Psychotic-like experiences, intrusive thoughts, and access to mental healthcare in the perinatal period

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Thesis submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology (ClinPsyD)

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> > 4 March 2024

Thesis portfolio word count (excluding appendices): 26,084

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Thesis Portfolio Abstract

Background: Perinatal mental health (PMH) is a growing area of research and clinical practice. Strategies to improve PMH access needs to be tailored to the population and environment. Much of the PMH research has focused on mothers experiencing clinical mental health problems, but less is known about distressing symptoms of PMH problems in community samples. This thesis explores barriers to accessing PMH support in sub-Saharan Africa (SSA), factors associated with distressing intrusive thoughts (ITs) and psychotic-like experiences (PLEs), and the prevalence of these experiences in postnatal parents.

Method: A systematic review of barriers to accessing PMH support in SSA was conducted. A cross-sectional quantitative study was carried out exploring factors associated with distressing PLEs and ITs in postnatal parents using an online survey.

Results: Thirteen studies met inclusion criteria for the systematic review. Main barriers to accessing PMH included low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, training, and not involving loved ones. Factors unique to SSA included the lack of PMH policy, pluralism of traditional and biomedical care, stigma faced by adolescent mothers, and the need to integrate PMH into PHC.

The empirical paper found that 88.8% of parents experienced distressing PLEs and 90.8% experienced distressing ITs. Results showed that 35% of parents scored above the cut-off for potential risk of psychosis. Fewer parents were cohabiting, more were accessing mental health services, and mental health symptoms were more prevalent and severe in the potential risk group. Depression and distressing ITs were associated with increased PLE distress, while cohabitation reduced the likelihood of distress. A history of mental health difficulties, the number of ITs reported, stress, and anxiety were associated with increased IT distress.

Conclusion: There are barriers to accessing PMH support that are unique to SSA. These barriers should be considered when implementing PMH services in the region. PLEs and ITs are common. The rates of postnatal parents experiencing distressing PLEs and ITs and scoring above clinical cut-offs is higher than those accessing mental health services, indicating that further screening is needed to identify and support those at risk of developing postnatal mental health difficulties.

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Table of Contents

Contents

Acknowledgements 5
Chapter 1 6
Abstract
Background9
Methods12
Results
Discussion
References
Chapter 2 47
Systematic review findings
Background for the empirical paper
References
Chapter 3
Abstract
Introduction
Materials and Methods60
Results
Discussion
Conclusion
References
Chapter 4
Overview of Findings
Strengths and Limitations
Theoretical Implications
Clinical implications
Future Research
Thesis Portfolio Conclusion
References
Appendices 102

Acknowledgements

I would like to thank my supervisors, Dr Jo Hodgekins and Dr Jo Peterkin, for their guidance, expertise, and insightful contributions throughout the thesis process. I would also like to thank Dr Peter Beazley and Dr Leila Allen for their support during challenges in the ClinPsyD course. Thank you to all the parents who contributed their time and experiences to the empirical project, without you this work would not be possible.

I am immensely grateful to my friends and family, whose love, prayers, and humour have carried me through this thesis. It takes a village, and my village is strong.

> If you want to go fast, go alone. If you want to go far, go together. AFRICAN PROVERB

Chapter 1

Systematic Review

Barriers to Accessing Perinatal Mental Health Care in Sub-Saharan Africa: A Qualitative Systematic Review

Prepared for Submission to BMC Health Services Research (Appendix 1.1)

Word count (excluding abstract, references, tables, and figures): 8,703

Barriers to Accessing Perinatal Mental Health Care in Sub-Saharan Africa: A Qualitative Systematic Review

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Abstract

Background: There is a high prevalence of mental health difficulties in sub-Saharan Africa (SSA), and perinatal women are extremely vulnerable to mental health issues in SSA due to fragile health systems, high poverty rates, and minimal social safety nets. While barriers to accessing and implementing perinatal mental health (PMH) support have been studied, SSA is underrepresented in this research. This systematic review identifies barriers to accessing PMH care in SSA.

Methods: A systematic review was carried out across five online databases in June 2023 and February 2024. Studies focused on women in the perinatal period and/or those involved in supporting women experiencing mental health difficulties in the perinatal period. Eligible studies focused on perceived barriers to PMH care access or implementation in SSA, had a qualitative or mixed-methods design, were published in a peer-reviewed journal, and written in or translated into English. Papers were assessed for quality using the Mixed Methods Appraisal Tool. Data were analysed using thematic synthesis.

Results: A total of 13 papers were included in the review, which incorporated 803 participants across six countries; Ethiopia, Kenya, Malawi, Nigeria, South Africa, and Uganda. Main barriers included low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, training, and not involving loved ones. Factors unique to SSA included the lack of PMH policy, pluralism of traditional and biomedical care, stigma faced by adolescent mothers, and the need to integrate PMH into primary health care.

Conclusions: This is the first systematic review looking at barriers to accessing PMH in SSA alone. Many of the emerging themes, like stigma and limited resources, are also seen in the global literature, which suggests that findings and recommendations of these previous reviews can be applied to PMH in SSA. Factors unique to SSA should be considered when implementing PMH care in the region, particularly when implementation models and interventions are designed in high-income countries. Further research is needed across more SSA countries so that findings are more representative of the region.

Keywords: perinatal mental health, barriers, sub-Saharan Africa, systematic review

Background

Perinatal mental health (PMH) problems are those experienced during pregnancy and/or in the year following birth. Perinatal depression and anxiety disproportionately burden women in low- and middle-income countries (LMIC), affecting an estimated 1 in 5 women, compared to 1 in 10 in high-income countries (HIC)¹. Low-income countries are defined as countries with a Gross National Income (GNI) per capita of \$1,135 or less in 2022, calculated using the World Bank Atlas method. Middle-income countries are those with a GNI per capita between \$1,136 and \$13,845². A recent meta-analysis found that 24.7% of women in sub-Saharan Africa (SSA) experience Generalised Anxiety Disorder during the perinatal period³, and suicidal ideations were found to be more prevalent in pregnant women in SSA compared to high-income countries⁴. The prevalence of common perinatal mental illness in SSA varies with 8.3 - 41% in pregnancy, and 3.5 - 34.7% in the year following birth⁵. Health conditions arising from the perinatal period account for a major contribution to disease burden in SSA⁴.

SSA is a region comprised of 48 African countries that lie south of the Sahara. It consists of 22 low-income countries and 25 middle-income countries. Seychelles is the only HIC in SSA. Mental health is a significant public health issue across the area due to the high disease burden⁶, yet there are limited interventions for the treatment of common perinatal mental health disorders across the low and lower-middle income countries in SSA⁷. Both the Lancet Commission on Perinatal Health and recent guidance by the World Health Organisation indicate that there is a global need for a focus on PMH^{1,8,9}. Research focused specifically on SSA is needed, as SSA is often grouped with the current LMIC guidance and reviews⁷. This lack of focus on SSA has been a raised as a significant criticism of literature focusing on LMIC⁷. While there is ethnic, linguistic, and political diversity across the countries, there are thought to be similar common socio-historical experiences and some similar culture traits due to culture contact and acculturation¹⁰.

Poor PMH is associated with an increased risk of suicide, and therefore, an increased risk of the child growing up without a parent⁴. People with Adverse Childhood Experiences (ACEs), such as losing a parent and experiencing mental illness in the household, have an increased risk of developing mental health difficulties and chronic diseases. Furthermore, ACEs can disrupt neurodevelopment, resulting in impaired cognition and social functioning,

which can then lead to engaging in health risk behaviours¹¹. Poor PMH can disrupt parentchild bonding, resulting in a negative impact on children's cognitive, behavioural, and language development^{1,12}.

Untreated perinatal depression is associated with harmful mental, physical, and social effects on the mother, foetus, and family⁴. Women with PMH difficulties are more than twice as likely to give birth prematurely and to have children with low birth weight¹³.

Poor PMH in one parent increases the risk of mental health difficulties in the other parent, and increases the likelihood of housing and financial stressors, parental conflict, substance misuse, domestic violence and abuse, isolation, and reduced wellbeing and quality of life for all family members^{14–16}. This highlights the impact of PMH problems far beyond the perinatal period. Nevertheless, the detection and treatment of PMH problems remains limited.

PMH care is important in SSA because there is a high prevalence of PMH conditions, which accounts for a significant disease burden in the region^{7,17}. Factors correlated with maternal mental health problems are prevalent in SSA, resulting in an increased likelihood of women in SSA needing PMH support. These factors include poverty, limited emotional and practical support systems, substance use, lack of security in relationships, intimate partner violence, expose to violence, fragile health systems and chronic health conditions such as HIV^{6,7,18–20}.

Promoting PMH has benefits across several sectors. It supports optimal childhood development and improves parental functioning, self-esteem, resilience, and quality of life²¹. Improved PMH has also been shown to improve adherence to medication for HIV and tuberculosis, reducing the significant problems in SSA of mother-to-child HIV transmission and high maternal mortality rates²¹.

The United Nations' Sustainable Development Goals (SDG) aim for universal health coverage and quality mental health care for all. Meeting this goal includes increasing PMH support in SSA. The SDGs also pledge to improve newborn, child and maternal health, and notes that this is a particular issue in Africa²². Spedding et al.²³ argue that prioritising the mental health of women in Africa is central to achieving the SDGs.

A meta-review of the barriers and facilitators to accessing PMH has been conducted, but SSA is underrepresented in this study, with only 4% of studies including SSA countries¹². Most of the studies included in the meta-review (78%) covered only HIC. SSA was also underrepresented in a systematic review looking at barriers and facilitators to implementing PMH care, with 7% of studies covering SSA. The studies in the review came mostly from HIC (87%)²⁴. The majority of studies in a systematic review examining barriers and facilitators to help-seeking for perinatal women with depressive symptoms were from HIC (88%), and 5% of studies were from SSA²⁵. These papers do not comment on the reason for this underrepresentation of LMIC and SSA countries, but it may be a result of limited primary research and reviews being conducted in the area. The problem, however, lies in the generalisability of the findings and whether the recommendations for improving PMH care from these reviews are applicable in SSA.

Key barriers to PMH care globally include women not recognising that they need to seek help, HCPs needing training on PMH and cultural sensitivity, continuity of care, and stigma¹². Barriers to accessing general mental health care in LMIC are similar but included a scarcity of mental health services, a low priority given to mental health, few trained professionals in rural areas, and the cost of both care and transport to the facilities¹⁸.

While much is known about barriers to PMH care in HIC¹³, it is not clear whether these findings are generalisable to SSA. Findings from research in HIC cannot be directly applied to SSA because this region is distinctly different in that there are high rates of poverty and the highest rates gender-based violence²⁶, both of which are risk factors for common PMH disorders²⁷, there is a lower availability of healthcare professionals and formal services²⁸, poorer health seeking behaviour in mothers²⁹, and women in this region are disproportionately affected by PMH difficulties³. These factors can all impact access to PMH support and therefore research focused on this region is needed. Differences in barriers in SSA will highlight where recommendations can be tailored to better suit the development of PMH care in SSA. Therefore, this paper aimed to identify the perceived barriers to accessing PMH care and treatment in SSA.

Research Questions

- 1. What are the main barriers to accessing PMH care in SSA?
- 2. What barriers are unique to SSA?

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines³⁰ (Appendix 1.2, 1.3) and was registered with the International Prospective Register of Systematic Reviews (PROSPERO, registration number CRD42023398712).

Search strategy

Pre-planned searches were carried out on 5 June 2023 and repeated on 23 February 2024 across five electronic databases (Academic Search Ultimate, CINAHL Ultimate, MEDLINE Ultimate, APA PsycInfo, and AMED) to identify all relevant articles. The search strategy included terms related to women in the perinatal period (e.g. 'perinatal', 'mothers'), mental health services (e.g. 'mental health care', depression'), access to these services (e.g. 'help-seeking', 'utilization'), barriers and facilitators to access (e.g. 'challenges', 'enablers'), qualitative research (e.g. 'focus group', 'interview'), and countries in sub-Saharan Africa (e.g. 'Angola', 'Benin'). MeSH terms were used in the search strategy to increase the discoverability of papers. All countries in sub-Saharan Africa, as defined by the World Health Organization, were included as search terms. No limits were put on language or publication date. Search terms were identified from inclusion and exclusion criteria and finalised in supervision discussions and with guidance from the University Medical Librarian. See Appendix 1.4 for the full search syntax and databases searched.

Inclusion and exclusion criteria

The following inclusion criteria were adopted: 1) studies including women in the perinatal period and/or those involved in supporting women experiencing mental health difficulties in the perinatal period, 2) studies focused on the perceived barriers to perinatal mental healthcare access or implementation, 3) studies conducted in sub-Saharan Africa, and 4) qualitative or mixed-methods design. Studies were included if they were published in a peer-reviewed journal and were written in or translated into English.

Screening and study selection

Search results were imported into Zotero³¹ and duplicate publications were removed. The remaining studies were imported into Rayyan³², where papers were screened by title and abstract. Full-text screening was then completed in Zotero. All screening was carried out by TH, and 20% of the full texts were independently blind screened by IF. Decisions to include/exclude were concordant between reviewers in 92% of cases. Discrepancies were resolved following discussions with TH and IF.

Quality assessment

The quality of included studies were assessed using the Mixed Methods Appraisal Tool (MMAT)³³. The MMAT is a well-established critical appraisal tool designed for use in systematic reviews that include qualitative, quantitative, and mixed methods studies. The MMAT was chosen for this review as we included qualitative and mixed methods studies. MMAT guidance advises that at least two reviewers should independently appraise included studies.

The MMAT consists of two core measures of quality, and further questions tailored to the study's methodology. Question on the MMAT require answers of 'yes', 'no', and 'can't tell'. To obtain an overall score for each paper, 'yes' was given a value of 1, 'no' a value of 0, and 'can't tell' a value of 0.5. These scores were calculated into total percentage score. All studies were included in this review regardless of the methodological quality level³³.

Data extraction

Initial data extracted from the papers included the authors, year, country, study setting, study design, population, sample size and recruitment, outcomes, and outcome measures used. This data was tabulated to present the study characteristics (Table 1).

Thereafter, the findings were extracted by TH into Taguette³⁴, an open-source qualitative data analysis tool which allows for line-by-line coding. This included all text labelled as 'results' or 'findings' in the studies, including participant quotes and author's summaries.

Thematic synthesis

Results were analysed using thematic synthesis³⁵. The Enhancing Transparency in Reporting the Synthesis of Qualitative (ENTREQ) research guidelines³⁶ were followed (Appendix 1.5). This approach was chosen as it is well suited to the systematic aggregation of existing evidence and identifying patterns within and across data, it offers good transparency, and outcomes are accessible³⁷. First, text from primary studies were coded line by line. These codes were re-read and organised into descriptive themes that described patterns found in the data across the included studies. Finally, analytic themes were developed by inferring barriers to perinatal mental health care from the descriptive themes. We used inductive, data driven coding for the 11 papers found in the first search, and deductive coding for the final two papers from the second search. To present these analytic themes in a translatable way, they were then grouped according to the level at which these barriers might impact access and a model was created. This model was based on Bronfenbrenner's ecological systems model³⁸. Factors that were mentioned in more than half the papers were considered main barriers.

Results

Database searches yielded 18 829 papers (Figure 1). This number was high as every country in SSA was added to the search terms and there were many duplicates. We did not exclude search terms like 'HIV' or 'cancer', so many papers were related to physical maternal health. After duplicates were removed, papers were title screened. Thereafter, the remaining 171 papers were abstract screened. After abstract screening, 68 full texts were screened for eligibility, with 13 meeting the inclusion criteria. PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only





For more information, visit: http://www.prisma-statement.org/

Figure 1. PRISMA Flow Diagram

Study Characteristics

All 48 SSA countries were included in the search syntax and 14 countries were represented in the 68 studies that were screened at full text. The 13 included studies were conducted in 6 SSA countries; Ethiopia^{39,40}, Kenya⁴¹, Malawi^{42,43}, Nigeria^{44–46}, South Africa^{47,48}, and Uganda^{5,49,50}. These countries lie within the regions of South (South Africa), East (Ethiopia, Kenya, Malawi, and Uganda), and West Africa (Nigeria). No Central African countries were represented in this review. Ethiopia, Malawi, and Uganda are low-income countries, Kenya and Nigeria are low-middle income, and South Africa is upper-middle income. With 46% of SSA countries classified as low income, and 40% classified as lowmiddle income, and 13% as upper-middle income, the six countries included in the review are somewhat representative of the economic context of SSA.

This review incudes studies from on 12.5% of SSA, which does limit the generalisability of the findings. While no date constraints were imposed, all included studies were published between 2016 and 2023. Studies covered the full extent of the healthcare system from rural health teams, through primary care health centres, hospitals, up to healthcare administrative leads and policymakers. Participants included perinatal women (n = 320), caregivers/partners (n = 56), healthcare workers (n = 398), managers and health administrators (n = 29). Four papers focused solely on adolescent mothers^{41,43,45,47}. There was a mixed of study settings, with five studies focusing on urban areas^{40,41,44,45,47}, one on rural areas⁵, and the other covering both urban and rural areas^{39,42,43,46,48–50}. Six studies focused on perinatal depression^{39,40,42,44–46}, while the other seven studies looked PMH as a whole, rather than disorder-specific^{5,41,43,47–50}. All studies used interview guides as part of their data collection.

	Tal	ble	1	Study	^c Characteristics
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Author, year	Study aim	Country	Study setting	Study population	Sample size	Research Method
Adefolarin & Arulogun, 2018	To identify the needs of PHC workers to deliver routine health talk on maternal depression	Nigeria	Comprehensive clinics in PHC centres	Health workers	4 key health workers, 100 health workers	Mixed methods; key informant interviews (KIIs), researcher's observations, survey
Adeponle et al., 2023	To describe help-seeking steps and the decision-making process for perinatal depression treatment, and elucidate cultural processes that influence help- seeking	Nigeria	Maternal and child clinics, faith healing and traditional centres	Women with perinatal depression, family caregivers, healthcare providers	14 women, 14 family caregivers, 11 healthcare providers (community midwives, traditional and faith healers, general practitioners)	Qualitative; in- depth interviews
Bitew et al., 2020	To understand stakeholder perspectives on antenatal depression and the potential for psychological intervention in rural Ethiopia	Ethiopia	PHC centres, urban and rural health posts	Women, healthcare workers	88 women, 8 facility-based Primary Healthcare providers, 7 Health Extension Workers	Qualitative; in- depth interviews
Dadi et al., 2021	To understand barriers and enablers of implementing perinatal depression health services in Ethiopia	Ethiopia	Across the healthcare system	Health administrators	13 health administrators	Qualitative; semi-structured interviews
Field et al., 2020	To understand barriers and facilitators to adolescent mothers accessing mental health care in a low-resource setting in Cape Town, South Africa	South Africa	Midwife obstetric units	Pregnant adolescents	12 women	Qualitative; semi-structured interviews
Kola et al. 2020	To identify factors influencing health service utilisation for adolescent perinatal depression and to inform new strategies of care delivery	Nigeria	PHC facilities	Low-income young mothers, primary care providers	17 mothers, 25 primary care providers	Qualitative; focus group discussions
Kumar et al., 2017	To understand the mental health challenges and experiences of adolescent new mothers	Kenya	Maternal and child PHC centres	Pregnant adolescents, caregivers, health service providers, community health workers	8 pregnant adolescents, 6 caregivers of pregnant adolescents, 13 new adolescent mothers, 20 health service providers and community health workers	Qualitative; semi-structured interviews, KIIs, focus group discussions

Lovero et al., 2019	To evaluate progress and challenges in the implementation of mental healthcare integration into primary care	South Africa	TB clinics, maternal-child health clinics	District program managers, nurses, mental health practitioners	9 district program managers interviewed, 59 nurses and 17 mental health practitioners surveyed.	Mixed methods; semi-structured interviews, survey
Mhango et al., 2023	To explore risk and protective factors for common mental health problems, and barriers to accessing mental health care among perinatal adolescents	Malawi	Urban and rural health centres	Perinatal adolescents, family members, healthcare workers	14 perinatal adolescents, 4 family members, 8 healthcare workers	Qualitative; semi-structured interviews
Nakku et al., 2016	To understand barriers, facilitators and needs in perinatal mental health care in a rural African district	Uganda	Village health teams, district hospital maternity clinic, health facilities	Village Health team members, postpartum women, midwives, nurses, health managers	24 pregnant women, 24 postpartum women, 20 village health team members, 8 key informants	Qualitative; KIIs, focus group discussions.
Ng'oma et al. <i>,</i> 2019	To understand perceptions of perinatal depression and treatment needs in Malawi	Malawi	PHC clinic, rural hospital	Antenatal and postnatal women, primary healthcare workers, maternal health coordinators	22 women, 6 primary healthcare workers, 4 maternal health coordinators	Qualitative; in- depth interviews, KIIs
Sarkar et al., 2022	To understand the extent to which integration of perinatal mental healthcare into maternal healthcare was considered desirable, possible, and opportune	Uganda	Community, district, national health settings	Key stakeholders, perinatal women, partners	7 policymakers and managers, 22 healthcare providers, 4 alternative health system care providers, 2 academics, 4 local council members, 14 village health team members, 30 pregnant women, 30 new mothers, 32 partners	Qualitative; in- depth interviews, focus group discussions
Tol et al., 2018	To examine perspectives on mental health-related priorities, help-seeking behaviours, and existing resources to guide the development of maternal mental health integration	Uganda	Village health teams, health centres	Health workers, perinatal women, religious, traditional healers	26 primary healthcare workers,24 community healthcare workers, 24 perinatal women, 10 traditional and religious healers, 9 mental health specialists	Qualitative - free listing interview, KIIs, semi- structured interviews

Quality appraisal

All studies met the screening criteria having presented clear research questions and the collected data allowed for these questions to be answered (Table 2). Therefore, all were included in the study. Qualitative studies were screened with questions three to seven and mixed methods studies were also screened with questions eight to twelve. The quantitative components of the mixed methods papers were not assessed at this review only utilized the qualitative components.

The 11 qualitative studies were of high quality, and all scored 100%, as appropriate qualitative approaches and adequate data collection methods were used, and findings were adequately derived from the data, interpretation of results was sufficiently substantiated by the data, and coherence was present between data sources, collection, analysis, and interpretation. The two mixed-methods studies scored 79%⁴⁴ and 71%⁴⁸. The quality of the qualitative components of these studies was high and rationales were given for using a mixed methods approach in both papers, but divergences and inconsistencies between quantitative and qualitative results were not adequately addressed. IR assessed 46% of the papers, with 83% agreement. Discrepancies were resolved through discussion between TH and IR.

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Score
Adefolarin et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Ν	Ν	?	79
Adeponle et al. (2023)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Bitew et al. (2020)	Y	Y	Υ	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Dadi et al. (2021)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Field et al. (2020)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Kola et al. (2020)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Kumar et al. (2017)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Lovero et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	Ν	?	Ν	Ν	71
Mhango et al. (2023)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Nakku et al. (2016)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Ng'oma et al. (2019)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Sarkar et al. (2022)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100
Tol et al. (2018)	Y	Y	Y	Y	Y	Y	Y	n/a	n/a	n/a	n/a	n/a	100

Table 2 Methodological quality assessment

*Y yes; *N no; ?* can't tell; n/a not applicable

Screening questions (all papers)

Q1: Are there clear research questions?

Q2: Do the collected data allow to address the research questions?

Qualitative

Q3: Is the qualitative approach appropriate to answer the research question?

Q4: Are the qualitative data collection methods adequate to address the research question?

Q5: Are the findings adequately derived from the data?

Q6: Is the interpretation of results sufficiently substantiated by data?

Q7: Is there coherence between qualitative data sources, collection, analysis, and interpretation? Mixed methods

Q8: Is there an adequate rationale for using a mixed methods design to address the research question? Q9: Are the different components of the study effectively integrated to answer the research question? Q10: Are the outputs of the integration of qualitative and quantitative components adequately interpreted? Q11: Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?

Q12: Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Analytic themes

Barriers to accessing perinatal mental healthcare were seen across individual,

community, healthcare professional, treatment, service, policy, and societal levels. These are

illustrated in Figure 2. Main barriers were those mentioned in more than half the papers,

and included mental health literacy, stigma, where help is sought, resources, screening,

formal support, training, and involving loved ones.



Figure 2: Barriers to accessing PMH care access in SSA. Main barriers are in bold.

Society

Factors affecting access to PMH care at a societal level were mental health literacy^{5,39,40,42–44,48,49}, stigma^{5,40,41,43,45–47,49}, and where help is first sought^{5,39,40,42,43,46,50}.

Mental health literacy

The co-occurrence of traditional and biomedical understandings of mental health were present across the studies. Nine studies referenced beliefs about PMH being related to witchcraft^{5,39,40,42–44,46,49,50} across urban and rural areas in Ethiopia Nigeria, Uganda, and Malawi. Mental health symptoms were seen as a sign of bewitchment, and perinatal women are warned against leaving their homes as diseases and spirits could be encountered outdoors in rural Ethiopia³⁹ and Uganda⁵. Low mental health awareness was reported across four countries at both the community⁴⁴ and healthcare administration levels^{40,42,48}. Low awareness and understanding of PMH was found to impact health-seeking and healthcare policy. Concerns about healthcare professionals and managers not being up to date with the evidence base or holding views that there is no evidence of mental health issues or treatment options in the perinatal period were raised in studies in Uganda⁴⁹ and Ethiopia⁴⁰.

In postnatal for example, ... a mother is not left alone..., there is another religious saying or it is evil, or demon they will say, ... um, during that time, if she has an accident, ... she might encounter depression. [Healthcare provider]^{39(p.5-6)}

Factors contributing to low mental health literacy were cited across more than half the included studies, and therefore considered a main barrier to accessing PMH care in SSA.

Stigma

Negative beliefs about the causes and impact of mental illness resulted in significant stigma around PMH and help-seeking^{5,40,41,43,45–47,49} across studies in all six countries. The four papers focusing specifically on adolescent mothers all highlighted stigma as a barrier to help-seeking. Mothers felt judged by their peers, families, and HCPs for having an unplanned pregnancy, so did not feel safe in asking for PMH support. A Nigerian study found that common stereotypes for women with perinatal depression included being aggressive, violent, cursed, and vagrant⁴⁶.

First of all, friend's judge, they judge and when you tell them something, they go tell their mothers. You see, once you tell people you are seeing a counsellor, they assume that you are having big problems, so I didn't want them to assume that about me. [Postnatal mother, age 19]^{47(p.5)}

Stigma was cited across more than half the included studies, and therefore considered a main barrier to accessing PMH care in SSA.

Where help is sought

Beliefs about the causes of mental illness and availability of support influenced where help was sought. Six studies^{5,39,40,42,46,50} found that women are advised to first seek religious or traditional help for symptoms of PMH. These studies included participants from rural and urban areas, indicating that it is not limited to rural settings where there is limited clinic access. The remaining studies reported initial care being provided by PHC facilities. In a Malawian study, most of the perinatal adolescents and their families felt that medical attention would be most helpful in addressing common mental health problems, but none sought mental health support despite half the participants scoring moderate to high on measures of depression⁴³. In fact, in addition to the lack of data, in our area where we are living, culturally, mothers would not prefer to go to health facilities when such disorder is happening to them. As depression is considered evil and demonic, most of the time, perinatal women prefer to go other places for service such as spiritual places to use holy water. [Health administrator]^{40(p.8)}

This factor was cited across more than half the included studies, and therefore considered a main factor in accessing PMH care in SSA. First seeking religious or traditional help, while possibly helpful, was a barrier in that it often contradicted support available in clinics and delayed women going to clinics.

Policy

Factors affecting access to PMH care at a policymaker level were the priority given to PMH^{40,49} and funding^{5,40,41,48,49}.

Prioritisation of PMH

Guidance was discussed at length in an Ethiopian study that interviewed health administrators about the implementation of PMH services⁴⁰. Inadequate guidance about managing PMH at different healthcare levels resulted in the necessary systems to prevent, screen, and treat perinatal depression were not put in place. One health administrator shared that guidance was not in place as perinatal depression was not considered a public health problem of significance, and others believed there was no evidence indicating the presence of depression during pregnancy. HCPs raised concerns that without mental health policies and guidance, implementation, training, resources, and funding would not be sustainable.

I do not have any idea about perinatal depression though I am a non-communicable disease officer. We are using the new non-communicable disease guideline developed by the Federal Ministry of Health and perinatal depression is not included in the guideline. [Health administrator]^{40(p.5)}

Another health administrator argued that while PMH is an issue, priority needs to be given to other communicable and noncommunicable diseases with higher mortality rates. HCPs in Uganda argued that greater commitment and action is need towards improving PMH, but that without collective ownership and support from the Ministry of Health, any efforts would fall short⁴⁹.

Because of many other communicable and noncommunicable diseases that need fast attention, perinatal depression is not given a high priority... We are also one of the low-income countries with limited resources, and the Ministry of Health might believe that more attention should be given for such conditions than depression. As you see, due to there being many health issues in the country, the government prioritises and focuses on interventions that benefit most of the women. [Health administrator]^{40(p.9)}

Funding

Limited funding was seen as the result of poor prioritisation of PMH. Adequate funding for PMH is not allocated as mental health remains 'low risk' on the global health security agenda⁴⁹. Volunteer village healthcare teams form the basis of rural healthcare in Uganda and the limited funding for training these workers were seen as a barrier to effective care, coordination, and treatment⁵. Volunteers lost motivation when funding was cut or requests for training were denied. Funding cuts were also responsible for ending effective PMH support programs in Kenya; "there was a support group in existence last year don't know how and why it died probably the funding faded away"^{41(p.21)}.

In Ethiopia, in areas where funding has increased, there have been sustained improvements in detection of PMH difficulties, interventions started, and protocols developed ⁴⁰.

Service

Factors affecting access to PMH care at a service level were care pathways^{5,43,46,48,50}, service structures^{5,39,42–44,48}, and resources^{5,39,40,42–44,48,49}.

Care Pathways

It was unclear whether policy-led, formal care pathways were in place, aside from severe cases of PMH being referred to hospitals. Where care pathways were in place, these were either informal and determined by availability of trained professionals or set up as part of a longstanding research project. The most developed care pathway was available in South Africa, the only upper-middle income country in the review. The participants in South African study about integrating PMH into existing health services shared their care pathway.

If [the nurse] find [s] any "yes" answer on the screening tool, then [they] are supposed to refer this to a mental health practitioner... Then she can do a proper screening. There is a screening, assessment questionnaire that we have that she can use to do the assessment and come to a diagnosis, a nursing diagnosis. And then if she feels this person needs to be referred, sometimes she, she can either do some counselling with this person herself, if it's manageable, or she can—If she thinks this person needs medication, she can refer this person to the nearest hospital where there is an outpatient clinic [District program manager]^{48(p.5)}

While successful, this pathway relied on mental health practitioners visiting local clinics. When mental health practitioners were not available, patients were referred to a different facility for diagnosis, often during an involuntary hold. This study had the lowest quality rating (71/100), but it does highlight the importance of adequate staffing in maintaining care pathways.

In a Ugandan study, women first sought help from family and their community⁵⁰. Thereafter, they sought help from a traditional or spiritual healer. These healers refer to community health workers if they feel they are unable to help. Community health workers then help women to access primary healthcare facilities⁵⁰. In doing so, this care pathway incorporates traditional and western approaches to care and facilitates access to care. Traditional healers make up a large proportion of the informal healthcare system in SSA, so this type of care pathway, where care begins with traditional or spiritual healers, is likely seen across SSA.

A study in rural Uganda found that there were low levels of PMH referrals due to PMH difficulties not being identified in local clinics⁵. Where PMH difficulties are identified, women are referred up the care pathway to district or regional hospitals as this is where mental health services and medication can be accessed.

In Malawi, HCPs would sometimes refer adolescents to clinical officers for counselling, but these officers were only trained to provide basic psychosocial support to people living with HIV/AIDS⁴³. Severe cases were referred to the psychiatric hospital.

In a Nigerian study on perinatal depression, ambiguity and uncertainty around the care pathway was evident. Families moved back and forth between biomedical and traditional care, particularly in cases where symptoms worsened despite accessing treatment, where treatment resulted in adverse effects, or where the available treatment options were perceived as ineffective in curing symptoms⁴⁶.

Service structures

Integration was the main issue raised across the studies when discussing service structures. Most antenatal and post-natal services in Nigeria are largely physical health focused⁴⁴. In Ethiopia, healthcare strengthening initiatives that aim to deliver mental healthcare were identified, but these are unintegrated and ran in parallel³⁹.

In South Africa, there were great efforts to integrate primary and mental healthcare at the clinic level, but these efforts were hindered by a lack of coordination at the district level⁴⁸. HCPs in Malawi faced a similar problem and felt that interventions would be easily accepted by staff if there were collaboration among all stake holders and interventions were nested within the existing healthcare system. Concerns were also raised that, without integration, initiatives would be considered burdensome by staff and these initiatives would then fail.

Every program is focused on itself. There is very little talk between programs. So, from the top level, it's already been separated, these programs, so it's actually a pity that they have separated it so because it's now difficult to come down and bring them all together because that's what needed at the prim- at the gr- at the root level, grassroot level. You need to integrate the clinics. That's what frustrates the clinic staff so much because you have so many programs, and um, they have to comply with every program and, for themselves, they don't talk to each other. It's like the programs—Each program is important. [District program manager]^{48)p.6)}

In Malawi, judgement from older mothers was identified as a barrier to adolescent mothers accessing support and therefore, HCPs suggested that creating youth-friendly health services would help reduce stigma for these mothers⁴³.

Resources

A lack of resources was identified as a barrier to care across eight studies^{5,39,40,42–44,48,49}. Low staffing levels, a shortage of trained personnel, and no private spaces were identified as barriers in Ethiopia, South Africa, Uganda, and Malawi. The importance of screening for PMH was acknowledged^{5,40,42,43,49}, but HCPs raised concerns about how much time screening would take in already stretched healthcare systems. In two studies in Nigeria and Malawi, HCPs did not have education materials on PMH so this information could not be shared between HCPs or with patients^{43,44}. Two HCPs in Malawi⁴² and Uganda⁵ proposed that the volunteer staff, who have less work than the HCPs, be trained to screen for PMH difficulties so that more people could be screened while not increasing the workloads of nurses and midwives.

Everything is possible but if you engage the nurses, they are already overwhelmed but maybe use the volunteers as HIV Testing Counsellors are used, just train them and of course train the nurses and the clinicians so that they should supervise. ..., as long as they are given a little something [some incentives] [Maternal Health Coordinator]^{19(p.12)}

Resource constraints were cited across more than half the studies, and therefore considered a main barrier to accessing PMH support in SSA.

Treatment

Factors affecting access to PMH care at a treatment level were confidentiality^{42,47}, screening^{5,39,40,42,43,47–49} and formal support^{5,39–43,45,46,48,50}.

Confidentiality

Concerns of confidentiality were raised by mothers in studies, rather than HCPs. Adolescent mothers in South Africa were initially very wary of speaking openly with HCPs, particularly if the HCPs were part of their community⁴⁷. Finding HCPs outside of one's community may be more difficult in rural areas. Confidentiality was a significant concern in rural Malawi where women had encountered HCPs and fellow therapy group members who they knew socially⁴². These women raised concerns the impact this would have on the relationship with their partner and in-laws as sharing family problems with people in the community would be seen as culturally inappropriate. I know what I say will stay here, it will not go. It was confidential. I was so happy because she didn't know me, she didn't know any friend of mine or family member that she could go and gossip to me about. [Postnatal adolescent mother]^{47(p.5)}

Screening

Screening for mental health problems was the factor with most coverage across the included studies. Due to this factor being cited across so many studies, it was considered a main barrier to accessing PMH support in SSA. Without screening, PMH difficulties were likely to be missed or misdiagnosed as physical illness. Few HCPs felt adequately prepared to conduct PMH screenings, and it was unclear which professionals were required to do so^{39,40,47,49}. Screening rates and HCPs involved in screening differed significantly across services⁴⁸. In Malawi, no screening tools were routinely used⁴³. Instead, HCPs identified women needing PMH support by looking at how they presented or behaved. Some HCPs in South Africa and Ethiopia felt confident in asking about PMH symptoms as they had been trained to use formal screening tools^{39,48}. Most screening in Uganda was conducted by HCPs because low literacy rates prevented the use of self-report questionnaires⁵. The need for simple screening tools was also raised⁴⁹.

I think you need to design simple tools that [nurses and midwives] can use. Because they need to be able to assess, to look out for these things. We should have a way of asking these things in antenatal, and the same applies to the ward. So, sensitization and screening, those are the things that are needed. Because if people don't know that the problem is there, they will not look for it, and if they do not look for it, they will miss it. [Doctor]^{49(p.5)}

There were also concerns raised by HCPs in South Africa about screening questions feeling too personal and that patients might feel forced to answer when questions were asked during routine perinatal clinics⁴⁷. Furthermore, screening for mental health difficulties was seen as unnecessary where PMH was not considered problematic⁴⁰.

Formal support

PMH support from HCPs in the community was limited across the papers and was often only available for women presenting with severe symptoms. The community support from that was available psychoeducation^{41,45}, medication from visiting doctors⁴⁸, and counselling^{40,43,48,50}, and group counselling⁴⁵ and psychotherapy from visiting psychologists⁴⁸. Low-level mental health difficulties were also supported through psychosocial advice to carers and signposting^{39,41}. It was not clear whether this support was evidence-based, and this support was dependent on available staffing. Studies in Kenya and rural Uganda reported that there were no available services in the community^{5,41}. Severe cases were referred for treatment in psychiatric hospitals.

Limited access to evidence-based formal support and treatment was cited across more than half the papers, and therefore considered a main barrier in SSA.

Healthcare professionals

Factors affecting access to PMH care at a healthcare professional level were training^{5,39,41–43,48,49} and approaches to patients^{39,43,45}.

Training

Most HCPs reported receiving inadequate training and being motivated to learn more and provide better care. This was cited across more than half the included papers, and therefore considered a main barrier to accessing PMH support in SSA.

HCPs felt that they would benefit from training on mental health awareness, screening, discussing sensitive topics, maternal depression, counselling skills, parenting, and evidence-based treatment^{5,39,41}. Barriers to accessing this training included a lack of training programmes, low funding, inadequate guidance about who should receive training. Much of the training seems to be delivered by international organisations and research groups.

Voluntary village health team members in Uganda requested training in counselling so that they could integrate these skills into their work and offer PMH support in their local area⁵. Knowledge gaps among Ugandan midwives were acknowledged and multiple respondents advocated for training in screening, identification, and treatment for PMH difficulties. Other participants called for all staff that work with mothers with PMH difficulties to receive training^{43,49} to allow for more effective care and task sharing.

I think they should health educate the midwives and then also other health workers need to be sensitized because not only the midwives will come across such mothers ... So at least other health workers also need to be educated on how to manage these mothers. So, this applies to everybody even the nursing assistants. So, if we train them, they can help us manage those mothers. [Nurse]^{49(p.4)}

Approaches to patients

HCPs in Ethiopia shared that the way women are asked about their difficulties will influence whether they feel comfortable sharing their symptoms³⁹. They emphasised the importance of gaining the trust of the woman, confidentiality, professional ethics, and of asking about social adversities before raising mental health difficulties.

Adolescent mothers in Nigeria and Malawi, however, reported stigmatising attitudes of HCPs, even where training on managing perinatal depression had been given^{43,45}. HCPs in both studies shared views that adolescent mothers were rude. Adolescent mothers reported having better experiences with senior matrons, who had more experience and were trained in delivering PMH groups.

Many of these girls are irresponsible and promiscuous and do not listen to parents ...it is no wonder that they receive very little support from relatives. They need to learn the hard way. [Healthcare provider]^{45(p.5)}

Community

Factors affecting access to PMH care at a community level were involving loved ones^{5,39,41–43,45–47,50} and partner dynamics^{5,39,50}.

Involving loved ones

The importance of involving loved ones in the mothers' care was raised in studies across all six countries and in all studies involving adolescent mothers^{41,43,45,47}. Not including loved ones in care was considered a main barrier to women accessing PMH support in SSA.

In rural Uganda, when levels of partner support were low, mothers were seldom supported in returning to healthcare facilities following birth⁵. HCPs in rural Ethiopia noted that in communal cultures, healthcare decisions are shared or made on a woman's behalf by parents or her partner. A woman might not be able to freely attend a healthcare facility without the approval of her partner. Therefore, it was seen as important to involve one's

close community in help-seeking and supporting treatment. The concept of help-seeking decision making being held by a woman's parents or spouse, rather than the woman herself, was also present in urban and rural Nigeria⁴⁶. Mothers and HCPs in Malawi noted low levels of social support and advocated for involving partners as part of treatment for perinatal depression⁴².

HCPs in Kenya attributed a lack of support from loved ones to exacerbating PMH symptoms⁴¹. The practice of polygamy, which was reported to be common in the Ugandan Kamuli district, was also raised as a barrier to care as this practice reduces the amount of support that a male partner can give his pregnant partner⁵.

We miss the opportunity of male involvement because we introduced the concept of male involvement [in maternal health care] but the way we are involving our men. ...we miss a lot of opportunity because there is no standard, so unless there are specified antenatal interventions that could be incorporated in antenatal care so that when a man escorts a woman, at least you should not miss the psychological aspect, we should take advantage of the male involvement because the man is key. [Maternal Health Coordinator]^{19(p.8)}

Partner dynamics

Problematic partner dynamics was a significant barrier in accessing PMH care in rural Ethiopia and Uganda^{5,39,50}. HCPs reported husbands being a barrier to care as they were unsupportive, drank heavily, or refused to allow their wife to attend appointments or meet with other women in the area³⁹. A governmental policy in Uganda requires men to attend antenatal appointments and be tested for HIV at each visit. This was established to improve engagement in antenatal services and to increase HIV detection rates. However, men who do not wish to have an HIV test will not attend the appointment, but their partners will not be allowed to attend alone. The women who do push their partner to attend appointments put themselves at risk of physical violence⁵⁰.

There are some men who don't want to come to hospital with their wives. He tells her that if you don't go to hospital, can't you survive, can't you deliver, will you die? He refuses her to go to hospital. [Pregnant woman]^{5(p.6)}

Individual

Finally, factors affecting access to PMH care at an individual level were help-seeking behaviours^{39,42,43,45}, logistics^{5,39,41,46,47}, and healthcare expectations^{39,45,47,49}.

Help-seeking behaviours

Women in Ethiopia shared that they struggled to trust and confide in HCPs or struggled to articulate their difficulties. While some of these women confided in partners or neighbours, most did not share their difficulties with anyone as this would be seen as bothering other people; *"most of the time I did not want to bother anyone. Some people come and only tell part of their problem to get pills or some kind of medicine for temporary relief"*^{39(p.6}.

There was also the worry of finding out that their symptoms were as a result of a physical disease³⁹. Adolescent mothers in Malawi shared this about being a burden and not wanting to be seen as someone who is always complaining⁴³. Mothers in Nigeria reported needing to overcome significant self and social stigma to ask for help⁴⁵. Women in rural Malawi chose not to seek help as either clinics were full or they encountered HCPs with negative attitudes towards PMH⁴².

Logistics and clinic attendance

Barriers to attending clinic appointments were shared by adolescent mothers and those in rural areas. In rural Uganda and Ethiopia, women struggled to get to the clinics due to transport costs, social obligations, and the distance and topography between a woman's home and the clinic^{5,39}. This not only prevented women from accessing PMH care, but also from attending general antenatal care, where mental health problems might be recognised early. Women in rural Uganda spoke about wanting to access PMH care but they could not afford the transport cost; "a mother may be aware of the service, know the advantage of going to a health facility but she doesn't have transport money. Even if you give a health education talk, she will be aware but she will not have transport"^{5(p.6)}. HCPs in Ethiopia also noted that attending PMH services would be influenced by cultural practices, where women are restricted from social activities in the final months of pregnancy. Women who were pregnant with their first child, diagnosed with HIV, or frequently pregnant were more likely to avoid being in public for fear of evil spirits or being labelled 'shameless'³⁹.

Adolescent mothers struggled to attend clinics as they needed to take multiple taxis to the healthcare facilities, which were then situated in dangerous places⁴⁷. When clinics were busy, mothers were sent home and asked to return the next day. One Kenyan adolescent mother spoke about the difficulty of walking long distances to the clinic while pregnant and after birth as her partner and mother refused to pay for her transport ⁴¹. With significant transport costs, mothers were unlikely to return to clinics without a guaranteed appointment⁴¹.

Healthcare expectations

Three studies found that women were nervous about sharing mental health difficulties with HCPs due to negative experiences of physical perinatal appointments, where they might have been ridiculed or dismissed^{39,47,49}. However, adolescent mothers in South Africa and Nigeria who had engaged in PMH support found that the workers trained in delivering PMH interventions were empathetic and non-judgemental^{45,47}. HCPs in Ethiopia also noted the power that their position carries by sharing that mothers see them as authority figures, "sometimes next to their Lord,"^{39(p.8)} and that their advice is seen as more valuable than money. This high value placed on HCPs facilitates service engagement.

Discussion

Summary of main findings

Barriers to accessing PMH care were seen across individual, community, healthcare professional, treatment, service, policy, and societal levels. The model developed in this review was based on Bronfenbrenner's ecological systems model³⁸, and contained analytic themes inferred from the descriptive themes in the paper. Main barriers to accessing PMH support in SSA were low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, and training, and not involving loved ones.

Our findings are similar to those of a global meta-review of the barriers to accessing PMH¹² in that barriers were identified across levels and included culture, stigma, limited resources, service structures, interactions between patients and HCPs, previous experiences of healthcare, beliefs about mental illness, and logistics. This suggests that these themes are applicable in SSA. However, our findings also identified factors that may be unique to SSA.

Specifically, the policy and guidance needed to direct implementation and management of PMH in SSA was found to be either lacking or non-existent. The studies showed that support for PMH is sought from both traditional healers and PHC, allowing for a range of treatment options but resulting in a confused system which contradicting treatments. Adolescent mothers emerged as a group facing significant stigma. Current service structures in SSA are behind those seen in many HIC, and the focus needs to be on integrating PMH support into PHC. Help-seeking in some areas was decided by one's spouse or parents, and some cultural practices prevent perinatal women from leaving home to access care. Each of these factors will now be considered in more detail.

Policy and guidance

Policy and guidance specific to PMH in SSA would allow for the establishment of sustainable systems to prevent, detect and treat PMH difficulties⁴⁰. Systems established without policies struggled to maintain funding, which resulted in limited resources. PMH policy has not been available in SSA largely due to policy for other health conditions needing to be prioritised. However, our findings show that some policymakers are not aware that PMH difficulties are common or have a significant impact⁴⁰. This highlights the need for increased mental health awareness in both the administration and general population levels⁴⁸. Clear policy and guidance would allow for funding to be directed towards PMH and standardised services to be established.

Adolescent mothers

The SSA region has the highest adolescent birth rate, with 99.4 births per 1000 women (15-19 years), compared to 13.1 per 1000 in the European region⁵¹. Of the studies included in this review, four focused on adolescent mothers. This is unsurprising, given the high adolescent birth rate in the region. The main barriers found in these papers were around stigma, concerns about confidentiality, needing the support of loved ones, and logistics in accessing clinics. With high adolescent birth rates, HCPs may wish to tailor PMH support to this group. Adolescent mothers in Kenya suggested that they would benefit from group interventions where they can meet other adolescent mothers, receive psychological support, and learn necessary skills like caring for their child and starting a business⁴¹.

Integrating PMH into PHC

The WHO recommend integrating mental health services into PHC to scale up services. The Mental Health Gap Action Programme⁹ supports the delivery of care by non-specialist health workers with specialist staff providing supervision and support. HCPs in this review also called for non-specialist HCPs and volunteers to be trained to deliver screening and treatment so that they could offer better care and share the workload of the few specialised clinicians.

There are several examples of successful PMH interventions being integrated into PHC. Group Problem-Solving Therapy delivered by trained peer counsellors in Zimbabwe was found to be feasible, acceptable, and more effective compared to pharmacotherapy in treating postnatal depression⁵². Psychosocial interventions delivered by trained community midwives in Nigeria were found to be feasible and acceptable, and showed significant symptom reduction⁵³.

Traditional and biomedical approaches

In many SSA countries, traditional and faith healing practitioners exist alongside biomedical practitioners. While this allows for a wide range of treatment options, regulation and standardisation of traditional and faith practitioners can be challenging⁴⁶. This increases the risk of unsafe practices, and the efficacy of these treatments is difficult to measure. There have been efforts to integrate traditional and biomedical health systems in rural Ghana to expand the reach and improve outcomes of community healthcare, which could serve as a framework for integrating these systems in PMH care⁵⁴. The researchers note that the extensive infrastructure of traditional medicine, grassroots initiatives, and openness to collaboration are opportunities to be harnessed by biomedical HCPs. They recommend investing in relationships between traditional and biomedical practitioners, identifying appropriate healers, promoting best practices, establishing appropriate forms of recognition of healers, providing equipment, and using communication campaigns to promote integration.

Integrating traditional and biomedical care could also assist in overcoming cultural barriers to care. Examples of women not being able to leave the home during the parts of perinatal period or needing to take steps to avoid bewitchment illustrated situations where biomedical PMH support in clinics, if available, would not be accessible to these women. Traditional healers may be able to advise HCPs on culturally appropriate adaptations to care that would allow for women to access clinics or for care to be delivered at home. Traditional healers may also be well placed to support and upskill the family. In instances where one's spouse or parents make help-seeking decisions, traditional healers working alongside biomedical HCPs could support families in decision making around appropriate care.

Strengths

This review has several strengths. To our knowledge, it is the first systematic review focused on barriers to PMH care in SSA alone. The included papers all used similar data collection methods, which allows for integration of findings. There is a dearth of research addressing HCP's perspectives on PMH care⁴, so the inclusion of 11 papers with HCPs' perspectives on barriers in addresses this gap in some part.

Limitations

There are also several limitations with this review. The papers are heterogeneous and originate from countries which have varying healthcare contexts and socioeconomic backgrounds. It is possible that the eligibility criteria for this study were too restrictive. The decision to keep strict eligibility criteria was to produce robust research but include grey literature. We only included manuscripts published in English, and thus we may have facilitated publication bias by not including more languages especially given how diverse SSA is linguistically.

The views of women who do not access PMH care are important in understanding barriers to PMH care. However, there was no literature found that included this population and met our inclusion criteria. As a result, the views of these women were not represented in this review.

The limitations of the sensitivity of the MMAT should also be considered when interpreting the review's conclusions. The MMAT does not consider the appropriateness of the ontological stance chosen, congruity between the philosophical perspective and the research methodology, the influence of the researcher on the research, adequate
representation of all participants. These factors can influence the quality of qualitative research, and the inclusion of these factors may have influenced the quality score.

All qualitative studies included in this review scored 100% on the MMAT, which prevented the consideration of quality differences when analysing the results. Thomas and Harden³⁵ recommend using a sensitivity analysis to test the effect of including and excluding findings from studies of differing quality. However, without detecting quality differences across our papers, this was not possible.

Finally, there were limitations in grouping themes according to levels at which these barriers might impact access. While this grouping illustrated where barriers might predominantly lie and that barriers are present at every level, there are barriers that could fit across multiple themes. For instance, the understanding that bewitchment causes mental health difficulties was placed within the 'mental health literacy' theme as it spoke to the traditional understanding of mental health. However, it might also have fit within the 'stigma' theme, as one's perceptions of the causes of PMH difficulties will influence how they view someone experiencing PMH difficulties. Other researchers might have grouped these results differently.

Implications

Based on these findings, future practice should focus on designing and implementing PMH services that aim to address these barriers. Ideally, support is needed at administrative and policy levels to issue PMH policy and guidance, support integrated care, and provide appropriate, sustained funding for PMH. However, we recognise that this may be a challenge in countries where healthcare is chronically underfunded. Further evidence of the disease burden of PMH difficulties in SSA may be necessary to prioritise PMH more accurately amongst other physical and mental health care needs.

Funding for training and continuous professional development would improve mental health literacy and reduce stigma in HCPs and result a larger workforce of trained practitioners. This review found that there is a shortage of trained HCPs to deliver PMH interventions as well as a cohort of volunteers who are wanting to receive training. A taskshifting implementation approach would allow for these volunteers to be trained to take on some of the HCPs' tasks. This approach has been shown to increase the availability of mental

37

health services for adolescent mothers¹⁷. This could allow for more availability of PMH services in rural areas, which would help mothers struggling with logistics and transport costs. Local services, particularly in rural areas, could work alongside community and traditional leaders to share learning and develop collaborative care pathways.

Service providers should consider screening all women for PMH difficulties during and after pregnancy to determine if support is needed or if there are concerning changes in one's wellbeing.

Low literacy rates were highlighted at a barrier to screening in Uganda. Low literacy rates would likely also limit women's' ability to engage with information leaflets or self-help material. Therefore, services may wish to use songs and visual aids for psychoeducation. This has been successfully used to deliver psychoeducation in Nigeria⁴⁴. These strategies may also be useful to incorporate into public health initiatives to support psychosocial understandings of mental health within the general population.

There should also be regular reviews of current formal and informal PMH literacy campaigns and services to highlight where funding should continue and share learning about what works and what does not work. While many of the barriers to women accessing PMH are like those seen in other areas, there are factors unique to SSA that need consideration. Cultural sensitivity is especially important when applying interventions or approaches that we developed in western health systems to SSA contexts. Health services would benefit from joint working, interdisciplinary collaboration, and information sharing across PMH networks in SSA.

Future research

Further research is needed to expand the evidence base for PMH in SSA. This would provide a more comprehensive understanding of variations across countries and the specific challenges faced. Further research into how cultural factors influence PMH support and how cultural nuances support or hinder help-seeking behaviours and service utilisation. This research should be co-produced with service users or community leaders to ensure that cultural nuances are accurately understood. This would allow services to adapt to better suit the communities they serve. Qualitative findings in this review should be complemented with further quantitative research to gain insight into the prevalence of PMH difficulties, screening and referral rates, and intervention outcomes. Longitudinal studies would allow for researchers to track changes in access to and perceptions of PMH services. This could help inform the development of PMH interventions.

Further research could also investigate involving partners in PMH support and the impact of PMH awareness campaigns on the public and HCPs. Funding was a barrier faced across the studies, so economic evaluations of current PMH interventions could be used to measure cost effectiveness and provide evidence for the benefits of investing in PMH services.

Conclusion

This systematic review has provided an exploration of the barriers influencing access to PMH support in SSA. Barriers were seen across individual, community, healthcare professional, treatment, service, policy, and societal levels. Main barriers in SSA included low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, and training, and not involving loved ones. Many of these themes were also seen in the global literature, which suggests that these findings and recommendations of these reviews can be applied to PMH in SSA. However, barriers that are unique to SSA include the lack of PMH policy, stigma faced by adolescent mothers, the need to integrate PMH into PHC, and pluralism of traditional and biomedical care. Future practice should focus on designing and implementing PMH services that aim to address these barriers, and further research is needed to understand these factors across other SSA countries.

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Chapter 2

Bridging Chapter

Word count: 722

This chapter aims to summarise the findings of the systematic review and provide a background to the empirical paper.

Systematic review findings

The systematic review aimed to identify barriers to accessing perinatal mental health (PMH) care in Sub-Saharan Africa (SSA). The review included 13 studies that met the eligibility criteria. An evaluation of their methodological quality was also carried out.

The findings highlighted a range of barriers across individual, community, healthcare professional, treatment, service, policy, and societal levels. The main barriers were low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, and training, and not involving loved ones.

Similarities were found with findings in a recent global meta-review (Webb et al., 2023), including PMH-specific training, limited resources, and healthcare structures impacting PMH access. Factors unique to SSA included the lack of PMH policy, pluralism of traditional and biomedical care, stigma faced by adolescent mothers, and the need to integrate PMH into PHC.

Background for the empirical paper

The systematic review focused on a large region with an underdeveloped mental health system. The empirical project shifts to focus on PMH in the UK, where specialist services for perinatal mental health are already in place. The project investigates how common psychotic-like experiences (PLEs) and intrusive thoughts (ITs) are in a community sample, what differentiates parents who are at risk of psychosis from those at low risk of psychosis, and what factors are associated with distress from these phenomena.

Psychotic-like experiences and intrusive thoughts

PLEs are non-clinical experiences of hallucinations or delusions that are distinguishable from clinically significant symptoms in their severity, frequency, associated distress, interpretation, preoccupation with and conviction of beliefs (DeRosse & Karlsgodt, 2015; Hinterbuchinger & Mossaheb, 2021; Holt et al., 2018). ITs are unpleasant, unrealistic or unwanted thoughts that intrude into an individual's mind (Abramowitz et al., 2006; Fairbrother & Woody, 2008). Subclinical ITs are similar in incongruency with one's belief system, context, and form to those seen in obsessive-compulsive disorder (OCD), but differ in frequency, intensity, distress caused and perceived thought control (Berry & Laskey, 2012; Clark, 2004).

Both PLEs and IT are relatively common in the general population, with an estimated 1-17.5% of the non-clinical population experiencing PLEs (Nordgaard et al., 2019) and 80-90% experiencing ITs (Clark & Rhyno, 2005; Rachman & De Silva, 1978; Salkovskis & Harrison, 1984).

Continuity hypotheses

The fully dimensional model of schizotypy (Claridge, 1997) and the psychosis continuity hypothesis (Johns & van Os, 2001) suggest that psychosis exists within the population along a continuum, from 'no symptoms' to clinical psychosis. PLEs fall along the continuum and are defined as subclinical hallucinations or delusions, like those seen in psychosis, but in a diminished form (Cicero et al., 2013).

ITs and obsessions have also been understood to fall on a continuum (Clark & Rhyno, 2005), and vary in frequency, intensity, and perceived thought control (Berry & Laskey, 2012; Clark, 2004). In the context of OCD, ITs are linked with expected action/personal meaning and concern about whether one may be responsible for harm or the prevention of harm – ITs without these features are thought to be less distressing (Abramowitz et al., 2003).

Cognitive models of psychosis and OCD propose that the development of delusions, hallucinations, and ITs originate in normal experiences and that a negative interpretation of the meaning behind the experience increases one's distress (Abramowitz et al., 2009; Morrison, 2002). This theory differs from the neurobiological models that propose the development of OCD is related to a dysfunctional serotonin system (Abramowitz et al., 2003).

Unsurprisingly, there is an overlap between risk factors of psychosis and PLEs in the general population (Healy & Cannon, 2020). PLEs are associated with anxiety, depression, stressful life events, current or historical of mental health difficulties, ethnic minority status,

living in an urban area, social adversity, low income status, drug use, and childhood trauma (Bortolon & Raffard, 2015; Castiajo & Pinheiro, 2017; Connell et al., 2019; Morrison & Baker, 2000). Depression, anxiety and stressful events are also associated with ITs in the general population (Morrison & Baker, 2000; Wahl et al., 2020) People who experience auditory hallucinations also experience more intrusive thoughts, and found these thoughts more distressing, uncontrollable, and unacceptable than controls (Morrison & Baker, 2000).

The empirical paper explores these PLEs and ITs in postnatal papers, and the factors associated with parents finding PLEs and ITs distressing.

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Chapter 3

Empirical Paper

Factors associated with distressing psychotic-like experiences and intrusive thoughts in the postnatal period

Prepared for submission to 'Journal of Clinical Psychology' (Appendix 3.1)

Word count (excluding abstract, references, tables and figures): 5,357

Factors associated with distressing psychotic-like experiences and intrusive thoughts in the postnatal period

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Abstract

Objectives: Psychotic-like experiences (PLEs) and intrusive thoughts (ITs) are common in the postnatal period. Little is known about the distress caused by these phenomena, and what contributes to this distress. This study aims to understand factors associated with distressing ITs and PLEs and the prevalence of these experiences in postnatal parents.

Methods: A community sample of 349 parents completed an online survey measuring demographic factors, PLEs using the Prodromal Questionnaire (PQ-16), ITs using the Parental Thoughts and Behaviours Checklist (PTBC), and depression, anxiety, and stress using the Depression Anxiety Stress Scale (DASS21).

Results: The results showed that 88.8% of parents experienced distressing PLEs and 90.8% experienced distressing ITs. A total of 35% of parents scored above the cut-off indicating potential psychosis risk. Fewer parents were cohabiting, more were accessing mental health treatment, and scores on the PQ-16, PTBC, and DASS21 were significantly higher in the potential risk group. Depression and distressing ITs were associated with increased PLE distress, while cohabitation reduced distress. A history of mental health difficulties, the number of ITs reported, stress, and anxiety were associated with increased IT distress.

Conclusions: PLEs and ITs are common in the postnatal period and many parents experience at least some distress from these phenomena. The rates of postnatal parents scoring above clinical cut-offs is higher than those accessing mental health services, indicating that further screening is needed to identify and support those potentially at risk of developing postnatal mental health difficulties, as is further research to identify additional risk factors.

Keywords: postnatal, perinatal mental health, psychotic-like experiences, intrusive thoughts, distress

Introduction

Perinatal mental health

The perinatal period can involve significant changes in identity, family dynamics, physical changes for the birthing parent, and fluctuating emotional and stress levels (Howard & Khalifeh, 2020). There is an increased risk for emotional disorders during this time (Mannion & Slade, 2014), with at least 10% of mothers experiencing mental health difficulties during the perinatal period (Bauer et al., 2015), and 13% following birth (Fisher et al., 2012). Anxiety (Fairbrother et al., 2016) and depression (Gavin et al., 2005; Stuart-Parrigon & Stuart, 2014) are commonly reported perinatal mental health concerns by mothers. Approximately 0.1% of postpartum mothers develop psychosis (Mannion & Slade, 2014) and 2-3% develop OCD (Russell et al., 2013). OCD symptoms develop more quickly in postpartum women than in the general public (Abramowitz et al., 2003). Untreated and unsupported perinatal mental health difficulties have significant, long-term impacts on the mother, child, and surrounding family environment. This has a significant financial impact, with perinatal anxiety, depression, and psychosis carrying a long-term cost to the United Kingdom of £8.1 billion for each one-year cohort (Bauer et al., 2015).

PLEs and ITs in the perinatal period

The rates of PLEs are considerably higher in mothers during the perinatal period than in the general population, with 90% of mothers experiencing at least one PLE during the postnatal period (Holt et al., 2018) compared to 1-17.5% of the general population (Nordgaard et al., 2019). Symptoms of mental health conditions can emerge or be heightened during the perinatal period due to stress, sleep deprivation, hormonal changes, immunological factors, and the significant changes that occur at this time (Lu et al., 2022). This may explain the difference in PLE rates between perinatal mothers and the general population.

The 70%-100% rate of ITs in the perinatal period (Abramowitz et al., 2006; Collardeau et al., 2019) is similar to the 80-90% rate of ITs in the general population (Clark & Rhyno, 2005; Rachman & De Silva, 1978; Salkovskis & Harrison, 1984).

ITs are often linked to one's current concerns, therefore, ITs experienced by postnatal parents, who have an increased responsibility for protecting infants from harm, often experience ITs related to their child experiencing harm (Abramowitz et al., 2003). While the presence of these experiences is common, it is not clear whether there is a difference in the frequency of, distress caused by, and impact of these experiences in the postnatal period, compared to the general population.

The significant difference in the rates of postpartum PLEs and ITs compared to postpartum psychosis and OCD supports the continuum theories and illustrates that PLEs and ITs are often not indicative of mental illness. It is important, therefore, to normalise these experiences in instances where they are not causing distress or impacting on functioning.

However, further understanding of the factors that might increase one's risk of developing mental health difficulties like post-partum OCD (ppOCD) and post-partum psychosis (ppPsychosis) is needed to differentiate normal experiences from those which require further support. If non-clinical PLEs differ from psychosis in severity, frequency, associated distress, interpretation, preoccupation with and conviction of beliefs (DeRosse & Karlsgodt, 2015; Morrison & Baker, 2000; Peters et al., 2004), and nonclinical ITs differ from ITs seen in OCD in frequency, intensity, associated distress and perceived thought control (Berry & Laskey, 2012; Clark, 2004), then measuring the occurrence of distressing PLEs and ITs, and who experiences this distress, is an important step in identifying parents in need of early intervention and additional support.

ITs and PLEs have largely been explored separately, yet within this project they will be explored together, as symptoms have been seen to overlap in the literature and clinically (Bortolon & Raffard, 2015). To our knowledge, there are currently no studies investigating both PLEs and ITs in the postnatal period.

It is hypothesised that the postnatal period provides a unique setting in which themes of care and responsibility are activated, which can link to attributing greater meaning and experiencing enhanced emotions regarding ITs and PLEs (Abramowitz et al., 2006).

Predictors of PLEs and ITs in parents

Holt et al. (2018) found that birth trauma and difficulty in adjusting to parenthood were predictors of PLEs in first-time mothers. Sleep deprivation, depressive symptoms, birth trauma, fear of labour, unemployment, education below a graduate level, and low social support are significantly associated with PLEs and postpartum psychosis in mothers (Mannion & Slade, 2014). Our study builds on this evidence base by focusing on factors associated with distressing PLEs.

Fairbrother and Woody (2008) found that high parenting stress and low social support predicted parents experiencing ITs of intentional harm. Mothers also report longer duration of ITs and more associated distress than fathers (Abramowitz et al., 2003). Our study adds to this evidence by identifying factors associated with distressing ITs.

Primary research question:

RQ1: How common are PLEs and ITs in postnatal parents?

RQ1: What factors are associated with parents experiencing distressing psychotic-like experiences in the postnatal period?

RQ2: What factors are associated with parents experiencing distressing intrusive thoughts in the postnatal period?

Materials and Methods

Design

The study used a cross-sectional, quantitative approach using an anonymous online survey to explore the prevalence of and factors associated with distressing ITs and PLEs in parents in the postnatal parents (one year after birth). A quantitative design was chosen as it allows for a broader study with a greater number of participants, and thus, a wider generalisation of findings than could be achieved by a qualitative design. This design allows for associated factors to be identified but does not attempt to determine the direction of the relationship between factors.

Participants

This project recruited a voluntary community sample of parents of children under one year. The study was not limited to mothers and was advertised to include birthing and non-birthing parents aged 16 and above. Participants needed to be proficient in English as the survey and measures were written in English. Participation in the study required access to the internet to complete the online survey. A Multiple Regression Sample Size Calculator was used to determine that a minimum of 118 participants was required for this study (alpha = 0.05, expected effect size = 0.15, statistical power = 0.8, and 10 predictor variables). A small effect size of 0.15 was chosen, as per Gignac and Szodorai's (2016) normative guidance.

Participants were recruited through targeted social media advertising on Facebook and Instagram as well as posts on Twitter and the research forum on 'Mumsnet,' a widely known UK parenting resource. Most participants were female, so social media advertising was adjusted to specifically target men and the study advertisement was shared with Twitter users in the fathers and LGBTQ+ parent networks to increase variation in the sample.

Measures

The online questionnaire included demographic questions and validated self-report measures, as detailed below:

Demographics, birth, and mental health information (Appendix 3.2)

We asked participants for their age, gender, relationship status, whether they are the birthing or non-birthing parent, number of conceptions and number of births. We also asked if they have a history of mental health difficulties, are currently receiving mental health treatment, and whether they perceived their most recent birth experience as traumatic.

The 16-item Prodromal Questionnaire (PQ-16; Ising et al., 2012) (Appendix 3.3)

The PQ-16 is a brief self-report screening tool for psychosis risk, adapted from the original 92-item prodromal questionnaire (Loewy et al., 2005), that assesses for the presence of positive and negative psychosis symptoms. Parents were asked about their experience of these symptoms within the postnatal period only. The PQ-16 is a clinical

screening tool, developed for use in a 'help-seeking' population. It is a measure of psychosis risk rather than clinical psychosis, so identifies PLEs rather than psychosis (Savill et al., 2018). It is not specific to the postnatal period but was chosen as it measures distress.

The presence of PLEs is assessed using 'true/false' questions. If an item is rated as 'true' participants are asked to rate how much distress is experienced, ranging from 0 (no distress) to 3 (severe distress). The 16 true/false questions are summed, with each 'true' answer scoring 1 and 'false' answer scoring 0. This is the PQ-16 score, with scores ranging 0-16. Higher scores indicate a greater presence of PLEs. A score \geq 6 on the PQ-16 indicates one is at risk of developing psychosis. The scores indicating the amount of distress (distress score) can also be summed, with scoring ranging 0-48. Higher scores indicate greater distress. We included a distress scale score of \geq 9 as an additional indication of a potential atrisk mental state (Howie et al., 2023).

Levey et al. (2018) evaluated the use of the Spanish language version of the PQ-16 as a screening tool for psychosis in pregnant Peruvian women, and their findings support the construct validity of the PQ-16 in the perinatal population. The PQ-16 is freely available for use in the public domain and has been found to have good psychometric properties and internal consistency (Ising et al., 2012; Jong et al., 2021).

Parental Thoughts and Behaviours Checklist (PTBC; Thiséus et al., 2019) (Appendix 3.4).

The PTBC is a self-report measure, developed from a semi-structured interview that measured ppOCD (Abramowitz et al., 2006), that covers postpartum-specific intrusive thoughts and behaviours. Current thoughts referred to thoughts experienced within the postpartum period. Intrusive thoughts and the strategies used to manage them are scored (range 0-46), with higher scores indicating greater symptom severity. The measure also includes questions around frequency, severity, resistance to, control over, and interference of a range of obsessions and compulsions, and these ten questions are each scored 0-5.

The PTBC is freely available for use in the public domain. It shows good to excellent internal consistency and good psychometric properties with mothers, but psychometric properties have not been calculated for fathers (Thiséus et al., 2019). It can be used with all parents as it is not specifically designed for mothers, and the developers encourage further exploration of the measure with postpartum fathers.

Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) (Appendix 3.5)

The DASS is a 21-question self-report questionnaire measuring depression, anxiety, and stress. It consists of three, seven item self-report scales, measuring depression, anxiety, and stress. Scores for each subscale are summed and multiplied by two. Scores for each subscale range from 0-42, with higher scores indicating greater severity of symptoms. Scores above nine for depression, seven for anxiety, and 14 for stress subscales indicate the presence of clinical symptoms.

The DASS-21 was selected for this study as (1) it includes three emotional states within one measure, (2) it can be used to identify comorbidity, (3) it has been recommended for use in non-clinical and postpartum populations (Miller et al., 2006), and (4) it does not include potential confounding items seen in the postpartum period, such as sleep disturbances, appetite changes, tiredness, lack of energy, and poor concentration (Meades & Ayers, 2011; Miller et al., 2006).

The DASS-21 is freely available for use in the public domain. It shows convergent and divergent validity as the anxiety scale highly correlates with the Beck Anxiety Inventory

(r=.81) and the depression scale correlates strongly with the Beck Depression Inventory-II (r=.74) (Miller et al., 2006). It has been found to have excellent reliability (Osman et al., 2012), excellent criterion validity, and good to excellent internal consistency (Gloster et al., 2008).

Procedure

The study was conducted online using the survey platform 'Jisc Online Surveys' (www.onlinesurveys.ac.uk/), with all participants accessing the study via an anonymous link. Participants were presented with a participant information sheet (PIS) (Appendix 3.6) and asked to complete an online consent form (Appendix 3.7). If participants gave consent, they completed a series of outcome measures as detailed above. The order of outcome measures was randomised to account for participant fatigue and/or drop-out. Participants could withdraw from the survey at any point, before submission of responses. Only complete survey entries were recorded.

We added a 'not applicable' option to the question on the Parental Thoughts and Behaviours Checklist related to breastfeeding (Q31 "Unacceptable sexual thoughts during breastfeeding") to accommodate parents who were not breastfeeding their child. The total completion time for the study survey was estimated at 30 minutes. This is a similar duration and number of measures seen in other literature (Holt et al., 2018; Thiséus et-al., 2019).

Following survey completion (or withdrawal), participants were presented with a debrief form (Appendix 3.8) which included sources of further information and perinatal and mental health support services available in the UK. All participants had the option of being entered into a prize draw as a small contribution for their time.

Ethical Considerations

The University of East Anglia Faculty of Medicine and Health Sciences Research Ethics Committee granted ethical approval for the project. A joint ethics application was submitted in Autumn 2021. Research was undertaken according to the BPS Code of Human Research Ethics (Fisher, 2021).

Results

This study used descriptive, mean comparison, and multiple regression analyses to answer the research questions. Statistical analysis was conducted using SPSS, V.27 (IBM Corp, 2020). The three social media advertisements reached 56 831 people had an average engagement rate of 2.76%.

Descriptive Statistics

Descriptive statistics were used to describe the demographic characteristics of the participants. Categorical demographic variables (age, gender, relationship status, birthing/non-birthing parent, a history of mental health difficulties, whether one was receiving or awaiting mental health treatment, birth trauma, and pregnancy loss) are presented in the form of counts and percentages (Table 1). Continuous demographic variables (number of conceptions and births) are presented in the form of means and standard deviations (Table 1). Due to most respondents being married or cohabiting, the 'cohabitating' variable was added to better group participants. Parents were categorised as 'cohabiting' if they were married, in a civil partnership, or cohabiting.

Most of our sample were aged between 25 and 34 years (74.8%), female (90.5%), and cohabiting (90.8%). Approximately half had a history of mental health difficulties

(48.4%) perceived their birth to be traumatic (49.9%). Within our sample, 25.2% were awaiting or receiving mental health support and 36.1% reported more conceptions than births, indicating possible previous pregnancy loss.

Clinically, scoring above the cut-off on the PQ-16 would indicate that further assessment is needed to confirm whether someone is at risk of developing psychosis. Scoring above this cut-off, alone, does not imply that someone will develop psychosis. However, scores above the PQ-16 cut-off indicate some severity and complexity of mental health difficulties. Participants were characterised as screening positive for potential psychosis risk if they scored both \geq 6 on the symptom list and \geq 9 on the distress scale on the PQ-16. This group were categorised as 'potential risk'. These criteria were met for 35% of participants. Parents who scored below these cut-offs were categorised as being at low/no risk of developing psychosis.

Table 1

Descriptive statistics

	Frequency (%)						
	All parents	Potential risk	No/low risk				
n	349	123	226				
Age							
16 – 19	0 (0)	0 (0)	0 (0)				
20 – 24	33 (9.5)	18 (14.6)	15 (6.6)				
25 – 29	127 (36.4)	60 (48.8)	67 (29.6)				
30 - 34	134 (38.4)	33 (6.8)	101 (44.7)				
35 – 39	44 (12.6)	9 (0.3)	35 (15.5)				
40 - 44	11 (3.2)	3 (2.4)	8 (3.5)				
45+	0 (0)	0 (0)	0 (0)				
Gender							
Female	316 (90.5)	105 (85.4)	211 (93.4)				
Male	28 (8)	15 (12.2)	13 (5.8)				
Non-Binary	3 (0.9)	2 (1.6)	1 (0.4)				
Transgender	1 (0.3)	0 (0)	1 (0.4)				
Prefer not to say	1 (0.3)	1 (0.8)	0 (0)				
Relationship status							
Single	13 (3.7)	7 (5.7)	6 (2.7)				
In a relationship, not cohabiting	18 (5.2)	9 (7.3)	9 (4)				
Cohabiting	144 (41.3)	57 (46.3)	87 (38.5)				
Married	171 (49.0)	47 (38.2)	124 (54.9)				
Divorced/Separated	1 (0.3)	1 (0.8)	0 (0)				
Civil Partnership	2 (0.6)	2 (1.6)	0 (0)				
Cohabiting ^a	317 (90.8)	106 (86.2)	211 (93.4)				
History of mental health difficulties ^a	169 (48.4)	78 (63.4)	91 (40.3)				
Currently receiving or awaiting treatment	88 (25.2)	46 (37.4)	42 (18.6)				
for mental health difficulty ^a							
Perception of birth as traumatic ^a	174 (49.9)	54 (43.9)	105 (46.5)				
Previous pregnancy loss ^{a, b}	119 (36.1)	46 (39.3)	73 (34.3)				
		Mean (SD)					
Number of births	1.36 (0.68)	1.37 (0.63)	1.36 (0.7)				
Number of conceptions	2.01 (1.556)	2.09 (1.68)	1.95 (1.47)				
^a Reflects the number and percentage of partic	cipants answering "y	es" to this question	· ·				

^b Previous pregnancy loss indicated by a higher number of conceptions than births

PLEs and ITs in postnatal parents

Of the 349 parents who participated in this study, 89.7% reported experiencing at

least one PLE, and 98% reported currently experiencing ITs. The seven parents who did not

report current ITs had reported past ITs. Therefore, all parents in our sample reported having

experienced ITs. Most (90.8%) parents experienced distress from an IT, and 88.8%

experienced distress from a PLE (Table 2).

The most common PLEs were "I feel uninterested in the things I used to enjoy" (50.1%) and "I get extremely anxious when meeting people for the first time" (49.3%). The PLE "I feel that parts of my body have changed in some way, or that parts of my body are working differently than before" was excluded when calculating PQ-16 scores and risk cutoffs as this question was not a reliable measure of psychosis risk in this population as physical changes will take place during pregnancy. The most common ITs were around thoughts that the baby might stop breathing (79.9%), that something may happen to you (or spouse/partner) and you can't care for the baby (74.8%), and fears that the baby might choke on something (72.8%) (Appendix 3.9).

Table 2

Descriptive statistics

		All parents	Potential risk	Low/no risk
			Mean (SD)	
PQ-16				
	PLE symptom score (0-15)	4.34 (3.53)	8.24 (2.68)	2.22 (1.59)
	PLE distress score (0-45)	9.07 (7.72)	17.2 (6.70)	4.65 (3.49)
PTBC				
	PTBC Thoughts score	6.42 (3.36)	8.33 (3.25)	5.39 (2.94)
	Total PTBC score	12.38 (6.64)	16.09 (6.51)	10.37 (5.79)
DASS				
	Depression Score	13.42 (10.9)	20.21 (10.5)	9.73 (9.23)
	Anxiety Score	10.46 (9.53)	16.11 (9.91)	7.39 (7.77)
	Stress Score	19.51 (10.07)	25.46 (9.39)	16.27 (8.9)
			Frequency (%)	
PLEs				
	Reported at least one PLE	313 (89.7)	123 (100)	190 (84.1)
	Reported experiencing distress	310 (88.8)	123 (100)	187 (82.7)
ITs				
	Reported at least one IT	342 (98)	122 (99.2)	220 (97.3)
	Experienced distress from ITs	317 (90.8)	119 (96.7)	198 (87.6)
Depres	sion scale			
	Below clinical cut-off	154 (44.1)	20 (16.3)	134 (59.6)
	Above depression cut-off	195 (55.9)	103 (83.7)	92 (40.4)
	Mild	33 (9.5)	12 (9.8)	21 (9.3)
	Moderate	78 (22.3)	37 (30.1)	41 (18.1)
	Severe	40 (11.5)	25 (20.3)	15 (6.6)
	Extremely Severe	44 (12.6)	29 (23.6)	15 (6.6)
Anxiety	/ Scale			
	Below clinical cut-off	164 (47)	25 (20.3)	139 (61.5)
	Above anxiety cut-off	185 (53)	98 (79.7)	87 (38.5)
	Mild	19 (5.4)	5 (4.1)	14 (6.2)
	Moderate	68 (19.5)	32 (26)	36 (15.9)
	Severe	32 (9.2)	14 (11.4)	18 (8)
	Extremely Severe	66 (18.9)	47 (38.2)	19 (8.4)
Stress S	Scale			
	Below clinical cut-off	136 (39)	16 (13)	120 (53.1)
	Above stress cut-off	213 (61)	107 (87)	106 (46.9)
	Mild	39 (11.2)	14 (11.4)	25 (11.1)
	Moderate	63 (18.1)	29 (23.6)	34 (15)
	Severe	76 (21.8)	37 (30.1)	39 (17.3)
	Extremely Severe	35 (10)	27 (22)	8 (3.5)

The 'potential risk' group

Rates of cohabitation were significantly lower (p < 0.001) and the number of parents awaiting/receiving mental health support were significantly higher (p < 0.001) in the potential risk group than the low/no risk group. While there were no significant differences in age across the two groups, most parents in the potential risk group were within the 25-29 age range compared to the no/low risk group where the majority were 30-34. The potential risk group was comprised of more males and parents with a history of mental health difficulty. Rates of traumatic births and previous pregnancy loss were similar across the potential risk and not low/no risk groups.

Independent t-tests were conducted to compare scores between the potential risk and low/no risk groups on the PQ-16, PQ-16 distress, PTBC thoughts, and DASS depression, anxiety and stress measures (Table 3). The differences in scores across all measures were statistically significant (p < 0.001). Therefore, the potential risk group experienced significantly more PLEs, distress from PLEs, ITs, and symptoms of depression, anxiety, and stress than the group of parents not at risk of psychosis.

Table 3

	Poten	tial risk	Low/no risk					
	Mean	SD	Mean	SD	df	t	р	Cohen's d
PQ-16 ^a	8.24	2.68	2.22	1.59	170	22.82	< 0.001	2.95
PQ-16 distress ^a	17.20	6.71	4.65	3.49	159	19.36	< 0.001	2.58
PTBC thoughts	8.33	3.25	5.39	2.95	347	8.57	< 0.001	0.96
DASS depression	20.21	10.50	9.73	9.23	347	9.65	< 0.001	1.08
DASS anxiety ^a	16.11	9.92	7.39	7.78	205	8.45	< 0.001	1.02
DASS stress	25.46	9.40	16.27	8.90	347	9.04	< 0.001	1.01
^a Welch test is reported because Levene's test indicated that the homogeneity of variances assumption was								
not met for this variable.								

Differences between potential risk and low/no risk groups on PQ-16, PTBC, and DASS21

Factors associated with postnatal parents experiencing distressing PLEs

A multiple linear regression was used to determine factors associated with distressing PLEs (PQ-16 distress score) using the following variables: age, cohabitation, history of mental health difficulties, traumatic birth, PTBC thought score, PTBC distressing thoughts, DASS21 stress score, DASS21 anxiety score, and DASS21 depression score.

Categorical variables (age, cohabitation, history of mental health difficulties, traumatic birth) were recoded as dummy variables to allow for these variables to be included in both regression analyses.

The PQ-16 symptom score was excluded from the regression as the strength of the correlation with distressing PLEs r(347) = .94, p < .001 may have skewed the results of the regression. The number of births and conceptions were not included as these were not significantly correlated with the PQ-16 distress score.

Using the enter method on SPSS, it was found that the included variables explain a significant amount of the variance in the PQ-16 distress scores (F(9,339) = 23.45, p < 0.05, R = 0.62, $R^2_{Adjusted}$ = 0.37).

There was a significant relationship between the PQ-16 distress score and cohabitation (p = 0.031), PTBC Distress score (p = 0.020), and DASS Depression score (p = 0.001). As PQ-16 distress scores increased, there a 1.557 increase in PTBC distress scores and a 0.178 increase in DASS depression scores. Higher PQ-16 distress score were associated with not cohabiting. The R² value (0.384) indicates that 38% of the variation in PQ-16 distress scores can be explained by the model containing cohabitation, distressing ITs, and depression (Table 5).

Table 5

			95%	_		
	Estimate	SE	LL	UL	β	p
Age	-0.626	0.374	-1.362	0.110	-0.075	0.095
Cohabitation	-2.498	1.153	-4.766	-0.230	-0.093	0.031
MH History	0.573	0.736	-0.875	2.020	0.037	0.437
Traumatic birth	0.363	0.689	-0.992	1,719	0.024	0.598
PTBC distress	1.557	0.668	0.244	2.870	0.169	0.020
DASS Depression	0.178	0.060	0.073	0.284	0.252	0.001
DASS Anxiety	0.090	0.057	-0,023	0.203	0.111	0.118
DASS Stress	0.056	0.054	-0.061	0.173	0.073	0.349

Multiple linear regression using PLE distress as the criterion

Factors are associated with postnatal parents experiencing distressing ITs

A multiple linear regression was used to determine factors associated with distressing ITs (PTBC distress score) using the following variables: history of mental health difficulties, traumatic birth, number of conceptions, PQ-16 score, PQ-16 distress score, PTBC thought score, DASS21 depression score, DASS21 anxiety score, and DASS21 stress score. Age, cohabitation, and number of births were not included as these were not significantly correlated with the PTBC distress score.

Using the enter method on SPSS, it was found that these variables explain a significant amount of the variance in the PQ-16 distress scores (F(9,325) = 65.56, p < 0.05, R = 0.80, $R^2_{Adjusted} = 0.64$).

There was a significant relationship between the PTBC distress score and mental health history (p = 0.001), PTBC Thoughts score (p < 0.001), DASS Stress score (p = 0.036), and DASS Anxiety score (p = 0.022). As PTBC distress score increased, there was a 0.182 increase in PTBC Thoughts scores, 0.011 increase in DASS Stress score, and 0.011 decrease in DASS Anxiety score. The R² value (0.645) indicates that 65% of the variation in PTBC distress
scores can be explained by the model containing mental health history and PTBC Thoughts,

DASS Stress, and DASS Anxiety scores (Table 6).

Table 6

Multiple linear regression with PTBC distress as the criterion

	95% CI					
	Beta	SE	LL	UL	β	р
MH history	0.196	0.060	0.078	0.314	0.118	0.001
Traumatic birth	-0.018	0.058	-0.131	0.096	-0.011	0.756
Number of conceptions	0.025	0.018	-0.011	0.060	0.046	0.173
PTBC Thoughts	0.182	0.010	0.162	0.203	0.732	< 0.001
DASS Depression	-0.002	0.004	-0.011	0.007	-0.030	0.661
DASS Anxiety	-0.011	0.005	-0.020	-0.002	-0.124	0.022
DASS Stress	0.011	0.005	0.001	0.020	0.129	0.036
PQ-16 score	-0.027	0.023	-0.073	0.019	-0.113	0.245
PQ-16 distress	0.019	0.010	-0.002	0.039	0.170	0.076

Discussion

Our aim in the present study was to understand factors associated with distressing ITs and PLEs in the postnatal period. This study found that PLEs and ITs are common in this period, as is the tendency to find these experiences distressing.

Most parents in our sample reported PLEs, which is in line with Holt et al.'s (2018) findings where 90% of mothers experienced PLEs during the postnatal period, but significantly higher than Nordgaard et al.'s (2019) estimated 1-17.5% of the nonclinical general population experiencing PLEs. This supports findings that PLEs are more common in the postnatal period. Most parents in our sample also experienced ITs, which is consistent with previous findings that 70-100% of new mothers reported ITs (Abramowitz et al., 2006; Collardeau et al., 2019).

Parents at potential risk of psychosis

Over one third of our community sample (35.2%) was categorised as being at possible risk of psychosis using the recognised cut-off scores on the PQ-16. This aligns with psychosis risk prevalence rates seen in other studies, where 27% of pregnant Peruvian women (Levey et al., 2018) and 18.5 to 27.3% of pregnant Ghanaian women (Adjorlolo et al., 2022) were at-risk.

The rates of cohabitation were significantly lower in the potential risk group. Mannion and Slade (2014) found that low social support is significantly associated with PLEs. While we did not measure social support, not cohabiting with a partner may indicate a lower level of social support.

The potential risk group included female, male, and non-binary parents. This suggests a need for further research on the mental health of men and non-binary parents in the perinatal period.

Approximately two-thirds of the potential risk group had a history of mental health difficulties and a third were awaiting or receiving mental health support. Scores on the PQ-16, PTBC, and DASS21 were also significantly higher in this group. This is in line with findings that mental health difficulties, mood, stress, depressive symptoms, and anxiety are significantly associated with PLEs in mothers (Davies et al., 2020; Levey et al., 2018; Lu et al., 2022; Mannion & Slade, 2014). It also shows that the presence of PLEs is likely indicative of greater complexity and severity of mental health symptoms.

While Davies et al. (2020) found that having three or more previous pregnancies was a risk factor and one pregnancy as a protective factor for psychosis, we did not find a correlation between PLE distress and number of conceptions. We were surprised to find that rates of birth trauma were similar across the potential risk and low/no risk groups, as previous research found birth trauma to be a risk factor for psychosis (Barrett et al., 2016; Holt et al., 2018; Mannion & Slade, 2014).

Distressing PLEs and ITs

Our model found that PLE distress was associated with distressing ITs, depression and not cohabitating. This suggests that parents who find ITs distressing, have symptoms of depression, and are not living with a partner are more likely to find PLEs distressing, and therefore, be at greater risk of developing psychosis. This indicates that parents who find PLEs distressing are likely also experiencing distress from other mental health difficulties and possibly experiencing lower levels of social support.

Our second model found that IT distress was associated with the number of ITs experienced, having a history of mental health difficulties, higher scores on the DASS Stress scale, and lower scores on the DASS Anxiety scale. This finding is consistent with studies that found depression predicted the presence of ITs (Abramowitz et al., 2003; Jennings et al., 1999). It also highlighted that distressing ITs were more likely to cause stress symptoms than anxiety symptoms. Together, distressing PLEs and ITs are indicative of possible complexity of current and historical mental health symptoms.

Clinical Relevance

Routine screening of PLEs and ITs by clinicians will help identify parents who may benefit from mental health support or early intervention. A higher proportion of our sample scored above the cut-off for potential risk of psychosis than those currently awaiting or receiving mental health support. This suggests that mental health difficulties in postpartum parents might be being missed by healthcare services.

Scores were significantly higher on the PTBC and DASS21 in the potential risk group, suggesting that comorbidity and complexity is an indicator of risk. Measures of ITs and depression were also significant in explaining the presence of distressing PLEs and ITs. Therefore, we suggest that postpartum parents, irrespective of gender, should be offered screening for mental health difficulties. Screening should include questions about ITs, PLEs, depression, stress, anxiety, mental health history, and level of social support.

This research is important in the field of clinical psychology as psychologists are wellplaced to provide consultation and training to healthcare professionals who have regular contact with parents and can therefore identify parents experiencing distress and in need of additional support. PLEs are highly stigmatised in the general population (Healy & Cannon, 2020), so it is important to increase public awareness through public health campaigns of how common these experiences are in the postnatal period as this may lead to more parents seeking support when these experiences cause distress. There also needs to be increased awareness of PLEs and ITs in universal services (maternity, health visiting, and GP) to aid psychoeducation of parents and identification of those at increased risk of perinatal mental health problems.

Clinicians may wish to expand services to provide preventative programmes that promote prenatal mental well-being. This could reduce the prevalence of mental health difficulties in the postnatal period, allow for the normalization of common experiences and regular screening, and reduce the impact that poor perinatal mental health can have on parenting and the infant. Parents with a history of mental health difficulties, currently

76

experiencing distressing mental health symptoms, and those with low social support should be prioritised.

Further research

While this study identified some factors associated with distressing PLEs and ITs, further research should explore factors not addressed in this research, like social support, socioeconomic status, experience of pregnancy, and ethnicity. Much of the literature on perinatal mental health and psychosis highlights strong relationship between ethnicity and socioeconomic status and mental health difficulties (Field, 2018; Fisher et al., 2012; Ghaedrahmati et al., 2017; Peters et al., 2004; Pignon et al., 2018). The exclusion of these demographic factors from this study limited the possible outcomes.

Unlike previous research, our study did not find that age and birth trauma were significantly related to distressing PLEs or ITs. This warrants further investigation to decipher a clearer relationship between these factors.

Researchers may also wish to investigate the relationship between the interpretation of PLEs and ITs and distress, as cognitive models of psychosis and OCD suggest that a negative interpretation of the meaning behind these experiences can increase one's distress (Abramowitz et al., 2009; Morrison, 2002). Furthermore, research specifically targeting nonbirthing parents would allow for a greater understanding of the experience of all postnatal parents.

Longitudinal research, beginning antenatally, would allow for a researchers to decipher whether levels of distressing PLEs and ITs change over the course of the perinatal period and investigate the factors that influence these changes, especially as the occurrence of PLEs has been shown to be higher in pregnancy than postpartum (Mannion & Slade, 2014). Longitudinal research with the potential risk group of parents could allow for further insight into the development of postpartum psychosis and factors that might influence this.

Strengths

To our knowledge, this is the first study investigating PLEs and ITs together in the postnatal period. It also used a clinical tool to assess for psychosis-risk, which allowed for a comparison between parents at potential risk and low/no risk of psychosis. To our knowledge, it is also the first study to identify parents at potential risk of psychosis in the postnatal period, rather than during pregnancy. By focusing on the distress associated with PLEs and ITs, this study builds on Collardeau et al.'s (2019) and Holt et al.'s (2018) findings that these experiences are very common in the perinatal period but adds to this by suggesting that clinically relevant levels of these experiences may be lower.

Limitations

Our sample was mostly female, despite using targeted social media advertising to recruit parents of all genders. This may be due to our advertising being possibly more appealing to women or the belief that perinatal mental health only concerns women. The Royal College of Psychiatrists (2021) recommend perinatal services extend to support all parents, which requires perinatal research to broaden its focus to include all parents. Data on gender and birthing-parent was collected to investigate differences between factors associated with distressing PLEs and ITs in mothers and non-birthing parents, as well as the number of postpartum men experiencing PLEs as this is not yet known. However, due to the low response rate of men and the unreliable data obtained by the question about whether one gave birth to their child this analysis was not possible. Furthermore, the use of the PQ- 16 was helpful is identifying distressing PLEs, but this measure is only indicative of risk. Further follow-up with participants would be needed to accurately group parents as 'at risk' of developing psychosis rather than 'potential risk'.

There is a possibility of response bias in this study, as with any research using only self-reported data. Participants who had not experienced any PLEs or ITs may not have felt that this study pertained to them, and therefore did not take part or dropped out, resulting in a skewed sample.

We removed item 16 ("I feel that parts of my body have changed in some way, or that parts of my body are working differently than before") as this question was not a reliable measure of psychosis risk in this population due to physical changes being a normal part of pregnancy. A study measuring the psychometric properties of the PQ-16 as a screening instrument for perinatal psychosis used the standard cut-off of ≥6 on the PQ-16 to indicate psychosis risk (Levey et al., 2018). We, therefore, felt it was appropriate to keep this cut-off for our population. However, we did not want to overestimate risk by keeping this item in. This item was most frequently endorsed and therefore would significantly impact on one's PQ-16 score. All subscales of the PQ-16 are still measured if one item is removed as the measure contains nine items covering perceptual abnormalities/hallucinations, five items covering delusional ideas/paranoia, and two items covering negative symptoms (Ising et al., 2012). We acknowledge, however, that removing this item may have impacted the validity of the measure.

The sensitivity of the PQ-16 scores in identifying the presence of PLEs should also be considered. At least one PLE was reported by 89.7% of parents. However, the most common PLEs may be more indicative of depression ("I feel uninterested in the things I used to enjoy") and anxiety ("I get extremely anxious when meeting people for the first time"). Whereas items associated with positive psychosis symptoms like "I have heard things other people can't hear like voices of people whispering or talking" had fewer endorsements. This may have impacted the conclusions drawn.

A further limitation was the minimal data collected about mental health history. It would have helpful to include data about whether parents were accessing or awaiting perinatal-specific mental health support to investigate differences in these groups. Finally, the cross-sectional nature of this study meant that it was not possible to establish cause and effect.

Conclusion

PLEs and ITs are common in the postnatal period and many parents experience at least some distress from these phenomena. Over one third of parents in this community sample scored above the cut-off on a clinical measure indicating possible risk of psychosis. Compared to the low/no risk group, fewer of the potential risk group were cohabiting and more were awaiting or receiving mental health support. Scores on the PQ-16, PTBC, and DASS21 were significantly higher in the potential risk group. Distressing PLEs were found to be associated with distressing ITs, depression, and not cohabiting. Whereas, distressing ITs were found to be associated with the amount of ITs experienced, a history of mental health difficulties, increased stress, and decreased anxiety. It is imperative for healthcare professionals to identify and support parents experiencing high levels of distress from PLEs and ITs.

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Chapter 4

Discussion and Critical Evaluation

Word count: 3,157

This chapter aims to further discuss the findings of the systematic review and empirical paper, providing a critical evaluation of their methodological strengths and weaknesses, and suggesting areas of future research.

Overview of Findings

The systematic review aimed to identify barriers to accessing perinatal mental health (PMH) care in Sub-Saharan Africa (SSA). The review included 13 studies that met the eligibility criteria. An evaluation of their methodological quality was also carried out.

The findings highlighted a range of barriers across individual, community, healthcare professional, treatment, service, policy, and societal levels. Main barriers included low mental health literacy, significant stigma, contradictive support, limited resources, screening, formal support, and training, and not involving loved ones. Similarities were found with findings in a recent global meta-review (Webb et al., 2023), including PMH-specific training, limited resources, and healthcare structures impacting PMH access. Factors unique to SSA include lack of PMH policy, pluralism of traditional and biomedical care, stigma faced by adolescent mothers, and the need to integrate PMH into primary health care (PHC).

The empirical study explored distressing psychotic-like experiences (PLEs) and intrusive thoughts (IT) in postnatal parents. A sample of 349 parents completed an online survey measuring demographic factors, PLEs, ITs, and depression, anxiety, and stress. Compared to the low/no risk group, fewer were cohabiting, and more were accessing mental health services in the potential risk group. Furthermore, scores on the PQ-16, PTBC, and DASS21 were significantly higher in the at-risk group, indicating that this group were experiencing more complex and severe mental health symptoms. Depression and distressing ITs were associated with increased PLE distress, while cohabitation reduced the likelihood of distress. A history of mental health difficulties, the number of ITs reported, stress, and anxiety were associated with increased IT distress.

Taken together, the findings of these papers broadly fit with one another in several ways. Both identified a need for the development of PMH services. In SSA, there is a need to prioritise PMH and to follow this with funding for training and employing a greater workforce. With these in place, there can be increased screening, integration of care and the

development of evidence-based, culturally adapted interventions to prevent and support PMH difficulties.

The results from the UK community sample showed high numbers of parents at potential risk of developing psychosis as well as a gap between the number of parents experiencing mental health symptoms and the number accessing or awaiting mental health support. As evidenced by the large gap between the prevalence of PLEs and of psychosis in the perinatal period, it is unlikely that many of these parents will develop ppPsycosis. However, the findings point to the complexity and severity of mental health symptoms experienced by this group of postnatal parents. This emphasises the need for increased screening, that includes distressing PLEs and IT, to better identify of parents in need of support. PMH services will need to continue to expand to meet this growing need. These papers add to the evidence base supporting further development of PMH services.

Strengths and Limitations

Systematic Review

The systematic review had several strengths. The review was registered on PROSPERO, an international database that allows for researchers to prospectively register systematic reviews with health-related outcomes, which helps to increase transparency in the review process and minimise the risk of duplications (Booth et al., 2012). The included papers all used similar data collection methods, which allows for integration of findings.

To my knowledge, this is the first systematic review exploring barriers to accessing PMH in SSA. While other reviews have included studies from SSA (Hu et al., 2020; Webb et al., 2021, 2023), this region has been relatively underrepresented with most of the included studies being from western, high income countries. The World Health Organisation's (2021) Comprehensive Mental Health Action plan 2013-2030 that calls for research to be conducted in different cultural contexts, include local understandings of mental distress and ways of help-seeking. This review includes studies that fulfil this purpose and highlights common themes across these studies. Furthermore, Asare and Rodriguez-Muñoz (2022) highlight the dearth of research addressing HCP's perspectives on PMH care. This gap is addressed in some part by including papers with HCPs' perspectives on barriers to accessing PMH. This review included perspectives from multiple key stakeholders including mothers, carers, HCPs, traditional healers, and policymakers.

The review also presented several limitations. Screening studies was time consuming due to the high number of papers identified during the database searches. This search strategy was developed with the medical school librarian and extended out to ensure that the search captured papers from across SSA. However, the search also captured many papers about physical health during the perinatal period. In future, adding exclusion terms to the search would limit the irrelevant papers from coming through and allow for a more efficient screening process.

A second limitation was the low representation of SSA countries in the review. The heterogeneous studies imply that the generalisation and transferability of its findings to other SSA countries need to be considered cautiously. Thirdly, the review only included peer-reviewed papers, therefore the risk of publication bias needs to be acknowledged. It is also possible that the eligibility criteria for this study were too restrictive. The decision to keep strict eligibility criteria was to produce robust research but include grey literature. We only included manuscripts published in English, and thus we may have facilitated publication bias by not including more languages especially given how diverse SSA is linguistically.

The validity of the findings may have been increased and bias reduced by having multiple researchers analysing the data and developing the themes. When conducting future qualitative research, I will ensure multiple research members are involved in the thematic analysis and will employ group reflective spaces to discuss results and their implications.

Lastly, it must be acknowledged that this review of studies from SSA took place in a UK university. I was able to bring my own experience as a person from a SSA country who has experience of the healthcare disparities, extremely limited mental health support, and joint work with traditional healers in this country to this research. However, I am now working within a healthcare system that benefits from significantly more investment and research. I hope to continue my research in this area, collaborating with other SSA researchers and people in SSA with lived experience of PMH difficulties. As highlighted by the Pan African Network of People with Psychosocial Disabilities (2014, pp. 385), "there can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health".

Empirical Study

To my knowledge, this is the first study investigating PLEs and ITs together in the postnatal period. It adds to the existing evidence base by exploring the presence of these experiences and the complexity of clinical presentations. This study builds on Collardeau et al.'s (2019) and Holt et al.'s (2018) findings by including measures of distress.

This study also had several limitations. Our sample was mostly female, despite using targeted social media advertising to recruit parents of all genders. This may be due to our advertising being possibly more appealing to women or the belief that perinatal mental health only concerns women. The Royal College of Psychiatrists (2021) recommend perinatal services extend to support all parents, which requires perinatal research to broaden its focus to include all parents. Data on gender and birthing-parent was collected to investigate differences between factors associated with distressing PLEs and ITs in mothers and non-birthing parents, as well as the number of postpartum men experiencing PLEs as this is not yet known. However, due to the low response rate of men and the unreliable data obtained by the question about whether one gave birth to their child this analysis was not possible.

I have since been in contact with several researchers that work primarily with fathers and have found their input helpful in considering different ways to recruit parents into perinatal research. If I were to conduct this research again, I would contact organisations that have databases of fathers interested in research and active parenting social group such as Fatherhood Institute, Dads Rock, Dads Matter, and Dad Pad UK. I would also recruit parents at various points of the perinatal journey where non-birthing parents tend to attend appointments alongside birthing parents, such as scans, birth and parenting courses, and infant check-ups.

There is also a possibility of response bias in this study, as with any research using only self-reported data. Participants who had not experienced any PLEs or ITs may not have felt that this study pertained to them, and therefore did not take part or dropped out, resulting in a skewed sample. Finally, the cross-sectional nature of this study meant that it was not possible to establish cause and effect.

Theoretical Implications

The findings of the systematic review and the empirical paper contributed to the area of perinatal mental health, by identifying barriers to accessing care and factors that might make a parent more likely to experience distress from mental health symptoms.

The results of the systematic review of identified similar barriers to accessing PMH support as those described in Goldberg and Huxley's (1992) framework for how people move through mental health services. They identify filters (barriers) that prevent people from accessing mental health services at different levels. The first filter is "illness behaviour", where a person needs to recognise their symptoms as a mental health difficulty and seek help. We identified factors such as low mental health literacy and where help is sought as those that might map onto "illness behaviour". However, we also identified barriers that might prevent a person from seeking help, even if they recognise their symptoms. These include cultural practices that might prevent a woman from leaving the home after birth, financial constraints that impact one's ability to travel to a healthcare facility, and stigma. The second filter is a healthcare professional's ability to recognise symptoms of mental illness. This was evident in the limited training and screening available to HCPs in our study. The third is making a referral to mental health services, possibly due to a lack of available services or a reluctance to label a mental health condition for fear of stigmatising the woman (Sambrook Smith et al., 2019).

The final is admission to a mental health facility. The barriers to these steps in this study were a lack of trained mental health professionals and services. This was largely due to limited funding, guidance, policy, and resources. The results of this systematic review can add to frameworks developed in HIC for implementing and improving healthcare systems by identifying barriers specific to PMH and SSA that may be overlooked.

The findings also highlight the role of stigma at the individual, interpersonal, and sociocultural levels in accessing PMH services. In Goffman's (1963) seminal writing on stigma, he discussed the relevance of three groups; the 'own', 'wise', and 'normals'. The 'own' are those who share the stigmatised condition (a mental health difficulty), the 'wise' are those who are regarded as 'normal' but have a relationship with a stigmatised person (family, friends, health professionals), and the 'normals' who do not carry a stigma. Goffman

94

theorised that the 'own' and the 'wise' are more sympathetic to the plight of stigmatised individuals than the 'normals'. He suggests that professionals who work closely with stigmatised groups would not succumb to stigmatising behaviour due to their level of insight. However, he also argues that stigma can spread ('courtesy stigma'), resulting in the 'wise' avoiding or distancing themselves from the stigmatised to avoid courtesy stigma.

The 'wise', therefore, seem to either take a sympathetic or distancing stance. The examples in the systematic review of women with PMH difficulties being judged, dismissed or considered aggressive and cursed illustrate the distancing stance held by professionals. This challenges Goffman's (1963) assertion that professionals would not succumb to stigma. In fact, many users of mental health services have felt most stigmatised when interacting with health professionals (Bates & Stickley, 2012). The professionals who emphasised the importance of building trust, creating a safe space, and developing services illustrate a sympathetic stance. The sympathetic professionals tended to be better trained in PMH, suggesting that appropriate training is likely a factor in reducing stigma. This aligns with Bates and Stickley's (2012) assertion that raising awareness and education for professionals could significantly reduce the effects of stigma.

The results of the empirical paper added to the current evidence base by exploring the prevalence of PLEs and ITs in postnatal parents, and identifying factors associated with distressing PLEs and ITs. Subclinical ITs differ from clinical symptoms of OCD in frequency, intensity, distress caused and perceived thought control (Berry & Laskey, 2012; Clark, 2004), and subclinical PLEs differ from clinical symptoms of psychosis in their severity, frequency, associated distress, interpretation, preoccupation with and conviction of beliefs (DeRosse & Karlsgodt, 2015; Morrison & Baker, 2000; Peters et al., 2004). Therefore, by focusing on the distress caused by ITs and PLEs in postnatal parents, this study adds to the understanding of who might be more likely to experience clinically relevant levels of ITs and PLEs. The findings of the empirical study are also in line with suggestions that PLEs may reflect increased severity and complexity of mental health problems (Stochl et al., 2015).

Clinical implications

Based in the findings of the systematic review, future practice should focus on designing and implementing PMH services in SSA that aim to address these barriers. Support

is needed from administrative and policy levels to issue PMH policy and guidance, support integrated care, and provide appropriate, sustained funding for PMH. However, this is likely to be difficult as healthcare budgets across the region are overstretched and physical conditions with high mortality and morbidity rates need to take priority. Therefore, support for PMH projects will need to, in large part, continue to be supported by international aid, research, and charities.

The findings of the empirical project highlight the complexity and comorbidity of mental health difficulties in postpartum parents. Scores on measures of ITs and depression were significant in explaining the presence of distressing PLEs and ITs.

Therefore, we suggest that postpartum parents, irrespective of gender, should be offered screening for mental health difficulties. Screening should include questions about ITs, PLEs, depression, stress, anxiety, mental health history and level of social support.

Acceptability of routine screening for PMH difficulties does need consideration when offering screening to partners. There is strong evidence for the validity and acceptability of screening to identify maternal PMH difficulties, however, evidence of acceptability of screening and the validity of screening measures for partners is lacking (Darwin et al., 2021). A systematic review of assessing the mental health of partners in the perinatal period found that some fathers would like to or felt they should be asked about their mental health, while others viewed it to be unnecessary or expressed resistance. When considering implementing screening, parents and professionals raised concerns about compromising support for birthing parents, fear of causing offence or distress, a need for appropriate tools, and service remits (Darwin et al., 2021). While we recommend extending screening to partners, more research and service development is needed to successfully implement effective routine screening.

In the UK, health visitors and midwives are particularly important in reaching underrepresented groups, which include minority ethnic communities, women with disabilities, women in custody, and teenage mothers who are less likely to access perinatal mental health services (The British Psychological Society, 2016). Health visitors screening for postnatal depression has resulted in fewer missed or undertreated incidents of post-partum depression (National Institute for Health and Care Excellence, 2021). These outcomes may be further improved if psychologists were to provide primary care workers with the knowledge and skills to screen for PLEs and ITs and support parents experiencing distress. As recommended by the Royal College of Psychiatrists (2021), this may include perinatal services extending support to non-birthing parents.

It is clear from these findings that the PMH services in SSA and the UK are at significantly different stages of development, yet both systems would benefit from increased screening and training of a range of HCPs. Parents would benefit from increased awareness of the causes of PMH distress, where to seek help, and when. It is also important to normalise symptoms where distress is not present.

Future Research

Further research is needed to expand the evidence base for PMH in SSA. This research should be co-produced with service users and community leaders to ensure that cultural nuances are accurately understood. Future reviews could be expanded to include recommendations to overcome each barrier identified.

Qualitative findings in the systematic review should be complemented with further quantitative research to gain insight into the prevalence of PMH difficulties, screening and referral rates, and intervention outcomes. The addition of longitudinal studies would allow for researchers to track changes in access to and perceptions of PMH services. This could help inform the development of PMH interventions. Furthermore, economic evaluations of current PMH interventions could be used to measure cost effectiveness and provide evidence for the benefits of investing in PMH services.

The results of the empirical project showed that PLEs and ITs are common in the perinatal period. It would be interesting to see if these findings were similar in SSA, and whether conceptualisation of these experiences had an impact on distress.

Dissemination

In number of steps have been taken to disseminate the findings. A summary of the results was sent by email to all participants who wished to receive a copy (as indicated on their consent form). The systematic review will be submitted for publication in the BMC Health Services Research, and the empirical paper will be submitted for publication in the

Journal of Clinical Psychology. Both papers will be submitted for presentations at the UEA research conference.

Thesis Portfolio Conclusion

In conclusion, the thesis provides important insights into barriers to accessing PMH care in SSA and factors that might make a parent more likely to experience distress from mental health symptoms. Barriers unique to SSA include the lack of PMH policy, pluralism of traditional and biomedical care, stigma faced by adolescent mothers, and the difficulties integrating PMH into primary healthcare. Increased research is needed to gain a richer understanding of how these differ across more countries in the region, and what can be done to overcome barriers to access. The findings of the empirical project show that PLEs and ITs are common in postnatal parents. The study also reveals the gap between the number of parents experiencing clinically significant mental health symptoms and those awaiting or receiving PMH support. Finally, the findings highlight the complexity and comorbidity of mental health symptoms experienced in the postnatal period, and the need for screening of all postnatal parents, and support for those at risk of postnatal mental health difficulties.

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Appendices

- 1.1 Author guidelines for BMC Health Services Research
- 1.2 Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) checklist

1.3 Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) abstract checklist

- 1.4 Search syntax
- 1.5 Enhancing Transparency in Reporting the Synthesis of Qualitative (ENTREQ) checklist
- 3.1 Author guidelines for Journal of Clinical Psychology
- 3.2 Demographics, birth, and mental health information
- 3.3 16-item Prodromal Questionnaire
- 3.4 Parental Thoughts and Behaviours Checklist
- 3.5 Depression Anxiety Stress Scale
- 3.6 Participant information sheet
- 3.7 Online consent form
- 3.8 Debrief form
- 3.9 Frequencies of psychotic-like experiences and intrusive thoughts

Appendix 1.1 Author guidelines for BMC Health Services Research

Accessed from: <u>https://bmchealthservres.biomedcentral.com/submission-guidelines/preparing-your-manuscript/systematic-review</u> 28 February 2024

Systematic Review

Criteria

Systematic reviews articles should describe meta-analyses, systematic reviews, scoping reviews or umbrella reviews that synthesize published research. We strongly encourage the use of the appropriate <u>reporting guideline</u>, including <u>PRISMA</u>.

Please note that non-commissioned pooled analyses of selected published research and bibliometric analysis will not be considered.

Registration of systematic reviews

BMC supports the prospective registration of systematic reviews and encourages authors to register their systematic reviews in a suitable registry (such as <u>PROSPERO</u>). Authors who have registered their systematic review should include the registration number as the last line of the manuscript abstract. We do not publish protocols for systematic reviews.

Data sharing

BMC Health Services Research strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section including all of the subheadings (please see below for more information).

Title page

The title page should:

present a title that includes, if appropriate, the study design e.g.:

"A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"

or for non-clinical or non-research studies a description of what the article reports

list the full names and institutional addresses for all authors

if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below

Large Language Models (LLMs), such as <u>ChatGPT</u>, do not currently satisfy our <u>authorship</u> <u>criteria</u>. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the <u>CONSORT</u> extension for abstracts. The abstract must include the following separate sections:

Background: the context and purpose of the study

Methods: how the study was performed and statistical tests used

Results: the main findings

Conclusions: brief summary and potential implications

Trial registration: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our <u>editorial policies</u> for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Background

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

The methods section should include:

the aim, design and setting of the study

the characteristics of participants or description of materials

a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses

the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusions

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

Ethics approval and consent to participate

Consent for publication

Availability of data and materials

Competing interests

Funding

Authors' contributions

Acknowledgements

Authors' information (optional)

Please see below for details on the information to be included in these sections.

If any of the sections are not relevant to your manuscript, please include the heading and write 'Not applicable' for that section.

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

include a statement on ethics approval and consent (even where the need for approval was waived)

include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval and for experimental studies involving client-owned animals, authors must also include a statement on informed consent from the client or owner.

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If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including any individual details, images or videos), consent for publication must be obtained from that person, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our <u>consent form</u> if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

See our editorial policies for more information on consent for publication.

If your manuscript does not contain data from any individual person, please state "Not applicable" in this section.

Availability of data and materials

All manuscripts must include an 'Availability of data and materials' statement. Data availability statements should include information on where data supporting the results reported in the article can be found including, where applicable, hyperlinks to publicly archived datasets analysed or generated during the study. By data we mean the minimal dataset that would be necessary to interpret, replicate and build upon the findings reported in the article. We recognise it is not always possible to share research data publicly, for instance when individual privacy could be compromised, and in such instances data availability should still be stated in the manuscript along with any conditions for access.

Authors are also encouraged to preserve search strings on searchRxiv <u>https://searchrxiv.org/</u>, an archive to support researchers to report, store and share their searches consistently and to enable them to review and re-use existing searches. searchRxiv enables researchers to obtain a digital object identifier (DOI) for their search, allowing it to be cited.

Data availability statements can take one of the following forms (or a combination of more than one if required for multiple datasets):

The datasets generated and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS]

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

All data generated or analysed during this study are included in this published article [and its supplementary information files].

The datasets generated and/or analysed during the current study are not publicly available due [REASON WHY DATA ARE NOT PUBLIC] but are available from the corresponding author on reasonable request.

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

The data that support the findings of this study are available from [third party name] but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of [third party name].

Not applicable. If your manuscript does not contain any data, please state 'Not applicable' in this section.

More examples of template data availability statements, which include examples of openly available and restricted access datasets, are available <u>here</u>.

BioMed Central strongly encourages the citation of any publicly available data on which the conclusions of the paper rely in the manuscript. Data citations should include a persistent identifier (such as a DOI) and should ideally be included in the reference list. Citations of datasets, when they appear in the reference list, should include the minimum information recommended by DataCite and follow journal style. Dataset identifiers including DOIs should be expressed as full URLs. For example:

Hao Z, AghaKouchak A, Nakhjiri N, Farahmand A. Global integrated drought monitoring and prediction system (GIDMaPS) data sets. figshare. 2014. <u>http://dx.doi.org/10.6084/m9.figshare.853801</u>

With the corresponding text in the Availability of data and materials statement:

The datasets generated during and/or analysed during the current study are available in the [NAME] repository, [PERSISTENT WEB LINK TO DATASETS].^[Reference number]

If you wish to co-submit a data note describing your data to be published in <u>BMC Research</u> <u>Notes</u>, you can do so by visiting our <u>submission portal</u>. Data notes support <u>open data</u> and help authors to comply with funder policies on data sharing. Co-published data notes will be linked to the research article the data support (<u>example</u>).

Competing interests

All financial and non-financial competing interests must be declared in this section.

See our <u>editorial policies</u> for a full explanation of competing interests. If you are unsure whether you or any of your co-authors have a competing interest please contact the editorial office.

Please use the authors initials to refer to each authors' competing interests in this section.

If you do not have any competing interests, please state "The authors declare that they have no competing interests" in this section.

Funding

All sources of funding for the research reported should be declared. If the funder has a specific role in the conceptualization, design, data collection, analysis, decision to publish, or preparation of the manuscript, this should be declared.

Authors' contributions

The individual contributions of authors to the manuscript should be specified in this section. Guidance and criteria for authorship can be found in our <u>editorial policies</u>.

Please use initials to refer to each author's contribution in this section, for example: "FC analyzed and interpreted the patient data regarding the hematological disease and the transplant. RH performed the histological examination of the kidney, and was a major contributor in writing the manuscript. All authors read and approved the final manuscript."

Acknowledgements

Please acknowledge anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials.

Authors should obtain permission to acknowledge from all those mentioned in the Acknowledgements section.

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Group authorship (for manuscripts involving a collaboration group): if you would like the names of the individual members of a collaboration Group to be searchable through their individual PubMed records, please ensure that the title of the collaboration Group is included on the title page and in the submission system and also include collaborating author names as the last paragraph of the "Acknowledgements" section. Please add authors in the format First Name, Middle initial(s) (optional), Last Name. You can add institution or country information for each author if you wish, but this should be consistent across all authors.
Please note that individual names may not be present in the PubMed record at the time a published article is initially included in PubMed as it takes PubMed additional time to code this information.

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You may choose to use this section to include any relevant information about the author(s) that may aid the reader's interpretation of the article, and understand the standpoint of the author(s). This may include details about the authors' qualifications, current positions they hold at institutions or societies, or any other relevant background information. Please refer to authors using their initials. Note this section should not be used to describe any competing interests.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

1 Section and Topic	ltem #	Checklist item	Location where item is reported	
TITLE				
Title	Title 1 Identify the report as a systematic review.			
ABSTRACT				
Abstract	2	See the PRISMA 2020 for Abstracts checklist.		
INTRODUCTION				
Rationale	3	Describe the rationale for the review in the context of existing knowledge.		
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.		
METHODS				
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.		
Information sources	formation 6 Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.			
Search strategy	Search strategy 7 Present the full search strategies for all databases, registers and websites, including any filters and limits used.			
Selection process	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.			
Data collection process	9 Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.			
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.		
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.		
Study risk of bias assessment	Study risk of bias assessment11Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.			
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.		
Synthesis methods	13a Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).			
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.		
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.		

Appendix 1.2 Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) checklist

1 Section and Topic	ltem #	Checklist item	
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17 Cite each included study and present its characteristics.		
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	
Results of individual studies	Results of ndividual studies 19 For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.		
Results of	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	
syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	
Certainty of evidence	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.		
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	
	23b	Discuss any limitations of the evidence included in the review.	
	23c	Discuss any limitations of the review processes used.	
	23d	Discuss implications of the results for practice, policy, and future research.	

1 Section and Topic	ltem #	Checklist item	Location where item is reported
OTHER INFORMA	TION		
Registration and	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	
protocol	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	
Competing interests	26 Declare any competing interests of review authors.		
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <u>http://www.prisma-statement.org/</u>

Section and Topic	ltem #	Checklist item	Reported (Yes/No)
TITLE	-		
Title	1	Identify the report as a systematic review.	Yes
BACKGROUND			
Objectives	2	Provide an explicit statement of the main objective(s) or question(s) the review addresses.	Yes
METHODS			
Eligibility criteria	3	Specify the inclusion and exclusion criteria for the review.	Yes
Information sources	4	Specify the information sources (e.g. databases, registers) used to identify studies and the date when each was last searched.	Yes
Risk of bias	5	Specify the methods used to assess risk of bias in the included studies.	Yes
Synthesis of results 6 Specify the methods used to present and synthesise results.		Yes	
RESULTS	•		
Included studies	7	Give the total number of included studies and participants and summarise relevant characteristics of studies.	Yes
Synthesis of results 8 Present results for main outcomes, preferably indicating the number of included studies and participants for each. If meta-analysis was done, report the summary estimate and confidence/credible interval. If comparing groups, indicate the direction of the effect (i.e. which group is favoured).		Yes	
DISCUSSION			
Limitations of evidence	9	Provide a brief summary of the limitations of the evidence included in the review (e.g. study risk of bias, inconsistency and imprecision).	Yes
Interpretation	10	Provide a general interpretation of the results and important implications.	Yes
OTHER			
Funding	11	Specify the primary source of funding for the review.	Yes
Registration 12 Provide the register name and registration number.		No	

Appendix 1.3 Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) abstract checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <u>http://www.prisma-statement.org/</u>

Appendix 1.4 Search syntax

perinatal OR perinatal period OR postnatal OR postpartum period OR pregnancy OR antenatal OR maternal OR peripartum OR women OR mothers OR motherhood

AND

Africa, south of the Sahara OR sub-Saharan Africa OR sub sahara Africa OR Angola OR Benin OR Botswana OR Burkina Faso OR Burundi OR Cabo Verde OR Cameroon OR Central African Republic OR Chad OR Comoros OR Democratic Republic of the Congo OR Republic of the Congo OR Cote d'Ivoire OR Equatorial Guinea OR Eritrea OR Eswatini OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR Sao Tome and Principe OR Senegal OR Seychelles OR Sierra Leone OR Somalia OR South Africa OR South Sudan OR Sudan OR Tanzania OR Togo OR Uganda OR Zambia OR Zimbabwe

AND

mental health services OR community mental health services OR health services accessibility OR preventative health services OR women's health services OR mental health services OR mental health care OR mental health treatment OR psychiatric services OR mental health support OR depression OR anxiety OR mental health OR mental distress OR intervention OR psychiatric

AND

help seeking OR treatment seeking OR treatment engagement OR utilization OR needs

AND

focus group OR survey OR questionnaire OR instrument OR measure OR assessment OR scale OR interview OR groups OR perspectives OR experiences OR qualitative

AND

barriers OR facilitators OR enablers OR factors OR obstacles OR challenges OR difficulties OR determinants OR drawbacks OR issues

Appendix 1.5 Enhancing Transparency in Reporting the Synthesis of Qualitative (ENTREQ) checklist

	Item	Guide and description	Page reported
1	Aim	State the research question the synthesis addresses	
2 Synthesis methodology		Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. metaethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available	
		studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type)	
5 Data sources D da E rec ir S se		Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	
6 Electronic Describe the literature search (e.g. provide electronic search strategy topic terms, experiential or social phenomena reference for qualitative research and search		Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	
10	Rational for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team. study	

		design, data analysis and interpretations, reporting).		
12	Appraisal	Indicate whether the appraisal was conducted		
process		independently by more than one reviewer and if consensus		
		was required.		
13	Appraisal	Present results of the quality assessment and indicate		
	results	which articles, if any, were weighted/excluded based on		
		the assessment and give the rationale		
14	Data	Indicate which sections of the primary studies were		
	extraction	analysed and how were the data extracted from the		
		primary studies? (e.g. all text under the headings "results		
		/conclusions" were extracted electronically and entered		
		into a computer software).		
15	Software	State the computer software used, if any		
16	16 Number of Identify who was involved in coding and analysis			
	reviewers			
17	Coding	Describe the process for coding of data (e.g. line by line		
		coding to search for concepts)		
18	Study	Describe how were comparisons made within and across		
	comparison	studies (e.g. subsequent studies were coded into		
		preexisting		
		concepts, and new concepts were created when		
		deemed necessary).		
19	Derivation of	Explain whether the process of deriving the themes or		
	themes	constructs was inductive or deductive		
20	Quotations	Provide quotations from the primary studies to illustrate		
		themes/constructs, and identify whether the quotations		
		were participant quotations of the author's interpretation.		
21	Synthesis	Present rich, compelling and useful results that go beyond		
	output	a summary of the primary studies (e.g. new interpretation,		
		models of evidence, conceptual models, analytical		
		framework, development of a new theory or construct).		

Appendix 3.1 Author guidelines for Journal of Clinical Psychology

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New submissions should be made via the <u>Research Exchange submission portal</u>. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our <u>FAQs</u> or contact <u>submissionhelp@wiley.com</u>.

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data availability statement

funding statement

conflict of interest disclosure

ethics approval statement

patient consent statement

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A short informative title containing the major key words. The title should not contain abbreviations

The full names of the authors with institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

Acknowledgments;

Abstract structured (objective(s)/methods/results/conclusion)

Up to six keywords;

Main body:

regular section formatted as introduction, materials & methods, results, discussion, conclusion

In Session (invitation only) formatted as introduction, Case Illustration (including separate sections on Presenting Problem & Client Description, Case Formulation, Course of Treatment, Outcome and Prognosis), Clinical Practices and Summary, and Selected References & Recommended Readings

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	significant contribution to knowledge		
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Introduction (untitled). The introductory section should provide a concise overview (approximately 1/3 of the length of the manuscript) of the therapeutic approach being illustrated. Please include a brief discussion of the theoretical foundations and treatment principles. Summarize the outcome research in a paragraph or two.

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The Therapist: A brief introduction about therapist's demographic, preferred orientation(s), years of experience as a psychotherapist both in general and in the problem presented by the specific client.

Case Formulation: In light of the presenting problem, describe how you formulated the case and how the formulation impacted on your treatment selection. Please avoid the use of jargon.

Course of Treatment: Describe the therapeutic process, focusing on the therapist's observations, the therapy relationship, specific interventions, and client reactions. Please use examples of therapist-client interactions to illustrate your approach. You may either

reconstruct prototypical exchanges or use excerpts from actual transcripts.

Outcome and Prognosis: Case presentations should conclude with a summary of the treatment outcome and a discussion of the client's prognosis. Pre-post measures of change are particularly encouraged. Authors may also elect to integrate personal reflections on the course of treatment and the therapeutic outcome in this section.

Clinical Practices and Summary. In this conclusion section, please discuss the implications of the case for future applications of the therapeutic approach and dealing with this type of patient in the future.

References. Due to space limitations, we ask that you **provide no more than 25 references**. Please adhere to stylistic guidelines set forth in the APA *Publication Manual* (sixth edition) when preparing your reference list. Journal or monograph series titles should not be abbreviated.

ILLUSTRATIVE MATERIAL

Tables. All tables should have descriptive titles or captions and clearly worded column headings. Tabular material should be organized as simply as possible, eliminating vertical rules and (where possible) special typography (e.g., Greek). Indicate in the text where tables should be inserted.

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Appendix 3.2 Demographics, birth, and mental health information

1. What is your age?

16-19
20-24
25-29
30-34
35-39
40-44
45+

2. What gender do you identify as?

Female
Male
Non-binary
Transgender
Other
Prefer not to say

3. What is your current relationship status?

Single
In a relationship, not cohabiting
Cohabiting
Married
Divorced/Separated
Civil Partnership
Widowed
Other

4. Did you give birth to your child?



5. How many conceptions and births have you had? If you are the father or non-birthing parent, how many conceptions and births has your partner had?

Number of conceptions: Number of births:

6. Do you have a history of mental health difficulties?

Yes	
No	

7. Are you currently receiving or awaiting treatment for a mental health difficulty?

Yes	
No	

8. Did you find the birth of your child (or a previous birth) traumatic?

Yes	
No	

Appendix 3.3 16-item Prodromal Questionnaire

				If TRUE: how much distress did you experience?			
				None	Mild	Moderate	Severe
1.	I feel uninterested in the things I used to enjoy.	🗆 True	□ False	0	01	□ 2	□ 3
2.	I often seem to live through events exactly as they happened before (déjà vu).	🗆 True	□ False	0	1	□ 2	□ 3
3.	I sometimes smell or taste things that other people can't smell or taste.	🗆 True	□ False	D 0	• 1	□ 2	□ 3
4.	I often hear unusual sounds like banging, clicking, hissing, clapping or ringing in my ears.	🗆 True	□ False	□0	• 1	□ 2	□ 3
5.	I have been confused at times whether something I experienced was real or imaginary.	🗆 True	□ False	□0	01	□ 2	□ 3
6.	When I look at a person, or look at myself in a mirror, I have seen the face change right before my eyes.	🗆 True	□ False	0	01	□ 2	□3
7.	I get extremely anxious when meeting people for the first time.	🗆 True	□ False	□0	01	□ 2	□ 3
8.	I have seen things that other people apparently can't see.	🗆 True	□ False	□0	1	□ 2	□ 3
9.	My thoughts are sometimes so strong that I can almost hear them.	🗆 True	□ False	□0	1	□ 2	□ 3
10.	I sometimes see special meanings in advertisements, shop windows, or in the way things are arranged around me.	🗆 True	□ False	□0	□ 1	□ 2	□3
11.	Sometimes I have felt that I'm not in control of my own ideas or thoughts.	🗆 True	□ False	0	1	□ 2	□ 3
12.	Sometimes I feel suddenly distracted by distant sounds that I am not normally aware of.	🗆 True	□ False	□0	1	□ 2	□ 3
13.	I have heard things other people can't hear like voices of people whispering or talking.	🗆 True	□ False	□0	1	□ 2	□ 3
14.	I often feel that others have it in for me.	🗆 True	□ False	□0	1	□ 2	□ 3
15.	I have had the sense that some person or force is around me, even though I could not see anyone.	🗆 True	□ False	D 0	□ 1	□ 2	□ 3
16.	I feel that parts of my body have changed in some way, or that parts of my body are working differently than before.	🗆 True	□ False	□0	01	□ 2	□3

The 16-item Version of the Prodromal Questionnaire (PQ-16)

Appendix 3.4 Parental Thoughts and Behaviours Checklist

Instructions

We are interested in your experiences with unpleasant, unrealistic, disturbing, or unwanted thoughts, images or impulses about your new baby that pop into your mind when you least want them there. Nearly everyone has such experiences, but people vary in how frequently these kinds of thoughts occur and how distressing they are. Some examples of negative baby-related thoughts that other people have reported are:

- an unwanted thought about intentionally hurting the baby even though you would never actually do it
- · the idea that you could drop the baby from a high place
- an unwanted urge to touch the baby's genitals
- · repeated thoughts about the baby choking or dying tragically

Remember that we are NOT asking about general worries about the baby's general health or other family matters. Rather, we ARE interested in SENSELESS thoughts, mental images or impulses that pass through your mind.

We realize that you might feel uncomfortable describing these kinds of thoughts. For example, you may be concerned that you are a bad parent if you have some of these thoughts. It is important for you to realize that most people have these kinds of experiences from time to time—and they are quite common among new parents.

Please indicate whether or not you have experienced each kind of thought listed below by checking YES or NO. If you have had the thoughts in the past, but not anymore, please place a check in the PAST column. Even if you have only briefly had these thoughts it is important for you to let us know.

1. Thought that he/she might stop breathing	Yes	No	Past
2. Thought about the baby being smothered	Yes	No	Past
3. Thought that the baby could suffocate while sleeping	Yes	No	Past
4. Thought that the baby could die of SIDS	Yes	No	Past
5. Thought of hitting the baby too hard when burping him/her	Yes	No	Past
6. Unwanted thoughts of screaming, shaking, or slapping the baby	Yes	No	Past
7. Thoughts of purposely drowning the baby	Yes	No	Past
8. Thoughts of stabbing the baby	Yes	No	Past
9. Thoughts of burning the baby with hot water	Yes	No	Past
10. Thoughts about mistakenly puncturing the baby's soft spot	Yes	No	Past
11. Thoughts about the baby dying because of an accident	Yes	No	Past
12. Fears of dropping the baby while holding him/her	Yes	No	Past
13. Thoughts of dropping the baby from a high place	Yes	No	Past
14. Fears that the baby will be injured if picked up wrong	Yes	No	Past
15. Fears that the baby will choke on something (e.g., toy, food)	Yes	No	Past
16. Thoughts that an animals (i.e., a dog) might attack the baby	Yes	No	Past

17. Thoughts about the baby drowning during a bath	Yes	No	Past
18. Thoughts about a car accident involving the baby	Yes	No	Past
 Thoughts of something happening to you (or spouse/partner) and you can't care for the baby 	Yes	No	Past
20. Fear that you will forget the baby in the car seat	Yes	No	Past
21. Unwanted thoughts that you could give the baby away	Yes	No	Past
22. Fear that someone might take the baby	Yes	No	Past
23. Unwanted thoughts about leaving the baby somewhere when he/she is crying	Yes	No	Past
24. Thought about the baby getting sick from the floor or unclean surfaces	Yes	No	Past
25. Thoughts about the baby getting sick from bodily waste	Yes	No	Past
26. Concerns about household items (cleansers/solvents/bleaches)	Yes	No	Past
27. Concerns about animals or insects coming into contact with the baby	Yes	No	Past
28. Concerns that you or someone else will somehow contaminate the baby	Yes	No	Past
29. Unacceptable thoughts about the baby's genitals	Yes	No	Past
30. Thoughts about the baby's sexuality or future sexual orientation	Yes	No	Past
31. Unacceptable sexual thoughts during breastfeeding (females only)	Yes	No	Past
32. Other senseless and unwanted sexual thoughts about the baby	Yes	No	Past
 Unrealistic fears that the baby has a serious medical illness or disease (cerebral palsy, MS, developmental disability) 	Yes	No	Past

Look through the questions for which you answered "YES" and then continue. The answers to the following questions should be based on the unreasonable/unwanted thoughts that you indicated that you had. Keep in mind the LAST WEEK when you answer the questions. Mark one option under each question.

 How much of your time is occupied by the senseless, unwanted thoughts about your new baby? How frequently do these thoughts or ideas occur? (Consider both the number of times and the duration of the thoughts)

- None
- Less than 1 hour per day, or occasional thoughts
- O 1 to 3 hours per day or frequent thoughts
- o 3 to 8 hours per day or very frequent thoughts
- O More than 8 hours per day or near constant thoughts

2. How much do these thoughts interfere with your family, social or work (or other role) functioning? Are there things you can't do because of the thoughts?

- None
- Slight interference, but overall performance not impaired
- Definite interference, but still manageable
- Causes substantial impairment in performance
- Incapacitating

3. How much distress do these senseless and unwanted thoughts cause you?

- None
- Not too disturbing
- Disturbing, but still manageable
- Very disturbing
- Near constant disabling distress

4. How much of an effort do you make to resist these thoughts? How often do you try to turn your attention away, or disregard them? (Rate only your effort to resist, not success or failure).

- I always make an effort to resist, or I do not need to make an effort
- I try to resist most of the time
- I make some effort to resist
- I yield to the thoughts without attempting to resist, but with reluctance
- I completely and willingly yield to all of the thoughts

5. How much control do you have over the thoughts? How successful are you at stopping or diverting them when they occur? Can you dismiss them?

- I have complete control over the thoughts
- Much control, I am usually able to stop or divert thoughts
- Moderate control, I am sometimes able to stop or divert the thoughts
- Little control, I'm rarely successful in stopping or dismissing thoughts
- No control, I am unable to even temporarily alter them

Again, consider the senseless, unwanted thoughts that you indicated on the previous pages. Please indicate whether any of these thoughts lead you to engage in the following strategies or activities...

1. Give yourself reassurance that things are OK	Yes	No	Past
Spend time trying to rationalize or make sense of the thought	Yes	No	Past
3. Check on the baby more frequently	Yes	No	Past
4. Distract yourself with other activities	Yes	No	Past
5. Distract yourself with other thoughts	Yes	No	Past
Try to suppress or stop the unwanted intrusive thoughts as quickly as possible	Yes	No	Past
7. Avoid situations in which the thought comes up	Yes	No	Past
8. Avoid your baby	Yes	No	Past
Get social support (such as by talking to your spouse or parent)	Yes	No	Past
Ask other people if the thoughts are "OK" or "normal"	Yes	No	Past
11. Confess to others that you've had the thoughts	Yes	No	Past
12. Pray about the thoughts	Yes	No	Past
13. Other strategies used to respond to the thoughts	Yes	No	Past

Now you will be asked several questions about the strategies and activities that you marked as YES. Please review the strategies you marked as YES above and then complete the questions below.

Please answer the following questions based on the strategies and activities that you indicated using on the previous page. Please consider THE PAST WEEK in choosing your answer. Mark one answer under each question.

 How much time do you spend engaged in the strategies? How often do you use them in response to unwanted thoughts? (Consider both the number of times and how much time you spend)

- None
- Less than 1 hour per day or occasional performance
- 0 1 to 3 hours per day or frequent performance
- 3 to 8 hours per day or very frequent performance
- More than 8 hours per day or near constant performance

2. How much do these strategies interfere with your family, social or work (or other role) functioning? Are there things you can't do because of the strategies?

- None
- Slight interference, but overall performance not impaired
- Definite interference, but still manageable
- Causes substantial impairment in performance
- Incapacitating

3. How would you feel if you were prevented from performing these strategies when you felt as if you needed to perform them? That is, how anxious/worried would you become?

- None
- Not too disturbing
- Disturbing, but still manageable
- Very disturbing
- Near constant disabling distress
- 4. How much of an effort do you make to resist performing these strategies?
 - Always makes an effort to resist, or doesn't need to make effort
 - Tries to resist most of the time
 - Makes some effort to resist
 - Yields to fears without attempting to resist, but with reluctance
 - Completely and willingly yields to all fears

5. How strong is the drive to perform these strategies when an unwanted thought comes to mind?

- Complete control
- Much control, usually able to stop or divert behaviors
- Moderate control, sometimes able to stop or divert behaviors
- Little control, rarely successful in stopping or diverting behaviors
- No control, drive to perform behaviors is overpowering, rarely able to even delay performance

Appendix 3.5 Depression Anxiety Stress Scale

D	Name:	Date:				
Plea appl on a	Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i> . There are no right or wrong answers. Do not spend too much time on any statement.					
7he 0 D 1 A 2 A 3 A	rating scale is as follows: id not apply to me at all pplied to me to some degree, or some of the time pplied to me to a considerable degree, or a good part of time pplied to me very much, or most of the time					
1	I found it hard to wind down	0	1	2	3	
2	I was aware of dryness of my mouth	0	1	2	3	
3	I couldn't seem to experience any positive feeling at all	0	1	2	3	
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3	
5	I found it difficult to work up the initiative to do things	0	1	2	3	
6	I tended to over-react to situations	0	1	2	3	
7	I experienced trembling (eg, in the hands)	0	1	2	3	
8	I felt that I was using a lot of nervous energy	0	1	2	3	
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3	
10	I felt that I had nothing to look forward to	0	1	2	3	
11	I found myself getting agitated	0	1	2	3	
12	I found it difficult to relax	0	1	2	3	
13	I felt down-hearted and blue	0	1	2	3	
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3	
15	I felt I was close to panic	0	1	2	3	
16	I was unable to become enthusiastic about anything	0	1	2	3	
17	I felt I wasn't worth much as a person	0	1	2	3	
18	I felt that I was rather touchy	0	1	2	3	
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3	
20	I felt scared without any good reason	0	1	2	3	
21	I felt that life was meaningless	0	1	2	3	

Intrusive Thoughts and Psychotic-Like Experiences in the Postnatal Period

v2, 06/12/2022

(1) What are the aims of the study and why is it important?

The time after having a baby is sometimes a joyous experience for parents. For others, it is a time of significant challenge. This is a time when many parents experience changes in their routine, lifestyle, mental health, and wellbeing.

Some unexpected changes may include experiencing unwanted, unwelcome thoughts that pop into your head without warning, at any time; these can be repetitive and distressing and can also be known as an 'intrusive' thought. Some people may hear/see things that others do not, often referred to as an 'unusual' or 'psychotic-like' experience.

Whilst these can sometimes be frightening, research indicates these experiences are normal and more common than once thought. Research also tells us that having unwanted thoughts or unusual experiences does not mean that people will act upon them.

We are interested in exploring these experiences in parents (both mums and dads/partners) who have had a baby in the last 12 months. This time is referred to as the 'postnatal period'. We hope to understand more about who has these experiences and whether parents find them distressing. We are also interested in exploring experiences of parenting and mental health during this time.

The aim of this study is to explore parents' experiences of unwanted thoughts and unusual experiences in the 12 months after having a baby. This study will be helpful in better understanding these experiences, their impact, and the support that parents may need during this time.

This Participant Information Sheet contains information about the research study that we hope will help you decide whether you want to take part. Please read this sheet carefully and contact us about anything that you don't understand or want to know more about.

Participation in this research study is voluntary. By giving consent to take part in this study you confirm that you:

- Understand what you have read.
- Agree to take part in the research study as outlined below.
- Agree to the use of your personal information as described.

(2) Who are we and why are we contacting you?

Our names are Ilana Foreman and Tammy Hunt. We are postgraduate researchers completing the Professional Doctorate in Clinical Psychology (ClinPsyD) at the University of East Anglia (UEA), currently in our second year of training.

As part of our thesis project, we are exploring parents' experiences of unwanted thoughts and unusual experiences in the postnatal period.

We are looking to recruit parents who have a child under 1 year, to participate in an anonymous online questionnaire.

You are eligible to participate in this study if:

- You have a child aged under 1 year old and you identify as a parent
- You are aged 16 and above
- You can read and understand English (the questions are written in English)
- You reside in the United Kingdom

(3) What will participation involve for me?

You will be asked to complete an online questionnaire and your responses will be completely anonymous. This questionnaire will consist of some questions asking about your age, gender, ethnicity, relationship status, and brief questions about your birth experience. There will then be questions exploring your experience of unwanted thoughts, unusual experiences, mental health, and parenting experiences.

Possible worries: You may find some of the questions mildly upsetting and may worry about what may happen if you answer honestly. Please be reassured your responses are completely anonymous and, as no personal information is collected, we have no way to identify you or link you to your responses. There will be no repercussions for your responses, so please answer honestly.

You may worry that reading questions about unwanted thoughts and unusual experiences could trigger you to experience these, however research has not shown this to be the case. Some parents may worry the presence of these experiences could affect their parenting ability or may worry about what will happen if they share their experiences. Research has found it is not uncommon for parents to experience unwanted, intrusive thoughts or unusual (psychotic-like) experiences after having a baby and is more common than once thought, which is why this is an important area to research. Research has also shown that the presence of unwanted thoughts and unusual experiences does not mean people are likely to act upon these.

We recognise that participating in this study may increase your awareness of your own experience of unwanted thoughts and unusual experiences, and that you may be concerned about these experiences and wonder what support is available to you. We have provided a list of relevant support resources which is available for you to view and download here:

https://static.onlinesurveys.ac.uk/media/account/112/survey/976395/question/participant_ support_informatio.docx

(4) How much of my time will the study take?

The study should take between 20-30 minutes to complete.

(5) Do I have to be in the study? Can I withdraw from the study once I have started?

Taking part in this study is completely voluntary and you do not have to participate.

Your decision on whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of East Anglia now or in the future. If you have accessed this study following advertisement via an online parenting forum/website or social media site, please be reassured your decision to participate will not affect your current or future relationship with these websites, now or in the future. This study is completely separate from any parenting groups, websites, or social media sites you may be subscribed to.

If you would no longer like to take part in the study, you are free to exit the survey at any point by closing your browser. You will not need to provide any reason for this, and your data will not be stored if you withdraw from the survey. If you close your browser window your responses will not be recorded, however, you will also not see the debrief form.

(6) What are the consequences if I withdraw from the study?

If you decide to take part in the study and then change your mind, you are free to withdraw until you submit your responses. Any responses that are not submitted will not be included in the analysis or any publications. There will be no consequences if you chose to withdraw from the study.

(7) Are there any risks or benefits to engaging in this study?

There is little risk involved in participating in this study, beyond that experienced in day-today life. There are no special precautions that you need to take before, during or after taking part in the study.

Potential risks could include you feeling some discomfort or distress about some of the questions asked. Please be assured your responses are anonymous and there will be no repercussions for your answers. Research has highlighted that the presence of postnatal unwanted thoughts and unusual experiences is common, and the presence of these experiences does not mean people will act on them.

The benefits of engaging in this study include directly contributing to our understanding of parents' experience of unwanted thoughts and unusual experiences, the frequency and distress of these experiences and the impact these can have upon mental health and parenting experiences.

Following completion of the study you can opt-in to a prize draw, where you can win one of ten £20 Amazon vouchers. You can also opt-in to be contacted about future research participation opportunities and to receive a summary of this research. Via a separate survey link you can provide a contact email address should you want to opt-in to any of the above. This email address will not be linked to your questionnaire responses in any way.

(8) What will happen to the results of the study?

Everything you tell us will be kept confidential. This means that only the research team will have access to anonymised survey responses. We will not be asking for your name or other personal or identifiable details. We will, however, have access to your email address if you enter the prize draw, wish to receive the study summary, or be contacted about future research participation opportunities. Your email address will be collected and stored separately from your questionnaire responses. You will be contacted by your email address once the study has finished if you have won the prize draw.

Your personal data and information will only be used as outlined in this Participant Information Sheet, unless you consent otherwise. Your data will be handled in accordance with the Data Protection Act 2018 (DPA 2018) and UK General Data Protection Regulation (UK GDPR), and the University of East Anglia's Research Data Management Policy.

The information you provide will be stored securely and your identity will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be identified in these publications if you decide to participate in this study.

Study data may also be deposited with a repository to allow it to be made available for scholarly and educational purposes. The data will be kept for at least 10 years beyond the last date the data were accessed. The deposited data will not include any identifiable information about you.

(9) Will I find out the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by providing a contact email address (this will not be linked to your survey responses).

This feedback will be in the form of a one-page lay summary and will be available at the end of the study, in approximately August 2024.

(10) What if I have questions or concerns about the study?

If you have any questions or concerns about the study, you can contact us on the following details:

Ilana Foreman and Tammy Hunt

Norwich Medical School, Faculty of Medicine and Health Sciences, University of East Anglia (UEA), Norwich, NR4 7TJ

i.foreman@uea.ac.uk and t.hunt@uea.ac.uk

This project is supervised by Dr Joanne Hodgekins and Dr Joanne Peterkin at the University of East Anglia.

If you would like to speak to somebody independent of the study, such as to discuss concerns or make a complaint, you can contact the UEA Acting Programme Director, Dr Sian Coker at S.Coker@uea.ac.uk.

(11) How do I know that this study has been approved to take place?

To protect your safety, rights, wellbeing and dignity, all research in the University of East Anglia is reviewed by a Research Ethics Body. This research was approved by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

Thank you for taking the time to read this information and considering taking part in this research. You will now be directed to the consent form where you can then complete the survey.

Should you want to download a copy of this information sheet for your records, you can do so here: https://static.onlinesurveys.ac.uk/media/account/1

Appendix 3.7 Online consent form

I am willing to participate in this research study.

In giving my consent I state that:

- I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- I have read the Participant Information Sheet, which I can download and keep, for my records, and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- The researchers have answered any questions that I had about the study, and I am happy with the answers.
- I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of East Anglia now or in the future.
- I understand that I am free to withdraw at any time during the online survey without giving any reason, and without being penalised or disadvantaged.
- I understand that once my data has been submitted, I will be unable able to withdraw my data as it will not be identifiable.
- I understand that the results of this study may be published but that any publications will not contain my name or any identifiable information about me.
- I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

I consent to participate in the survey:

Yes

No

Intrusive Thoughts and Psychotic-Like Experiences in the Postnatal Period

Thank you for participating in the study titled "Intrusive Thoughts and Psychotic-Like Experiences in the Postnatal Period". We appreciate the time you have taken and value your contribution!

The aim of this study is to explore parents' experiences of unwanted 'intrusive' thoughts and unusual (psychotic-like) experiences in the 12 months after having a baby. This study included questionnaires that asked about your experience of having unwanted thoughts, unusual experiences, mental health, percieved parenting ability and stress. We are interested to see how these experiences may be linked to each other and what this might mean.

Lots of research so far has focused on the experience of the birth mother; we are also interested in this and are also interested in the experience of the father/partner (non-birthing parent).

Your participation in this study will be helpful in better understanding these experiences, how distressing they are and can aid understanding about what support parents may be need during this time.

We appreciate some of the items in this questionnaire may have been uncomfortable or caused some distress. Research has shown that unwanted 'intrusive' thoughts and unusual (psychotic-like) experiences are common in the postnatal period. Research also tells us that the presence of these thoughts and experiences does not mean a person will act upon them.

Support information and resources

If you have experienced any distress as a result of your participation in this study, or have any questions concerning your general health and wellbeing, a list of support services available are available here:

- Samaritans, a national charity offering free and confidential emotional support 24 hours a day: www.samaritans.org/. They can be contacted on 116 123 (lines open 24 hours and number does not appear on phone bills), or at <u>jo@samaritans.org</u>.
- This website contains a comprehensive list of online support options for parents. The list includes resources for new parents, dads, LGBTQ+ parents, pregnancy and postbirth, miscarriage and baby loss, single parents, young parents, and older children. It also includes specific resources for perinatal OCD: https://www.talkingchange.nhs.uk/perinatal-resources

- The Mind website has a range of accessible perinatal resources: https://www.mind.org.uk/information-support/types-of-mental-health- problems/postnatal-depression-and-perinatal-mental-health/about-maternal-mental-health-problems/
- 'Best Beginnings' is a free NHS app for parents offering evidence-based information and self-care tools to help parents during pregnancy and early stages of parenting. App users also have access to a confidential, text-based crisis messenger which provides 24/7 support: <u>https://www.bestbeginnings.org.uk/</u>
- NHS mental health support resources and information is available here: <u>https://www.nhs.uk/mental-health/</u>
- This website provides national support resources and self-help guides for parents, you can also search for resources local to you: https://maternalmentalhealthalliance.org/resources/mums-and-families/
- You can also contact your healthcare professional, such as your GP, midwife or health visitor.
- In an emergency please contact 999 or attend your nearest A&E.

*Please note, these resources are based in the UK.

Confidentiality

Please note, your responses have been collected for analysis purposes only. As your responses are anonymous and no personal identifiable information has been collected, we have no way to link your responses back to you. This means that after you exit this page, you will no longer be able to withdraw your responses.

Your anonymous responses will be securely stored in a password protected file in the UEA system. They will only be accessed by the research team. The data set can be securely held for a period of up to 10 years, after which point it will be destroyed.

Prize Draw

If you would like to enter a prize draw, where you could win one of ten £20 Amazon vouchers, please click the below link. This will open a new page where you can provide a contact email address. This email will not be linked to your survey responses and will be deleted after the prize draw results. The prize draw results will be held once data collection is complete, in approximately July 2023.

Please only enter the prize draw if you have completed the main survey. One entry per person. https://uea.onlinesurveys.ac.uk/participant-prize-draw

Further Research

This research project focused on experiences during the post-natal period (the 12 months following birth). The research team is looking to explore these experiences across the entire perinatal period (from conception until 12+ months after birth). If you would like to participate in future research in this area, please click the below link. This will open a new page where you can provide a contact email address. This email will not be linked to your survey responses.

Research Results

If you would like to find out the results from this research study, we can provide a summary once the research is complete. We also hope to publish our research in a Psychology research journal. If this is something you are interested in please click the below link. This will open a new page where you can provide a contact email address. We will then contact you with a summary of this research once it is complete (approximately summer 2024). This email will not be linked to your survey responses.

Link: https://uea.onlinesurveys.ac.uk/participant-prize-draw

Contact Details

Please contact us if you have any further questions or concerns about this research.

Our emails are: i.foreman@uea.ac.uk and t.hunt@uea.ac.uk

Our supervisors email addresses are: j.hodgekins@uea.ac.uk or j.peterkin@uea.ac.uk

Thank you very much for your time in completing this study!

3.9 Frequencies of psychotic-like experiences and intrusive thoughts

Frequencies of psychotic-like experiences reported by all parents

Question	n (%)
I feel uninterested in the things I used to enjoy.	175 (50.1)
I often seem to live through events exactly as they happened before (déjà vu).	125 (35.8)
I sometimes smell or taste things that other people can't smell or taste.	111 (31.8)
I often hear unusual sounds like banging, clicking, hissing, clapping or ringing in my ears.	120 (34.4)
I have been confused at times whether something I experienced was real or imaginary.	138 (39.5)
When I look at a person, or look at myself in a mirror, I have seen the face change right before my eyes.	33 (9.5)
I get extremely anxious when meeting people for the first time.	172 (49.3)
I have seen things that other people apparently can't see.	37 (10.6)
My thoughts are sometimes so strong that I can almost hear them	109 (31.2)
I sometimes see special meanings in advertisements, shop windows, or in the way things are arranged around me.	51 (14.6)
Sometimes I have felt that I'm not in control of my own ideas or thoughts.	142 (40.7)
Sometimes I feel suddenly distracted by distant sounds that I am not normally aware of.	89 (25.5)
I have heard things other people can't hear like voices of people whispering or talking	44 (12.6)
I often feel that others have it in for me	105 (30.1)
I have had the sense that some person or force is around me, even though I could not see anyone	64 (18.3)
I feel that parts of my body have changed in some way, or that parts of my body are working differently than before	179 (51.3)

89.7% experienced at least one PLE

The most common PLEs were "I feel uninterested in the things I used to enjoy" (50.1%) and "I get extremely anxious when meeting people for the first time" (49.3%). These may indicate depression and anxiety
Frequencies of intrusive thoughts reported by all parents

Question	Present n (%)	Past n (%)
Thought that he/she might stop breathing	279 (79.9)	47 (13.5)
Thought about the baby being smothered	142 (40.7)	49 (14)
Thought that the baby could suffocate while sleeping	246 (70.5)	52 (14.9)
Thought that the baby could die of SIDS	253 (72.5)	59 (16.9)
Thought of hitting the baby too hard when burping him/her	113 (32.4)	60 (17.2)
Unwanted thoughts of screaming, shaking, or slapping the baby	107 (30.7)	52 (14.9)
Thoughts of purposely drowning the baby	22 (6.3)	8 (2.3)
Thoughts of stabbing the baby	22 (6.3)	10 (2.9)
Thoughts of burning the baby with hot water	36 (10.3)	15 (4.3)
Thoughts about mistakenly puncturing the baby's soft spot	98 (28.1)	50 (14.3)
Thoughts about the baby dying because of an accident	230 (65.9)	40 (11.5)
Fears of dropping the baby while holding him/her	244 (69.9)	43 (12.3)
Thoughts of dropping the baby from a high place	108 (30.9)	28 (8)
Fears that the baby will be injured if picked up wrong	177 (50.7)	53 (15.2)
Fears that the baby will choke on something (e.g., toy, food)	254 (72.8)	26 (7.4)
Thoughts that an animals (i.e., a dog) might attack the baby	174 (49.9)	38 (10.9)
Thoughts about the baby drowning during a bath	123 (35.2)	45 (12.9)
Thoughts about a car accident involving the baby	226 (64.8)	30 (8.6)
Thoughts of something happening to you (or spouse/partner) and you can't care for the baby	261 (74.8)	30 (8.6)
Fear that you will forget the baby in the car seat	83 (23.8)	16 (4.6)
Unwanted thoughts that you could give the baby away	58 (16.6)	21 (6)

Fear that someone might take the baby	171 (49)	25 (7.2)
Unwanted thoughts about leaving the baby somewhere when he/she is crying	112 (32.1)	26 (7.4)
Thought about the baby getting sick from the floor or unclean surfaces	119 (34.1)	20 (5.7)
Thoughts about the baby getting sick from bodily waste	66 (18.9)	16 (4.6)
Concerns about household items (cleansers/solvents/bleaches)	125 (35.8)	19 (5.4)
Concerns about animals or insects coming into contact with the baby	99 (28.4)	18 (5.2)
Concerns that you or someone else will somehow contaminate the baby	119 (34.1)	23 (6.6)
Unacceptable thoughts about the baby's genitals	28 (8)	14 (4)
Thoughts about the baby's sexuality or future sexual orientation	73 (20.9)	14 (4)
Unacceptable sexual thoughts during breastfeeding (females only)	25 (7.2)	10 (2.9)
Other senseless and unwanted sexual thoughts about the baby	23 (6.6)	6 (1.7)
Unrealistic fears that the baby has a serious medical illness or disease	136 (39)	27 (7.7)