information and awareness about perinatal mental ill health and would feel more comfortable talking about these problems if they began to experience them:

> ***'Being told before how you can feel is really important … My midwife talked me through all of it before I had my baby. I knew I might have ups and downs and could talk to her after when things went really bad in my head.' (P1, mixed white and Asian woman)***

The women also wanted to be able to talk to other women who had experienced the same problems:

> ***'To meet others who are also going through similar experiences.' (P28, Indian woman)***

They identified that couples, families and communities need to talk about perinatal mental health issues, and that education about perinatal mental ill health was vital to enable this:

> ***'There should be support for…families to help them think about how to be happier as a family.' (P32, Pakistani woman)***

What about women like me?

Women identified the impact of language barriers and health professional's prejudice on the women's ability to access support:

> ***'I do think that language may be a HUGE barrier to seeking help … (the) ingrained prejudices of healthcare professionals…play a huge role in the experiences of pregnant ethnic women. Unfortunately, racism does also play a role.' (P51, Indian woman)***

Some women who accessed support for their perinatal mental health problems described it as culturally inappropriate and inaccessible, as it was dominated by a majority of white women and failed to account for their cultural needs:

> ***'It was just group therapy with white women, no-one like me.' (P13, Indian woman)***

> ***'There is little specialised support for myself or my friends, the needs we have are different and the right level of respect for our needs is not being given.' (P34, Arab woman)***

The women identified the importance of support that is accessible and takes account of the needs and preferences of women from different cultures, and that this would require staff education and service redesign:

> ***'It should be made for all cultures.' (P41, mixed white and black African woman)***

> ***'There should be more help for people like me.' (P10, mixed white and black African woman)***

Discussion

There is a large body of evidence that most women who are suffering with perinatal mental health problems simply want the opportunity to talk about how they are feeling with someone who will listen to them without judgement, to feel that the nature and extent of their problems have been understood and to be reassured that there are other mothers who may experience similar feelings (Dennis and Chung-Lee, 2006). The ethnic minority women in this study echoed the desire to have the opportunity to talk and to be listened to, and as in wider studies, desired a connection with other women living through similar experiences (Raymond, 2009; Templeton et al, 2010; Gardner et al, 2014).

However, social stigma associated with mental ill health and cultural expectations impacted on the ability of women in this study to seek support and a place to share their feelings. Stigma is a process which involves labelling, separation, stereotype awareness, stereotype endorsement, prejudice and discrimination in a specific context where social power can be exercised to detrimentally affect members of a social group (Link and Phelan, 2001). Stigma associated with mental ill health leads to internal feelings of shame or embarrassment, social judgment or rejection, people being unwilling to disclose their problems, masking their symptoms and finding it difficult to talk to professionals (Clement et al, 2015) and is a well-documented barrier to people engaging with mental health services (Bates and Stickley, 2013; Tucker et al, 2013; Thomson et al, 2015). Stigma associated with mental ill health disproportionately affects people from ethnic minority backgrounds (Clement et al, 2015) creating a vicious cycle of loneliness and exacerbating the social isolation.

In certain cultures, family members actively discourage help-seeking for mental health problems, as it is unacceptable to admit to depressive symptoms or discuss such difficulties external to the family context,

Key points

- Women from ethnic minority backgrounds find accessing support for mental health problems during or shortly after birth very difficult
- Many women cannot identify any sources of support for women with perinatal mental health problems
- Women find it very difficult to talk about how they were feeling when they were suffering with perinatal mental health problems and this is influenced by cultural expectations and social stigma
- Women with perinatal mental health problems need a safe space to talk and feel listened to
- Support for women with perinatal mental health problems should be accessible to all women, and take account of the needs and preferences of women from different cultures

CPD reflective questions

- What are the risks of perinatal mental ill health for mothers and their families?
- What challenges do women from ethnic minority backgrounds face regarding access to perinatal mental health services?
- How can healthcare professionals best support women from ethnic minority backgrounds when it comes to optimising perinatal mental health?

as this would risk stigmatisation of the entire family (Dennis and Chung-Lee, 2006; Clement et al, 2015). The women in this study identified a need for wider family and community education interventions to raise awareness and change the cultural understanding of poor mental ill health, which may begin to address the powerful effect of social stigma. However, it is also important that services are designed to minimise the stigmatising effect of mental ill health, and this includes ensuring safe spaces that maintain confidentiality (Clement et al, 2015).

The women in this study also expressed that they wanted health professionals to be willing to discuss perinatal mental health and to offer information and support, as well as allowing opportunities for women to talk about their related issues and feel that they are being listened to. They found accessing support for perinatal mental ill health difficult due to poor encounters with health professionals. This resonates with wider evidence that health professional's attitudes often present a barrier to accessing support as they fail to ask about perinatal mental health problems (Edge and MacKian, 2010; Raymond, 2009; Edge, 2011; Redshaw and Henderson, 2016) are not interested in these problems (Parvin et al, 2004), fail to recognise women's symptoms (Templeton et al, 2010) or dismiss them and are perceived to discriminate against the women account of their ethnicity (Wittkowski et al, 2011).

Women from minority backgrounds are less likely to be asked about mental health during and after pregnancy than white women, and they are less likely to be offered treatment and receive support (Redshaw and Henderson, 2016). It is important that health professionals caring for women in the perinatal period do not defer responsibility for conversations about mental ill health with ethnic minority women (Noonan et al, 2017) and that care for perinatal mental health problems is in line with the requirements of the Equality Act (2010) which states that NHS treatment and care should be equitable and no person should be discriminated against on the basis of their ethnicity.

Health professionals, including midwives, general practitioners and health visitors need appropriate education and training to ensure they are fully equipped to raise and discuss perinatal mental health and wellbeing, so that they are able to identify and provide appropriate care for women with perinatal mental health problems (King et al, 2012). They also need access to clear referral pathways and a coordinated multidisciplinary team approach to ensure that support is available for women who need it, and that this support is linguistically and culturally appropriate (Knight, 2014; Thomson et al, 2015; Williams et al, 2016).

Strengths and limitations

This survey had a relatively large response rate from women from a wide range of ethnic backgrounds. However, the survey was only distributed in one large city in the north of England, and therefore it may not be a nationally representative sample. Using a survey reduced the depth of the qualitative data that the authors were able to collect; however, this method was adopted in response to the difficulty in recruiting ethnic minority women to participate in focus groups. Difficulty recruiting members of ethnic minority groups to participate in research about mental health is widely acknowledged (Brown et al, 2014). The authors are aware of some research-related barriers to participating in this study (Waheed et al, 2015), which include the survey only being available in English which may have excluded non-English speaking women or women with poor English literacy.

The women who completed the survey face-to-face expressed their anxiety about their family and community becoming aware of their participation in the study due to the stigma associated with mental health problems in their community. As this project had a short time-frame, the authors were not able to employ strategies to build trust with the

local community or to address the stigma related to participating in the face-to-face research (Waheed et al, 2015). However, providing an online option for survey completion enabled women to participate in the research anonymously, which was a unique feature of our study and resulted in a relatively large number of women sharing their experiences without fear of being stigmatised or exposed. This provided rich insight into the lived experiences of perinatal mental disorders and access to support among women from a wide range of ethnic backgrounds.

Conclusion

Women from minority ethnic groups face barriers to seeking help for perinatal mental ill health as a result of ongoing stigma, the poor behaviours of health professionals and inappropriately designed services. Healthcare providers should ensure that all women are able to access culturally appropriate spaces to talk and be listened to in community settings and wider services. Appropriate training for health professionals should be provided to facilitate the provision of culturally sensitive and compassionate care. Future interventions should explore the creation of safe spaces for mothers suffering or at risk of perinatal mental ill health including peer support, virtual networks and digital solutions. **BJM**

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