**Barriers to Accessing Perinatal Mental Health Services**

**What are the facilitators and barriers to help-seeking for women who experience Postpartum Psychosis from Black Asian and Minority Ethnic Backgrounds?**

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**THESIS PORTFOLIO: CANDIDATE DECLARATION**

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| **Declaration and signature of candidate** |
| I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.  I confirm that the decision to submit this thesis is my own.  I confirm that except where explicitly stated, the work has not been submitted for another academic award.  I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.  Signed:  Date: 30/04/20 |

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# Abstract

The author of this thesis has a specialist interest in perinatal mental health difficulties and postpartum psychosis. The author observed inequalities in clinical service access for minority groups, such as language barriers and cultural insensitivity. These observations led to the development of the literature review and further investigation in the form of the empirical paper.

Paper one presents a literature review which compares and contrasts the barriers to accessing services for women with perinatal mental health difficulties with a specific focus on literature that considers the experiences of women from White British backgrounds and Black Asian and Minority Ethnic (BAME backgrounds). The author brought together relevant literature from the two recently published literature reviews and searched for new literature, including grey literature. The findings highlighted similarities in the barriers to accessing services for the two groups alongside additional barriers and such as defining symptomology, communication with professionals and practical barriers.

Paper two presents the findings of the empirical paper, which considered the barriers to accessing services for five women from BAME backgrounds that have experienced postpartum psychosis aged between 21 and 35 years old. Mental health difficulties, such as PP pose huge risks to mother and baby, and it is known that fewer women from BAME backgrounds access timely support for such difficulties (NHS, 2019). Murray’s Narrative Framework (2000; 2008) was used to analyse the data and the researcher considered the findings through four lenses: the personal, interpersonal, positional and ideological. The barriers and facilitators to accessing services are discussed in relation to these four lenses.

Paper three is an executive summary that presents the findings of the empirical paper in a concise and accessible format. This paper is aimed at any person with interest in postpartum psychosis or lived experience of mental health difficulties. This paper is to be distributed by Action on Postpartum Psychosis in both paper and online format.

Word Count: 311

# **Paper One**: Literature Review

**What is known about the barriers to accessing Perinatal Mental Health Services? Do women from Black Asian and Minority Ethnic (BAME) backgrounds face different barriers to White British women?**

This review paper was written in line with the guidelines provided by the Journal of Evidence Based Midwifery (Appendix C). This journal was selected for submission as it promotes research that is relevant to midwifery, maternity services and professional standards. This paper adheres to the requirements of the journal, including the abstract, word count, formatting and referencing style (Harvard).

Word Count (Excluding References, Tables & Appendices): 7997

# Abstract

Objective: This review considers evidence from the literature to establish the barriers to accessing services for women experiencing perinatal distress. A synthesis of the research is included, providing a summary of how barriers may be experienced differently for women from BAME backgrounds in comparison to women from White British backgrounds in the UK.

Method: Two systematic reviews that address the separate facets of this research question were identified. The quality and findings of these papers were critically appraised. A thematic synthesis of the relevant literature from within these reviews was conducted. A literature search was conducted to establish whether any new literature had been published. Any literature found was critically appraised. Literature was not excluded on the basis of publication status.

Findings: The synthesis identified five overarching themes: Perinatal Mental Health (PNMH) symptoms, normalisation, isolation and peer support, speaking the same language and practical barriers. Each theme was considered in relation to women from BAME backgrounds and White British backgrounds.

Implications: Important findings are illuminated when the two bodies of literature are considered in relation to each other and new literature published after 2016. Women from minority backgrounds share many experiences with the broader population, although their experiences can also be compounded by multiple disadvantages. Implications for future practice, research and limitations are discussed.

Key Words: perinatal, mental health, ethnicity, barriers, service access

Word Count: 223

# Introduction

Awareness of the prevalence and risks of Perinatal Mental health (PNMH) conditions is increasing in the United Kingdom, which is reflected by a recent £365 million investment in PNMH services (National Health Service; NHS 2018). The term perinatal refers to pregnancy and the first 12 months post-birth (NHS, 2018). Around one in ten women experience a mental health difficulty during this period (Khan, 2015). The literature explores common conditions such as perinatal depression and anxiety as well as acute experiences such as postpartum psychosis affecting a smaller proportion of women (Megnin-Viggars et al, 2015).

In 2010 it was identified that less than 15% of trusts were providing the recommended level of specialist PNMH support, and around 40% had no services in place whatsoever (NHS, 2015). Recent investments, policies and government priorities outlined in documents, such as the PNMH development fund (NHS, 2014) have led to substantial changes in PNMH service provision. Whilst this is a positive step forward in a time of tumultuous change for the NHS, maternal suicide remains the largest direct cause of maternal death occurring in the perinatal period (Knight et al, 2017). Further, Khan (2015) estimated that only 50% of mothers experiencing depression and anxiety during the perinatal period are recognised, and less still are referred to specialist services. It is timely to investigate the barriers to accessing care and the under-identification of PNMH conditions as PNMH services continue to develop.

The barriers to accessing PNMH services are complex, and the process of seeking help and receiving care is not necessarily a linear process. A breadth of literature has considered the barriers to accessing care from the perspectives of women, their partners and Health Care Professionals (HCPs). Several studies have identified that for women stigma, fear of a child being removed and lack of communication around psychological wellbeing with professionals can prevent them from seeking help (Dennis & Chung-Lee, 2006; Goodman 2009; Megnin-Viggars et al, 2015). In terms of partner and family studies, research suggests that families can both facilitate and hinder access to services depending on their approach to the mother’s difficulties (Smith et al, 2019). Family members can often share the mother’s fears of stigma (Boddy et al, 2017; Wyatt et al, 2015) and have difficulty identifying symptoms (Chew-Graham et al, 2008; Brown, Mills & McCalmont, 2009). Literature regarding the perspectives of HCPs has ascertained that they often feel ill-equipped to assess PNMH (Rowan et al, 2010). Staff shortages and a lack of continuity of care have also been identified as barriers to access (Phillips, 2015; Wan et al, 2008).

The term Black Asian and Minority Ethnic group is frequently abbreviated to BAME – this abbreviation is used to refer to groups of people from minority ethnic backgrounds (Advance Higher Education, 2019). The limitation of this terminology in terms of grouping together several heterogeneous groups of people is acknowledged, and it is used in this review to refer to research in which the participants were not of White British descent. Research suggests that women from BAME backgrounds are at increased risk of mental health difficulties and less likely to access services (Sashidharan, 2003). Current literature cites several reasons for this such as; cultural beliefs about mental ill-health (Edge & Rogers, 2005), language barriers (Lam, Wittkowski & Fox, 2012) and culturally insensitive services (Wittkowski et al, 2011). Studies have also found that HCPs experience difficulty in assessing women from BAME backgrounds due to a lack of awareness of the issues surrounding these women (Wittkowski et al, 2011; Edge, 2011).

The barriers to accessing care for women with PNMH conditions are multifaceted, and it would appear that there are commonalities and differences between women from BAME backgrounds and their White British counterparts. Whilst previously published reviews have covered these populations separately amongst other research, this review will consider experiences of the potential service-user only. It is hoped that this review will provide useful insights into barriers to accessing PNMH services for women from both BAME and White British backgrounds which can be used to support service development and future research.

Two recently published systematic reviews have reviewed the literature in relation to the broader barriers to accessing care including research involving stakeholders, HCPs, partners and women themselves (Smith et al, 2019) and the barriers posed to women from BAME backgrounds (Watson et al 2019). Watson et al (2019) also included partner/family studies and sub-groups such as teenage mothers. The aim of the current review, therefore, is to pull together the research regarding the broad perspectives of women on access to services for PNMH difficulties and comparing the differences between women from White British Backgrounds and women from BAME backgrounds specifically.

# Aims

1. Evaluate existing literature to establish what is known about the barriers to accessing PNMH Services for service-users.
2. Using literature from two reviews published in 2019 to assess whether women from BAME backgrounds face different barriers in comparison to their White British counterparts
3. Replicate the review searches to establish whether any new literature can add to the findings.

# Method

The two reviews were scrutinized using the Critical Appraisal Skills Programme (CASP) Ten Item Checklist for Systematic Reviews. Booth, Sutton, and Papaioannou (2016) advocate for the use of checklist tools in order to assess reliability, validity and the extent to which findings have clinical applications. Each of the ten items on the CASP was tabulated alongside the outcome of the paper scrutiny (appendix A). A total of 27 papers were selected papers from both two reviews Watson et al, 2019 and Smith et al, 2019 that met the inclusion and exclusion criteria. The key findings were synthesised into themes using the steps of thematic analysis as outlined by Braun & Clarke (2006); familiarisation with the data, coding papers, searching for themes amongst codes, reviewing themes, defining themes and generating the synthesis.

The majority (26/27) of the data from the included studies was qualitative, and therefore it was practical to generate themes from the findings. Of the papers included 16 recruited women from BAME populations or ethnicity was a major focus of the paper. The remaining 11 papers either included a White British or mixed ethnicity sample, but ethnicity was not the major focus of the paper. The first stage of the analysis led to the conceptualisation of five overarching themes. The second stage was to consider the relevance of the themes to the research with BAME populations and White British or mixed ethnicity.

The researcher then replicated the searches and searched the grey literature to assess whether any literature published since the time of the reviews could add to the synthesis. Any published research papers were appraised using the CASP. Unpublished papers and author’s commentaries were considered but not formally appraised. The outcome of the paper scrutiny for the three published papers identified was recorded (appendix B).

*Replicating Searches*

The reviews detailed the dates during which the searches were completed, Watson et al’s (2019) search reached completion in 2017 and Smith et al’s (2019) in 2018. Both reviews provided information regarding the search strategy employed, and these searches were replicated as closely as possible where access to the same databases was obtainable. The researcher searched for literature published from 2016 onwards as the search strategies employed by the two reviews would have extracted any literature that pre-dated 2016.

# Inclusion & Exclusion Criteria

This criterion was developed since the aims of this review are to look at the barriers to access from the perspective of potential service-users. Only research undertaken in the UK was included as healthcare funding, and provision varies across countries, and there have been recent developments in UK PNMH Service Provision (NHS, 2014; NHS 2018).

**Inclusion Criteria**

1. Women’s experiences of PMNH or PNMH services is a major focus
2. Barriers to accessing services is a major focus
3. The research was conducted within the UK
4. The article is in the English language or is a reliable translation

**Exclusion Criteria**

1. The focus of the paper is on partners, carers or health care professionals’ experiences
2. The focus is determinants of PNMH problems or is biomedical in nature
3. The research was conducted outside of the UK

Watson et al (2019) detailed a search strategy comprised of four facets relating to (1) the perinatal period (2) ethnicity or possible countries of origin (3) mental health and (4) research undertaken in Europe. Terms that mirrored the first three facets were devised; however, for the purpose of this review, research from outside of the UK was excluded. The following search terms were inputted into the same databases that were used by Watson et al (2019); PsycINFO, CINAHL, and MEDLINE[[1]](#footnote-1)

**Search Terms Replicating Watson et al (2019)**

“perinatal” or “postnatal” or “prenatal” or “antenatal” or “postpartum” or “maternal” or “pregnant” or “pregnancy”

AND

“ethnicity” or “race” or “culture” or “minority” or “minorities” or “ethnic”

AND

“mental health” or “mental illness” or “mental disorder” or “psychiatric illness”

Smith et al (2019) detailed a search strategy comprised of four facets and also provided details of search terms. The same search terms were therefore used across the same databases: PsycINFO, CINAHL, and MEDLINE. Smith et al (2019) also included the term ‘qualitative research’; this term was omitted since this review did not seek to exclude studies on the basis of methodology.

**Search Terms Replicating Smith et al (2019)**

“perinatal” or “pregnancy” or “birth”

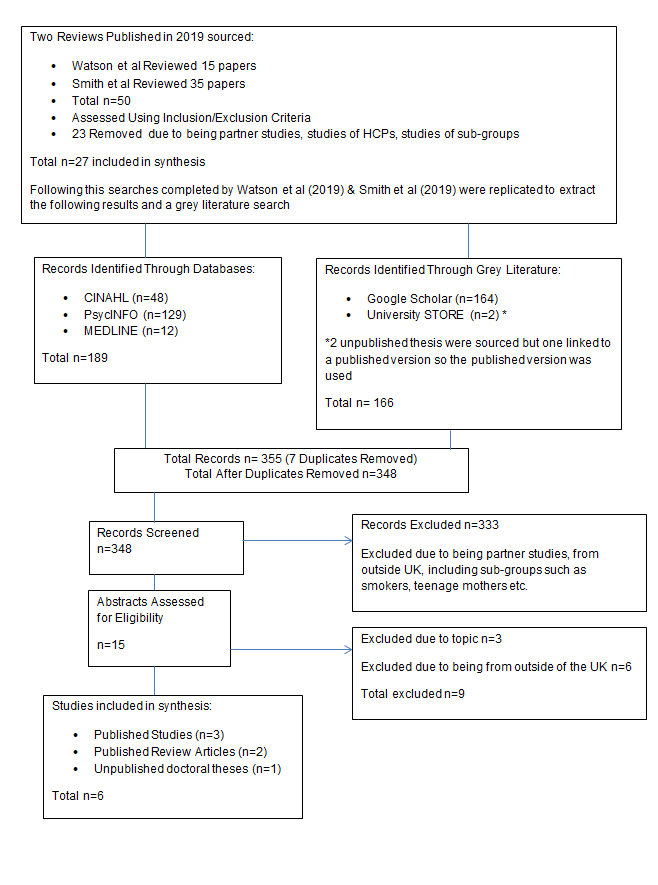
“mental health” or “mental disorder”

“health services accessibility” or “delivery” or “healthcare”

“attitudes of health personnel”

A search of the grey literature also dated from 2016 onwards was ran using Google Scholar and the University’s store of unpublished theses’, using the search terms listed above.

# Figure 1. Combined Results from Searches



# Figure 2. Papers Extracted from Reviews

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Author, Date & Title** | **Study Aim** | **Sample Size** | **Participants** | **Data Collection** | **Data Analysis** | **Rating** | | **Key Findings** |
| **Papers Meeting Inclusion/Exclusion Criteria from Review by Watson et al, (2019)** | | | | | | | | |
| Cantle, F. (2010). Tackling perinatal mental health among black and minority ethnic mothers. | To identify barriers to partnership  working in relation to perinatal mental  health in their area, to explore issues  and identify solutions to problems and  agree to and implement a plan of action | 60 | Unspecified BAME Groups | Survey | Not Specified | | Low | Lack of communication between participants and HCPs, reduced awareness of PNMH conditions in the sample, increase of cultural differences |
| Edge, D., & Rogers, A. (2005). Dealing with it: Black Caribbean women's response to adversity and psychological distress associated with pregnancy, childbirth, and early motherhood | To explore the models, experiences, and  meaning of perinatal depression held by  Black Caribbean women | 12 | Black Caribbean | Interviews | Constant Comparative Approach | | Acceptable | Rejection of ‘postnatal depression’ as a construct  ‘strong black woman’ identity served as protective – mastery and agency protective  Low self-esteem & hopelessness absent from discussions |
| Edge, D. (2011). ‘It's leaflet, leaflet, leaflet then, “see you later”’: black Caribbean women's perceptions of perinatal mental health care | To examine Black Caribbean women’s  perspectives on what might account for  low levels of consultation for perinatal  depression. | 42 | Black Caribbean | Focus Group Discussion | Framework Analysis | | Acceptable | Perceptions of lack of compassion from HCPS, new care pathways required, preference to receive care in mixed ethnic groups |
| Gardner, P. L., Bunton, P., Edge, D., & Wittkowski, A. (2014). The experience of postnatal depression in West African mothers living in the United Kingdom: A qualitative study. | To explore the lived experience of postnatal depression (PND) in West African mothers living in the United Kingdom (UK). | 6 | Nigerian and Ghanaian | Semi-structured Interviews | IPA | | Acceptable | Postnatal depression and distress resulted from social stress, difficulty disclosing feelings affecting help seeking. |
| Hanley, J. (2007). The emotional wellbeing of Bangladeshi mothers during the postnatal period | To explore Bangladeshi mothers’  interpretations of postnatal depression  and its effect on the wellbeing on the  Mother, family and community. | 10 | Bangladeshi | Focus Group Interview | Thematic Analysis | | Acceptable | Postnatal depression generally unfamiliar concept  Friends, family support and religious healers important  Reluctant to discuss gender specific health issues in the presence of husband |
| McLeish, J. (2005). Maternity experiences of asylum seekers in England. | To describe the maternity experiences  of asylum seekers in the UK. | 33 | Not specified | Interviews | Not specified | | Low | Financial barriers to access e.g. travel, accessing appropriate information lack of interpretation/translation  Hostility/discrimination |
| Masood, Y., Lovell, K., Lunat, F., Atif, N., Waheed, W., Rahman, A., ... & Husain, N. (2015). Group psychological intervention for postnatal depression: a nested qualitative study with British South Asian women | To assess the acceptability and overall  experience of the Positive Health  Programme by British South Asian  mothers. | 17 | South Asian – Pakistani, Bangladesh, Indian | Interviews | Thematic Analysis | | Acceptable | Culturally adapted PHP is acceptable to British South Asian Mothers  Appreciated understanding of facilitators – were able to speak Urdu  Safe environment – sharing similar experiences  Inclusion of family members in information sharing – positive |
| Parvin, A., Jones, C. E., & Hull, S. A. (2004). Experiences and understandings of social and emotional distress in the postnatal period among Bangladeshi women living in Tower Hamlets. | To explore first-generation Bangladeshi  women’s understandings and  experiences of postnatal distress, and to  describe coping strategies during the  postnatal period. | 25 | Bangladeshi | Focus Groups | Thematic Content Analysis | | Acceptable | Lack of understanding of extended roles of HCPs to address mental health (associated only with physical health)  Inclusion of family members – could help facilitate access  Conceptualised emotional distress separate to physical symptoms |
| Raymond, J. E. (2009). ‘Creating a safety net’: Women's experiences of antenatal depression and their identification of helpful community support and services during pregnancy | To explore depression during  pregnancy amongst women living in an  area of socio- economic deprivation. | 9 | Black African, Mixed  Asian/British, White  American, White  Australian, White other,  White British | Semi-Structured Interviews | Thematic Analysis | | Acceptable | Different ethnic/cultural backgrounds – emotional isolation (common reporting) contributor to antenatal depression  Partner support important factor  Need for peer support |
| Redshaw, M., & Henderson, J. (2016). Who is actually asked about their mental health in pregnancy and the postnatal period? F | To find out which women are asked  about their mood and mental health  during pregnancy and postnatally, and  about offer and uptake of treatment. | 4751 | Mixed, Asian, Black,  Other, White | Postal Survey | Descriptive statistics,  univariate analysis and  logistic regression. | | High | Non-white women, deprived women and lesser educated women were less likely to be asked about their mental health and receive support |
| Templeton, L., Velleman, R., Persaud, A., & Milner, P. (2003). The experiences of postnatal depression in women from black and minority ethnic communities in Wiltshire, UK | To describe the experiences of women  suffering from postnatal depression in  black and minority ethnic communities. | 18 | Bangladeshi, Indian, Asian, Portuguese, Other | Semi-structured  interviews and  focus groups | Descriptive Thematic Analysis | | Acceptable | Complex lives of participants  HCPs require further training  Language barriers – provision of information |
| Wittkowski, A., Zumla, A., Glendenning, S., & Fox, J. R. E. (2011). The experience of postnatal depression in South Asian mothers living in Great Britain: a qualitative study. | To understand the experience of PND  in South Asian mothers living in Great  Britain. | 10 | Bangladeshi, Pakistani & Indian | Interviews | Constant Comparison Method | | High | ‘Internalising misery’, feeling alone, communication with HCPs barrier |
| **Papers Meeting Inclusion/Exclusion Criteria from Review by Smith et al (2019)** | | | | | | | | |
| Coates, R., Ayers, S., & de Visser, R. (2014). Women’s experiences of postnatal distress: a qualitative study. | To explore mother’s experiences of Postpartutm emotional distress | 17 | Women experiencing distress <1 year after birth (all White except for 1 Chinese participant) | Interviews | IPA | High | | Psychological processes – guilt, self-blame, fear of bad mother etc.  Relationships with HCPs  Partner Support |
| Coates, R., de Visser, R., & Ayers, S. (2015). Not identifying with postnatal depression: a qualitative study of women’s postnatal symptoms of distress and need for support. | Mother’s experiences of assessment and PNMH symptoms | 17 | Women experiencing distress <1 year after birth (all White except for 1 Chinese participant) | Interviews | Inductive Thematic Analysis | High | | Lack of identification of concept of PND  Seeking support should be normalised  Increased awareness of symptoms required for both HCPs and women |
| Cooke, S., Smith, I., Turl, E., Arnold, E., & Msetfi, R. M. (2012). Parent perspectives of clinical psychology access when experiencing distress. | Parents perceptions of barriers to PNMH services | 7 | Parents – all women (>18 years) with psychological distress  White British 4  Mixed White and Black African 2  Black British 1  6 – single parents | Interviews | Thematic Framework Analysis | Low | | Feeling connected to HCPs increased disclosure, fear of child being removed/distress needing to be severe for referral, stigma – ‘mad’  Frontline healthcare for physical needs  Practical barriers |
| Edge, D. (2007). Perinatal depression and Black Caribbean women: lessons for primary care. | Explaining low PNMH service access | 12 | Black Caribbean | Interviews | Grounded Theory | Acceptable | | Unfamiliarity with symptoms, meaning (cultural)  Important to be perceived as strong, fear of stigmatisation  Different explanatory frameworks – difficulties diagnosing |
| Edge, D. (2008). ‘We don’t see Black women here’: an exploration of the absence of Black Caribbean women from clinical and epidemiological data on perinatal depression in the UK | Explaining low PNMH service access | 12 | Black Caribbean | Interviews | Thematic Framework Analysis | High | | Cultural – conceptualising PNMH, stoicism  Stigma  HCPs attitudes – willingness/ability to diagnose |
| Edge, D., & MacKian, S. C. (2010). Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among Black Caribbean women in the UK. | Black Caribbean women's accounts of help seeking for PND | 12 | Black Caribbean | Interviews | Thematic Framework Analysis | High | | Lack of awareness of PNMH conditions – ‘configuration’ of symptoms and whether they require external validation |
| Evans, K., Morrell, C. J., & Spiby, H. (2017). Women’s views on anxiety in pregnancy and the use of anxiety instruments: a qualitative study | Exploring women’s experiences of anxiety in perinatal period and assessment | 19 | Aged 18 and other – mixed ethnicities – demographics not provided  Given birth in last 9 months and self-reported anxiety | Interviews | Inductive Thematic Analysis | Acceptable | | Isolation – connecting with others would be helpful, communication with HCPs – positive relationship would facilitate disclosure, unclear care pathways – clarity of possible assessment outcomes |
| Glover, L., Jomeen, J., Urquhart, T., & Martin, C. R. (2014). Puerperal psychosis–a qualitative study of women’s experiences. | Exploring women’s experiences of postpartum psychosis and impact on help-seeking/support | 7 | Women accessing specialist service due to episode of PP <10 years ago | Interviews | Inductive Thematic Analysis | High | | Awareness of condition, stigma, focus on physical health, normalisation |
| Lam, E., Wittkowski, A., & Fox, J. R. (2012). A qualitative study of the postpartum experience of Chinese women living in England. | Chinese women’s experiences of PNMH condition | 8 | Chinese postnatal women | Interviews | Grounded Theory | High | | Lack of information/language barrier ,Reliance on family, friends internet, Fear of family being contacted, conflicting advice between family/professional’s |
| McGrath, L., Peters, S., Wieck, A., & Wittkowski, A. (2013). The process of recovery in women who experienced psychosis following childbirth. | To consider the experience of recovery in postpartum psychosis | 12 | Women with a diagnosis of PP – over 18, fluent in English – no ethnicity information | Interviews | Grounded Theory | High | | Stigma  Role of professional’s central  Loss/adjustment |
| Millett, L., Taylor, B. L., Howard, L. M., Bick, D., Stanley, N., & Johnson, S. (2018). Experiences of Improving Access to Psychological Therapy Services for Perinatal Mental Health Difficulties: a Qualitative Study of Women's and Therapists’ Views. | Women and HCPs experience of access to IAPT services during the perinatal period | 26 | Women (n=12)referred to mental health services with baby aged 6-9 months and therapists (n=14)  Women’s ethnicities  White British 5  White other 3  Black other 1  Black Caribbean 1  Arab 1  Asian 1 | Interviews | Thematic Analysis | High | | Normalising, IAPT not equipped for PNMH, lack of familial support, fear of stigma ‘bad mum’ |
| Patel, S., Wittkowski, A., Fox, J. R., & Wieck, A. (2013). An exploration of illness beliefs in mothers with postnatal depression | Exploration of beliefs around PND | 11 | Women with PND or depression in pregnancy that lasted after birth – no ethnicity information | Interviews | Ground Theory | High | | Stigma  Fear and Relief in diagnosis |
| Plunkett, C., Peters, S., Wieck, A., & Wittkowski, A. (2017). A qualitative investigation in the role of the baby in recovery from postpartum psychosis. | To explore role of baby in postpartum psychosis | 12 | Women who had experienced PP - no ethnicity information | Interviews | Thematic Framework Analysis | High | | Focus on baby can help recovery  Normalising negative feelings re: baby could be helpful? |
| Slade, P., Morrell, C. J., Rigby, A., Ricci, K., Spittlehouse, J., & Brugha, T. S. (2010). Postnatal women's experiences of management of depressive symptoms: a qualitative study. | Women’s experiences of having PNMH needs identified by HVs | 30 | Women experiencing PND – no ethnicity information provided | Interviews | Template Approach | High | | Perception of not coping, knowledge of HV not able to discuss psychological wellbeing, relationship with HV |
| Wyatt, C., Murray, C., Davies, J., & Jomeen, J. (2015). Postpartum psychosis and relationships: their mutual influence from the perspective of women and significant others | Identify how women and their partners make sense of experiences of Postpartum Psychosis | 7 | Women with PP and their carers/partners family or friends | Interviews | IPA | High | | Isolation, invalidation, loss, supportive relationships meaningful in recovery |

[[2]](#footnote-2)

# Findings

**Quality Assessment of the Reviews  
Critique of Literature Review Methodologies**

Smith et al (2019) defined a focussed aim: the paper considered the multilevel barriers to accessing services and considered studies that included potential service-users, a variety of HCPs and families/partners. The aim was to provide recommendations to improve access in line with current policy (NHS, 2014). The authors conducted a multifaceted search of relevant databases and included papers conducted in the UK. The rationale for this was plausible as the research aimed to inform UK service policy. The authors’ hand-searched reference lists and tracked citations to increase the breadth of the search. However, the search was limited by the authors’ decision to exclude quantitative research from the review. These quantitative papers may have provided additional insights that could have proved pertinent.

The authors made use of the CASP checklist to assess the quality of the studies included which ensured a comprehensive review of each paper was conducted. The authors scored the papers using the CASP and assigned each paper a quality rating. The quality assessment was conducted by one author, and a selection of papers was then assessed by two independent reviewers. The use of blinded independent reviewers can strengthen the reliability of a review since it reduces the likelihood of research bias. In this instance, there was a low rate of agreement between the researcher and the independent reviewers. Agreement on the quality of the study was then established through discussions between three of the authors. The authors reference the contentious issue of scoring qualitative papers on their quality and variations in reporting across papers as reasons for the low agreement between reviewer ratings. Thus, all papers meeting the inclusion criteria were reviewed, and none were excluded based on low quality. Conclusions made regarding the overall quality of the literature included in the review should therefore be tentative.

Watson et al (2019) addressed a precise aim to consider the literature in relation to ethnic minority women’s experiences of PNMH conditions and services in Europe however, the results of their search returned only papers published in the UK. The authors ran a multifaceted search of several databases including qualitative, quantitative and mixed methods studies. They did not exclude any studies on the basis of language or publication date and also followed-up reference lists of the included papers, increasing the scope and validity of the search. The search could have been strengthened by the inclusion of unpublished research and grey literature.

Watson et al (2019) made use of NICE checklist tools (NICE, 2012) to assess the quality of the included literature, a second reviewer assessed 10% of the papers and a third reviewer was referred to where disagreements occurred. The researchers developed a quality rating on the basis of the checklist tool, which allows the reader to quickly ascertain the quality of the research. The researchers synthesised information from a range of data sources, including qualitative and quantitative studies. The data were transformed into qualitative findings using thematic synthesis. The rationale for this approach to the data is made clear, and the use of multiple data sources strengthens the findings. Two independent reviewers synthesised 20% of the findings increasing the reliability of the results.

**Critique of Literature Review Findings**

The results of the papers included by Smith et al (2019) are clearly presented and combined appropriately, e.g. studies, including similar participants, are grouped. Smith et al (2019) identified multilevel barriers to accessing PMNH care at each stage of the care pathway (individual, organisational, socio-cultural and structural). The authors developed a conceptual model of the care pathway, which identifies which barriers are likely to be most pertinent in each stage of the pathway. The authors concluded that negative attitudes regarding PNMH were linked to stigma and avoidance of help-seeking. A lack of knowledge of PNMH amongst professionals also reduced the likelihood of women accessing care. Inadequate service provision served to exacerbate individual-level barriers alongside sociocultural barriers such as language barriers.

The findings from the literature are linked directly to the aims of the review. The authors are transparent regarding the challenges faced when appraising the quality of qualitative research and the limitations of the review. Papers deemed poor quality were not excluded from the review; however, the researchers noted that extracted themes did not appear to vary based on CASP scores, and therefore including these papers did not affect the analysis. Whilst the meta-synthesis of 35 papers and the development of the multilevel model is a real strength of this review, the methodological issues highlighted make it difficult to comment on the overall precision of the results.

The focus on papers published in the UK and the separation of papers that focus on the HCPS, service-users, and partners increases generalisability. Although some of the papers included service-users who were from subgroups, such as teenage mothers, that may have faced additional barriers to accessing services which may have warranted further exploration. Nevertheless, the decisions made regarding including papers are transparent and credible, making the review a worthwhile endeavour which combines a wealth of literature. The model derived from the literature could help to inform patient care although the researchers noted that additional barriers might exist, particularly at the structural and organizational levels, due to the research in this area being relatively limited.

The results of the review by Watson et al (2019) are presented clearly in the form of seven over-arching themes; awareness and beliefs about mental ill-health, the influence of culture, symptoms and coping strategies, isolation and seeking support, accessing PNMH services, experiences of PNMH services, and what women want. Watson et al (2019) adopted the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) approach, which produced scores that indicated the level of confidence the researchers had in the findings. These scores were assessed by two reviewers and then discussed amongst the research team to reach agreement. This approach validates and adds credibility to the findings. The majority of the findings were assigned a high or moderate CERQual score. Two findings were rated as low and the authors referenced concerns about adequacy for these since findings emerged from a small sample of studies.

Watson et al (2019) is the first systematic review to consider the role of ethnicity in PNMH experiences which may help to inform future research and healthcare. However, it is essential to note that women from ethnic minorities are a heterogeneous group with a plethora of life experiences. It is worthwhile combining research from women from a range of ethnic minorities since the area is still relatively under-researched. Watson et al’s (2019) review was sensitive to this and referenced the ethnic background of the woman from each data excerpt presented. Whilst the findings are important, generalisations to a population must be tentative.

# New Literature

New literature published from 2016 onwards that was extracted through the replicated searches was also assessed for quality using the CASP, the outcome of the quality assessments are detailed here.

**Quality Assessment**

Yapp et al (2019) laid out the clear research objective to explore women’s experiences of being asked about mental health difficulties during the antenatal booking appointment. The authors utilised thematic analysis in combination with framework approaches. A total of 52 women were recruited, and the sample was diverse in terms of ethnic and sociodemographic backgrounds. Three themes were identified: the experience of being asked about depression (including emotional responses, presence of others and wording of questions), experience of answering the questions (including implications of disclosure, desire to seek support and context/constraints of appointment) and the approach of the midwife (including confidence and competence in addressing mental health difficulties).

The analysis was rigorous, clearly structured, and the combination of the two methodologies was appropriate. The purposive sampling strategy is appropriate to qualitative research (Palinkas et al, 2015), and the authors demonstrated that the sample reflected the demographics of the broader pool of potential participants and saturation of themes was achieved. The epistemological standpoints of the researchers were considered, and evidence of reflexivity was provided. The researchers noted that a large number of women declined to participate highlighting a potential participation bias, and some women were not able to participate due to being unable to recall being asked the questions at the point of the antenatal appointment. These limitations impact the overall generalisability of the study.

McLeish and Redshaw (2017) explored the experience of women who participated in a peer support programme. The research mostly recruited women from ethnic minorities who had experience of several disadvantages. The authors utilised a thematic analysis approach from the perspective of phenomenological social psychology perspective. A total of 47 women were recruited and interviewed, 31 of which were born overseas. Two major themes were identified: mothers’ self-identified emotional needs (including emotional distress, stressful circumstances, lack of social support and unwillingness to be open with professionals) and how peer support affects mothers (including social connection, being heard, building confidence, empowerment, feeling valued, reducing stress through practical support and significance of mental health peer experiences).

Overall the design of the study was appropriate to the research question. The rationale for using a low inference analysis (thematic), i.e. an analysis that is grounded in the words of the participants is adequate as it allows for the voices of a minority group to be heard. The recruitment strategy of sourcing people through course providers was an appropriate way of reaching a relatively large sample for qualitative research. However, it also increases the risk of bias in the study, since participants may have had concerns about expressing negative experiences in this context. The method of data collection and analysis was made clear, although data saturation is not discussed. The relationship between the researcher and participants are briefly considered in the paper however due to the nature of the research a further exploration of issues of power and difference between researchers and participants could have enhanced the findings.

The paper by Lea, Heyes and Priest (2018) was deemed to be of a good quality providing a precise aim of giving voice to mothers and considering this within a service and society level context. The narrative methodology is ideal for illuminating voices of service-users, particularly since other research has highlighted that they often feel unheard (Cooke et al, 2012). The paper was novel in that it went beyond researching barriers and specifically sought to understand how services are experienced. The recruitment strategy was transparent, and reasons for exclusion made clear. The researchers made clear their reflexive position and personal/professional experiences of mental health difficulties which add transparency to the findings. Data was collected using unstructured interviews, which is concordant with the methodology. Narrative is less rigorous than other methodologies, and whilst the researcher clearly outlines the process of arriving at the findings, it is difficult to comment on rigour overall due to the flexibility of the approach. A sample size of 6 is relatively small but again appropriate to the methodology, and the report provides detailed findings from these 6 participants. The findings around the impact of trauma on PNMH, internal confusion, confused services and unhelpful interventions are clearly labelled. Overall, the paper offers valuable insights around the expectations of motherhood from a service-user perspective in a novel piece of research.

# Synthesis

The themes of (1) PNMH Symptoms, (2) Normalisation, (3) Isolation and Peer support, (4) Speaking the Same Language and (5) Practical Barriers are presented in more detail below.

**Theme One: PNMH Symptoms: Understanding & Conceptualisation**

Difficulty in identifying the symptoms of PNMH conditions was a recurrent barrier to accessing care across all populations of women. In several studies, it appeared that women were attempting to configure their symptomology in relation to their cultural context. Whilst there appeared to be a collective lack of awareness or understanding of symptoms, there was cultural variation in how these experiences were then configured. The analysis revealed subtle differences between women from African, South Asian and White British/Mixed ethnicity, and therefore, this theme was split accordingly.

**Studies Including Black Caribbean and African Women**

For Black Caribbean and African women participating in these studies there appeared to be two components awareness or lack thereof of PNMH conditions (Edge & Rogers, 2005; Edge, 2007; 2008; 2011; Edge & Mackian, 2010; Gardner et al, 2014); a lack of discourse regarding mental health difficulties within their communities and a conceptualisation of mental health difficulties which did not match with the dominant biopsychosocial model in UK healthcare. It would appear that within Black Caribbean and African communities, there is an unwillingness to engage in disclosures of mental health difficulties (Edge & Rogers, 2005). Research indicates that BAME people are more likely than White British people to be sectioned and medicated without consent and it is possible that this differential treatment contributes to a lack of disclosure (NHS, 2019):

*“I’m just going by what I’ve seen on chat shows, I keep thinking ‘what do they mean they’re depressed, what do they get so de-pressed about? I mean, I’ve never met a Black person who’s said they’ve got it”*

(Black Caribbean Participant, Edge, 2008)

In a study of West-African women, it was found that they were more comfortable with the word ‘stress’ and much less likely to use the word depression (Gardner et al, 2014). The concept of ‘mental health symptomology’ was primarily unfamiliar to this group, and they were, therefore, less likely to understand their feelings as something that could be helped through support or validation. Interestingly symptoms of low self-esteem and hopelessness appeared absent from experiences of these women (Edge & Rogers, 2005; Edge & Mackian, 2005). Whilst these women certainly experienced PNMH distress; it would appear that these concepts are either less familiar or less prevalent in this population. This is an important finding since such symptoms are considered markers that can help to differentiate depression from the expected emotional experiences of women during the perinatal period (NICE, 2018). If the diagnostic criteria are not relevant to the experience of a population, it places this population at a higher risk of their symptoms being missed.

**Studies Including Asian Women**

Cultural conceptualisations of illness were equally as important to women in these studies. Unfamiliarity with the concept of PNMH conditions in combination with suppression of negative thoughts and feelings reduced the likelihood of women in these studies accessing care (Parvin et al, 2004; Hanley, 2007; Wittkowski, et al, 2011). Asian women used specific terminology to describe their experiences and separated mental and physical symptoms in a way that might not fit with a professional’s expectations. For example, women in these studies often relied on somatic descriptions such as headaches and bodily pain (Wittkowski, et al, 2011). Religiosity was important to many of the women in these studies, and negative feelings were associated with sources of evil or perceived as being the will of Allah. It is understandable that this conceptualisation of experience would lead women to suppress their feelings rather than seek help for them.

*“If sadness comes from inside, you have to put up with it”*

(Bangladeshi Participant, Parvin et al, 2004)

*Studies Including White British Women (or ethnicity not specified)*

Difficulties in identifying PNMH symptoms were not unique to women from BAME groups/ Women from White/British mixed ethnicity also struggled to identify their symptoms (Coates, 2014; Millet et al 2018; Patel et al, 2013; Wyatt et al, 2013). Although amongst these participants it appeared that there was more awareness of PNMH conditions but that women struggled to identify when their thoughts and feelings were significant enough to indicate the presence of a mental health difficulty.

*“I found it difficult to distinguish between what was just complete exhaustion and maybe what was the depression really and I still think”*

(White British Participant, Patel et al, 2013)

It emerged that conceptualisations of motherhood were associated with perceptions of mental health, amongst the women participating in the studies the notion that a ‘good mother’ is someone who copes prevailed. Thus seeking help would be perceived as ‘not coping’ and therefore an indication that they are not as good a mother as they would like to be.

*“I remember thinking ‘I don’t want her to think I’m not coping’, which is stupid really because I wasn’t ...”*

(Unknown Ethnicity, Slade et al, 2010)

The difficulty in determining when distress has progressed beyond the realm of ‘normal’ perinatal experiences often termed ‘baby blues’, hormonal changes and fatigue coupled with a fear of not coping potentially explains why White British (or unspecified ethnicity) women in these studies may have been reluctant to access care. The lack of understanding of PNMH symptoms heightened the risk of not receiving care for women experiencing the severe condition of Postpartum Psychosis (PP) as the early symptoms were often minimised under such terminology (Glover et al, 2014; Wyatt et al, 2014).

**Theme 2: Normalisation: a Help and a Hindrance**

Stigma is a well-researched concept in the field of mental health; it is thought that the stigma associated with mental health difficulties is a significant barrier to help-seeking (Bilszta et al, 2010; Memon et al 2016). Despite endeavours to reduce stigma in mental health, stigmatisation and judgment still dominate much of the PNMH literature (Coates et al, 2014; 2015; Cooke et al, 2012; Patel et al, 2013; Plunkett et al, 2017; Millett et al, 2018).

*“I just can’t bring myself to say it. Fear of ridicule I suppose and I don’t want people to feel that I can’t look after my children because I can and I love them…”*

(White British Participant, Patel et al, 2013)

Whilst women from all ethnic backgrounds appeared to fear judgement and stigma, those from BAME backgrounds faced the ‘double stigma’ (Knifton, 2012) of:

a) Having a mental health difficulty

b) Experiencing it in the context of a dominant culture that may refute their difficulty and distress

*“There is a huge stigma of being mentally ill in the public but for us Asians there is a double disadvantage. I really fear that work will find out”*

(Asian Participant, Wittkowski et al, 2011)

In studies including women from BAME backgrounds the idea that admitting mental health difficulties would be judged negatively by their community emerged prevailed alongside fears of disclose and dominant cultures that may dispute their experiences (Parvin et al, 2004; Gardner et al, 2014; Edge, 2011; Wittkowski et al, 2011; Massood et al, 201; Raymond, 2009; Lam et al, 2012). Many of the studies included in this review advocated for the need for normalisation to allow women to feel validated (Plunkett et al, 2017; Masood et al, 2015; Raymond; 2009; Coates et al, 2015). The normalisation of negative thoughts during this perinatal period of life that is often stereotyped as blissful and harmonious was highlighted as particularly helpful (Plunkett et al, 2017). Conversely, some papers reflected a risk of normalisation, leading to minimisation of distress (Edge, 2011; Coates, 2014). The risk of minimisation is possibly associated with the lack of understanding of PNMH symptoms by women experiencing them and those around her. For a mother struggling to disencumber troubling experiences, fatigue, hormonal fluctuations and potential birth trauma, a poorly timed normalisation of her experience may compound her sense of distress and isolation.

*“There’s no point talking about this problem because everyone has to do it, it’s what women need to do, they have to do it”*

(Bangladeshi Participant, Parvin et al, 2014)

Whilst normalisation can be a helpful tool for validating people’s experiences; it would appear that fear of stigma and a lack of awareness of symptoms in this complex area of mental health can override the well-intentioned normalising statements of helpers. Until stigma in the field of PNMH is reduced on a larger scale, with careful attention paid to discrete differences in how stigma presents across cultures, attempts to normalise may fall short of the mark.

**Theme 3: Isolation & Peer Support: the Need to Share Experience**

. For women from BAME backgrounds loneliness was oftentimes exacerbated by the fact that they were geographically distanced from their immediate families (Parvin et al, 2004; Lam et al, 2012; Hanley, 2007).

*“I called back home, asked my friends and relatives to find out what to do because I have no other way to learn…I called everyday…”*

(Chinese Participant, Lam et al, 2012)

The research highlighted that for these women, their culture might also dictate that immediate family plays a crucial role in post-birth care. For example, Chinese women reported respecting the tradition of ‘Zuo Yue’ (Lam et al, 2012) where they remain at home for one month post-birth, and Bangladeshi women traditionally received family support for 40 days post-birth (Parvin et al, 2004). Further, female family networks were considered more responsible for support than fathers/husbands (Gardner et al, 2014; Parvin et al, 2004; Lam et al, 2012; Hanley, 2007) which conflicted with Westernised healthcare models and perceived paternal duties that expect fathers to share childcare responsibilities. A lack of familial care considered necessary during this period, the emotional upheaval of birth and a conflicting model of paternal expectations post-birth can lead to increased perception of isolation and difficulties in accessing care. However, the presence of immediate family did not automatically mediate feelings of isolation for many women and feelings of loneliness appeared to transcend across cultures. Indeed women from studies including a variety of populations expressed a yearning to connect with others (Masood et al, 2015; Edge, 2011; Raymond, 2009; Evans et al, 2007; Coates et al, 2015; Lam et al, 2012; Wyatt et al, 2015).

*“You also feel like you’re the only one that’s ever had all these problems, then you sit in a group with ten people all having the same problems as you breastfeeding and you think ‘oh’ that it’s not me, you know, it’s not me, it’s not because I’m a bad mum, it’s because that’s life. So that was definitely a help”*

(British Participant Ethnicity Unknown, Coates et al, 2014)

It emerged that during the perinatal period women often experience a sense of ‘emotional isolation’ (Raymond, 2009) which is a psychological experience that goes beyond the mere presence or absence of significant others in the woman’s life. For many women, the notion of connecting with peers to share experiences was more than merely appealing. From a study of peer-support as an intervention (Masood et al, 2015) it emerged that sharing experience was experienced as a powerful form of normalisation for participants from diverse ethnic backgrounds. Furthermore, a preference for single ethnicity peer support groups was not expressed by the women in many of these studies (Edge, 2011, Lam et al, 2012; Masood et al, 2015). Whilst cultural sensitivity in terms of language, culture, and diversity of group members would be important considerations in initiating peer support (Masood et al, 2015; Lam et a, 2012) grouping women by different ethnicities was by no means an essential component (Edge, 2011).

**Theme 4: Speaking the Same Language? Communication between Mother and HCPs**

Health Visitors and GPs are the first points of contact and the gatekeepers to more specialist PNMH care provisions (NHS, 2018). It is clear from the literature in this review that this link is not always explicit to service-users. On first examination of the literature, it would appear that there was a communication barrier between health visitors and women from BAME backgrounds that prevented discussions of mental health and access to specialist care (Wittkowski et al, 2011; Cantle, 2010; Parvin et al, 2004; McLeish, 2005; Lam et al, 2012). Indeed, this finding is common in studies where ethnicity is a significant focus of the paper.

*Researcher: “If you have sadness would you tell the Health visitor about this?”*

*“No why should we say?”*

*Researcher: “So you don’t tell the health visitor these things?”*

*“No!” [Whole group laughs]*

(Parvin et al 2004, Bangladeshi Participants)

The theory that cultural differences and understanding between professionals and service-users from BAME backgrounds can reduce service access is not refuted here. However, when these findings are contrasted with literature, including White British/Mixed Samples of women, an interesting finding is illuminated. Many women in these studies too were also unclear about the roles of primary care practitioners in mental health assessment and information provision (Coates et al, 2014; Evans et al, 2017; Slade et al, 2010; Cooke et al, 2012; Millet et al, 2018). The idea that primary care professionals were involved with physical health and infant care only emerged across each population.

Thus, women who are likely to have an understanding of the UK healthcare system also experienced confusion regarding who can help with perinatal distress. When this finding is combined with the aforementioned literature that suggests women from BAME backgrounds may conceptualise mental health difficulties under a framework that conflicts with Westernised models of health and care, a complex difficulty is encountered. Primary care professionals are seeking to assess specific symptomology, which women from BAME backgrounds may not present in the same way. Furthermore, these women may lack a rationale for the purpose of such discussions. With the link between physical health and mental health services seemingly unclear, the complexity of accessing care is magnified if the individual’s framework of their symptomology does not link the two either (Hanley, 2007), for example in cases of somatisation (Wittkowski et al, 2011; Parvin et al, 2004).

*“Well you won’t tell (the GP) your innermost problems. You might say, ‘I couldn’t sleep at night, because of pain, because of this and this”*

(Bangladeshi Participant, Parvin et al, 2004)

A lack of continuity of care and service-user perceptions of primary care professionals is a contributing factor to reduced access to PNMH services, although women from BAME backgrounds may face a double disadvantage. Interestingly in a survey of 4751 participants, Redshaw and Henderson (2016) found that during antenatal appointments, older women and women from Asian backgrounds were significantly less likely to be asked about PNMH. They also found that non-white, women with less formal education were less likely to be offered mental health support than White British women. Evidently more needs to be done to: increase awareness of care pathways, reduce cultural insensitivity and reduce inequity in service provision. More positively, where supportive relationships with professionals and continuity of care were established the likelihood of disclosure increased (Coates et al, 2014; Slade et al, 2010; Cooke et al, 2012; Millett et al, 2018; Massood et al, 2015).

**Theme 5: Practical Barriers**

Women from BAME backgrounds faced more practical barriers to accessing care than women in studies with White British/Mixed Ethnicity samples. Language barriers and a lack of translator was a frequently cited issue (McLeish, 2005; Templeton et al, 2003; Parvin et al, 2004; Lam et al, 2012). Written information was also often unavailable in languages other than English (Wittkowski et al 2011; Lam et al 2012).

*“…my husband left me in pregnancy, and I have no-body, my family are in India. I can’t speak English properly, and I can’t read English to fill out forms. My GP says go the HV and HV says go to GP. I don’t know what to do, I need help, don’t know where to go, or who to turn to”*

(Asian Participant, Wittkowski et al, 2011)

The issue of cultural insensitivity in services was again relevant here as two studies cited women from BAME backgrounds feeling uncomfortable discussing issues in front of male practitioners due to cultural beliefs (Raymond 2009; Wittkowski et al, 2011). Issues around childcare was a frequently cited barrier (or facilitator where it was provided) to access in studies across populations (Cooke et al, 2012; Millett et al, 2012; Massood et al, 2012; Plunkett et al, 2017). The social and psychological demand of attending appointments for women experiencing perinatal distress should not be underestimated, in addition, language barriers and cultural beliefs should be carefully considered in the provision of care to women from all ethnic backgrounds in order to work towards cultural sensitivity that is an actuality not just a healthcare discourse.

**Current Literature: Contribution to Findings**

The study by Yapp et al (2019) presents findings that make significant and current contributions to the synthesis. The results indicated that positive experiences which were likely to facilitate access involved midwives who were confident in discussing mental health difficulties. However, women who had historical experiences of mental health difficulties were more likely to experience the event negatively and fears of being perceived as ‘unable to cope’ also emerged. The results of this study complement the PNMH literature but also highlight that discussion of PNMH conditions at the first point of contact is generally acceptable and could increase access to services on the proviso that primary care HCPs have the appropriate knowledge of the symptomology.

The research by McLeish and Redshaw (2017) adds to the findings of this review in relation to the theme of isolation and peer support. This review found that peer support is a powerful form of normalisation, which is frequently cited as being useful during the perinatal period. It included a large proportion of women from BAME backgrounds and indicated that peer support may be crucial for those who have experiences of disadvantage in relation to their ethnicity and that there is power in sharing experiences with those who have encountered similar life events.

In a study of White British women, Lea, Heyes & Priest (2018) highlighted that women with Postnatal Depression often feel unheard by primary care services, and confusion from professionals regarding which services women should be referred to act as barriers to accessing care. Interestingly the report also highlighted that group support interventions were experienced as unhelpful when they were not specifically targeted at women with PNMH conditions which enhances the findings that women value peer support from those with similar experiences of postnatal depression. Overall, the findings from the new literature echo the findings of the literature included in this synthesis and add value to the aforementioned themes.

Two studies were extracted which were not formal reviews as they did not state a search strategy or a method. However, they do cite relevant literature which offers some valuable insights. Zaidi (2017) considered the link between PNMH and Islam and considered the interplay between cultural and religious beliefs which can impact positively and negatively on mental health. Zaidi (2017) highlights that: Muslim women are considered the major guardian of children, the fulfilment of religious duties in terms of breastfeeding, cultural stigma associated with not bearing male children, isolation derived from models of understanding that differ to Western society and stigma of mental health difficulties amongst the Muslim community. This paper supports the findings of this review and explores how dissonance between individual religious/cultural beliefs and British models of wellbeing and care, could be a catalyst for PNMH conditions. Firth and Haith-Cooper (2018) discuss the complexities of accessing care for vulnerable migrant women and reference a lack of knowledge of UK healthcare systems and fear that contacting services could impact their immigration status.

The findings of one unpublished doctoral thesis (Hassan, 2017) were also considered. Hassan (2017) conducted semi-structured interviews with 7 Muslim women and found that the perspectives on motherhood were unique as they were conceptualised in relation to Islamic teaching, Muslim women sourced information from many sources outside of healthcare, they experienced difficulties in expressing their religious requirements to services and assumed professionals would view Islam negatively. Improved communication and training for professionals again emerged as a recommendation from this body of work.

# Discussion

This review critically appraised two systematic reviews, evaluating the findings and combining the literature to answer the research question. The reviews were comprehensive, and of good quality, it was, therefore, appropriate to select papers from them for synthesis. From these reviews, 27 papers were thematically synthesised to pull together literature in order to produce a coherent story across them.

The review found that participants of the studies included in this review often attempt to conceptualise their PNMH symptomology using a cultural and contextual framework. A shared difficulty in identifying symptoms emerged for women from all backgrounds, which suggests that the complexity of this transitional period of life poses yet another barrier to seeking support. More needs to be done to educate women and their families about PNMH symptomology; however, culturally sensitive information should be devised rather than general information for women of all ethnicities and cultures.

The synthesis also explored the normalisation of symptoms and indicated that normalisation could be both helpful and hindering for women considering seeking help. It is postulated that normalisation can hinder women when either they, the people around them or professionals are not fully aware or understanding of PNMH symptomology. In these cases, there is a risk of under identification of PNMH conditions, where normalisation is coupled with a misunderstanding of symptoms; this risk is heightened for women who do not share the same cultural understandings as those supporting them. This is an interesting consideration for therapists and psychologists since normalisation often forms a part of a therapeutic approach, for example, Cognitive Behavioural Therapy (Dudley et al, 2007).

Experiences of isolation and peer support were identified as barriers and facilitators to help-seeking, respectively. Interestingly peer support emerged as the most powerful form of normalisation for women and reduced feelings of loneliness. This finding transcended across literature, including women from all walks of life. This holds valuable implications for service development since peer support groups could reach more people than individualised therapy and for some may even be more valuable.

The theme of speaking the same language identified communication difficulties between HCPs and service-users. It would appear that the ‘gate-keeping’ role of primary care services is unclear to many women and this forms a significant barrier to accessing care that can be compounded by different cultural beliefs and expectations of the perinatal period. Further, the common issue of practical barriers to accessing PNMH services was pertinent to this review, and indeed those from BAME backgrounds were likely to encounter more practical barriers to accessing care than those from White British or more advantaged backgrounds.

Whilst cultural sensitivity has been on the agenda some time (Bhui, Christie, & Bhugra, 1995) the research presented here would suggest that it is yet to be truly achieved in NHS services. Whilst practical barriers to accessing PNMH services remain apparent, inequity of care provision will remain across many pockets of society. Issues of diversity and difference should continue to be a focus of research and discussion across services. In addition, increasing the awareness of and reducing the stigma associated with PNMH conditions across society, and (specifically amongst harder to reach groups) may increase the likelihood of identification of PNMH conditions and service access. Whilst the funding of specialist PNMH services is a positive development (NHS, 2018), this review suggests that more work is needed at the level of primary care to facilitate discussions of mental health difficulties.

# Strengths & Limitations

This review is novel as it brings together two existing literature reviews, along with new research, with different populations to produce new findings regarding the barriers to accessing PNMH services. Women experiencing PNMH conditions are a heterogeneous group, as are the sub-groups of women that are included in this review of the literature. As such, research that groups together participants on the basis of ethnic background will still represent a diverse group of people and so transferability of experiences should be tentative. Some of the research included in this review contains a smaller sample size which limits the overall generalisability; however, findings have been supported by studies with larger sample sizes where possible. The exact demographics of participants were not always outlined in the studies. As much detail as possible was gleaned by the researcher when reviewing each study, however, in some cases, the ethnicity of individual participants could not be identified. In these cases, the papers were separated by whether ethnicity was a major focus of the paper or not (figure 2). Whilst the process of searching the literature and developing the synthesis is made transparent, the review and thematic synthesis were carried out by one researcher; as such, there is a risk of subjectivity in the review.

# Recommendations

The review provides an overview of the pertinent issues concerning accessing PNMH services. Much of the literature in the field of PNMH clusters women with a wide variety of difficulties together (Megnin-Viggars et al, 2015), another large proportion of the research focuses only on women who have experienced postnatal depression (Edge 2007; Edge 2008; Coates et al, 2015). There may be distinct differences between the experiences of women with different PNMH conditions which could be assessed further by future research. Women from BAME backgrounds are a heterogeneous group of women, many studies included here have focussed on specific sub-groups of women from BAME backgrounds but less so on the specifics of the PNMH conditions they have experienced. Future lines of enquiry could focus on specific experiences of those with different PNMH conditions and more targeted work with women from BAME populations.

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# **Paper Two**: Empirical Paper

**What are the facilitators and barriers to help-seeking for women who experience Postpartum Psychosis from Black Asian and Minority Ethnic Backgrounds?**

This empirical paper was written in line with the guidelines provided by the Journal of Prenatal and Perinatal Psychology and Health (Appendix D). This journal was selected for submission due to the particular interest in research that considers psychological factors that affect the postpartum period and influences family and society during this time. This paper adheres to the requirements of the journal, including the abstract, word count, formatting and referencing style (APA-7).

Word Count Excluding References & Appendices:7994

# Abstract

This study explored the narratives of five women who self-identified with being from Black Asian or Minority Ethnic (BAME) backgrounds and have experienced postpartum psychosis (PP). Narratives were analysed using Murray’s Framework (2000; 2008) considering the data through four lenses; personal, interpersonal, positional and ideological. Research in the field of Perinatal Mental Health is expanding but less is known about the experience of accessing care for BAME women who have experienced PP. This paper presents common themes found across the narratives including stigma, shame, and lack of compassion with consideration of the societal and cultural contexts of these experiences.

Word Count: 99

Keywords: postpartum psychosis; puerperal psychosis; postnatal psychosis; help-seeking; narrative; BAME; BME

# Introduction

*Perinatal Mental Health (PNMH) and Postpartum Psychosis*

A large proportion of women experience mental health difficulties during the perinatal period such as anxiety (13%) and depression (12%) (National Institute of Clinical Excellence; NICE; 2014). Postpartum Psychosis (PP, also known as postnatal and puerperal psychosis) is a rarer experience and affects 1-2 women of every 1000 that give birth (NICE, 2014). A prevalence rate of PP in BAME populations is not known. Research suggests the prevalence of PNMH conditions worldwide is consistent at 10% during pregnancy and 13% postnatally (Prince et al, 2007; O’Hara & Swain, 1996).

PP can be differentiated from other PNMH conditions by the presence of (but not limited to); hallucinations, delusions, mania, loss of inhibition, fearfulness, restlessness and confusion (NICE, 2014). There are no set diagnostic criteria for PP; hence this list is not exhaustive. The onset of PP is rapid, and the experience can become intense quickly (NICE, 2014). It is this rapid escalation that distinguishes PP from other PNMH difficulties (Di Florio, Smith & Jones, 2013). It is essential women experiencing PP access support quickly to promote recovery and reduce risk (Sit, Rothschild & Wisner, 2006). NICE (2018) guidelines state healthcare professionals should be vigilant for PP to support quick detection. However research suggests that women who experience PP have inconsistent encounters with services with women frequently reporting they received no information regarding PP prenatally (Forde, Peters & Wittkowski, 2020).

For some people, psychosis diagnoses are helpful as they indicate they are not alone in their experience (Pitt et al, 2007). However many people experience diagnoses as unhelpful and they can result in experiences of discrimination (Thornicroft et al, 2009) and powerlessness (Pitt et al, 2007). For those from minority groups already vulnerable to encounters of discrimination, the experience of being labelled with a psychosis diagnosis may serve to further compound distress (British Psychological Society; BPS, 2017). Mental health diagnoses, such as psychosis, are typically associated with a Westernised medical model of healthcare which uses them to describe a set of symptoms that represent a treatable illness (BPS 2017). Such diagnoses can present barriers to healthcare when a person uses non-Western terminology to describe their experience (Edge & Rogers, 2005; Edge & Mackian, 2010) The term PP is used here to refer to women who had a number of the experiences considered to be associated with PP from the perspective that it is an experience rather than an illness.

*Risk Associated with PNMH Difficulties*

Severe PNMH difficulties, including PP, pose a huge risk to mother and baby and remain a leading cause of maternal death (Knight et al 2017). Devastatingly, more than 50% of deaths during the perinatal period are of women with severe mental health difficulties or a history of them, and are attributed to suicide (Khan, 2015). Severe PNMH difficulties, without treatment or support, can lead to changes in the mother’s physical wellbeing, increased risk of suicide and impaired bonding (Ayers, Eagle & Waring, 2006).

Experiences of PNMH difficulties can also impact on foetus development which can lead to, an increased physiological stress response and difficulties in the emotional and behavioural development of the infant (Talge, Neal & Glover, 2007).Bauer et al (2014) estimated that missed detection and treatment of PNMH conditions could cost approximately £8 billion per year for each birth cohort, with the primary cost being associated with poor outcomes for children. PNMH services were established to ensure timely access to NICE recommended treatments for mental health difficulties during the perinatal period (NHS, 2018) to promote positive outcomes.

*Ethnicity and PNMH*

The abbreviation BAME is used in the UK to refer to Black Asian and Minority Ethnic communities. Whilst the term represents a heterogeneous group that make up approximately 14% of the population in England and Wales (Office for National Statistics, 2018). The most recent report presenting the Mental Health Services Data Set (MSHDS; NHS 2019) indicated for every 100,000 women, 20 less non-white British females access PNMH service, when compared to their white British counterparts.

According to the National Institute for Mental Health in England (2003) people from BAME backgrounds are more likely to experience poorer health outcomes than the majority population. The reasons for this disparity are complex; Karlsen et al (2005) demonstrated that ongoing experiences of discrimination and racism are a contributing factor to the development of mental health difficulties - including psychosis. Stress is a known contributor to poorer physical and mental health (Seeman et al, 2004) and a determinant of social inequalities in health (Pearlin et al, 2005); belonging to an ethnic minority group can increase exposure to stress, through the following mechanisms (Williams & Mohammed, 2009). Perceived ethnic discrimination is the experience of being treated unfairly due to one’s ethnic background which can occur subtly in day to day life (Ikram et al, 2015), the experience of perceived ethnic discrimination is an enduring stressor which is associated with adverse physical and mental health outcomes (Williams & Mohammed 2009; Ikram et al, 2015).

People from BAME backgrounds are also more likely to; receive psychosis diagnoses (Boydell et al, 2001) and be detained, secluded and medicated without consent (NHS, 2019). The BPS (2017) advocates that this differential treatment may be a product of institutional racism. Whereby an individual may not act in an explicitly racist manner, but through a wider level of misunderstanding, implicit bias, prejudice, discrimination and stereotyping, people from ethnic minorities are treated differently than those who belong to the majority population. As a result a person belonging to an ethnic minority group may become averse to seeking help early on (BPS, 2017).

Prady et al (2016) found, during the perinatal period, BAME women were 55-70% more likely to have anxiety identified on their medical record in comparison to White British women. However, they were significantly less likely to be offered pharmacological/non-pharmacological treatments. Knight et al (2017) also highlighted the risk of maternal death for women significantly higher for BAME women than for women from White British backgrounds. With the need for the early detection of PP, the risks associated being high, and funding for PNMH services increasing (NHS, 2016) it is imperative that more is done to understand why fewer women from ethnic minority groups are accessing PNMH services in order to promote better outcomes for this population.

# Research Question

This research aims to explore the subjective experiences of women from BAME backgrounds that have experienced PP using a narrative methodology:

1. What are the facilitators and barriers to help-seeking for women who experience PP from Black Asian and Minority Ethnic Backgrounds?

# Method

*Narrative Research*

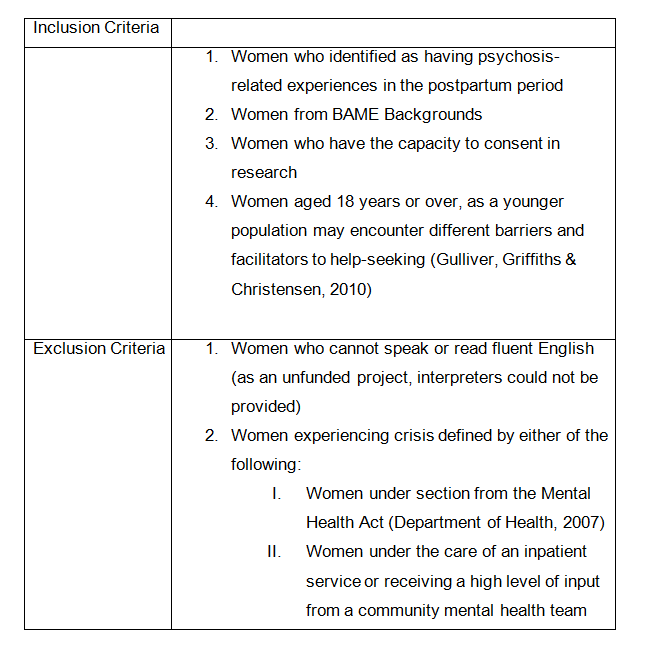
A narrative approach to the research question was adopted. This approach goes beyond considering causal inferences and allows for exploration of how individuals construct their experiences with consideration of personal, social and cultural contexts (Andrews Squires & Tamboukou, 2013). The narrative approach allows for the participants’ stories to remain whole throughout the analysis (Etherington, 2013) and therefore is an appropriate methodology for examining under-researched experiences.

A commonality of narrative approaches is that they are focussed on gathering detailed accounts of a person’s experience in order to provide comprehensive descriptions and meanings (Reissman, 2008). Murray’s Narrative Framework (2000; 2008) uses four lenses, the; personal, interpersonal, positional and ideological (as described below), in order to gain insight into lived experience. Squire (2008) advocates through stories, experiences become part of consciousness - the use of the four lenses allows for these stories to be examined in relation to societal and dialogical factors which influence the interview and story creation.

*Recruitment*

Participants were recruited using purposive sampling, in order to allow for the identification and selection of women who fit the inclusion criteria (Palinkas et al, 2015). Action on Postpartum Psychosis (APP) is the national UK charity for women affected by PP (APP, 2015). APP supported the recruitment for this project by advertising (appendix E) the study through their social media channels (Facebook, Instagram and Twitter). As users as of these channels could share the post, there was a snowball effect on the sampling method.

A total of nine (appendix F) women responded during the advertisement phase, which lasted six months. Data was collected as participants responded to the advert. Two women were excluded as they did not meet the inclusion/exclusion criteria. Of the remaining seven women, two did not respond to follow-up communications. A total of five women completed the interview process. Participants were invited complete the interview via Skype or in person. Four of the participants completed the interview via Skype, and one was completed in person.

**Table 1. Inclusion & Exclusion Criteria**

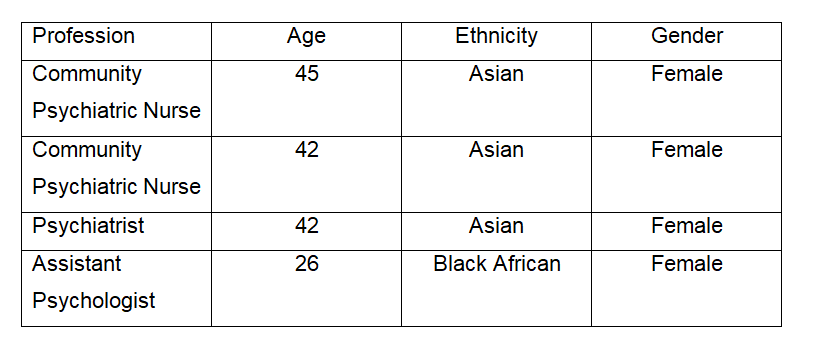
*Ethical Approval*

This study was granted ethical approval by the Faculty of Life Sciences and Education Ethics Panel at Staffordshire University (appendix I). Participants’ experiences were handled sensitively and ethically, with respect and concern for participants’ wellbeing. Participants were reminded of their right to withdraw and made aware of the support available (appendix G).

*Consultation*

Four research consultants from BAME backgrounds with experience of working in PNMH services were recruited to offer consultation on the analysis and results of this paper. Each consultant met with the researcher for one hour to discuss their views. Bryman (2016) states triangulation of data can take place with those who could offer different perspectives to the researcher, to strengthen the researcher’s standpoint. The aim of the consultation meetings was therefore to increase the researcher’s awareness of and sensitivity towards issues faced by people from BAME backgrounds when accessing mental health services.

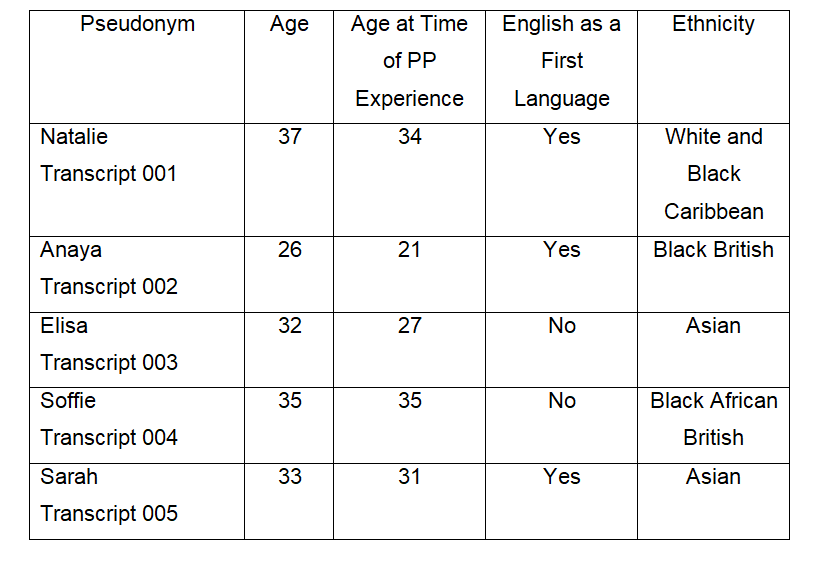
Table 2. Consultant Demographics



*Participants*

The following participant demographics were collected.

Table 3. Participant Demographics



*Procedure*

Participants responded to the advertisement by email. The researcher sent electronic copies of the participant information pack (appendix G), demographic collection form and consent form (appendix H). The researcher followed up with participants within 1 week. Participants signed two copies of the consent form before starting the interview. A copy of the signed consent form was retained by both the researcher and the participant. Each participant completed a semi-structured interview lasting up to 1 hour.

The interviewer utilised a broad interview schedule using open questioning (appendix M) as the narrative approach aims to elicit as much storytelling from the participant as possible (Andrews et al, 2013). Participants were invited to share their story to generate data. Interviews were recorded using a digital device and transferred to an encrypted device within 24 hours. All participants were advised they could withdraw their data for a period of up to two weeks following completion of the interview. Interviews lasted between 20 and 54 minute (mean duration 40 minutes).

*Reflexive Position*

The researcher holds a critical realist epistemological position assuming the data tells a story of reality (Bhaskar, 1989), but it may not be a direct mirroring of reality (Harper & Thompson, 2011). The researcher was concerned with what experiences the participants had encountered, the meanings they attributed to these experiences and the interpretation of those experiences (Casey, Proudfoot & Corbally, 2015).

The researcher is a female Trainee Clinical Psychologist with a specialist interest in PNMH. She is of a White British background. The interest in researching women from BAME backgrounds was born out of professional observations of inequality in service access. The researcher aimed to analyse and understand the participant’s narratives within the context of the their cultural experience; however it is possible due to her professional status and ethnicity the interpretation may have lacked some culturally specific nuances. Consultation was accessed to increase researcher awareness in relation to cultural elements of the work and issues faced by BAME communities.

Murray’s Narrative Framework (2000; 2008) allows for issues of difference and power to be considered within the analysis. A reflective diary and supervision were utilised to aid this process. This method of reflexive work can counter potential biases and enhance transparency (Ortlipp, 2008). The reflective journal allowed for the complexity of the research process to be made more visible to the researcher and supported with the organisation of data under each of the four lenses. The reflective diary was re-visited during the consultation phase, which allowed the researcher to further understand their own prioritisation of the data.

*Transcription and Analysis*

Audio recordings of the interviews were transcribed verbatim, removing any identifying information. Punctuation has been added to quotes to enhance readability. Each transcript was analysed using coding and memo writing (appendix J) in addition to both top-down (considering the broad stories contained within the narratives and working towards the specifics) and bottom-up (considering the specifics of the individual narrative and working back towards the broader story) approaches to keep the narrative whole (Andrews et al, 2013). The researcher moved back and forth between transcripts examining them under the four lenses (Murray, 2000; 2008), as below, and generated an integrated narrative (Appendix J-L). An integration of the key ideas from each narrative is presented to demonstrate how the narratives are connected.

# Results & Discussion

The analysis through each of the four lenses is described below (Murray 2000; 2008) beginning with (1) the personal: considering significant events and experiences to gain understanding, paying attention to the narrator's tone and use of language; moving to (2) the interpersonal: the researcher considered how the stories were constructed between the narrator and researcher by considering the flow of the interview and the context of it. At (3) the positional level: issues of difference and power were considered. Finally, at (4) the ideological level: the participants' perception of their experiences was analysed in relation to societal and cultural customs associated with ethnicity and PP.

*Analysis of Results*

*Personal Level*

At this level of the analysis, close attention was paid to how each participant constructed their experiences (Murray, 2000; 2008) and significant events that formed barriers and facilitators to accessing care.

*Natalie’s Story*

Natalie’s story is one of being unheard by medical professionals and resilience. During labour she experienced a lack of compassion from professionals. Soon after the birth of her son, she began to experience psychosis. Natalie described the frustrations of not being listened to, leading to her feeling ignored and powerless against clinicians.

*“I never really felt like anyone was keeping me in the loop of what was going on with either me or my son, again, I don’t know if that was because of the symptoms I was showing that they didn’t think I would understand what they were saying”* (T001-Pg6-L10-13)

Natalie’s mother and husband were key characters in her story that helped care for her during labour in the absence of compassionate professionals.

*“I begged my husband not to leave me which he didn't and they must have realised that something was going a bit wrong because they didn't insist my husband left”* (T001-Pg2-L24-26)

Themes of stigma and shame associated with the experience of PP transcended Natalie’s story. Stigma is the process during which the following happens or is anticipated; a person is recognized as belonging to a particular group, stereotypes are activated, and prejudice or discrimination occurs (Corrigan, 2004). Stigma can often be associated with shame; shame can be defined as the intense emotional experience of negative self evaluation caused by failing to meet expectations of either ones’ self or a societal/cultural norm (Benetti-McQuid & Bursik, 2005). Edge and Mackian (2010) found stigma associated with psychiatric labelling is more prevalent in BAME communities, this could be linked to findings which demonstrate people from BAME backgrounds are more likely to receive diagnoses and less likely to feel listened to by professionals (NHS, 2019; Wittkowski et al, 2011).

*“I think I was sort of ashamed of it of the experience and embarrassed by it… if it had been postnatal depression I like to think that I would have not felt that stigma” (T001-Pg16-L15-20)*

Natalie was ignored and disempowered by professionals during her labour. BAME women can be disempowered in maternity service when professionals make value judgements on the basis of invalid stereotypes such as perceiving BAME women as either too submissive or too demanding (Lyons, 2008) or more likely to complain about pain (Katbamna, 2000). Natalie was referred to an Early Intervention Service, which she experienced as supportive. Despite this, Natalie remained keen to dissociate herself with services.

*“I was just really wanting to put the whole thing behind me and didn’t want to be struggling with mental health issues ongoing”* (T001-Pg10-L9-11)

It is possible the costs to her own wellbeing associated with the lack of compassion from professionals was, to her, equally as detrimental as receiving no care at all. From here grew a sense of self-reliance and resilience out of a need for control.

*Anaya’s Story*

Anaya’s story progresses from disempowerment to empowerment. Anaya experienced physical trauma during birth and a lack of compassion from professionals.Anaya’s experience of psychosis, including sleeplessness and hallucinations, began once she returned home after giving birth. Anaya’s husband took the role of decision-maker in her story, and facilitated her access to services.

*“My parents in law spoke to my husband and said, “you know what the choice is yours you are Anaya’s sole carer well next of kin you make this decision - do you want her to go to the hospital to get help or do you want her to stay at home?”* (T002-Pg3-L24-27)

Her narrative of the pathway to being placed under section on an acute mental health ward before reaching a PNMH service was one of dehumanisation and disempowerment; statistics show people from BAME backgrounds are more likely to be medicated without consent (NHS, 2019).

*“They sedated me there was about six staff members that had to pull me down on the bed and then they said they gave me an injection on the bum they took off my trousers and I just thought that is so inhumane”* (T002-Pg5-L18-20)

Anaya experienced her mental health difficulty in the context of her family’s African cultural beliefs. A commonly held African cultural belief is mental health difficulties are associated with demons, curses possession etc. which can lead to those experiencing the difficulties being stereotyped as shameful or unpredictable (Kimotho, 2018).

*“I feel like it's such a stereotypical view that like when someone becomes unwell when it comes to mental health that they especially think that they’re possessed”* (T002-Pg10-L1-2)

When she was able accessed PNMH services Anaya experienced them as supportive. For Anaya, these positive experiences did restore her faith in services. From this juncture, Anaya thought about her own perspective on her family’s belief systems rather than subscribing to them.

*“What helped me is the fact that I was born here and I got married quite young to my husband, and even though we're both religious people, but at the same time we're in touch with reality”* (T002-Pg10-L8-11)

Anaya empowered herself by separating herself from those who attributed stigmatising, shaming beliefs on to her, cutting ties with her own parents, but like Natalie, developed a strong sense of independence and self-reliance.

*Elisa’s Story*

Elisa’s narrative was one of an unexpected mental health difficulty and gratitude. Elisa’s narrative began with her shock at having PP, having never encountered it before.

*“I didn't expect to have erm Postpartum Psychosis and there is not any history of having suffering from Postpartum Psychosis in erm in my gene”* (T003-Pg3-L18-20)

Elisa described difficulty sleeping, taking care of herself and of her baby. Throughout Elisa’s story, she conceptualised her experiences around a medicalised illness model, presenting PP as a genetic, treatable condition but also a perceived weakness.

*“I recover now and taking the medicine”* (T003-Pg2-L23-24)

*“And after taking errr ECT[[3]](#footnote-3) I was feeling better”* (T003-Pg4-L27)

Elisa reported she found services easy to access and noted location was a facilitator.

*“I heard that many places they hasn't got a mother and baby unit you have to travel from far away to get this ... so if every hospital has got the mother and baby unit it would be very easy for the mothers and babies”* (T003-Pg5-L6-8)

Elisa described positive experiences of PNMH services and she expressed gratitude for the care she received.

*“They erm really helpful and they really appreciated me so I'm really happy about that”* (T003-Pg4-L16-17)

Elisa also described a strong support network in the form of her husband family and friends who helped to facilitate her recovery.

*Soffie’s Story*

Soffie was of a Black African British background. Soffie was diagnosed with bipolar disorder at 24 years of age. Soffie was 35 years of age at the time of the interview. Soffie reported previous negative encounters with mental health services.

*“They (services) wait until… it as the very worst stage before there is any help available” (T004-Pg13-L24-25)*

Soffie was therefore reluctant to engage with services. Soffie described a lack of understanding from professionals she encountered and sense of inevitability to her distress.

*“There was nothing to prevent it from happening, because I was already from when the baby was ill, I was already not in the right state I was already going down but no one could see because it looked very similar to what a normal mother would feel after birth”* (T004-Pg7-L9-12)

Soffie also makes clear if they could have; her family would have prevented her from accessing services even when acutely unwell.

*“This doesn’t happen in our family we don't have ill - we don't have mentally ill people in our family” (T004-Pg6-L13-15)*

Admittance of a mental health difficulty was associated with a strong sense of stigma and shame which shared stark similarities to Anaya’s account.

*“Admitting that somebody in the family is unwell I think there's a stigma… a stigma attached”* (T004-Pg6-L9-10)

Soffie’s husband was a decision-maker who made choices that went against the family’s wishes. Soffie’s family did not face the reality of her being hospitalised creating a sense of isolation.

*“They want to pretend it's not happening…when everything is okay, when you get back to normal we'll come back, while you're having your issue you stay over there we'll be over here”* (T004-Pg9-L33-35)

Soffie appreciated the need for intervention whilst acutely unwell but an overall reluctance to engage with services remained. Soffie made an astute point, commenting on the availability of services but that accessing services presented its own challenges.

*“I don't think there's any barriers to services the services are there and they are available I'm just trying to think was I resistant to going? Yeah I was”* (T004-Pg8-L18-20)

Soffie’s narrative reflects a complex inextricable barrier faced by people from BAME backgrounds, their communities may stigmatise mental health difficulties (Kimotho, 2018). However it has been evidenced they are also more likely to encounter discriminatory practices (Lyons, 2008), which could intensify feelings of shame (Rüsch et al, 2010), leading them to further delay access. Despite Soffie’s family refusing to recognise her distress, Soffie was able to conceptualise their perspective from a position of acceptance.

*“Understanding that people cannot reach you where you are if they haven't got the capacity to reach you so with my family they don't they don't have that in them”* (T004-Pg11-L1-7)

Whilst being accepting of her family’s position, Soffie herself did not subscribe to it, she became self-reliant and expressed a desire to go against the status quo of her community and make her story heard.

*“I do want to get quite involved in raising awareness of stuff like that especially for postnatal psychosis… because it's really really needed”* (T004-Pg7-L8-11)

*Sarah’s Story*

Sarah is a resident of the United Kingdom, with the majority of her family residing in America. While on holiday in America, when her son was 2 months old, Sarah experienced psychosis and was hospitalised there before returning to the UK. Sarah’s story begins with the busyness of the trip, sleeplessness and familial pressure. Sarah described the importance of birth traditions in Korean culture and the pressure these traditions created. Sarah had gone against these traditions by not adhering to the confinement period.

*“They think the period the first hundred days is very, the baby is considered very vulnerable”* (T005-Pg1-L24-25)

Initially, Sarah was disempowered by the pressure of her family and the sense of duty to adhere to their principles.

*“A lot of other traditional things like they're very preoccupied with babies being cold and so they would like layer all these blankets on him which you know, the NHS is like don't do that to a new-born”* (T005-Pg2-L12-15)

Sarah also experienced high levels of stigma and shame associated with having a mental health difficulty.

*“I think there's still a very deep level of shame around it, and kind of the fact that kind of reflected in what my mother in law said, is that it's a choice in a way like I could have at some point I suppose been like no I'm not going to have a mental breakdown”* (T005-Pg4-L15-18)

Sarah’s husband was a source of support. Sarah’s husband was a gatekeeper who broke tradition and went against the wishes of her family in making the decision to access emergency services.

*“He’s not very Korean because he had zero sense of obligation we left we left like the day before the 100-day celebration”* (T005-Pg10-L21-22)

Sarah was able to be understanding of her familial belief systems and made sense of them in an accepting way. Her understanding of her separation from these cultural beliefs was similar to Soffie’s.

*“I am somewhere in the middle you know not entirely Western not entirely Korean either, but I stopped taking it so personally and because I - yeah I think that helped in that I realized they were just going to feel that way no matter what I was doing”* (T005-Pg7-L13-16)

Sarah also reflected on how her culture may contribute to women experiencing PNMH difficulties being hidden.

*“I think the sort of Asian confinement belief that must have existed for a reason the 21 days, I mean I guess it's meant to protect the baby, but I think it's also in a way to shield people from seeing like a new mother”* (T005-Pg8-L20-23)

Sarah had a positive experience in accessing PNMH services and she expressed gratitude for the service provided. Sarah believed her most significant barrier to care was the cultural pressures and familial belief systems. Despite this Sarah was not inhibited in being open with others about her experiences, through sharing her experience she took back control.

*“We've always been very honest about what happened and I think that always takes people by surprise, I do think it helps because then at least we're breaking the cycle, you know this is another secret that's like hidden away somewhere“* (T005-Pg11-L18-20)

*Integrated Personal Narratives*

Integrated narratives are distinct from the four lenses, the narratives are integrated to develop a common plot and generate meaningfulness across the stories (Murray 2000; 2008). The narratives presented are narratives of quest (Frank, 1995). According to Frank (1995), storytelling presents the opportunity to restore what could have been lost. The experience of psychosis may be psychologically disordered and chaotic (Bjornestead et al, 2018), but the integrated narrative demonstrates how the participants conceptualised this and overcame the challenges.

These women faced a diverse range of challenges. However, through analysis, commonalties were established. Each story opened with the chaos PP instilled upon the participant’s life and progressed towards restoration. Each narrator described the trials and tribulations posed to them by PP. A lack of compassion or understanding from professionals was frequently cited during or following labour. Stigma was a component throughout each of their stories, although it presented in different forms. Cultural pressures and negative perceptions of mental health difficulties were particularly pertinent to Anaya, Soffie and Sarah. From there emerged turning points and epiphanies where the narrator presented a shift during which they overcome a barrier. In Natalie and Elisa’s case, family members were protectors, who supported change. For Anaya, Soffie and Sarah oftentimes family members inhibited change, through accepting their families’ viewpoints without immersing themselves in them they were able to overcome the barriers presented. For each narrator, the husband was an essential character in their narrative that supported the access of services. Positive experiences of accessing PNMH services were common. Following the turning points and epiphanies, each woman emerged from their experience through resilience and recovery.

*Interpersonal Level*

At this level, the way in which the narrator developed their story, the tone of the story and how the story was constructed between the narrator and researcher is examined (Murray 2000;2008).

Since high levels of stigma and shame were present in the narratives, the restorative nature of each story may have served an essential function. It is hypothesised that the creation of progressive restorative narratives allowed the narrators to enforce order onto the chaos PP brought to their lives. Kreuter et al (2007), in research around cancer, described the process of creating a narrative as an opportunity reframe illness as an issue which provide an opening for positive change. Many of the stories began with the narrators experiencing adversity, overcoming it through a variety of mechanisms which culminated in epiphanies and change.

*“Everything worked out in the end it could have really gone badly erm when I was depressed I was able to pray and try you know and come out of that”* (T004-Pg12, L14-16)

Sharing stories that ended with restoration and hope potentially served a purpose and the researcher was a part of this purpose. The research interview may have presented the opportunity to be listened to where previously the participant had experiences of being unheard. By sharing stories of hope, the participants may have strengthened their own hope whilst perceiving the researcher as able to further strengthen hope for other women by distributing the findings of the study (Rosetto, 2014).

*“I just wish that more women would do research”* (T002-Pg13-L37-38)

Family pressures and cultural beliefs as disempowering were relevant to Soffie, Anaya and Sarah. The words ‘constant’ and ‘pressure’ both featured frequently in Sarah’s narrative. With the exception of Elisa, each of the women gave either reasons for why their stories have been hidden previously or examples of people not recognising them. The word ‘listen’ was used frequently in Natalie’s narrative. The sharing of their stories in the face of such adversity demonstrates courage in speaking out.

*“Overall like the reason I wanted to take part in the research because I know for a fact my parents will say that my family were very reluctant for me to get in contact with services”* (T004-Pg6-L5-7)

*Positional Level*

At this level, the context of the interview and the researcher’s position in relation to the participants is considered (Murray, 2000; 2008).

Participants were aware the interview was undertaken for research purposes. As such, ideas of who their story was being told for such as, other women with shared experience may have been held in their awareness. Hence, narratives had a performative function (Riessman, 2008), meaning the anticipated response of the researcher and the reader were implicated in the storytelling.

Whilst the researcher encouraged free-flowing storytelling as far as possible, participants were essentially primed to provide a story in line with the aims. In order to fulfil the ethical requirements of the research participants under section or receiving intensive support from services were excluded from the study. Therefore, participants were recounting their stories at a distance from the experience of psychosis which may have allowed for a more ordered narrative of a disorganised psychological experience.

Participants told their story to the researcher, a White British female, Trainee Clinical Psychologist, synonymous with the UK Mental Health Workforce. Whilst researching from a position associated with power and authority, Wolf (1992) maintains a feminist perspective and posits that researchers can endeavour to ensure participants are not powerless in the process, and power is a construct which is not indefinitely present but constructed between researcher and participant. Hence by eliciting storytelling without intensive direction from the researcher, it is hoped that participants were able to convey the issues they believed to be pertinent to their narrative. The researcher acknowledges her position as a historical being with social and professional interests that shaped her enquiry (Harding, 1989) and these can never be separated from the construction of the research in their entirety. However, a reflexive position was maintained throughout. This enabled the researcher to maintain knowledge of her position in relation to the research in an attempt to capture the narrative of the participant. Although the researcher presented as an empathic listener, her presence alone and the power imbalances inherent to her working status and ethnicity may have inhibited or placed emphasis on elements of the narrators' storytelling, for example, positive accounts of PNMH services. There is a sense that participating in this research is allowing these narratives to be heard which was of importance to participants, with the researcher experiencing a sense of urgency during interviews.

*“We will get published I am going to pray on that”* (T004-Pg14-L27)

Experiences of power are relative and contextual (Chen et al, 2001). The impact of visible difference, sense of belonging to a minority group, potential perception of researcher as a clinician and past experiences of powerlessness cannot be ignored. An individual’s power status cannot be defined in concrete terms however Keltner et al (2003) theorise that those with perceived lower power status (including those from minority ethnic groups) are more likely to be sensitive to evaluation from others and present with a higher tendency towards inhibition. It is therefore likely that participants were sensitive to how the researcher might treat their narratives. Hence concepts such as stigma and gratitude for PNMH services may have felt safer to discuss over more challenging narratives (Illingworth, 2006)

*Ideological Level*

At this level, dominant cultural representations of PP, ethnicity, gender and help-seeking are examined. The way in which participants positioned themselves in relation to these representations is discussed (Murray, 2000: 2008).

Research has highlighted inequalities in maternity service provisions for women from BAME backgrounds (Bharj & Salway, 2008). To date, inequitable care remains an issue in UK society (Knight et al, 2017). Many of the narratives of these women did not provide evidence to the contrary. For Natalie, Anaya, and Soffie, experiences of uncaring professionals was a part of their narrative. Sarah and Elisa provided little detail regarding their labour experience. Anaya, Soffie, and Natalie recognised the injustice in their treatment. Natalie described a dilemma in trying to understand and position herself in relation to dominant narratives regarding the treatment of people experiencing psychosis and those from ethnic minorities.

*“All I can say is I was the only one on the ward showing those symptoms and I was the only one from an ethnic minority so it's a bit chicken or egg isn't it? To say why I was treated so differently?”* (T001-Pg3-L23-26)

This statement summarises the likelihood of a person with an acute mental health need or from an ethnic minority being treated differently in the care system and her own struggle in trying to make sense of this. Mothers from BAME backgrounds are known to experience unsatisfactory care during labour (Bharj &Salway, 2008). Women from ethnic minorities are less likely to be offered pain relief during labour, more likely to deliver by emergency caesarean, less likely to feel listened to and as though they have been treated with kindness (Henderson, Gao & Redshaw, 2013). The literature also suggests those from ethnic minorities are less likely to access help for PNMH difficulties (Cantle, 2010) and Soffie sheds light over this issue from a community level.

*“I can’t speak for every Black and ethnic minority person including the Asian community but we let it get to that point but we let it get so far as almost untreatable before help is sought”* (T004-Pg13-L36-40)

Soffie reflects on the beliefs of her community to hide away a person with a mental health difficulty rather than encouraging them to access care. The reluctance to access services may be further compounded by poor experiences with services (Henderson, Gao & Redshaw, 2013). PP is a lesser-known PNMH condition, and a lack of recognition of it at the primary care, family and cultural level was found across the narratives. This lack of recognition could lead to increased risk to mother and baby’s wellbeing (Ayers et al, 200; Talge et al, 2007).

*“They couldn't understand why I was there because I was very calm it does psychosis it's a bit like that your focusing on all these things but then there are times where you're very normal and a functioning but all of these people that know you can tell that the minute you are not yourself”* (T004-Pg4-L28-32)

Participants recognised PP has more stigma attached to it within society than other more commonly experienced PNMH conditions.

*“It sounds weird but depression and anxiety postnatal depression and postnatal anxiety… people aren’t freaked out by them if you say psychosis to somebody it’s still a conversation stopper”* (T001-Pg16-L7-10)

In a survey of 740 BAME people, Rehman and Owen (2013) reported 32% of participants indicated they had been treated differently or discriminated against by their community because of their mental health difficulties. Goodman (2009) found stigma was the second most commonly associated barrier to help-seeking for women experiencing postpartum depression, with the first being a lack of time to seek treatment. There is a stigma associated both with PNMH conditions (Bilszta et al, 2010), and mental health difficulties within BAME communities (Knifton, 2012), thus, women from BAME communities experiencing PP are vulnerable to multiple stigmas, which may further compound the barriers to services.

Participants frequently came up again cultural conceptualisations of their distress, which conflicted with dominant Westernised illness conceptualisation (BPS, 2017). It is important services develop further understanding of such conceptualisations to facilitate access. These conceptualisations were often associated with a strong sense of stigma. Whilst stigma is widely documented in broader mental health (Clement et al, 2015), and BAME literature (Memon et al, 2016) a much deeper level of fear amongst ethnic minority communities in relation to PP was revealed in these narratives. This fearfulness could have been compounded further in the absence of compassionate caregiving.

*“She (midwife) was horrible really…I remember the words she said “oh you think this is pain? Wait until you feel real pain”* (T002-Pg2-L1-3)

In some cases, families held collective shame for mental difficulties, which led them to delay access to healthcare.

*“So once the actions of one individual reflect on the entire family”* (T005-Pg11-L30)

Further, Knifton (2012) in BAME communities’ families experience associated stigma. This level of stigma and shame in combination with culturally insensitive services serves as a further hurdle to accessing services (Knifton, 2012).

*“He was hearing voices and then they sent him back my family is from Gambia they sent him back to Gambia and he just sat there like a sitting duck you know”* (T004-Pg6-L18-20)

Several women spoke of how they were able to separate themselves from cultural representations of mental health difficulties by examining their own perspectives. All of the women who participated in this study had husbands who supported them to access care and often made decisions that went against cultural beliefs in their community.

*“I do think it's interesting that the only reason he took me to the hospital was that he was talking to one of our non-Korean friends who immediately was like she sounds really unwell I think you should take her to the emergency room”* (T005-Pg8-L12-14)

The importance of men as decision-makers in these narratives cannot be ignored. Traditionally marriage occurred in patriarchal societies allowing for male dominance (Howell, 1987), an artefact that can still be found in modern society. Their roles in the narratives presented here raises important questions about what outcomes may have arisen should these husbands have been complicit in familial suggestions (Greenwood et al, 2015; Boydell et a, 2006) to delay access to care and is an issue that warrants further investigation specifically in relation to PNMH and PP.

In broader studies of help-seeking behaviours for people experiencing psychosis several barriers to help-seeking have been identified, such as poor community awareness and lack of understanding of the severity of symptoms (Addington et al, 2004; Etheridge et al, 2004; Boydell et al, 2006). Not knowing the signs to look for, or having awareness of them, alongside avoidance of healthcare service, for reasons such as stigma (Edge & Mackian , 2010) and poorer treatment offers for people from BAME backgrounds (Prady et al, 2016) can have serious detrimental consequences to the physical and mental wellbeing to mother and baby (Knight et al, 2017, Ayers et al, 2006).

# Strengths & Limitations

The aim of much qualitative research is to understand a specific experience or phenomenon in detail over an analysis that allows for broad generalisations to be made (Leung, 2015). Whilst generalizing these findings to the diverse and homogeneous population BAME women in the UK was not the aim of this research, their narratives illuminate the ways in which BAME women who experience PP, might encounter healthcare services and the context of their narratives is supported and reflected in existing research. A strength of this research is its originality. The experience of accessing care for women from BAME backgrounds who have experienced PP are absent from the current evidence base.

The online recruitment strategy whilst far-reaching prevented those without access to the internet from participating. Hence the recruitment was limited to the demographic reached by APP, the overall characteristics of this demographic are not known. Of the women who went on to participate, though not asked about this explicitly, four of the five mentioned their careers. The study was not accessed by women from BAME populations without partners or from more impoverished socioeconomic standing. This may be representative of the multifactorial barriers to making one’s self heard as discussed above (Watson et al, 2019) and women from these groups may have added further insight into the challenges and barriers to accessing care.

Stigma was a pertinent facet of the narratives presented. Stigma is well cited concept in the field of mental health (Thornicroft et al, 2016) and therefore, potentially a safer topic for discussion. The lack of compassion presented may reflect experience of perceived discrimination and structural racism (BPS, 2017). On conceptualisation of the interview schedule open rather than specific questions regarding experience were devised. On reflection the power status of the researcher in the interview context may have impacted and/or inhibited certain elements of what was told in the narratives. In order to enhance the researcher’s analysis of the results, consultation was sought. Still, participants may have benefitted from more specific invitations to tell stories of racism, or discrimination, which may have felt less safe to do. Further studies which consider issues of structural racism and discrimination directly are recommended.

Due to time constraints of the project, participant validation of analysis was not possible, a process thought to increase the rigour of qualitative work (Willig, 2013). However, the critical realist reflexive position (Bhaskar, 1989) recognises the contextual nature of the results and research interview. Whilst participant validation could add weight to the researcher’s findings it would have occurred some time after the interview, adding new conditions and context to the research. With regards to validity, the analysis utilised the methods laid out by Murray’s Narrative Framework (2000; 2008), and the process of completing the analysis has been documented to demonstrate the process and depth of the analysis (appendix J-L).

The research was conducted by a single researcher, although steps were taken to minimise researcher bias through the use of consultation, supervision and a reflective diary. In addition, the reliability of multiple analysts in narrative methodologies has been queried due to the time required to achieve sufficient familiarity with the data (Andrews et al, 2013).

# Clinical Implications

The sample was heterogeneous in terms of their ethnicity. Nevertheless, commonalities were found that shed light on their experience, which holds important implications for practice. There is a significant impact of stigma, shame and cultural beliefs which are detrimental to the process of help seeking for women from BAME backgrounds. The findings presented here suggest more work is needed to reduce the stigma associated with PP at a grass-roots level before reducing stigma becomes close to an actuality.

However this forms only a part of a complex picture, which is impacted further when these women come up against service, systems or professionals which do not treat them with compassion – an issue which warrants further investigation. Despite legislation to promote equitable access and delivery for all across maternity services dating back to 2008 (Bharj & Salway, 2008), the narratives presented here suggest this is yet be achieved, and more work in this area is still required.

The NHS Constitution guidance (NHS, 2015) lays out several values services should strive to uphold, including compassion. Participants felt they were treated without compassion and this was compounded by experiences of powerlessness. Compassion is an experience that should be common to all encounters with healthcare services and not limited by the presence of race or a mental health difficulty. For those from ethnic minority backgrounds experiencing a mental health difficulty the issue of double-stigma remains (BPS, 2017) and requires targeted work across UK healthcare systems.

PNMH services were experienced positively by participants who reported feeling heard by such services. Many of the women commented on the helpfulness of the care planning received by such services. It is essential that such services continue to raise the profile of the lesser-known PNMH conditions such as PP. Findings may contribute to the developing evidence base and support the need for more BAME service user involvement in the development of healthcare provisions and training of healthcare professionals.

# Future Research

Partner studies in relation to PNMH are increasing (Burgess, 2011; Wong et al, 2016). Future lines of enquiry might consider both the role of partners for BAME women who experience PP and how PP impacts mothers without partners. Studies that further examine; awareness of PP amongst professionals and women of childbearing age, prevalence of PP in BAME communities, assessment of PNMH for women from BAME backgrounds, and longer terms risks of PP to women from BAME backgrounds are warranted.

The lack of compassion and experiences of disempowerment voiced in these narratives raises important questions about the state of current healthcare provisions for people BAME backgrounds. Their narratives reflect current statistics that women from BAME backgrounds receive poorer care in maternity services and BAME people are more likely to be sectioned and medicated without consent in mental health services (NHS, 2019). Studies on the larger social impact of racism, discrimination, prejudice and inequities in service provision could build upon these Consultation on service provision, with people from BAME backgrounds, could be sought to further support the development of services.

# Summary & Conclusions

This study explored the barriers and facilitators to accessing care for women from BAME backgrounds that have experienced PP using Murray’s Narrative Framework (2000; 2008). A lack of recognition and compassion in maternity services, stigma and shame at a personal and ideological level, family members as both facilitators and barriers to help-seeking, an ability to separate one’s self from stigmatising perceptions of PP and avoidance of services were amongst the key findings. Supportive family members, experiences of being heard and supported, access to PNMH services were all key facilitators to accessing care. This research may be of interest to women with similar lived experiences, clinicians, managers and commissioners.

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# **Paper Three**: Executive Summary

**What are the facilitators and barriers to help-seeking for women who experience Postpartum Psychosis from Black Asian and Minority Ethnic Backgrounds?**

Word Count Excluding References: 2326





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**Background**

The target audiences for this executive summary are women with lived experience of postpartum psychosis, their families. It may be of more general appeal to people with an interest in Postpartum Psychosis or issues pertinent to people from Black Asian and Minority Ethnic (BAME) communities. Two peer-support workers from Action on Postpartum Psychosis (APP), with lived experience of postpartum psychosis, were consulted with regards to the production of this executive summary and provided feedback on the accessibility to the general public.

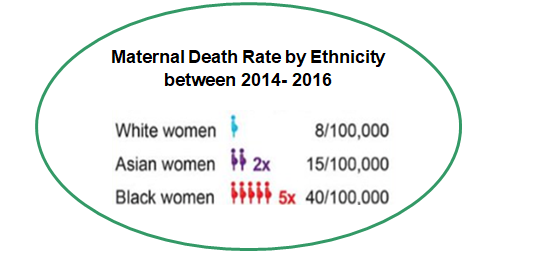
The perinatal period is the period of time that runs from pregnancy through the first year following birth1-2. Postpartum psychosis is also referred to as a ‘puerperal psychosis’ and ‘perinatal psychosis’; these terms all describe the same difficulty. Throughout this executive summary, the word postpartum psychosis is used. There are no set criteria for diagnosing postpartum psychosis; however according to the National Institute for Health and Care Excellence (NICE), the following symptoms are commonly reported1-2:

* Hallucinations
* Delusions
* Mania
* Loss of Inhibition
* Fearfulness
* Restlessness
* Confusion

Whilst these are the commonly reported symptoms, they are not the only symptoms, and every woman’s experience of postpartum psychosis is different. Postpartum Psychosis is a severe mental health difficulty that is thought to affect 1-2 women out of every 1000 that give birth1. Postpartum psychosis is a mental health difficulty that occurs within the perinatal period. Postpartum psychosis is considered a mental health emergency as the symptoms can worsen quickly1. It is, therefore, crucial that women who have postpartum psychosis are able to seek help swiftly3. Postpartum psychosis poses many risks to mother and baby; sadly, severe mental health difficulties account for 50% of deaths during the perinatal period, the leading cause of these deaths is suicide4. However, research shows that timely access to support promotes recovery and reduces the risk to mother and baby3.

People from Black Asian and Minority Ethnic backgrounds are often referred to using the abbreviation BAME. This abbreviation represents a diverse group of people that make up approximately 14% of the population in England and Wales5. The existing research has shown that women from BAME backgrounds may be more likely to experience physical and mental health difficulties during the perinatal period6-7 but that they are also less likely to access mental health services than women from White British backgrounds9. The most recent investigation into maternal death revealed that the maternal death rate (figure 1) was higher in women from BAME backgrounds than in women from White British Backgrounds10. The reasons for this inequality in maternal death rates are yet to be explored and understood fully, but it is thought that poorer mental health and physical health outcomes may be contributors.

Figure 1. Inequalities in Maternal Death Rates: Data Replicated From Report Produced by Maternal, New-born and Infant Clinical Outcome Review Programme10



More common perinatal mental health difficulties such as perinatal depression11 have been researched more widely; postpartum psychosis, a rarer perinatal mental health difficulty, has been researched to a lesser extent. There is very little research that considers postpartum psychosis in women from BAME backgrounds. It is therefore essential that more research is undertaken that seeks to understand the experiences of women from BAME backgrounds and the reasons why they might or might not seek help for postpartum psychosis.

**Aim**

The aim of this study was to understand the reasons that women from BAME backgrounds are able or unable to seek help for postpartum psychosis.

**Method**

* Five women from BAME backgrounds with experience of having postpartum psychosis participated in one interview each lasting approximately one hour
* Action on Postpartum Psychosis (APP) is the leading UK charity that supports women and their families around postpartum psychosis12
* APP advertised the study online via Facebook, Twitter and Instagram
* APP then put women that responded to the advertisement in contact with the researcher
* After being provided with further information regarding the study, the contacted women decided whether they wished to participate
* The five women that chose to participate met with the researcher either in person or via Skype
* During the meeting, the researcher asked broad questions about the women’s experiences of postpartum psychosis and the things that helped or hindered them in accessing care
* These interviews were audio-recorded and transcribed by the researcher
* During transcription, the researcher removed any information that could be used to identify the women and assigned them alternative names
* These transcripts were then analysed using a narrative technique known as Murray’s Narrative Framework13-14
* Narrative techniques look at the meanings in the stories that are told by the participants and the commonalities and differences across the stories
* Narrative analysis is a suitable technique for this type of research and the data collected

**Summary of Findings**

The researcher examined the transcripts using the following four levels that makeup Murray’s Narrative Framework:

* The personal level: looking at each individual story, significant events, how each participant constructed their story and how the stories could be integrated into an overall narrative
* The interpersonal level: the way in which the participant developed their story, the tone of their story and their relationship with the researcher
* The positional level: the context in which the interview took place, issues of power and the position of the interviewer in relation to the participant
* The ideological level: cultural and societal issues that are related to the stories told by the participants

The analysis was written up using these four levels. A summary of the findings is provided below alongside some quotes from the participants.

*The Personal Level*

Each narrative was different, but commonalties were found across them. Each story progressed from beginning to end, opening with the chaos that postpartum psychosis brought to the participant’s life and ending with a restoration of life through recovery. The participants faced a diverse range of challenges when trying to access care, such as:

*“You hide the person away it's not happening you know and that's the kind of thing that's sort of what I think my family was trying to do”*

* Lack of compassion from professionals during the labour period
* Stigma
* Cultural pressures
* Negative perceptions of mental health difficulties amongst family or community

Each participant overcame the barriers to accessing care in different ways, for example:

* Via partners who supported their need to access care
* Through support from family members that agreed they should access care
* Breaking away from cultural beliefs or traditions to access care

*The Interpersonal Level*

Most of the participants spoke of how their stories might have previously gone unheard due to pressure to hide their difficulties or them not being listened to. It is hypothesised that sharing their stories with a definite beginning, middle and end allowed the participants to enforce an element of order over the chaos that postpartum psychosis brought to their lives.

*“Overall like the reason I wanted to take part in the research because I know for a fact my parents will say that my family were very reluctant for me to get in contact with services”*

The participants told their story to the researcher, a White British female who is a representative of the clinical workforce. It is possible that certain parts of the story were either focussed on or withheld by the participants based on who they were telling their story to due to power and racial dynamics. It is also possible that the participants wanted to share their stories and experiences of overcoming postpartum psychosis to share and instil hope for other women with similar experiences

*“I just wish that more women would do research I'm not saying don’t rely on doctors doctors are great but just for your own self-awareness”*

*The Positional Level*

Participants were aware that they were recounting their stories for research purposes, and this might have affected how they told their stories. The participant is the ‘storyteller’, and the researcher is the ‘listener’ this causes a power imbalance between the two people involved in the storytelling. The researcher holds more power than the participant as they are the one that hears the story, collects the data and analyses the findings.

The researcher was empathic and used open questions to allow the participants to tell their story freely. However, the presence of the researcher, her status as a health care professional and the difference in her ethnicity to that of the participants might have created further power imbalances in the storytelling. It is possible that sharing stories that ended with restoration and hope was important to the participants as they perceived the researcher as having the power to strengthen both their hope and the hope of other women by distributing the findings of the research.

*“It sounds weird but depression and anxiety postnatal depression and postnatal anxiety… people aren’t freaked out by them if you say psychosis to somebody it’s still a conversation stopper”*

*The Ideological Level*

Evidence demonstrates that there is inequity in the provision of maternity services for women from BAME backgrounds15, and this was the case for the women that participated in this study. The findings from this study highlighted a two-way difficulty in accessing services for women from BAME backgrounds:

*“All I can say is I was the only one on the ward showing those symptoms and I was the only one from an ethnic minority so it's a bit chicken or egg isn't it? To say why I was treated so differently?”*

1. People from BAME communities may be less likely to access services
2. When women from BAME communities access maternity services, they may have experiences of being treated differently or without compassion

Stigma in society was recognised as a barrier to accessing services, and it was identified that postpartum psychosis might carry more stigma than other more common mental health difficulties. The participants in this study also identified high levels of fear and stigma associated with their mental health difficulty within their families. Participants spoke of how their families conceptualised postpartum psychosis in a way that fitted with their own cultural beliefs, for example:

* Demonic possession
* Weakness
* Indulgence
* Punishment

These were all cited by participants as their families’ explanation for their mental health difficulty. Therefore, women from BAME backgrounds who experience postpartum psychosis are likely to be vulnerable to multiple stigmas.

Each participant in the study spoke of having a husband who supported them in accessing perinatal mental health services. Participants frequently spoke of how their husbands helped them to break away from their family’s beliefs about mental health and resistance to mental health service. It is important to consider whether the participants would have been able to access services without this support. It is also noteworthy that these women chose to participate in this study, and there are potentially more women without this type of support who are not able to access services or share their stories.

**Conclusions**

When the five narratives were integrated they revealed the difficulties and the chaos postpartum psychosis brought to the participants and the many trials and tribulations that they experienced in terms of barriers, but also turning points and epiphanies that led to recovery through support from husbands, intrinsic and extrinsic resilience. Supportive family members, experiences of being heard and supported, access to specialist mental health services were all key factors that helped these women to access care. Stigma, shame and cultural beliefs around mental health and lack of compassion from professional’s were found to be considerable barriers to accessing care for women from BAME background experiencing postpartum psychosis. The lack of compassion these women described could be representative of a larger issue related to institutional racism, whereby professionals do not set out to behave in a racist manner, but through their own biases’ and misunderstanding treat people from ethnic minorities’ differently16. This study unpicks some of these issues, but more research into this complex area is required.

**Recommendations**

More work is needed to reduce the stigma and shame associated with postpartum psychosis at a community level before reducing stigma becomes close to being achievable. The findings of this study may contribute to existing research regarding postpartum psychosis and support the training of healthcare professional to increase awareness of the condition and challenges faced by BAME communities. Future research could also consider:

* Awareness of PP amongst professionals and women of childbearing age
* Prevalence of PP in BAME communities
* Assessment of PNMH for women from BAME backgrounds
* Longer terms risks of PP to women from BAME backgrounds
* Experience of PP for women from specific ethnic backgrounds, for example, South Asian

There is growing interest in research regarding the partners of women who have experienced perinatal mental health difficulties; future studies could consider the role of partners for women who experience postpartum psychosis and how mothers without partners access services.

**Dissemination**

The findings of this study will be submitted to an academic journal for publication. This executive summary will be shared with Action on Postpartum Psychosis who can distribute it through any of their online portals or via post/email. It is hoped that by sharing the research in this way, other women, their families, researchers, professional’s and clinicians will be able to access the findings and learn more about postpartum psychosis and the experiences of BAME women from the stories presented here. It is hoped that the results will be particularly relevant clinicians working in maternity services and perinatal mental health services and that the findings will help to raise awareness and understanding of the issues faced by BAME women who have experienced postpartum psychosis. Where there is opportunity to do so, the researcher will present the findings at conferences with an ethnicity or perinatal mental health focus to further the distribution of the results.

**Helpful Information**

* The APP website has useful information regarding postpartum psychosis and peer support:

**APP:** <https://www.app-network.org/>

**Twitter:** @ActionOnPP

**Facebook:** <https://en-gb.facebook.com/ActionOnPP/>

* The Samaritans provide a 24-hour telephone and email support listening service that anyone can access:

**Samaritans:** <https://www.samaritans.org/how-we-can-help/contact-samaritan/>  
**Tel:** 116 123   
**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

* MIND is a mental health charity that provides information and support for a range of mental health difficulties:

**MIND**: <https://www.mind.org.uk/>   
**Tel:** 0300 123 3393

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# Appendices

# Appendix A: Outcome from CASP Checklist – Literature Reviews*[[4]](#footnote-4)*

|  |  |  |
| --- | --- | --- |
|  | Smith et al (2019) | Watson et al (2019) |
| 1. Did the review address a clearly focused question? | Yes | Yes |
| 2. Did the authors look for the right type of papers? | Yes | Yes |
| 3. Do you think all the important, relevant studies were included? | Partially | Partially |
| 4. Did the review’s authors do enough to assess the quality of the included studies? | Yes | Yes |
| 5. If the results of the review have been combined, was it reasonable to do so? | Yes | Yes |
| 6. Are the results precise? | Partially | Partially |
| 7. Can the results be applied to the local population? | Yes | Partially |
| 8. Were all important outcomes considered? | Partially | Yes |
| 9. Are the benefits worth the harms and costs? | Yes | Yes |

# Appendix B: Outcome from CASP Checklist – Qualitative Studies

|  |  |  |  |
| --- | --- | --- | --- |
|  | Yapp et al (2019) | Mc Leish & Redshaw (2017) | Lea, Heyes & Priest (2018) |
| 1. Was there a clear statement of aims of the research? | Yes | Yes | Yes |
| 2. Is the qualitative methodology appropriate? | Yes | Yes | Yes |
| 3. Was the research design appropriate to address the aims of the research? | Yes | Yes | Yes |
| 4. Was the recruitment strategy appropriate to the aims of the research? | Yes | Partially | Yes |
| 5. Was the data collected in a way that addressed the research issue? | Yes | Yes | Yes |
| 6. Has the relationship between the research and participants been adequately considered? | Yes | Partially | Yes |
| 7. Have ethical issues been taken into consideration? | Yes | Yes | Yes |
| 8. Was the data analysis sufficiently rigorous? | Yes | Yes | Partially |
| 9. Is there a clear statement of findings? | Yes | Yes | Yes |
| 10. Is the research valuable? | Yes | Yes | Yes |

# Appendix C: Target Journal Guidelines (Literature Review)

Aim and Focus

Evidence Based Midwifery aims to promote the dissemination, implementation and evaluation of midwifery evidence at local, national and international levels. Papers on qualitative research, quantitative research, philosophical research, action research, systematic reviews and meta-analyses of qualitative or quantitative data are welcome. All authors are encouraged to discuss their research paper with peers or editorial staff with regard to issues of importance to the local, national and international readership.

The journal is published four times a year and all papers should be sent to Rob Dabrowski – rob@midwives.co.uk – in MS Word format. Any hard copy material should be posted to: Rob Dabrowski, Deputy editor, Evidence Based Midwifery, Redactive Publishing Ltd, 17-18 Britton Street, London EC1M 5TP.

Referees and Reviews

All suitable papers submitted to Evidence Based Midwifery are subject to double-blinded peer review to assess their academic rigour, quality and relevance to the overall aim of the journal. Referees with relevant expertise in the subject area and/or methodology will be asked to provide a structured critical review of papers and reviews will be forwarded to the authors along with comments from the editors. Where necessary, papers will also be sent to members of the advisory panel for expert opinion on matters to do with for example, statistical accuracy, professional relevance or legal ramifications.

All authors will receive acknowledgement of receipt of their paper and the review process should be complete within 12 weeks. Major changes will be agreed with the authors, but the editors reserve the right to make modifications in accordance with house style and demands for space and layout. All papers are sent to the first named author for essential corrections only before publication and should be returned promptly. Corrections at this proofreading stage should be kept to a minimum and references and quotations should be checked carefully. Galley proofs will be sent to all authors for final proofing prior to publication and the accuracy of the content is the responsibility of the corresponding (first) author. Figures and tables that have to be redrawn in-house may not be included with proofs. The editors will decide on the time of publication.

Authorship

(Adapted from International Committee of Medical Journal Editors, 1997)

All persons designated as authors should qualify for authorship, and all those who qualify should be listed. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. One or more authors should take responsibility for the integrity of the work as a whole, from inception to published article. Authorship credit should be based only on: 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published. All three conditions must be met. Acquisition of funding, the collection of data, or general supervision of the research group, by themselves, do not justify authorship. All others who contributed to the work who are not authors should be named in the acknowledgments, and what they did should be described. Increasingly, authorship of multi-centre trials is attributed to a group. All members of the group who are named as authors should fully meet the above criteria for authorship. Group members who do not meet these criteria should be listed, with their permission, in the acknowledgments or in an appendix. The order of authorship on the byline should be a joint decision of the co-authors. Authors should be prepared to explain the order in which authors are listed.

All contributors who do not meet the criteria for authorship, such as a person who provided purely technical help, writing assistance, or a department chair who provided only general support, should be listed. Financial and material support should also be acknowledged. Groups of persons who have contributed materially to the paper, but whose contributions do not justify authorship may be identified as ‘clinical investigators’ or ‘participating investigators’, and their function or contribution should be described – for example, ‘served as scientific advisors’, ‘critically reviewed the study proposal’, ‘collected data’, or ‘provided and cared for study patients’. Because readers may infer their endorsement of the data and conclusions, all persons must have given written permission to be acknowledged.

Copyright

Evidence Based Midwifery cannot consider papers that are not original or have been submitted elsewhere, and the exclusive right to the manuscript should be set out in an accompanying statement. The author(s) transfer(s) the copyright of her or their paper to the RCM, effective if and when the paper is accepted for publication. A copyright form will be sent to each author prior to this. The copyright covers the exclusive and unlimited rights to reproduce and distribute the paper in any form of reproduction. All manuscripts should conform to the Uniform requirements for manuscripts submitted to biomedical journals (International Committee of Medical Journal Editors, 1997).

Style and Format

Papers should be typed using double spacing with a 12pt size common font, such as ‘Times’ or ‘Arial’. No identifying details of the authors or their institutions should appear in the submitted paper. Author details should be communicated separately, including an address to which all correspondence should be sent and a daytime telephone number. A fax number should also be included, if possible. The paper should be preceded by a structured abstract of up to 300 words that summarises the paper content. If appropriate, a suitable example would include: aim; objective; method; findings/results; and implications. The abstract should be followed by up to ten key words that identify accurately the paper’s subject, purpose and focus. These key words will be used to assist indexers in cross-indexing the article and may be published with the abstract. Where approval for reproduction or modification of material is required, the principal author must obtain this. Details of sources of research funding, commercial affiliations and acknowledgements must also be included.

Tables should be typed, double spaced, on separate sheets, with a short descriptive title. All relevant statistical data should be included. Illustrations are welcomed and encouraged where appropriate. Black and white photographs or transparencies are suitable. If charts or graphs are to be included, original or coordinate values should also be sent. Charts and graphs must be clearly labelled, and the axes on graphs made clear. Captions should be supplied for all illustrations. If using or adapting illustrations from another source, it is the author’s responsibility to obtain written permission to reproduce the material and to credit it accordingly. All illustrations are submitted at the owner’s risk. While every effort will be made to return all illustrations, the publisher accepts no liability for loss or damage while in possession of the material. Always include a citation in the text for each figure and table.

All work referred to in the manuscript should be fully cited using the Harvard system of referencing. The reference list should be in alphabetical and chronological order using the first author’s name. All references cited must have been previously published or publicly accessible. All references in the text should be cited from primary sources and should include the authors’ names and date of publication in date order. Where there are three or more authors, the first author’s name followed by ‘et al’ is acceptable in the text, e.g. (Smith et al, 2002), but all authors must be cited in the reference list. Page numbers should be included in the text for all quotations, e.g. (Jones, 2002: 45).

Reference to a journal article should include the author’s surname and initials, date of publication, title of the paper, name of the journal, volume and issue number and its first and last page numbers, e.g.

Symon A. (2003) Including men in antenatal education: evaluating innovative practice. Evidence Based Midwifery 1(1): 12-9.

Reference to a book should include the author, date of publication, title, publisher and town of publication, e.g. Smith A, Jones B. (1989) Evidence Based Medicine. BMJ Publishing Group: London. Chapters in edited books should include the additional detail of chapter title, e.g. Brown C. (1993) Best practice: In: Smith A, Jones B. (Eds.). Evidence-Based Health Care. Elsevier Science: The Netherlands.

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Sinclair M, Ratnaike D. (2007) Writing for Evidence Based Midwifery. Evidence Based Midwifery 5(2): 66-70.

Publication

On publication, ten print editions of the journal will be supplied to the corresponding authors of each paper, as will an electronic version.

# Appendix D: Target Journal Guidelines (Empirical Paper)

Guidelines for Contributing Authors

*The Journal of Prenatal and Perinatal Psychology and Health*accepts only original material that is not under consideration by any other publications. Articles should be word-processed and transmitted electronically as a Word document to the Editor. The Editor reserves the right to edit manuscripts for length, clarity, and conformity with the journal’s style. The author should retain his/her copy. American spelling should be used. The paper should be between 2,000 and 8,000 words with a 100–word abstract and at least three keywords. (See further guidelines for submitting a manuscript in the current APA Publication Manual (2009), specifically, “Author Responsibilities” (pp. 228-231)

The journal is interested in publishing theoretical and empirical articles utilizing data gained from clinical work, experimental research, case studies, and self-report.

Among the areas of special interest are:

Psychological factors that affect conception, pregnancy, labor, delivery and the post-partum period;

The reciprocal mechanisms of interaction between the pregnant mother and her unborn and sentient child and the mother and her newborn;

The influence of the family, society, and the environment on the pregnant mother and her unborn child;

Evidence-based measures that will improve the emotional well-being of mothers, fathers, and newborns;

The psychological effects of medical technology during conception, pregnancy, labor, and delivery on all parties concerned;

Methods of prevention and intervention/resolution of prenatal and perinatal traumas with children and adults;

Interfaces between prenatal and perinatal psychology and medicine, genetics, developmental psychology, anthropology, ethics, and the law.

Illustrations, Figures and Tables

All illustrations and tables should be included separately from the manuscript (in a separate document) and should be clearly identified in Arabic numerals, showing which is the top of the illustration if this is not obvious. Tables must supplement the text without duplicating it.

Refer to APA publication manual for detailed instructions on tables and figures.

Illustrations should either be black-and-white glossy photographs or India ink drawings.

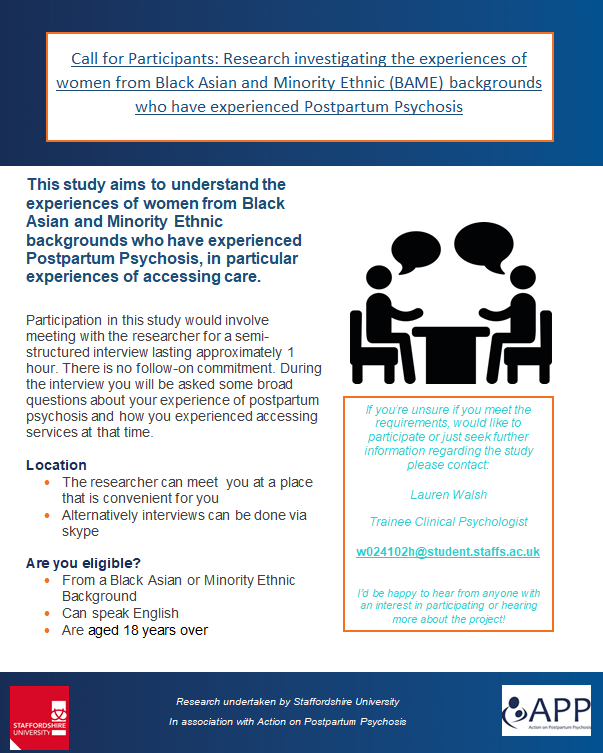
Tables, figures, and illustrations should include an appropriate title and be in**jpg or png** file format.

**APA Style**

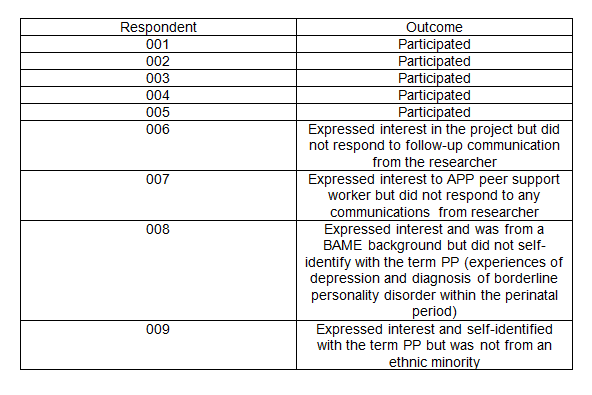
Formatting and referencing must follow APA style. References should be limited to work cited in the article. All cited material should be on the reference list.

American Psychological Association (2009).*Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author.

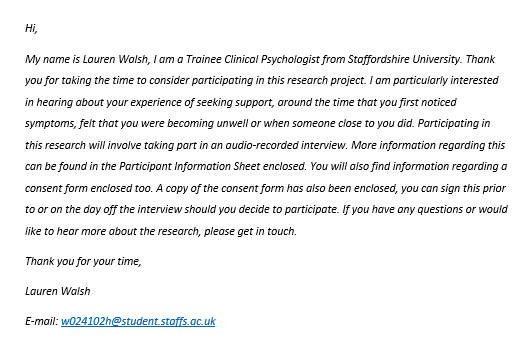
# Appendix E: Study Advertisement



# Appendix F: Table of Respondents



# Appendix G: Participant Information Pack



**Participant Information Sheet v1.2**

**Participant Information Sheet**

**Title of Project:** Barriers and facilitators to help-seeking for women who experience post-partum psychosis from Black Asian and Minority Ethnic (BAME) backgrounds

You are invited to take part in a study that seeks to examine the factors that both help and prevent women seeking support for PP. Before you decide whether to take part, you need to understand why the research is being done and how you would be involved, should you choose to participate. Please take you time to read the following information sheet carefully and discuss with other people, if you wish to. The researcher will be happy to discuss the study further to answer any questions you may have, offer clarification over anything that is unclear and/or provide any additional information.

**What is the purpose of the study?**

The onset of PP is rapid, and symptoms can become severe quickly, it is therefore essential that women experiencing symptoms access appropriate treatment quickly to promote recovery and reduce risk. Due to the rapid onset of symptoms and the recommendation for swift assessment, it is important to understand factors that can both facilitate and prevent women from accessing services. It is also known that fewer people from BME backgrounds access services in comparison to other populations. Understanding the barriers and facilitators to seeking-help from the perspective of the mother could help to shape recommendations to improve access to support and treatment in the future

**Why have I been invited?**

You have been invited to take part in this study because you may have previously experienced PP symptoms (there is not a specific diagnostic criterion for PP, therefore those that have had psychosis-related experiences in the postpartum period will be deemed appropriate) and are from BAME Background. You need to be aged 18 years or over to take part in the research.

There are several circumstances in which you will not be able to take part in the research, these are described below. If you would like to know more about these exclusions, you can ask the researcher.

1. You cannot understand written or spoken English sufficiently enough to read this information sheet or to discuss your experiences fluently
2. You are currently under the care of an inpatient ward, mental health crisis team or subject to section of the mental health act 2007.

**Do I have to take part?**

No. It is your choice as to whether you to wish to take part. The research will discuss the study and go through this information sheet with you. You can ask any questions and discuss the study with the researcher via telephone or email, prior to meeting them, should you wish to. If you choose to take part, you will be asked to sign a consent form. Signing the consent form does not commit you taking part, you are free to leave the study at any time without giving a reason until one week after the interview has taken place. It will not be possible to remove your data after this point. The care that you receive either now or in the future will not be affected by your decision to participate in this study. You will be given this information sheet to keep and given as much times as to you need to consider whether you would like to participate.

**What will happen if I take part?**

If you decide to take part you will be asked to sign two copies of a consent form, one for you to keep and one for the records of the study. You will then be asked to take part in audio recorded interview. Interviews will be carried out by the same researcher after you have provided consent. The interview is mostly open-ended as each person’s experience is different. It is expected that interviews will last between thirty minutes and two hours but is fine if they are shorter or lengthier than that this, the interview can stop at any time. The interview will focus on how and when you sought support from healthcare services for symptoms of PP. There will be some questions around any challenges or obstacles you faced when seeking support and any things that helped or enabled you to seek support. You are encouraged to only talk about things you feel comfortable discussing. There are no right or wrong answers to any of the questions.

**Will my information be confidential?**

The information you provide will be kept confidential in line with General Data Protection Regulation (GDPR) and the new Data Protection Act (DPA, 2018). All personal identifiable information will be stored separately from the audio recording. The only time confidentiality would be broken is if you tell us something which indicates there is serious risk of harm posed to your or someone else. Should this happen, the researcher will inform an appropriate service. Information stored about you will have your named removed from it and a unique participant number will be assigned instead. Audio recordings will be stored on an encrypted device and deleted after they have been transcribed. Transcribed interviews will be stored on secure, encrypted device held at the University archives for 10 years. Only members of the research team will have access to the original transcriptions.

**What are the possible advantages of taking part?**

The information you provide will aid our understanding of the barriers and facilitators to accessing care for women experiencing PP from BAME backgrounds. Rapid assessment and treatment of PP are considered imperative due to the severity of the symptoms. A better understanding of women’s experiences of accessing care could help to improve access to appropriate health care services in the future.

**What are the possible disadvantages of taking part?**

The researcher will ask you questions that you may find difficult to answer at times. You can take your time answering questions and do not have to answer any questions that you do not want to. Participating in the study requires you reflect on some past experiences and discuss them with the researcher. Answering the interview questions may cause emotional distress and/or anxiety for some people which could have an adverse effect on psychological wellbeing. Participation may exacerbate symptoms that are related to PP.

You will have the opportunity to discuss any concerns you may have with the researcher at the end of the interview and the researcher will ask if you require any additional support. If you find that you do require support after participating in the study, you can contact the following charities that specialise in mental wellbeing and PP.

**MIND**: <https://www.mind.org.uk/>   
Tel: 0300 123 3393  
**APP:** <https://www.app-network.org/>  
Samaritans 24 hour support Tel: 116 123

**Researcher contact details**: Lauren Walsh - w024102h@student.staffs.ac.uk  
– can assist you in finding appropriate support locally

**Clinical Research Supervisors:** Dr Joanna Heyes (Tel: 014782 294 774)

**What if there is a problem?**

If you have any concerns about the study, you should speak to the researcher who will do their best to answer your questions.

**What will happen to the results of the study?**

The results of this study will be written up in a Doctorate Thesis Project and may be published in academic journal. We will not use your name or any details that would identify you in a publication. Copies of the final paper will be available from the researcher. You can indicate whether you would like to receive a copy on the consent form.

**Who has approved the study?**

The study has been reviewed by the University of Staffordshire ethics committee and has been given full ethical approval.

For further information please contact: Lauren Walsh (Principal Investigator)   
Email: w024102h@student.staffs.ac.uk

You will be given a signed copy of the consent form and this information sheet, should you choose to participate in the study.

***Thank you for taking the time to read this.***

**Consenting to Participate**

**Title of Project:** *Barriers and Facilitators for help seeking for women who experience PP*

**Principal Investigator:** *Lauren Walsh*

You will be asked to sign a document to confirm that:

* You have read and understood the participant Information Sheet
* You have had time to think about the study and ask questions
* You understand that participation is voluntary, that you can withdraw at any time without giving a reason and without your care being affected
* You understand written or spoken English sufficiently
* You are from a Black Asian Minority Ethnic Background
* You have experienced symptoms of PP
* You are over 18 years of age
* You are not currently subject to a section of the Mental Health Act, 2007
* You are not currently accessing support from a Mental Health Crisis Team or under the care of an inpatient ward
* You give permission for the interview to be audio recorded
* You understand that anonymised information will be collected about you and used in published research studies
* You understand that anonymised findings of research may be presented at conferences and university teaching
* You understand that after completion of the interview you will have a period of 2 weeks during which you can contact the researcher to request that your data be removed from the study
* Anonymised information can be stored in the University of Staffordshire’s research archives for a period of 10 years
* Whether you would like a copy of the report on completion
* You agree to take part in the study

# Appendix H: Consent and Demographic Collection Forms

**PARTICIPANT CONSENT FOM v1.2**

**Title of Project:** *Barriers and facilitators to help-seeking for women who experience PP*

**Principal Investigator:** Lauren Walsh

*Please initial each box*

I have read and understood the Participant Information Sheet (March 2019: v1.2) for the above study.

I have had time to think about the study and ask questions, which have been answered satisfactorily.

I understand that my participation is voluntary and that I can withdraw at any time, without giving a reason and without my care being affected.

1. under the care of an inpatient ward, mental health crisis team or subject to section of the mental health act 2007.

I can understand written and /or spoken English sufficiently

I am from a Black Asian Minority Ethnic Background

1. under the care of an inpatient ward, mental health crisis team or subject to section of the mental health act 2007.

I have experienced symptoms of PP

I am over 18 years old

I am not currently subject to a section of the Mental Health Act, 2007

I am not currently accessing support from a Mental Health Crisis Team or under the care of an inpatient ward

I give permission for my interview to be audio recorded

I understand that anonymised information collected about me will be collected and used in research publications

I understand that the anonymised findings of the research may presented in research conferences and university teaching

I understand that on completion of this interview I can contact the researcher to withdraw my data for a period of 2 weeks (contact the researcher on or before insert date to withdraw)

I understand that the anonymised information will be stored in the University of Staffordshire’s Clinical Psychology research archives for 10 years

I would like to receive a copy of the report when the study is complete

I agree to take part in this study

……………… …………… ……………

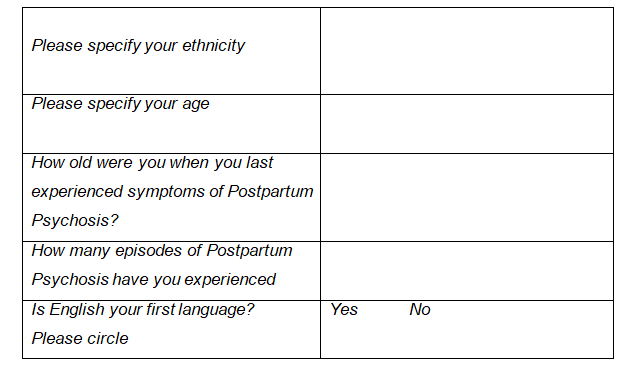
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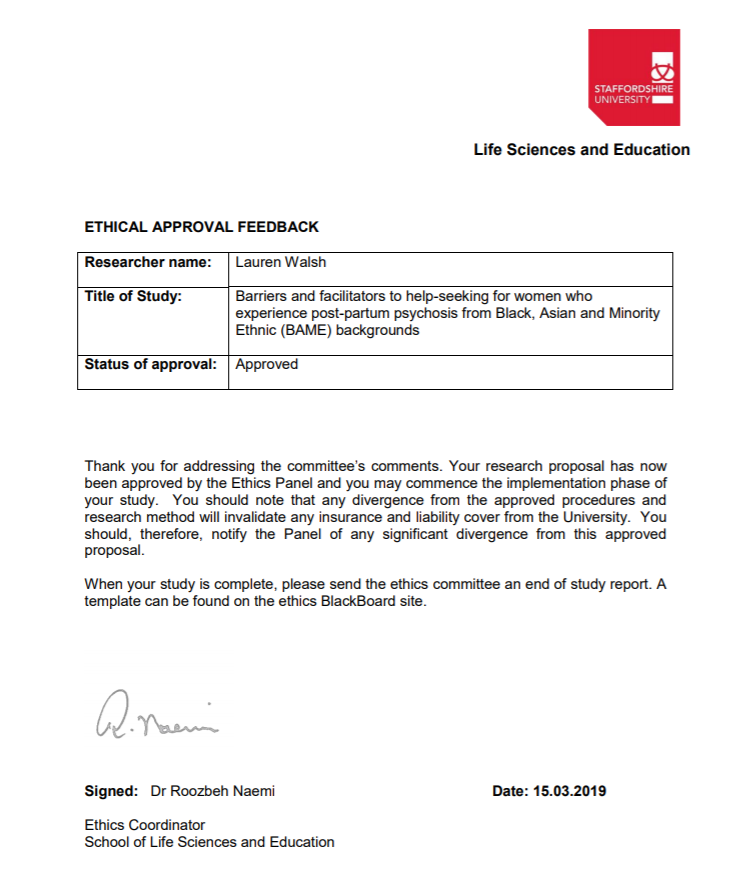
Researcher Name Signature Date

**Demographics Collection Form**

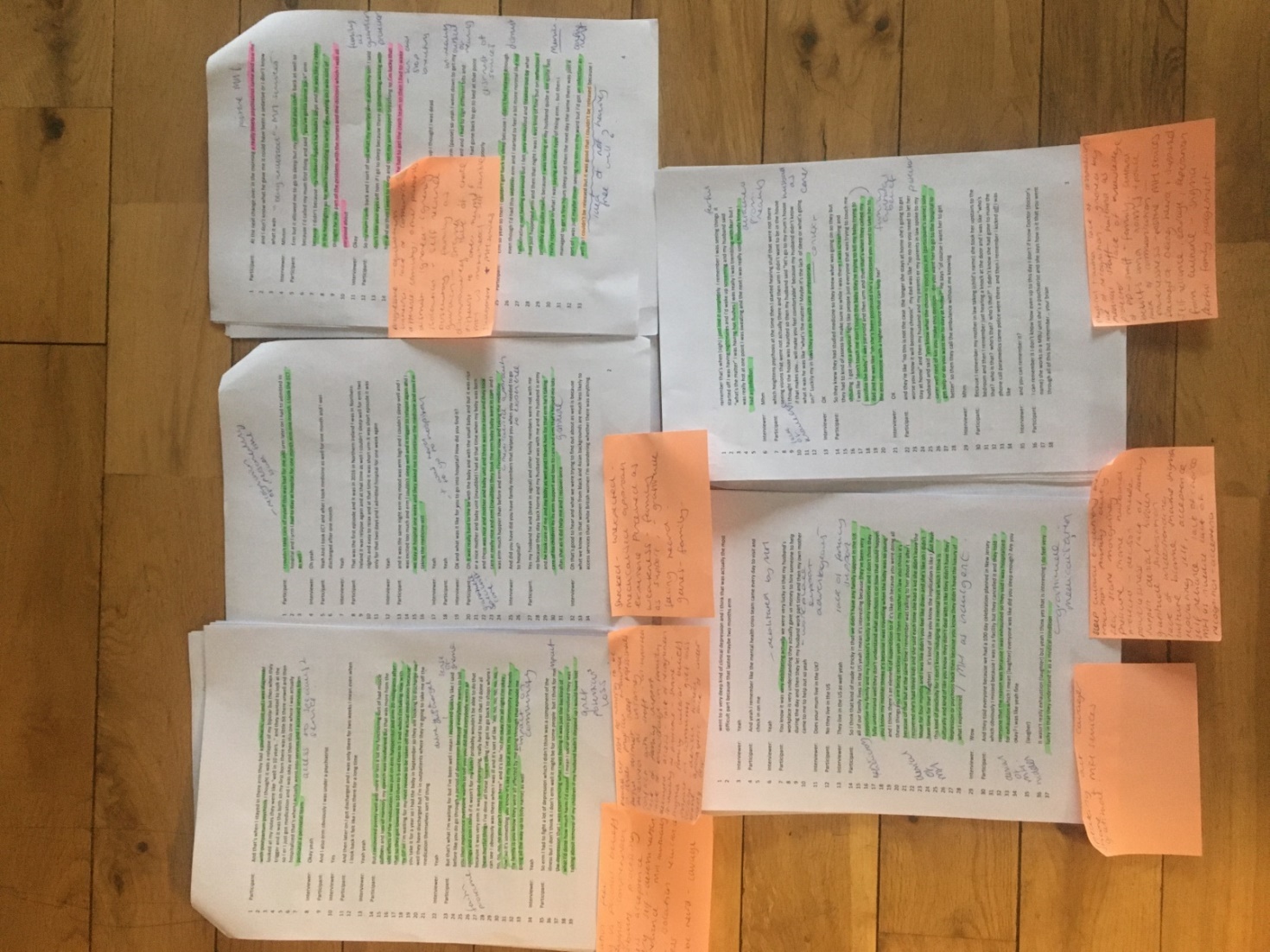
**This information is anonymous and will be stored separately from any identifying information in the consent form**



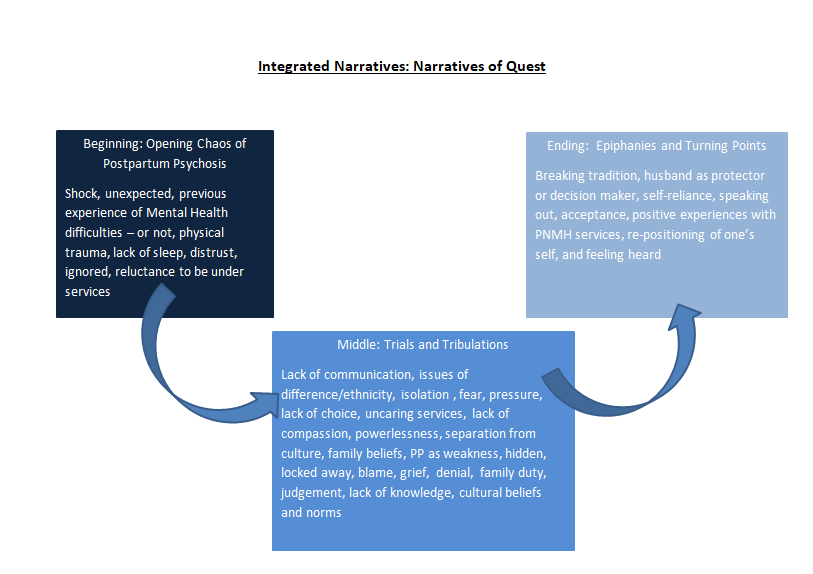
# **Appendix I: Ethical Approval**



# Appendix J: Examples of Coding & Memo Writing



# Appendix K: Integrated Personal Narratives



# Appendix L: Analysis

**Positional-quotes that emphasise the positional part of the analysis (purpose of sharing story, gratitude for PNMH services etc.)  
Interpersonal- quotes that emphasise the interpersonal part of the analysis (restorative function of narratives, speaking out, empowerment etc.)  
Ideological- quotes that emphasis the ideological part of the analysis (societal and cultural contextual factors, poor treatment experiences)**

|  |  |  |  |
| --- | --- | --- | --- |
| Natalie’s Story | | | |
| **Juncture In Narrative** | **Themes Present in The Narrative** | | **Data Excerpts** |
| Opening the story with the chaos of PP and illness | Physical Trauma Lack of sleep | | *it was quite a long labour it was about 21 hours so I was very tired*  *and he ended up with a forceps delivery*  *I started to feel really unusual and I couldn't go to sleep*  *so I had to take olanzapine alongside the other stuff I had had for the infection and the other pain relief and all the rest of it all that sort of stuff so yeah and then the next day it all sort of morphs into one the day or the day* |
| Psychotic Experience | | *probably 3 or 4 hours when I started to feel really really strange*  *it had been a few hours erm I still couldn't sleep erm  and I was hallucinating I thought that my husband’s head was changing shape* |
| Trials and Tribulations of having PP and barriers to accessing care | Professional’s as uncaring (Lack of communication Issues of difference & ethnicity distrust, ignored, **unheard)**  N.B the word listen was used 7 times by Natalie | | *I was made to feel like I was making a fuss really*  *I just felt that like I wasn't being listened to like none of my concerns were being taken seriously and I was getting more and more agitated*  *and I didn't didn't feel as though I'd been listened to about my son and stuff anyway*  *because I was saying it none of them believed me*  *So they were just  they were just sort of staring through me or well that's what it felt like just not taking any notice*  *I went down one of the times and his nappy was dirty and they had said that they was doing all of that stuff and then they hadn’t so I started like getting like I can’t trust anyone to do anything sort of thing*  *I thought that the nurses were trying to hurt him and hurt me and then again my thoughts just started from that which sort of wasn’t based in complete un-reality but then that just morphed in to really really bizarre thinking*  *it’s weird like I say I don’t know if the way that they treated me was anything to do with my ethnicity or my symptoms or what it was but I didn’t ever feel like I was being treated compassionately particularly*  *just didn’t really feel like they were sort of taking anything that I said very seriously and then really reactionary like you know when I was being discharged they were sort of implying that I was suicidal or that I might hurt my son and things like that and I remember thinking “I have been trying to tell you that I need help for days and you’ve not been listening and now you’re putting it on me that I want to do something awful to my son you know but no one wants to be better more than I do”* |
| Ignored and Disempowered | | *I was sort of being dismissed about what it was and I was saying that I was in a lot of pain and they were saying that they didn't think I should be but sort of*  *I said to one of the nurses I think I'm going to need something to sleep my thoughts are really racing and I feel really weird… and she said no…*  *I don't know no I never got to the bottom of it why she just said no*  *and it took about 14 hours and that was in that time no one explained whether it was that a doctor wasn't available or whether they didn't agree with me or what I was saying so no one was really telling me I wasn't getting any feedback so I just thought that they weren't listening to me*  *I don't know if it was anything to do with being from an ethnic minority if that played any part in any of those clinical decisions to not respond to what I was saying or to not tell me those sorts of things or not get treatment for me quickly I have got no idea what the rationale was behind any of those things*  *all I can say is I was the only one on the ward showing those symptoms and I was the only one from an ethnic minority so it's a bit chicken or egg isn't it? To say why I was treated so differently?*  *It’s hard to say whether they treated me differently because I was the only one showing those symptoms at that time so I've got nothing to really compare it to*  *I couldn’t be released but it was good that I couldn’t be released because I slightly when nuts again so I didn’t leave I didn’t to be sectioned because all of the everything happened whilst I was still in the hospital*  *erm I never really felt like anyone was keeping me in the loop of what was going on with either me or my son again I don’t know if that was because of the symptoms I was showing that they didn’t think I would understand what they were saying erm or they just took the decision not to tell me it felt as though they were always talking to my mum or to my husband or you know somebody else in the room you know it was never sort of directed at me even though it was my son’s treatment which I found really frustrating*  *I really wanted to have treatment but I didn’t feel like I could make people listen to me*  *because I felt that at times it was implied that I didn’t want to get better like at times where I’d say I wanted to reduce my dosage and stuff like that and they would say “well you know…” patronising me like as if I was being risky*  *because I always associate the medical route with being prescribed medication and I really wouldn’t have wanted that in pregnancy so erm even though obviously there is more than that and they offer more than that sort of thing* |
| Stigma & Shame | | *I felt like I had not just the reason that nobody wants social services involved with their family but also the fact that it would really kind of undermine me professionally with all that sort of stuff as well*  *everybody else all the sort of midwives and other people that I was coming in to contact with I still felt the stigma associated with the psychosis*  *I felt a lot of fearfulness from the non-mental health related people like the health advisors and the midwives and those people they just didn’t really know how to ask the questions*  *I do think it was a factor that now I do live in a very very white county and there was a real lack of kind of anyone who was anything like me*  *it sounds weird but depression and anxiety postnatal depression and postnatal anxiety… people aren’t freaked out by them if you say psychosis to somebody it’s still a conversation stopper and you can still see people are sort of like “aaarrhhh”*  *I think I was sort of ashamed of it of the experience and embarrassed by it If it had been postnatal depression I like to think that I would have not felt that stigma and I would have just been okay to get more treatment but because of the psychosis and the fact that people still don’t seem to really know what that means* |
|  | Self-Sacrifice/self as unimportant | | *On reflection I don’t think that was probably the best decision I think that probably if I had of erm spoke to somebody that I could have managed the anxiety symptoms a lot better and that might have meant for a nicer maternity leave with my son well I mean we had a great time*  *So I just sort of forgot about myself if that makes sense?*  *How little I’d gone out but then I was forced to go out (laughter) because I was back at work and life had to go differently I realised then that I could have done with extra help at that time*  *I just sort of put it down to new motherhood*  *It felt like you became unimportant everyone is so worried about the child and not worried about the mum that it was easy to go to all of his appointments and stuff and never ever talk about me*  *His developmental milestones were being reach which I was happy with but it just meant that I could slip under the radar*  *And for it to not really come to anyone’s attention that I was still sort of suffering* |
| Facilitators, Turning Points & Epiphanies | Family as guardian | | *So my mum came back and I sort of said what my worries were about my son I said don’t take your eyes off him if I go to sleep*  *Erm and I was saying to my husband you have got to get me a psychiatrist something is going really wrong something is not right in my head*  *I begged my husband not to leave me which he didn't and they must have realised that something was going a bit wrong because they didn't insist my husband left*  *and then my son stopped breathing so I’m lucky that my mum was with him because she had to get the crash team so then I had to wake up* |
| Positive experiences of specialist MH Services | | *in the morning a really lovely psychiatrist came and saw me*  *so yeah and they were really nice and gave me and my husband loads of phone numbers and different things to … different advice if I were to show symptoms again different things I could do to get treatment more quickly next time sort of thing erm*  *she came a few more times the care manager lady she was lovely we just sort of spoke about my experiences and she helped me to sort of process it a little*  *I think some of the staff once it was clear that I had the psychosis all the staff that I dealt with after that that was their erm bread and butter you know they were psychiatrists and the psychiatric nurses … they were all fabulous and I didn’t feel judged by them at all*  *It just feels really proactive and really good to know that all the clinical staff whether they’ve got experience with mental health or not that this is relevant and they will know what I need from them and it will be clear* |
| Self-reliance/resilience | | *So thought that I had to you know like I thought it was only me that was going to look out for my son*  *I managed to get a big block of sleep and I started to feel more human again my son had stopped his treatment so I think that was a big factor because we kept being separated and I didn’t trust the clinical decisions that were being made and all that sort of stuff*  *then I was just getting on with just trying to be a mum to my little boy and I think on reflection I probably had postnatal anxiety but I never sort of I was so jaded by how I felt I had been treated by the professionals I just thought I’m just going to get on with this myself it didn’t feel dangerous to do that I didn’t feel a risk to myself or to my son so I just sort of really lost faith in erm… in services*  *I was just really wanting to put the whole thing behind me and didn’t want to be struggling with mental health issues ongoing really sort of thing so I think that was a big factor in not deciding to access help because I didn’t know if that would be mean that other services would start sniffing around if they was concerned about my capacity sort of thing*  *I just felt like I’ll just do this on my own  I’ll just sort of just crack on and I’m sure it will go over time but it wasn’t until I went back to work when my son was one that I realised (laughter) how bad the anxiety had been*  *I don’t want to take a risk I want to be well more than they want me to be well*  *I’d lost faith that they was going to treat me kindly so I thought I would rather just get on with myself kind of thing..*  *Yes definitely I think I’m a lot more articulate now I think I would stand my ground a bit more effectively now so I like to think that those things wouldn’t happen to me now  I was just wanting to get on with normal life I didn’t want to be I didn’t want to be a part of services anymore so I was just keen to just erm get on with being my son’s mum sort of thing* |
| Anaya’s Story | | | |
| Opening the story with the chaos of PP and illness | Physical trauma | | *labour was traumatic it was 48 hours in total*  *it was the worst because they have to force the labour and then that's when the contractions started but the maximum I went to was five centimetres dilated*  *yeah you know I'd gone several days a couple of days without sleep So I'd probably not be asleep for like a week*  *Nobody knew I had an infection* |
| Experience of being ignored during birth | | *eventually I had a nice midwife who came in and she was in charge of me so then she said “do you want pain relief? It's been like more than 24 hours and you haven’t received no pain relief”* |
| Psychotic Experience | | *I remember I just I was talking a lot like more than usual then I was very I was very emotional*  *I remember I was seeing thins it started off as I was having nightmares and I’d wake up screaming*  *I thought the house was haunted*  *I was paranoid* |
| Trials and Tribulations of having PP and barriers to accessing care | Professional’s as uncaring (lack of compassion  lack of communication, lack of understanding) | | *the first one who checked me argh she was horrible actually I remember the words she said “Oh you think this is pain wait until you feel what real pain is” And I thought that's not how you speak to a first time mum or anybody?*  *then when the midwives came to do their checks to do their home visits they just said “oh it’s baby blues it's nothing”*  *so I was in there at the psychiatric unit which was full of men and females so you can imagine where some men were weeing everywhere walking around half naked and stuff*  *I still wasn’t sleeping it got to the point I remember I used to wake up in the night walk they would say “go back” I would say “I can't sleep I'm having nightmares” it’s just really disgusting I feel like that there is a way in (city name) they treat mental patients like as if they are nothing especially in (hospital name) because of where the area and stuff*  *Midwife? Noo they just said “oh it’s alright it’s okay it’s normal to be anxious” to a certain degree yes*  *no one ever said “you wanna go for counselling?” because I've had anxiety since I was sixteen and that's on my records but nobody ever like I didn't have like a specialist mental health midwife and I thought which was sad because I know people that had that* |
| Stigma | | *and up to now a lot people don't know what happened because they kind of kept it amongst themselves like the close knit*  *the thing about mental health especially in the African community it’s such a taboo subject where it’s er… you don't talk about it like “shh shh don’t say that no no that person's been cursed you know maybe she did something wrong when she was little”*  *I don’t think they even know his extended aunties because they just kind of just kept it amongst themselves not in the wrong way but I just I told him like “I don't want anybody knowing because it’s my personal business I don’t want them to look at me differently or to treat me different especially because I know how it is like people are like (whispers) “are you okay?”*  *I'm not saying that people aren’t suffering with anxiety but I feel like everyone is saying I suffer from anxiety and I feel like now everybody on social media suffers from anxiety but that's the comment that’s meant to help you but they are forgetting there are things like bipolar BPD you know depression and nobody wants to speak about those*  *definitely the family my side not my husbands side family urm stereotypes being afraid of how I’ll be seen you know and how it will affect me especially with work I thought “Oh I'm never going to work again with children”*  *that is something that came into my head more than a few time so I thought I might not seek help so my profession and urm just how like I'll be seen in society like “oh my gosh first time and she's in hospital”* |
| Family beliefs and cultural beliefs | | *that’s when they called my dad and he was like “oh she’s been possessed she’s possessed you need to take her to the erm someone with a higher source that can help her”*  *my dad was like “no no no you need to let her stay at home”*  *do you know that's just some people still think in my family that maybe she was possessed… No no maybe she's like a witch or something but there's all sorts of reasons but people were like “it doesn't make sense how was she so in tune but she wasn't?”*  *I feel like it's such a stereotypical view that like when someone becomes unwell when it comes to mental health that they especially think that they’re possessed*  *and even at one point he came to the hospital and he brought like what was it? Like a er jug a jerrycan with water in it was this kind of special water he said “drink it is going to make you feel better”*  *It was a relative and I just thought “how’re you telling me I'm exaggerating I know how I'm feeling” so other than that* |
| Disempowerm-ent | | *they put me in there (hospital room) not knowing that they were actually assessing me*  *I just I remember they took me and they got these two big guys to take me across*  *it's just sad it was so sad because at that time I didn't have my daughter and I thought to myself “why? why are they leaving me here?*  *so then they had to one night I really kicked off they sedated me there was about six staff members that had to pull me down on the bed and then they said they gave me an injection on the bum they took off my trousers and I just thought that is so inhumane*  *and I think she felt sorry for us so she came into the hospital they transferred me back into the hospital so they took me from the mental unit back to the hospital because they realize I've got an infection that's heightening things*  *and she was like “oh my name is so and so and I'm the head of the mother and baby unit for (city’s name) so if you do want to come you have to promise me that you are going to be calm because at the hospital we have new born young babies and I understand you’ve just had a baby but you can’t be the way you are because I heard so much stories about you” I said “of course” she said “now are you sure?” I said “I promise”*  *I just kind of feel like I shouldn’t voice how I'm feeling that someone could be like that like “oh you’re exaggerating you're a drama queen”* |
| Facilitators, Turning Points & Epiphanies | Husband as decision maker, and in-laws as protector  Male gender roles | | *I thought you are not being professional so my husband made a complaint*  *so then my husband said “let's go to my mum's house if that makes you… will make you feel comfortable”*  *Luckily my in laws they are ex-health care professionals… So they knew they had studied medicine so they knew what was going on*  *my husband and my parents er my parents in law spoke to my husband and said “you know what the choice is yours you are Anaya’s sole carer well next of kin you make this decision - do you want her to go to the hospital to get help or do you want her to stay at home?” He says “of course I want her to get better” so then they call the ambulance without me knowing*  *it was a mixture of staff male and female I’d never seen a male nurse… so I used to kind of tease them like “why are you here? Why are you working with females? Especially with females and babies”*  *I know at the time I was unwell so I started believing it because my dad was enforcing it and my husband had to kind of snap me out of it like to say “no stop believing your dad”*  *I don't want see your dad because he made you… we could have lost you and imagine how that would have affected my son do you understand? All because he has these rituals and beliefs that you was being possessed and he's not correct”*  *how is it that my own in-laws and husband are more supportive than my own parents? Which is sad*  *my in laws they are of African descent but they are completely different they support me they come with me for appointments* |
| Separation from cultural beliefs  & family | | *so I remember ermm my mum… this was when I was still in touch with my mum I’m no longer in touch with her but she was still around and she kept coming around and I was just telling her like “give us some space” but she just kept on interfering and then er in end me and her would have an argument and I told her “just leave”*  *But everybody suffers with postnatal psychosis differently*  *I'm the first in my family and that's it I'm the first in my family that's why people are so like “oh she's being possessed” and this and that when that's not the case…*  *it's like how can you say that to somebody and I guess what helped me is the fact that I was born here and I got married quite young to my husband and even though we're both religious people but at the same time we're in touch with reality to say like “no that's not true” that's not what's happening to me you know it can't be*  *I did trust my dad at the time because I thought this is my dad who you know he's the first one I've ever loved why would he lie to me? But then I thought my husband actually he knows more things about me than my dad so I'm going to trust my husband I married him he’s the one who I live with you know and then something just clicked where I said “do you know what? My in-laws they’ve never lied to me I should trust them now this is the time I must trust them and believe what they're saying” you know that they are ex health care professionals so they know what they're talking about you know and that's true that's what's made me kind of made my brain relax and just to say this is reality like this is what's not real…*  *it took a while but even when we did like speak again things were different and I just it's awful right I mean we did try with the relationship for those like years after that there was a few arguments here and there and stuff and just memories came back and said “you know what for the sake of my mental health I think it's just best if you just stay out of my life”*  *when I did relapse they weren't really supportive so I just thought I would rather have them out my life here*  *I thought what I did was so wrong like how can you not speak to the people that brought you into this world but then I thought if they are affecting my mental health then I should if their absence is bringing me peace I think it speaks volumes* |
| Positive experience of specialist MH Services  Feelings of being heard and supported | | *I was transferred to the mother baby unit which was (whispers) amazing*  *Highly recommend it so even if I could go now and I'm not… I'm well (laughter) just so that I can have the food I have the freedom to watch TV there’s a swimming pool I could just use the facilities again because it was so nice like the staff were amazing*  *it was just so nice like it was nice having that support like at night time I could sleep for 10 hours I mean up to I don't sleep for 10 hour now tonight with but for 8 hours which is good and the sleep really helped*  *“do you have any suggestions that that make you relax?” I was like “watching movies” so the manager went out and bought the movie's DVDs she bought snacks and I went into the office where used to do the you know like the big meetings?... And we all sat there and watched a movie it was really nice and they were like “if you have any more suggestions just let us know”*  *I'm planning to become pregnant next year hopefully and I’ve gone for my perinatal appointments with the psychiatrist and they said moment I find out I'm pregnant I call them I'll be straight away referred to them well I already be on the system so straight away I’ll be in contact with them then they will refer me to a specialist midwife that specialises in mental health and on top of that I’ll have the community midwife so I have extra additional support*  *where with someone online you know when I shared my story of mental health briefly they were like “oh my gosh you're so brave that you seemed so happy wow I went through this, I had so and so” I look through it and I'm like there's a lot of people who have similar stories to me* |
| Self- reliance/resilience  Courage | | *and what made me I think to recover so quickly… was the fact that I came to terms with my illness I accepted it I was no longer in denial I didn't believe that someone was after me and I was with my daughter*  *I went to (city name) and I bought an iPad a mini iPad and I came back and I asked them for the Wi-Fi password and they gave it to me and I was listening to music and I feel like up to now music has been my therapy*  *I feel like it's time that I share my story let people be aware of the silent symptoms to look out for*  *I don't want it to put me off on becoming a mum again because I know I've spoken to women on the the post on the forum who've gone on and they've had child number 2 and child number 3 and they've been fine and everyone's different but I guess if you get the help from the early onset then you know*  *when I had like when I had my last relapse I was able to call the crisis team myself and say “hi my name is so-and-so I don’t feel well I've been crying for the last week I need help” and that's how the home treatment team came and they was like “do you have a history?” and I explained everything and they said “do you know what not many women do what you have just done”*  *I went through such a traumatic experience that from that I know the many signs and symptoms to watch out for I know like when I’m feeling like you know you know you’re about to catch a cold you can tell oo I got a head ache I got a fever a cold is coming let me take paracetamol to prevent it so it's the same with my mental health I know the signs and symptoms to watch out for now before it becomes where it’s like an explosion*  *you know and sometimes if I’m feeling a bit more a bit emotional I say “could you just give mummy five minutes? Mummy’s was feeling a bit poorly”*  *I just wish that more women would do research I'm not saying don’t rely on doctors doctors are great but just for your own self awareness*  *I guess you just have to self-educate yourself and know what to do the people around you let them be aware as well let them do research* |
| Elisa’s Story | | | |
| Opening the story with the chaos of PP and illness | PP as a shock and unexpected | *Erm first of all we didn't expect that one errm I was just the discharged from hospital and...er... I went home and I went to back home I couldn't do or have good idea because I couldn’t sleep for three nights*  *after er one week I had to go admitted to hospital again just for them to know how erm what was going wrong and after that er the doctors say that I had a PP*  *I didn't expect to have erm PP and there is not any history of having suffering from PP in erm in my gene as well it was first experience for me*  *I shared everything with my friends and families and erm erm they was not expecting like that* | |
| Psychotic Experience | *my mood was er low and I was er so low and I was so tearful and I couldn't sleep well and my appetite has gone down*  *I was really struggle to sleep at erm and and my appetite has gone down at that time and I couldn't eat properly*  *I was like I was hearing voice that erm presence of people was not actually there and I was erm erm a little bit of manic as well and I was so so excited to to and erm sometime I used to see that people who was not surrounded there I was hearing a voice like* | |
| Trials and Tribulations of having PP and barriers to accessing care | Difficulties associated with PP | *I couldn't take care of my baby as well*  *I couldn't take care of myself this was bad for me*  *it was really hard to it was really hard cope with that one*  *I heard that many places they hasn't got a mother and baby unit you have to travel from far away to get this ... so if every hospital has got the mother and baby unit it would be very easy for the mothers and babies so to request to have this erm at the hospital*  *there is no attachment with the baby as well you couldn't feel the attachment with baby and erm I couldn't feel that I could erm take care of baby* | |
| Mental Health as weakness | *I I erm used to express my feeling and I used to share my weaknesses and erm what was going with on me*  *of course we have to say it out to the feelings and erm thoughts to everybody because at that time when you feel really erm lack of erm you know lack of strength* | |
| Facilitators,  Turning Points & Epiphanies | Acceptance of Medicalised conceptualisation of PP | *And I took ECT and after I took medicine as well for one month and I was discharged after one month*  *to relapse again and I we stay at hospital one week and they asked me to continue the medicine and erm I'm taking the medicine still and I was erm much happier than before and erm I recover now and taking the medicine and obviously I didn't like to realize what I was the cause of erm my health*  *erm but later on erm after a few weeks and it was normal and after taking errr ECT I was feeling better and much quicker and to later on it was normal for me* | |
| Family as support | *my husband was with me and… he took care of me and my baby as well and I thank him for that erm he's taking care of his children its its erm support and love to care and erm that's helped me lots after that as it did help me and I recover*  *my husband and really supportive and helpful and he loves and care and he he erm really was positive towards my erm (inaudible) PP*  *I shared everything with my friends and families*  *I used to go outside with my family friends and I tried to keep busy with that things so it was so easy for me at that time*  *erm I feel so grateful when I sit with my friends and families* | |
| Positive experience of mental health service  Gratitude | *it was nice er a nice mother and baby unit (inaudible) I had at that time when my baby was born and there was nice and mother and baby unit and there was nice team and they took care er really nice and erm*  *th treat me well when and I never heard before that PP to be honest these help would take me and they erm really helpful and they really appreciated me so I'm really happy about that*  *I used to express my feeling to mental health nurse and they say this to me not to erm think like that and in case in*  *other things and to keep busy with the baby ermm and I didn't feel that bond with the baby and they erm used to do console me a lot* | |
| Soffie’s Story | | | |
| Opening the story with the chaos of PP and illness | Previous experience of MH – negative perception of services  Fearful distrust | *As a background I was diagnosed with bipolar when I was 24*  *I'm now 35 so I didn't have any after that I didn’t have any symptoms I recovered I was not on any medication I was not in services until this last experience last year* | |
| Physical Trauma | *I have a narrow birth canal so I have to have a C-section but I have actually had 4 C-sections this last one I was told that it was tricky because all my organs were sticking and something like this so erm it was an elected C-section*  *I called my 111 and they told me that I had an infection erm went to A and E straight away told that I was that I did have an infection and then got readmitted again in hospital for something called a removal of erm I don't know what it was basically they'd messed up my placenta*  *so erm so anyway I ended up with an infection and I was at risk of sepsis and I think just having all that told to me in*  *the hospital just made me…it made me panic*  *recovered well and they wanted to discharge me so I gave birth on Thursday as elective and they wanted to discharge me on the Friday leaving the baby behind* | |
| Psychotic Episode | *I started to get quite stressed out because I didn't want to leave the baby there erm especially in that condition because they said that she is very poorly that her breathing is not good and all these different things*  *we got discharged still quite under pressure still a little bit unwell but I wasn't sort of erm (inaudible) because of the whole stress of the baby not being well and the feeling like she was going to die and if I left the hospital for something something would happen to her and stuff like this so I think when we got home I was just really relieved to be home*  *You can't sleep but there was a difference because there's erm there's somebody there's the sort of someone who can be awake and then there's you not being able to get any rest at all*  *got discharged I went to do a car boot sale erm I rearranged all the furniture I reorganized all my cupboards erm to the point where I don't even know where things are I'm still looking for things*  *I started to believe that my husband was harming my children as well*  *So I went to the church erm apparently I was arguing with people* | |
| Trials and Tribulations of having PP and barriers to accessing care | Shame, Blame and Stigma | *you do go through a period of depression because everybody wants to tell you their experience everyone wants to tell you you did that everybody wants an apology*  *think that admitting that somebody in the family is unwell I think there's a stigma a stigma attached and also I think from what my mum had said is that she felt like she was to blame for what happened because she wasn’t there to support me*  *this doesn’t happen in our family we don't have ill we don't have mentally ill people in our family and having to sort of take that now okay somebody is mentally ill in our family*  *so it's just the whole stigma and then having to erm accept that this is actually happening*  *want to avoid they want to pretend it's not happening well it's happening but its not happening every day when everything is okay when you get back to normal we'll come back while you're having your issue you stay over there we'll be over here just make sure everything is happening over there and not in our space I got that sort of impression*  *It's a fear they think it's contagious*  *growing up people with mental illness are abandoned they are literally abandoned on the street and family members would deny them you know is that your cousin over there? Oh, no, no, no, no I don’t know who that is and they're just wandering around in the street*  *if that can happen to her well what does that say about you? What does that say about our genes or how we look after each other*  *it was all just a big humiliation I don't know what I've done*  *when I'm sitting in the church some people are like "oh no I'm not sitting there" because it's like er well "who is she really? Is it the nice one before or the one..."* | |
| Family and Community cultural beliefs  Lack of recognition  Lack of family support  Delayed access  Hidden | *my parents weren't advised to call mental health services because they seen it before and it happens you know it happens*  *I didn't know erm my family was very reluctant to put me in services again*  *overall like the reason I wanted to take part in the research because I know for a fact my parents will say that my family were very reluctant for me to get in contact with services*  *my mum's brother he's had schizophrenia he's suffers from schizophrenia my mum's brother he was in he was in Europe and then he lost his wife you know he had a break down and he was hearing voices and then they sent him back my family is from Gambia they sent him back to Gambia and he just sat there like a sitting duck you know this guy he is ill*  *you hide the person away it's not happening you know and that's the kind of thing that's sort of what I think my family was trying to do*  *she's said well "I think you would have got better if you just came home you stayed at home nobody knew the police wouldn’t have to be called in and we could have got medication of being you from somewhere you know that's the kind of erm "you'll be okay if we looked after you you would have been okay you would have got back to yourself"*  *I'm not in control of my actions so the only other option would've been to lock me in a house that would have been more harm than good because they're medically trained to deal with whatever that might come from that*  *All you had to do was say at home and we'd look after you you need to sleep we could have got your medication from your team too*  *I think also where I was found because I was away from them you know erm if they would have they probably would have persuaded me not to go in*  *They probably would have persuaded me not to go in if they were able to get me home and come find me erm definitely think I would have gone with their plan I would have gone with their plan*  *it is er it is a world outside of their world when you come up with that kind of mentality where normal is a erm (inaudible) "she's gone mad basically" it's normal to disown family members that have gone mad and pretend like they don’t exist and "that person's gone she's gone that's it she's gone"*  *I cant speak for every black and ethnic minority person including the Asian community but we let it get to that point*  *but we let it get so far as almost untreatable before help is sought you know it is keeping the person at home and let's*  *see if we can manage all the while they can't measure the person is deteriorating* | |
| Lack of support  Isolation | *my mum wasn't around at the time of the birth actually she was away*  *so I didn't really have much support other than my husband coming in to come and visit me with the kids*  *think for erm but I feel for my mum is a bit like "where was your mum?" that did keep coming up*  *They don’t want to see me in there they don’t want to see me in that place and they will see me when I get out that’s it*  *they'll call me mum used to call me almost every day but she's not coming to visit*  *that's why I just love APP because we're able to talk to people I'm just saying "look you're not alone in there" because*  *I felt alone I felt absolutely alone it' felt like it never happened to anybody else in the whole world just me* | |
| Lack of recognition in services | *got it got really worse having arguments with the staff you know*  *I'd been taken to (name of hospital) A and E erm I was being assessed to erm find out if I was okay for the most part I was okay and even they couldn't understand why I was there because I was very calm it does psychosis it's a bit like that your focussing on all these things but then there's times where you're very normal and a functioning but all of these people that know you can tell that the minute you are not yourself you're saying these things you're believing these things there was nothing to prevent it from happening because I was already from when the baby was ill I was already not in the right state I was already going down but no one could see because it looked very similar to what a normal mother would feel after birth she may feel unwell she may seem tearful she may not sleep you know but it looks very similar to what would be normal but if the character outside of that that makes it less about erm that something underlying is not right*  *And mental health services overall they always wait until it is the very worst it is as the very worst stage before there is any help available* | |
| Reluctant to access services | *you know it was quite traumatic for me I don't like hospitals because of my past experience of institutions of staff so*  *I'm waiting for my next review to be taken off the actual medication because you take it for a year so I had the baby in September so they are looking to discharge me well they have discharged but I'm in outpatients where they're going to take me off the medication themselves sort of thing… But that's what I'm waiting for but I've been well I mean I recovered quickly*  *but I don't think there's any barriers to services the services are there and they are available I'm just trying to think was I resistant to going? Yeah I was..* | |
| Grief and Loss | *really hard to hear that I'd done all these hurtful things I've done all these bizarre thing I've got to go back to shops where I can see I obviously was there when I was ill and it's sort of like "no, no, no, no, no, no, no, no, no, no you can't come in here"*  *it's something you know it's like my local area my local community my friends my family is you know they were all affected by me going through that episode*  *the depression that I was experiencing what I was feeling it was just the backlash of what I'd done how much harm I'd caused I mean I social services got involved they was talking about removal of my children if my husband hadn't stepped up I would have lost my children*  *but I think even if it happened just at home and around it would not have affected me as much but it went right into the church community*  *Where you know I had some reputation you know I was one of the people that was always helping people counselling people I appeared like I had it all together* | |
| Facilitators,  Turning Points & Epiphanies | Separation from family beliefs | *you know like she said " oh you know you would have been alright if you just stayed at home and if you just..." there is still now I still feel there is a lack of understanding that I would NOT have been able to stay at home*  *you know everything obviously I just think there is just such a lack of understanding of "you would have been okay"*  *understanding that people cannot reach you where you are if they haven't got the capacity to reach you so with my family they don't they don't have that in them to be that support system understanding what's happening to me*  *Because they just don't have it you know I can't expect them it would've been good for them to be there but you know they don’t have that understanding*  *I'm not I'm not upset with them at all like I said when I came out of hospital they were very supportive with the children* | |
| Husband as source of support | *He knew "she needs to go into something to help her because this is she's saying this now what else could she say? What else could happen?"*  *So he was the only person that I think was relieved to be honest*  *And he was the only one who visited me in hospital the rest of them would not they refused*  *my husband has been extremely supportive was there cooking me meals he came to visit me every day in hospital you know I said a lot of horrible things to him our marriage was sorry it was challenging for our marriage but I never once thought my marriage was at risk of breaking down that's how supportive he was he totally got what was going on* | |
| Spirtuality as source of support  Making peace  Acceptance | *I think if it wasn't for my faith I probably wouldn't be able to do that because it was very erm it was quite depressing*  *that there is two elements of me there but I sort of lost control over the function of my mind because of something that went wrong so they're taking your (inaudible) whatever that is actual physical cause but I feel like there's a spiritual pain as well and with speaking to the pastor what gave me a lot of closure*  *there was lots of support as well from the church*  *gives a lot that takes away a lot of the depression and the anger and you know the sense of abandonment my faith was really really very low I think was thinking why did God allow this happen and why now?*  *know it's not about religion but just having time with God the God I believe in and say "look I'm really angry at you that this has happened and erm being candid about it*  *God gave me the strength to revisit people that were avoiding me and say "look I know this is what happened"*  *because some people didn’t even known I was having psychosis* | |
| Self-reliance and resilient, courage | *it is just being able to work all those things out and being honest about every emotion at every stage you know and I've just come to the understanding that there are things that are going to happen*  *its coming to terms with you know what this happens and God you're still God I'm alive and my children are safe and everything worked out in the end it could have really gone badly erm when I was depressed I was able to pray and try and you know come out of that*  *I'm slowly over time being able to work through because I'm not dead my family have come round we've managed to talk managed to resolve I've rebuilt relationships*  *I've actually returned back to the same church and erm you know but I had to have those times away I had to go away and erm stuff like that so it's a process of recovery you know*  *that's why I help with APP not everyone is and it's not even about belief in God I just think it's erm I just think just being able to help people help women in particular who may have lost their children you know and being able to reassure them*  *but when I found APP it was such a relief because what was it then you know and I was able to put a name to it I never heard of it before now never*  *I do want to get quite involved in raising awareness of stuff like that especially for postnatal psychosis… because it's really really needed* | |
| *Sarah’s Story* | | | |
| Opening the story with the chaos of PP and illness | Being busy and  lack of sleep | *erm I guess my one might be a slightly complicated because I actually experienced psychosis when I was in the US*  *and erm we went to the US when my son was 2 months old which would get and again kind of breaks all the er the rules of what you're supposed to*  *so er we did like five cities in 30 days… It was silly I know in retrospect you know I didn't know what I was taking on*  *we ended it in my in-laws house in (name of US State) and that's when I experienced psychosis I was actually doing really well you know I had like sleeplessness and but my mood was great I was feeling good* | |
| Psychotic Episode | *just like it just like completely triggered something in me and so I by that point like my son's face was like a devil's face*  *I went through a complete psychotic episode where I thought we were all in a simulation that we were all in hell*  *in Korean culture a lot of the fairy tales the women always die they're always sacrificing themselves so there was a lot of that motif of like oh I have to sacrifice myself or I have to die and you know all this kind of stuff* | |
| Trials and Tribulations of having PP and barriers to accessing care | Blame Shame & Stigma/hidden/denial | *I remember was talking to her about it after I recovered she's had three kids and she said each time she had a kid she didn't leave the house for four months and I was like didn't you feel like down and she's like oh I didn't have time for that (laughter) … It's kind of like you know the implication is like I just have this kind of proclivity for I don't know indulging in a mental trait*  *I think is culturally and kind of like you know they didn't deal with it like they didn't have they depression or psychosis*  *back then because you know they didn't have the luxury of what I experienced*  *they told everyone that the reason was because I was exhausted so they said I was hospitalized for exhaustion*  *it's a sense of erm yeah it's interesting because you know when I was hospitalized the doctors kept asking about our history family history and anyone else had experienced this and everyone was like no gosh no you know really like they were very adamant about it*  *I think there's still a very deep level of shame around it and kind of the fact that kind of reflected in what my mother in law said is that it's a choice in a way like I could have at some point I suppose been like no I'm not going to have a mental breakdown*  *you know they've heard these kind of things their entire lives so they're like why does she? why she's so sensitive? It became the narrative of it like Sarah is so sensitive*  *It is really blaming I think even now they think I was oversensitive*  *I mean you know even my mother says it now to me you know what happened is really she's like you have no reason to blame errr she just said you carry the entire responsibility because you went on this stupid trip and you were very arrogant and you know it's all like it's all my fault and you know how could that have affected yours son*  *I do know that when my husband so my husband before taking me to the emergency room was trying to figure out he didn't know what was wrong with me and he didn't know what was going on but he called my parents to let them know that I was a bit weird and erm they said their solution was bring her to their house which is like six a six hour drive they said just bring her to our house and we'll take care of it*  *at least in Korean culture is that rather than going to the hospital if you're unwell especially mentally because I don't think they see a mental illness as the same as like if I'd broken my arm*  *from the women I've spoken to there's a fear that you know they'll be separated from their child or that it looks bad on their family and kind of you know* | |
| Familial and Cultural Taditiions – lack of understanding of MH/lack of recognition | *I guess what I will just say about like cultural my family background they're Korean we're Korean and actually that had a lot to do with what triggered my psychosis um culturally after you give birth in Korea you don't leave your house for 21 days it's like a very traditional sort of confinement period*  *they think the period the first hundred days is very the baby's considered very vulnerable and actually there's like a big sort of celebration called the hundred day celebration once your baby hits a hundred days and that's supposed to be like then everything's fine*  *lot of other traditional things like they're very preoccupied with babies being cold and so they would like layer all these blankets on him which you know the NHS is like don't do that to a new born so me I was constantly taking off blankets and they were constantly putting them in*  *they said I held him too much they said I shouldn't spoil him so much which you know he was like three months old so you know you cant spoil a new born*  *that actually urm culminated in my having a conversation with my father in law where he said that you know he thought I was depressed because he was a paediatrician he'd seen it and he said that's completely fine to be depressed*  *just be careful because one of my patients was depressed and then she shook her baby and he went blind I don't think they fully understand well they don't understand what psychosis is or how that could happen*  *my mother thinks it's because I was travelling when the baby was so young and I think there's an element of superstition to it it's like oh because you were doing all these things you are being reckless yeah and then my mother in law also thinks it's because of that*  *and I think that understanding that mental illness can be physically debilitating is something that they struggle with understanding*  *so she came when I was kind of on the up in the recovery and I think she just thought yeah I don't really know I think she just thought it was like kind of a... a choice*  *I think they see it as very selfish I think that's the thing is they see this mental health any mental health difficulty it's selfish*  *so once the actions of one individual reflect on the entire family and so I think that's why they do think of mental health as something selfish because it's all about keeping showing face for your family and you know making sure that the family looks good*  *you're not an individual with your own responsibility you're part of the unit we've shared responsibility*  *think my mother in law she felt a sense of shame with her mother in law I went through this kind of thing like the fact*  *that she had to cancel that one hundred days celebration she felt a lot of shame and I felt like it made her look bad to her mother in law so just like it.. it's like a never ending cycle like oh gosh now I have to worry about her mother in law because it's all collective* | |
| Powerlessness, pressure and lack of choice/duty | *think it was upon landing at my in-laws house and really understanding how much fear there was surrounding my baby's well-being and there also medical doctors so there was this whole thing where they thought you know they kept talking about what could happen to him or how you know what I was doing was endangering him*  *I actually didn't realize is this sort of cultural pressure of listening to you know what my in-laws say and feeling a sense of duty which I hadn't really considered until you know having a baby*  *like my erm mother in law didn't think I should be I was breastfeeding so she didn't think I should be feeding my son so much and again this whole thing where every time I tried to feed him she would be like are you sure you should be feeding him um and I tried to explain that actually feeding on demand when you're breastfeeding but she kept saying that and she kept saying trying to push me to use a bottle like she wanted to feed him this whole thing complicated with the fact that I had mastitis it was like a whole thing and then I think I started questioning you know was I actually over feeding my son*  *plus like actually everything I was doing they thought it was wrong and I think rather than having that separation of actually no they're wrong I'm right you know*  *I think because it wasn't possible culturally for me to say no it was very difficult to navigate that*  *and at the general facility they just kind of pumped me full of antipsychotic medication and I was in the facility for about a little over a week*  *we've talked about having a second child of course it's like 50 percent likely then anyway and the conversation is always like oh if you know if you do have a second child like you're not allowed to leave the house for a hundred days*  *I think part that's partly why my psychosis felt so inevitable is that these people were very close to me and you know saying these things that you know actually constantly before my psychosis I was constantly being warned and people tell telling these horrible stories like oh you know my my my eldest brother this is true my mother in laws eldest brother died from a pot of soup falling on him at a party when he was a baby and like that kind of thing but then you would hear like 5 6 times*  *you know somebody dropped their baby at a celebration party which they told me about it's like you don't actually see that these kind of things just aren't healthy for a new mother to hear...*  *warnings there's a lot of warning I think in Korean culture about something that can go wrong there's a lot of sense of it's superstitious I think and then if you're too happy if you're too like reckless or arrogant about avoiding bad things they try to warn you that actually bad things happen*  *we went back over Christmas and stayed with my in-laws again and I just was reminded of how overpowering their opinions can be but at the same time you can't they don't take very well to confrontation I could never like confront them about it because it just won't I don't think it would register*  *Yeah exactly yeah she's like no matter what you say I'm coming that's what she said and I'm like okay great...*  *I remember feeling a lot of there were like 300 guests coming or something ridiculous I was like oh no we can't be cancelling he's like forget the celebration were just leaving*  *I was very lucky that I gave birth in (UK City) otherwise I would have given birth and all my family would have been extended family would have been sitting in the waiting for me* | |
| Admitted to hospital in the US | *so my husband took me to the emergency room because it was the US we didn't have health insurance which was this whole other saga and then they don't have mother and baby units as they do here so I was admitted to a general facility*  *after four days of being in the emergency room k*  *you know by that point I came out and then three days later we flew back to (UK City Name)* | |
| Facilitators,  Turning Points & Epiphanies | Husband as decision make and protector | *we left the house so my husband you know was very much on my side but he didn't really understand how much er it was really affecting my well-being so he took me out to the house and we went to a hotel*  *we were very lucky in that my husband's workplace is very understanding they actually gave us money to hire someone to help during the day and then they let my husband work part time*  *husband my husband had a huge argument with his parents about after I was hospitalized and everything and he was like you know all the things that you said it really made an impact they couldn't see that*  *do think it's interesting that the only reason he took me to the hospital was that he was talking to one of our non-Korean friends who immediately was like she sounds really unwell I think you should take her to the emergency room*  *my husband had to make the decision about whether to fly or to stay and he actually when I left the facility he took me to a hotel he didn't take me to my in-laws house he didn't want me to be staying there and he decided that because of the whole insurance situation which was terrible erm that going back home to the UK was the best idea*  *You know it was very strange and like my in-laws actually wanted to come with us to like help out and my husband was like no no no*  *he was very very actually he's not very Korean because he had zero sense of obligation we left we left like the day before the 100 day celebration* | |
| Positive experience of MH  Services/gratitude | *yeah I do feel very lucky that I went to hospital when I did otherwise you know who knows? Yeah I think it could get really bad if you if you don't do that for sure*  *they were very patient with me and yeah just a very a sense of they just kind of were like we know what's going on and they told my husband that this is what's happening to her this is why she's acting this way and they just kind of took it from there I think I mean the psych facility also was very positive but at the same time they are just over completely overworked like you know I was put there and sedated and they just kind of left me to it*  *nobody came and talked to me or was like this is what's happening nobody was like this is when you can leave erm they didn't even tell my husband actually they were just kind of she's involuntary admitted and she's gonna figure it out erm so it was a lot of question marks around that erm but overall I mean they were everybody was very kind*  *yeah I just had like the perinatal team the mental health crisis team came every day to the apartment which was amazing and then I was referred to the first team which deals with psychosis erm and they worked with me for a little over a year*  *I erm this whole experience has made me just really grateful for the support systems that are here and I feel like the attitude towards mental health is so much more advanced here in the UK definitely much more preventative*  *Yeah it's like you know like of course it makes sense to have a good network and not just like throw medication at the problem and just have people come back and forth and back yeah it's just a completely different mind-set* | |
| Separating self from culture  Acceptance  Breaking tradition | *I don't know if it's just because anytime something like that happens people just hide away and they're saying that they have they had exhaustion so people don't actually know and it kind of perpetuates this misunderstanding*  *that's kind of like and it's kind of trying to explain that actually that's the reason why it happened and of course that doesn't you know it doesn't register*  *they have a family friend who's also Korean who was a psychiatrist and was actually very helpful but at the same time he said Sarah just has a disposition that makes her this way so which I found really upsetting because it was kind of trying to say that you know I'm just very sensitive and this this is kind of my tendency he said I have a tendency so I have to be very careful about stress because I have a tendency towards psychosis which is like no I don't know you know what does that even mean*  *Yeah I mean I think in a way it's a bit easier because I live separately from them they're an ocean away and so I can I have the space too*  *I think what helped with this is that I understood where they were coming from and I understood that this is where they sit in their beliefs and everything*  *I see where I am somewhere in the middle you know not entirely Western not entirely Korean either but I stopped taking it so personally and because I yeah I think that helped in that I realized they were just going to feel that way no matter what I was doing I wasn't actually doing anything wrong that's just that's how they are you know I've been thinking about that a lot actually I think the sort of Asian confinement belief that must have existed for a reason the 21 days I mean I guess it's meant to protect the baby but I think it's also in a way to shield people from seeing like a new mother erm you know and I think I think that's really important too when I look at the experience often stereotypically husbands take the family side rather than their wives side but he from the very beginning was very much on my side and he immediately think he feels a level of guilt that he didn't really feel so used to his family that he didn't notice that it was affecting me*  *so much so you've got a level of guilt in not speaking up sooner with them but the moment I was like I need to leave your house I think he easily could have been like no you have to stay here and sort of but he was like okay let's go like do you want to go back to (city name)*  *you know zero sense of like maybe we shouldn't do that like none... none at all like you know yeah it's interesting this sense of like yeah no boundaries*  *it's it is really sad like that people feel that extra level of pressure and when actually it's about taking care of yourself* | |
| Self-reliance/resilience  Speaking out | *I obviously was very lucky that I could take it with a grain of salt but I think if I didn't it could have been very like just make me feel even worse about the situation*  *you know it's lucky that I have very thick skin I suppose from years of hearing this kind of thing but it's very much my mother was kind of like you know this really could have affected your son's development so it's kind of like okay (laughter) like okay*  *I mean I was very lucky everyone was incredibly positive they were very helpful*  *So he kind of had to figure out what might be best for my recovery and he had done a lot of research himself but he didn't know what to expect yeah so I think he kind of so the plane itself was fine I think once we landed in (city name)it was kind of like well how does he take care of the baby and take care of me at the same time? Yeah that was hard*  *I wrote a book about it actually so I think that's been a whole erm it's coming out next month*  *anytime somebody has asked us we've always been very honest about what happened and I think that always takes people by surprise I do think it helps because then at least we're breaking the cycle you know this is another secret that's like hidden away somewhere you know?* | |

# Appendix M: Schedule of Questions

The researcher planned to use the following interview schedule

The researcher used the following questions and prompts:

* *I would like to hear about your experiences of seeking support around the time that you noticed that you were becoming unwell or someone close to you had noticed*
* *What happened?*
* *How do you feel about asking for help?*
* *Is there anything that made it harder for you to seek help?*
* *Is there anything that made it easier for you to seek help?*
* *Is there anything that prevented you from seeking help?*
* *Is there anything else you would like to tell me or that you feel is relevant to your experience of help seeking?*

It was not mandatory for each of these questions to be asked at each interview since each participants experience is unique, these questions were used as prompts to elicit the participant’s story

1. Both Watson et al (2019) and Smith et al (2019) also accessed Ovid for the purpose of their searches, this database was not accessible at the time of the search. [↑](#footnote-ref-1)
2. Smith et al (2019) categorised the methodological quality of the research included in their review as strong, adequate or weak using the CASP checklist tool, whilst Watson et al used the terms high, acceptable and low using the NICE critical appraisal checklist. Whilst the tools used to rate the quality of the research differed, the terms used to describe the quality, map on to one another. Therefore the qualitative ratings of high acceptable and low have been included in the table to reflect original quality ratings of the studies as assigned to them by the authors of the systematic reviews. [↑](#footnote-ref-2)
3. ECT is an abbreviation for Electroconvulsive Therapy which involves placing a person under anaesthetic and delivering an electrical stimulation to the brain for the treatment of mental health difficulties (American Psychiatric Association, 2019). [↑](#footnote-ref-3)
4. All responses on the CASP can be categorised into ‘yes’ ‘no’ or ‘partially’ apart from one questions which asks ‘what are the overall results of the review?’, this question will be addressed throughout the appraisal and synthesis and is therefore omitted from the table. [↑](#footnote-ref-4)