“YOU’VE GOTTA BE A MAN AND BE STRONG”: FATHERS’ EXPERIENCES OF PERINATAL LOSS IN THE PAKISTANI COMMUNITY

by

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Thesis Overview

The literature review includes a meta-analysis of the prevalence rates of Postnatal Depression (PND) in Black ethnic groups compared to White ethnic groups. A systematic search found 27 articles up to April 2023, reporting prevalence rate data. The prevalence rate of PND was 15% in Black ethnic groups. The relative risk of PND in Black ethnic groups compared to White ethnic groups was higher at 1.29. The measure used for PND, country of recruitment and ethnic subtype are significant factors in these estimations. There appears to be no difference in prevalence rate of PND between Black ethnic groups and the global population. However, further research is needed to determine the suitability of PND measures alongside increased research with more Black ethnic subgroups.

The empirical paper is a qualitative Interpretative Phenomenological Analysis study exploring Pakistani father’s experiences of perinatal loss. Five men who had experienced perinatal loss took part in semi-structured interviews. Three Group Experiential Themes were identified – ‘A rollercoaster of emotions: from shock and distress to having hope’, ‘The hidden experience of baby loss as a Muslim man’, and ‘The felt stigma of baby loss in the Muslim community’. Findings suggest that perinatal loss results in ever-changing emotions for men. Perinatal loss was perceived as taboo, and the men wanted to be viewed as strong, meaning their emotional responses were often masked. Further research is necessary to consider how different experiences of perinatal loss (e.g. time since loss) may influence how men interpret their experiences of loss.

Dedication

There are a number of people who have played an important part in my Psychologist journey who I would like to dedicate this thesis to.

Firstly, to my Mum, Dad and Richard. Without your continuous encouragement and support, I would not be where I am today and writing this thesis. Thank you for always being behind me in my life choices.

To my teachers who encouraged me to pursue a career in this field, and my placement supervisors who have offered their support.

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And finally, to my daughter, Isla. This is all for you. You make me a better person, mother, and Psychologist. Thank you for keeping me grounded throughout all of this.

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I would like to thank the men who participated in the empirical research and opened up conversations about perinatal loss within the Pakistani community. Without them, this research would not have been possible.

I am very grateful to the organisations who advertised the empirical research and supported me in identifying individuals to participate in this project.

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Contents Listing

Table of Tables and Figures

Glossary of terms

PND	Postnatal Depression
PR	Prevalence Rate
RR	Relative Risk
DSM-V	Diagnostic and Statistical Manual for Mental Disorders
USA	United States of America
UK	United Kingdom
EPDS	Edinburgh Postnatal Depression Scale
PHQ	Patient Health Questionnaire
ICD-9	International Classification for Diseases
PRAMS-3D	Pregnancy Risk Assessment Monitoring
RMI	Rutter Malaise Inventory
AUDADIS-IV	Alcohol Use Disorder and Associated Disabilities Interview Schedule
IPA	Interpretative Phenomenological Analysis
PETS	Personal Experiential Themes
GETS	Group Experiential Themes

1. LITERATURE REVIEW: THE PREVALENCE OF POSTNATAL DEPRESSION IN BLACK ETHNIC GROUPS COMPARED TO WHITE ETHNIC GROUPS: A META-ANALYTIC STUDY

Abstract

Background

Postnatal Depression (PND) is a major depressive disorder occurring during pregnancy or up to a year following childbirth, with a global prevalence rate (PR) of 10-20%. It is suggested that ethnic minority groups are at an increased risk of developing PND.

Aim

The prevalence rate of Postnatal Depression in Black ethnic groups is unknown. This meta-analysis aimed to synthesise the PR of PND in Black ethnic groups and demonstrate the relative risk (RR) of PND in Black ethnic groups compared to White ethnic groups.

Method

A systematic search of studies in which PND was reported after childbirth in Black ethnic groups via electronic databases (Embase, Medline and PsychINFO) was undertaken, resulting in a total of 27 articles up to April 2023.

Results

The PR of PND was 15% (CI 95% 0.12 – 0.18) in Black ethnic groups. The RR of PND in Black ethnic groups compared to White ethnic groups was higher at 1.29 (CI 95% 1.14 – 1.47),. Significant factors for PR and RR were the PND measure used and country of recruitment. Ethnic subtype was only significant in the analysis of PR.

Conclusion

The consistent PR for PND in Black ethnic groups suggests no difference between Black ethnic groups and the global population. However, further research is necessary to determine the

influence of the suitability of measures used to screen PND on the PR, alongside global research with more Black ethnic subgroups for PR and RR to reduce publication and methodological bias.

Introduction

The Diagnostic and Statistical Manual for Mental Disorders (DSM-V) describes Postnatal Depression (PND) as a major depressive disorder with mood symptoms that occur during pregnancy or in the four weeks following childbirth (APA, 2013). The presentation of PND ranges from mild depression to puerperal psychosis, requiring a multidisciplinary team approach to intervention (Babatunde & Moreno-Leguizamon, 2012; Ling et al., 2022). The global prevalence rate (PR) of PND ranges between 10% and 20% (Abbasi et al., 2013; Ling et al., 2022; Royal College of Psychiatrists, 2018; Wang et al., 2021). The variation in this prevalence is thought to be due to discrepancies in screening methods used and the timings of assessment (Afolabi et al., 2020; Mersky & Janczewski, 2018), with longer time frames associated with higher PR (Wisner et al., 2006). A biopsychosocial model can be used to explain the factors that influence the development of PND (Almond et al., 2009; Colella et al., 2022), with evidence suggesting the role of changes in postpartum hormones, family history of depression, previous psychiatric history, family history of mental health difficulties, stress, social support, and marital difficulties (Amankwaa, 2003; Public Health England, 2019). Women across the world are more likely to experience a psychiatric illness following childbirth than at any other time in their lives (Almond et al., 2009; Wang et al., 2021). There are adverse consequences associated with PND including maternal mortality, poor pregnancy outcomes and poor maternal-infant interactions that can impact on the psychosocial development of children (Sambrook Smith et al., 2019; Stein et al., 2014; Watson et al., 2019). Therefore, PND is a global public health problem with significant cost and resource implications for health services (Almond et al., 2009; Watson et al., 2019).

PND is underdiagnosed and undertreated (Afolabi et al., 2020), meaning the global PR may not be accurate (Arifin et al., 2018). There is an idealised societal norm regarding motherhood, which may result in mothers feeling guilty and embarrassed about their experiences, meaning symptoms are underreported (Afolabi et al., 2020). Some cultures may find the diagnosis of PND unacceptable, or it might not be used, resulting in underreporting of symptoms (Arifin et al., 2018). Common reasons for not reporting symptoms included concerns about feeling weak, being judged as a bad mother and a fear of having their children removed and/or referred to social services (Arifin et al., 2018). Some of these experiences are shared cross culturally, but others are culturally unique (Amoah, 2021; Arifin et al., 2018), with cultural factors influencing the understanding of and ways of coping with PND, including family structure and dynamics, social organisation, socially sanctioned defence mechanisms (e.g. only White women have PND), rituals, social stresses, distinctive language in relation to depression and beliefs about healthcare and the healthcare system (Babatunde & Moreno-Leguizamon, 2012; Moore et al., 2019). Migrant women are considered to be at an increased risk for developing PND as they try to comply with childbirth rituals within a western society which may not match their own values, alongside the overall transition to motherhood (Wittkowski et al., 2016).

Although perceptions and attitudes towards mental illness may influence help seeking behaviour and attitudes (Arifin et al., 2018), there is evidence to suggest poorer healthcare outcomes, experiences with treatment and access to services for ethnic minority communities (Knight et al., 2021; Ling et al., 2022). The Five Year Forward View for Mental Health (2016) set out to transform mental health services in the United Kingdom (UK) and identified a specific aim to improve perinatal mental health services. There is evidence of systemic racism within maternity services with issues identified such as lack of physical and psychological safety, being ignored and disbelieved, racism by caregivers, dehumanisation, lack of choice, consent and coercion, structural barriers and workforce representation and culture (Arefadib et al., 2022; Babatunde & Moreno-Leguizamon, 2012; Birthrights, 2022; Ling et al., 2022). The use of western methods of diagnostic classification systems may also be culturally insensitive

(Babatunde & Moreno-Leguizamon, 2012), meaning that the underreporting of symptoms and service accessibility may be better understood through organisational and systemic factors related to the cultural appropriateness and competence of healthcare settings, as opposed to specific cultural characteristics of ethnic minority groups (Di Florio et al., 2017; Memon et al., 2016; Moore et al., 2019; Watson et al., 2019).

Research and policy suggest that individuals from ethnic minority groups are at an increased risk of developing PND (Afolabi et al., 2020; Knight et al 2021), with Black ethnic groups in particular having an increased risk (Edge et al., 2004; Edge, 2007) and more likely to experience health inequalities (Birthrights, 2022; Knight et al., 2021; Ling et al., 2022). Women from Black ethnic groups are reported to be 22% more likely to receive inpatient mental health care for postpartum mental health and have four times higher mortality rates (Birthrights, 2022; Chan et al., 2021; Knight et al., 2021; Ling et al., 2022) compared to other ethnic groups. It is known that global PR is variable as a result of differences in measurement (Afolabi et al., 2020; Mersky & Janczewski, 2018), however it is not known how the PR of PND is comparable in Black ethnic groups given the evidence of health inequality and underreporting of symptoms. Therefore, the aim of this current meta-analysis is to describe and evaluate the current literature estimating the prevalence of PND in Black ethnic groups to:

1. Synthesise PR of PND in Black ethnic groups in order to generate robust estimates.
2. Demonstrate the relative risk (RR) of PND in Black ethnic groups compared to White ethnic groups.
3. Evaluate how study characteristics (ethnic subtype, measure of PND used, time frame after childbirth measure was administered, country of study, recruitment location) influence the reported PR and RR.

Methods

Identifying primary studies

Search of Electronic Databases

A systematic search of the literature was carried out on 27th April 2023 using Embase, Medline and PsychINFO. The aim of the search was to obtain a comprehensive overview of the literature into the prevalence of PND in Black ethnic groups. The search terms used to identify relevant studies are outlined in Table 1.

Table 1: Search Criteria

Construct	Free Text Search Terms	Method of Search	Limits
Ethnicity	"ethnic identity" OR "racial identity" OR "ethnicity" OR "ethnic group" OR "racial group"	Free search terms All search terms combined with *OR*	Peer reviewed articles 1967-April 2023
	AND		
Postnatal depression	"post partum depression" OR "postpartum depression" OR "post natal depression" OR "postnatal depression" OR "perinatal depression" OR "peri natal depression" OR "puerperal depression"		

Inclusion Criteria

Full inclusion/exclusion criteria are described in Table 2. Studies were included in this meta-analysis if participants were from Black ethnic groups, PND was measured after childbirth, papers were available in the English language and were empirical research enabling event rates to be calculated.

Table 2: Inclusion and exclusion criteria.

Inclusion criteria	Justification
Language of research	
Papers published available in English language	Limited resources available to translate papers that are not available in the English language
Measurement of PND	
Studies were included if they measured PND after childbirth. Studies which measured PND during pregnancy or combined participants during and post pregnancy were excluded.	The definition of PND utilised in this analysis was based on depression developing after childbirth. To ensure consistency with this definition, studies that measured PND during pregnancy were not included in the analysis.
Participant focus	
Studies that included individuals from Black ethnic groups (African American, Black, Non-Hispanic Black, Non-Latina Black, Black African) were included.	This is to address a gap in the literature regarding the prevalence of PND in this ethnic group. There is evidence to suggest that PND may be underreported or not recognised, with little research being conducted to explore the prevalence. Therefore, including studies that measure PND in these ethnic groups provide useful information regarding prevalence for the analysis.
Outcomes	
The studies are required to report the presence of PND by ethnic group.	To ensure that the event rate can be calculated and compared to other ethnic groups (e.g., White/Caucasian).
Type of article	
The following article types were excluded: meta-analysis/theoretical papers/ reviews/commentaries/ clinical guidance/non-outcome focused studies i.e., validation of psychometric scales/qualitative papers	These articles do not provide the outcome data needed for this meta-analysis.
Year of publication	
Articles from 2000-2023 were included in the review	To ensure the research included in the analysis is the most up to date and relevant to the topic.

The results of the systematic search are presented in Figure 1. The search yielded a total of 1041 articles and then 751 once duplicates were removed. These articles were then screened using the exclusion criteria using the study titles and abstract with 357 articles excluded. The full text of the remaining 394 articles were then reviewed against the exclusion criteria. The total number of full text articles excluded was 367. Twenty-seven articles met the full inclusion/exclusion criteria for the meta-analysis.

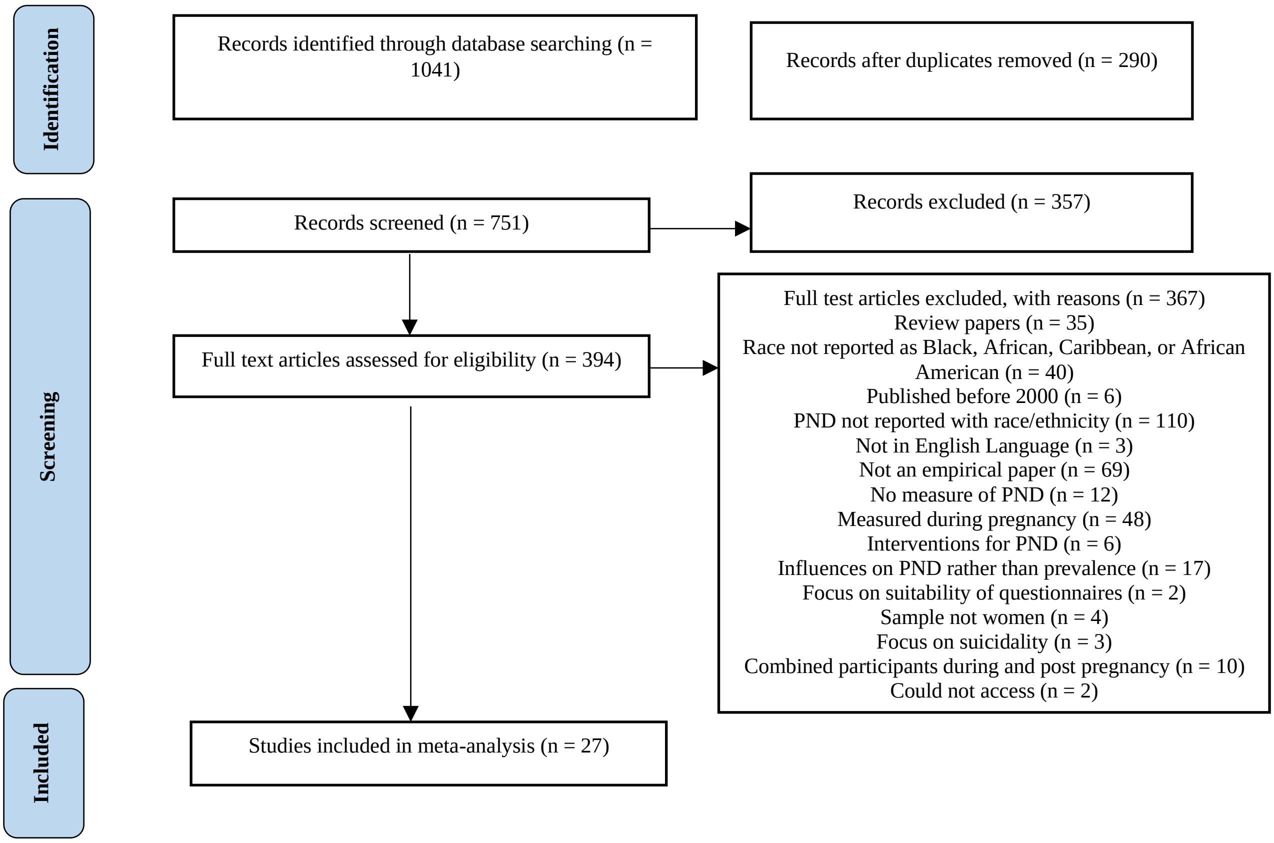


Figure 1: Results of the systematic search and the application of the inclusion criteria

Data extraction

All data were extracted by the author. Event rates were reported as the number of participants with and without the condition of interest. When RR or risk difference estimates were calculated, then event rates were reported as the number of participants with and without the condition of interest in both a control and exposure/risk groups.

Event rates could also be calculated using regression-based procedures such as logistic regression. However, it should be noted that regression-based event rates are frequently calculated from data that has been adjusted for the association with one or more additional covariates. Such adjustments emphasise the idiosyncratic character of the reported regression coefficients (and, therefore, PR) and may result in dissimilarity with the effects reported within the other primary studies. The contribution of standardised regression coefficients to overall heterogeneity was examined empirically if problematic heterogeneity was identified in the random effects model.

Defining problematic variance

A study level effect was considered heterogeneous if it presented with variation from the meta-analysis synthesis that could not be attributed to true variation in the distribution of effects in the population. Heterogeneity could result from methodological variation in the studies, measurement error or uncontrolled individual difference factors within the body of literature. Higgins I^2 is a commonly used measure of heterogeneity, with greater values of I^2 indicating variation in effect attributable to factors other than the true PR (such as variation in study design and methodology, study level differences in precision of measurement and variation in sample characteristics). Higgins et al. (2003) summarises heterogeneity as low (0%-50%), moderate (50%-75%) and high (75%-100%). As there was considerable variation in methodologies of the primary studies that were used to calculate the meta-analytic synthesis, problematic heterogeneity was defined as a Higgins I^2 value greater than 75%. Where unacceptable or problematic heterogeneity is observed then the focus of any subsequent analyses was on the identification of the sources of heterogeneity between the estimates of the prevalence of PND in the primary studies.

Risk of Bias Assessment

A set of criteria were developed to assess study level risk of bias within this literature. The criteria were adapted to be specific to the current analysis from existing risk of bias frameworks, including The Cochrane Collaboration Risk of Bias Tool (Higgins et al., 2011) and the Risk of Bias Assessment Tool for Nonrandomised Studies (Kim et al., 2013). The current framework assessed risk of bias in seven domains: selection bias, performance bias, treatment fidelity, detection bias, statistical bias, reporting bias, and generalisation. The risk of bias in the seven domains and the criteria for Low, Unclear or High risk is described in Table 3 and the application of these criteria are reported in Table 5.

Table 3: Domains of risk of bias and the criteria for ratings of low, unclear or high risk

Domain	Details	Risk of Bias
Selection Bias	Does the study design yield a sample of respondent's representative of the target population? Is the target population defined clearly? Was some form of random sampling used to select potential respondents?	High Risk - The study has used opportunistic or non-random sampling to select participants. The characteristics of the study group are not representative of the target population. (e.g., age restrictions, older women could still have PND) Other exclusion/inclusion criteria may contaminate estimate of events e.g., not including twin births or those who not first birth, selecting on basis of gestation, excluding based on type of birth (e.g., hospital/midwifery vs home), only looked at individuals who are hospitalised. Unclear Risk - The characteristics of the study group are not clearly defined (e.g., location, age). It is not clear how the researchers sampled the study group. Sampling is adequate but is selected from a pre-existing (clinical) sample. Selection method is not ideal (e.g., quasi randomised), although characteristics of the study group are representative of the target population. Not clear whether the selection of participants would contaminate estimate of event (recruitment from antenatal clinics/teaching hospitals). Convenience sampling was used. Low Risk - The characteristics of the study group are clearly described and without evidence of bias (i.e., not from a preselected postnatal depression sample). Sampling method used is unbiased (i.e., some form of random sampling taken from representative population). The recruitment method is clearly reported and well defined. The article provides some reassurance that there is no selection bias
Performance Bias	Performance bias may occur through participants underreporting or over reporting symptoms due to social desirability. Were these adequately controlled for? Were participants offered an incentive for their participation? Did the outcome impact access to treatment?	High Risk – Self-report. Responses are not confidential or anonymous. Participants were rewarded for their participation in the study. Participants were told what questionnaires they were completing and why and any proposed hypotheses. Questionnaires were administered by the HCP's individuals were currently under Unclear Risk - Data is self-report, although attempts are made to blind personnel to outcome assessments and check for inter-rater reliability, or anonymisation has taken place. The study does not report levels of confidentiality and anonymity. It is not clear if participants were rewarded for their participation (e.g., motivation to respond in a certain way). It is unclear how much information was provided to the participant prior to taking part in the study Low Risk - Anonymity was maintained. Study reports level of confidentiality and anonymity.

Domain	Details	Risk of Bias
		Participants were not rewarded for their participation in the study Information and procedures are provided in a way that does not differentially motivated participants
Detection Bias	Was the study instrument that measured the parameter of interest shown to have reliability and validity?	High Risk - Outcome measures used are non-standardised and do not report psychometric properties, or global self-evaluation (e.g., yes/no) of postnatal depression. Measure not fit for purpose. The outcome measure is standardised but does not report psychometric properties. The outcome measures used had poor reliability and validity reported e.g., Cronbach's Alpha < 0.6. and/or test/retest reliability < 0.6 States that it has been translated but does not detail how this was conducted or clear problems in translation. Unclear Risk - Assessment measure is not widely recognised, or peer reviewed and/or the psychometric properties are reported but poor. Cronbach's Alpha for outcome measures is between 0.6 and 0.7. Test-retest reliability for outcome measures is between .6 and .7 It is not clear if the measure was implemented consistently across all participants. The research question is unclear. Unclear if translated. Reliance on diagnostic codes as opposed to a formal measure, not clear how diagnosis was assessed and if this was consistent across all participants. Low Risk - Standardised measures with good psychometric properties used to assess symptoms of postnatal depression. Outcomes are blindly rated.
Statistical Bias	Bias resulting from the statistical treatment of the data. Was PR appropriately reported (e.g., including descriptive statistics such as ethnicity)? Are appropriate statistical methods used for the analysis?	High Risk - Event rate is unclear, inadequately reported, not provided or calculated based on additional statistical analyses e.g., logistical regression. Event rates are adjusted for methodological confounds. Statistics were not reported. Wrong statistical test was used and not appropriate for the study design. Unclear Risk - Raw event rate or percentage is provided, however descriptive statistics are not clearly provided Unclear what statistical test was used. Appropriate statistical test was used but the statistic cannot be transformed into a Pearson's value. Confidence intervals or exact p-values for effect estimates were not reported and could not be calculated. Low Risk - Adequate descriptive statistics are provided including raw event rate or percentage. Appropriate statistical testing was used. The study has reported a Pearson's value, or the statistic can be transformed into a statistical equivalent. Confidence intervals or exact p-values for effect estimates were given or possible to calculate.
Reporting Bias	Reporting bias due to selective outcome reporting. Does the study describe the completeness of outcome data for each main outcome (including attrition and exclusions from the analysis)?	High Risk - Not reported full outcome measures that are stated in the method section. Reported only a subsample of results/only significant results. Did not report on entire sample. Data does not appear to be accurately reported (e.g., final values are suspect, or data is reported in a manner requiring reconstruction from description). Unclear Risk - Did not report the results of all measures used. Only reported those above a threshold, not those below or different thresholds. (e.g., only included those who scored above 10/13 on the EPDS) Not all descriptive and/or summary statistics are presented. There is a description (narrative) in the results but do not record statistics. Low Risk - Full sample size reported. Reported all results of measures as outlined in the method.

Domain	Details	Risk of Bias
	Does the study provide reasons for attrition or exclusions where reported, and any re-inclusions in analyses for the review?	
Generalisation	Can the research findings be applied to settings other than that in which they were originally tested? Are there any differences between the study participants and those persons to whom the review is applicable?	High Risk - Studies that preselect participants on diagnosis postnatal depression. Studies that preselect participants with additional mental health difficulties. Small sample with or without idiosyncratic feature. The sample size is not adequate to detect an effect. Unclear Risk - Sample size is sufficient, but a sample size justification, estimate and power analysis were not provided Low Risk - Sufficient sample for generalisation and representative of target population. A sample size justification, estimate and power analysis were provided. The sample size is adequate to detect an effect

The application of the risk of bias criteria to the included studies is shown in Table 5 alongside an overall quality index. This index was calculated by first assigning a numerical weighting according to the methodological rigour of a study's overall design (see Table 4). A total risk of bias score was then calculated by summing the seven risks of bias domains (low risk = 2 points, unclear risk 1 point, high risk = 0 points) such that the total risk of bias score could vary between 0 and 14 points. The study design score and the total risk of bias score were then summed and the overall quality index for each study was expressed as a percentage of the theoretical maximum score (i.e., the highest quality design without risk of bias).

Table 4: Study design hierarchy

Study Design	Numerical Weighting	Description
Prospective case cohort study	40	Cohort Study (prospective) is a study of a group of individuals, some of whom are exposed to a variable of interest (e.g., drug or environmental exposure), in which participants are followed up over time to determine who develops the outcome of interest and whether the outcome is associated with the exposure.
Retrospective case cohort study	30	Cohort Study (retrospective) is when data is gathered for a cohort that was formed sometime in the past. Exposures and outcomes have already occurred at the start of the study. You are studying the risk factor and see if you can associate a disease to it. Individuals split by exposure.
Case control study	20	Case Control Study is a study in which patients who already have a specific condition or outcome are compared with people who do not. Researchers look back in time (retrospective) to identify possible exposures. They often rely on medical records and patient recall for data collection.
Cross-sectional studies	10	Cross-Sectional Study is the observation of a defined population at a single point in time or during a specific time interval to examine associations between the outcomes and exposure to interventions. Exposure and outcome are determined simultaneously. Often rely on data originally collected for other purposes.

Therefore, the overall quality index provided a rating that simultaneously considered the overall quality of the study design and the presence of specific risks of bias. The overall quality index ranged in value between 25% (Bennett et al., 2008) to 88% (Ertel et al, 2010; Rich-Edwards et al, 2006).

Table 5 Ratings of risk of bias. Red indicates high risk, amber marks an unclear risk and green is a low risk of bias.

Study.name	Study.Design	Selection.Bias	Performance.Bias	Detection.Bias	Statistical.Bias	Reporting.Bias	Generalisability	Overall.Quality.Index
Abbasi et al 2013	Cross-sectional studies	High risk	Unclear risk	High risk	Low risk	Low risk	Unclear risk	31%
Bascom and Napolitano 2016	Retrospective case cohort study	High risk	Unclear risk	Low risk	Unclear risk	Low risk	Unclear risk	71%
Bennett et al 2008	Cross-sectional studies	High risk	High risk	High risk	Unclear risk	Unclear risk	Unclear risk	25%
Chan et al 2021	Retrospective case cohort study	High risk	Low risk	Unclear risk	High risk	Unclear risk	Unclear risk	67%
Correa et al 2016	Cross-sectional studies	Low risk	Unclear risk	High risk	Low risk	Low risk	Low risk	37%
Declercq et al 2022	Cross-sectional studies	High risk	Unclear risk	High risk	High risk	Low risk	Unclear risk	27%
Docherty et al 2022	Cross-sectional studies	Unclear risk	Unclear risk	High risk	Low risk	Low risk	Unclear risk	33%
Edge 2007	Cross-sectional studies	Unclear risk	Unclear risk	High risk	Low risk	Unclear risk	Unclear risk	31%
Edge et al 2004	Cross-sectional studies	Unclear risk	Unclear risk	High risk	Low risk	Unclear risk	Low risk	33%
Ertel et al 2010	Prospective case cohort study	High risk	Unclear risk	High risk	Low risk	Low risk	Unclear risk	88%
Hayes et al 2010	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	69%
Kim et al 2012	Cross-sectional studies	Unclear risk	High risk	High risk	Unclear risk	Low risk	Unclear risk	29%
Liu and Tronick 2014	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	69%
Liu et al 2018	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	69%
Liu et al 2016	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	69%
Mersky and Janczewski 2018	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Unclear risk	Unclear risk	67%
Moore et al 2019	Cross-sectional studies	Low risk	Unclear risk	High risk	Low risk	Low risk	Unclear risk	35%
Onozawa et al 2003	Cross-sectional studies	Unclear risk	Unclear risk	High risk	Low risk	Low risk	Unclear risk	33%
Rich-Edwards et al 2006	Prospective case cohort study	Low risk	Unclear risk	High risk	Unclear risk	Unclear risk	Unclear risk	88%
Savitz et al 2011	Retrospective case cohort study	High risk	Low risk	Unclear risk	High risk	High risk	High risk	63%
Saxton and Archer 2022	Cross-sectional studies	Unclear risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	31%
Segre et al 2006	Retrospective case cohort study	Unclear risk	Unclear risk	High risk	Unclear risk	Unclear risk	Unclear risk	67%
Smithson et al 2020	Cross-sectional studies	Unclear risk	High risk	High risk	Low risk	Low risk	Unclear risk	31%
Truong et al 2021	Cross-sectional studies	High risk	Unclear risk	High risk	High risk	Low risk	Unclear risk	27%
Walker et al 2013	Cross-sectional studies	High risk	Low risk	High risk	Unclear risk	Unclear risk	Unclear risk	29%
Wouk et al 2017	Cross-sectional studies	Low risk	Unclear risk	High risk	Unclear risk	Low risk	Unclear risk	33%
Tebeka et al 2016	Cross-sectional studies	Unclear risk	Unclear risk	Unclear risk	Unclear risk	Low risk	Unclear risk	33%

Selection Bias

Overall, selection bias was unclear within the studies. Fourteen studies were rated as unclear risk with four rated as low risk. The low-risk studies outlined a clear recruitment process with some form of random sampling and described the sample characteristics (Correa et al., 2016; Moore et al., 2019; Rich-Edwards et al., 2006; Wouk et al., 2017). The unclear studies sampling methods were often vague but they appeared to use convenience sampling. Some of the unclear studies relied on recruitment from university affiliated hospitals which could have biased individuals who were likely to participate. Nine studies were rated as high risk, and this was a result of the characteristics of the sample (i.e. excluding mothers with more than one child, women above the age of 35, mothers who had premature births and those not receiving pre- or post-natal care). The characteristics of the sample selected may not be representative of a population of women with PND, consequently impacting on the analysis.

Performance Bias

Overall, performance bias was unclear within the studies. Twenty-one studies were rated as unclear risk, with most rated as unclear because it was not reported whether participants were incentivised for participation, which may have influenced their participation or answers on self-report measures. Three of the studies were rated as high risk (Bennett et al., 2008; Kim et al., 2012; Smithson et al., 2020) due to the questionnaires being administered by clinicians who were delivering routine care to the participants, which may have influenced responses.

Detection Bias

Detection bias was overwhelmingly high risk in the studies due to the lack of information on the reliability and validity of the scales used to assess PND. Although some studies used standardised measures (Table 6), no psychometric properties were reported. One study was rated as low risk (Bascom & Napolitano, 2016) as reliability and validity of the measure was reported. Three of the studies were rated as unclear risk (Chan et al., 2021; Savitz et al., 2011; Tebeka et al., 2016) due to using diagnostic codes from a database as opposed to administering a formal measure (Chan et al., 2021; Savitz et al., 2011). It was not clear how the diagnosis was assessed and if this was consistent across participants. Tebeka et al. (2016) was rated as unclear as their measure was a measure of depression through The National Institute on Alcohol Abuse and Alcoholism's Alcohol Use Disorder and Associated Disabilities Interview Schedule–DSM-IV (AUDADIS-IV), not PND which may have impacted on PR reported.

Statistical Bias

Fourteen papers were rated as unclear risk for statistical bias, with four as high risk and nine as low risk. The papers were rated as a high risk where the PR was not clearly reported or p values were not reported in the results section (Chan et al., 2021; Declercq et al., 2022; Savitz et al., 2011; Truong et al., 2021). Studies were rated as unclear if there was not an exact p value or confidence intervals reported. Papers that were low risk had used descriptive statistics and reported clear event rates.

Reporting Bias

Overall, the full reporting of the outcomes within the studies was considered to be good, with eighteen being classed as low risk. Eight studies were found to be of unclear risk due to only reporting participants who scored above a threshold score on measures of PND (Bennett et al., 2008; Chan et al., 2021; Edge, 2007; Edge et al., 2004; Mersky & Janczewski, 2018; Rich-Edwards et al., 2006; Segre et al., 2006; Walker et al., 2013). By only reporting those who scored above the threshold meant a comparison between those who do and do not score highly on measures of PND was unable to be carried out. One study was rated as high risk as the event rates required additional calculations to make sense of how this related to the PR of PND (Savitz et al., 2011).

Generalisability

Twenty-four studies were rated as unclear risk, with common reasons being that they did not provide a sample size justification or power analysis, making it difficult to know if the sample had adequate statistical power to provide an estimate of the prevalence of PND. One study was rated as high risk (Savitz et al., 2011) as it only included individuals who were hospitalised so could be biased towards individuals at the more severe end of the PND spectrum. Two studies were rated as low risk (Correa et al., 2016; Edge et al., 2004).

Summary

Overall, there was a mixed level of bias across the studies included in the meta-analysis. There was a notable high risk of bias in detection bias. Generalisability, statistical bias, performance bias, and selection bias were ambiguous across studies. Due to the low number of studies in this field, studies with medium to high risk of bias were included in the meta-analytic review. Consequently, the results of this meta-analysis should be interpreted with caution. However, the studies included are considered to be a representative summary of the research literature as it stands currently, and it is hoped that future research will include higher quality research with samples that are more representative of women with PND, who are not influenced by social desirability bias as well as utilising measures of PND which report reliability and validity data.

Approach to meta-analysis

Once articles were reviewed, considered appropriate for this meta-analysis and risk of bias established, data extraction was completed to obtain information for PR and RR. The PR for

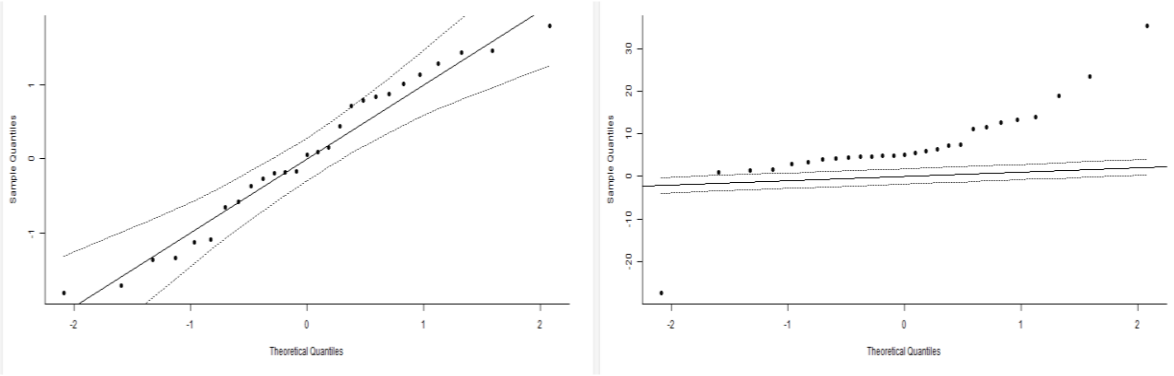
Black ethnic groups were obtained by collating the number of individuals who did and did not meet the criteria for PND and who were also from a Black ethnic group, which enabled an event rate to be calculated. The RR was obtained by comparing the PR data from Black ethnic groups to the number of individuals who did and did not meet the criteria for PND in White ethnic groups, enabling a risk difference to be calculated.

Meta-analysis

Prevalence of Post-natal depression in Black ethnic groups

Selection of the meta-analytic model

The distribution of primary study effects is shown in Figure 2. The between studies variance (tau^2) was calculated using the restricted maximum-likelihood estimator. QQ plots are presented for both the fixed effects model and the random effects model (see Figure 12). If the data do not conform to a normal distribution, then using the random effects model and the restricted maximum-likelihood estimator to estimate between studies variation is recommended, as the REML estimator is more robust than other estimators to non-normal distributions of effects (Banks et al., 1985). As can be seen from Figure 2, there is clear evidence of non-normality in the distribution of the RR of PND in Black ethnic groups within the fixed effects model, which is largely absent within the random effects model, supporting the use of the random effects model and REML in this analysis.



Random Effects Model Fixed Effects Model

Figure 2 QQ plot of the distribution of the prevalence of PND in Black ethnic groups within the primary studies

The omnibus test

The prevalence of PND in Black ethnic groups described in the included studies are reported in Table 6. There were 27 studies reporting a total of 1,561,932 participants from either the United States of America (USA), UK or Brazil. Participants were recruited from both maternity and non-maternity services (defined as services that are not associated with maternity at the point of recruitment, e.g. consumer opinion panel, child benefit register, national postal surveys). A range of measures were used across the studies to determine whether or not a participant met the criteria for PND, which included the Edinburgh Postnatal Depression Scale (EPDS), Patient Health Questionnaire (PHQ), International Classification for Diseases (ICD-9) diagnostic codes, Pregnancy Risk Assessment Monitoring (PRAMS-3D), Rutter Malaise Inventory (RMI), Phase 6 CORE, Alcohol Use Disorder and Associated Disabilities Interview Schedule (AUDADIS-IV), Barriers Questionnaire (Segre et al., 2006), a three item screener, and being asked whether or not they had received a diagnosis by a healthcare professional. The measures used all had different cut off scores for what defined PND. The time in which symptoms of PND was assessed varied from the last 7 days (EPDS), last two weeks (PHQ-2, PHQ-4, Barriers), since baby was born which varied from two months postpartum to 12 months postpartum (PRAMS, Phase 6 CORE), the last 12 months (AUDADIS) and no time frame but based on questions such as “do you often” (RMI). The time at which participants were administered the assessment also varied from short term (which was defined for this meta-analysis as up to two months postpartum) and longer term (defined as between two and 12 months postpartum for the analyses reported here).

Table 6: Outcomes and study level characteristics.

	Prevalence of PND in Black Ethic Minorities	N	Relative risk	N	Population	PND Measure	Country	Recruitment	Measure cut off[1]	Time to estimate
Abbasi et al 2013	0.09	216	1.99	2591	Black	EPDS[2]	USA	Maternity	12-13	Short term[3]
Bascom and Napolitano 2016	0.27	49	0.87	1087	Black	EPDS	USA	Non-maternity	9	Short term
Bennett et al 2008	0.05	41	0.84	178	African American	EPDS	USA	Maternity	13	Longer term[4]
Chan et al 2021	0.01	59754	1.27	373791	Non-Hispanic Black	ICD-9-CM [5]	USA	Non-maternity	NA	Longer term
Correa et al 2016	0.19	2361	1.03	2927	Black	EPDS	Brazil	Non-maternity	11	Short term
Declercq et al 2022	0.31	72	1.13	216	Non-Latina Black	PHQ-4[6]	USA	Maternity	Not stated	Longer term
Docherty et al 2022	0.17	867	1.67	4861	Black	PHQ-2[7]	USA	Maternity	always/often	Longer term
Edge 2007	0.24	70	1.44	200	Black	EPDS	UK	Maternity	12-13	Short term
Edge et al 2004	0.27	70	0.91	200	Black	EPDS	UK	Maternity	12	Short term
Ertel et al 2010	0.12	65	1.98	740	Black	EPDS	USA	Maternity	13	Longer term
Hayes et al 2010	0.14	147	1.66	1492	Black	PHQ-2	USA	Maternity	always/often	Not stated
Kim et al 2012	0.21	82	1.66	130	African American	EPDS	USA	Maternity	10	Short term
Liu and Tronick 2014	0.04	1027	1.33	2070	Black	Asked if diagnosed	USA	Maternity	NA	Longer term
Liu et al 2018	0.15	724	0.85	1562	African American	PRAMS-3D[8]	USA	Maternity	9	Longer term
Liu et al 2016	0.11	464	1.69	1263	African American	PHQ-2	USA	Maternity	always/often	Longer term
Mersky and Janczewski 2018	0.21	209	0.75	430	Non-Hispanic Black	EPDS	USA	Maternity	9	Longer term
Moore et al 2019	0.13	287	0.98	8144	Black African	RMI[9]	UK	Non-maternity	4	Longer term
Onozawa et al 2003	0.04	24	0.28	484	Black	EPDS	UK	Maternity	13	Short term
Rich-Edwards et al 2006	0.11	120	1.67	1094	Black	EPDS	USA	Maternity	12	Longer term
Savitz et al 2011	0.001	105633	2.06	885343	Black Non-Hispanic	ICD-9-CM	USA	Non-maternity	NA	Short term
Saxton and Archer 2022	0.21	519	1.55	2395	Black	PHQ-2	USA	Maternity	always/often	Longer term
Segre et al 2006	0.25	591	1.63	25103	Black	Barriers	USA	Maternity	NA	Short term
Smithson et al 2020	0.03	91	2.05	1271	Black	EPDS	USA	Maternity	10	Short term
Truong et al 2021	0.10	1618	0.19	20509	Non-Hispanic Black	PHQ-2	USA	Maternity	always/often	Not stated
Walker et al 2013	0.24	37	1.09	104	African American	3 item screener	USA	Non-maternity	Not stated	Not stated
Wouk et al 2017	0.12	9146	1.02	38479	Black	Phase 6 CORE	USA	Maternity[10]	9	Longer term
Tebeka et al 2016	0.15	137	1.46	847	Black	AUDADIS-IV[11]	USA	Non-maternity[12]	NA	Longer term

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[1] Measure cut off are the scores from the measures used to determine whether someone would be classified as having PND. The scores reported are what each study used.

[2] Edinburgh Postnatal Depression Scale (EPDS)

[3] Time to estimate is the time in which participants were administer the measures in the postnatal period. Short term (up to two months postpartum)

[4] Time to estimate is the time in which participants were administer the measures in the postnatal period. Longer term (between two and 12 months postpartum)

[5] Classification for Diseases (ICD-10) diagnostic codes

[6] Patient Health Questionnaire 4 (PHQ-4)

[7] Patient Health Questionnaire 2 (PHQ-2)

[8] Pregnancy Risk Assessment Monitoring (PRAMS-3D)

[9] Rutter Malaise Inventory (RMI)

[10] Maternity (services associated with maternity at the point of recruitment e.g. maternity hospitals, antenatal clinics)

[11] Alcohol Use Disorder and Associated Disabilities Interview Schedule (AUDADIS-IV)

[12] Non-maternity (services that are not associated with maternity at the point of recruitment, e.g. consumer opinion panel, child benefit register, national postal surveys)

A random effects models was calculated using the generic inverse variance method and the restricted maximum-likelihood estimator (Figure 3). The random effects model suggested a weighted average for the prevalence of PND in Black ethnic groups effect = 0.14 (z = 8.72, p = <0.0001) and a 95% confidence interval of between 0.11 to 0.17.

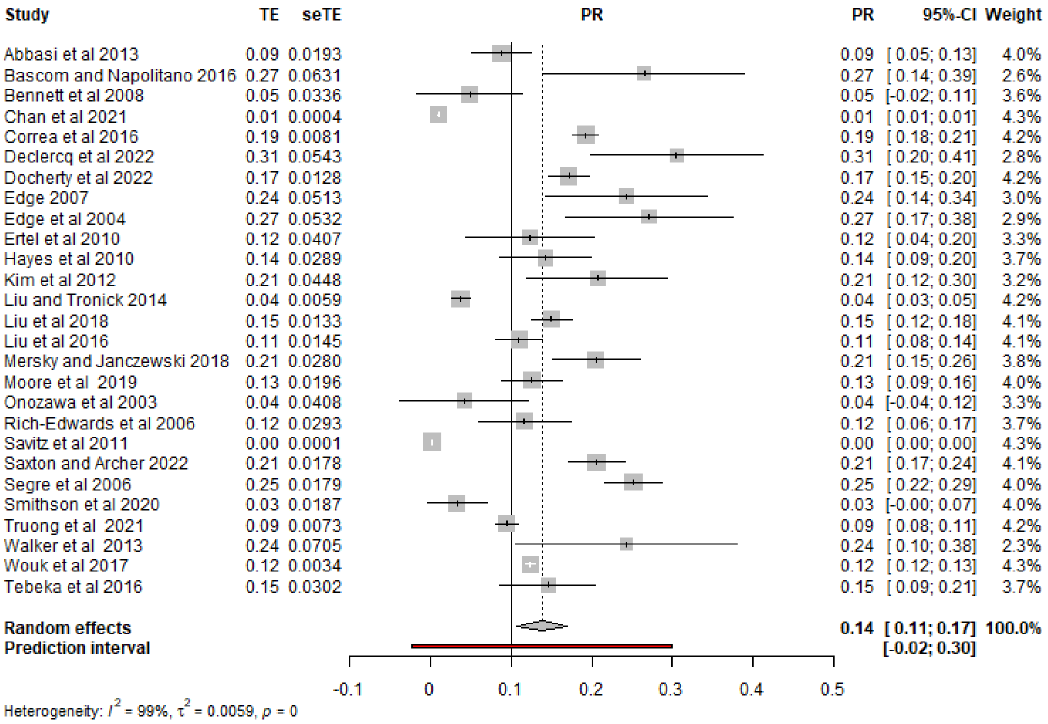


Figure 3 Forest plot of prevalence of PND in Black ethnic groups. The horizontal axis of the forest plot indicates increasing prevalence rates.

A high level of heterogeneity in the primary studies was observed (tau^2 = 0.006, Higgin’s I^2 = 99.2%; Q = 3377.70, p < 0.001), suggesting that the estimates of prevalence of PND in Black ethnic groups in the primary studies may be biased by the presence of uncontrolled or confounding factors. Therefore, the focus of the subsequent analyses will be upon the identification of the sources of heterogeneity between the estimates of the prevalence of PND in Black ethnic groups in the primary studies.

The impact of influential primary studies

The impact of disproportionately influential studies was assessed using a "leave-one-out" analysis, in which the random effects model was calculated with each of the primary studies removed in turn and change in weighted average effect size (i.e., influence) and the change in heterogeneity (i.e., discrepancy) were recorded. The result of this "leave-one-out" analysis is presented on the Baujat plot (Baujat et al., 2002) in Figure 4.

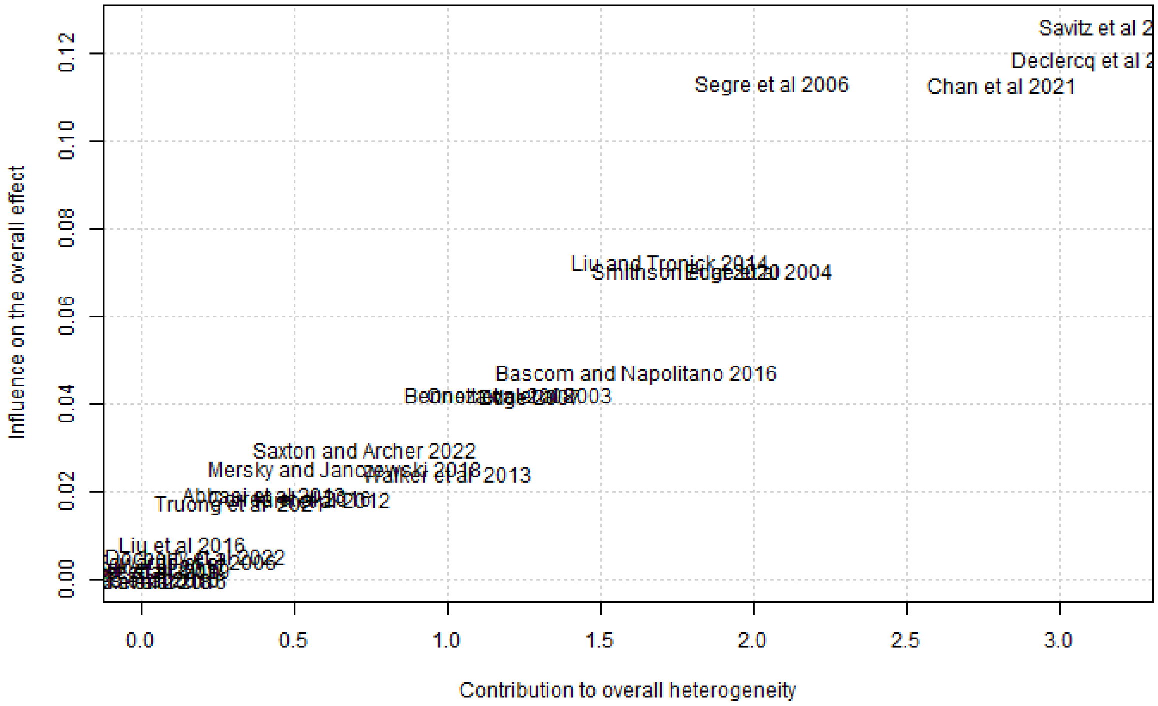


Figure 4 Baujat diagnostic plot of sources of heterogeneity. The vertical axis reports the influence of the study on the overall effect and the horizontal axis reports the discrepancy of the study with the rest of the literature.

The studies by Chan et al. (2021), Declercq et.al. (2022) and Savitz et al. (2011) were shown to be both influential and discrepant with the other literature. The random effects model was recalculated with the three studies showing disproportionate influence removed. The corrected random effects model reported a synthesis of the prevalence of PND in Black ethnic groups effect = 0.15 (95% CI 0.12 to 0.17, $p<0.0001$, Higgins $I^2 = 94.9\%$). The corrected random effects model evidences an approximately 4% increase relative to the uncorrected estimate.

These studies were re-examined with a view to their removal from the meta-analysis if substantive reason for its discrepancy could be identified. Both Chan et al. (2021) and Savitz et al. (2011) relied on the use of ICD-9 diagnostic codes to determine the prevalence of PND in their sample. As all of the other studies used measures of PND and reported on these measures, it is not clear from Chan et al. (2021) and Savitz et al. (2011) how PND was measured prior to the diagnosis being given. This could have an influence on the PR reported, therefore both of these studies were removed from subsequent analysis. The study by Declercq et al. (2022) was also examined, but there was not anything characteristic about the study that would warrant its removal from the analysis. Therefore, this study was included with the remainder of the meta-analysis. The final corrected REM model, omitting Chan et al. (2021) and Savitz et al. (2011), resulted in a prevalence of PND in Black ethnic groups effect = 0.15 (95% CI 0.12 to 0.18).

The Higgins I^2 value reduced with the removal of influential studies but was still considered to represent high heterogeneity (Higgins et al., 2003). Consequently, methodological variation was explored using subgroup analysis of the areas of risk bias and the impact of publication bias, so that these factors can be taken into consideration when interpreting the findings of the subgroup analyses.

The effect of risk of bias in the primary studies

In order to assess the impact of study level risk of bias upon heterogeneity, a series of subgroup analyses were conducted on the PR for the risk of bias ratings of “low risk” and “any risk” (i.e., unclear risk and high risk of bias combined) for each of the six types of methodological bias (Table 7).

Table 7 The effect of risk of bias

	Low Risk			Any Risk				
	EFFECT	**95% CI**	**k**	**EFFECT**	**95% CI**	**k**	**X^2**	**P**
Selection bias	0.14	0.10 – 0.18	4	0.15	0.12 – 0.19	21	0.15	0.70
Performance bias	0.24	0.11 – 0.38	1	0.15	0.12– 0.18	24	0.76	0.18
Detection bias	0.27	0.14 – 0.39	1	0.15	0.12 – 0.18	24	3.36	0.07
Statistical bias	0.14	0.09 – 0.19	9	0.16	0.12 – 0.19	16	0.34	0.56
Reporting bias	0.14	0.11 – 0.16	18	0.19	0.13 – 0.26	7	2.49	0.11
Generalisability bias	0.21	0.15 – 0.28	2	0.14	0.11 – 0.17	23	3.44	0.06

Although there were not any statistically significant differences, detection bias and generalisability bias both showed trends towards significance that could be suggestive of impact on the reported prevalence of PND in Black ethnic groups. A lower risk of detection bias and generalisability bias were both associated with a higher estimated PR for PND. However, for both types of biases there was a small number of studies in the low-risk category (one and two) in comparison to the any risk category (24 and 23). Therefore, the PR may also be influenced by the number of studies as well as consideration of the type of bias.

Studies rated as low risk for generalizability in this analysis had an average sample size of 1,564 participants (range from 200-2,927), whereas studies rated at any risk of generalizability had an average sample size of 54,975 participants (range from 104-885,343). Given this difference in average sample size the difference in estimates between those studies that are at risk of generalizability bias and those at low risk, may reflect small study effects (in that small studies tend to show more variability on the estimation of prevalence).

Subgroup analyses and meta regression

To further explore the impact of study level covariates upon PR of PND in Black ethnic groups a series of subgroup analyses were conducted

The effect of the design of the study

The studies were categorised by their overall study design into either cross sectional studies, prospective case cohort studies and retrospective case cohort studies. There was no significant difference ($X^2(2) = 1.44$, $p = 0.49$) between the weighted average prevalence of cross-sectional studies, prospective cohort studies and retrospective case cohort studies (Figure 5).

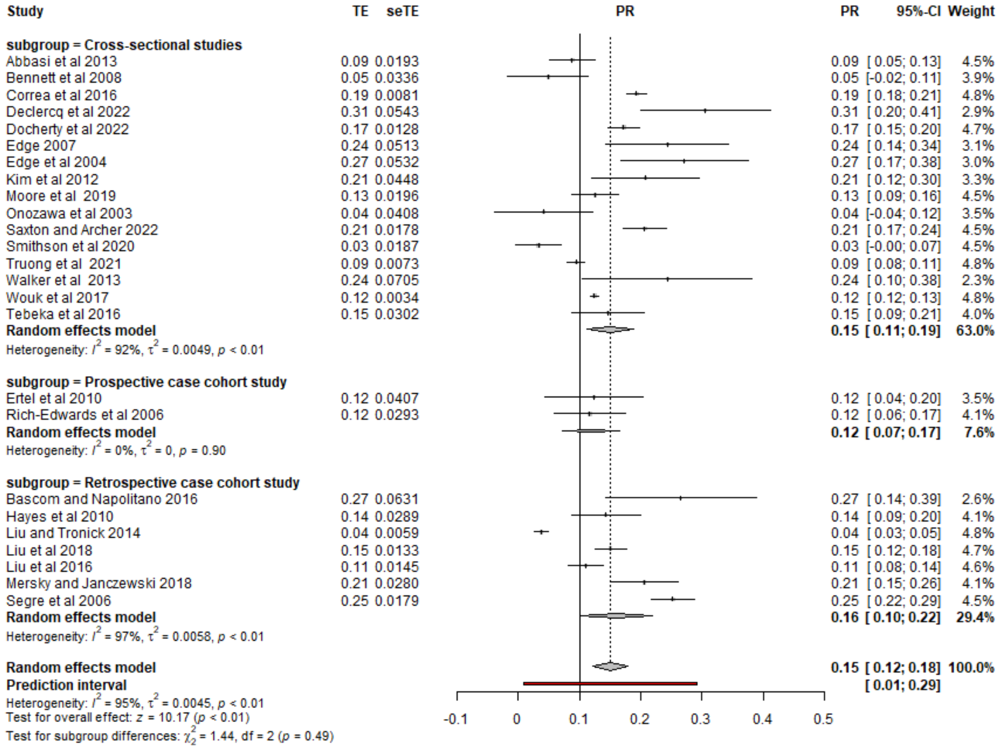


Figure 5 Subgroup plot of type of study. The horizontal axis of the forest plot indicates increasing prevalence rates.

The effect of ethnic subtype

The impact of ethnic subtype upon the prevalence of PND was explored by comparing the weighted prevalence of PND in each of six subtypes (Figure 6).

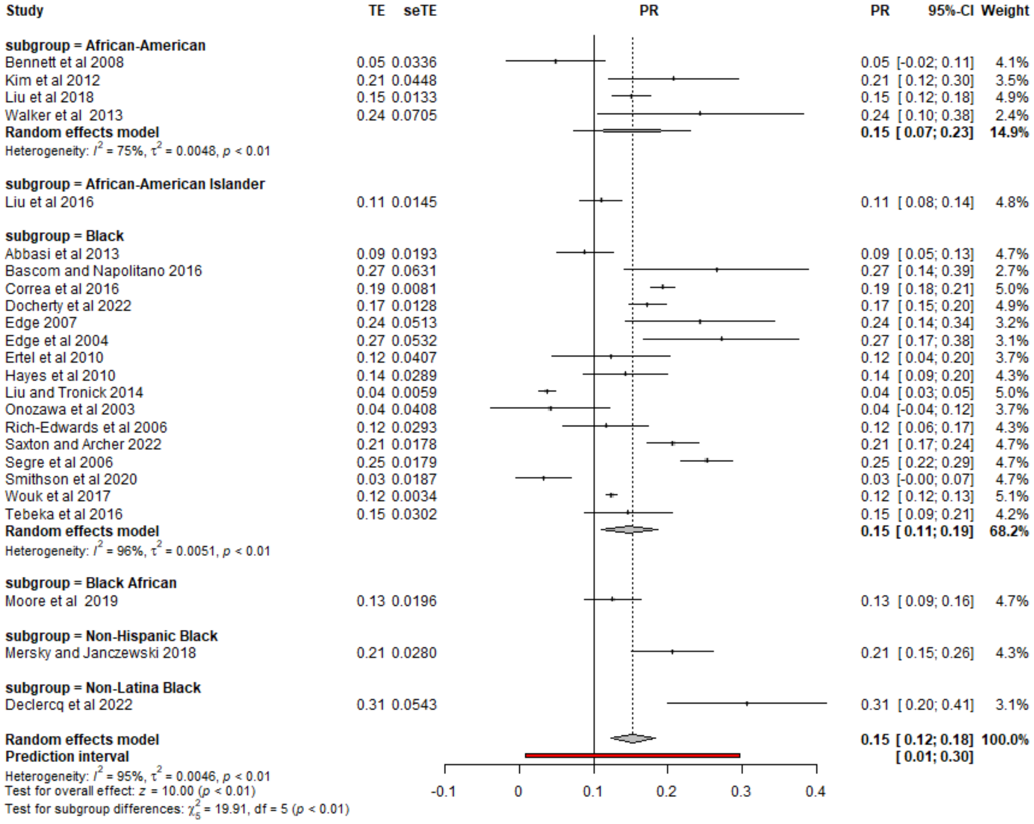


Figure 6 Subgroup plot of ethnicity subtype. The horizontal axis of the forest plot indicates increasing prevalence rates.

There was a significant difference ($X^2(5) = 19.91$, $p < 0.01$) between the weighted average prevalence of ethnic subtypes. Participants who were categorised as Non-Latina Black had higher PR (0.31) in comparison to the other ethnic subtypes, which had relatively similar PR (0.11-0.21). However, the effect size for the Non-Latina Black category was calculated from only one study. Therefore, this estimate will be highly likely to change given the publication of further studies using this ethnic category. The weighted average prevalence for the Black and African American subtypes were the same as the overall weighted average prevalence.

Effect of choice of questionnaire

Studies were categorised by the measure they used to assess PND (Figure 7) and included: EPDS, PHQ-2, PRAMS-3D, RMI, Phase 6 CORE, AUDADIS-IV, Barriers Questionnaire, a three-item screener, and being asked whether or not they had received a diagnosis by a healthcare professional.

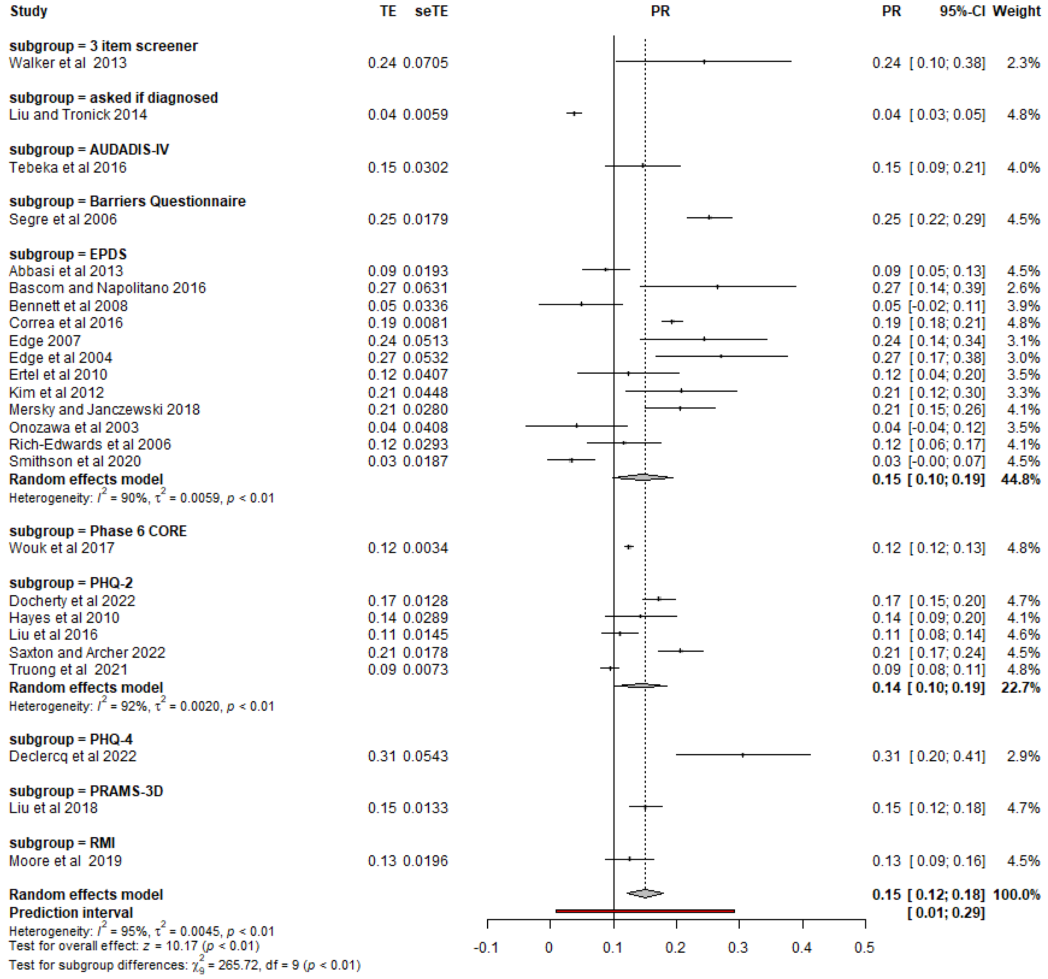


Figure 7 Subgroup plot of measure of PND. The horizontal axis of the forest plot indicates increasing prevalence rates.

A statistically significant difference ($X^2(9) = 265.72$, $p < 0.01$) was observed between the studies dependent on what measure was used to assess PND. However, the effect sizes for those measures that show the greatest difference from the overall weighted average prevalence were calculated from either one or a small number of studies, and therefore these estimates will be highly likely to change given the publication of a further studies using these outcome measures. The weighted average effect size for the EPDS and PHQ-2 both show effect sizes consistent with the overall weighted average prevalence.

Effect of country of recruitment

The studies were examined based on the three countries they were conducted in (Figure 8).

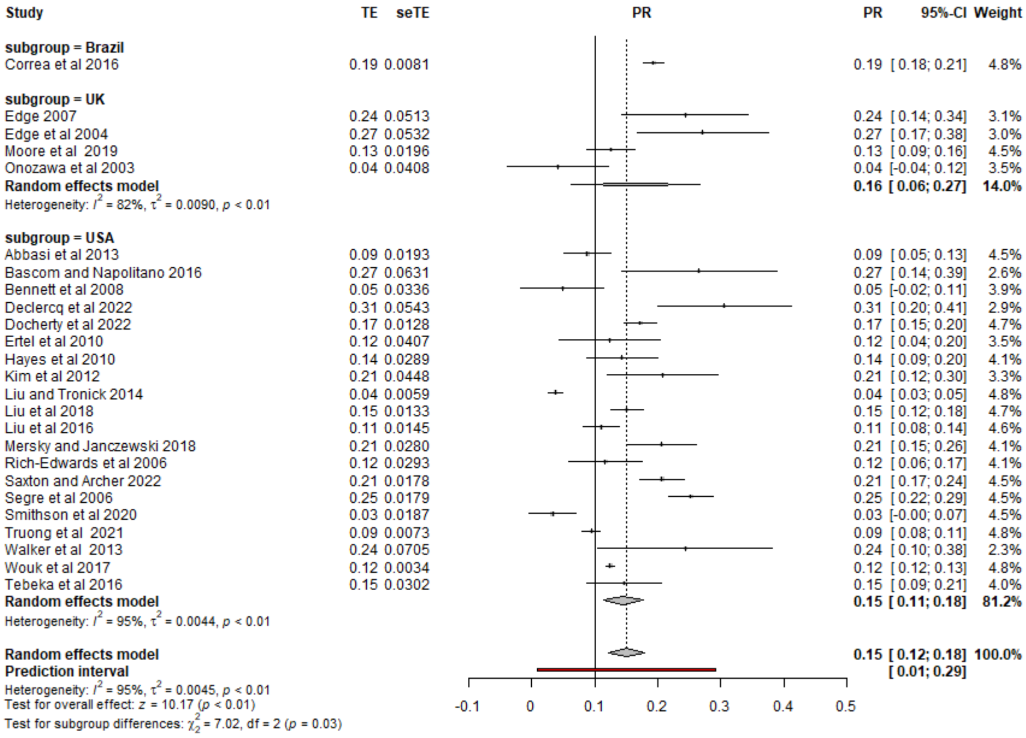


Figure 8 Subgroup plot of country study was conducted in. The horizontal axis of the forest plot indicates increasing prevalence rates.

A statistically significant difference ($X^2(2) = 7.02$, $p < 0.03$) was observed between the studies dependent on what country the study was conducted in. Brazil had the highest PR for PND in Black ethnic groups, but this effect size was based on only one study, and therefore this estimate will be highly likely to change given the publication of further studies in Brazil. The weighted average effect sizes for the USA and UK both show effects consistent with the overall weighted average prevalence.

Effect of where participants were recruited from

The studies were also categorised in terms of where participants were recruited (see Figure 9).

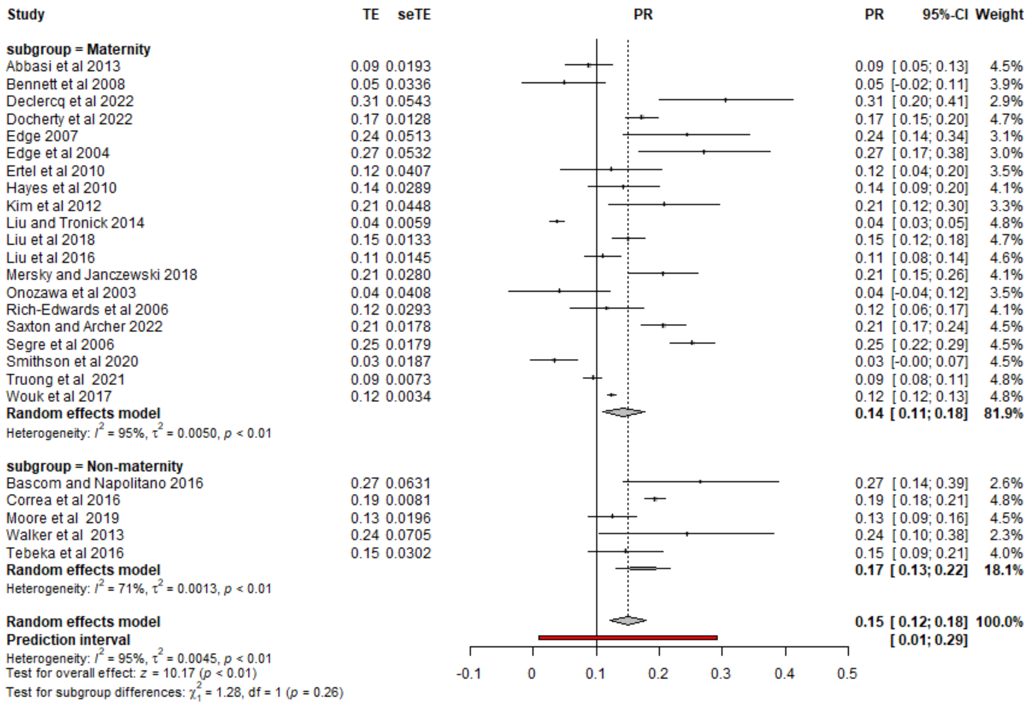


Figure 9 Subgroup plot of where participants were recruited from. The horizontal axis of the forest plot indicates increasing prevalence rates.

The recruitment of participants from either maternity (e.g. maternity hospitals, antenatal clinics) or non-maternity services (e.g. consumer opinion panels, child benefit registers, databases of medical records, national postal surveys) did not show a statistically significant difference in estimates of prevalence of PND in Black ethnic groups ($X^2(1) = 1.28$, $p = 0.26$).

Effect of time to estimate

Studies were analysed in regard to the time that the measure of PND was administered to participants (Figure 10). A short-term time to estimate was defined as up to two months postpartum and a longer-term estimate was two to 12 months postpartum.

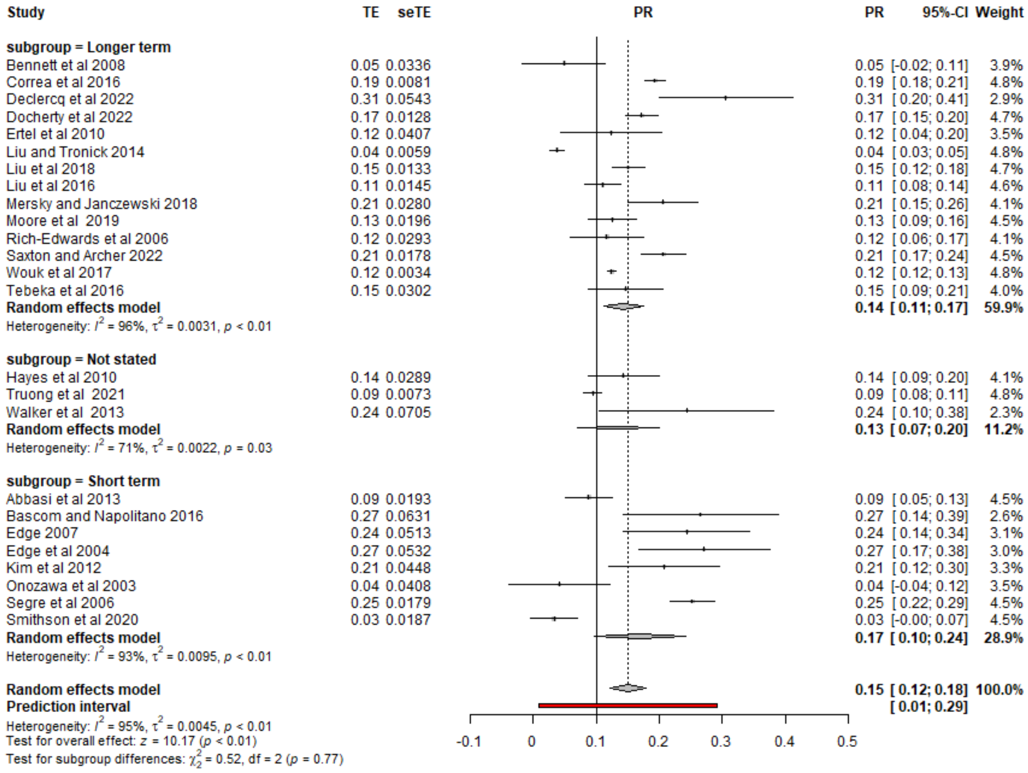


Figure 10 Subgroup plot of time to estimate. The horizontal axis of the forest plot indicates increasing prevalence rates.

The time to estimate did not show a statistically significant difference in estimates of prevalence of PND in Black ethnic groups ($X^2(2) = 0.52$, $p = 0.77$). This finding suggests that the timeframe in which a questionnaire is administered postpartum (up to twelve months), did not have any influence on the prevalence of PND.

The impact of publication and small study biases

Publication bias is caused by the tendency for statistically significant results to be published and the reticence to publish papers with non-significant results. Small study bias is the tendency for studies with smaller sample sizes to show greater variability in their measurement of PR. These biases can be identified in a funnel plot, which plots the magnitude of a study's PR (i.e., the importance of the study in the synthesis) to estimate the study's deviation from the meta-analytic average (i.e., the discrepancy of the study within the literature). If there is an absence of publication bias, the effects from the studies with small sample sizes which show greater variability will scatter more widely at the bottom of the plot compared to studies with larger samples at the top which will lie closer to the overall meta-analytic effect, creating a symmetrical funnel shape. If there is an absence of studies in the area of the plot associated with small sample sizes and non-significant results, then it is likely there is some publication bias leading to an overestimation of the true effect. The funnel plot of the PR of PND in Black ethnic groups is presented in Figure 11.

As can be seen from Figure 11, there is no evidence of publication bias in the distribution of the PR of PND in Black ethnic groups. This conclusion was substantiated by a non-significant test of funnel plot asymmetry (Egger's tests = 1.46; $p = 0.16$). Therefore, no simulation of and adjustment for publication bias and small study effects was undertaken.

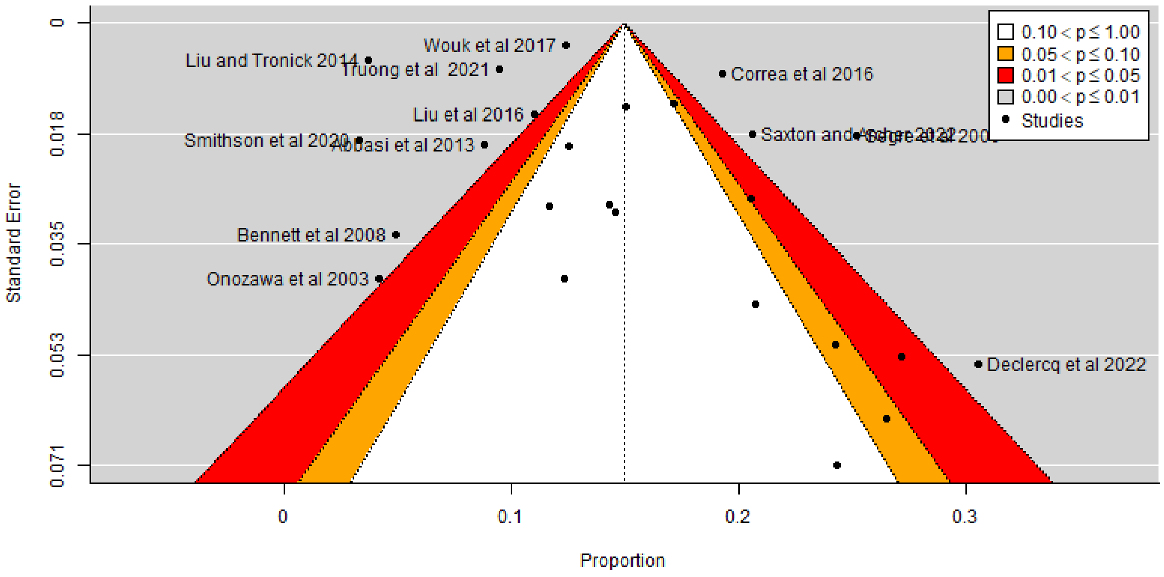


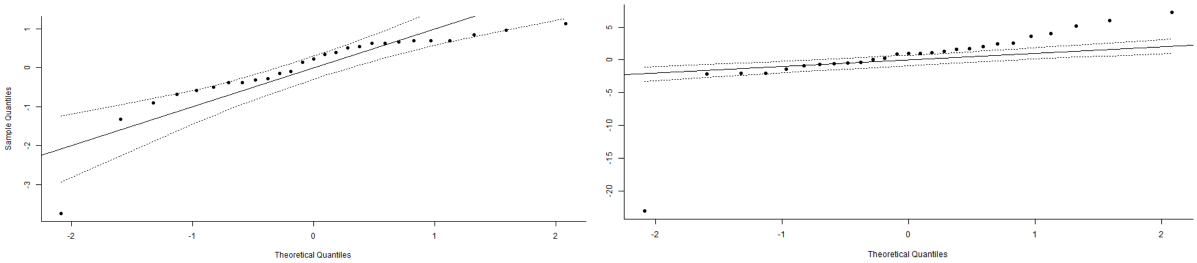
Figure 11 funnel plot of the prevalence of PND in Black ethnic groups. The 95% confidence interval of the expected distribution of prevalence rate is shown as an inverted "funnel".

Relative Risk of PND in Black ethnic groups compared to White ethnic groups

The first part of the meta-analysis focused on identifying the PR of PND in Black ethnic groups. Although this provided helpful data, this does not allow us to understand how the PR in Black ethnic groups are comparable to other ethnic groups. RR enables us to identify how much more likely Black ethnic groups may develop PND in comparison to a control group. For the purposes of this analysis, the control group was White ethnic groups. The natural logarithm of the RR ratio was used for the calculation of weighted average RR. However, unless otherwise indicated, the log of the RR was back transformed to the native RR ratio for reporting in Tables and Figures.

Selection of the meta-analytic model

The distribution of primary study effects is shown in Figure 12. The between studies variation (tau^2) was calculated using the restricted maximum-likelihood estimator.



Random Effects Model

Fixed Effects Model

Figure 12 QQ plot of the distribution of the relative risk of PND in Black ethnic groups compared to White within the primary studies

QQ plots are presented for both the fixed effects model and the random effects model (see Figure 12). If the data do not conform to a normal distribution, then using the random effects model and the restricted maximum-likelihood estimator to estimate between studies variation is recommended, as the REML estimator is more robust than other estimators to non-normal distributions of effects (Banks et al., 1985). As can be seen from Figure 12, there is clear evidence of non-normality in the distribution of the RR of PND in Black ethnic groups within the fixed effects model, which is largely absent within the random effects model, supporting the use of the random effects model and REML in this analysis.

The omnibus test

The RR of PND in Black ethnic groups compared to White ethnic groups is summarised in Table 6 in the previous section. Data for White ethnic groups were included in the original papers, so these data were extracted for the calculation of RR. It is not known from the articles what ethnic groups constitute White, as they were only defined as White in the research.

A random effects models was calculated using the generic inverse variance method. The random effects model suggested a weighted average RR of PND in Black ethnic groups compared to White ethnic groups effect=1.18 (z = 1.59, p = 0.11) and a 95% confidence interval of between 0.96 to 1.46.

A high level of heterogeneity in the primary studies was observed (tau^2 = 0.24, Higgin's I^2 = 96%; Q = 674.81, p = 0.01) (Figure 13). A RR greater than one indicates greater risk of PND in the Black sample, whereas a RR ratio of less than one would indicate greater risk of PND in the White sample. Therefore, for this meta-analysis, the RR (1.18) indicates a greater risk of PND in Black ethnic groups compared to White ethnic groups. However, this value was statistically non-significant. Therefore, we cannot be confident that there is a real difference in risk of developing PND between Black ethnic groups and White ethnic groups in this sample of papers.

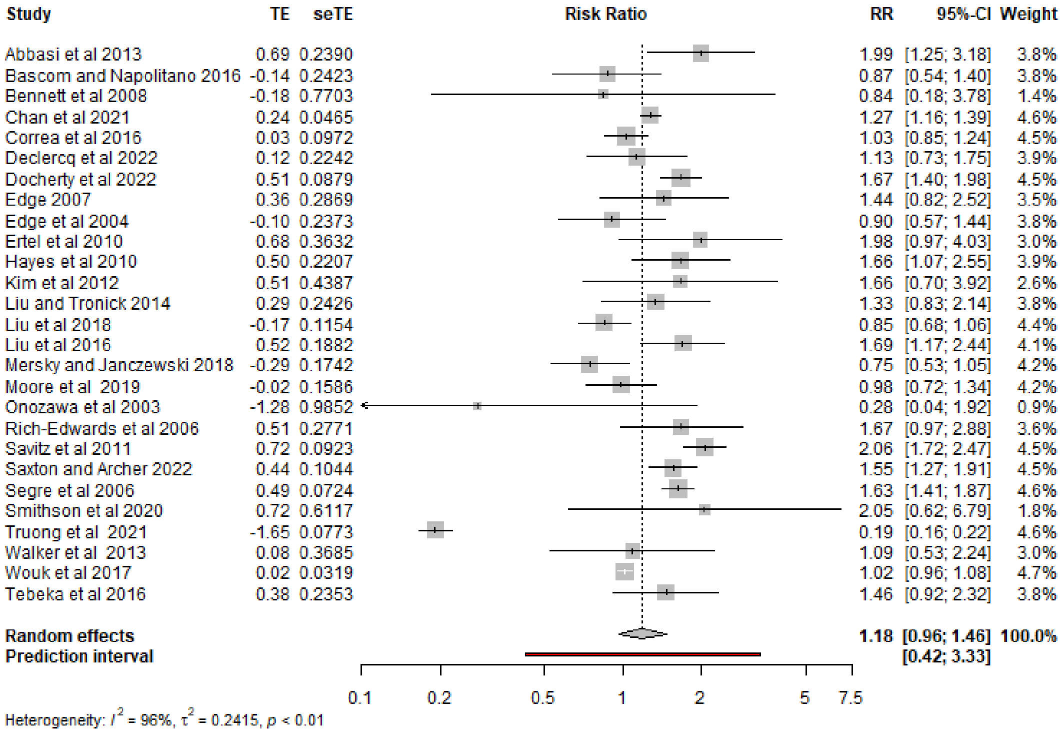


Figure 13 Forest plot of relative risk of PND in Black ethnic groups compared to White. The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

The impact of influential primary studies

The impact of disproportionately influential studies was described earlier, and the same approach used for exploration of prevalence data effects was used here for RR data (see Figure 14).

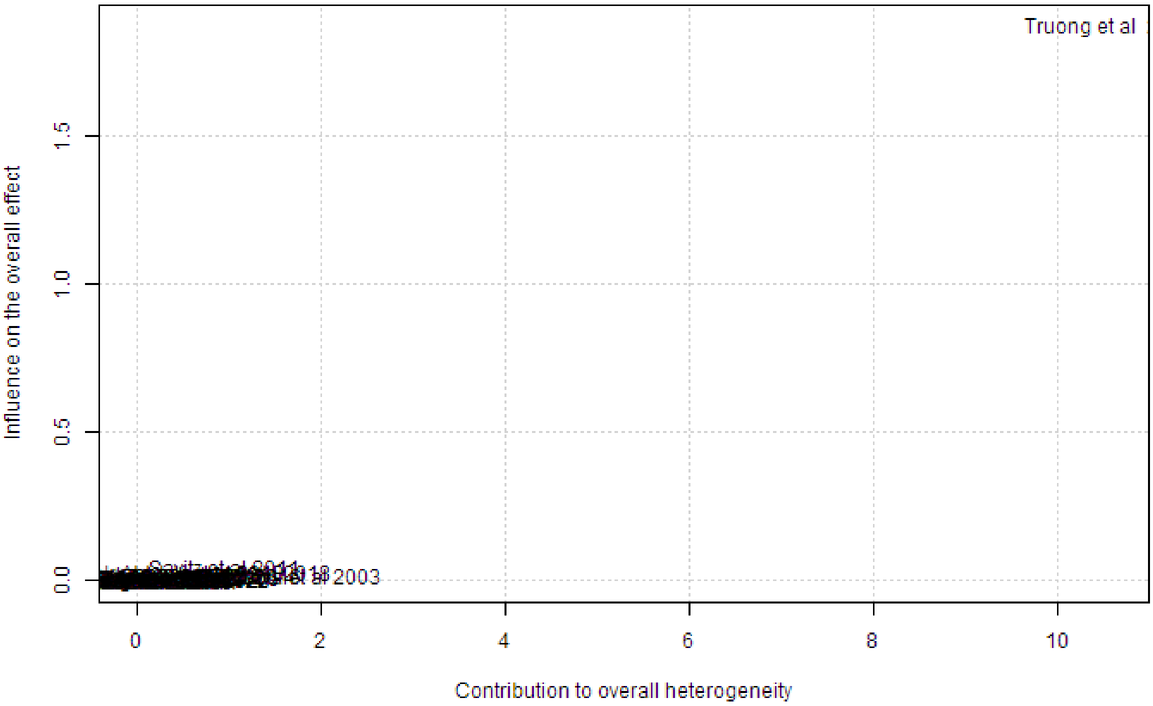


Figure 14 Baujat diagnostic plot of sources of heterogeneity. The vertical axis reports the influence of the study on the overall effect and the horizontal axis reports the discrepancy of the study with the rest of the literature.

The study by Truong et al. (2021) was shown to be both influential and discrepant with the other literature. The random effects model was recalculated with this study removed. The corrected random effects model reported a synthesis of the RR of PND in Black ethnic groups to compared to White ethnic groups effect = 1.29 (95% CI 1.14 – 1.47, $p<0.0001$, Higgins I^2 = 82.4%). The corrected random effects model evidences an approximately 9% increase relative to the uncorrected estimate. This one study was re-examined with a view to its removal from the meta-analysis if substantive reason for its discrepancy could be identified. Truong et al.

(2021) was the only paper in the analysis that specifically excluded women who had given birth at full term (the study focussed on pre-term, before 37 weeks gestation, deliveries). It is possible that this exclusion criteria may have had an influence on the RR of PND in Black ethnic groups compared to White ethnic groups. There is evidence to suggest that pre-term births are higher in Black ethnic groups compared to White ethnic groups (Centers for Disease Control and Prevention, 2022; Tommy’s, 2022). Therefore, the RR may not be an accurate reflection given the higher rate of preterm births in Black ethnic groups. Consequently, this study was removed from subsequent analysis and the corrected effect of 1.29 was taken as the final RR value.

The Higgins I^2 value reduced with the removal of influential studies but was still considered to represent high heterogeneity (Higgins et al., 2003). Consequently, methodological variation was explored using subgroup analysis of the areas of risk bias and the impact of publication bias, so that these factors can be taken into consideration when interpreting the findings of the subgroup analyses.

The effect of risk of bias in the primary studies

The assessment of the impact of study level risk of bias upon heterogeneity was described earlier, and the same approach used for prevalence data was used here for RR data (see Table 8).

Table 8 Effect of risk of bias

	Low Risk			**Any Risk**				
	EFFECT	**95% CI**	**k**	**EFFECT**	**95% CI**	**k**	**X^2**	**P**
Selection bias	1.02	0.97 – 1.08	4	1.35	1.17 – 1.56	22	12.14	<0.01
Performance bias	1.50	1.02 – 2.20	3	1.26	1.10 – 1.44	23	0.71	0.40
Detection bias	0.87	0.54 – 1.40	1	1.31	1.15 – 1.50	25	2.70	0.10
Statistical bias	1.30	1.03 – 1.65	9	1.29	1.10 – 1.51	17	0.00	0.97
Reporting bias	1.28	1.10 – 1.48	17	1.31	1.02 – 1.67	9	0.02	0.89
Generalisability bias	1.01	0.85 – 1.21	2	1.33	1.16 – 1.53	24	5.94	0.01

Selection bias evidenced statistically significant differences in estimates of RR, with lower levels of bias being associated with lower estimates of RR of PND in Black ethnic groups compared to White. The Higgins I^2 value for the four studies at low risk of selection bias was I^2=8% (Figure 15).

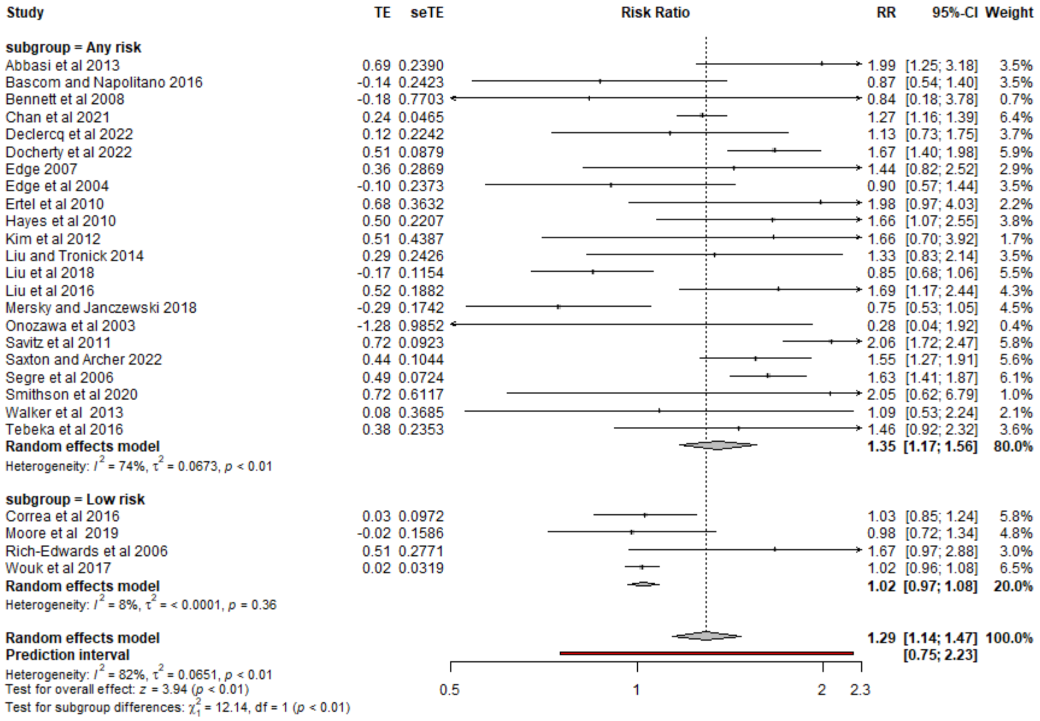


Figure 15 Subgroup plot for selection bias. . The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

Twenty-two studies were rated at any risk of selection bias, with seventeen of these studies reporting higher RR than the weighted average for the low-risk studies. This suggests that the inclusion of studies that are at any risk of selection bias may contribute to heterogeneity and increase the estimate of RR of PND in Black ethnic groups compared to White, with low-risk studies reporting a weighted average RR of 1.02 (95% CI 0.97 to 1.08).

Generalisability bias evidenced statistically significant differences estimates of RR, with lower levels of bias being associated with lower estimates of RR. The Higgins I^2 value for the two studies at low risk of generalisability bias was I^2=0% (Figure 16).

Twenty-four studies were rated at any risk of generalisability bias, with eighteen of these studies reporting higher RR than the weighted average for the low-risk studies. This suggests that the inclusion of studies that are at risk of generalisability bias may contribute to

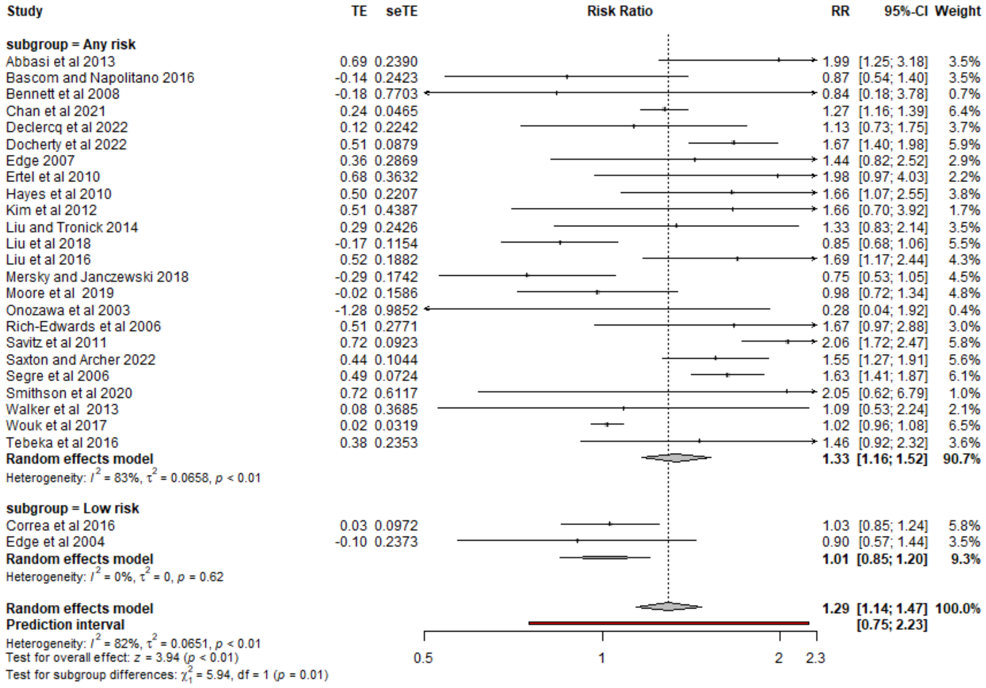


Figure 16 Subgroup plot for generalisability bias. . The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

heterogeneity and increase the estimate of RR of PND in Black ethnic groups compared to White, with low-risk studies reporting a weighted average RR of 1.01 (95% CI 0.85 to 1.20).

Impact of Study Level Differences

To further explore the impact of study level covariates upon the RR of PND in Black ethnic groups compared to White, a series of subgroup analyses were conducted.

The effect of the design of the study

The studies were categorised by their overall study design into either cross sectional studies, prospective case cohort studies and retrospective case cohort studies. There was no significant difference ($X^2(2) = 2.26$, $p = 0.32$) between the weighted average RR of cross-sectional studies, prospective cohort studies and retrospective case cohort studies (Figure 17).

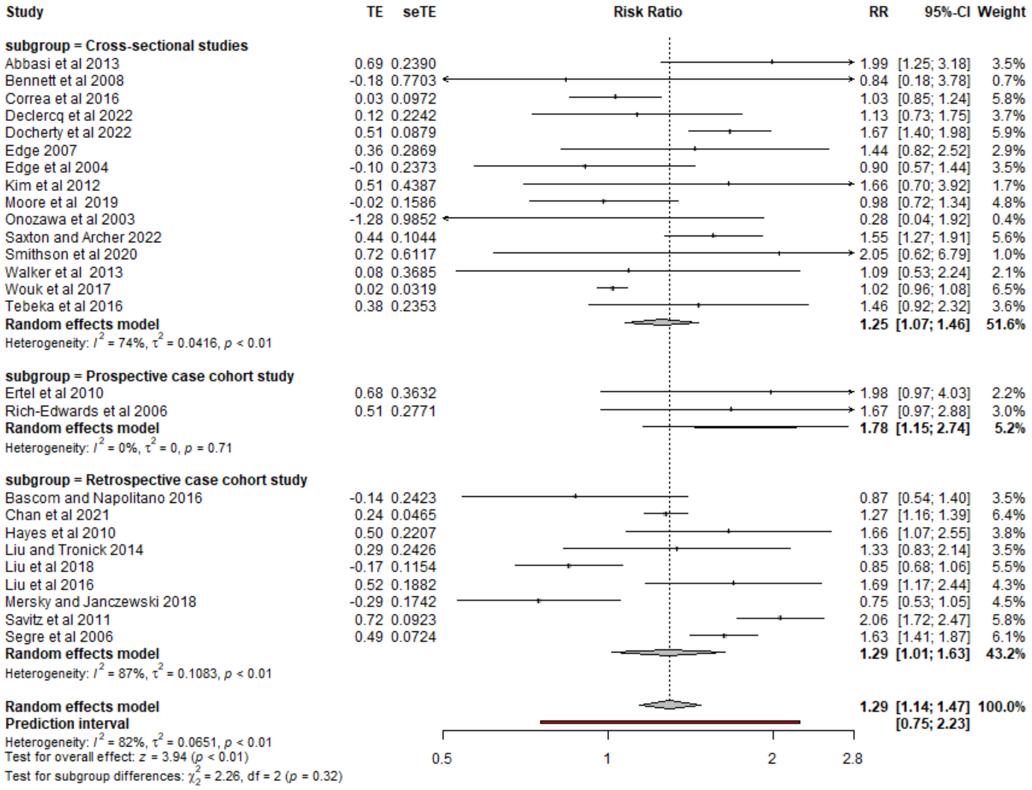


Figure 17 Subgroup plot of study design. . The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

The effect of ethnic subtype

The impact of ethnic subtype upon the RR of PND was achieved by comparing the weighted RR of PND in each subtype. There were no significant differences between ethnic subtypes on the RR of PND in comparison to White ethnic groups (Figure 18).

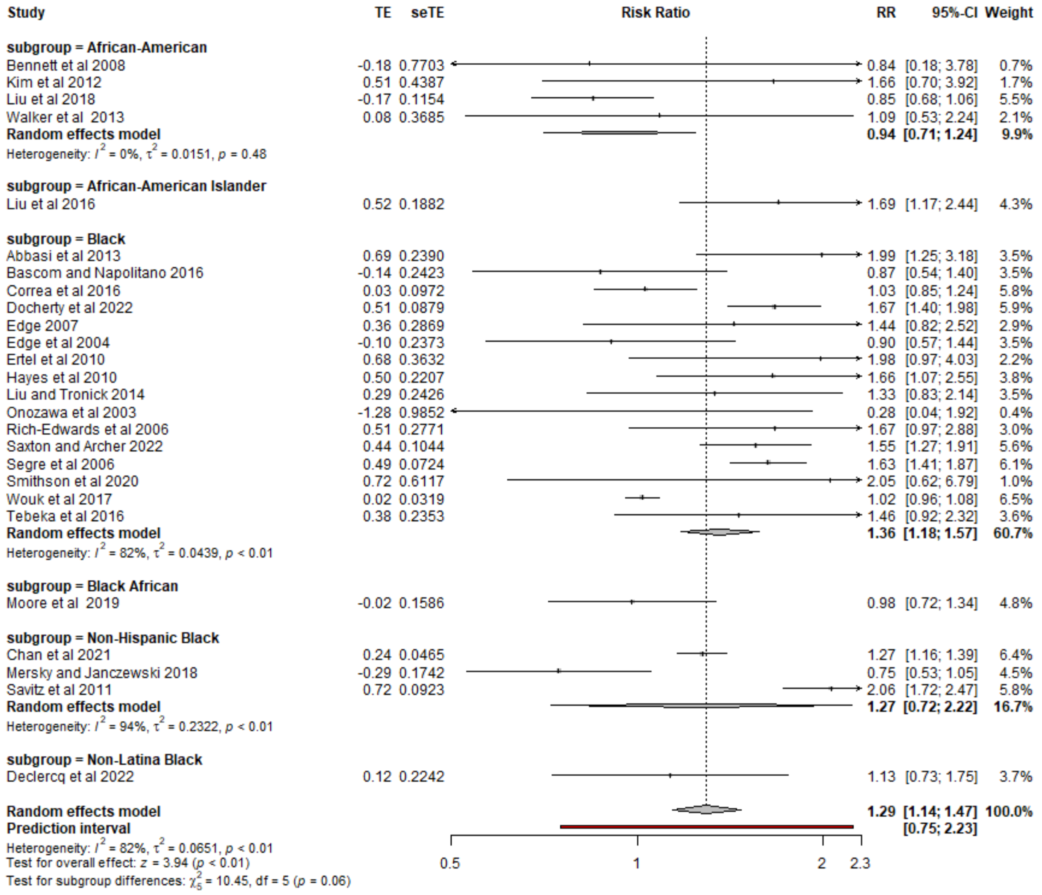


Figure 18 Subgroup plot for ethnicity. . The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

Effect of choice of questionnaire

Studies were categorised by the measure they used to assess PND (Figure 19). This included the EPDS, PHQ-2, PRAMS-3D, RMI, Phase 6 CORE, AUDADIS-IV, Barriers Questionnaire, a three-item screener, and being asked whether or not they had received a diagnosis by a healthcare professional.

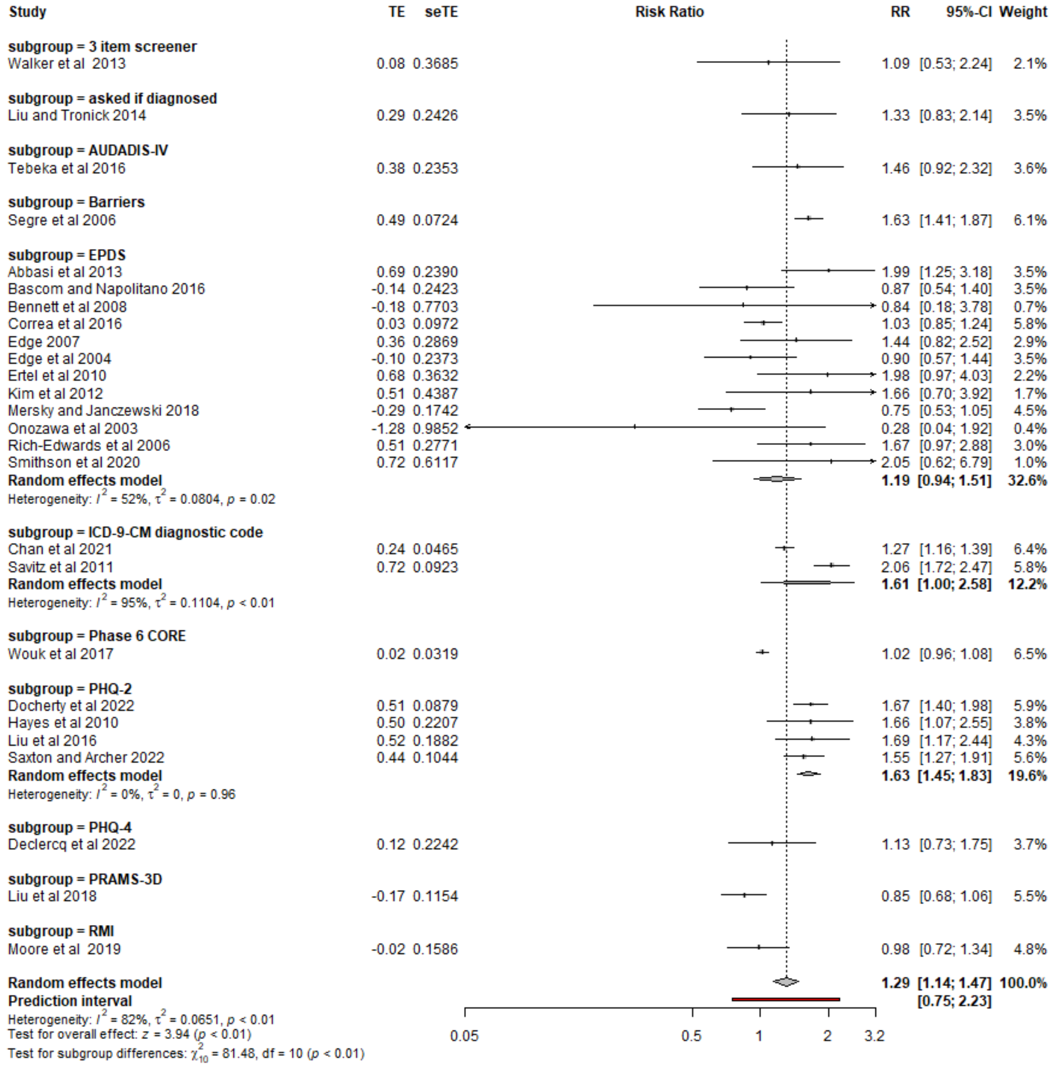


Figure 19 Subgroup plot of measure used to assess PND. . The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

A statistically significant difference ($X^2(10) = 81.48$, $p < 0.01$) was observed between the studies dependent on what measure was used to assess PND. However, the RR for those measures that show the greatest difference from the overall weighted average RR tended to be calculated from either one or a small number of studies, and therefore these estimates will be highly likely to change given the publication of further studies using these measures. The higher rates of RR for PND were found in those questionnaires that were not specifically designed to assess for PND or relied on shorter measures (e.g. PHQ-2).

Effect of country of recruitment

The studies were examined based on the country that they were conducted in (Figure 20).

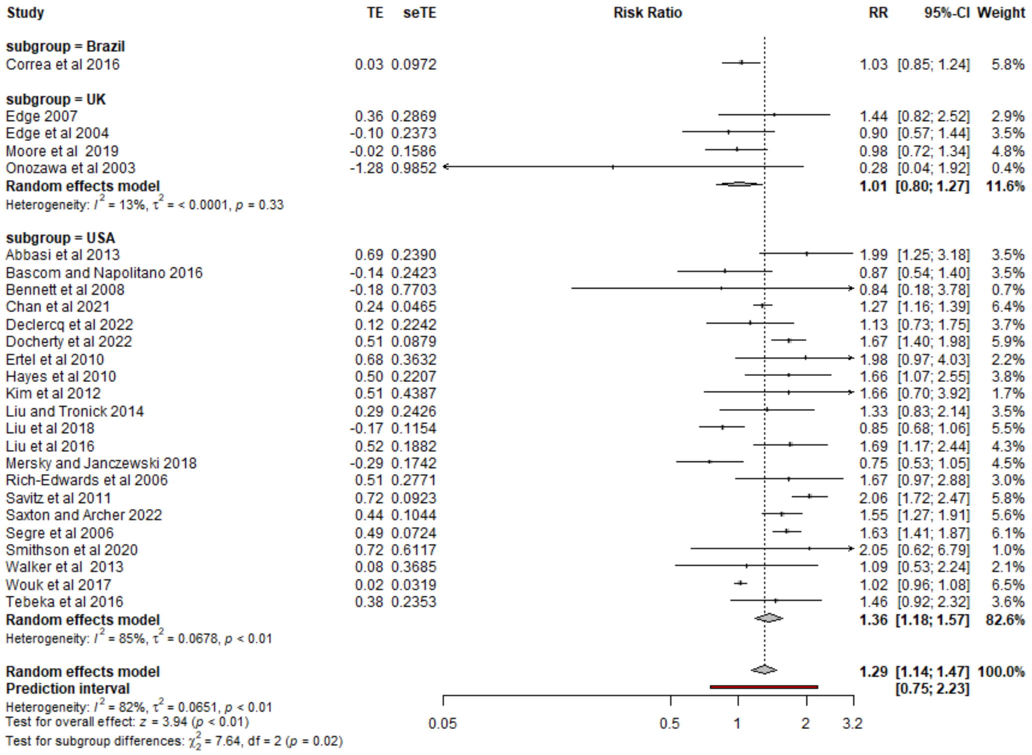


Figure 20 Subgroup plot for country of recruitment. The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

A statistically significant difference ($X^2(2) = 7.64$, $p = 0.02$) was observed between the studies. USA had the highest RR for PND in Black ethnic groups compared to White ethnic groups. This leads to questions about how maternity and antenatal services are organised in the USA that might mean individuals from Black ethnic groups are more likely to receive a diagnosis of PND. This needs further consideration but could be a result of systemic racism, with research suggesting that individuals from Black ethnic groups are more likely to be hospitalised with PND in the USA (Chan et al., 2021). However, there was a larger number of studies in this category compared to the UK and Brazil (four and one respectively). The weighted average RR for the USA is consistent with the overall weighted average RR.

Effect of where participants were recruited from

Studies were also categorised in terms of how participants were recruited (Figure 21).

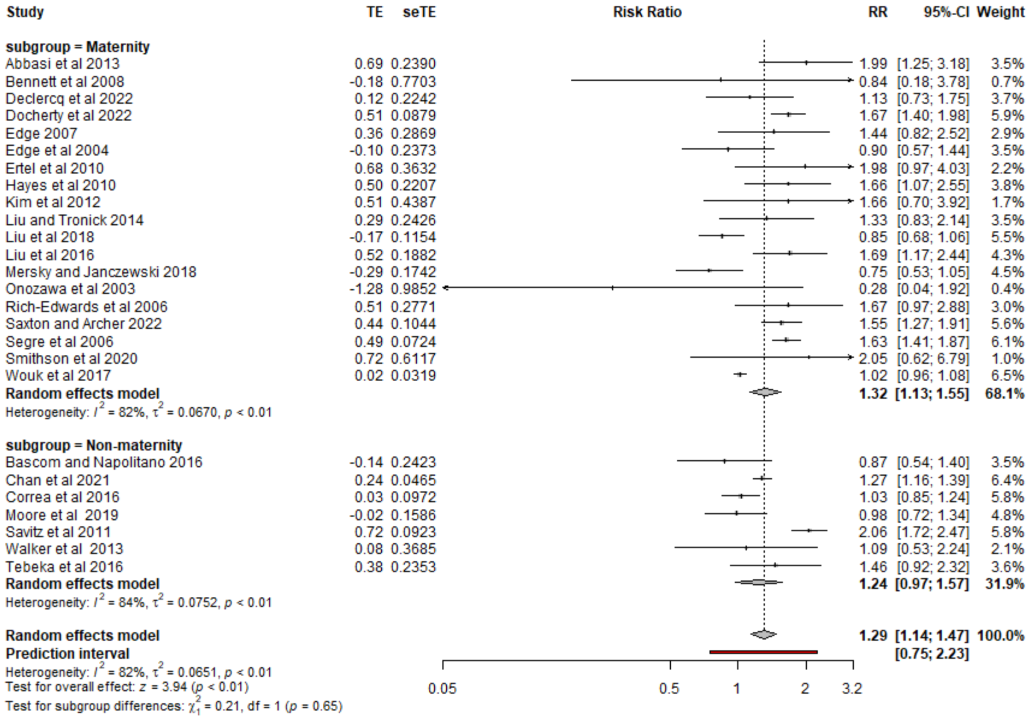


Figure 21 Subgroup plot of where participants were recruited from. The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

The recruitment of participants from either maternity or non-maternity services did not show a statistically significant difference in RR of PND in Black ethnic groups compared to White ethnic groups ($X^2(1) = 0.21$, $p = 0.65$).

Effect of time to estimate

The studies were also analysed for the time that the measure of PND was administered to participants (Figure 22). A short-term time to estimate was defined as up to two months postpartum and a longer-term estimate was two to 12 months postpartum. The time to estimate did not show a statistically significant difference in estimates of RR of PND in Black ethnic groups compared to White ($X^2(2) = 0.59$, $p = 0.75$).

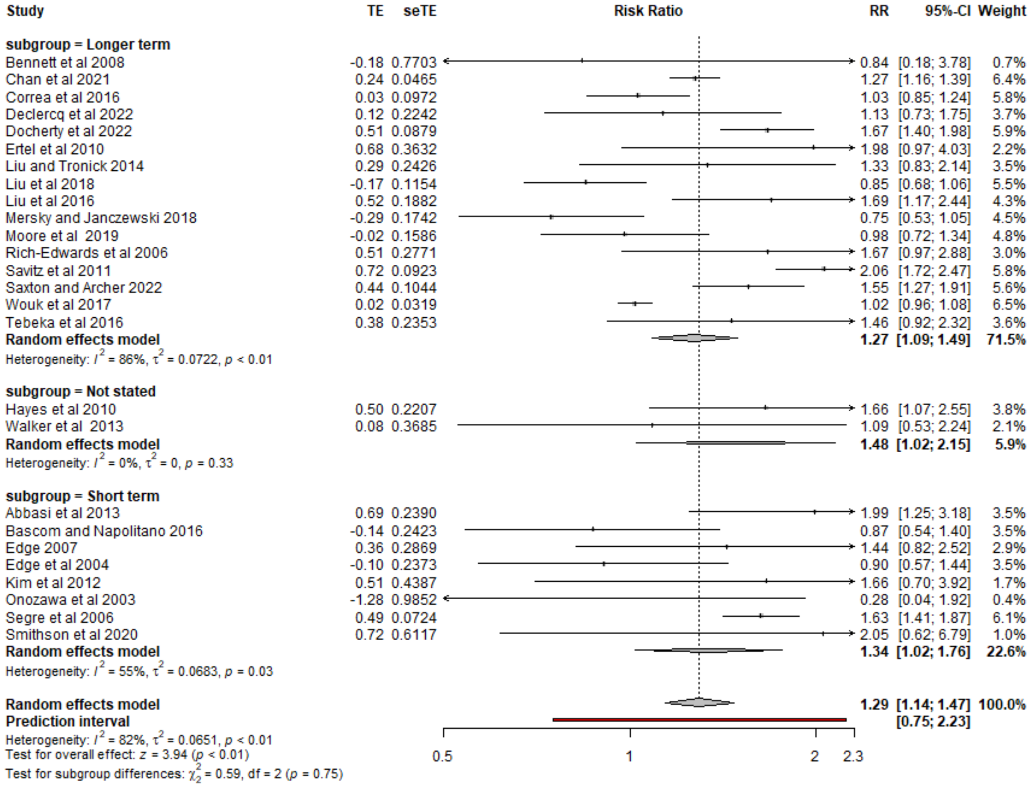


Figure 22 Subgroup plot for time to estimate. The horizontal axis of the forest plot indicates increasing relative risk of PND for Black ethnic groups compared to White.

The impact of publication and small study biases

Publication bias and small study bias were described earlier, and the same approach used for exploration of prevalence data effects was used here for RR data. The funnel plot of the RR of PND in Black ethnic groups compared to White is presented in Figure 23.

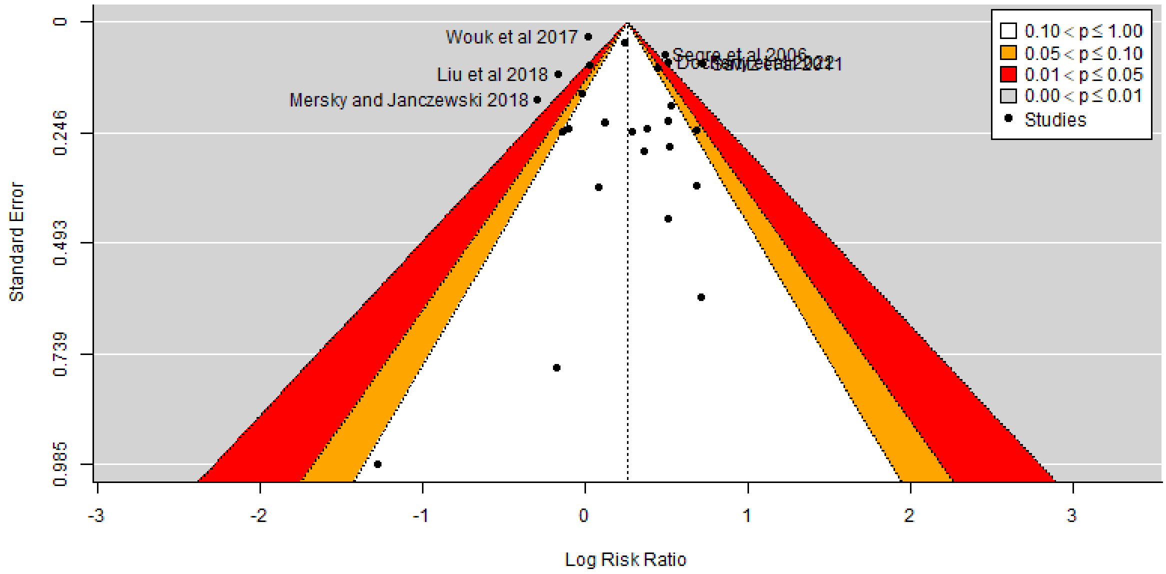


Figure 23 Funnel plot of the relative risk of PND in Black ethnic groups compared to White. The 95% confidence interval of the expected distribution of relative risk is shown as an inverted "funnel".

There is no evidence of either small study effects or publication bias in the contour enhanced funnel plot depicted above. This conclusion is supported by a nonsignificant test of funnel plot asymmetry (Egger's t = 1.08, p = 0.29). Therefore, no simulation of and adjustment for publication bias and small study effects was necessary.

Summary of results

The results from this meta-analysis are summarised in Table 9. For both PR and RR analyses, the study type, effect of where participants were recruited from, and the time to estimate were found to be non-significant factors in estimates of the prevalence of PND (15%) or RR of PND (1.29) in Black ethnic groups. The factors that appeared to be important in PR and RR, supported by statistically significant outcomes were effect of choice of questionnaire and effect of country of recruitment, with some subgroups showing higher values than others. Ethnic subtype was only found to be a significant factor in the analysis of PR, suggesting that RR for

Black ethnic groups compared to White ethnic groups was not impacted by ethnic subgroups in this analysis. However, there may be nuances within ethnic subgroups for the overall prevalence of PND within these categories of Black ethnic groups.

Table 9 Summary of results

	Prevalence rate ***p***	**Relative risk** ***p***
Study type	0.49	0.32
Ethnic subtype	<0.01	0.06
Effect of choice of questionnaire	<0.01	<0.01
Effect of country of recruitment	<0.03	0.02
Effect of where participants were recruited from	0.26	0.65
Time to estimate	0.77	0.75

Discussion

This is the first meta-analysis to have examined the PR of PND in Black ethnic groups and consider the RR of PND in comparison to White ethnic groups. A total of 27 studies were included in this meta-analysis, covering three countries, and a total of 1,561,932 participants.

Prevalence of PND in Black ethnic groups

The overall weighted average prevalence for PND in Black ethnic groups was 15%, which is consistent with the global PR ranging between 10% and 20% (Abbasi et al., 2013; Ling et al., 2022; Royal College of Psychiatrists, 2018; Wang et al., 2021). The variation in the global PR was reported to be a consequence of discrepancies in screening methods and the time to estimate (Afolabi et al., 2020; Mersky & Janczewski, 2018), which were explored further as part of this meta-analysis. Subgroup analyses identified three factors that were significant in estimating the prevalence of PND in Black ethnic groups: ethnic subtype, measure of PND, and country of recruitment.

The studies included had high levels of heterogeneity which will have influenced the estimated PR of PND in Black ethnic groups. Detection bias and generalisability bias both showed trends towards significance, suggesting that these may have impacted on the estimated PR. For both detection and generalisability bias, a low risk of bias resulted in a higher estimated PR, however there were only a small number of studies in these categories. Therefore, the estimated PR may be influenced by the number of studies as well as the risk of bias.

The Non-Latina Black ethnic subtype demonstrated the highest estimated PR in the analysis (0.31), but this was only calculated from one study so may change given the publication of further research. Black and African American subtypes had weighted average PR (0.15) that were consistent with the average prevalence of the studies included in the meta-analysis as well as the global prevalence estimate. Further studies need to be published incorporating different ethnic subtypes, to determine whether a significant difference exists or if this is the result of limited studies.

Considering the assessment of PND, the highest estimated PR (0.24 – 0.31) were similarly calculated from a small number of studies (Figure 7). The PR was lowest when individuals were asked if they had been diagnosed with depression since the birth of their baby, suggesting clinicians need to consider how questions are asked to prevent PND being missed or under-reported, possibly due to shame and fear (Arifin et al., 2018). The EPDS and PHQ-2 displayed consistent PR (15% and 14%) with the overall average PR for the meta-analysis, which could imply that the EPDS and PHQ-2 are more accurate to use in screening for PND compared to the other measures reported here. However, the EPDS is specifically designed to screen for

PND, whereas the PHQ-2 asks individuals about a person’s mood over a two-week period and is a screening tool for depression, not specific to PND (American Psychological Association, 2020). Given that both the EPDS and PHQ-2 showed similar PR, it is plausible to consider the utility of the PHQ-2 as a screening tool for PND. Research has suggested that the EPDS and PHQ-2 have fair inter-rater reliability (0.2) between the two measures (Larsen et al., 2023), but research is needed to explore the correlation between them to determine the appropriateness of using the PHQ-2 as a screening tool for PND. There is some evidence to suggest that the PHQ-2 may result in less referrals for higher intensity interventions for PND (Larsen et al., 2023), but more research is needed to determine the effectiveness of the PHQ-2 in screening for PND compared to the EPDS. This could impact on how PND is identified within services as the use of a two-item screening tool is quicker to administer, but this needs to be considered with the risk of over or underdiagnosing PND with a non-specific measure.

In terms of country of recruitment, Brazil displayed the highest estimated PR for PND (19%) which is consistent with the global PR but was only calculated from one study so could change. The USA and the UK had consistent PR with the overall weighted average prevalence (15% and 16%, respectively). Brazil’s maternity services are known to operate differently to the UK and USA in that there is no guarantee of a hospital admission or care, so women may have to travel to various hospitals (Duarte de Azevedo-Bittencourt et al., 2016). Stress is known to be a risk factor for PND (Public Health England, 2019) so the higher PR could be related to the difficulties associated with maternity care in Brazil, but this needs further evidence.

The non-significant finding of time to estimate is interesting, as previous research suggested time to estimate could influence PR (Afolabi et al., 2020; Mersky & Janczewski, 2018; Wisner et al., 2006), which was not observed in this meta-analysis. The PR when PND was assessed up to two months postpartum and up to 12 months postpartum were similar (0.14 and 0.17) and consistent with the overall PR (0.15). It may be beneficial for services to be aware of this to ensure women are able to access the right services and support postpartum, as if the focus is on women who develop PND within four weeks postpartum (APA, 2013) this meta-analysis suggests that there are more women beyond this threshold who could have a diagnosis of PND that services may miss.

The non-significant finding in PR of PND in Black women recruited from either maternity (hospital and antenatal clinics) or non-maternity services (consumer opinion panels, databases and medical records) suggests that prevalence rates for PND are similar irrespective of whether the service is maternity specific. It would be important for researchers to consider this to ensure PR reflect those from the general population. Furthermore, clinicians need to be aware that there may be a subgroup of individuals who have PND but are unable to access services. It could be that these individuals do not feel they need support from services, but alternatively they may not know how to access services. There is evidence to suggest poorer healthcare outcomes and access to services for ethnic minority communities (Ling et al., 2022; Knight et al., 2021) alongside systemic racism issues of being ignored and disbelieved and structural barriers (Arefadib et al., 2022; Babatunde & Moreno-Leguizamon, 2012; Birthrights, 2022; Ling et al., 2022). Consequently, clinicians and services need to ensure they are taking steps to engage with non-maternity services to think about the needs of individuals who may not be able to access NHS services. This may include engagement with Black communities to further enhance understanding of PND in this ethnic group and what is required from organisations to support these individuals. As a result, the global PR may not be an accurate reflection of PND given that some communities may not have been included due to them not presenting at services.

Relative risk of PND in Black ethnic groups compared to White ethnic groups

The overall weighted RR for PND in Black ethnic groups compared to White ethnic groups was 1.29 ($p<0.001$) implying an increased risk of PND in Black ethnic groups compared to White ethnic groups in this meta-analysis. Subgroup analyses identified two factors that were significant in estimating RR of PND; measure of PND and country of recruitment.

The studies had high levels of heterogeneity which will have influenced the RR of PND in Black ethnic groups compared to White ethnic groups. Selection and generalisability bias were both significant, with studies rated as any risk of bias having higher RR estimates and studies with low risk of bias having lower RR estimates. Consequently, selection and generalisability bias may be contributing to the heterogeneity of the studies and subsequently increase the RR estimate. Further research is needed without evidence of selection or generalisability bias to enable further understanding of the RR of PND in Black ethnic groups in comparison to White ethnic groups. If there is a higher RR, this opens up discussion about why this difference exists given the evidence suggesting individuals from ethnic minority groups experience poorer outcomes (Arefadib et al., 2022; Babatunde & Moreno-Leguizamon, 2012; Birthrights, 2022; Knight et al., 2021; Ling et al., 2022). However, due to study bias, these concepts can only be speculative and further research is needed to support these claims.

For the measure of PND used, the RR estimate was larger for those measures used in a smaller number of studies (1.61 - 1.63). This included the Barriers Questionnaire (one study), ICD-9 diagnostic code (two studies) and PHQ-2 (four studies), with it being possible that the RR value may change given the publication of more studies using these measures. Other than the diagnostic code, the measures that displayed the highest RR (1.63) were not specifically designed to assess PND (i.e. The Barriers Questionnaire covers a broad range of health indicators with one question focused on depression and the PHQ-2 is a two-item screener for depression). Using measures not specific to PND could risk over diagnosing PND resulting in an overestimation in the RR. Future research needs to consider the choice of measures when investigating PND to ensure an accurate representation of PND and not over or underestimating its presence which has clinical implications. If clinicians are using questionnaires not specifically designed to assess or screen PND, this could result in people being under or over diagnosed, meaning that individuals may not access the correct service.

For country of recruitment, the USA had the highest RR of PND (1.36) in comparison to the UK and Brazil (1.01 and 1.03). Research implies that systemic racism, policy, and procedures mean that is more likely for women from Black ethnic groups to be hospitalised as a result of PND in the USA (Chan et al., 2021; Leitch et al., 2021). However, systemic racism is not only problematic in the USA, as there is research suggesting this occurs in the UK (Arefadib et al., 2022; Babatunde & Moreno-Leguizamon, 2012; Birthrights, 2022; Ling et al., 2022) but the RR for Black ethnic groups was lower for the UK. Therefore, to better understand why this difference is observed with the RR, it would be useful for further research to be conducted that covers other countries as well as increased research in the UK to rule out publication bias as more studies were published in the USA. Given the evidence of selection and generalisability bias, further research is also needed with large, randomised samples, using measures with good specificity, reliability and validity to further understand the RR of PND in Black ethnic groups compared to White ethnic groups.

Limitations

Studies were only included in this meta-analysis if they were available in the English language due to limited resources. However, PND may be evident in other Non-English speaking cultures, but this has not been captured in this meta-analysis. It is not known if the PR of PND in Non-English cultures is comparable to that of English cultures. The PR may change given the inclusion of research published in other languages, therefore the results of this meta-analysis may only be applicable to Black individuals in English speaking countries. Additionally, there were only three countries that were included in this meta-analysis (UK, USA and Brazil). Therefore, the findings of this meta-analysis may not represent global PND PR and RR, with figures likely to change given the inclusion of more global research.

Furthermore, this meta-analysis did not include “Black ethnicity” as a search term. Reasons for not including this were that there were lots of nuances to Black ethnicity, so the author chose to search for articles using a broader ethnicity term and then exclude articles that did not include Black ethnic groups in their abstract to prevent missing articles. However, it is possible that some articles that had Black in their title may have been excluded by not including Black as part of the search strategy, meaning the PR and RR could change given the inclusion of these articles.

The measures that were included in this meta-analysis all used different timescales in their assessments. The short term and long term time to estimate captures the time in which the questionnaires were administered in the postnatal period, however, this does not capture the time scale that the measures are designed to assess symptoms of PND. The time in which symptoms of PND was assessed varied from the last 7 days (EPDS), last two weeks (PHQ-2, PHQ-4, Barriers), since baby was born which varied from two months postpartum to 12 months postpartum (PRAMS, Phase 6 CORE), the last 12 months (AUDADIS) and no time frame but based on questions such as “do you often” (RMI). The current definition of PND suggests that symptoms must be present in the first four weeks following childbirth (APA, 2013). However, some of the measures that were used in the assessment of PND in this meta-analysis assessed

PND beyond this time frame (e.g. symptoms in the last 12 months or since the birth of the baby which could have a varying time frame). Alongside this, although some of the measures aim to assess symptoms that are present within the last one to two weeks, these measures were administered to women who were between two and twelve months postpartum. Therefore, we cannot be confident that the findings of this meta-analysis are fully inclusive of PND. It is possible that depression within the postnatal period may have also been captured within these results, given the timescales of the assessments, which warrants consideration in the implications of these findings.

The meta-analysis may be limited by type 1 errors as a result of multiple subgroup analyses. Multiple subgroup analyses are known to increase the risk of type 1 errors, with recommendations suggesting significance levels for the analyses may need to be adjusted to account for this (Li et al., 2017). However, adjusting significance levels was not done for this meta-analysis, therefore caution is needed in interpretation of the significant findings, given the increased risk of false positive conclusions.

Implications

There are important clinical and research implications to consider from these findings, though some caution is required in the interpretation. Overall, the findings suggest that the prevalence of PND in Black ethnic groups is consistent with the overall global PR, with Black ethnic groups at a statistically increased risk of PND compared to White ethnic groups.

Research

Further research needs to be conducted including different Black ethnic subtypes to determine if ethnic subtype is a significant factor in the estimate of prevalence in PND. The measures used to determine the presence of PND in research also needs consideration given the use of non-specific measures which resulted in higher estimates of prevalence and RR. Additionally, research examining the correlation between the EPDS and PHQ-2 would be useful to determine the appropriateness of using the PHQ-2 as a screening tool for PND.

Increased research is also needed globally and including Non-English papers to understand if there are PR and RR differences across different countries. This research would enable further consideration of the factors that may be influencing the prevalence and RR estimates for these countries and determine the influence of publication bias, considering larger randomised samples.

Researchers may need to reconsider their inclusion criteria for future PND research as some women may have been excluded as some studies only administered measures within a short time frame. Further research focusing on women up to 12 months postpartum would be useful to obtain more accurate PR. Alongside this, increased research outside of maternity services may also provide more accurate PR, given the finding of this analysis of there being no significant difference between maternity and non-maternity services.

Further research may want to consider the differences between PND and depression in the postnatal period, as it is likely the findings from this meta-analysis have combined PND and depression in the postnatal period. Future research understanding prevalence rates of PND may want to consider examining PND and depression in the postnatal period separately, to obtain more accurate prevalence rates.

Clinical

Clinicians need to consider how questions are asked to individuals about PND, as some individuals may be misdiagnosed or underdiagnosed dependent on how they are assessed for PND. The utility of briefer measures needs consideration in clinical services alongside the research evidence about the specificity and reliability of briefer and current measures used in the assessment of PND.

Services may want to review the timings of when assessments are offered to postpartum women to ensure women are able to access the right services and support. Additionally, it is likely that there may be a subgroup of individuals who meet the diagnostic criteria for PND but are not accessing services. It would be helpful for clinicians to consider the review and development of policy alongside service development projects to think about how organisations can better engage with the Black community to support women with PND.

Clinicians need to be aware of PND and depression in the postnatal period. The findings of this meta-analysis did not distinguish between the two. Clinicians need to consider whether individuals may present similarly or differently at services and whether different assessments need to be offered dependent on when symptoms developed, to ensure the most accurate assessment of needs is able to be undertaken.

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2. EMPIRICAL PAPER: “YOU’VE GOTTA BE A MAN AND BE STRONG”: FATHERS’ EXPERIENCES OF PERINATAL LOSS IN THE PAKISTANI COMMUNITY

Abstract

Introduction:

Although women physically experience pregnancy, and grief might manifest differently, both mothers and fathers are affected similarly by perinatal loss. Research has predominately focused on Caucasian men, with the experiences of men from ethnic minority groups being unknown. Nationally, the Pakistani community has one of the highest rates of perinatal loss, therefore this research aimed to explore the experiences of perinatal loss in Pakistani men.

Method:

Five Pakistani men who experienced perinatal loss, sometime between four months to eight years ago, were recruited via posters placed at NHS maternity and mental health services, a third sector service and social media. Semi-structured interviews were used and analysed using Interpretative Phenomenological Analysis.

Results:

Three Group Experiential Themes with a total of six group level subthemes were identified: 'A rollercoaster of emotions: from shock and distress to having hope', 'The hidden experience of baby loss as a Muslim man', and 'The felt stigma of baby loss in the Muslim community'.

Discussion:

Perinatal loss results in ever-changing emotions, with a shift from shock to sense making through religion. Perinatal loss was considered a hidden experience, with men masking emotional responses by a desire to be seen as strong and supportive. The felt stigma of perinatal loss was discussed in the context of silenced conversations and a disconnection between religion and community. Further research is needed to consider different experiences of

perinatal loss such as time frames since loss, having children prior or after a loss and other subgroups of Muslim communities.

Introduction

Perinatal loss

Perinatal loss includes the events of miscarriage (up until 24 weeks gestation), still birth (from 24 weeks gestation), termination for foetal abnormality and neonatal death (death within 28 days of birth) (Herbert et al., 2022). Perinatal loss is an emotionally and physically traumatic event for parents (Nguyen et al., 2019). Perinatal loss is considered to be stigmatised, with individuals reporting that friends, families, and healthcare professionals are uncomfortable discussing their loss (Bellhouse et al., 2018). Consequently, women have reported perinatal loss to be isolating, with the grief being viewed as disenfranchised, meaning the experience often remains silent (Ng, 2021; Tseng et al., 2017). In Western cultures there are no typical rituals for processing the grief associated with perinatal loss, such as a funeral (Markin & Zilcha-Mano, 2018). Perinatal loss appears to be viewed as less significant in comparison to other bereavement, for example an older child (Alvarenga et al., 2019; Galvão et al., 2020). However, grief associated with perinatal loss is recognised as complex and unique to that individual (Furtado-Eraso & Marín-Fernandez, 2020). For some, a long and anticipated journey to have a child suddenly changes into a journey of loss (Das et al., 2021). Grief is a universal response, but it is important to consider the social and cultural structures influencing how grief is manifested and coped with (Aydin & Kabukcuoğlu, 2020).

Men’s experiences of perinatal loss

Because women physically bear a pregnancy, perinatal loss is often positioned as only impacting on them (Nguyen et al., 2019). Research indicates that grief manifests differently for mothers and fathers, with the feelings experienced (such as grief, depression, stress, and anxiety) being similar but less intense for men (Due et al., 2017; Williams et al., 2020). Experiences of loss are, however, situated within wider sociocultural narratives around female and male roles and the associated ideas of femininity and masculinity (Jones et al., 2019). For men / fathers across cultures there can be an expectation that men are strong, don’t show emotions and support their partners (Aydin and Kabukcuoğlu, 2020; Galvão et al., 2020; Nguyen et al., 2019). This expectation might come from healthcare professionals, friends, family and be part of an identity men hold themselves (Nguyen et al., 2019). Fathers across ethnic groups commonly report blaming themselves, losing their identity as a father and feeling they need to hide their own grief and anger (Jones et al., 2019; McCreight, 2004; Nguyen et al., 2019). For many men in both majority and minority ethnic groups, it seems there is conflict in wanting to be strong alongside being a grieving father (Ayebare et al., 2021; Nguyen et al., 2019).

Current models of antenatal healthcare risk neglecting expectant fathers as emphasis is placed on the woman’s welfare (Eboru, 2018; Kowlessor et al., 2015), meaning men who experience perinatal loss can feel isolated and disconnected (Chavez et al., 2019). Fathers across ethnic groups report feeling unacknowledged by healthcare professionals, family, and society which exacerbates feelings of guilt, isolation, and hopelessness in loss (Alvarenga et al., 2019). The NHS Long-Term Plan (2019) aimed to ensure that fathers or partners of women accessing perinatal mental health services were also offered evidence-based assessments for their mental health needs to address men feeling unacknowledged by professionals. There is increasing interest in men’s experiences of perinatal loss, but the evidence base predominately focuses on mothers (Hodgson et al., 2021; Jones et al., 2019). When fathers have been included in research about perinatal loss, they have been as part of a couple (Nguyen et al., 2019) or focused more on reasons for the loss rather than fathers’ experiences and support needs (Aydin & Kabukcuoglu, 2020). Further qualitative research is needed to improve the depth of understanding of men's experiences and support needs in relation to perinatal loss (Fernández-Basanta et al., 2019).

Men from ethnic minority groups and perinatal loss

Social and culture structures influence how grief is manifested and the coping strategies individuals may adopt (Ayebare et al., 2021; Fernández-Basanta et al., 2020; Jones et al., 2019; Sutan & Miskam, 2012). Research into perinatal loss has, however, primarily focused on Western societies, White or Caucasian individuals, or ethnicity has not been recorded (Due et al., 2017; Markin & Zilcha-Mano, 2018). Although the limited evidence base suggests some similarity in experiences (Jones et al., 2019; McCreight, 2004; Nguyen et al., 2019), research with men from diverse communities suggests that they face particular challenges such as stigma and an expectation of prioritising their partners wellbeing (Ayebare et al., 2021; Das et al., 2021; Pabón et al., 2019).

Understanding the interaction of cultural practices and beliefs could be helpful in informing clinical practice, developing services and training (Ahmed et al., 2020). Indeed, the Care Quality Commission (CQC, 2022) highlights the importance of culturally appropriate care, through being sensitive to individual's cultural needs and responsive to their beliefs. Maternity services need to be shaped by the diverse needs of the communities they work with and limited information about religious, cultural, and ethnic influences could result in culturally insensitive care being delivered (Firdous et al., 2020; Hassan et al., 2019; Kalu, 2019; The Maternity Alliance, 2004). There is therefore a need to explore perinatal loss within the context of culture.

Perinatal loss in the Pakistani community

The United Kingdom is a multicultural society with individuals from ethnic minority groups experiencing a higher rate of perinatal loss (Office of National Statistics, 2019; Rethink, 2007). Nationally, the city of Birmingham has a high rate of perinatal loss, with disproportionate loss in the Pakistani community compared to other ethnic groups (Birmingham City Council, 2021; Garcia et al., 2020). Cultural and religious beliefs and practices can determine how publicly parents can grieve following perinatal loss (Hamid et al., 2014). For example, within Pakistani communities, some religious rituals such as wrapping the body in white sheets, funeral prayers, naming the baby and having family view the baby are only offered if signs of life are witnessed after birth (Hamid et al., 2014).

Perinatal loss is reported to be stigmatised within the Pakistani community, where couples may face difficult interactions (Batool & Azam, 2016; Sultana, 2014). Women notice their social circle becoming smaller as there is a belief that Parchawan (the possession of evil forces) causes perinatal loss and if a young married or unmarried woman is in close proximity to someone who has experienced perinatal loss, this will result in them experiencing gynaecological difficulties (Sultana, 2014). Within the Pakistani community, there can be stigma associated with mental health services which impacts on an individual's help seeking behaviour (Karasz et al., 2019; Rethink, 2007). The disclosure of mental health difficulties could result in shame for the family and be viewed as a sign of weakness, meaning individuals are more likely to seek counsel from religious leaders (Karasz et al., 2019). Therefore, it is important for healthcare providers to be aware of the complexity, variability, and heterogeneity in the beliefs of the Pakistani community that may impact on experiences of perinatal loss, help seeking behaviour, and health related decisions (Alaradi et al., 2021; Aroussell & Carlbom, 2016).

Summary and aims

The experiences and practices of fatherhood are influenced by culture, discourse, and societal expectations (Pabón et al., 2019). As fathers from ethnic minority groups are underrepresented in research about perinatal loss, more studies are needed to include men from different cultural backgrounds, to understand how perinatal loss can differ in relation to culture and expressions of grief (Jones et al., 2019). Expanding research allows services and communities to identify ways to support fathers through the experience of perinatal loss, improve healthcare service delivery and enhance outcomes for individuals and families hit by perinatal loss (Nguyen et al., 2019). Given that the Pakistani community experiences disproportionately higher rates of perinatal loss, the underrepresentation of fathers in perinatal research, and there not being any research exploring Pakistani men's experiences, this research will aim to explore the lived experience of perinatal loss to:

1. Understand how fathers in the Pakistani community experience perinatal loss.
2. Consider what factors may influence experiences of perinatal loss for men in the Pakistani community.
3. Understand how the experience of perinatal loss for Pakistani men may influence decisions on accessing support.

Method

Design and recruitment

Study design

The research method is qualitative in nature, with a phenomenological and idiographic emphasis. Qualitative methods with a phenomenological emphasis aim to identify descriptions of experience that are understood by those who have the experience (Coyle, 2015). The idiographic focus enables identification of generic themes, but also the narrative of individual participants who have told their story (Smith & Eatough, 2015). These points are relevant for this research as it is an area which is under-researched, which is why a qualitative approach can be helpful (Karin, Young & Schultz, 2015).

Furthermore, the research is focusing on participants lived experiences of perinatal loss. Interpretative Phenomenological Analysis is a qualitative approach that allows researchers to make sense of participants lived experiences (Alase, 2017). The phenomenological emphasis encourages researchers to have a deeper understanding of how the experience has impacted on the lives of participants, by putting themselves in the shoes of the participants (Alase, 2017). As the experiences of perinatal loss in Pakistani men is a new topic area, an IPA approach fits well as there is a need for a method that is participant orientated, allowing individuals to share their stories. Additionally, for the researcher to gain a true understanding of the experiences, IPA as an approach enables the researcher to own the differences between herself and the participants. This is particularly relevant given the cultural and gender differences which are explored further in the reflective statement section, to prevent bias and distortion and the interpretation of lived experiences.

Experts by experience

Two experts by experience were collaborated with as, given the dominant white western narratives in the literature, it was imperative to be culturally sensitive and accessible. The individuals were a White British male and a Pakistani male who had both experienced perinatal loss, recruited by a peer support worker from an NHS trust in the West Midlands. They reviewed the research documents which included the advert, information sheet, consent form, debrief and topic guide. Their involvement resulted in the addition of support organisations as part of the debrief and placing more emphasis on the lead researcher in the information sheet so participants knew who they would be talking to. A consultation forum with experts by experience who had accessed mental health services, but whose experiences of perinatal loss were unknown, was facilitated by one of the recruiting NHS trusts in the West Midlands. The forum shared recruitment ideas to best target the audience for this research.

Advertisement and recruitment

Between October 2022 and May 2023, a qualitative study using semi-structured interviews was conducted exploring Pakistani men's experiences of perinatal loss. Advertisement of the study and identification of potential participants took place at maternity services, perinatal and maternal mental health services at two NHS trusts within the West Midlands, a third sector organisation (who offer services and parenting courses based on Psychology and faith principles) in the West Midlands, and via social media. These organisations were provided with posters (Appendix 1) to distribute to eligible participants, which was also shared on social media. Participants who contacted the researcher were emailed an Information Sheet (Appendix 1) providing further information and an opportunity to ask questions. Potential participants were informed of their right to withdraw, the voluntary nature of participation, and confidentiality through the use of pseudonyms. Participants agreed to their participation by completing and emailing a Consent Form (Appendix 1) before an interview date was arranged. Individuals who consented to participate were entered into a prize draw for a £20 Amazon voucher as compensation for their time and participation in the research.

In line with the research aims eligibility criteria included: being part of the Pakistani community, being born and identifying as male, and to have experienced perinatal loss (see Table 10). There was no minimum time frame for experience of perinatal loss, given recruitment barriers, but individuals were excluded if they were receiving support for acute distress.

Table 10 Eligibility criteria

Inclusion criteria	**Exclusion criteria**
Participants must be aged over 18years	People under the age of 18 years
Participants must have been born male and identify as male at the time of the study	People who were born female or currently identify as female at the time of the study
Participants must have experienced perinatal loss (miscarriage, still birth, medical termination, or death soon after birth)	People who have not experienced perinatal loss
Participants must identify as being part of the Pakistani community.	People who do not identify as being part of the Pakistani community
Individuals living in the UK	People who do not live in the UK
	People who are currently receiving support for acute / long term distress

Initially, the recruitment criteria specified that perinatal loss must have occurred within the last three years and participants must be able to participate without the use of an interpreter. However, recruitment feedback suggested that this criterion was excluding individuals unnecessarily. As this is a new area of research, therefore recruitment barriers were unknown, the criteria were amended following this feedback to remove the time limit for perinatal loss and include individuals who needed an interpreter. This was done to enable more voices to be heard in line with the study aims. This change was approved by the NHS London-Surrey Research Ethics Committee.

Ethical Approval

Ethical approval was obtained from the University of Birmingham Research and Governance Committee and NHS London-Surrey Research Ethics Committee (Ref: 22/LO/0593) (Appendix 2).

Participants

Five participants were recruited from two NHS organisations in the West Midlands (n = 1), a third sector organisation in the West Midlands (n=3) and social media (n=1). The response rate for NHS organisations was 3% and the third sector organisation was 20%. Table 11 provides a summary of the participant characteristics with pseudonyms. Most participants had one experience of loss of either a miscarriage or a stillbirth, occurring from four months up to eight years ago. All participants had children prior to their loss. One of the participants required the use of an interpreter. None of the participants withdrew from the study post-interview and no difficulties were reported following their participation.

Table 11 Summary of participant characteristics

Participant	Age	Type of loss experienced	Number of losses experienced	Time frame since loss	Number of children prior to loss
Imran	30-34	Stillbirth	0-4	0-4 years	3-4
Bilal	35-39	Stillbirth	0-4	5-10 years	3-4
Zain	30-34	Stillbirth	0-4	0-4 years	0-2
Hassan	35-39	Miscarriage	0-4	5-10 years	3-4
Nabeel*	35-39	Miscarriage	5-10	0-4 years	0-2

* required interpreter

Data collection

Data were collected using semi-structured interviews that were audio recorded and transcribed. The author had a Topic Guide (Appendix 1) to inform the structure of the interview. Participants were offered a face to face or online / remote interview. All opted for the online / remote option, which were audio recorded. Most of the participants preferred to keep their cameras turned off throughout the interview. Interviews ranged in duration from 45 to 60 minutes. Participants' wellbeing was monitored throughout the interviews and at the end of the interview by observing any changes in tone, checking they were happy to continue and reminding they could take a break if needed and asking at the end how they were feeling following the interview ending. All participants were emailed a Debrief (Appendix 1) immediately after the interview. Participants were able to request the removal of their data up to two weeks following the interview.

Data analysis

The interview transcripts were analysed using Interpretative Phenomenological Analysis (IPA). As this is a new topic area, the phenomenological and idiographic emphasis lends itself well to IPA as participants were active in shaping the structure of the interview, enabling them to tell their story (Smith & Eatough, 2015; Smith et al., 2022).

IPA consists of several steps which include reading and re-reading, exploratory noting, constructing experiential statements, searching for connections across experiential statements, naming and organising the Personal Experiential Themes (PETs) and developing Group Experiential Themes (GETs) (Smith et al., 2022). Table 12 provides a summary of each stage of the analysis and what this involves.

Table 12 Summary of IPA stages of analysis (Smith et al., 2022)

Stage of analysis	Description
Reading and re-reading	Immersing yourself in the data through listening to the audio recording, transcribing the interview and reading and re-reading the interview transcript
Exploratory noting	Beginning to note anything of interest whilst reading the transcript, maintaining an open mind to understand the ways participants begin to talk about things
Constructing experiential statements	Providing a concise summary of what was important from the exploratory notes. Should relate directly to the participants experience or the sense they have made of this.
Searching for connections across experiential statements	Process of linking statements together in way that could represent PETs. Not all experiential statements may be used.
Naming and organising the PETs	Once the experiential statements have been organised, they are named based on their characteristics. Subthemes are developed within the PETs
Develop GETs across participants	Once all participants have been analysed separately, begin to look for patterns of similarity and differences across the PETs to create GETs

The transcripts were analysed according to Smith et al. (2022) stages of analysis. An extract from a transcript including exploratory noting and experiential statements, and the GETS can be found in Appendix 3. Exploratory noting was made down one side of the transcript from the author reading and re-reading the transcript, The author noted down any points of interest, paying attention to language participants may have used to describe their experience or any repetition of words. For example, one participant referred to the word “strong” throughout their transcript when talking about how they coped with their loss. Data quality was assured through the use of peer supervision groups and use of a reflective diary which are discussed in more detail in the next section.

Reflexive statement and quality assurance

In line with IPA's focus on personal lived experience and participant meaning making, there are four quality indicators for IPA research which include constructing a compelling narrative, developing an experiential account, close analytic reading and attending to convergence and divergence (Nizza et al., 2021). For research to be considered of good quality, and ensure participants lived experiences have been captured, it is important for the author to be aware of her own positioning and how this can influence the interpretation of experiences. The positioning adopted by the author fits with a critical realist epistemological stance. This perspective suggests that knowledge is positioned in power, which influences how humans experience reality (Albert et al., 2020). This reality is considered separate from human perceptions and can never be known with certainty as a result of the language and ideas that are used to describe our world (Pilgrim, 2020).

Awareness of the author's positioning in the research was facilitated by a reflective diary, which was used to record initial thoughts and reflections on the research process, content of the interviews and data analysis.

Through the use of a reflective diary, the author also considered her own positioning in relation to the research and how this may influence and shape the research process. The author is a White British, female, Atheist, Psychologist, and it was not known how this may influence engagement with Pakistani Muslim men. Prior to completing the interviews, the author had completed a clinical placement in a Maternal Mental Health service, working with women who had experienced perinatal loss. Based on clinical experiences, the author had presumptions about participants finding it difficult to talk about the emotive experience that can be associated with perinatal loss. However, the author was surprised at how openness varied between participants as some matched the expectation, but others spoke more openly than expected about their experiences. Consequently, it was important for the author to be aware of the assumption about openness, to ensure this did not influence participants abilities to speak openly in the interview. The author wondered whether being from a different cultural background, religious positioning and gender may have made it easier for the participants to talk openly about their experiences of loss, given the theme of disconnection between religion and community that arose. As a White British, Atheist, female, the author would not have the same beliefs as the Pakistani Muslim community, so it may have felt safer for participants to be honest about their experiences.

The author was uncertain how participants would respond talking to a female interviewer, particularly about emotive experiences. From the authors personal and clinical experience, typically men have found it difficult to acknowledge and talk about emotions, therefore assumed participants may respond similarly. The author ensured questions about emotions were asked and not avoided during the interviews. Sharing of transcripts in peer supervision supported the author in identifying where participants were talking about emotional responses, to ensure this experience was not misinterpreted as a result of presumptions about how emotions may be communicated.

To minimise potential bias from the authors experiences and expectations, a process of triangulation was used. Because this research was conducted by a single author, supervision and peer support IPA workshops were used to ensure that the development of PETs and GETs, and construction of the narrative, were not influenced by the authors positioning. This strategy for analysis enabled alternative perspectives on participants' experiences to be captured and ensured the themes were grounded in the data. Additionally, participants were contacted to share the themes and invited for their thoughts via email but did not respond. The lack of response matches the authors experience of recruiting and supports the literature of perinatal loss being a silent topic, as it appears challenging to encourage and invite participation in discussion about experiences.

Results

Three GETs and six group level subthemes were identified from the analysis of the data (Table 13).

Table 13 Summary of GETs

Group Experiential Themes	Group level subthemes
A ROLLERCOASTER OF EMOTIONS: FROM SHOCK AND DISTRESS TO HAVING HOPE	A moment of calamity: nothing compares The lens of religion for sense and comfort
THE HIDDEN EXPERIENCE OF BABY LOSS AS A MUSLIM MAN	I focus on you not me: responsibility and duty as a Muslim man The cultural mask of strength
THE FELT STIGMA OF BABY LOSS IN THE MUSLIM COMMUNITY	The silence of baby loss A disconnect between Muslim culture and community

Each GET will be summarised and then the associated group level subtheme will be presented and discussed.

A. A ROLLERCOASTER OF EMOTIONS: FROM SHOCK AND DISTRESS TO HAVING HOPE

This theme describes the variation of emotions that individuals have when experiencing baby loss. There is a journey through the sudden nature of loss and associated feelings of shock and upset then, as time goes on, participants seem to look to their religion to provide comfort, hope and make sense of their experiences.

A moment of calamity: nothing compares

The experience of baby loss was felt to be an experience like no other. For many of the participants, this was the first time they had experienced a loss of this nature. When participants realised they had lost their babies, this news appeared to come unexpectedly with a sense of unpreparedness. The process of hearing the news seemed to bring up ever changing emotions for the participants, which felt overwhelming, sudden, and hard to make sense of in the moment.

Bilal describes positive emotions associated with the pregnancy which are then changed to being indescribable feelings *“Everything’s just stopped if that makes any sense like you know you’ve got these emotions of happiness, joy, laughing and then all of a sudden bang you can’t, I can’t even put it into words how it was.” (Bilal, page 3, line 44, stillbirth, 5-10 years ago).* Use of the phrase “all of a sudden bang” adds emphasis to the fast pace and shock of finding out about the loss. In contrast, there is the idea that “everything stopped”. There is the sense that nothing compares to the experience of baby loss, and the use of contrasting phrases of fast versus stopped may relate to not being in this situation before and confusion in knowing how to react to the loss.

Confusion also appeared to be communicated in sense making, where it seemed participants struggled to initially make sense of why they had lost their baby. They hoped there might be other reasons their baby was not moving, such as the baby being tired, rather than facing the news that the loss had occurred. This reaction may have been a way of seeking to control the uncontrollable and unexpected.

> *"I could see different doctors coming in, you know there's something wrong. And I was just in time I was thinking oh please hopefully there's nothing wrong but hopefully he's just, you know, the baby's not moving cos he's tired or something." (Imran, page 1, line 25, stillbirth, 0-4 years ago).*

Zain's description suggested him having a sense of predictability, a sense of what to expect based on his previous experiences with pregnancy, which appeared to be reassuring to him. This is then disintegrated by the news of the loss of his baby, which is utterly in contrast to what he had predicted and expected. His use of a pause and phrase "that gets taken from you" could reflect this shift from the predictability of pregnancy to the utterly unexpected nature of loss. This shift as well as the outcome of losing his baby is difficult for him to comprehend. There is the sense that he is left helpless in response to this unexpectedness and lack of control which the loss caused.

> *"With my daughter when she was being born I was there every step of the way, every scan every appointment, my daughters you know my world. And (pause) then that gets taken from you. And you have to accept it, because there's absolutely nothing you can do." (Zain, page 5, line 87, stillbirth, 0-4 years ago).*

The acceptance of lack of control in baby loss seemed to represent a divergence in experiences. Hassan acknowledged that loss is a part of life and something we have no control over, but still difficult to experience. However, he appeared more accepting of not having control over the loss and holding this with God in comparison to Zain who seemed to feel angry, suggesting individual differences in how fathers respond to and process baby loss.

> *"But yeah, it was really difficult to feel but it's part of life and there's nothing you can do. You can't control it. It's God's gift when you have a child so, you know, if you can lose it you just can't do anything about it." (Hassan, page 2, line 38, miscarriage, 5-10 years ago).*

This enormity of emotion was connected to and spoken about by participants in different ways. Nabeel was able to connect to his own emotional response, using descriptions such as upset or feeling heartbroken. His expression of felt emotion appeared to be a way of coping with difficult, confusing, and unknown experiences. Nabeel's experiences are shared through an interpreter.

> *"His wife went into the bathroom, and she miscarried in the bathroom. And so basically she delivered in the bathroom the, the baby and after seeing this, so he was very heartbroken. He was very, very upset, and he didn't know what to do." (Nabeel, page 1, line 22, miscarriage, 0-4 years ago).*

However, Imran spoke about emotional distress from his wife, rather than his own distress. He suggested never witnessing this level of emotion in his wife before, suggesting shock in how she had responded to the loss. It seemed easier for him to describe the emotional reaction he witnessed in his wife, rather than talk about how loss affected him. Imran appeared unable to relate to or recognise the emotional experience of loss in himself, instead coping with the loss in other ways.

> *"But then er I remember when er the doctors said that there was er there was no heartbeat, er my wife started crying pretty much straight away. She had a both her hands on her face and she was just crying like mad like, she was, I haven't seen her cry like that ever. We've been married like er over seven eight years now and I've never seen her cry like that." (Imran, page 2, line 36, stillbirth, 0-4 years ago).*

The lens of religion for sense and comfort

All participants referred to the role their religion and beliefs play in coping with the loss of their baby. Some participants spoke about believing when they die, their baby will be waiting and looking for them in paradise on the day of judgement, which provided a sense of reassurance. Participants described how the day of judgement is when God decides how people will spend their afterlife, encouraging individuals to live their lives in a good way. For some, the hope of being able to see their baby again felt like a reward for coping with the pain of baby loss.

> *"My religion teaches me that you know, if you, ok yeah it's a loss erm a big loss when you lose a child like that. But our belief is that, you know, on the day of judgement when everyone passes away from this life and is brought back together, our child then looks for the parents. So that's something that is kind of for me reassuring. It gives me the comfort that yeah ok we had a loss, but yeah." (Hassan, page 2, line 27, miscarriage, 5-10 years ago).*

Participants looked to their faith to help them process why they experienced baby loss. They detailed a belief that baby loss is God's will, in that God decides who will be able to have a child and who is ready to leave this world. God’s will appeared particularly relevant in sense making when a medical cause had not been identified for the loss. Belief in God’s will could represent a sense of clarity, as not being able to attribute the cause of the loss might mean they are unable to make sense of and process the loss.

> *“We don’t know to be honest, erm they took a few samples, erm they took a blood test a urine analysis, you know all of that stuff. When it came back that they couldn’t figure out why this had happened, there wasn’t a clear-cut reason. I mean from a religious point of view it’s every soul is here until the time it is meant to be here.” (Zain, page 4, line 66, stillbirth, 0-4 years ago).*

However, even when there was not a sense of uncertainty in why the loss had occurred, participants continued to refer to God’s will in supporting them to make sense of the loss. *“No we, see we are strong believers in our faith. We are Muslim’s we believe, you know, it was Gods will.” (Bilal, page 4, line 70, stillbirth, 5-10 years ago).* It seemed that loss was positioned as being out of participants control, with a suggestion of God’s will helping with accepting the loss. Attributing the loss to a powerful figure like God appeared to feel easier in accepting and coping with the loss, because having to hold responsibility to yourself may be really difficult to tolerate.

> *“But there’s nothing you can do. I mean you’ve done everything you can and if it’s not meant to be its not meant to be. This is why I say it's God's will, it happened and there’s nothing we can do. Just, if you want another child you try again.” (Hassan, page 6, line 113, miscarriage, 5-10 years ago).*

Religion and faith were also considered important in having hope after loss. As baby loss and the gift of children are viewed as being in the hands of God, continuing to follow and respect your faith may mean you receive the reward of children. It seemed for Nabeel, whose experiences were communicated through an interpreter, he did not lose hope that he would be blessed with children. Faith appeared important for Nabeel to focus on in coping with his previous losses and hopes for the future.

> *"He says, yeah, he was 100% faithful that God would give him a child, and he said the first step was that conception and which was happening. She had been pregnant for 9 times, and, and it was there, and one day God will bless him with children. And he has, and he has, it's his faith that kept him strong and to go through." (Nabeel, page 4, line 71, miscarriage, 0-4 years ago).*

Participants communicated a range of emotions throughout their experience of loss. The emotions and experiences described reflected a sense of unpredictability, lack of control and uncertainty. However, participants were able to look to their religion and faith to support them in making sense of the loss by attributing an uncontrollable situation to the power of God.

B. THE HIDDEN EXPERIENCE OF BABY LOSS AS A MUSLIM MAN

This theme describes the experiences of baby loss as often being hidden, especially for Muslim men. There was a sense that men did not talk about their feelings in relation to the loss and this was kept private as they had other responsibilities and needed to be seen as strong by others around them.

I focus on you not me: responsibility and duty as a Muslim man

Participants emphasised the roles and responsibilities they have as a Muslim man, particularly in the context of baby loss. Responsibilities included supporting their wife by offering comfort and support, helping with household tasks, taking care of children and arranging the burial. It appeared the responsibility left no time or space for their feelings about the loss to be acknowledged. Imran's use of "maybe other men could relate to this" suggests the responsibility as a man could be a shared view within the Pakistani community.

> *"Maybe, maybe, other men could also relate to this I don't know. I, I, the way I felt at the time was because, you know, being a man you have responsibility looking after your wife and then the children and comforting them, and then you know er it was on me to do the burial and er all these other things." (Imran, page 36, line 745, stillbirth, 0-4 years ago).*

The sense of responsibility to your wife and family felt so powerful, it seemed there was no space for these men to consider their own feelings about the loss. However, there was also a sense of avoidance, whereby it seemed participants would prefer to keep busy to prevent the feelings about loss from coming up. *"Yeah and my wife wasn't able to do a lot so that kept me busy like washing up, cleaning, that sort of stuff, taking care of my daughter." (Zain, page 9, line 175, stillbirth, 0-4 years ago).* The presence of feelings or emotions could be seen as interfering with participants ability to fulfil their responsibility and duty as a Muslim man. Therefore, keeping busy could be a coping mechanism to ensure they do not have to focus on their own pain and can remain focused on the needs of their wife and family.

> *"Blocked, yeah I blocked it out. I knew what had to be done with regards to the burial procedure and everything and my wife needed support, which obviously I was there for, and er I didn't er consider myself in anyway." (Bilal, page 5, line 88, stillbirth, 5-10 years ago).*

Participants may have chosen to not talk to their wives about the loss, , as there was a sense they did not want to add to the emotional load their wives were currently experiencing. It could be that participants did not want to feel responsible for causing additional distress, instead wanting to maintain the responsibility of support. There was a sense of internal conflict, whereby participants recognised their own emotional response to the loss, whilst knowing they could not share their experience as they had their duty as a Muslim man and husband to fulfil.

> *"Whereas my wife, I wouldn't talk to her about it because I, I, didn't want to hurt her coz she cried so much like I said, and you know she was already, I knew she was going through, she was really upset." (Imran, page 29, line 611, stillbirth, 0-4 years ago)*

There was also suggestion that men were not able to be affected by baby loss due to not physically experiencing pregnancy. Focusing on physical experience minimised experiences of loss, possibly making it harder for men to share their experiences. *"Yeah ok we had a loss, but yeah I did feel really, I probably don't, you felt, you wouldn't feel as much as a woman does because I suppose that's in the woman's stomach and stuff." (Hassan, page 2, line 34, miscarriage, 5-10 years ago).*

The cultural mask of strength

Participants talked about being a strong man, with it seeming important to be viewed as strong by those around you. There was a sense of strength feeling like a mask for Muslim men, with strength being important for other people to see, even in the context of loss. Most of the participants opted to not be seen during the interview, reflecting the idea that emotions associated with baby loss are not visible to others. The idea of needing to be a strong man was not necessarily spoken about, but something the participants instinctively knew they had to do, which could represent a cultural stereotype about how men should be viewed by others.

> *"So like, you know, crying too much and like, you know, I, I, just felt like there's nothing. You know, no one says this but it's just a feeling where, you know, you gotta be er a man and strong." (Imran, page 36, line 750, stillbirth, 0-4 years ago).*

In Muslim cultures men are seen as the head of the family, and participants all spoke of how this narrative impacted their experiences of loss and ways of coping. It seemed that showing emotions equated to weakness, with a sense that this would be looked down upon and impact on a man's status both in the family and community. The power of others in viewing you as strong, seems influential in how men may communicate their experiences.

> *"I think it men, men, are looked at as very, very strong. You know, um the head of the family kind of strong person that's gotta be strong. So I think emotions and stuff we, we, don't really share cos I don't know, if we start I, I'm just assuming this. I think if we start to share these things then people think you're really weak. I think men don't want to show that they're really weak. That's my assumption." (Hassan, page 10, line 213, miscarriage, 5-10 years ago).*

There was a sense of needing to be strong and carry on, irrespective of what you were experiencing. Needing to be strong could relate to a desire to show others you are not suffering. It seemed important for other people to be able to see participants continuing with their lives, but there was a sense of the emotions still remaining. Consequently, baby loss for Muslim men is a hidden experience as it seems no one is permitted to see the emotive experience of loss underneath the mask of strength.

"There's no point crying about it. Yeah you can cry about it, but you just gotta get on with it. You've just gotta get on with it. Be strong about it. Yes, you might feel sad about it but, but there's nothing you can do about it. You have to kind of pick yourself up and and continue." (Hassan, page 13, line 270, miscarriage, 5-10 years ago).

However, there was divergence in how the mask of strength was used. For some individuals the mask of strength was displayed to both the Muslim community and family. There was a sense of weighing up the risk of exposing your emotive self, versus maintaining the mask of strength. There was acknowledgement of an emotive experience, but the emotional response itself remained hidden for some.

"You know, I wouldn't you know do it [cry] in front of my father for example, my parents and my brothers I wouldn't be able to. I, I, did explain to someone my brothers and my cousins and everyone later on that, you know, I had to go through this. But I wouldn't openly cry in front of them". (Imran, page 9, line 182, stillbirth, 0-4 years ago).

For others, it seemed the mask was maintained for the community, but the true self was revealed when in company with your wife. Emotions were able to be freely displayed, which seemed to be without judgement. It seemed that the wider Muslim community has a dominant narrative of needing to maintain the mask of strength, but individual families have their own interpretation of the narrative, whereby the presence of emotion feels valued.

“When you're with husband and wife you are you, you can cry, you can show your emotions. You can talk about the child, and you can grieve. But when you're alone with the community it's totally different. Right now he goes I'm talking about my children, and it's very, very hard for me, but I’m putting everything together, and I’m having this conversation. It's difficult, but when it's just himself and the Mrs it's different. Then he can, you know, let his emotions out and tell her how he's feeling, and how he's dealing with stuff.” (Nabeel, page 4, line 77, miscarriage, 0-4 years ago).

Overall, there is a sense that men’s experiences of baby loss are not valued in the same way as women’s experiences. The duty and responsibility that Muslim men feel to support and protect their wives, means there can be no time or space for them to process their own responses to the loss. Alongside the cultural pressure of being a Muslim man, is the idea of needing to maintain strength in the face of adversity. There appears to be a narrative of the presence of emotions being viewed as weak, which impacts on a how a man is perceived within his community.

C. THE FELT STIGMA OF BABY LOSS IN THE MUSLIM COMMUNITY

This theme focused on the felt stigma associated with baby loss in the Muslim community. Participants referenced difficult interactions and beliefs which have meant they felt unable to talk about their loss. There was a sense of disconnection between religion and community, resulting in frustration and isolation.

The silence of baby loss

Participants suggested that baby loss is a silent and private experience within the Muslim community. It felt that the ability to share baby loss and the associated experiences was often shaped by the reactions and responses of others. Keeping baby loss silent could be a way of individuals protecting themselves from the opinions of others in their community.

> *"Yeah not, being told you know that you've got to get over it was the biggest things, and you know being told you know you've got your daughter at least. And I thought ok fine,* let me *go and kill one of your children and that's ok because at least you have the others." (Zain, page 12, line 243, stillbirth, 0-4 years ago).*

There was a sense that baby loss was not viewed in the same way as other bereavements. Zain felt being told to "get over his" loss because he still has a daughter minimised his experience of loss. He described the response as being similar to him killing someone else's child but reminding them it would be ok because they had another child. The term "kill" is a very powerful term to use in this context, suggesting Zain needed an extreme way to show there is no difference irrespective of how your child's life ended. There was a sense of confusion and anger for why baby loss was viewed so differently. Zain's experience seemed to suggest there is no other option but to remain silent given that baby loss is misunderstood.

Participants felt baby loss was not spoken about openly within their community, suggesting possible stigma around this subject. There was a sense of not knowing anyone else who had experienced baby loss, implying it was not a topic directly spoken about. *"Er eh see (pause) that's a hard one, because er I don't know a lot of people er who've lost babies."* (Imran, page *31, line 646, stillbirth, 0-4 years ago).*

In contrast to not knowing anyone, there was suggestion of knowing people who had experienced baby loss, but this was not spoken about openly. It could be that baby loss as an event has been acknowledged, but conversations about the experience or impact of this have not occurred. Therefore, it seems that the experience of baby loss is silent rather than the loss itself. The decision to remain silent about the experience of loss could be influenced by systems around the individual, such as family or community views. *"You know, in our community it's like brushed under the carpet, don't mention it again, it's done move on."* (Bilal, page 10, line *211, stillbirth, 5-10 years ago). "They've gone through this which no one knew about. Two of my aunts, they told me they had been told to be quiet, they had been hushed up."* (Zain, page *14, line 287, stillbirth, 0-4 years ago).*

Alongside differences in experiences of hearing about baby loss, was the sense of men not being open about their losses compared to women. Men not talking about their experiences could relate to the cultural dynamics discussed in the previous theme about needing to be strong and support their wives. It could be seen as gender stereotypes in the context of culture influencing the expression of baby loss.

> *"Hmm yeah well to be honest you know; I've not heard from any male friends that I have that any of their wives have had a miscarriage. So you can, you can see from that that men don't talk about it." (Hassan, page 18, line 386, miscarriage, 5-10 years ago).*

A divergence in the theme of the silence of baby loss is that some participants created opportunities to talk about their experiences. Talking openly about the loss appeared to result in a realisation that this was a helpful rather than harmful thing to do. There was a sense that the realisation of the benefits of talking helped them to cope with the loss but also resulted in a ripple effect in encouraging others to open up about their experiences.

> *"The best thing I did was actually talk about it. My sisters a X and she said you got to talk about it, you got feelings as well. I said I'm fine, don't worry about me. She says what do you mean don't worry about you, and my wife was there obviously, and she said it as well. And then I opened up and I spoke to them, and to this day we speak about it and obviously if I know of anyone within the friends and family circle, I speak to the guy." (Bilal, page 11, line 221, stillbirth 5-10 years ago).*

It seemed that although initiating open conversations about experiences of loss was a start, there was a sense of more needing to be done to actively encourage a cultural shift in understanding baby loss. Nabeel felt conversations needed to be started by those who have significant influence in the community, such as religious scholars, implying that status is considered an important factor in challenging cultural narratives. There was a sense that if any other man attempted to challenge these ideas, they may be ridiculed as "the crazy man who keeps talking about it". There was a sense of needing powerful influence to encourage more people in the Muslim community to hear the reality of baby loss.

"We need a platform within our Muslim communities or any culture. We have lots of religions within our culture. We have Muslim, we have the Indians, we have the Bangladesh . . . you need a platform where religious scholars approach these topics and deal with these topics in a big level, and if he just sits on the pilgrim and starts speaking, there's no one going to listen to him. So just classify him as the crazy man who keeps talking about it. But if someone who's a religious authority with a big name, and who has a voice within the community. . . they listen to them . . . that can bring a change in the culture." (Nabeel, page 9, line 185, miscarriage, 0-4 years ago).

A disconnect between Muslim culture and community

Participants reflected how there felt a disconnection between what their Islamic religion teaches them compared to the response of the Muslim community and their own personal views. There was a sense of religion teaching one perspective but participants experiencing a very different interpretation from their community.

"Islamically, no after 17 weeks your babies one of their rights is they get named, they have a name. So I did the right thing there. And then the burial I was told, why don't you just let the hospital take care of it, why are you burying your child. No, Islamically you have to, that's one of their rights, you have to bury them. But no, they put on this Islamic disguise when actually they know jack shit about their religion." (Zain, page 13, line 264, stillbirth, 0-4 years ago).

Zain highlighted the criticism he received from the community but was clear from a religious perspective he had followed Islamic teaching. Zain's use of "Islamic disguise" seems to communicate anger about the lack of understanding from the Muslim community about baby loss. There was a sense of Islamic teaching not being appreciated, with assumptions being made about how baby loss should be managed within the Muslim community.

Similarly, participants also noted negative interactions from the Muslim community in relation to their loss. There was a sense that the Muslim community would not be supportive of experiences of loss, which could suggest felt stigma as a result of the loss. *“Yeah, just to be quite frank with you, I just feel there's, there's not a lot of well-wishers in the community to be honest.” (Hassan, page 8, line 152).* Although religion offered comfort to Zain in his own experience of loss, he suggested other people’s use of religion to explain his loss was unhelpful. Zain felt being told by others the loss of his baby was God’s will closed down conversations he wanted to have. There was the sense of wanting the loss of his baby to be acknowledged but instead being told to “move on”. Zain appeared understandably frustrated and hurt by the response to his loss, reflected by his use of language “fucking heartless people”. His use of a pause within this conversation also suggests it was a difficult concept for him to make sense of in relation to his own experience of loss. The felt disconnect between community and religion could result in individuals feeling rejected and isolated in relation to their experience of baby loss.

> *“Like its Gods will ok move on. And it’s, you know, I was being told you, you know so and so went through a miscarriage and they never looked back, they never saw their baby again. And it’s like you fucking heartless people.” (Zain, page 11, line 228, stillbirth 0-4 years ago).*

There was a sense of uncertainty about what Islam teaches in relation to baby loss. Nabeel’s experience suggested disconnection from his religion as he felt there was no guidance in how to manage the loss of his baby commenting “he didn’t know at all”. Nabeel also appeared to be communicating regret for the disconnection and not knowing the procedures to follow. Nabeel, through the use of an interpreter, suggested the Muslim community needed to acknowledge baby loss so that there was clarity on what people needed to do in these circumstances, to provide the connection between religion and community.

"He didn't know at that time, because how to do it culturally or Islamically, and what to do with the pregnancy, and he didn't know at all. So he would just give it to the hospital. Now he's come to realize that he shouldn't have, and he had, he should have got it back from the hospital and buried the, the, the pregnancy. With that, because the baby was in the mom's tummy, and you know, even if the first short period of time he had, he or she had a heartbeat, so he would be a, it would be buried. But unfortunately, he did not know that erm, so he didn't get the opportunity to do this" (Nabeel, page 2, line 38, miscarriage, 0-4 years ago).

Participants wanted there to be more education about baby loss, so the Muslim community could better understand and support those who have experienced loss. Zain and Nabeel reflected on the disconnection between religion and community in the context of increased education. There was a sense that Islamic teaching could offer support to individuals experiencing loss, but the Muslim community needed increased awareness of the teachings. *"And he knows this, and he just wants his community to realize, basically wake up from this and just, just be realistic and deal with it in a proper and educated manner." (Nabeel, page 8, line 180, miscarriage, 0-4 years ago).*

"A lot of it comes from not being educated, most of it comes from not being educated. When I say educated, they are not educated in Islamic. Because when I read up on the Islamic side

that's what gave me a lot of erm support, because you then get, you then realised actually no you had your baby, your baby has rights, and these are the rights they have." (Zain, page 12, line 255, stillbirth, 0-4 years ago).

Bilal similarly reflected wanting to challenge the cultural narrative in talking about baby loss. There was a sense of the perception of being a macho man as a "backward mentality". Honesty felt more powerful for Bilal than pretending to be strong. He seemed to be communicating the need to be more open to prevent the wrong impressions being created about people.

> *"We have a saying amongst ourselves it's like a backward mentality that the man's a man. Speak about it, speak to your wife, help your wife, there's nothing wrong with that. It's the wrong perception for certain people especially in the Pakistani Muslim community. There is a macho man image type of thing but it's not, you're only fooling yourself." (Bilal, page 14, line 287, page 14, stillbirth, 5-10 years ago).*

There is a sense that the experience of baby loss had to remain silent for most participants, due to the felt disconnection between their religion and community. It seemed that the Muslim community could hold assumptions about baby loss, which the participants did not agree with. There was a sense of wanting to change the narrative that currently exists, through increased education and awareness about baby loss. However, it was felt this needed to be led by religious scholars within the community for the difference to be noticed.

Discussion

This is the first piece of research exploring Pakistani men's experiences of perinatal loss. This study aimed to contribute to the existing body of literature on men's experiences of perinatal loss, by considering the experiences of individuals from an ethnic minority group.

Summary of findings

This research aimed to explore Pakistani men's experiences of perinatal loss. IPA was used to explore the participants lived experiences which identified three GETS with six group level subthemes: 'A rollercoaster of emotions: from shock and distress to having hope', 'The hidden experience of baby loss as a Muslim man', and 'The felt stigma of baby loss in the Muslim community'. The findings will be discussed in relation to the existing body of literature, considering limitations of the current research. Clinical implications and considerations for future research will also be presented.

A rollercoaster of emotions: from shock and distress to having hope

This theme captured the range of emotions that Pakistani men experienced following baby loss. The men spoke about shock, feeling there was nothing they could do. These emotional experiences reported by Pakistani men are also reported by Caucasian men (Aydin & Kabukcuoğlu, 2020; Pabon et al., 2019), implying men's emotional responses following baby loss may be similar across cultures. However, the difference for Pakistani men in moving from shock to hope is the role of religion. Religion was not commonly identified in the existing literature on men's experiences of perinatal loss. Aydin & Kabukcuoğlu, (2020) acknowledged the role of God, but this was more in terms of spirituality than religion. Research exploring Muslim women's experiences of perinatal loss identified the role of religion in coping with and making sense of the loss (Batool & Azam, 2016; Sutan & Miskam, 2012). Consequently, emotional experiences associated with perinatal loss maybe similar across some cultures, but sense making and coping is unique to each culture. For Pakistani men, culturally specific experiences included believing the loss was God’s will, and feeling reassured that they would meet their babies again in paradise on the day of judgement.

The hidden experience of baby loss as a Muslim man

This theme captured the experience of Pakistani men needing to continue their responsibilities and duties to their family, irrespective of their emotional responses. Participants described focusing on their wife’s needs, putting their own feelings aside. It was important for the participants to be viewed as strong, with expression of emotions being considered weak. Some participants acknowledged not physically experiencing the loss, so minimised their own experiences as a result. Needing to be strong, support your wife and not being physically affected is shared with the literature on Caucasian men’s experiences of perinatal loss. The literature suggested that Caucasian men felt they had a duty to support their partner, with any physical experience of loss outweighing their own emotional experience, stoicism and not showing any emotional response to the loss (Aydin & Kabukcuoğlu, 2020; Chavez et al., 2019; Due et al., 2017; O’Leary & Thorwick, 2006; Wagner et al., 2018; Williams et al., 2020). This theme appeared to be one that is most consistent with the literature that currently exists on men’s experiences of perinatal loss. Therefore, it appears across some cultures there is a social constructionism of the male identity and stoicism. Although not unique to Pakistani men, the social construction of the male identity is useful to understand in terms of how Pakistani men experience baby loss. Interestingly, the literature on Muslim women’s experiences acknowledges the desire for their husbands to take on decision making and arrange the burial (Sutam & Miskam, 2012), but did not share the narrative of needing a strong husband. Therefore, women may not be aware of this felt societal pressure for men and assume their husbands are coping with the loss when there may be hidden feelings men feel unable to share.

The felt stigma of baby loss in the Muslim community

This theme captured the experience of baby loss not being spoken about in Muslim communities, with men feeling lonely, angry, frustrated, and disconnected in their experience of loss. This contrasts the previous theme where men highlighted the need to be strong and not talk about their emotions. Conversations were closed down, or perinatal loss was viewed differently and lesser to other types of bereavement, such as the death of an older child. Wagner et al. (2018) identified that perinatal loss was a disenfranchised experience, but this is also seen in Western populations. What is specific to the Pakistani community is how beliefs about loss impact on disenfranchisement. Participants reported judgement for decisions they made, feeling blamed for the loss and assumptions being made. Baby loss felt like it had to be a silent experience, which is supported by the literature on Muslim women's experiences of perinatal loss, with women not wanting their community to know about their loss as they were afraid of the response (Garcia et al., 2020). Women reported being questioned about things they had done wrong in their life, feeling they were being blamed for the loss (Batool & Azam, 2016). These findings support the narrative of a disconnect between religion and community, as there appears a difference in how the community respond and what religion teaches. Consequently, perinatal loss may be a hidden experience, but there are culturally specific nuances which impact on the felt stigma of perinatal loss.

Within this theme, some participants wanted conversations to be opened up about perinatal loss. However, it is important to note the interest in opening conversations was highlighted by individuals who had chosen to participate in research talking about this topic. Therefore, it may not be a view that is representative of all Pakistani men.

Participants discussed support they would like to be available following perinatal loss, but this was unable to be captured as a theme as the data was not rich enough. Some suggested only accessing support if it was offered for couples and would not access support alone. Others wanted to access something specific to men and would value hearing from other men in the same circumstances as themselves. Therefore, support could be explored further to better understand what Pakistani men need.

Limitations

This research aimed to capture the experiences of perinatal loss in Pakistani men. As this is the first piece of research exploring the experiences of this group, there are some limitations that need considering when conducting further research into the experiences of Pakistani men.

The sample size of five is adequate for qualitative research but may not be representative of all Pakistani men. It is likely those individuals who came forward were able to talk openly about their experiences of loss, which may not be the same for all men in the Pakistani community. It is possible that some experiences and voices remain unheard and have not been captured in this research.

Participants had varying time frames since the loss was experienced, ranging from four months to eight years. Although there were similarities in the experience of loss, it is not known how the time frame since the loss may have influenced recollection of the experience.

All participants had children prior to perinatal loss. Therefore, the experiences captured in this research may only be relevant to those who already had children. It is unknown whether experiences of perinatal loss are different given your family set up.

Clinical implications

Given the themes of silence and disconnection, an important clinical implication is dissemination of the findings to encourage working together in perinatal loss. The implications listed are suggestions of what could be achieved, but engagement is needed with the Pakistani community, NHS and third sector organisations to hear their perspective. These organisations have been contacted with the aim of opening discussions around the findings of this research and to think together regarding the implications of these. This engagement and working together is important to avoid perinatal loss feeling a silenced topic and providing opportunities for connection between religion, community, and services.

Services may need to consider how support is offered to Pakistani men. Participants suggested that their initial focus was on the needs of their wife and arranging the burial. Therefore, it would be important to consider the timing at which support is offered. If support is offered soon after the loss, it may not be the right time for men given the felt pressure to maintain their other responsibilities. It would also be useful to consider how men may present to services. Some participants found it easier to talk about their wife's distress rather than their own. Consequently, services may need to think about how they include men in the assessment of women's mental health needs. As part of the NHS Long Term Plan (2019), it is recommended that partners of women who have experienced perinatal loss have improved access to evidence based psychological therapies and are offered mental health checks and signposting to further support. However, there may be barriers to this that warrant consideration. Participants in this research all opted for online / remote interviews, with most preferring to remain anonymous which may be related to the felt stigma in talking about baby loss. Services may need to consider options for men to engage anonymously, however, due to management of risk this may not be best placed in the context of NHS services. Therefore, how support is offered to men warrants further discussions in clinical services.

As participants focused on the felt stigma of perinatal loss and the need for increased education and awareness, it may be helpful to consider how increased education and awareness could be achieved. It may be helpful to offer joint education or information-based sessions with religious leaders to encourage understanding perinatal loss to begin breaking down barriers in talking about loss. Religious leaders would be key, as a participant referenced the need for conversations to be started from their scholars. Engagement with religious communities could include having posters up in mosques that specifically mention baby loss, as a way of giving permission for loss to be acknowledged and spoken about as a way of beginning to address the silence in experiences of perinatal loss.

Services may benefit from culturally sensitive training specific to the Pakistani community and perinatal loss. For example, it may be useful to gain insight in how men may talk about their loss, in terms of focusing more on the needs of their wife. Services may also need to consider how questions are asked during assessments given the disconnection between religion and community. As participants did not always connect to wider cultural narratives, such as not talking about loss, services may need to consider how they can work with this disconnection so that it does not influence service accessibility.

Given the low response rate from NHS services suggesting 97% of eligible individuals declined to participate, it may be useful to consider why this is through employing a Pakistani male peer support worker. A Pakistani male peer support worker may provide a link to the Pakistani community, provide connection between religion and culture, consider potential barriers in service accessibility, and think about what men need or not from NHS services. However, given the sense of disconnection and the authors experiences of conducting the interviews, it may be useful to complete this engagement work alongside someone of a different cultural background (e.g. White) so the Pakistani community have a choice in who they may feel most comfortable to engage with.

Future research

As this is the first piece of research specifically focusing on experiences of Pakistani men, there are a number of different avenues for future research.

Given the recruitment barriers identified, future research may want to consider recruiting from non-NHS organisations for potential participants as there was a greater response rate from third sector organisations compared to the NHS.

Future research should consider differences in experiences on the time frame of the loss, to explore the influence on how participants define their experience and support they are looking for. Additionally, it would be useful to explore the differences in experiences depending on whether or not fathers already have children.

This research focused specifically on Pakistani men, but it is not known about the experiences of other subgroups of Muslim communities. It would be useful to see if their experiences are similar or if there are nuances between subgroups.

Finally, it would be helpful to further understand the support needs of Pakistani men who have experienced perinatal loss. It was suggested how Pakistani men may present to services based on their presentation in this research. However, support in itself was not rich enough to establish a theme. Therefore, increased understanding about experiences of accessing support and if support is needed would be beneficial.

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3. PRESS RELEASE FOR LITERATURE REVIEW

Press Release: The Prevalence of Postnatal Depression in Black ethnic groups compared to White ethnic groups

Postnatal Depression (PND) is a depressive disorder that can occur during pregnancy or in the four weeks following childbirth, PND affects everyone differently, with some women requiring hospitalisation and others having support at home, There are some factors which make it more likely that a woman may experience PND including changes in postpartum hormones, having a family history of mental health difficulties, previous mental health difficulties, stress, social support and marital difficulties.

The global prevalence rate for PND is estimated to be between 10-20%. However, PND is underdiagnosed and undertreated, meaning we cannot be certain these estimates are accurate. There is evidence to suggest that individuals from ethnic minority groups are at an increased risk of developing PND, with Black ethnic groups in particular having an increased risk. A meta-analysis was performed to provide an estimate of the prevalence rates of PND in Black ethnic groups compared to White ethnic groups and the factors that might influence this.

Searching through different databases and articles, the review found 27 articles which reported the prevalence rates of Black ethnic groups and White ethnic groups published up until April 2023. In all 27 articles there was a total of 1,561,932 participants from either the United Kingdom (UK), United States of America (USA) or Brazil. The records were reviewed according to a set of quality criteria which outlined possible risks of bias. Overall the quality of the studies was mixed, with most rated as unclear or high.

The prevalence of PND in Black ethnic groups was estimated as 15% for this review. The factors that were considered to influence the prevalence rate of PND in this analysis were ethnic subtype, the type of assessment used for PND, and the country individuals were recruited from.

Compared to White ethnic groups, Black ethnic groups were not found to be at an increased risk of PND, however the factors identified that may influence this risk were the type of assessment used, and the country individuals were from.

The studies included all varied in terms of their quality, which may have an influence on the estimated prevalence rates and risk of PND in Black ethnic groups compared to White ethnic groups. More research is needed to further explore the influential factors that may impact on prevalence rates and risk of PND, as some of these factors only included a very small number of studies. Specifically, more research is needed to include studies looking at different subtypes of Black ethnicity and increased research globally to be able to understand the differences across countries. Increased research would enable us to be more confident in identifying those factors which truly influence prevalence rate and risk of PND in Black ethnic groups.

There are also important implications for the type of assessments used for PND. Prevalence rates were lowest when women were asked outright if they had a diagnosis, suggesting that PND could be missed or underreported depending on how questions are asked to women. Some of the assessments were short screening tools not specific to PND but were found to have similar prevalence rates to those that were specific for PND. Non-specific measures also increased the estimate of risk of PND in Black ethnic groups compared to White ethnic groups. It could be plausible that the use of shorter screening tools may be more efficient for services to use for their assessments of women with possible PND. However, this needs to be considered alongside the risk of over or underdiagnosing PND with the use of a non-specific measure. Therefore, further research is needed to explore the reliability of these measures to contribute to understanding how PND can be accurately identified in services, meaning that women are accessing the services that can best meet their mental health needs. However, there may be a proportion of women who do not present at services, given the evidence of PND being undertreated. Therefore further engagement may be needed with the Black community to better understand how to support women in the Black community with their mental health needs when they do not present to services.

4. PRESS RELEASE FOR EMPIRICAL PAPER

Press Release: “You’ve Gotta Be A Man And Be Strong”: Fathers’ Experiences Of Perinatal Loss In The Pakistani Community

The term perinatal loss includes miscarriage, still birth, termination due to medical reasons and neonatal death. Perinatal loss is known to be a difficult experience for parents. However, many parents report feeling that family, friends and other professionals feel uncomfortable talking about their loss. As a result, many individuals are left feeling that others do not understand their experiences, so tend not to share how they are coping with the loss. Everyone experiences grief differently, but there are some factors that can influence how we may grieve any type of loss, such as culture and gender.

Some people feel that as women experience pregnancy, perinatal loss only impacts on them. However, although men may show their grief differently, they still report similar feelings to women when they have experienced perinatal loss. For some men, they believe they need to be strong, not show their emotions and be able to support their partners. Men have not always been included in research about perinatal loss, with the main focus being on women’s experiences.

There is very little research that looks at the experiences of perinatal loss in individuals from ethnic minority groups. We know that culture can influence grief, so it is important to consider how culture may impact on experiences of perinatal loss. The city of Birmingham has one of the highest rates of perinatal loss, with some of the highest figures being recorded in the Pakistani community. Therefore, this research was conducted to understand how fathers experience perinatal loss in the Pakistani community.

Five men from the Pakistani community in the West Midlands took part in interviews about their experiences of perinatal loss. The men were aged 30-39 and had experienced either a stillbirth or a miscarriage. The losses had occurred within the last eight years.

Analysis of the interviews identified three main themes from the men’s experiences of perinatal loss.

A rollercoaster of emotions: from shock and distress to having hope

Men described the range of emotions they experience when finding out they have lost their baby. There is a sense of loss feeling sudden, meaning men feel shocked and upset when they find out. However, as time goes on, the men seemed to look to their religion to make sense of why they experienced a loss. Religion also provided hope and comfort to the men that they would be able to meet their baby again when they die on the day of judgement. The day of judgement is when God decides how people will spend their afterlife, encouraging people to live their lives in a good way.

The hidden experience of baby loss as a Muslim man

Men described their experiences of baby loss being hidden. It felt that men were unable to talk about their feelings about the loss due to other responsibilities they had. It was important to the men to be able to support and provide for their wife. However, despite how they felt about the loss, the men needed to be seen as strong by their community. Being strong meant not showing emotions, so their feelings were often not prioritised.

The felt stigma of baby loss in the Muslim community

The men acknowledged feeling perinatal loss was stigmatised in their community. Many talked about difficult interactions they had with people in their community, and assumptions that other people hold about baby loss. As a result of the assumptions and responses to their loss, the men felt they were unable to talk about their experiences. Some men spoke about disconnection between their religion and community. It appeared that Islam taught about baby loss, but the Muslim community response did not always match the teaching, resulting in frustration and isolation.

This is the first piece of research exploring the experiences of perinatal loss in Pakistani men. As only five individuals took part, the views captured may not be representative of all Pakistani men. However, there are important findings to consider in terms of the need for increased education and awareness about the impact of perinatal loss for Pakistani men. Healthcare organisations may benefit from engaging with the Muslim community to think about how this can be achieved. Further research is needed to explore other factors that may influence experiences of perinatal loss in Muslim men (e.g. time frame since the loss, other Muslim subgroups and understanding support needs of Pakistani men).

APPENDICES

1. Study materials

Participant information sheet

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PARTICIPANT INFORMATION SHEET

Title of Project: **Fathers' Experiences of Perinatal Loss in the Pakistani Community**

Name of Researcher: **Rebekka Harrison, Trainee Clinical Psychologist (Birmingham and Solihull Mental Health NHS Foundation Trust; University of Birmingham)**

We are sorry that you have experienced perinatal loss and are aware this may be the first time you have been asked to think about your experiences of this loss. We would like to invite you to take part in a research study that is being undertaken as part of Rebekka Harrison's Doctorate in Clinical Psychology at the University of Birmingham. It is hoped that this research will allow increased understanding of the needs of the Pakistani community, especially fathers, in relation to perinatal loss which is an area that currently very little is known about. It is hoped this will also support professionals to think about how their services can be adapted and developed to be more accessible and sensitive to needs of fathers and the Pakistani community. We would like you to read the information below before you decide to take part, so that you can understand why the research is being carried out and what might be involved for you. Contact details for the researchers are provided at the bottom, so please feel free to contact us if you have any further questions.

Why are we doing this research?

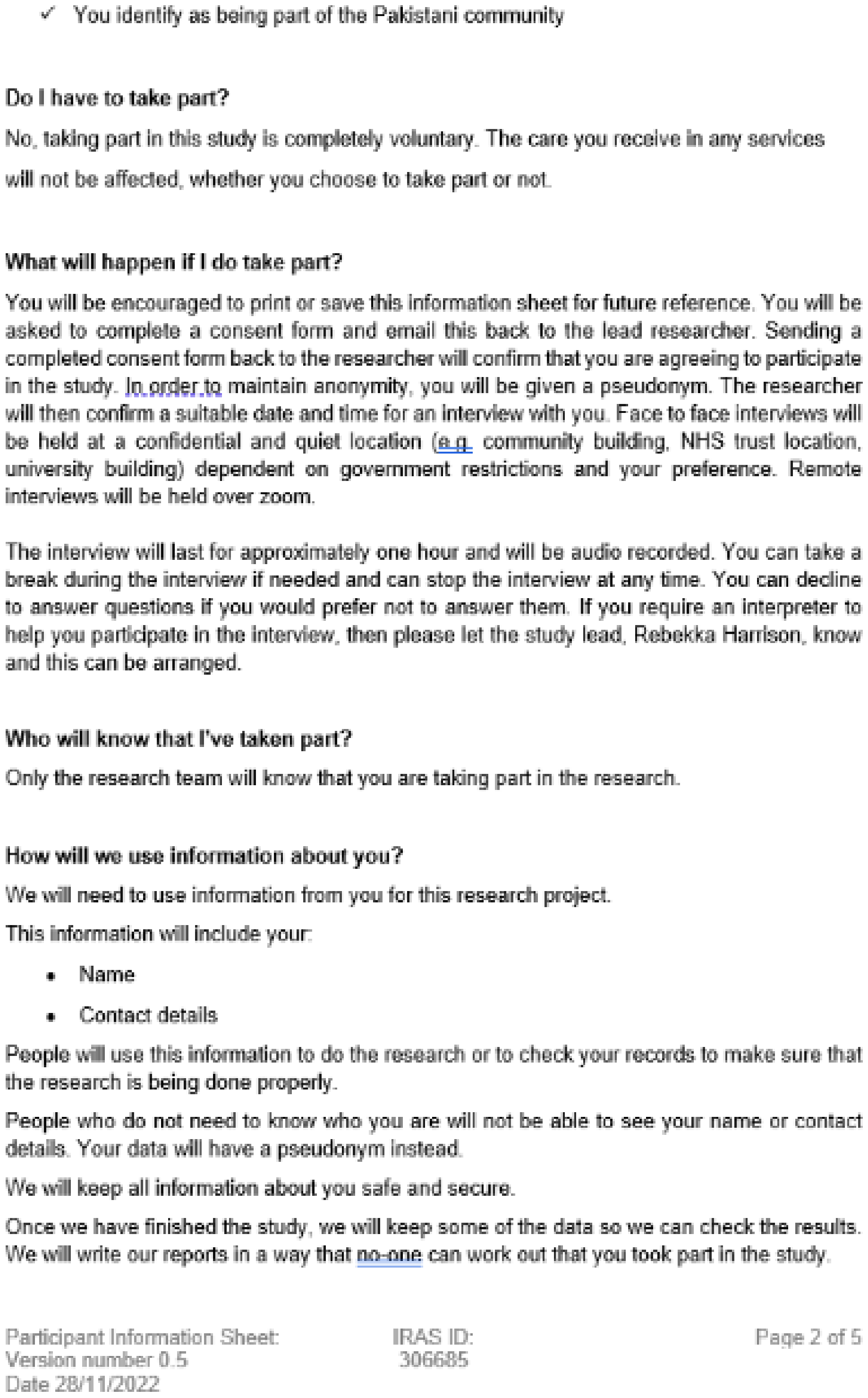
Perinatal loss (miscarriage, still birth, medical termination or death soon after birth) is known to be both an emotionally and physically traumatic event for parents. Overall, most of the research that has been conducted on perinatal loss has primarily focused on women and mothers. When fathers have been included in research, this has often been as part of a couple or focused more on incidents and reasons for the perinatal loss as opposed to fathers' experiences and support needs. Furthermore, there has been little research focusing on perinatal loss within the context of culture. Most research has focused on Western societies, and it is unknown how culture may influence experiences of perinatal loss. It is known that there is a high rate of perinatal loss within the Pakistani community. Therefore, this research will focus on understanding the experiences of perinatal loss for fathers in the Pakistani community.

This study aims to understand how fathers in the Pakistani community experience perinatal loss and gain insight into to the barriers and facilitators that a father may face when accessing services.

Can I take part?

You can take part if:

- ✓ You over the age of 18 years
- ✓ You are male
- ✓ You have experienced perinatal loss (miscarriage, still birth, medical termination or death soon after birth)



- ✓ You identify as being part of the Pakistani community

Do I have to take part?

No, taking part in this study is completely voluntary. The care you receive in any services will not be affected, whether you choose to take part or not.

What will happen if I do take part?

You will be encouraged to print or save this information sheet for future reference. You will be asked to complete a consent form and email this back to the lead researcher. Sending a completed consent form back to the researcher will confirm that you are agreeing to participate in the study. In order to maintain anonymity, you will be given a pseudonym. The researcher will then confirm a suitable date and time for an interview with you. Face to face interviews will be held at a confidential and quiet location (e.g. community building, NHS trust location, university building) dependent on government restrictions and your preference. Remote interviews will be held over zoom.

The interview will last for approximately one hour and will be audio recorded. You can take a break during the interview if needed and can stop the interview at any time. You can decline to answer questions if you would prefer not to answer them. If you require an interpreter to help you participate in the interview, then please let the study lead, Rebekka Harrison, know and this can be arranged.

Who will know that I've taken part?

Only the research team will know that you are taking part in the research.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We will use direct quotes from the interviews in the write up of the report, but these will be anonymized so you will not be able to be identified. Your quotes will be used to support the explanation of the results found from the research.

The information about you and that you provide during the research will be stored on the University of Birmingham's electronic data store. This information will be encrypted, and password protected, with this password only being shared with Rebekka Harrison's academic supervisor. The audio files from the interview will be deleted as soon as they have been transcribed. Any information that could identify you will be stored separately to the transcribed interviews to maintain your confidentiality. All data collected will be stored and handled in accordance with the Data Protection Act (2018) and the General Data Protection Regulation (GDPR).

Information will be destroyed and disposed of securely once it is no longer required, after agreed periods of retention have expired, or in cases where destruction is required for legal or ethical reasons, in accordance with the University of Birmingham Information Handling Policy. Electronic data will be securely erased, and advice from the University of Birmingham's IT services will be sought to complete this. In addition, the study will comply with any additional legal or ethical requirements regarding the secure disposal of confidential data. Research data will be retained for a period of approximately ten years.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information at:

- www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By sending an email to dataprotection@contacts.bham.ac.uk

Are there any benefits to taking part?

You may find relief in the process of talking about your loss, which may be helpful for you. Participation in the study will also contribute to evidence about the needs of the Pakistani community, particularly fathers, in relation to perinatal loss which is an area that very little is known about. It is hoped that participation will enable professionals to further their understanding of perinatal loss in the Pakistani community.

Are there any risks to taking part?

Talking about perinatal loss and emotions associated with this can be difficult. Some people may find this upsetting. If you experience any difficulties as a result of this study, we recommend that you speak to your Imam, GP, IAPT, Lily Mae Foundation (www.lilymaefoundation.org), or Samaritans (telephone number 116 123). You can also access local services for support via https://hubofhope.co.uk/. Rebekka Harrison will also have a professional from the university and maternal mental health team to liaise with following the interview, so if any other services may be helpful to you, this will be able to be offered following this conversation.

Will I get paid?

You will be entered into a prize draw to win a £20 Amazon voucher as an expression of our gratitude for your participation in the study.

What if I change my mind?

You can choose to opt-out of the study at any point before the data is analysed, without giving reason. You can do this by emailing the lead researcher at [redacted]. Once the data analysis has begun, we will be unable to remove your data, so please let us know **within two weeks of taking part** if you have changed your mind.

What will happen to the results?

The results will be written up as part of Rebekka Harrison's Doctoral thesis and may be published in a scientific journal. You will be sent a summary of the findings following completion of the study.

Who is conducting the research?

The research is being conducted by Rebekka Harrison as part of her Doctorate in Clinical Psychology at the University of Birmingham. The research is being supervised by Dr Gary Law at the University of Birmingham. Please feel free to use the contact details provided below, should you have any concerns or questions about this study.

Mrs Rebekka Harrison (Study Lead)	**Dr Gary Law (Academic Supervisor)**
University of Birmingham	University of Birmingham
Clinical Psychology Office	School of Psychology
Edgbaston, Birmingham, B15 2TT	Edgbaston, Birmingham, B15 2TT
Telephone: 0121 414 6296	Telephone: 0121 414 6296
Email [redacted]	Email g.u.law@bham.ac.uk

Who has funded/sponsored the research?

There are no external funders providing financial support for the project. The project is sponsored by the University of Birmingham who agrees to provide indemnity for the research.

Who has reviewed the study?

The study has been reviewed and approved by a Research Ethics Committee (REC).

What if I want to raise concerns about the research?

If you have any concerns about the research and would prefer not to contact the researchers involved in the project, you can contact Dr Chris Jones (Director of Research for the

Doctorate in Clinical Psychology at the University of Birmingham) via email at c.a.jones@bham.ac.uk.

You can also contact the Independent Sponsor of the research using the following details: Dr

Birgit Whitman, Head of Research Governance and Integrity, Research Support Group, C/o Room 106, B Block, Aston Webb Building, University of Birmingham, Edgbaston, B15 2TT, Email: researchgovernance@contacts.bham.ac.uk, Phone: 07814 650003

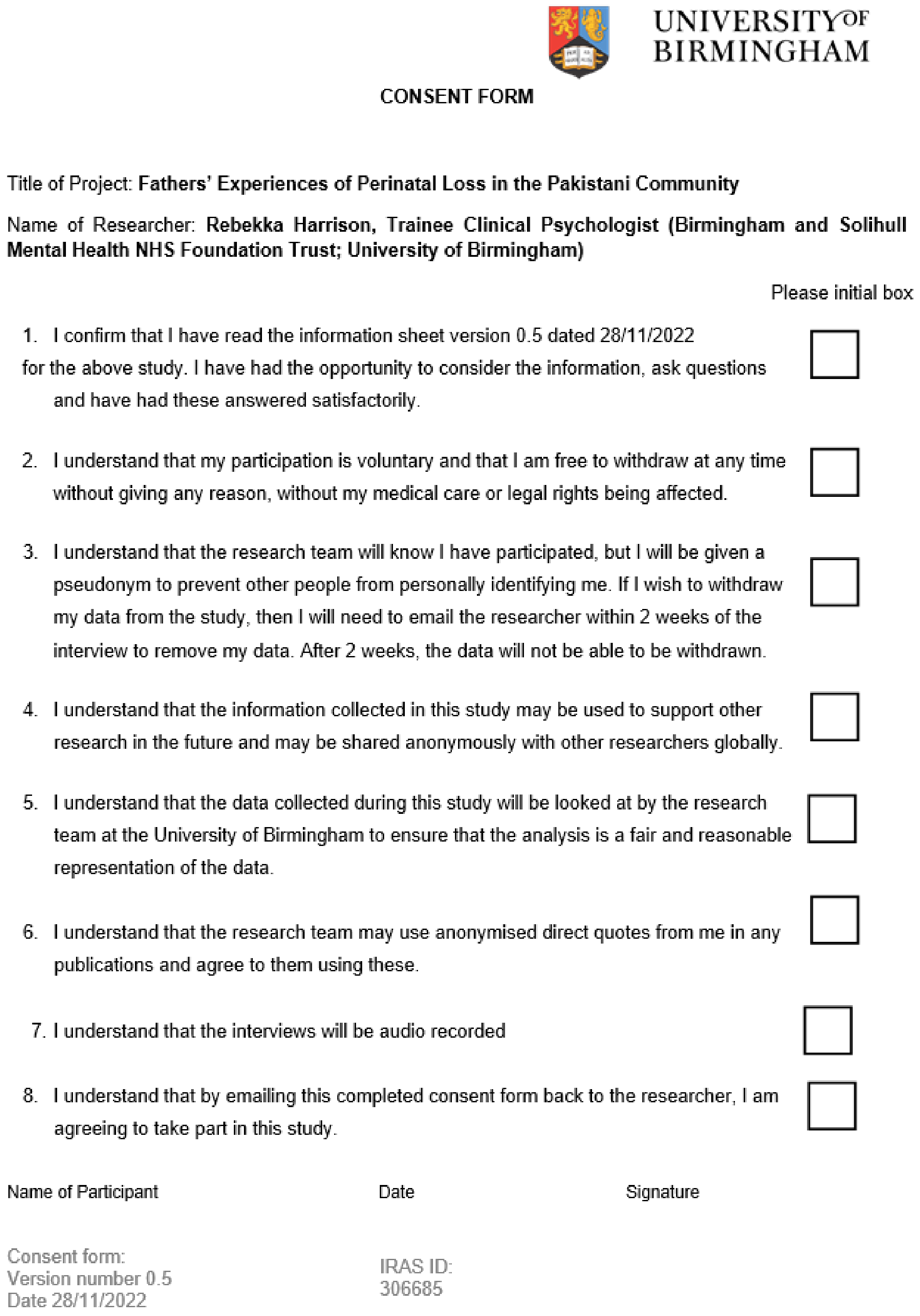
What happens now?

Please consider the above information carefully and decide whether or not you would like to take part in the study. You may take as much time as you need to make this decision. If you decide you would like to take part in the study, please complete the consent form and email this back to the lead researcher.

Thank you for taking the time to consider this study.

Please feel free to print this information sheet if you would like a copy for your own records.

Participant consent form



UNIVERSITY OF BIRMINGHAM

CONSENT FORM

Title of Project: **Fathers' Experiences of Perinatal Loss in the Pakistani Community**

Name of Researcher: **Rebekka Harrison, Trainee Clinical Psychologist (Birmingham and Solihull Mental Health NHS Foundation Trust; University of Birmingham)**

Please initial box

1. I confirm that I have read the information sheet version 0.5 dated 28/11/2022 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the research team will know I have participated, but I will be given a pseudonym to prevent other people from personally identifying me. If I wish to withdraw my data from the study, then I will need to email the researcher within 2 weeks of the interview to remove my data. After 2 weeks, the data will not be able to be withdrawn. ☐
4. I understand that the information collected in this study may be used to support other research in the future and may be shared anonymously with other researchers globally. ☐
5. I understand that the data collected during this study will be looked at by the research team at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. ☐
6. I understand that the research team may use anonymised direct quotes from me in any publications and agree to them using these. ☐
7. I understand that the interviews will be audio recorded ☐
8. I understand that by emailing this completed consent form back to the researcher, I am agreeing to take part in this study. ☐

Name of Participant	Date	Signature

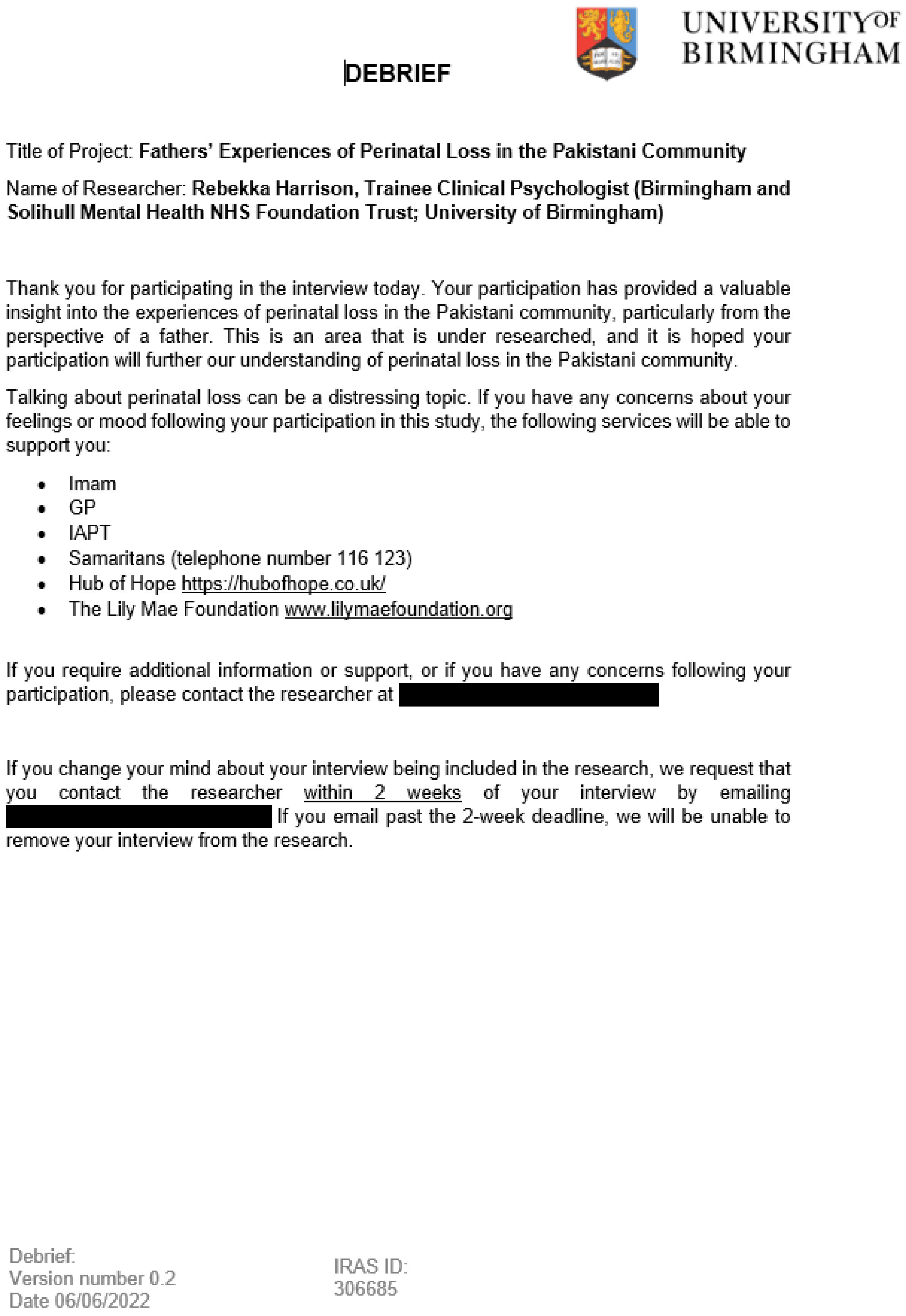
Consent form:
Version number 0.5
Date 28/11/2022

IRAS ID:
306685

Name of Person seeking consent Date Signature

Please feel free to print this consent form if you would like a copy for your own records.

Participant debrief



DEBRIEF

UNIVERSITY OF BIRMINGHAM

Title of Project: **Fathers' Experiences of Perinatal Loss in the Pakistani Community**

Name of Researcher: **Rebekka Harrison, Trainee Clinical Psychologist (Birmingham and Solihull Mental Health NHS Foundation Trust; University of Birmingham)**

Thank you for participating in the interview today. Your participation has provided a valuable insight into the experiences of perinatal loss in the Pakistani community, particularly from the perspective of a father. This is an area that is under researched, and it is hoped your participation will further our understanding of perinatal loss in the Pakistani community.

Talking about perinatal loss can be a distressing topic. If you have any concerns about your feelings or mood following your participation in this study, the following services will be able to support you:

- Imam
- GP
- IAPT
- Samaritans (telephone number 116 123)
- Hub of Hope https://hubofhope.co.uk/
- The Lily Mae Foundation www.lilymaefoundation.org

If you require additional information or support, or if you have any concerns following your participation, please contact the researcher at [redacted]

If you change your mind about your interview being included in the research, we request that you contact the researcher within 2 weeks of your interview by emailing [redacted] If you email past the 2-week deadline, we will be unable to remove your interview from the research.

Debrief:
Version number 0.2
Date 06/06/2022

IRAS ID:
306685

Recruitment poster

UNIVERSITY OF BIRMINGHAM

RESEARCH PARTICIPANTS WANTED

PAKISTANI MEN'S EXPERIENCES OF BABY LOSS

- Are you a Pakistani male aged 18 years or above?
- Have you experienced a baby loss through miscarriage, still birth, medical termination or neonatal loss
- Will you talk to us about your experiences of baby loss and support you received from NHS services, your family, friends and community?
- Will you share your story to help improve the support that can be offered to men like you after baby loss?

IF YOU HAVE ANSWERED YES TO THE ABOVE, ARE YOU WILLING TO TAKE PART IN A 60 MINUTE INTERVIEW?

This research hopes to understand how Pakistani men have coped with these difficult experiences and understand if there are barriers or facilitators present for these men who want to access services. It will hope to understand what support was helpful and what could be improved.

Interviews are confidential and can be arranged at a convenient time for you. If you require an interpreter, please let the Chief Investigator know.

Your decision to participate will remain anonymous and will not be shared with any other organisations.

Please email the Chief Investigator, Rebekka Harrison, on

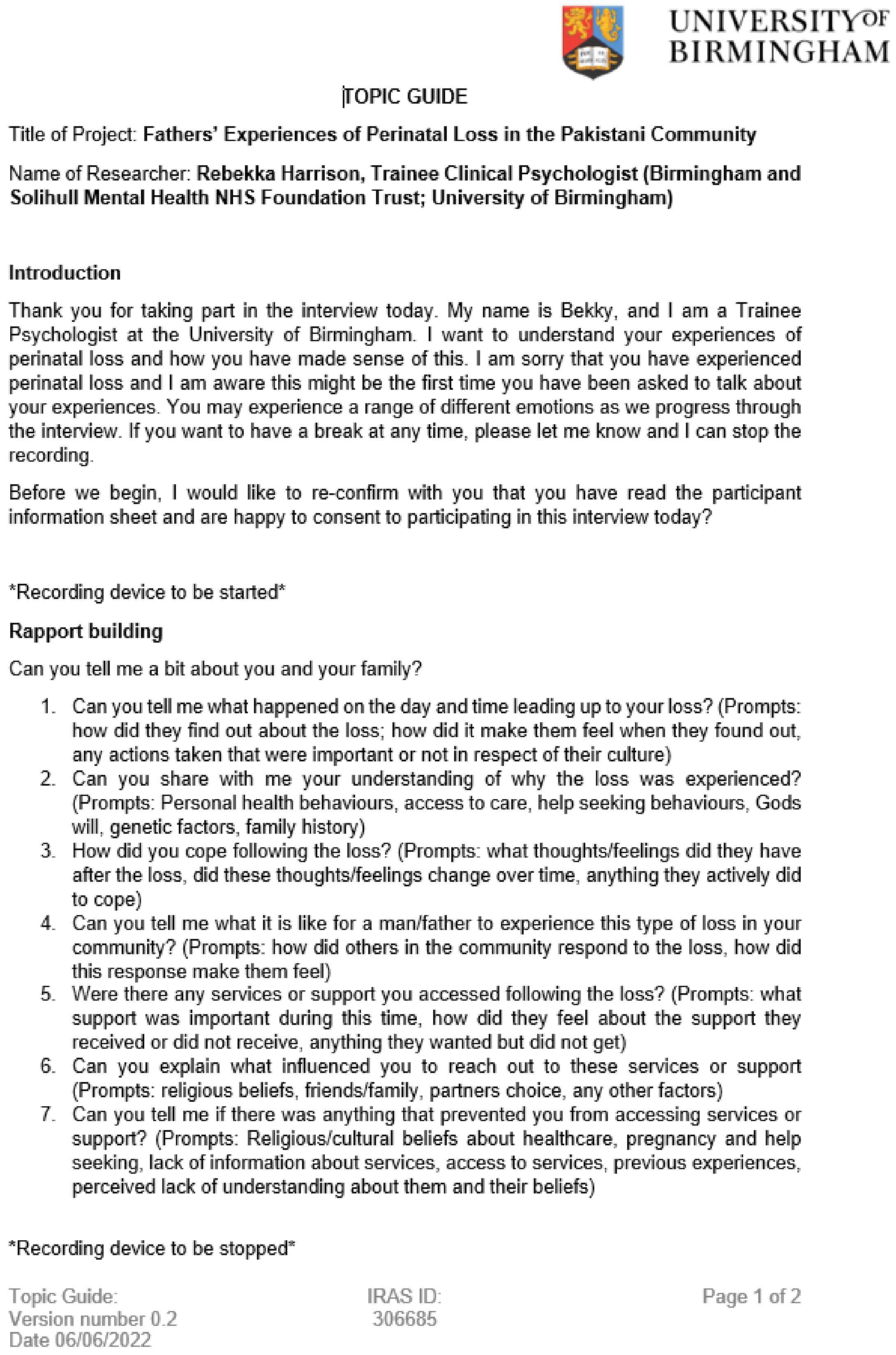
[redacted] if you are interested and would like to find out more information.

Participation will be for individuals residing in the UK.

Study flyer:
Version number 0.3
Date 28/11/2022

IRAS ID:
306685

Topic guide



UNIVERSITY OF BIRMINGHAM

TOPIC GUIDE

Title of Project: **Fathers' Experiences of Perinatal Loss in the Pakistani Community**

Name of Researcher: **Rebekka Harrison, Trainee Clinical Psychologist (Birmingham and Solihull Mental Health NHS Foundation Trust; University of Birmingham)**

Introduction

Thank you for taking part in the interview today. My name is Bekky, and I am a Trainee Psychologist at the University of Birmingham. I want to understand your experiences of perinatal loss and how you have made sense of this. I am sorry that you have experienced perinatal loss and I am aware this might be the first time you have been asked to talk about your experiences. You may experience a range of different emotions as we progress through the interview. If you want to have a break at any time, please let me know and I can stop the recording.

Before we begin, I would like to re-confirm with you that you have read the participant information sheet and are happy to consent to participating in this interview today?

Recording device to be started

Rapport building

Can you tell me a bit about you and your family?

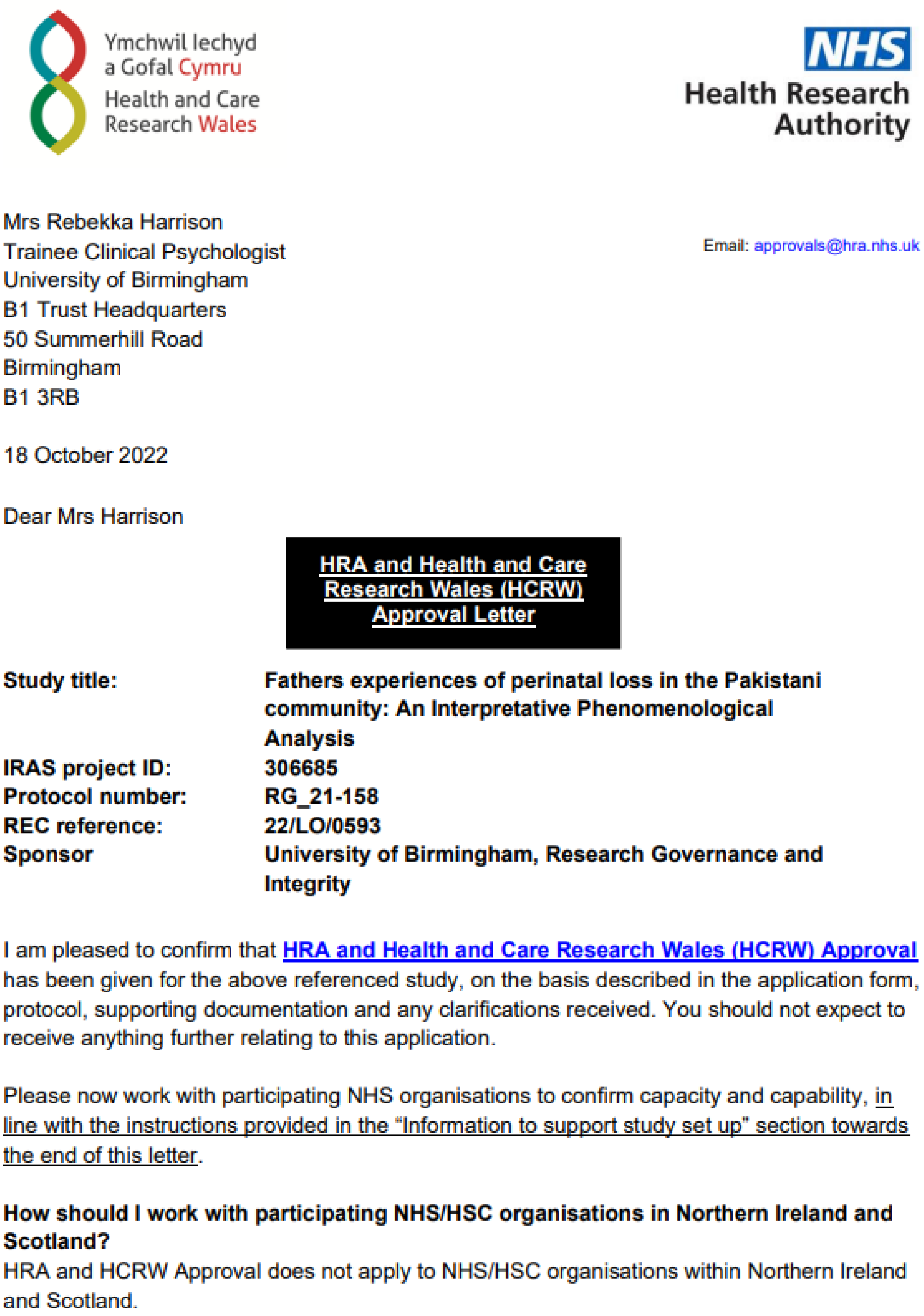
1. Can you tell me what happened on the day and time leading up to your loss? (Prompts: how did they find out about the loss; how did it make them feel when they found out, any actions taken that were important or not in respect of their culture)
2. Can you share with me your understanding of why the loss was experienced? (Prompts: Personal health behaviours, access to care, help seeking behaviours, Gods will, genetic factors, family history)
3. How did you cope following the loss? (Prompts: what thoughts/feelings did they have after the loss, did these thoughts/feelings change over time, anything they actively did to cope)
4. Can you tell me what it is like for a man/father to experience this type of loss in your community? (Prompts: how did others in the community respond to the loss, how did this response make them feel)
5. Were there any services or support you accessed following the loss? (Prompts: what support was important during this time, how did they feel about the support they received or did not receive, anything they wanted but did not get)
6. Can you explain what influenced you to reach out to these services or support (Prompts: religious beliefs, friends/family, partners choice, any other factors)
7. Can you tell me if there was anything that prevented you from accessing services or support? (Prompts: Religious/cultural beliefs about healthcare, pregnancy and help seeking, lack of information about services, access to services, previous experiences, perceived lack of understanding about them and their beliefs)

Recording device to be stopped

Closing

I would like to thank you for sharing your views and experiences with me today. As we mentioned earlier, this may be the first time you have been asked to share your experience. Your contributions are important, and I hope you have not found it too upsetting to share this. Your views will help us to understand how fathers in the Pakistani community experience loss and what support is helpful and unhelpful. Do you have any questions you would like to ask before we finish the interview?

2. Ethics committee approval letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Rebekka Harrison
Trainee Clinical Psychologist
University of Birmingham
B1 Trust Headquarters
50 Summerhill Road
Birmingham
B1 3RB

Email: approvals@hra.nhs.uk

18 October 2022

Dear Mrs Harrison

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Fathers experiences of perinatal loss in the Pakistani community: An Interpretative Phenomenological Analysis**
IRAS project ID:	**306685**
Protocol number:	**RG_21-158**
REC reference:	**22/LO/0593**
Sponsor	**University of Birmingham, Research Governance and Integrity**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **306685**. Please quote this on all correspondence.

Yours sincerely,

Sarah Prothero
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Dr Birgit Whitman*

3. Data Analysis

Extract from transcript including noting and experiential statements

Normally suggests it depends on the situation/who you're with to whether or not loss is spoken about Loss is not spoken about which is hard for everyone Stigma about baby loss	P: Normally it's never talked about. They never mention it. And it's really upsetting for these guys for you know everyone involved you know having gone through it it's like a taboo.	**Baby loss is not spoken about in Muslim communities which is difficult for everyone involved.**
	I: Mm	
Idea of being a strong man so not needing to talk about impact of loss Notion that should not be talking about loss, but he disagrees and feels this is important to talk about	P: You know don't mention it sort of thing. You know without saying it no one mentions it it's like a macho man thing	**There is a cultural idea of needing to be a strong man, so you don't talk about these things**
	I: Mm	
Having the courage to start opening conversations about loss Talking about loss is helpful for everyone in the conversation	P: And you think the amount of friends and family I've got, and I mention it to them, and they didn't know and they like open up it's like a without sounding bad it's like a counselling session	**The ripple effect of opening up a conversation about loss means that other people start to open up and find it helpful too**
	I: Yeah	
Recognising that people have been suffering in silence The power of being able to start these conversations and help other men talk about how they are feeling	P: Both us grown men actually talk about it when I talk about it I bring up the subject without knowing they've had a loss and that other guys become emotional which you think you poor thing you've bottled this up for the last 5,6,7,8 years	**People in the Muslim community have experienced baby loss and are suffering in silence because it is too hard to talk about**

GETS

Themes	Quotes
A ROLLERCOASTER OF EMOTIONS: FROM SHOCK AND DISTRESS TO HAVING HOPE	
A moment of calamity: nothing compares	“With my daughter when she was being born I was there every step of the way every scan every appointment my daughters you know my world. And (pause) then that gets taken from you. And you have to accept it because there's absolutely nothing you can do.” (Zain, Line 87, page 5). “And I asked them as well what are you talking about nothings making sense it wasn’t it was just such a blow. We had gone in for a scan and just been told that so wait for my mum to come and get my daughter and it was just a shock so er.” (Bilal, Line 26, page 2). “Yeah I I initially I was just I couldn’t I was shocked I was really shocked.” (Imran, Line 57, page 3). “Everything’s just stopped if that makes any sense like you know you’ve got these emotions of happiness, joy, laughing and then all of a sudden bang you can’t I can’t even put it into words how it was.” (Bilal, Line 44, page 3). “At the time she was there everyone with us you know not realising what was happening (sigh) and that was my initial reaction just complete shock, and it didn't hit me until until the day after and you know the following days beyond that” (Zain, Line 46, page 3). “I could see different doctors coming in, you know there’s something wrong. And I was just in time I was thinking oh please hopefully there’s nothing wrong but hopefully he’s just you know the baby’s not moving cos he’s tired or something.” (Imran, Line 25, Page 1). “The chap came in erm he did the erm the the scan and said erm yeah your baby has no heartbeat erm or you know. On the previous one the baby was fine he was kicking around really active and ah it was like I couldn’t believe what I was hearing so.” (Bilal, Line 17, Page 1). “Cos obviously when we found out we were having a child I was really excited and stuff and then we had this incident where I had to take her to the hospital and and then I think at that time we found out that erm you know we lost the child.” (Hassan, Line 19, page 9). “Just like it was unreal I wouldn’t even say a bad dream it’s like never have I ever experienced such feeling.” (Bilal, Line 41, page 2). “Er you know thinking about it er because it was the first you know time you know, and it was just the shock wasn’t it, so I just remember this half an hour and it was all happening that I was trying to process.” (Imran, Line 136, page 7). “But to have your foundation shaken like that and I ended up I ended up saying you know you took out of that you took you took my baby you took something that was mine. And you have to square that with actually no everything is from God, and everything belongs to him you know that’s his time and that that took me a long time”. (Zain, Line 81, page 4). “I mean I went through a year of essentially just crying. Messed my eyes up for a long time doing that” (Zain, Line 218, page 11). “His wife went into the bathroom, and she miscarried in the bathroom. And so basically she delivered in the bathroom the the baby, and after seeing this, so he was very heartbroken. He was very, very upset, and he didn't know what to do,” (Nabeel, Line 22, page 1). “But then er I remember when er the doctors said that there was er there was no heartbeat er my wife started crying pretty much straight away she had a both her hands on her face and She was just crying like mad like she was I haven’t seen her cry like that ever. We’ve been married like er over seven eight years now and I’ve never seen her cry like that” (Imran, Line 36, page 2). “At first he he was, he wouldn't say he wasn't upset, he was upset, but he wouldn't. But by the third fourth time he was very disheartened. He had a his heart would which would basically fall once the baby had gone.” (Nabeel, Line 5, page 1).

The lens of religion for sense and comfort	“Er you know and our son whose gone you know we can you know pray for him and hopefully will you know being Muslims obviously you know so we would say things like you know hopefully we’ll meet him when we get read in paradise and things like that.” (Imran, Line 621, page 30). “My religion teaches me that you know, if you ok yeah it’s a loss erm a big loss when you lose a child like that. But our belief is that you know on the day of judgement when everyone passes away from this life and is brought back together, our child then looks for the parents. So that’s something that is kind of for me reassuring. It gives me the comfort that yeah ok we had a loss but yeah.” (Hassan, Line 27, page 2). “And at that time like there were two things that were going on that in the moment of calamity if you show patience with outlook that you’ll get the spiritual reward there up my baby’s gonna be there I knew that.” (Zain, Line 77, page 4). “No we see we are strong believers in our faith we are Muslim’s we believe you know it was Gods will.” (Bilal, Line 70, page 4). “But there’s nothing you can do I mean you’ve done everything you can and if it’s not meant to be its not meant to be This is why I say it's God's will it happened and there’s nothing we can do. Just if you want another child you try again.” (Hassan, Line 113, page 6). “But yeah it was really difficult to feel but it's part of life and there's nothing you can do. You can't control it. It’s God's gift when you have a child so you know if you can lose it you just can't do anything about it” (Hassan, Line 38, page 2). “We don’t know to be honest erm they took a few samples erm they took a blood test a urine analysis you know all of that stuff when it came back that They couldn’t figure out why this had happened there wasn’t a clear-cut reason. I mean from a religious point of view it’s every soul is here until the time it is meant to be here.” (Zain, Line 66, page 4). “He says, yeah, he was 100% faithful that God would give him a child, and he said the first step was that conception and which was happening, she had been pregnant for 9 times, and and it was there, and one day God will bless him with children, and he has and he has it's his faith that kept him strong and to go through.” (Nabeel, Line 71, page 4).
THE HIDDEN EXPERIENCE OF BABY LOSS AS A MUSLIM MAN	
I focus on you not me: responsibility and duty as a Muslim man	“Maybe maybe other men could also relate to this I don't know I I the way I felt at the time was because you know being a man you have responsibility looking after your wife and then the children and comforting them and then you know er it was on me to do the burial and er all these other things.” (Imran, Line 745, page 36). “And especially your wife’s feelings cos by the Muslim perspective you would be there helping her with the housework and that’s another story but with the children upbringing support but its more culture of that angle is erm the macho man thing comes into it.” (Bilal, Line 300, page 14). “Yeah and my wife wasn't able to do a lot so that kept me busy like washing up cleaning that sort of stuff taking care of my daughter.” (Zain, Line 175, page 9). “Because in our culture it’s like deal with it doesn’t matter its happened and your wife might, no, will need that support from you you are a father you are her partner you are her husband. Macho man image kind of thing.” (Bilal, Line 272, page 13). “All these other things I think maybe I got consumed in too much into that as well and then trying to get information on how what to do things erm and then er so I think that kind of took some attention away from what had happened er not fully obviously it was still upsetting I wish I would have it didn't happen.” (Imran, Line 202, page 10). “Obviously I was upset like you know really upset about what happened I wish it never happened but then you know it’s like it’s like a different responsibility as well where you know cos she’s going through it emotionally mentally and you know I'm trying to give her some comfort as well and at the same time I did other things that you have to do legally like you know er when my son was born obviously er I had to arrange for funeral er burial and all these other things I had to go through.” (Imran, Line 172, page 8). “Because maybe it’s a cultural thing you know part of me thought I don’t want to mention anything cos I don’t want to upset my wife you know bringing it up a week later a month later a year later.” (Bilal, Line 112, page 6).

	“And you give them, and you support your wife as much as you can whatever but that’s about it really and you talk about it but me and my wife to be honest I didn’t think we, we did talk about it, but I don’t think we talked about it that much.” (Hassan, Line 97, page 5). “Whereas my wife I wouldn’t talk to her about it because I I didn't want to hurt her coz she cried so much like I said, and you know she was already I knew she was going through she was really upset.” (Imran, Line 611, page 29) “Blocked yeah I blocked it out I knew what had to be done with regards to the burial procedure and everything and my wife needed support which obviously I was there for and er I didn’t er consider myself in anyway.” (Bilal, Line 88, page 5). “Yeah ok we had a loss but yeah I did feel really I probably don’t, you felt you wouldn't feel as much as a woman does, because I suppose that's in the woman's stomach and stuff.” (Hassan, Line 34, page 2).
The cultural mask of strength	“You know don’t mention it sort of thing. You know without saying it no one mentions it it’s like a macho man thing.” (Bilal, Line 143, page 7). “So like you know crying too much and like you know I I just felt like there's nothing you know no one says this but it’s just a feeling where you know you gotta be er a man and strong.” (Imran, Line 750, page 36). “I think it men men are looked at as very very strong. You know um the head of the family kind of strong person that's gotta be strong. So I think emotions and stuff we we don't really share cos I don't know if we start I I'm just assuming this. I think if we start to share these things then people think you're really weak. I think men don't want to show that they're really weak. That's my assumption.” (Hassan, Line 213, page 10). “No, I think it depends how you are as an individual erm you know if you're a very strong character. I'm I'm a very strong character like that very strong. Erm and you know, I've been through a lot of other stuff that's happened so for me it's like it's one of those things you get on with it, it's part of life” (Hassan, Line 238, page 11). “Yeah macho man image kind of thing it doesn’t affect me no I’m fine let’s move on.” (Bilal, Line 277, page 13). “There’s no point crying about it, yeah you can cry about it but you just gotta get on with it. You've just gotta get on with it. Be strong about it. Yes, you might feel sad about it, but but there's nothing you can do about it. You have to kind of pick yourself up and and continue.” (Hassan, Line 270, page 13). “You know I wouldn’t you know do it [cry] in front of my father for example my parents and my brothers I wouldn’t be able to I I did explain to someone my brothers and my cousins and everyone later on that you know I had to go through this. But I wouldn’t openly cry in front of them”. (Imran, Line 182, page 9). “I wouldn’t openly cry in front of them er whereas my wife she she just couldn't hold the tears and she couldn’t control her emotions which I er you know I know like she had to go through it.” (Imran, Line 186, page 9). “When you're with husband and wife you are you you can cry, you can show your emotions. You can talk about the child. and you can grieve. But when you're alone with the community it's totally different right now he goes I'm talking about my children, and it's very, very hard for me, but I’m putting everything together, and I’m having this conversation. It's difficult, but when it's just himself and the Mrs it's different. Then he can you know let his emotions out and tell her how he's feeling, and how he's dealing with stuff.” (Nabeel, Line 77, page 4).
THE FELT STIGMA OF BABY LOSS IN THE MUSLIM COMMUNITY	
The decision on silence about baby loss	“Er eh see (pause) that’s a hard one because er I don’t know a lot of people er who’ve lost babies.” (Imran, Line 646, page 31). “See there are people but not openly no they mention it but it’s like unfortunately there aren’t people who are openly talk about it.” (Bilal, Line 243, page 12). “Hmm yeah well to be honest you know; I've not heard from any male friends that I have that any of their wives have had a miscarriage. So you can you can see from that that men don’t talk about it.” (Hassan, Line 386, page 18). “You know in our community it’s like brushed under the carpet don’t mention it again it’s done move on.” (Bilal, Line 211, page 10).

	"They've gone through this which no one knew about two of my aunts they told me they had been told to be quiet they had been hushed up." (Zain, Line 287, page 14). "Men don't talk about it at all so and I and and like I said, you know, like I would, I wouldn't go around telling my mates if my wife had a miscarriage. I just wouldn't do that, and I don't think men would do that." (Hassan, Line 390, page 18). "Normally it's never talked about. They never mention it. And it's really upsetting for these guys for you know everyone involved you know having gone through it it's like a taboo." (Bilal, Line 140, page 7). "Yeah not being told you know that you've got to get over it was the biggest things, and you know being told you know you've got your daughter at least. And I thought ok fine let me go and kill one of your children and that's ok because at least you have the others." (Zain, Line 243, page 12). "Cos everyone else was my whole family was why are you doing this he wasn't a baby he wasn't born you should get over it you should move on I was like what a joke it's disgusting what they said." (Zain, Line 186, page 9). "He's saying we need a platform within our Muslim communities or any culture. We have lots of religions within our culture. We have Muslim, we have the Indians, we have the Bangladesh, and so he says that you need a platform where religious scholars approach these topics and deal with these topics in a big level, and if he just sits on the pilgrim and starts speaking, there's no one going to listen to him. so just classify him as the crazy man who keeps talking about it. But if someone who's a religious authority with a big name, and who has a voice within the community. If they take upon these topics. then the word people be educated more, they listen to them. They listen to the person who's giving the hope or the giving the speech, and they that can bring a change in the culture. Otherwise, it's not going to be very very difficult." (Nabeel, Line 185, page 9). "The best thing I did was actually talk about it my sisters a X herself and she said you got to talk about it you got feelings as well. I said I'm fine don't worry about me she says what do you mean don't worry about you and my wife was there obviously and she said it as well and then I opened up and I spoke to them and to this day we speak about it and obviously if I know of anyone within the friends and family circle I speak to the guy." (Bilal, Line 221, page 11). "I talked him through no these are his rights and then he did that so in in some respects it brought up a lot of stuff that wasn't allowed to be talked about, but it helped at least some people do the right thing." (Zain, Line 292, page 14). "Me speaking to my wife about it er about the baby and speaking openly about it to family members er not only helped me but it helped everybody my wife and family members." (Bilal, Line 104, page 5). "You know people don't realise especially men me going through it speaking about it is a massive, massive help." (Bilal, Line 348, page 16). "Both us grown men actually talk about it when I talk about it I bring up the subject without knowing they've had a loss and that other guys become emotional which you think you poor thing you've bottled this up for the last 5,6,7,8 years." (Bilal, Line 150, page 8). "Talk about it like we didn't keep it from our children even when the younger ones were getting older we explained to them look you had a brother he's no longer here with us it's good to talk about it that's all it is people don't realise that it's a massive help." (Bilal, Line 339, page 16). "So yeah people don't realise guys don't realise especially the Muslim community you know bottling it up you know not talking about it it has an effect on people. They probably thought there's no one to speak to and the worst thing I think without knowing the facts, but I believe they don't speak to their partner about it the wife is left dealing with it on her own there's no communication speak about it you know it was your child." (Bilal, Line 154, page 8).
A disconnect between Muslim culture and community	"We have a saying amongst ourselves it's like a backward mentality that the mans a man speak about it speak to your wife help your wife there's nothing wrong with that. it's the wrong perception for certain people especially in the Pakistani Muslim community there is a macho man image type of thing but it's not you're only fooling yourself." (Bilal, Line 287, page 14).

	“Islamically, no after 17 weeks your babies one of their rights is they get named they have a name, so I did the right thing there and then the burial I was told why don’t you just let the hospital take care of it why are you burying your child. No Islamically you have to that's one of their rights you have to bury them but no they put on this Islamic disguise when actually they know jack shit about their religion.” (Zain, Line 264, page 13). “And he knows this, and he just wants his community to realize, basically wake up from this the and just just be realistic and deal with it in a proper and educated manner.” (Nabeel, Line 180, page 8). “A lot of it comes from not being educated most of it comes from not being educated. When I say educated they are not educated in Islamic. Because when I read up on the Islamic side that’s what gave me a lot of erm support, because you then get you then realised actually no you had your baby your baby has rights, and these are the rights they have.” (Zain, Line 255 page 12). “In our culture I wouldn't say it's lack of education. I think it's lack of awareness. And so when a woman has a miscarriage, and they attend to blame the woman and and it's not the woman's fault. It's something that that happens. So they have a lot of negativity towards a woman. That you are a transgender. You are infertile it’s something that you did so. She will get a lot to the blame.” (Nabeel, Line 89, page 4). “Yeah, just to be quite frank with you I just feel there's there's not a lot of well-wishers in the community to be honest.” (Hassan, Line 152, page 8). “No I mean forget the community my own mum told us and my mum one of the first things she actually said to me was look at what you’ve done wrong in your life that God is punishing you for.” (Zain, Line 272, page 13). “I was told I was stupid for naming my baby.” (Zain, Line 262, page 13). “It makes no sense that you can be resented, and you can be looked down on for wanting to give your child a burial or to actually care that you have a lost child it is I don’t understand that.” (Zain, Line 280, page 14). “He didn't know at that time, because how to do it culturally or Islamically, and what to do with the pregnancy, and he didn't know at all. So he would just give it to the hospital. Now he's come to realize that he shouldn't have, and he had. He should have got it back from the hospital and buried the the the pregnancy. With that because the baby was in the mom's tummy, and you know, even if the first short period of time he had, he or she had a heartbeat, so he would be a it would be buried. But unfortunately, he did not know that erm, so he didn't get the opportunity to this” (Nabeel, Line 38, page 2). “Like its Gods will ok move on. And it’s you know I was been told you you know so and so went through a miscarriage and they never looked back they never saw their baby again and it’s like you fucking heartless people.” (Zain, Line 228, page 11). It was just that, so I was low for a long time. And I didn’t have anywhere to turn because everywhere I did turn I was being told you know this is (pause) you know some people say this is Gods will and that the end of the conversation.” (Zain, Line 224, page 11). “And otherwise I am a very firm you know what I would say is I am a very strong Muslim, but you know reading about how things are destined and then actually living something that’s destined like that two very very different things.” (Zain, Line 71, page 4).