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# Family members' experiences of supporting black and South Asian women with perinatal mental illness: a qualitative study in the UK

Sarah Bicknell<sup>1,2</sup>, Nikolina Jovanović<sup>3,4,9\*</sup>, Jelena Janković<sup>1</sup>, Katy Packer<sup>4,5</sup>, Maev Conneely<sup>3,4,6</sup>, Kiren Bains<sup>1</sup>, Rose McCabe<sup>7</sup>, Stefan Priebe<sup>7</sup> and Alex Copello<sup>1,8</sup>

## Abstract

**Background** Women from Black and South Asian backgrounds with perinatal mental health difficulties face significant barriers to accessing healthcare. Clinical guidelines recommend that services collaborate with families, as they not only influence women's decisions to seek help and engage with care but also serve as a vital source of support. However, family members' experiences in providing this support remain poorly understood. This study aims to address this evidence gap.

**Methods** Individual semi-structured qualitative interviews were conducted with family members of Black and South Asian women who had experienced moderate to severe perinatal mental illness. The interviews explored the family members' experiences, the personal impact of their relative's condition, and their perspectives on accessing help and support. Interview transcripts were analysed using framework analysis, by a multidisciplinary team including psychiatrists, psychologists, methodologists, and people with a lived experience of perinatal mental illness.

**Results** Fifteen family members of women with perinatal mental illness were interviewed; twelve husbands and/or partners, and three Mothers and/or Mothers-in-Law. Three themes were identified: (1) Recognising and understanding their relative's perinatal mental illness was important to make sense of the situation (2) High emotional cost of supporting a relative with perinatal mental illness and (3) Varied experiences and expectations of services, with opportunities for improvement. Family members described how their relative's illness had a pronounced negative impact on their own physical and mental health and wellbeing, and on relationships within their families. Whilst many family members felt listened to and well supported by services, several barriers that prevented or delayed getting professional support were identified. Families would value improved communication, more information and proactive care from perinatal mental health services.

**Conclusions** This paper offers valuable insights into perinatal mental illness for Black and South Asian women from a family perspective. Despite individual experiences being varied and wide-ranging, the suggestions for service improvement were congruent and often repeated, indicating a widespread need for a greater awareness and wider support for the family members of women in perinatal services, who are often struggling themselves.

\*Correspondence:  
Nolina Jovanović  
n.jovanovic@qmul.ac.uk

Full list of author information is available at the end of the article



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**Keywords** Perinatal mental illness, Mental health, Family, Carers, Carer wellbeing, Ethnic minorities, Framework analysis, Qualitative study

## Background

The perinatal period is defined as the period during pregnancy and the first year after giving birth [1]. Mental health problems during the perinatal period are estimated to affect around 20% of women and range from common mental health problems (mild-moderate depression and anxiety) to severe mental illness (such as postpartum psychosis) [1, 2]. Despite higher rates of perinatal mental illness in ethnic minority groups [3, 4], fewer women from these groups access treatment for perinatal mental illness [3, 5]. A recent study conducted as part of the current project identified Black and South Asian women as being particularly vulnerable: more likely to be admitted against their will, and less likely to access routine perinatal mental health services [5].

Women experiencing perinatal mental health difficulties need support from their partners, extended families, and healthcare services to aid their recovery. Jackson et al. [6] identified three types of support that women especially value from their extended family: companionship, practical support, and emotional support. Indeed, families may be an important influencing factor in accessing mental health services during this time - partners and family members are often the first individuals that women talk to about their mental health difficulties [7, 8], and for many they are a more frequent source of help and support than healthcare professionals [9]. Partners can also have an important role in increasing the likelihood that women seek professional support for their mental illness- encouragement from partners is shown to be linked to increased professional help-seeking in physical health as well as mental health [10, 11]. It is also important to recognize that women's relationships with partners and family members are not always positive, particularly in cases of domestic abuse and violence. For some women who are experiencing mental health difficulties, their own cultural and family beliefs (for example fear, shame and stigma regarding accessing mental health services) can be a barrier to accessing services [12, 13]. Furthermore, perinatal mental health services often focus on the needs of mothers and their babies, leaving partners and families marginalised [14] and missing the opportunity to utilise this important source of support.

The role of partners and extended families in the lives of women from ethnic minority backgrounds experiencing mental health difficulties has received little attention so far. In many South Asian families, the traditional dyadic co-parenting unit is expanded to include other family members living in the same household. The extended family, particularly grandmothers and

grandmothers-in-law, plays an essential role within the family unit [15]. They provide significant support and care for their grandchildren, often influencing child-rearing practices [16] and sometimes taking on important co-parenting responsibilities [15]. Despite extended families frequently sharing the same home and being directly involved in the care of babies, research exploring their experiences and perspectives has been limited, with much of the focus placed on families with two parents [16]. This approach overlooks diverse family structures, including multi-generational homes, single-parent families, and co-parenting arrangements involving multiple caregivers.

This research aims to address this evidence gap by exploring the experiences of partners and wider family members, with a specific focus on being a family member of women from ethnic minority backgrounds with perinatal mental illness in the UK. Results of this research will be relevant for organisations offering perinatal mental health support, particularly NHS perinatal services, because supporting partners is a key area of service development - they are expected to offer fathers and partners of women accessing services an assessment for their own mental health and provide appropriate signposting to support as part of the NHS Long Term Plan [17]. Results of this study will provide a helpful guide on how to shape that support for partners of Black and South Asian women, based on what they themselves feel would help them.

The authors recognise the use of different terminology in services and in research literature. For consistency in this paper, we will use the term 'family member' to refer to the participants- who may identify as partners, carers, caregivers, or supporters. We use the term 'relative' to refer to the women who have experienced perinatal mental illness. Perinatal Mental Health Services (PMHS) refers to National Health Service (NHS) secondary perinatal mental health services in the UK, which includes community care and inpatient care (including Mother and Baby Units; MBUs). It is also important to acknowledge that not all pregnant and lactating individuals suffering from perinatal mental illness identify as women or as mothers.

## Methods

### Aim

This qualitative interview study focused on family members' who had experience of supporting a relative with perinatal mental illness. Two research questions guided the analysis: How did family members experience

supporting a relative with perinatal mental illness? How did family members of someone receiving support from perinatal mental health services experience these services?

### Design and setting

Individual semi-structured interviews were conducted with family members of Black and South Asian women who had experienced moderate to severe perinatal mental health problems within the last two years. Family members did not have to be accessing any kind of support or healthcare service themselves. This study was nested within a wider study aiming to investigate and improve the acceptability and accessibility of perinatal mental health services to Black and South Asian women in the UK (the PAAM Study; the protocol can be found on the Open Science Framework here: <https://osf.io/s94bp/>). The PAAM study has previously reported on women's views and experiences of perinatal mental health services [18], women's perceived barriers to accessing services [13] and healthcare professionals views of service acceptability and accessibility [19]. The study was approved by Health Research Authority and Health and Care Research Wales by London–Queen Square Research Ethics Committee, Ref:19/LO/1830, and all methods were performed in accordance with the relevant guidelines and regulations.

### Participants and recruitment

The study participants met the following eligibility criteria: (1) participants needed to be related to, or supporting, a Black or South Asian woman who had experienced moderate to severe perinatal mental health problems, (2) aged 16 or above, and (3) were willing and had capacity to give informed consent. Participants were recruited through their relatives, who were the Black and South Asian participant mothers who took part in the wider PAAM research project, but the family member participants could be from any ethnic background. Interpreters were available if required. The mothers included in the PAAM study were identified through NHS perinatal mental health services and third sector organisations in the UK. They were asked to suggest a person (family member or friend) who had provided support to them through their perinatal mental illness, and to invite the person to participate in the current study. An information sheet was provided and a consent to contact form was completed if women agreed for their family member to be approached by the research team. A maximum of one family member per participant was interviewed. If women identified more than one individual, the person who they felt was the most important source of support during their mental health difficulties was approached first.

### Materials

A semi-structured interview topic guide was used for data collection (see Supplementary material). This was co-developed by the research team and lived experience advisory panel, who all had lived experience of perinatal mental illness, and identified as being from a Black or South Asian background. Interviews explored family members' experiences and personal impacts of living with, and supporting their relative who had perinatal mental illness, and their views on accessing support and help.

### Data collection

Interviews were conducted via online video calls and over the phone between July 2020 and August 2021. Interviews could not be conducted in person due to COVID-19 restrictions. Prior to the interview, the interviewer obtained informed consent and completed a demographic information sheet with participants. All participants were reimbursed with a £30 shopping voucher for their time. The interviews were conducted by one of four study researchers: SB (Female, Research Fellow), KP (Female, Research Assistant), HKM (Female, Research Assistant) and AS (Female, Peer Researcher). AS was a peer researcher with lived experience of perinatal mental illness. The role of the peer interviewer was to serve as a bridge between the researchers and the participants, facilitating good rapport, capturing lived experiences, and ensuring a comfortable and trusting environment for sharing experiences. AS received comprehensive training and regular supervision in qualitative interviewing and attended weekly group supervision meetings with the wider team.

### Sample size

The sample size was determined based on several factors: the need to capture a wide range of ideas, practical considerations for completing the study within the given timeframe, and established guidelines for sample size in qualitative analysis. It has been suggested in a relatively homogeneous sample that saturation often occurs around 12 participants [20]. Additionally, we were limited to interviewing family members whose relative had participated in the broader project. With a sample size of 15, we felt confident that we achieved adequate coverage, and broad consensus within themes was achieved.

### Analysis

Interviews were audio recorded, transcribed, and anonymised. Transcripts were then uploaded into NVivo for management and analysis. Framework Analysis was used, which is an applied systematic qualitative method, well suited to shape policy and service developments [21]. The team followed the five steps of Framework Analysis

outlined by Ritchie and Spencer [21]. After '*familiarization*', the '*initial thematic framework*' was developed based on initial interview transcripts (KP, HKM), and once it was felt to broadly capture the data, all further transcripts were indexed and matrixed (KP). '*Indexing*' involves systematically applying labels, or codes, to segments of the data based on the emergent themes identified in the earlier stages of analysis. It is a structured way of categorizing data for easy retrieval and interpretation. It involves identifying themes, segmenting the data, applying codes and cross-referencing. '*Matrixing*' (or charting) involves organizing the indexed data into a structured format- a matrix or table. This step allows for a visual representation of relationships, patterns, and variations in the data. Stages of matrixing involve developing a framework matrix (a table where rows represent individual participants, and columns represent key themes or sub-themes identified during indexing), populating the matrix, and comparative analysis. Two researchers (SB, KP) then met weekly to identify, review and develop themes collaboratively from the data during the process of '*Mapping and Interpretation*' where the data was synthesized to identify key findings, patterns, and implications, and explore connections between the themes to build a coherent narrative. The themes were iteratively reviewed and revised by the wider study supervisory team JJ (Female, consultant perinatal psychiatrist), AC (Male, professor in psychology and consultant clinical psychologist), MC (Female, research assistant), NJ (Female, clinical reader in perinatal psychiatry and consultant perinatal psychiatrist), RC (Female, professor of clinical communication), and the lived experience advisory panel. All team members received comprehensive training in qualitative interviewing and framework data analysis.

### Positionality and reflexivity

The multidisciplinary research team working on this project comprised researchers with backgrounds in psychology (SB, KP, MC, KB, RC, AC) and psychiatry (JJ, NJ, SP). All had previous experience of working within clinical mental health services, including two clinicians currently working with NHS perinatal mental health services (JJ, NJ). The team had a variety of personal experiences with regards to ethnicity and migration, including first generation migrants to the UK and people from minority ethnic backgrounds in the UK. Reflexivity was prioritized throughout the recruitment and analysis process, with careful consideration of how individual positions could influence the research. Further details of researchers involved is given in supplementary materials. While the core research team was predominantly female and of white ethnicity, efforts were made to mitigate potential biases by engaging with wider supervision and

collaborating with the lived experience advisory group to ensure a balanced and inclusive approach to the analysis, and that these varied perspectives and voices informed discussions about the themes.

### Patient and public involvement

As part of the wider research project described above, a lived experience advisory panel was formed, and met regularly throughout the project. The Lived Experience Advisory Panel (LEAP) included seven members all identifying as from South Asian or Black backgrounds: six with lived experience of perinatal mental illness and one carer. All members received training in data analysis and interpretation from the research team. During the data analysis phase of the project, they met three times with the research team to discuss data. Their input was vital in shaping data analysis. By involving them in this way, we ensured their perspectives were fully integrated before the study findings were finalised.

## Results

### Participants

15 family members were interviewed, including family members of women that accessed NHS perinatal mental health services ( $n=10$ ) and those that did not access NHS perinatal mental health services ( $n=5$ ). All interviews were conducted in English, and participants resided in Birmingham or London in the UK. The demographic characteristics of the sample are given in Table 1. The interviews ranged in length from 24 min to 62 min ( $M=41.04$ ,  $SD=10.75$ ).

In the detailed descriptions of the data given below, the terms used reflect the relationship to the person with perinatal mental illness, not to the infant. The term 'partner' will be used to identify all quotes made by husbands and partners of women with perinatal mental illness, and the term 'mother' will be used for both women's mothers and mothers-in-law (i.e. grandmothers to the new infant). This will ensure there is no risk participants could be identified due to small numbers.

### Themes

Three main themes were identified in the analysis. A summary of the themes and related subthemes is given in Table 2. The themes focus on the experiences of the family members and the care they received, and were identified from the data that directly addressed the research questions. Other areas that were covered in the interviews (for example comments on how their relative felt about services) will be reported elsewhere.

**Table 1** Demographic characteristics of participants (n = 15)

| Characteristics                             | n  | % of sample |
|---|----|-------------|
| <b>Relationship</b>                         |    |             |
| Husband or partner                          | 12 | 80%         |
| Mother                                      | 2  | 13%         |
| Mother-in-Law                               | 1  | 7%          |
| <b>Gender</b>                               |    |             |
| Male  | 12 | 80%         |
| Female                                      | 3  | 20%         |
| <b>Age</b>                                  |    |             |
| 20–29                                       | 4  | 27%         |
| 30–39                                       | 7  | 47%         |
| 40–49                                       | 2  | 13%         |
| 50–59                                       | 1  | 7%          |
| 60–69                                       | 1  | 7%          |
| <b>Country of Birth</b>                     |    |             |
| UK  | 8  | 53%         |
| Outside of UK                               | 7  | 47%         |
| <b>Ethnicity</b>                            |    |             |
| Black Caribbean                             | 4  | 27%         |
| White British                               | 3  | 20%         |
| Asian Bangladeshi                           | 2  | 13%         |
| Asian Pakistani                             | 2  | 13%         |
| Asian Mauritian                             | 1  | 7%          |
| Mixed/Multiple                              | 1  | 7%          |
| White and Black Caribbean                   | 1  | 7%          |
| White Irish                                 | 1  | 7%          |
| <b>Religion</b>                             |    |             |
| Christian                                   | 7  | 47%         |
| Muslim                                      | 4  | 27%         |
| No Religion                                 | 3  | 20%         |
| Buddhist                                    | 1  | 7%          |
| <b>Mental Health Diagnosis</b>              |    |             |
| None  | 11 | 73%         |
| Anxiety and Depression                      | 4  | 27%         |
| <b>Mental Health Diagnosis of Relative*</b> |    |             |
| Depression/Postnatal Depression             | 8  | 53%         |
| Anxiety                                     | 6  | 40%         |
| Bipolar Disorder                            | 2  | 13%         |
| Post Traumatic Stress Disorder              | 2  | 13%         |
| Personality Disorders                       | 2  | 13%         |
| Postpartum Psychosis                        | 1  | 7%          |
| Autistic Spectrum Disorder                  | 1  | 7%          |
| Not known                                   | 2  | 13%         |

\* Many participants reported their relatives had multiple diagnoses

### Theme 1: recognising and Understanding their relative's perinatal mental illness was essential

#### *What's happening to them? Changes in their relative's behaviour and mood were distinct and often upsetting*

Over time, family members developed a good understanding of their relative's mental health problems. They identified several signs and behavioural changes in their relatives whilst they were unwell, including being easily frustrated, feeling low in mood or having baby blues,

showing low self-esteem, experiencing loneliness or being withdrawn, or having difficulties bonding with their baby. More severe presentations included relatives having flashbacks or feeling suicidal.

*"There's days when her anxiety is so bad, she don't want to leave and I can't leave the kids with her. Because sometimes she's not there, like responding to them... no one knows the struggle that we have to go through with her" (Participant 10, Partner).*

*"Her anxieties were terrible. She did have a lot of them. She also didn't think she was good enough to be a mother (...), she didn't think great of herself, even though everyone, you know, we all tried to keep her mood up and everything else. It's, it's very hard to do that when they don't feel it. Yeah. But, but we, but, obviously everyone was here for her. It isn't an easy thing to go through, so she did struggle." (Participant 8, Mother).*

Several family members mentioned that their own lived experience of mental health problems, or previous education, helped them to recognise and understand their relative's mental health problems.

*"After she had [baby] we kind of realised that something wasn't quite right and she was really low... and I've suffered with it... depression myself. I would have found it hard to understand what it's all about. Unless you've gone through it with it yourself you don't know what, what the feeling is like" (Participant 5, Mother).*

#### **Why is this happening? Making sense of what contributed to their relative's mental illness**

Family members suggested a range of factors that they felt caused or contributed to their relative's perinatal mental health problems. These included physical health problems during pregnancy and childbirth (including hormone changes, lack of sleep, and breastfeeding issues), trauma and psychological distress (including traumatic experiences during labour, previous perinatal loss, childhood trauma and family bereavement), and lifestyle changes and social factors (including homelessness and care proceedings). These extremely difficult circumstances made some family members feel like the distress of their partner was something to be expected, which delayed seeking help from services. This can be seen in this partner's description of watching his wife struggle:

*"I think at the time I associated it more to the fact that she's pregnant so hormones flying everywhere and you're okay one minute and the next you're not."*



**Table 2** Summary of themes

| Theme name   | Subtheme name  | Subtheme description  |
|--|--|---|
| Theme 1:<br>Recognising and understanding their relative's perinatal mental illness was important to make sense of the situation | What's happening to them? Changes in their relative's behaviour and mood were distinct and often upsetting | Family members identified several signs and behavioural changes in their relatives including being irritable, low in mood, or withdrawn. Experiences of their own mental health struggles helped them recognise their relative was struggling.  |
|  | Why is this happening? Making sense of what contributed to their relative's mental illness                 | Contributing and causal factors identified included physical, lifestyle, cultural and circumstantial factors.   |
|  | Wider family networks can be helpful but are often uninvolved  | Extended family and friends that were aware of their relative's mental health problems were a source of support. Some had no understanding, and mental health was not spoken about or supported, often due to their cultural understandings.  |
| Theme 2:<br>High emotional cost of supporting a relative with perinatal mental illness   | Taking on a varied caregiver role is essential for family functioning                                      | Family members gave both emotional and practical support to their relative, and children.   |
|  | Supporting a relative often had a negative impact on own well-being  | Their relative's illness often had a negative impact on their own physical and mental health and wellbeing, and the relationship with their relative.   |
|  | Family is important in accessing mental health services  | Families encouraged their relatives to get professional support, including therapy and medication. Their own views of treatment impacted the way they supported their relative to access care.  |
| Theme 3:<br>Varied experiences and expectations of services, with opportunities for improvement                                  | Barriers to accessing support and different expectations from families                                     | Expectations varied, with some concerns about mother and baby units, which did not come into fruition. Barriers that prevented or delayed getting professional support were identified, several related to culture and ethnicity.   |
|  | Family support and involvement with services was mixed   | Staff were understanding and open about the impact mental illness can have on the wider family, but more could have been done to support families. Most felt involved, and felt that their opinions were acknowledged, but some felt uncomfortable at appointments and their views were not taken into consideration. |
|  | Importance of good communication with services   | Communication from perinatal services was mostly good, and services provided updates and adequate information. At times communication and reliability was poor and unresponsive.  |

*Also in her personal life she was going through a hell of a time on top of being pregnant...so I thought even someone who has good mental health would be at their breaking point..." (Participant 2, Partner).*

Others reflected on the 'huge' life change of having a new baby:

*"This massive change you know having the baby...[it] does mess with hormones for a while...[she] started feeling kind of, I guess you could say a regret. Not a regret about having [our baby] you understand, more of a fact that freedom has been lost..." (Participant 1, Partner).*

One partner reflected on differences in cultural norms and availability of social support during motherhood being a contributing factor to their partner's difficulties.

*"So basically, back home in [country of birth] she would only breastfeed and not, lift a finger for three or four months, would have sisters and aunts and mum around you know teaching her about parenting, about bringing up a child... Whereas you know in our culture my parents are around for a couple of weeks and.... and I think that culturally it was very different... when you've migrated that you don't have*

*your family around you to do what they would've done back home" (Participant 9, Partner).*

Another family member also talked about how uncertainties around COVID-19 restrictions had an impact on his wife's mental health and anxiety.

*"She's always fearful of what could happen to baby and what could happen to her... Covid has impacted the antenatal sessions, so they've all been cancelled and what, what has been done has been online sessions. So, there's an anxiety there about...what value am I missing by doing these online sessions and not having the in-person sessions?" (Participant 12, Partner).*

Other contributing factors, such as upbringing of woman with perinatal mental health difficulties was also mentioned:

*"From what I've been told, she has had issues with her own upbringing and family on her side. So I'm not told a lot about it but, from what I gather, it, it wasn't great. So, but her mental health, her outlook on everything is a lot different to, say, me or, or anyone around her." (Participant 8, Mother).*



### **Wider family networks can be helpful but are often uninvolved**

Many extended family members and friends were aware of their relative's mental health problems and seemed to be a good source of support, showing understanding and empathy. For example, *"they did clearly understand that my wife was suffering something, which she needed treatment from the doctors."* (Participant 14, Partner); *"It, it was getting too much for her I thought but then she said, you know, she says, I think I'm suffering a bit of postnatal depression. (...) You have to push them to get medical help."* (Participant 5, Mother). In contrast, others said their wider family members were not aware, or had no understanding, of their relative's mental health problems. One family member described living with his parents who were from an *"old school Pakistani"* background where mental health is not understood or spoken about.

*"These kinds of things are not really talked about or, or known about if I'm honest with you, in our cultures... I've got these two families living here and I've got my own family and you know, we don't really discuss our problems...we're married, so it's between us really, it's got nothing to do with anybody else"* (Participant 3, Partner).

Other family members also said their families do not understand mental health at all and were not supportive, or they lived too far away to have a real impact.

*"I personally don't think [my wife's family] understand her mental health issues at all. I don't think she gets the right amount of support that she should be getting from her family...maybe it's just that whole generation way of thinking about it... I've had to speak with [my wife] about maintaining these boundaries so that she's not impacted by them during this pregnancy"* (Participant 12, Partner).

Sometimes not being aware of the extent of the problem and amount of support needed was identified as the cause of families not being supportive. Other participants felt it was deliberate avoidance and not wanting to have anything to do with the mental illness that was impeding their relatives accessing more support.

*"My mum like, she knew what was going on, but it's like she didn't really want to know...she wants to keep her distance like she, she didn't really want to have anything to do with it"* (Participant 10, Partner).

### **Theme 2: high emotional cost of supporting a relative with perinatal mental illness**

#### **Taking on a varied caregiver role is essential for coping**

Family members spoke about the different ways that they supported their relatives, saying that they often provided emotional support, and reassurance.

*"Mainly partner and amateur counsellor...I would be her listening ear, if she's having stresses or worried or is just feeling a bit overwhelmed...help her kind of keep grounded... she called me her rock."* (Participant 1, Partner).

*"I feel, even in terms of me caring, I think I've given that to her, she has opened up to me here and there... and when she does, we have kind of really long conversations regarding these things."* (Participant 6, Partner).

Others also provided support in practical ways, for example taking on more responsibility of the childcare and night feeds, cleaning the house, making sure their relatives look after themselves and take medication, and attending various appointments with them.

*"A lot of night-time activity would be me in the beginning, because [she] is more sleep reliant than me...if I miss a night or two it doesn't affect me too badly...I would kind of get up and... kind of change nappies and things like that, or at bare minimum I would support her to do it to kind of help and be up with her"* (Participant 1, Partner).

A few family members also spoke about keeping a balance between being a caregiver and allowing their relative to maintain their independence.

*"Stepping in and taking a little bit of control over the situation is what I could do but, at the same time I listened to [her] thoughts and tried to make sure that what I'm not doing is just taking too much control and running her life for her...So I don't really like to have an overbearing sense of control on things"* (Participant 7, Partner).

One partner also acknowledged the partnership between him and his wife and reflected on it being a fluid, two-way caregiver role.

*"She's been actually quite positive about the pregnancy, and it's me actually that's been quite anxious not knowing how the baby is, and sometimes it goes to her being anxious not knowing how baby is, but we bounce off of each other like supporting our-*

*selves...let's just enjoy the journey and we'll tackle issues as they come" (Participant 12, Partner).*

### **Supporting a relative often had a negative impact on own well-being**

The degree to which their relative's perinatal mental health problems impacted family members themselves varied, but many spoke about the difficulties of having a relative who was unwell: "As someone close to her that was watching it was upsetting for us...It was hard" (Participant 8, Mother). For many family members there was a clear impact, for example causing a fractured or strained relationship, in addition to the struggles of adjusting to their own new family role.

*"It was very difficult because I erm, I couldn't really enjoy the relationship...she was very, very pessimistic about things and it was very hard to do that on top of becoming a dad for the first time as well" (Participant 2, Partner).*

*"Pretty much I was doing everything, I was under so much pressure. Like I feel like I was going to break down one day. But I know I have to fight through it...I can't give up, because if I give up, who's going to take care of my kids?...I have to push through it even though I was struggling. Everything was pretty much difficult for me" (Participant 10, Partner).*

Some family members spoke about the influence on their own mental health. Family members reported life being extremely difficult and described their relative being ill as being a very upsetting and traumatic time.

*"I just had a really horrific period of it... [my wife] being pretty much impossible to talk to...yeah, fairly traumatising for me to have someone saying that they, they're off, like you know, relatively frequently" (Participant 9, Partner).*

*"Obviously if you're sort of very close to somebody who has a poor mental health it can also affect your own mental health erm, and erm the pressures that kind of come with it. Someone sort of relying on you that heavily." (Participant 2, Partner).*

For one family member the impact was significant, and he reported feeling suicidal at times. He felt the impact was worse because he did not have a good relationship with his own family, meaning he felt he had to carry the 'burden' alone: "There was no one to run to...like my family member, they didn't want to know me, they disowned me for a while." (Participant 10, Partner). Others spoke about the physical and practical implications, such as

feeling exhausted from helping with childcare, finding it difficult to manage juggling work and supporting their relative, or needing to reduce working hours to part-time.

In contrast, some family members, described that their relative's mental health problems had no impact, or only a slight impact, on them or other family members. Some partners spoke about how it was being separated from their child that was most difficult: "When she was being taken to the hospital, and she had to stay over, and the baby had to go as well. That's when really it had significantly impacted me that time that we're looking forward to it after having the baby" (Participant 14, Partner). Several family members reported that it was easier to cope with their relative's perinatal mental health problems with their second or third children because of their prior experience.

*"To be honest, we were fortunate that we were prepared for it. It didn't actually impact tremendously. It did put a little bit of strain like, you know kind of we were already adjusting to a new situation and then this difficulty had arrived but we, luckily, we did prepare for it. We knew it was coming" (Participant 1, Partner).*

### **Family is important in accessing mental health services**

Many family members encouraged their relative to get support for their mental health and were instrumental in helping them accessing support from services. This included being encouraging of help in general, or specifically encouraging women to attend counselling or other therapies such as CBT or take their prescribed medication.

*"And I did advise her to get some help. You know, I said it will help if you have some counselling...the youngsters these days, they don't want to take any anti-depressants or anything like that...they don't feel they need it" (Participant 5, Mother).*

*"The doctor had recommended some counselling sessions, which I was really positive about...I said to her make sure you go" (Participant 3, Partner).*

Families welcomed professional support and recognised that they couldn't offer all the specialist support that was needed.

*"I was happy that she could go and talk to somebody different from me and somebody who would be trained to know what question to ask and what, what symptom or signs to look for." (Participant 13, Mother).*

*"All I was looking for is to just get some help for [my wife] because she was in a state. She was in a very*

*poor state so...any help at that time would have been helpful for us.” (Participant 10, Partner).*

Family views also influenced the type of support relatives received, with one partner going on to say that whilst encouraging counselling, he did not want her to take medication: *“But I discouraged her from taking them. I said don’t take those because they’re a downward spiral.”* (Participant 3, Partner), favouring more natural ways to improve mental wellbeing (e.g., religion, cold-water swimming).

### **Theme 3: Varied experiences and expectations of services, with opportunities for improvement**

#### **Barriers to accessing support and different expectations from families**

Family members described different barriers in accessing perinatal mental health services. None of the family members, except one who worked within the NHS, had any knowledge of perinatal services before their relative’s referral, and were not sure who made the referral.

*“I mean I knew there was things for people that had postnatal depression because I mean I’ve had four kids myself, so I did know there was things out there for people...I hadn’t actually heard of that section until then.” (Participant 8, Mother).*

*“I guess like I didn’t realise there was a specific unit... I never really understood what that might mean for obviously either a pregnant mother or a mother with a new-born baby. So, I’m very, you know, unfamiliar with I guess the facilities and the, the types of care and support that they do.” (Participant 7, Partner).*

Some family members however also spoke about struggle to get support for their acutely unwell relative, and how they had to be in crisis before they were able to get help.

*“She had a few spells of attempting suicide and it got to a point where I was like we need to get help now...We basically spoke to someone... and it got to a point where I was saying, unless something was put in place for her, I am not leaving where I am, I will be here overnight and day after day until something happens.” (Participant 2, Partner).*

Family members also had different expectations about what support services offered. This included having someone to talk to who will listen, learning child-rearing skills (e.g., nappy changing, bathing, and playing), and receiving individualised support. Two family members were unsure what support was provided, with some family members still unfamiliar with specialist perinatal

services, despite their partner being offered a referral to the service.

*“One thing that I don’t like about it is that it’s offered but it’s not explained what it’s about, or how it can help...I’m still unaware of the support they provide.” (Participant 12, Partner).*

Other barriers that initially prevented their relatives from seeking help or led to delayed help-seeking included stigma and taboo around mental health, cultural attitudes towards mental health, not being comfortable opening up to practitioners from white backgrounds, language barriers, and prior negative experiences in other NHS settings.

*“You have it in the back of your mind that... I had a friend of mine who they... tried to help him and they ended up sectioning him and then they put him in the worst place for his mental health and wellbeing and it sort of went downhill.” (Participant 4, Partner).*

Others shared that culture and ethnicity did not play a significant role in accessing services:

*“It’s nothing to do with any of that. It’s you just treating a mother with issues and, and her baby with, like, the issues she was having. It wasn’t nothing to do with colour or race or, or ethnic, yeah, it, there was none of that involved.” (Participant 8, Mother).*

Some worries expressed were in relation to mother and baby units prior to admission in terms of separation from the baby and distance from home.

*“I was not happy being separated from baby but understood that it was for mother-baby bonding. My thought was obviously I want her to have a better treatment, so wherever they were wanting to take her, I was more than happy. But I wasn’t quite happy to let the baby go...” (Participant 14, Partner).*

Some families however did have a more positive experience of accessing perinatal mental health support.

*“It was quite quick...very simple process... it was just near enough instant. Whereas before she was on sort of list to get help from erm with mental health and stuff like that and they were taking forever” (Participant 4, Partner).*

#### **Mixed experiences of relative’s care**

Experiences of attending appointments with perinatal mental health services overall were positive, with family members often feeling involved in care plans and that their presence and opinions were acknowledged, *“She*

*liked to have me around whenever there was a meeting or something to do with perinatal team*" (Participant 1, Partner). Family members described several ways in which their involvement was helpful, including helping with childcare during appointments and translating for their partner, support and flexible visiting hours at Mother and Baby Unit and that the staff they came across were very friendly and welcoming and flexibility of appointments. Communication was also an important element and some family members reported that the communication from perinatal mental health services was good and provided them with adequate information and updates. This included explaining appointments well and in advance, sending letters if appointments were cancelled, and providing updates on how their relative was doing and what medication she had taken.

*"They explained everything and in decent time as well. It wasn't just like oh come here tomorrow for this. They gave good time"* (Participant 2, Partner).

However, some family members had largely negative experiences such as services focusing on supporting the relative rather than the whole family and discharging their relative without discussion with them: *"And, and then they just basically closed her case without discussing with me, and certainly which I was a bit shocked by given that I was just trying to hold it together."* (Participant 9, Partner).

There were also concerns regarding poor communications with services, and a need for this to be improved.

*"It was good at one point but then towards the end we kind of felt like she was a bit like abandoned... [they] just assumed that everything was fine because [my wife] hadn't contacted...that was just miscommunication within the system, because when she wasn't in the best of frame of mind she wasn't thinking about reaching out and contacting"* (Participant 4, Partner).

Family members suggested they would find it supportive if they had a number to call to talk to someone when they are struggling or need a break, highlighted gaps in current support suggesting a carer peer support group or buddy system would be helpful and reported that they would also value support with practical issues, for example signposting to other services, liaising with the council to get updates, or someone to support by attending appointments with the family. Family members reflected on how proactive communication from services is needed and that families would value services regularly checking in on women's and families' wellbeing.

*"[My wife] wasn't telling the full picture when we were there. And yes, I should've followed it up, but it's quite awkward for me going behind [my wife]'s back...I guess my hope was that [they] would've picked up that there's stuff I needed to say... even though I didn't follow it up."* (Participant 9, Partner).

## Discussion

### Summary of results

The present study provides new insights into the experiences of family members of women from Black and South Asian backgrounds living with perinatal mental illness. Results emphasise that families can play an important role in identifying the emotional and behavioural signs and symptoms associated with perinatal mental illness, encouraging, and supporting women to access care. However, the findings also suggest that families are not always able to make sense of the signs and symptoms associated with the relative's experiences, and may benefit from additional, accessible information during the early stages of illness. Families can provide a combination of emotional support and practical care to mothers, and their children, whilst they are unwell.

Importantly, one of the key findings of this study is highlighting that family members can experience significant distress while their relative is unwell, and often must manage this alongside the struggles of becoming a new parent or grandparent. This appears to be a universal experience, across the families and ethnic backgrounds included in our study. Family members are often advocates for their relative accessing, and getting appropriate care from services, and this can form a complex triad that includes the relative and services. Our results show possible tensions within families, both immediate and extended, and in interactions with services that are important to understand, acknowledge and address.

### Implications of findings

This paper explores the impact of perinatal mental illness on family members, their perspectives on mental health services, and the care and support (or lack thereof) they received for their own well-being. The needs of family members are often overlooked—both by services and by the families themselves—as they tend to prioritise the mother's recovery and infant care over their own concerns. However, in families affected by perinatal mental illness, partners or grandparents play many important roles, including often taking on the role of primary caregiver while the mother recovers. Research has largely neglected the voices of family members, instead focusing on women's views of their partner's needs or their families' perceptions of the mother's care. It is important to understand the perspectives of all involved to ensure comprehensive support for families, ultimately leading to

positive long-term outcomes for both the mother and her family.

Previous research has shown that early recognition and treatment of perinatal mental illness is essential, with delays resulting in longer and more severe illness, and with increased risks to mother and baby [22], and it appears that families can potentially be influential in reducing the time delay before accessing services. A previous qualitative study identified similar initial experiences to those in theme 1, with partners of women experiencing postpartum psychosis trying to make sense of the changes they observed in their relative's behaviour [23]. Descriptions given by our participants of early behavioural signs, and causal explanations provide valuable information about family members' understandings of perinatal mental illness and highlight the need for raising awareness of perinatal mental health and the support available. Some studies have shown that this is especially difficult for families from minority ethnic backgrounds, including Black [24] and South Asian [25, 26] families, due to a lack of awareness of perinatal mental health symptoms [27]. The present findings showed that some family members disagreed with some treatment modalities offered, and other research has shown that family members can sometimes act as a barrier to accessing treatment, attributing this to the stigma associated with mental illness [27] or simply being dismissive of their symptoms [10].

This research highlights the significant negative impact that supporting a relative with perinatal mental illness had on family members, regardless of whether they were partners or mothers. The psychological impact on partners is well documented in the perinatal literature with partners feeling frustrated, angry, helpless, fearful, overwhelmed, isolated and confused [28, 29], and often under additional pressure if their partner turns to them for support when experiencing distress rather mental health services [12]. It has been established that when mothers experience post-partum depression, 24–50% of partners will also experience depression [30], with approximately 10% of fathers experiencing depression in the first year postpartum [31]. In the present study, approximately one third of participants reported that they experienced anxiety and/or depression. It is possible that their own experiences of mental health difficulties in the post-natal period may have impacted their relationship with their relative [32, 33], and relationship breakdown can often be triggered by post-partum illness [34].

The varied caregiver roles described by our participants have also been echoed in previous studies, with others reflecting on the need to split their attention between their partner and baby [23], and taking on additional childcare responsibilities [28, 35]. Caregivers do not exist within a vacuum but are part of a broader environmental

surround that influences their own and their children's development. There are prototypical mother and father roles that often vary little across cultures [36], but these roles may differ in families affected by perinatal mental illness, as the primary caregiver role can shift depending on the healthcare needs of the parents.

Experiences of perinatal mental health services whilst sometimes good, appeared to be highly varied depending on services available and could be improved. In line with these mixed reports of support and involvement with services, another recent meta-synthesis of women's views of perinatal mental health care in the UK reported that information and support for partners and wider family was often insufficient, despite the benefits of bridging communication gaps with families, and increased awareness and education being well reported [27]. A recent UK study of 25 fathers showed a lack of overall support for fathers, despite their desire for information on how to help their partner, and signposting to services available to support them and their own mental health [37]. Men often feel excluded from perinatal health care [38, 39]. It has also been reported that services frequently focus on individual women (and their babies), with minimal attention to their wider family context. This is partly due to the challenges of engaging and supporting partners and families, as well as the ambivalence among women and their families about increased family involvement [40]. However, our findings indicate that family members should be seen by professionals as key partners in supporting recovery and, when appropriate, encouraged to play an active role in care, being routinely involved and well-informed. Our study adds a cultural context that may have intensified these challenges within our sample. The wider family, family expectations, and gender roles are particularly important in many Black and South Asian families. This paper highlights some of the nuances of these relationships and the impact they have on family experiences of perinatal mental illness.

### Strengths and limitations

This paper adds a unique perspective to the evidence base. Whilst all participants identified as being a family member of someone from Black and South Asian ethnicity, our sample included a diverse range of ethnicities within this, and a mix of immigration generation. Due to small numbers of participants from each ethnicity, it was not possible to draw any firm justifiable conclusions on the specific cultural relevancies of the data, which could be seen as limitation. However, most of the data emphasised the universality of supporting someone with perinatal mental illness across groups. The sample size of 15 participants was large enough to allow for theme saturation, so we believe that a larger sample would be unlikely to provide additional insights. Furthermore, our sample

was wider than many previous studies, including mothers and a mother-in-law, who can be an important part of the wider family unit. However due to the small number of mothers recruited, we were not able to consider how the views of partners and mothers/mothers-in-law may have differed. This context may have introduced limitations however, and we recognise that ethnicity and culture, and the family groups within them, are complex and diverse, and our analysis grouped all participants together as a homogenous group. Whilst some of the views described in our paper will be common to all partners and family members of women with perinatal mental illness, including the view of wider family members, some of our findings will be specific to carers in this specific study of women from Black or South Asian backgrounds.

Whilst a strength of the study is the mix of participant ethnicities recruited, it is possible that those partners from White British backgrounds may have had different views about impact that their relative's ethnicity and culture had on their experiences of services, although this comparison was not possible in this analysis.

Another limitation of our sample is that, despite having translation resources available, we were only able to recruit participants who spoke English as their first language. An additional challenge was recruiting mothers, fathers, and in-laws of women with perinatal mental illness, as it was significantly easier to include their partners/husbands.

It is possible that the experiences reported in this paper mainly reflect those of family members who were willing to be interviewed and may have had either positive or more negative views. However, the data showed a wide range of experiences, which indicates that diverse views were captured.

### Future research

This paper provides novel insights into wider family members experiences of women from South Asian and Black ethnic backgrounds. Future research should expand the equity and diversity lens to consider the experiences of family members of women of other ethnicities, and also families with pregnant people with different gender identities. The family members interviewed in this study were all generally supportive of their relative accessing services, and whilst they reflected on wider family members who were not aware of their relatives' difficulties, or were not supportive, it would be important to hear directly from these family members, and to explore what would be helpful to support them to engage with services. Further research may also be needed to explore the impact carers and family members' views play in the ultimate decision to reach out for help, or to accept help from services, and therefore to direct resources to raising

family awareness of perinatal mental illness and engaging these groups in perinatal mental health services.

### Conclusions

This paper provides valuable insights into perinatal mental health from a family perspective. Consistent with previous studies, family members of women from Black and South Asian backgrounds played a crucial role in identifying and encouraging early help-seeking for mothers showing mental health symptoms. While the experiences of relatives were diverse, the solutions identified were universal: better communication, proactive support, and transparency from services. This can improve family communication, prompt timely access to support, and strengthen relationships within the family unit. Wider dissemination of information about available services and practical support could further enhance this process. While many families felt supported and heard, some unhelpful experiences highlighted areas for service improvement, which should be addressed by perinatal mental health services in line with the NHS Long Term Plan. These findings underscore the importance of involving families in care, showing that informed and supportive relationships are pivotal to recovery during perinatal mental illness.

### Abbreviations

|      |   |
|------|---|
| A&E  | Accident and Emergency (NHS acute hospital)         |
| PMHS | Perinatal Mental Health Services                    |
| PMI  | Perinatal Mental Illness                            |
| NHS  | National Health Service (UK)                        |
| MBU  | Mother and Baby Unit (Inpatient mental health unit) |

### Supplementary Information

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Supplementary Material 1

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### Author contributions

All authors read and approved the final manuscript. SB analysed data, revised the framework and themes, and drafted the manuscript. NJ supported the analysis and supervision, revised and finalised the manuscript. JJ was involved in the design, analysis, individual supervision, and revising the manuscript. KP conducted analysis, drafted results, and drafted the initial manuscript. MC revised the analysis and manuscript. KB supported the analysis. RM contributed to the group supervision. SP contributed to study design and interpretation of results. AC supported the design, individual and group supervision, and revising the manuscript.



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## Data availability

The data that support the findings of this study are available from the corresponding author on reasonable request. Restrictions apply to the availability of these data to maintain participant confidentiality, in line with study consent statements.

## Declarations

### Ethics approval and consent to participate

The results presented in this paper formed part of a wider study titled 'Accessibility and acceptability of perinatal mental health services for women from Ethnic Minority groups (PAAM)'. The study was approved by Health Research Authority and Health and Care Research Wales by London–Queen Square Research Ethics Committee, Ref:19/LO/1830. Informed consent was obtained from all participants prior to participation.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

### Author details

<sup>1</sup>Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham, UK

<sup>2</sup>Warwick Applied Health, Warwick Medical School, University of Warwick, Coventry, UK

<sup>3</sup>Centre for Psychiatry and Mental Health, Wolfson Institute of Population Health, Queen Mary University of London, London, UK

<sup>4</sup>East London NHS Foundation Trust, London, UK

<sup>5</sup>Camden and Islington NHS Foundation Trust, London, UK

<sup>6</sup>Division of Psychiatry, University College London, London, UK

<sup>7</sup>School of Health and Psychological Sciences, City University of London, London, UK

<sup>8</sup>School of Psychology, University of Birmingham, Birmingham, UK

<sup>9</sup>Associate Professor in Perinatal Psychiatry, Wolfson Institute of Population Health, Queen Mary University of London, Yvonne Carter Building, London E1 2AB, UK

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