UNDERSTANDING THE PROCESS OF DIAGNOSIS IN PERINATAL MENTAL HEALTH: DETECTION OF DIFFICULTIES AND SERVICE USER EXPERIENCE

by

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VOLUME ONE

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Thesis Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology at the University of Birmingham. The thesis comprises of two volumes. All identifying information has been anonymised for confidentiality.

Volume One

This volume comprises three chapters. The first chapter is a meta-analysis of the diagnostic accuracy of the Edinburgh Postnatal Depression Scale in detecting depression during the perinatal period. The second chapter is a qualitative study that investigates the experience of women receiving a psychiatric diagnosis during the perinatal period. The third chapter is a press release document, providing an overview of the meta-analysis and qualitative study.

Volume Two

This volume comprises five clinical practice reports (CPRs). The first report presents the case of a 32-year-old female diagnosed with emotionally unstable personality disorder, formulated from a cognitive behavioural and psychodynamic perspective. The second report presents a service evaluation of staff personality disorder training workshops. The third report presents a case study of a 25-year-old male with a learning disability presenting with difficulties with aggression, using cognitive behavioural and systemic models. The fourth report is a single-case experimental design, evaluating the effectiveness of a cognitive behavioural intervention with a 82-year-old female. The final report presents an abstract of an oral presentation of an exposure and response prevention intervention with a 15-year-old female presenting with obsessive compulsive disorder.

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Literature Review: The diagnostic accuracy of the Edinburgh Postnatal Depression Scale during the perinatal period: A meta-analysis

Abstract

Background

Perinatal depression is a common mental health difficulty that presents a significant burden to the mother, child and society. The Edinburgh Postnatal Depression Scale (EPDS) is the most widely used screening tool for perinatal depression. Previous reviews on the EPDS have only conducted systematic reviews of the literature and not a meta-analysis of the validity. Therefore, the present review examined the diagnostic accuracy of the EPDS in detecting depression during the perinatal period, both in men and in women, using a meta-analysis.

Method

A systematic search of the literature was carried out using the PsycINFO, EMBASE, MEDLINE and Pubmed electronic databases. 223 papers were screened, resulting in the inclusion of 73 datasets from 66 primary studies.

Results

Results demonstrated the EPDS as an accurate measure at detecting depression in the perinatal period, with a pooled diagnostic odds ratio of 26.597 (95% CI 20.681-34.206), a positive likelihood ratio of 5.686 (95% CI 4.844-6.674) and a negative likelihood ratio of 0.242 (95% CI 0.216-0.271). A bivariate meta-analysis produced an area under the curve value of 0.873 and a SROC curve showing good diagnostic accuracy.

Discussion

Conclusions on the efficacy of the EPDS can be more firmly drawn regarding the diagnostic accuracy in postnatal women due to the large number of studies that have studied this group. Further research with clearer reporting of methodology information and stricter methodology would reduce the risk of bias and therefore improve upon the existing literature presented in this review.

Introduction

Maternal perinatal depression

Perinatal depression is defined as a non-psychotic depressive episode prevalent during pregnancy and the first-year post-partum. Depression and anxiety are the most common mental health difficulties within the perinatal period (O'Hara & Wisner, 2014). A recent systematic review and meta-regression of the prevalence rates of maternal perinatal depression in 96 studies (Woody et al., 2017) found an overall pooled prevalence rate of 11.9% (95% Confidence Interval [CI] 11.4–12.5).

Perinatal depression poses a significant burden and public health issue, with negative consequences for the mother, child and family (Moore Simas et al., 2019). Research has demonstrated adverse child outcomes such as preterm birth (Smith et al., 2011) and emotional, behavioural and cognitive problems (Grace et al., 2003; O'Connor et al., 2002). Perinatal depression has also been shown to have a potentially adverse impact on the relationships around the mother (Zelkowitz & Milet, 2001). The experience of depression during the perinatal period also raises the risk of developing later episodes of depression throughout the lifespan (Cooper & Murray, 1995). Perinatal depression also presents as a significant economic burden, with the average cost of one case of perinatal depression on society being around £74,000 (Bauer et al., 2014). This cost can be divided up into the cost to the mother, approximately £23,000, and the cost relating to the impact on the child, approximately £51,000.

Paternal perinatal depression

Maternal perinatal depression has been extensively researched, but more recently paternal depression has been a focus of perinatal research. A recent meta-analysis of prevalence found a rate of 8.4% (95% CI 7.2-9.6%) for paternal depression during the antenatal and

postnatal period (Cameron et al., 2016). Similar to maternal perinatal depression, paternal depression has been associated with adverse child outcomes (Ramchandani et al., 2008) and a negative impact on relationships (Don & Mickelson, 2012).

Screening for perinatal depression

An investigation into perinatal mental health and the costs to society suggests that about half of cases of perinatal depression and anxiety go undetected (Bauer et al., 2014). Routine screening through self-report measures proves one way of detecting perinatal depression (Earls, 2010; The National Institute of Health and Clinical Excellence [NICE], 2014). Therefore, self-report measures that demonstrate sound diagnostic validity are imperative.

The NICE guidelines (NICE, 2014) on recognising depression during pregnancy and the postnatal period recommend using two depression identification questions known as the 'Whooley' questions (Whooley et al., 1997) during routine check-ups: 'during the past month have you often been bothered by feeling down, depressed or hopeless' and 'little interest or pleasure in doing things'. If a woman answers 'yes' to either of these questions, administration of either the Edinburgh Postnatal Depression Scale ([EPDS], Cox et al., 1987) or the Patient Health Questionnaire (Kroenke et al., 2001) is recommended, or referral to an appropriate professional.

Research has also been carried out exploring the acceptability of perinatal depression screening. A meta-synthesis in 2010 found screening to be acceptable to women and health care professionals (Brealey et al., 2010). Furthermore, a study exploring the public's view of routine perinatal depression screening suggested that the public agreed that routine screening is valuable (Kingston et al., 2014).

Edinburgh postnatal depression scale

The EPDS is the most widely used screening tool for perinatal depression (Cox et al., 1987). It is a self-report questionnaire that requires the individual to answer 10 statements that ask about symptoms of depression over the last seven days. There are four possible responses to each question, rated between 0 and 3, which result in a score ranging from 0 to 30. The most commonly suggested cut-off score for 'probable depression' is 12/13 and for 'possible depression' is 9/10 (Cox et al., 1987).

Although the EPDS was originally developed to screen for postnatal depression, it has also been extended to use within the antenatal population (e.g. Murray & Cox, 1990) and in fathers (e.g. Lai et al., 2010; Loscalzo et al., 2015; Massoudi et al., 2013; Matthey et al., 2001; Tran et al., 2012).

Previous reviews

Previous reviews have been conducted into the validity of the EPDS in the perinatal period (Eberhard-Gran et al., 2001; Gibson et al., 2009), antenatal (Bergink et al., 2011; Kozinszky & Dudas, 2015) and the postnatal period (Zubaran et al., 2010). These reviews have reviewed the sensitivity, specificity and positive and negative predictive values of the EPDS. Specificity and sensitivity have been found to vary across studies, for example, Gibson et al. (2009) found sensitivity to range from 34-100% and specificity to range from 44 to 100%. Previous researchers have considered a variety of reasons for this variation in validity data, such as the impact of different language administrations of the EPDS and cultural variations in the validity of the EPDS (e.g. Kozinszky & Dudas, 2015).

Previous reviews have focussed only on a systematic review of the literature and not a statistical analysis of the validity through a meta-analysis. Previous reviews have stated heterogeneity between studies as the reason for not conducting a meta-analysis. For example,

Gibson et al. (2009) noted the heterogeneity of EPDS cut-offs scores used amongst studies, study design, language and diagnostic criteria. To date, there have not been any reviews conducted of the validity of the EPDS in screening for paternal depression. There is therefore an absence of a review that quantitatively synthesises the available data on the validity of the EPDS in diagnosing depression during the perinatal period in both men and women.

Aim of current review

The aim of this meta-analysis was to determine the validity of the EPDS compared to a structured clinical interview for the detection of depression during the perinatal period, for both men and women. The validity was assessed over various settings, populations, languages and cut-offs.

Method

Scoping work

Prior to conducting the systematic search of the literature, the author conducted a scoping exercise of the available literature exploring the validity of the Edinburgh Postnatal Depression Scale (EPDS) and previous systematic reviews. Given the heterogeneity highlighted in previous systematic reviews (Gibson et al., 2009), this scoping exercise allowed the author to consider the type of data available, how the data could be extracted and how the heterogeneity of the research could be overcome in order to conduct a meta-analysis. Data extraction rules were generated to account for this heterogeneity and to ensure consistent extraction of the data (see Data Extraction section).

Search strategy

A systematic search of the literature was carried out using the PsycINFO, EMBASE, MEDLINE and Pubmed electronic databases. The search included articles published between 1967 and 22 July 2019. Table 1 below shows details of the search terms. Studies published in English language were reviewed. To supplement electronic searches, reference lists of all included publications and relevant reviews were evaluated for inclusion. If conference abstracts or protocols were identified in the electronic search without the full text article, the full articles were identified by hand searches.

Table 1

Search terms utilised in systematic literature search

Construct					Limits
All constructs combined with [AND]					
Index Test	**Diagnosis**	**Psychometrics**	**Perinatal period**	**Depression**	
Edinburgh postnatal depression scale [OR] EPDS	Diagnos* [OR] Interview*[OR] Clinical interview*[OR] Semi?structured interview*[OR] Structured clinical interview	Sensitivity [OR] Specificity [OR] Likelihood functions [OR] Valid* [OR] Predic* value* [OR] Test Validity [OR] PPV [OR] NPV [OR] Likelihood ratio* [OR] ROC [OR] AUC [OR] Area under curve	Post?natal [OR] Post?partum [OR] Ante?natal [OR] Ante?partum [OR] Pregnan*[OR] Pre?natal [OR] Peri?natal [OR] Father* [OR] Dad* [OR] Parent* [OR] Paternal* [OR] Men*[OR] Male*[OR] Spous* [OR] Female* [OR] Maternal* [OR] Mother* [OR] Postnatal period [OR] Perinatal period	Depression [OR] Depressive disorder* [OR] Major depress* [OR] Mood disorder* [OR] Postnatal depression [OR] Postpartum depression [OR] Perinatal depression [OR] Antenatal depression	Type of article: Peer reviewed articles Year: 1967

Inclusion and exclusion criteria

Papers were screened according to a number of inclusion/exclusion criteria; details of which can be found below in Table 2. Studies were included if they compared the results from the EPDS to formal diagnostic depression criteria in a perinatal sample over the age of 18 years old. Depression diagnoses must have been based on either the Diagnostic and Statistical Manual (DSM) (current edition: DSM-5; American Psychiatric Association, APA, 2013) or the International Classification of Diseases (ICD) (current edition: ICD-11; World Health Organisation, WHO, 2018) criteria for depression, through either a semi-structured or structured diagnostic interview. In order to select the highest quality research and reduce the risk of bias in studies, studies were included if they administered the EPDS and a psychometrically validated diagnostic interview within two weeks of each other.

Table 2

Exclusion criteria and rationale

Exclusion Criteria	Rationale
Type of Study	
Studies using the EPDS to screen for depression but not validating the EPDS against a structured or semi-structured diagnostic interview.	This review focussed on studies validating the EPDS against a structured or semi-structured diagnostic interview to ensure a high-quality reference test.
Studies that exclusively used a cut off score of the EPDS for participants to enter a diagnostic interview. Studies that used a cut off score for entering diagnostic interview but selected a random sample of those scoring below the cut off score will be included.	This review aimed to select to the highest quality validity evidence and these methods would introduce bias into the results.

Exclusion Criteria	Rationale
Reference Test	
No validated structured or semi-structured interview used (e.g. Structured Clinical Interview for DSM). Diagnostic and Statistical Manual (DSM) or International Classification of Diseases (ICD) criteria not used for depression diagnosis.	This review focussed on DSM & ICD diagnostic criteria through structured or semi-structured interview to provide a 'gold standard' valid reference standard.
Study Population	
Study population not antenatal or postnatal women or men.	This review only aimed at evaluating the validity of the EPDS in the perinatal period.
Study population under the age of 18 years old.	This review only aimed at evaluating the validity of the EPDS in adults, due to the small number of studies conducted in adolescent populations and the associated heterogeneity given this, and the EPDS is designed and normed for adult women.
Timing of Index Test and Reference Test	
Over 2 weeks between EPDS administration and diagnostic interview. Studies that did not specify the time between EPDS and diagnostic interview will be included but will be rated as high risk in this domain in the risk of bias assessment.	A period of over 2 weeks between the index and reference test is likely to introduce bias and misclassification.
Outcome Data	
Do not provide sufficient data to construct a 2 × 2 contingency table (Figure 1) of screening × diagnosis (i.e. able to calculate sensitivity,	This review required data on sensitivity, specificity, positive likelihood ratio and negative likelihood ratio to evaluate validity of the EPDS.

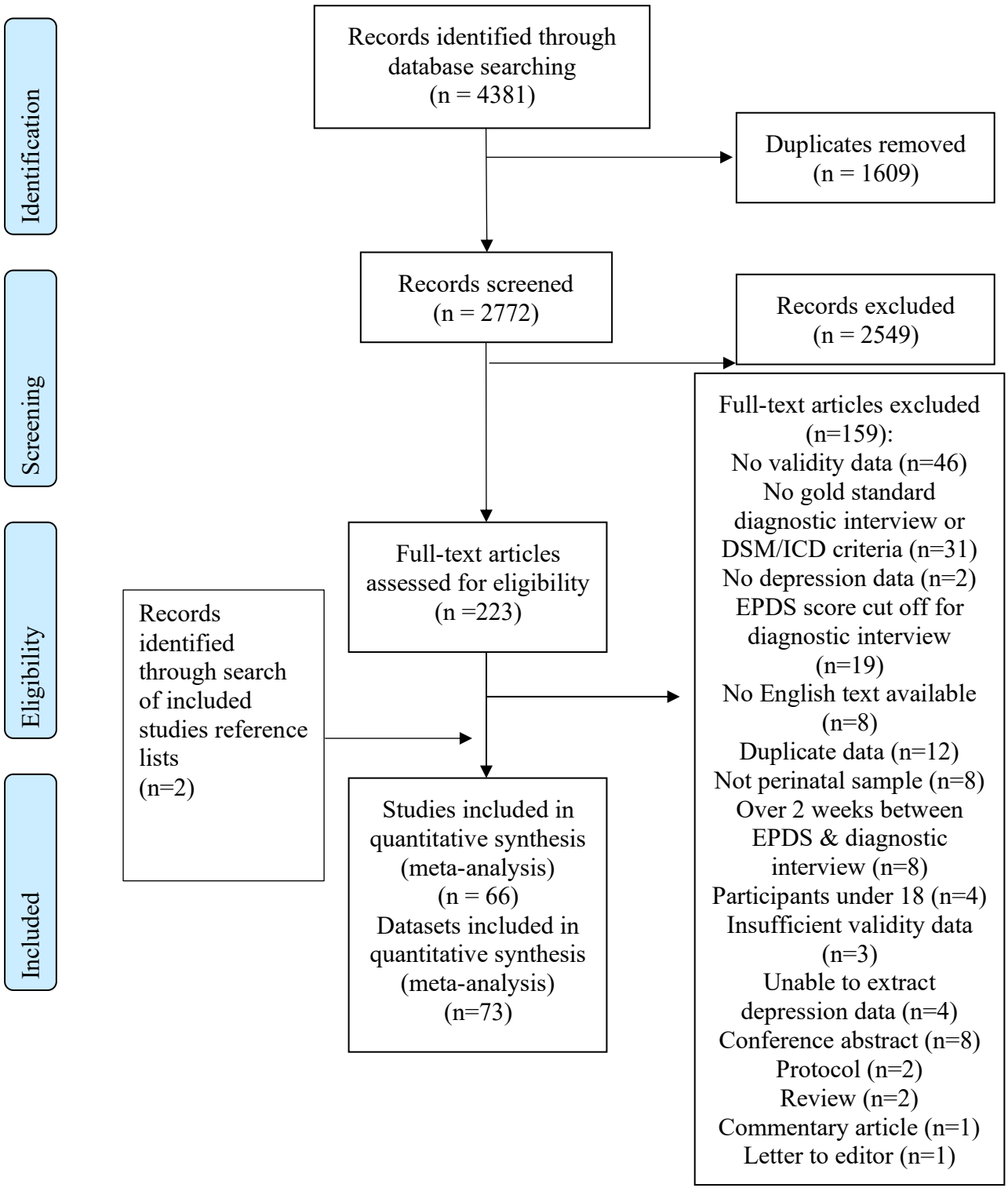
Exclusion Criteria	Rationale
specificity, positive likelihood ratio and negative likelihood ratio values).	
English Language	
Articles not published in English language.	The resources required for translation of articles were not available.
Duplicate Data	
Studies reporting the same data set to another study.	The inclusion of duplicate data would bias outcomes in this review.
Type of Article	
Books, book chapters, reviews, letters to editor, commentaries, conference abstracts, protocols, and 'grey literature' (e.g. unpublished doctoral theses).	These sources would not provide the required data for this review.

Paper selection

PRISMA guidelines were followed for paper selection and the process can be found in Figure 1. Titles and abstracts were screened by inclusion and exclusion criteria (see Table 2) and removed at this stage if it could be confirmed that they met any exclusion criteria or did not meet all inclusion criteria. If this could not be determined, the full paper was screened. Following identification of studies meeting the inclusion criteria, reference lists of the included studies were searched.

Figure 1

Prisma flow chart showing the selection of papers



Data extraction

The author extracted all data. The following data items were extracted from each study:

1) Descriptive characteristics of the sample and setting (year of publication, sample size, country, setting, age of sample, gender of sample, number depressed, number not depressed, severity of depression [i.e. major, minor or mixed]);

2) Descriptive characteristics of the EPDS (language, cut off score used, time between EPDS and gold standard reference test);

3) Descriptive characteristics of the gold standard reference test (language, type of gold standard, type of depression diagnoses (i.e. ICD or DSM);

4) Quality assessment criteria (see section below); and

5) The 2×2 contingency tables for the EPDS against gold standard diagnosis of depression (Figure 2).

Figure 2

2 x 2 contingency table required for data extraction

EPDS	Diagnosis of depression: **Present**	**Absent**
Positive	True positive	False positive
Negative	False negative	True negative

Psychometric properties (i.e. sensitivity, specificity, positive and negative predictive values, positive and negative likelihood ratio values, and diagnostic odds ratio) that were not provided in the included studies were calculated.

It was expected that the studies would show considerable variation in the reporting of diagnostic accuracy. In anticipation of this variation, the following rules were followed for data extraction:

- If psychometric data was available at multiple cut-off points on the EPDS, data was extracted from the cut-off point found to be optimum in terms of sensitivity and specificity
- If psychometric data was available for both major and minor depression for the same sample and unable to be separated, data was extracted for mixed depression to cover both diagnoses
- If results of psychometric properties across multiple time points were reported for the same sample (e.g. sensitivity and specificity over each trimester of pregnancy), only mid-point data was extracted.

Data analysis strategy

The data analysis strategy follows the guidelines for the Centre for Applied Psychology, University of Birmingham and is paraphrased below.

Traditional measures of diagnostic test accuracy

Diagnostic tests generally have multiple or continuous outcomes, but in order to classify results in positive or negative, a dichotomous variable is frequently used by either the grouping of categories or the application of a cut-off value. This allows the comparison between a diagnostic test and a reference standard. Common indicators of diagnostic test performance are sensitivity, specificity, positive and negative predictive values, and the

positive and negative likelihood ratios. These univariate test performance indicators are described in Table 3.

Table 3

Univariate and global test performance indicators

		Formula	Definition
Univariate measures ↓	Sensitivity = true positive rate	TP / (TP + FN)	The proportion of positive test results among "depressed" respondents
	Specificity = true negative rate	TN / (TN + FP)	The proportion of negative test results among the "non-depressed"
	Positive predictive value	TP / (TP + FP)	The proportion "depressed" respondents among subjects with a positive test result
	Negative predictive value	TN / (TN + FN)	The proportion of "non-depressed" respondents among subjects with a negative test result
	Positive likelihood ratio	Sensitivity / (1-specificity)	The ratio of a positive test result among "depressed" respondents to the same result in the "non-depressed"
	Negative likelihood ratio	(1-sensitivity) /specificity	The ratio of a negative test result among "depressed" respondents to the same result in the "non-depressed"
Global measures	Overall accuracy	(TP + TN)/(TP + TN + FP + FN)	The proportion of correctly identified subjects
	Diagnostic odds ratio	$\left\lvert \frac{\frac{TP}{FN}}{\frac{FP}{TN}} \right\rvert = \left\lvert \frac{\left(\frac{PPV}{(1-PPV)}\right)}{\left(\frac{(1-NPV)}{NPV}\right)} \right\rvert = \frac{\lvert LR+ \rvert}{\lvert LR- \rvert}$	The ratio of the odds of depression in test positives relative to the odds of depression in test negatives

TP True Positives, ***FP*** False Positives, ***FN*** False Negatives, ***TN*** True Negatives

These univariate test performance indicators cannot validly represent a test's discriminatory performance and cannot be interpreted in isolation from one another. Furthermore, positive and negative predictive values can be significantly impacted by the disease prevalence, so even if a test demonstrates high sensitivity and specificity, the positive predicative value would be low if the disease prevalence was low.

Therefore, combining sensitivity and specificity, negative and positive likelihood ratios and predictive values into one global measure of test performance is required. Unfortunately, the "overall accuracy" of the test is also affected by the disease prevalence, but the diagnostic odds ratio (DOR) provides a measure of global test performance that is not prevalence dependent (Glas et al., 2003). A DOR of 1 indicates no discriminatory power between "diseased" and "healthy" subjects, and the higher the value, the better the test is at discriminating between "diseased" and "healthy".

Current data analysis strategy

Diagnostic accuracy meta-analyses have traditionally pooled univariate measures of accuracy, such as diagnostic odds ratios, positive likelihood ratios or the negative likelihood ratios. However, sensitivity and specificities of a diagnostic test cannot be considered in isolation, and it is therefore preferable to use a bivariate meta-analytic method (Zwindermann & Bossuyt, 2008). Bivariate models allow consideration of the effects of sensitivity and specificity simultaneously by means of a receiver operator characteristic (ROC) analysis. A ROC curve plots the true positive rate as a function of the false positive rate for all possible cut-off values of the test. The obtained area under the curve (AUC) can used as an alternative global indicator of test performance and can be interpreted as the average sensitivity across all possible specificities.

The current meta-analysis firstly calculated the univariate meta-analytic synthesis for positive and negative and likelihood ratios, and the diagnostic odds ratio. These univariate

analyses are then supplemented by the calculation of the bivariate random effects model using the procedures described by Reitsma et al. (2005). This model has been shown by Harbord et al. (2008) to be equivalent to the HSROC linear mixed effects model proposed by Rutter & Gatsonis (2001).

The bivariate random effects model can be used to calculate the summary receiver operating characteristic curve (SROC). In an SROC curve the point estimate of the pair of sensitivity (y-axis) and false positive rates (x-axis) are plotted together with a 95% confidence interval for both the x and y axis. The bivariate random effects model calculates the average trajectory of these point estimates (weighted by a measure of precision of the study) across the range of the original data and, optionally, extrapolated for values beyond the original data range.

Data quality assessment

The quality of the selected studies was assessed using the Quality Assessment of Diagnostic Accuracy Studies-2 (QUADAS-2) quality assessment tool (Whiting et al., 2011). The QUADAS-2 is a validated quality checklist composed of 14 items, which encompass the most important sources of bias and variations observed in diagnostic accuracy studies. The selected studies were classified according to unclear, low or high risk for bias and applicability. Table 4 details the definition of the different risk domains and descriptions of the grading of unclear, low and high risk for each risk domain. Results of the risk of bias ratings for each study can be found below in Table 5. Table 5 demonstrates that the overall quality of the included studies was found to be mixed. The selection bias and flow and timing assessments indicated the most problematic domains due to significant unclear and high risk of bias.

Table 4

Overview of the quality criteria framework applied for assessing risk of bias

Risk Domain	Definition	Rating	Description of Rating
Selection Bias	Was a consecutive or random sample of patients enrolled?	Unclear	Insufficient information on sampling method and inclusion/exclusion criteria.
		Low	Random or consecutive sampling. No inappropriate exclusions.
	Was a case–control design avoided?	High	Not random sampling methods. Inappropriate exclusions (e.g. previous depression). Recruited from high risk sample (e.g. from psychiatric unit). Not all those recruited went through to diagnostic interview (e.g. EPDS used as cut off for interview).
	Did the study avoid inappropriate exclusions?		
Selection Applicability Concerns	Are there concerns that the included patients and setting do not match the review question?	Unclear	Insufficient information on characteristics of participants.
		Low	Representative sample to review question recruited.
		High	Sample restricted to subgroup (e.g. only HIV positive women).
Index Test Bias	Were the index test results interpreted without knowledge of the results of the reference standard?	Unclear	Insufficient information on order of administration of reference standard & EPDS. Insufficient information on interviewer's blindness to reference standard.
	If a threshold was used, was it prespecified?	Low	EPDS administered prior to reference standard. EPDS cut off used pre-specified prior to start of study and based upon prior research.
		High	Interviewer not blind to EPDS scores.

Risk Domain	Definition	Rating	Description of Rating
Index Test Applicability Concerns	Are there concerns that the index test, its conduct, or its interpretation differ from the review question?	Unclear	Insufficient information on administration or scoring of EPDS.
		Low	EPDS administered the same and scored the same for all.
		High	EPDS not administered as intended (i.e. self-administered). Differences in administration of EPDS between participants (e.g. some verbally read out, others self-administered, or different languages and no separation of this in analysis).
Reference Standard Bias	Is the reference standard likely to correctly classify the target condition? Were the reference standard results interpreted without knowledge of the results of the index test?	Unclear	Insufficient information on order of administration of reference standard & EPDS, or insufficient information on interviewer's blindness to EPDS scores. Insufficient information on reference standard or diagnostic interview used (e.g. states DSM but does not state type of semi-structured or structured diagnostic interview used).
		Low	Diagnostic interviewer blind to EPDS score. Different EPDS cut-offs evaluated. Clearly states diagnostic interview and reference standard.
		High	Diagnostic interviewer not blind to EPDS scores.
Reference Standard	Are there concerns that the target condition as defined	Unclear	Insufficient information on reference standard provided.

Risk Domain	Definition	Rating	Description of Rating
Applicability Concerns	by the reference standard does not match the question?	Low	Structured, 'gold standard' reference standard that is likely to correctly classify the target condition (depression).
		High	Reference standard used is unlikely to correctly classify depression.
Flow and Timing	Was there an appropriate interval between the index test and reference standard?	Unclear	Insufficient information on time period between EPDS & interview (not explicitly stated).
		Low	Less than 24 hours between EPDS administration and diagnostic interview. All participants included in analysis, or appropriate reasons for exclusion, or some exploration of difference between those who dropped-out (and therefore excluded from analysis) to those who completed study.
	Did all patients receive the same reference standard?		
	Were all patients included in the analysis?		
		High	Over 24 hours between EPDS administration and diagnostic interview. All participants not included in analysis.

Table 5

Summary of risk of bias ratings for each included study

Study	Selection Bias	Selection Applicability Concerns	Index Test Bias	Index Test Applicability Concerns	Reference Standard Bias	Reference Standard Applicability Concerns	Flow and Timing
Abiodun (2006)							
Adewuya et al. (2006)							
Adouard et al. (2005)							
Agoub et al. (2005)							
Alvarado et al. (2015)							
Alvarado-Esquivel et al. (2006)							
Aydin et al. (2004)							
Barnett et al. (1999a)							
Barnett et al. (1999b)							
Barnett et al (1999c)							
Beck & Gable (2001a)							
Berle et al. (2003)							
Benvenuti et al. (1999)							
Bergink et al. (2011)							
Benjamin et al. (2005)							
Bhusal et al. (2016)							
Boyce et al. (1993)							
Brancaglion et al. (2013)							
Bunevicius et al. (2009a)							
Bunevicius et al. (2009b)							
Castro et al. (2015)							
Chaudron et al. (2010)							
Chibanda et al. (2010)							
Chorwe-Sungani & Chipps (2018)							
Eberhard-Gran et al. (2001)							

Study	Selection Bias	Selection Applicability Concerns	Index Test Bias	Index Test Applicability Concerns	Reference Standard Bias	Reference Standard Applicability Concerns	Flow and Timing
Felice et al. (2006)							
Fernandes et al. (2011)							
Figueira etla. (2009)							
Garcia-Esteve et al. (2003)							
Gausia et al. (2007)							
Green et al. (2018a)							
Green et al. (2018b)							
Harris et al. (1989)							
Husain et al. (2014)							
Ing et al. (2017a)							
Ing et al. (2017b)							
Ji et al. (2011)							
Kadir et al. (2004)							
Khalifa et al. (2015)							
Lai et al. (2010)							
Lawrie et al. (1998)							
Leonardou et al. (2009)							
Littleworth et al. (2018)							
Mahmud et al. (2003)							
Marsay et al. (2017)							
Matthey et al. (2001a)							
Matthey et al. (2001b)							
Mazhari & Nakhaee (2007)							
Phillips et al. (2009)							
Pitanupong et al. (2007)							
Rados et al. (2013)							
Regmi et al. (2002)							
Rochat (2013)							
Rowel et al. (2008a)							
Rowel et al. (2008b)							
Rubertsson (2011)							

Study	Selection Bias	Selection Applicability Concerns	Index Test Bias	Index Test Applicability Concerns	Reference Standard Bias	Reference Standard Applicability Concerns	Flow and Timing
Santos et al. (2007)							
Shaheen et al. (2019)							
Smith-Nielsen et al. (2018)							
Su et al. (2007)							
Tandon et al. (2012a)							
Tandon et al. (2012b)							
Tendais et al. (2014)							
Teng et al. (2005)							
Tesfaye et al. (2010)							
Thiagayson et al. (2013)							
Toreki et al. (2014)							
Toreki et al. (2013)							
Uwakwe (2003)							
van Heyningen et al. (2018)							
Vazquez & Miguez (2019)							
Werret & Clifford (2006)							
Wickberg & Hwang (1996)							

= High Risk = Unclear Risk = Low Risk

Selection bias

Overall, selection bias was present in the majority of studies. Nineteen studies were rated as low risk due to their consecutive sampling and selection of participants that did not include any inappropriate exclusions. However, twenty-one studies were rated as high selection bias. Twelve studies were rated as high risk of selection bias due to only a subset of participants being selected for diagnostic interview. Nine studies were rated as high risk of selection bias due to convenience sampling and one study was rated as high risk of selection bias due to the

exclusion of participants with a prior history of mood disorder (Bhusal et al., 2016). Thirty-two studies were rated as unclear in risk of selection bias due to insufficient information on sampling method and inclusion or exclusion criteria.

Selection applicability concerns

Overall, the majority of the studies demonstrated low selection applicability concerns, with 64 studies rated as low bias in this domain. Studies were rated as low bias in applicability concerns due to recruiting a representative sample to the study. Nine studies were rated as high risk of bias in selection applicability concerns due to the representativeness of the recruited sample. Three studies were rated as high risk of bias in this domain due to recruiting women from high risk pregnancy centres (Adouard et al., 2005; Marsay et al., 2017; Thiagayson et al., 2013), one due to recruiting from a sample of parents experiencing complex early parenting difficulties (Phillips et al., 2009) and two due to the significant recruitment of HIV positive women (Chibanda et al., 2010; Rochat, 2013). A further study was rated as high risk due to the exclusion of women with past psychiatric history (Shaheen et al., 2019) and one due to the inclusion of only women with a history of mental illness (Ji et al., 2011). One further study was rated as high risk of bias in this domain due to recruiting only women from a low-income, socially disadvantaged area who were attending follow-ups due to birth complications (Lawrie et al., 1998). No studies were rated as unclear risk of selection applicability concerns due to insufficient sample information.

Index test bias

The majority of studies were rated as low risk of index test bias, with 59 studies having administered the EPDS prior to the diagnostic interview and/or blinded the interviewer to the EPDS scores. Fourteen studies were rated as unclear in this domain due to insufficient information provided on the blinding of the diagnostic interviewer to EPDS scores. No studies were rated as high index test bias.

Index test applicability concerns

Fourteen studies were rated as high risk of bias in index test applicability concerns due to differences in the administration of the EPDS between participants in the study or differences in the intended administration method of the EPDS (i.e. self-administered). Seven of these studies were rated as high risk due to some of the study sample having been read out the EPDS by the researcher, whereas others self-administered the scale (Abiodun, 2006; Adewuya et al., 2006; Agoub et al., 2005; Aydin et al., 2004; Leonardou et al., 2009; Uwakwe, 2003; Werret & Clifford, 2006). One study (van Heyningen et al., 2018) administered the EPDS in different languages across the study sample and the remaining studies six were rated as high risk due to the administration of the EPDS by the researcher (Chibanda et al., 2010; Husain et al., 2014; Ing et al., 2017 a & b; Khalifa et al., 2015; Lawrie et al., 1998). Three studies were rated as unclear risk due to insufficient information on the administration of the EPDS (Figueira et al., 2009; Kadir et al., 2004; Regmi et al., 2002). The remaining 56 studies were rated as low risk of bias in index test applicability concerns.

Reference standard bias

Of the 73 included studies, 36 were rated as low risk of reference standard bias due to the blinding of administrator of the reference test. A total of 33 studies were rated as unclear risk of bias in this domain; 25 due to insufficient information regarding the blinding of the reference test administrator, and eight studies were due to insufficient information provided on the type of diagnostic interview reference standard utilised (Alvarado-Esquivel et al., 2006; Bhusal et al., 2006; Harris et al., 1989; Rowel et al., 2008 a & b; Santos et al., 2007; Shaheen et al., 2019; Tesfaye et al., 2010). Four studies (Littleworth et al., 2018; Smith-Nielson et al., 2018; Tandon et al., 2012 a & b) were rated as high risk of reference standard bias due to the administrator of the reference standard not being blind to participants EPDS scores.

Reference standard applicability concerns

Overall, all but one of the studies (72 of 73) were rated as low risk of bias in reference standard applicability concerns. Studies were rated as low risk in this domain due to their use of a standardised diagnostic interview reference test (e.g. Mini Mental State Examination). One study was rated as high risk in this domain (Leonardou et al., 2009) due to differing administration methods of the reference test within the study, with some being administered in person and some by telephone.

Flow and timing

Overall, the majority of studies (41 of 73) were rating as unclear risk of bias in regard to flow and timing. All of these studies did not provide ample information on the timing between the administration of the EPDS and the gold standard reference test. A total of 17 studies were rated as high risk of bias in regard to flow and timing, 15 of which were due to a period over 24 hours between the administration of the EPDS and the reference standard and two due to missing participants from the analyses (Castro et al., 2015; Shaheen et al., 2019). Fifteen of the studies were rated as low risk due to a time period of less than 24 hours between index and reference test administrations.

Results

The systematic search identified 223 articles for further inspection through full text review. Of these 223 studies, there were 159 that were excluded due to not meeting the inclusion/exclusion criteria. An additional two studies were identified through hand searching the reference lists of the included studies. Therefore, a total of 66 articles met the inclusion criteria. The Prisma Flow Chart in Figure 1 shows the flow of studies through the review. Within the included studies, some articles provided data for more than one population that were able to be separated, which resulted in the inclusion of 66 articles yielding 73 sets of psychometric data. Corresponding paper references have been separated to account for multiple sets of data (e.g. Ing et al., 2017a and Ing et al., 2017b). Three articles presented separate antenatal and postnatal samples (Green et al., 2018; Rowel et al., 2008; Tandon et al., 2012), two articles presented separate datasets for different languages of the Edinburgh Postnatal Depression Scale (EPDS) (Barnett et al., 1999; Ing et al., 2017) and one article presented separate data for men and women during the postnatal period (Matthey et al., 2001).

Characteristics of included studies

An overview of the characteristics of included studies can be found in Tables 6 and 7 below.

Study samples

Of the 73 data sets included, 49 were postnatal samples, comprising of 47 female postnatal samples and two male samples (Lai et al., 2010; Matthey et al., 2001b). The remaining 25 datasets were antenatal samples, comprising of 24 female antenatal samples and one male (Shaheen et al., 2019).

Of the 73 data sets included, 25 screened for major depressive disorder only, 39 screened for both minor and major depression and nine did not state the severity of depression they assessed for.

Study size

The number of participants across all studies totalled 14,152 (range= 23-845; median= 148; mean= 193.863).

Diagnostic criteria and reference test

Eight different reference tests were used across the studies: The Composite International Diagnostic Interview (n=5), The Clinical Interview Schedule-Revised (n=4), The Diagnostic Interview Schedule (n=6), The Montgomery-Asberg Depression Scale delivered in an interview (n=1), The Mini-International Neuropsychiatric Interview (n=16), Primary Care Evaluation of Mental Disorders (n=2), The Present State Examination (n=2) and The Structured Clinical Interview for DSM Disorders (n=26). Eleven studies did not state the type of semi-structured or structured interview that they utilised. The most commonly utilised depression diagnostic criteria were different versions of The Diagnostic and Statistical Manual of Mental Disorders (DSM): the DSM-III (n=8), DSM-IV criteria (n=43), DSM-5 criteria (n=5), and one study did not state the version of the DSM criteria used. Twelve studies utilised the International Statistical Classification of Diseases and Related Health Problems-10 (ICD-10) diagnostic criteria and four studies used both the DSM and ICD diagnostic criteria.

Country and language

The studies took place over 39 different countries, with very few studies in each country and the largest number of studies (n=7) conducted in Australia. The EPDS was administered in 39 different languages across the included studies, with English the most common language of administration (n=19) followed by Spanish (n=6). One study did not state the language of administration of the EPDS (Regmi et al., 2002) and five studies used different language

administrations and did not separate results according to language (Abiodun, 2006; Adewuya et al., 2006; Husain et al., 2014; Lawrie et al., 1998; van Heyningen et al., 2018).

Administration of the EPDS

The majority of the studies (n=70) administered the EPDS in person, whereas one study administered the EPDS by telephone (Rubertsson, 2011) and two administered it by either telephone or in person (Khalifa et al., 2015; Leonardou et al., 2009).

Time between EPDS and reference test

The majority of studies (n=42) did not explicitly state the time between the administration of the EPDS and the diagnostic interview. Sixteen studies had a period of under 24 hours between administrations, four studies up to 72 hours (Green et al 2008 a & b; Matthey et al, 2001 a & b), three up to one week (Khalifa et al., 2015; Tendais et al., 2014; Werret & Clifford, 2006) and six up to 2 weeks (Brancaglion et al., 2013; Littleworth et al., 2018; Mazhari & Makhaee, 2007; Robertsson, 2011; Santos et al., 2007; Wickberg & Hwang, 1996) and one up to four weeks (Husain et al., 2014).

Cut-off used for EPDS

The cut-off of the EPDS used varied widely between studies, ranging from 6 to 16. The most commonly used (n=14) cut off was 10, followed by 9 (n=10) and the least commonly used were 8.5 (n=1) and 14.5 (n=1).

Table 6

Overview of included studies of postnatal samples

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Abiodun (2006)	PSE, ICD-10	Nigeria	English or Yoruba	N/R	Female	360	27.9
Agoub et al. (2005)	MINI, DSM-IV	Morocco	Arabic	<24 hours	Female	144	30.3
Alvarado-Esquivel et al. (2006)	N/R, DSM-IV	Mexico	Mexican	<24 hours	Female	51	24.7
Aydin et al. (2004)	SCID, DSM-IV	Turkey	Turkish	N/R	Female	341	26.6
Barnett et al. (1999a)	DIS, DSM-III	Australia	Arabic	N/R	Female	98	28
Barnett et al. (1999b)	DIS, DSM-III	Australia	Vietnamese	N/R	Female	113	28

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Barnett et al. (1999c)	DIS, DSM-III	Australia	English	N/R	Female	105	26
Beck & Gable (2001)	SCID, DSM-IV	America	English	<24 hours	Female	150	31
Benjamin et al (2005)	CIS-R, ICD-10	India	Tamil	N/R	Female	129	23.4
Benvenuti et al. (1999)	MINI, DSM-III	Italy	Italian	<24 hours	Female	113	31.9
Berle et al. (2003)	MINI, DSM-IV	Norway	Norwegian	N/R	Female	100	N/R
Bhusal et al. (2016)	N/R, ICD-10	Nepal	Nepali	<24 hours	Female	346	22.75
Boyce et al. (1993)	DIS, DSM-III	Australia	English	N/R	Female	103	28.4
Bunevicius et al. (2009a)	CIDI, DSM-IV	Lithuania	Lithuanian	N/R	Female	94	29

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Chaudron et al. (2010)	SCID, DSM-IV	USA	English	N/R	Female	198	24.6
Chibanda et al. (2010)	SCID, DSM-IV	Zimbabwe	Shona	N/R	Female	210	25
Eberhard-Gran et al. (2001)	PRIME-MD, DSM-IV	Norway	Norwegian	<24 hours	Female	56	30
Figueira et al. (2009)	MINI, DSM-IV	Brazil	Spanish	<24 hours	Female	245	30.7
Garcia-Esteve et al. (2003)	SCID, DSM-III	Spain	Spanish	<24 hours	Female	334	N/R
Gausia et al. (2007)	SCID, DSM-IV	Bangladesh	Bengali	<24 hours	Female	100	25.5
Green et al. (2018b)	SCID, DSM-5	Kenya	Kiswahili	≤3 days	Female	132	26.6
Harris et al. (1989)	N/R, DSM-III	Wales	English	N/R	Female	126	24.6

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Ing et al. (2017a)	SCID, DSM-IV	Thailand	Burmese	N/R	Female	128	26
Ing et al. (2017b)	SCID, DSM-IV	Thailand	Karen	N/R	Female	534	24
Littleworth et al. (2018)	CIS-R, ICD-10	UK	English	≤2 weeks	Female	334	32.3
Kadir et al. (2004)	CIS, ICD-10	Malaysia	Malay	N/R	Female	52	N/R
Khalifa et al. (2015)	MINI, DSM-IV/ICD-10	Sudan	Arabic	≤1 week	Female	40	N/R
Lai et al. (2010)	SCID, DSM-IV	Hong Kong	Cantonese	N/R	Male	551	33.4
Lawrie et al. (1998)	SCID, DSM-IV	South Africa	Various, mostly Afrikaans	N/R	Female	102	28.1
Leonardou et al. (2009)	SCID, DSM-III	Greece	Greek	N/R	Female	81	31.5

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Mahmud et al. (2003)	CIDI, ICD-10	Malaysia	Malay	N/R	Female	64	28.7
Matthey et al. (2001a)	DIS, DSM-IV	Australia	English	≤3 days	Female	230	27.2
Matthey et al. (2001b)	DIS, DSM-IV	Australia	English	≤3 days	Male	200	29.1
Mazhari & Nakhaee (2007)	N/R, DSM-IV	Iran	Persian	≤2 weeks	Female	200	25.6
Phillips et al. (2009)	SCID, DSM-IV	Australia	English	N/R	Female	165	31.9
Pitanupong et al. (2007)	N/R, DSM-IV	Thailand	Thai	N/R	Female	351	27.9
Rados et al. (2013)	SCID, DSM-IV	Croatia	Croatian	N/R	Female	272	29
Regmi et al. (2002)	N/R, DSM-IV	Nepal	N/R	N/R	Female	100	N/R

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Rowel et al. (2008b)	N/R, ICD-10	Sri Lanka	Sinhalese	<24 hours	Female	204	N/R
Santos et al. (2007)	N/R, ICD-10	Brazil	Portuguese	≤15 days	Female	378	N/R
Shaheen et al. (2019)	N/R, DSM-5	Saudi Arabia	Arabic	<24 hours	Male	57	N/R
Smith-Nielsen et al. (2018)	SCID, DSM-5	Denmark	Danish	N/R	Female	320	32.7
Tandon et al. (2012b)	SCID, DSM-IV	USA	English	<24 hours	Female	63	24.7
Teng et al. (2005)	MINI, DSM-IV	Taiwan	Taiwanese	N/R	Female	203	N/R
Tesfaye et al. (2010)	N/R, DSM-IV	Ethiopia	Amharic	<24 hours	Female	100	N/R
Toreki et al. (2014)	SCID, DSM-IV	Hungary	Hungarian	N/R	Female	266	30.5

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Uwakwe (2003)	CIDI, ICD-10	Nigeria	Igbo	<48 hours	Female	225	28.9
Werret & Clifford (2006)	CIDI, ICD-10	England	English	1 week	Female	23	28.6
Wickberg & Hwang (1996)	MADRS, DSM-III	Sweden	Swedish	1-2 weeks	Female	128	28.1

PSE The Psychiatric State Examination, ***MINI*** The Mini International Neuropsychiatric Interview, ***SCID*** The Structured Clinical Interview for DSM-IV, ***DIS*** The Diagnostic Interview Schedule, ***CIDI*** The Composite International Diagnostic Interview, ***CIS*** The Clinical Interview Schedule, ***CIS-R*** The Clinical Interview Schedule- Revised**,** ***MADRS*** The Montgomery-Asberg Depression Scale**,** ***PRIME-MD*** The Primary Care Evaluation of Mental Disorders**,** ***DSM-III*** The Diagnostic and Statistical Manual of Mental Disorders- Version III**,** ***DSM-IV*** The Diagnostic and Statistical Manual of Mental Disorders- Version IV**,** ***DSM-5*** The Diagnostic and Statistical Manual of Mental Disorders- Version 5**,** ***ICD-10*** The International Statistical Classification of Diseases and Related Health Problems- Version 10**,** ***N/R*** Not Reported in paper, ***N*** The number of participants in analysis.

Table 7

Overview of included studies of antenatal sample

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Adewuya et al. (2006)	MINI, DSM-IV	Nigeria	English or Yoruba	N/R	Female	86	24.89
Adouard et al. (2005)	MINI, DSM-IV	France	French	N/R	Female	60	31.5
Alvarado et al (2015)	MINI, DSM-IV	Chile	Spanish	N/R	Female	111	N/R
Bergink et al. (2011)	CIDI, DSM-IV	Netherlands	Dutch	N/R	Female	845	29.5
Brancaglion et al. (2013)	MINI, DSM-IV/ICD-10	Brazil	Spanish	≤ 2 weeks	Female	90	28.57
Bunevicius et al. (2009b)	SCID, DSM-IV	Lithuania	Lithuanian	N/R	Female	230	29

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Castro et al. (2015)	MINI, DSM-IV	Brazil	Spanish	N/R	Female	245	N/R
Chorwe-Sungani & Chipps (2018)	MINI, DSM-IV	Malawi	Chicewa	N/R	Female	97	97
Felice et al. (2006)	CIS-R, ICD	Malta	Maltese	N/R	Female	223	27.1
Fernandes et al. (2011)	MINI, DSM-IV	India	Kannada	N/R	Female	194	21.5
Green et al. (2018a)	SCID, DSM-5	Kenya	Kiswahili	≤ 3 days	Female	61	26.6
Husain et al. (2014)	PSE, DSM-IV	UK	English or Urdu	≤ 4 weeks	Female	237	N/R
Ji et al. (2011)	SCID, DSM-IV	USA	English	<24 hours	Female	285	N/R

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Marsa et al. (2017)	SCID, DSM-IV	South Africa	English	N/R	Female	145	31.1
Rochat et al. (2013)	SCID, DSM-IV	South Africa	Zulu	N/R	Female	109	N/R
Rowel et al (2008a)	N/R, ICD-10	Sri Lanka	Sinhalese	<24 hours	Female	265	N/R
Rubertsson et al. (2011)	PRIME-MD, DSM-IV	Sweden	Swedish	12 days (Mean)	Female	121	29.7
Su et al. (2007)	MINI, DSM-IV	Taiwan	Taiwanese	N/R	Female	185	31.55
Tandon et al. (2012a)	SCID, DSM-IV	USA	English	<24 hours	Female	32	23.8
Tendais et al. (2014)	SCID, DSM-IV	Portugal	Portuguese	1 week	Female	148	28
Thiagayson et al. (2013)	MINI. DSM-ICD	Singapore	English	N/R	Female	200	N/R

Study	Diagnostic interview and reference standard	Country	Language of EPDS	Time between EPDS & diagnostic tool	Gender	N	Age (Mean)
Toreki et al. (2013)	SCID, DSM-IV	Hungary	Hungarian	N/R	Female	219	30
van Heyningen et al. (2018)	MINI, DSM-IV/ICD-10	South Africa	English and Africaans	N/R	Female	376	26.8
Vazquez & Miguez (2019)	SCID, DSM-IV	Spain	Spanish	N/R	Female	569	32.8

PSE The Psychiatric State Examination, ***MINI*** The Mini International Neuropsychiatric Interview, ***SCID*** The Structured Clinical Interview for DSM-IV, ***DIS*** The Diagnostic Interview Schedule, ***CIDI*** The Composite International Diagnostic Interview, ***CIS*** The Clinical Interview Schedule, ***CIS-R*** The Clinical Interview Schedule- Revised**,** ***MADRS*** The Montgomery-Asberg Depression Scale**,** ***PRIME-MD*** The Primary Care Evaluation of Mental Disorders**,** ***DSM-III*** The Diagnostic and Statistical Manual of Mental Disorders- Version III**,** ***DSM-IV*** The Diagnostic and Statistical Manual of Mental Disorders- Version IV**,** ***DSM-5*** The Diagnostic and Statistical Manual of Mental Disorders- Version 5**,** ***ICD-10*** The International Statistical Classification of Diseases and Related Health Problems- Version 10**,** ***N/R*** Not Reported in paper, ***N*** The number of participants in analysis.

Diagnostic accuracy of EPDS

Univariate random effects meta-analysis

A total of 73 datasets evaluated the accuracy of the EPDS and the sensitivity, specificity, positive likelihood ratio, negative likelihood ratio and diagnostic odds ratio were calculated for each dataset. The psychometric data of each study can be found in Tables 8 and 9 below. The sensitivity of each study varied between 0.50 (Green et al., 2008b) to 1.0 (Boyce et al., 1993; Garcia-Esteve et al., 2003), and the specificity ranged from 0.5139 (Wickberg & Hwang, 1996) to 1.0 (Kadir et al., 2004; Mahmud et al., 2003). Diagnostic odds ratios varied between 2.333 (Green et al., 2008b) and 29669726.275 (Mahmud et al., 2003).

A forest plot was generated to demonstrate the log transformed diagnostic odds ratios for all 73 datasets (Figure 3 below). The forest plot indicated extraordinarily large effects for nine studies (Boyce et al., 2003; Fernandes et al., 2011; Garcia-Esteve et al., 2003; Green et al., 2018a; Ing et al., 2017 a & b; Kadir et al., 2004; Mahmud et al., 2003; Regmi et al., 2002). On further exploration of these large effects, seven of the studies report a 100% sensitivity rate (Boyce et al., 2003; Fernandes et al., 2011; Garcia-Esteve et al., 2003; Green et al., 2018a; Ing et al., 2017 a & b; Regmi et al., 2002), one a near 100% sensitivity rate and no false positive events (Mahmud et al., 2003) and one reports no false positive events (Kadir et al., 2004). Given these unfeasible high sensitivity and specificity estimates and the impact they would have on the meta-analysis, a decision was made to remove these nine studies from further analysis. A forest plot of log transformed diagnostic odds ratios for the remaining 64 studies can be seen in Figure 4 below, where the effects of the other studies can now be seen more clearly.

The pooled diagnostic odds ratio was 26.597 (95% CI 20.681-34.206) and there was not a significant degree of heterogeneity observed in diagnostic odds ratios (Higgins' I^2= 2.755%, Q=64.785, df=63, p=0.414). A higher diagnostic odds ratio indicates better diagnostic

accuracy (Glas et al., 2003) and therefore the value of 26.597 indicates sound discriminatory performance of the EPDS. The pooled positive likelihood ratio was 5.686 (95% CI 4.844-6.674) and there was not a significant degree of heterogeneity observed (Higgins' I^2=13.65%, Q=72.959, df=63, p=0.183). As the positive likelihood ratio increases, the probability of depression if the EPDS was positive increases, with a value above 10 considered a large and significant increase in probability (Egger et al., 2008). The value of 5.686 indicated in this meta-analysis therefore indicates a moderate increase in the probability of depression given a positive screen using the EPDS. The pooled negative likelihood ratio was 0.242 (95% CI 0.216-0.271) and there was no significant heterogeneity noted (Higgins' I^2=0%, Q= 61.623, df=63, p=0.526). A smaller negative likelihood ratio indicates a more informative test, with a value below 0.2 indicating strong evidence for the diagnostic test (Egger et al., 2008). Therefore, the value of 0.242 indicate moderate to large evidence for the EPDS. Pooled sensitivity and specificity were not calculated due to the inaccuracy of looking at either of these constructs in isolation, instead the bivariate random effects model meta-analysis below looked at these constructs simultaneously.

Table 8

Overview of validity data of included papers studying postnatal population

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Abiodun (2006)	5.611 (4.241-7.425)	0.141 (0.074- 0.269)	0.881 (0.784-0.938)	0.843 (0.797-0.880)	39.752 (17.965-80.796)
Agoub et al. (2005)	23.000 (0.940-56.268)	0.083 (0.023-0.300)	0.920 (0.759-0.977)	0.960 (0.908-0.983)	276.000 (51.968- 1465.819)
Alvarado-Esquivel et al. (2006)	4.688 (2.121-10.361)	0.298 (0.089-0.995)	0.750 (0.409-0.929)	0.840 (0.703-0.921)	15.750 (2.614-94.903)
Aydin et al. (2004)	2.649 (2.080-3.374)	0.343 (0.208-0.563)	0.755 (0.619-0.854)	0.715 (0.661-0.764)	7.731 (3.844-15.551)
Barnett et al. (1999a)	3.929 (2.279-6.774)	0.277 (0.081-0.9450)	0.778 (0.453-0.937)	0.802 (0.707-0.872)	14.195 (2.709-74.375)
Barnett et al. (1999b)	17.500 (7.987-38.344)	0.021 (0.000-9.791)	0.9800 (0.543-1.000)	0.944 (0.883-0.974)	826.000 (1.495-456331.700)
Barnett et al. (1999c)	5.258 (3.060-9.033)	0.171 (0.028-1.050)	0.857 (0.487-0.974)	0.837 (0.751-0.897)	30.774 (3.468-273.041)

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Beck & Gable (2001)	4.214 (2.471-7.187)	0.477 (0.334-0.680)	0.590 (0.446-0.720)	0.860 (0.780-0.914)	8.840 (3.942-19.821)
Benjamin et al. (2005)	9.602 (5.407-17.053)	0.065 (0.010-0.437)	0.941 (0.730-0.989)	0.902 (0.833-0.944)	146.797 (17.772-1212.547)
Benvenuti et al. (1999)	7.492 (4.360-12.875)	0.064 (0.010-0.428)	0.944 (0.742-0.990)	0.874 (0.792-0.926)	116.930 (14.338-953.558)
Berle et al. (2003)	8.800 (4.059-19.078)	0.133 (0.058-0.307)	0.880 (0.747-0.948)	0.900 (0.797-0.954)	66.000 (18.551-234.812)
Bhusal et al. (2016)	20.948 (12.234-35.866)	0.084 (0.033-0.2140)	0.920 (0.812-0.968)	0.956 (0.926-0.974)	250.346 (78.232-801.117)
Boyce et al. (1993)	23.256 (8.961-60.354)	0.000 (0.000-1.529 e+80)	1.000 (0.701-1.00)	0.957 (0.895-0.983)	2003001.00 (0-2.651 e+91)
Bunevicius et al. (2009a)	3.399 (2.302-5.018)	0.106 (0.016-0.697)	0.923 (0.667-0.986)	0.728 (0.623-0.813)	32.182 (3.949-262.258)
Chaudron et al. (2010)	3.526 (2.376-5.233)	0.245 (0.164-0.367)	0.811 (0.728-0.873)	0.770 (0.671-0.846)	14.365 (7.210-28.618)
Chibanda et al. (2010)	6.769 (4.407-10.398)	0.138 (0.071-0.269)	0.880 (0.778-0.939)	0.8700 (0.806-0.915)	49.077 (20.053-120.108)
Eberhard-Gran et al. (2001)	23.00 (3.303-160.161)	0.343 (0.187-0.630)	0.667 (0.454-0.828)	0.971 (0.854-0.995)	67.066 (7.636-589.064)
Figueira et al. (2009)	10.667	0.148	0.864	0.919	72.078

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
	(6.453-17.633)	(0.080-0.272)	(0.761-0.927)	(0.870-0.951)	(29.741-174.685)
Garcia-Esteve et al. (2003)	9.434	0.000	1.000	0.894	843387.792
	(6.502-13.686)	(0.000-9.245 e+21)	(0.963-1.00)	(0.848-0.927)	(0-6.984 e+32
Gausia et al. (2007)	6.738	0.128	0.889	0.868	52.605
	(3.790-11.981)	(0.020-0.814)	(0.565-0.980)	(0.783-0.923)	(6.036-458.436)
Green et al. (2018b)	1.667	0.714	0.500	0.700	2.333
	(0.717-3.874)	(0.318-0.160)	(0.188-0.812)	(0.615-0.773)	(0.450-12.089)
Harris et al. (1989)	13.571	0.054	0.950	0.930	252.429
	(6.691-27.523)	0.009-0.333)	(0.776-0.930)	(0.864-0.965)	(32.174-1980.464)
Ing et al. (2017a)	30.480	0.000	0.999	0.967	176879.061
	(11.629-79.890)	(0.000-1.417 e+23)	(0.609-1.00)	(0.919-0.987)	(0-1.482 e+32)
Ing et al. (2017b)	76.326	0.000	0.999	0.987	602611.687
	(36.351-160.261)	(0.000-1.043 e+23)	(0.675-1.00)	(0.973-0.994)	(0-5.024 e+32)
Kadir et al. (2004)	298070	0.273	0.727	1.000	1091828.839
	(0-3.931 e+90)	0.104-0.716)	(0.434-0.902)	(0.914- 1.00)	(0-1.447 e+91)
Khalifa et al. (2015)	4.885	0.136	0.889	0.818	35.997
		(0.036-0.509)	(0.672-0.969)	(0.615-0.927)	(5.795-223.582)
	(1.984-12.024)				
Lai et al. (2010)	30.333	0.093	0.9100	0.970	326.926
	(18.308-50.258)	(0.020-0.421)	(0.690-0.979)	(0.952-0.981)	(57.735-1851.214)
Lawrie et al. (1998)	4.176	0.293	0.7600	0.818	14.233

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
	(2.477-7.040)	(0.145-0.594)	(0.566-0.885)	(0.717-0.888)	(4.809-42.126)
Leonardou et al. (2009)	32.143	0.103	0.900	0.972	312.429
	(8.038-128.529)	(0.016-0.6610)	(0.596-0.982)	(0.903-0.992)	(25.614-3810.937)
Littleworth et al. (2018)	6.685	0.195	0.829	0.876	34.248
	(4.774-9.362)	(0.094-0.405)	(0.674-0.919)	(0.834-0.909)	(13.315-88.091)
Mahmud et al. (2003)	53990.000	0.018	0.982	1.0000	29669726.275
	(0-7.120 e+90)	(0.000-2.208)	(0.676-0.999)	(0.935-1.00)	(0-4.159 e+92)
Matthey et al. (2001a)	2.914	0.386	0.708	0.757	7.553
	(2.048-4.144)	(0.206-0.723)	(0.508-0.851)	(0.694-0.811)	(2.963-19.254)
Matthey et al. (2001b)	11.487	0.305	0.714	0.938	37.669
	(5.585-23.629)	(0.095-0.984)	(0.359-0.918)	(0.895-0.964)	(6.609-214.691)
Mazhari & Nakhaee (2007)	9.667	0.205	0.812	0.916	47.099
	(5.430-17.209)	(0.125-0.336)	(0.704-0.887)	(0.856-0.952)	(19.859-111.705)
Phillips et al. (2009)	3.737	0.358	0.710	0.810	10.437
	(2.472-5.647)	(0.221-0.579)	(0.560-0.825)	(0.732-0.870)	(4.669-23.333)
Pitanupong et al. (2007)	2.846	0.351	0.740	0.740	8.101
	(2.183-3.711)	(0.205-0.603)	(0.583-0.853)	(0.689-0.785)	(3.760-17.453)
Rados et al. (2013)	4.390	0.276	0.773	0.824	15.918
	(3.090-6.237)	(0.127-0.597)	(0.566-0.899)	(0.772-0.866)	(5.576-45.439)

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Regmi et al. (2002)	13.511 (6.633-27.521)	0.000 (0.000-1.775 e+23)	0.999 (0.565-0.899)	0.926 (0.855-0.964)	62555.054 (0-5.229 e+ 31)
Rowel et al. (2008b)	4.261 (3.098-5.859)	0.128 (0.055-0.296)	0.899 (0.784-0.956)	0.789 (0.718-0.846)	33.284 (12.170-91.030)
Santos et al. (2007)	2.383 (1.981-2.867)	0.265 (0.173-0.406)	0.827 (0.743-0.887)	0.653 (0.595-0.707)	8.996 (5.119-15.808)
Shaheen et al. (2019)	4.148 (2.092-8.226)	0.274 (0.080-0.936)	0.778 (0.453-0.937)	0.813 (0.681-0.898)	15.167 (2.687-85.598)
Smith-Nielsen et al. (2018)	14.143 (7.969-25.101)	0.220 (0.155-0.314)	0.7920 (0.710-0.855)	0.9440 (0.903-0.968)	64.187 (30.424-135.417)
Tandon et al. (2012b)	4.00 (2.109-7.586)	0.203 (0.081-0.505)	0.840 (0.653-0.936)	0.790 (0.637-0.890)	19.750 (5.256-74.219)
Teng et al. (2005)	6.400 (4.480-9.143)	0.047 (0.006-0.383)	0.960 (0.784-0.994)	0.850 (0.791-0.895)	136.000 (14.768-1252.439)
Tesfaye et al. (2010)	3.678 (2.348-5.763)	0.200 (0.056-0.7190)	0.846 (0.577-0.957)	0.770 (0.671-0.846)	18.391 (3.763-89.884)

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Toreki et al. (2014)	5.193 (3.576-7.540)	0.317 (0.195-0.5160)	0.727 (0.581-0.836)	0.860 (0.808-0.900)	16.359 (7.620-35.117)
Uwakwe (2003)	25.000 (11.018-56.724)	0.258 (0.129-0.516)	0.750 (0.551-0.880)	0.970 (0.936-0.986)	97.000 (28.381-331.524)
Werret & Clifford (2006)	3.428 (1.392-8.440)	0.191 (0.030-1.195)	0.857 (0.487-0.974)	0.750 (0.505-0.898)	17.979 (1.632-19.122)
Wickberg & Hwang (1996)	1.984 (1.556-2.529)	0.069 (0.017-0.276)	0.9643 (0.879-0.990)	0.5139 (0.401-0.626)	28.543 (6.465-126.025)

PLR Positive Likelihood Ratio***, NLR*** Negative Likelihood Ratio***, DOR*** Diagnostic Odds Ratio, ***CI*** Confidence Interval.

Table 9

Overview of validity data of included papers studying antenatal population

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Adewuya et al. (2006)	10.200 (4.636-22.441)	0.145 (0.040 – 0.530)	0.867 (0.622-0.963)	0.915 (0.827-0.960)	70.173 (12.720-387.132)
Adouard et al. (2005)	4.000 (2.116-7.562)	0.250 (0.090 – 0.6950)	0.800 (0.548-0.930)	0.800 (0.662-0.891)	16.000 (3.713-68.955)
Alvarado et al. (2015)	11.142 (4.695-26.444)	0.254 (0.143-0.451)	0.763 (0.608-0.870)	0.932 (0.849-0.970)	43.822 (13.513-142.111)
Bergink et al. (2011)	17.500 (11.863-25.817)	0.312 (0.201-0.486)	0.700 (0.556-0.813)	0.960 (0.944-0.972)	56.000 (27.174-115.405)
Brancaglion et al. (2013)	2.667 (1.753-4.057)	0.286 (0.117-0.696)	0.800 (0.584-0.919)	0.700 (0.585-0.795)	9.333 (2.786-31.269)
Bunevicius et al. (2009b)	11.000 (6.453-18.752)	0.130 (0.015-1.139)	0.880 (0.480-0.983)	0.920 (0.877-0.949)	84.333 (6.859-1036-851)
Castro et al. (2015)	3.059 (2.335-4.007)	0.251 (0.131-0.481)	0.816 (0.672-0.905)	0.733 (0.669-0.789)	12.181 (5.214-28.455)
Chorwe-Sungani & Chipps (2018)	5.602 (2.846-11.025)	0.364 (0.204-0.649)	0.680 (0.484-0.828)	0.879 (0.783-0.935)	15.381 (5.128-46.131)

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Felice et al. (2006)	17.857 (8.812-36.185)	0.261 (0.143-0.476)	0.750 (0.579-0.867)	0.958 (0.919-0.979)	68.429 (23.524-199.048)
Fernandes et al. (2011)	6.620 (4.615-9.496)	0.000 (0.000-136293.5)	0.999 (0.879-1.00)	0.849 (0.787-0.896)	15737.424 (0.000-5.158 e+12)
Green et al. (2018a)	3.999 (2.550-6.271)	0.000 (0.00-2.735 e+23)	0.999 (0.510-1.00)	0.750 (0.624-0.844)	11997.000 (0.000-1.002 e+31)
Husain et al. (2014)	1.978 (1.646-2.377)	0.190 (0.091-0.397)	0.896 (0.797-0.950)	0.547 (0.473-0.619)	10.403 (4.392-24.639)
Ji et al. (2011)	2.897 (2.313-3.629)	0.183 (0.080-0.417)	0.872 (0.733-0.944)	0.699 (0.639-0.753)	15.820 (5.949-42.073)
Marsay et al. (2017)	7.442 (4.481-12.357)	0.122 (0.042-0.355)	0.893 (0.728-0.963)	0.880 (0.809-0.927)	61.203 (16.322-229.484)
Rochat (2013)	3.062 (1.832-5.117)	0.404 (0.263-0.621)	0.686 (0.550-0.797)	0.776 (0.653-0.864)	7.572 (3.221-17.80200)
Rowel et al. (2008a)	6.871 (4.825-9.785)	0.107 (0.045-0.257)	0.907 (0.794-0.961)	0.868 (0.816-0.907)	64.131 (22.634-181.706)
Rubertsson (2011)	12.833 (5.678-29.004)	0.245 (0.074-0.809)	0.770 (0.445-0.933)	0.940 (0.880-0.971)	52.449 (9.231-298.018)
Su et al. (2007)	7.441 (4.630-11.959)	0.196 (0.080-0.478)	0.8260 (0.629-0.930)	0.8890 (0.831-0.929)	38.0198 (11.633-124.254)

Study	PLR (95% CI)	NLR (95% CI)	Sensitivity (95% CI)	Specificity (95% CI)	DOR (95% CI)
Tandon et al. (2012a)	5.356 (2.076-13.819)	0.170 (0.028- 1.052)	0.857 (0.487-0.974)	0.840 (0.653-0.936)	31.463 (2.939-336.885)
Tendais et al. (2014)	2.457 (1.731-3.487)	0.376 (0.202- 0.699)	0.737 (0.556-0.862)	0.700 (0.612-0.775)	6.539 (2.619-16.325)
Thiagayson et al. (2013)	2.655 (1.977-3.566)	0.314 (0.169- 0.583)	0.778 (0.619-0.883)	0.707 (0.633-0.771)	8.456 (3.597-19.882)
Toreki et al. (2013)	4.869 (3.375-7.024)	0.219 (0.092- 0.521)	0.818 (0.620-0.925)	0.832 (0.773-0.878)	22.259 (7.238-68.453)
van Heyningen et al. (2018)	4.526 (3.519-5.823)	0.173 (0.101-0.295)	0.860 (0.769-0.919)	0.810 (0.761-0.851)	26.188 (13.198-51.965)
Vazquez & Miguez (2019)	3.498 (2.669-4.854)	0.348 (0.198-0.611)	0.724 (0.552-0.848)	0.793 (0.757-0.825)	10.049 (4.503-2.243)

PLR Positive Likelihood Ratio***, NLR*** Negative Likelihood Ratio***, DOR*** Diagnostic Odds Ratio, ***CI*** Confidence Interval.

Figure 3

Forest plot of diagnostic odds ratios for all 73 data sets

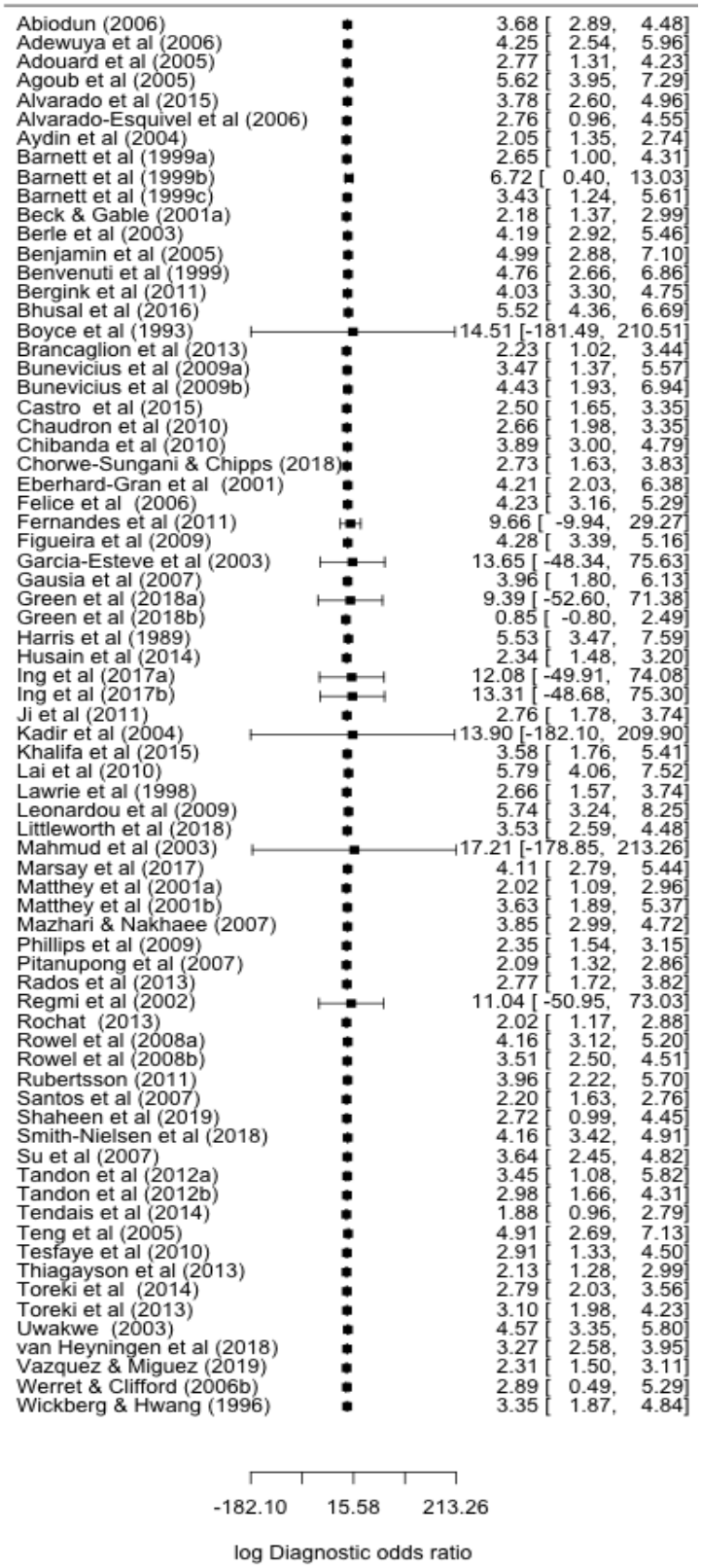
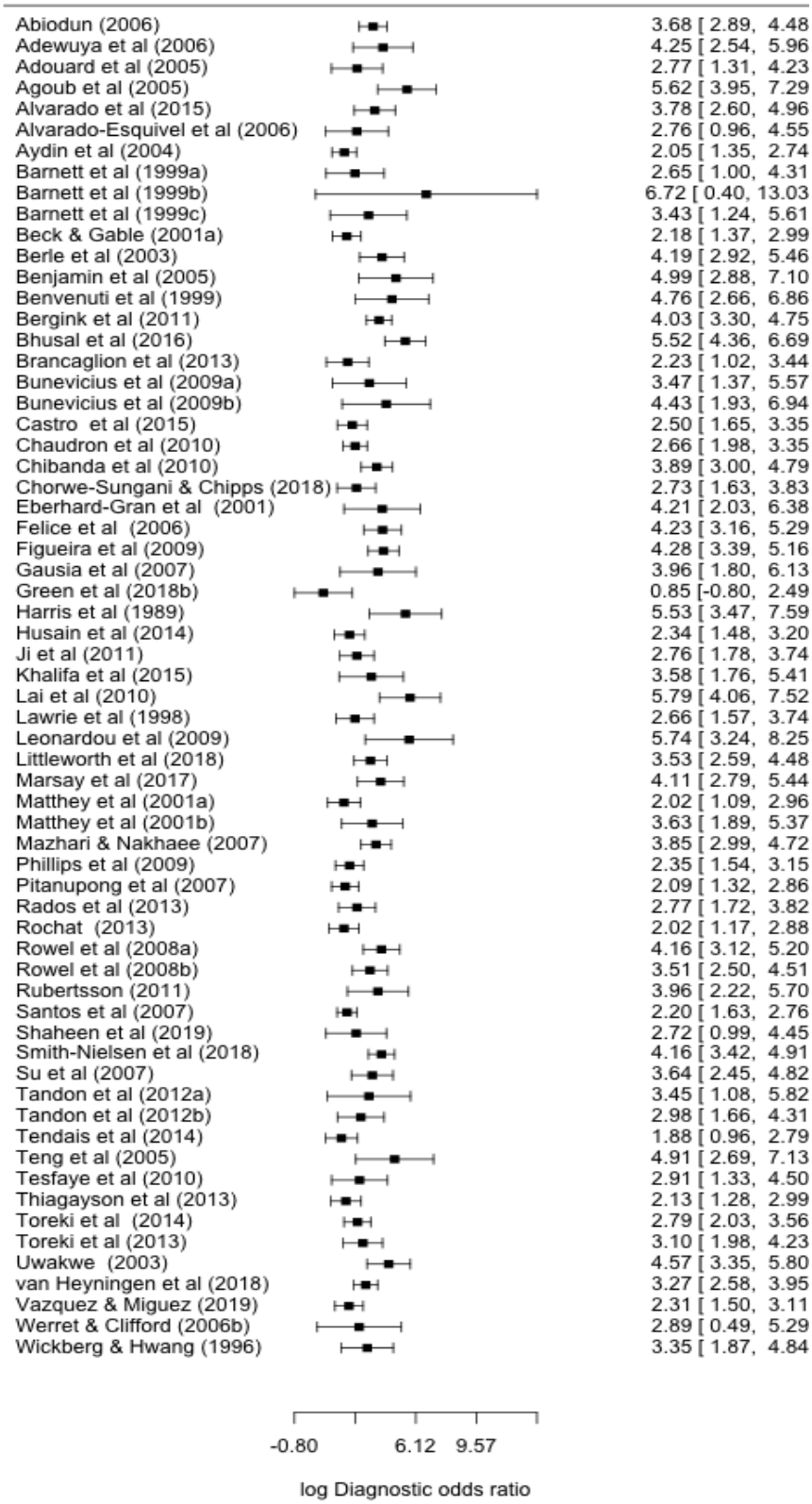


Figure 4

Forest plot of diagnostic odds ratios for 64 datasets having removed 9 datasets with unfeasible effect sizes



Separation of antenatal and postnatal samples. A univariate random-effects meta-analysis was undertaken separating the postnatal and antenatal samples. The univariate effects meta-analysis of the postnatal samples indicated a diagnostic odds ratio of 30.493 (95% CI 21.669-42.910) and no significant heterogeneity among diagnostic odds ratios of postnatal samples (Cochran's Q= 42.333, df= 41, p= 0.413; Higgins' I^2= 3.149%). A forest plot of the diagnostic odds ratios of antenatal samples can be found in Figure 5 below. The positive likelihood ratio was 5.997 (95% CI 4.885-7.362) and no significant heterogeneity was noted in positive likelihood ratios (Cochran's Q= 47.586, df=41, p=0.222; Higgins' I^2= 13.841%). The negative likelihood ratio was 0.228 (95% CI 0.194-0.269) and no significant heterogeneity was noted (Cochran's Q= 40.968, df= 41, p=0.472; Higgins' I^2= 0%). The diagnostic odds ratio, and the positive and negative likelihood ratio in this analysis therefore indicate a good diagnostic accuracy of the EPDS in detecting depression during the postnatal period.

The univariate effects meta-analysis of the antenatal samples indicated a diagnostic odds ratio of 21.441 (95% CI 14.973-30.703) and no significant heterogeneity among diagnostic odds ratios of antenatal samples (Cochran's Q= 19.923, df= 21, p= 0.526; Higgins' I^2= 0%). A forest plot of the diagnostic odds ratios of antenatal samples can be found in Figure 6 below. The positive likelihood ratio was 5.179 (95% CI 3.979-6.640) and no significant heterogeneity was noted in positive likelihood ratios (Cochran's Q= 23.148, df=21, p=0.336; Higgins' I^2= 9.279%). The negative likelihood ratio was 0.266 (95% CI 0.230-0.309) and again no significant heterogeneity was noted (Cochran's Q= 20.16, df= 21, p=0.511; Higgins' I^2= 0%). The overall diagnostic odds ratio for antenatal samples was therefore lower than that of postnatal samples, but this number still indicates good diagnostic accuracy, alongside the positive and negative likelihood ratios.

Further analysis of this subgroup is presented later in this paper.

Figure 5

Forest plot of diagnostic odds ratios for postnatal samples

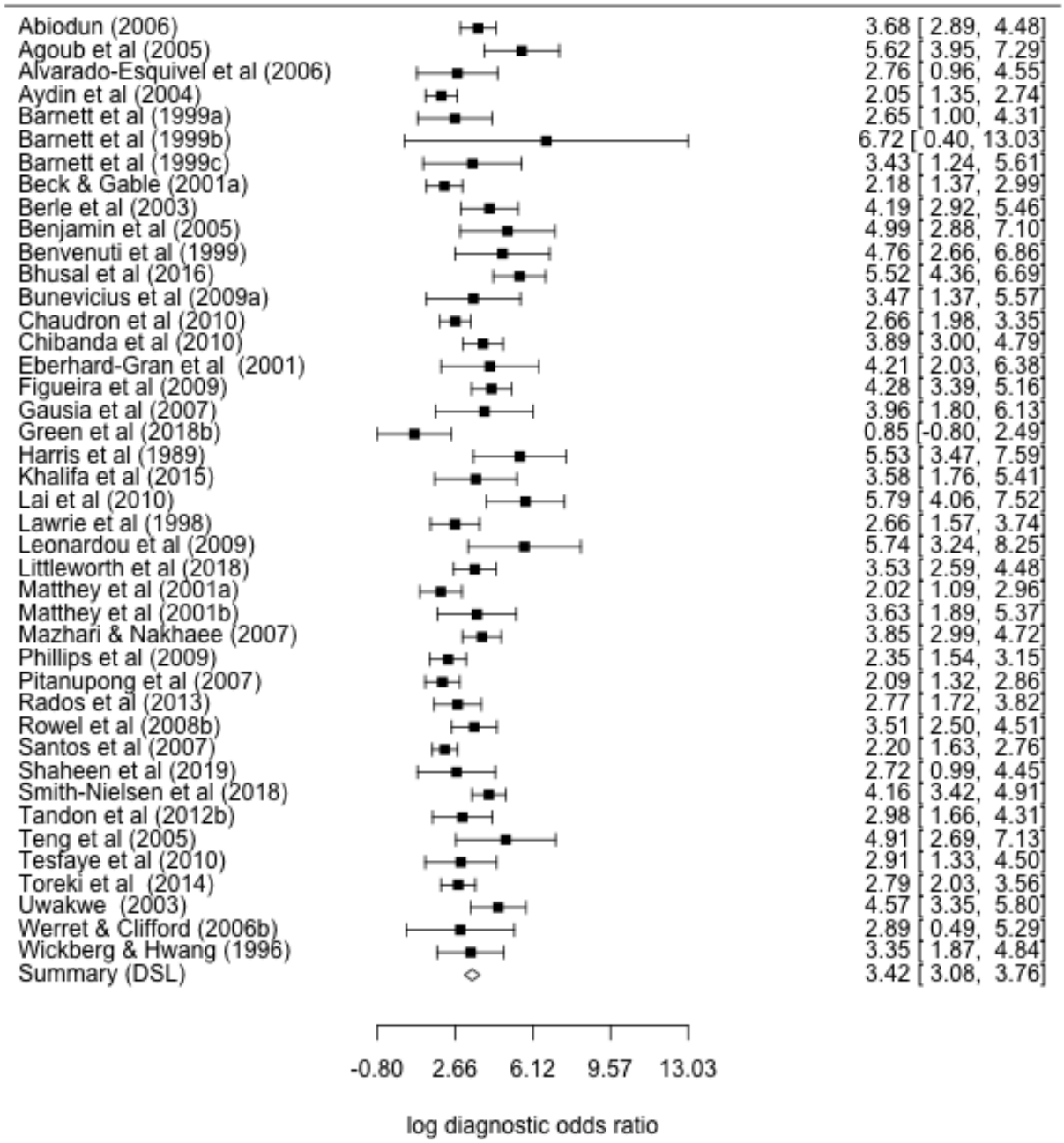
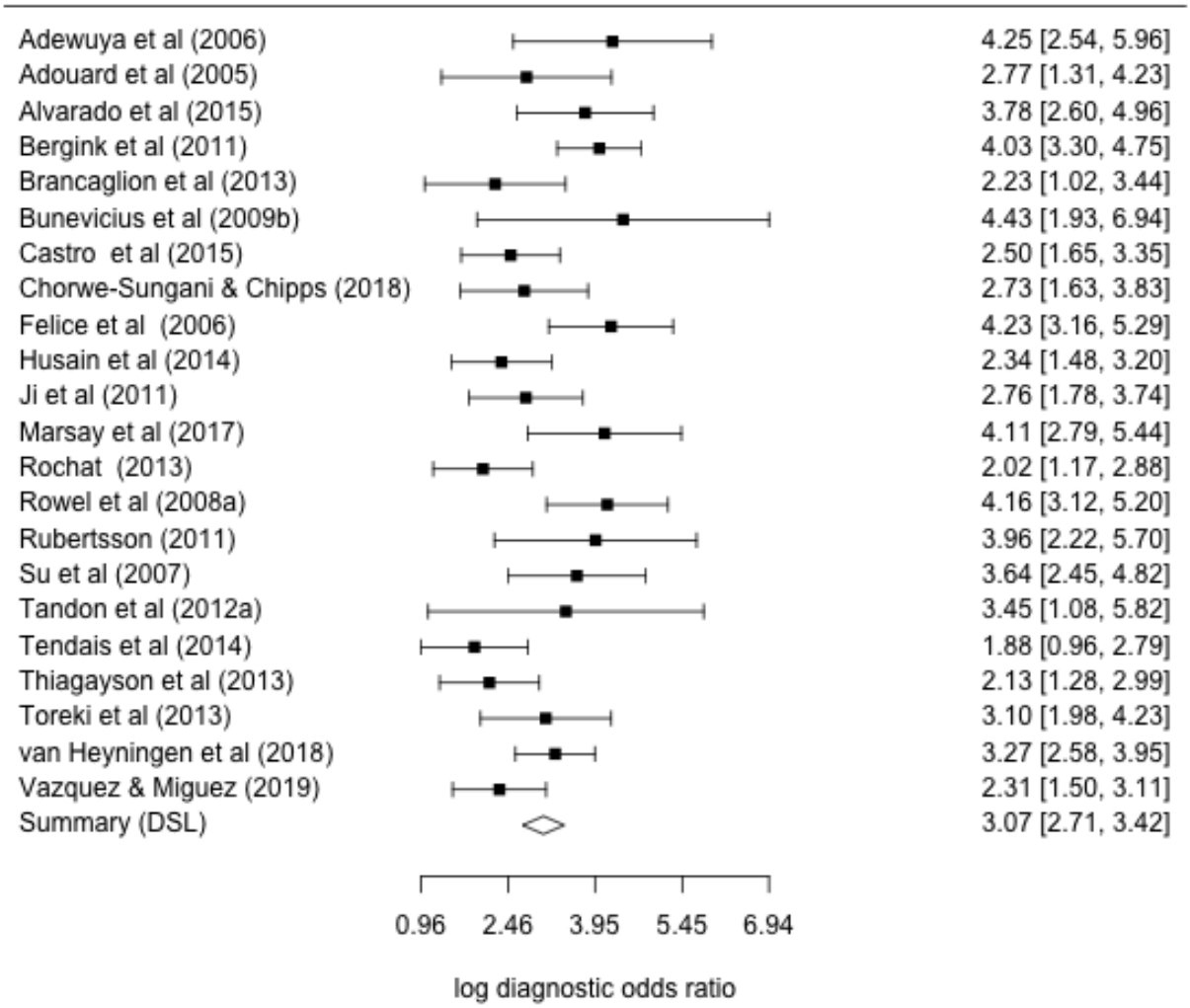


Figure 6

Forest plot of diagnostic odds ratios for antenatal samples



Bivariate random effects model meta-analysis

The Reitsma et al. (2005) bivariate random effects model meta-analysis results indicated an area under the curve value of 0.873 and a partial area under the curve value of 0.827 (restricted to observed false positive rates and normalised). The closer the value of an area under the curve value to 1, the better the accuracy of a test (Glas et al., 2003). Therefore,

a value of 0.873 indicates the EPDS has good diagnostic accuracy. The Zwindermann & Bossuyt (2008) Markov Chain Monte Carlo (MCMC) procedure generated summary points for positive negative likelihood ratio, negative likelihood ratio and diagnostic odds ratio. Results of this MCMC can be found in Table 10 below.

Table 10

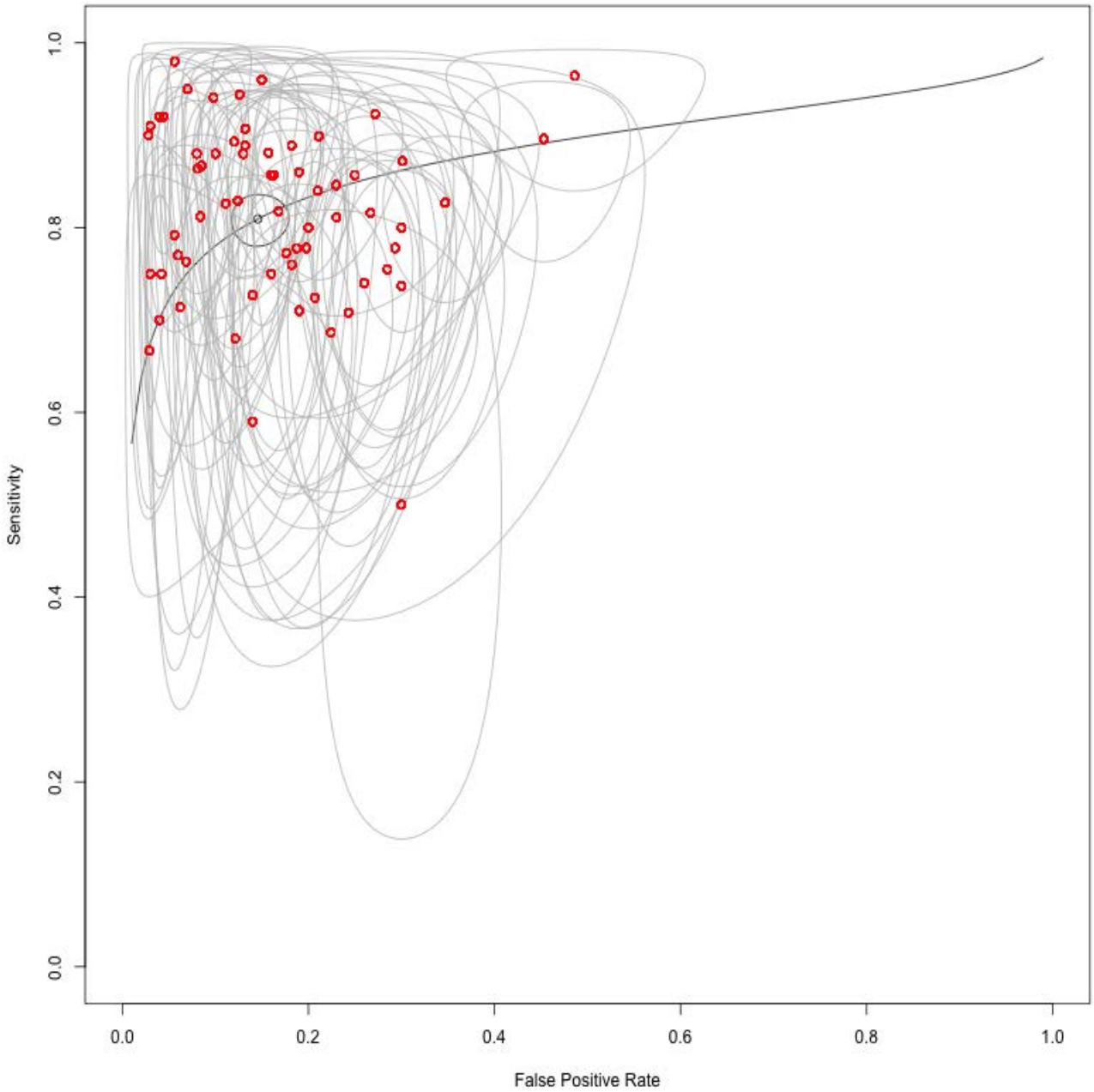
Bivariate random effects models results for positive and negative likelihood ratios, and diagnostic odds ratio

	Mean	**Median**	**95% Confidence Interval**
Positive Likelihood Ratio	5.580	5.560	4.700-6.600
Negative Likelihood Ratio	0.224	0.223	0.198-0.251
Diagnostic Odds Ratio	25.100	24.900	19.600-31.700

A summary receiver operating characteristic plot (SROC) was generated to provide a summary of the relationship between sensitivity and 1-specificity implied across all 64 datasets (Figure 7). The shape of a SROC curve helps estimate the discriminative power of the EPDS. The closer the curve is located to upper-left hand corner, the better the EPDS is at discriminating between depressed and non-depressed individuals. Figure 7 shows the SROC curve approaching the upper-left hand corner of the plot, indicating good discriminatory power of the EPDS in detecting depression.

Figure 7

SROC curve



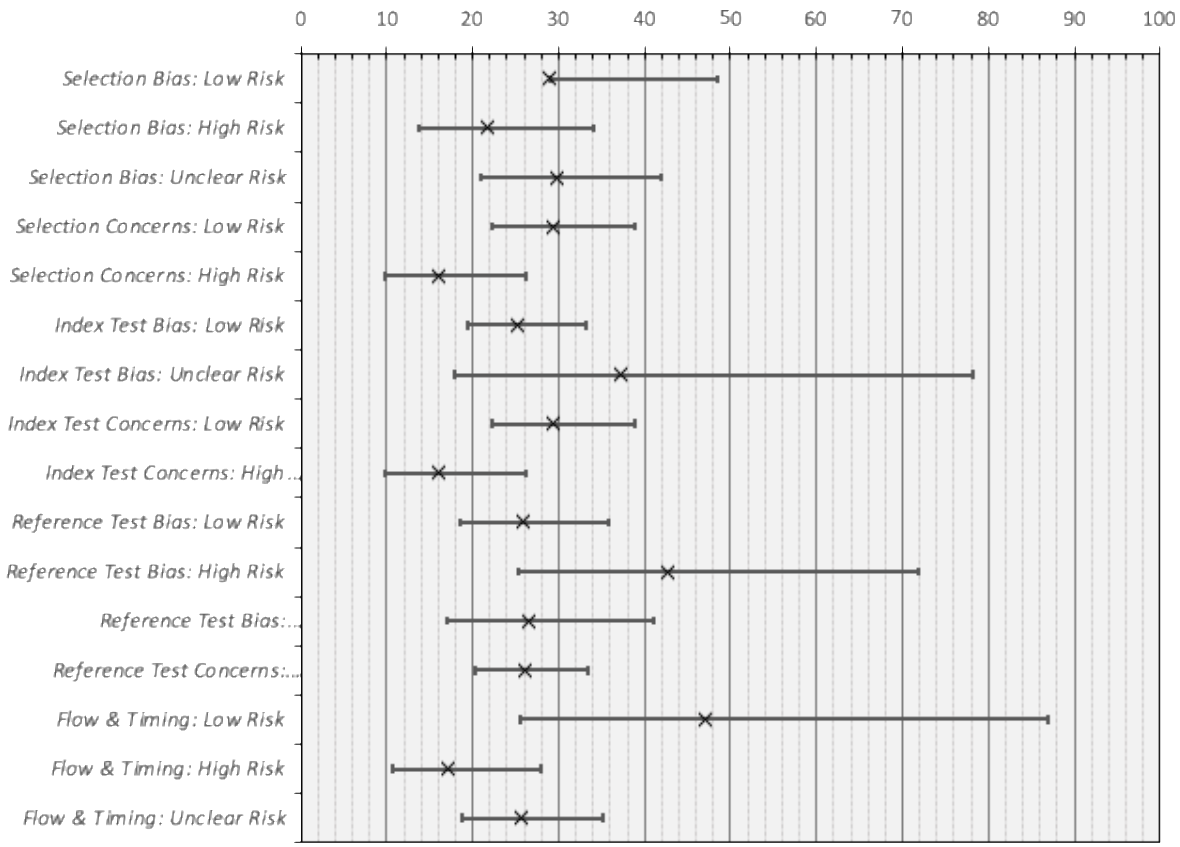
Subgroup analyses

Quality rating

The diagnostic odds ratios (DOR) and associated confidence intervals (CI) of each quality rating domain were compared (Figure 8). Subgroup analysis indicated that on selection bias there was not a significant difference between studies rated as low risk of bias (DOR= 28.962, 95% CI 17.278-48.547), high (DOR= 21.631, 95% CI 13.729-34.082) or unclear risk (DOR= 29.696, 95% CI 20.981-42.032). The effect of studies noted in studies rated as low risk of bias on selection concerns (DOR= 29.373, 95% CI 22.174-38.908) was larger than those rated as high risk in this domain (DOR=15.94, 95% CI 9.731-26.112), but this difference was not found to be significant. In index test bias, there was no identified significant difference between the effect of studies rated with low risk (DOR= 25.289, 95% CI 19.327-33.091) to those rated as unclear risk (DOR= 37.306, 95% CI 17.793-78.22), though there was a large noted variability in the effects noted in those rated as unclear risk that is evidenced by the large confidence interval. In the quality domain of index test concerns, studies rated as low risk in this domain showed a non-significant larger effect (DOR= 29.373, 95% CI 22.174-38.908) than those rated as high risk (DOR= 15.94, 95% CI 9.731-26.112). Studies rated as high risk in reference test bias showed a larger effect and large confidence interval (DOR= 42.583, 95% CI 25.253-71.804) compared to those rated as low risk (DOR= 25.846, 95% CI 25.846, 95% CI 18.65-35.817). There were no studies rated as high or unclear risk in terms of reference test concerns, so it was not possible to compare to those rated as low risk of bias in reference test concerns (DOR= 26.075, 95% CI 20.295-33.501). In the final quality domain of flow and timing, the effect was noted to be non-significantly larger in studies rated with low risk of bias (DOR= 47.134, 95% CI 25.566-86.897) compared to those rated as high (DOR= 17.7224, 95% CI 10.63-27.908) or low risk of bias in this domain (DOR=25.667, 95% CI 18.789-35.063).

Figure 8

Subgroup analysis of the diagnostic odds ratios and confidence intervals of the quality ratings of studies

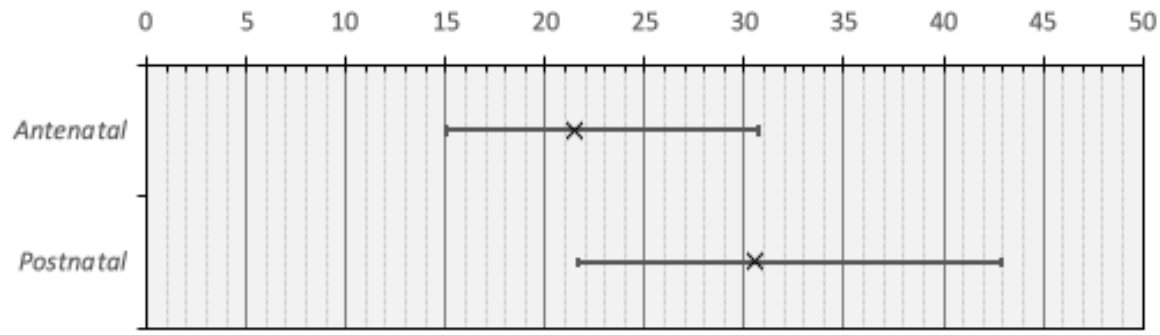


Antenatal and postnatal samples

The diagnostic odds ratios and associated confidence intervals of the antenatal samples and postnatal samples studies were compared (Figure 9). There was not a significant difference in the effects of antenatal samples (n=23) (DOR= 21.441, 95% CI 14.973-30.703) and postnatal samples (n=41) (DOR= 30.393, 95% CI 21.669-42.91).

Figure 9

Subgroup analysis of the diagnostic odds ratios and confidence intervals for antenatal and postnatal samples

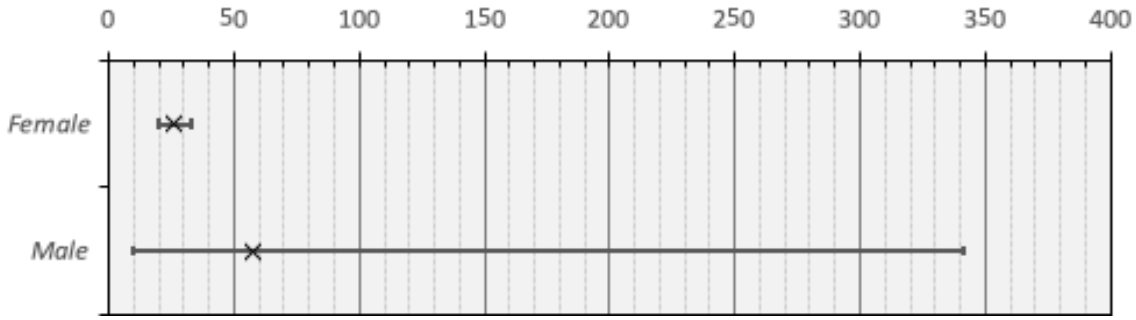


Gender

The diagnostic odds ratios and associated confidence intervals of the female sample (n=61) and male sample (n=3) studies were compared (Figure 10). This subgroup analysis was important to conduct due to previous research suggesting that the validity of the EPDS may differ between genders (e.g. Matthey & Agostini, 2017). There was not a significant difference noted in the effects between female samples (DOR= 25.795, 95% CI 20.027-33.225) and male samples (DOR= 57.15, 95% CI 9.572-341. 219). However, given the small number of studies of male samples, the confidence interval is extremely large and it is therefore hard to draw conclusions in this subgroup analysis.

Figure 10

Subgroup analysis of the diagnostic odds ratios and confidence intervals for male and female samples



Language and country of use

Unfortunately, due to the small number of studies under each subgroup, it was not possible to carry out subgroup analyses for the language of EPDS administration and the country of use. Previous research has stressed the importance of the language of administration of the EPDS and culture of those completing it, and how these factors can significantly impact the validity of the test. For example, optimum cut-off scores have been found to differ across cultures and language (Norhayati et al., 2015).

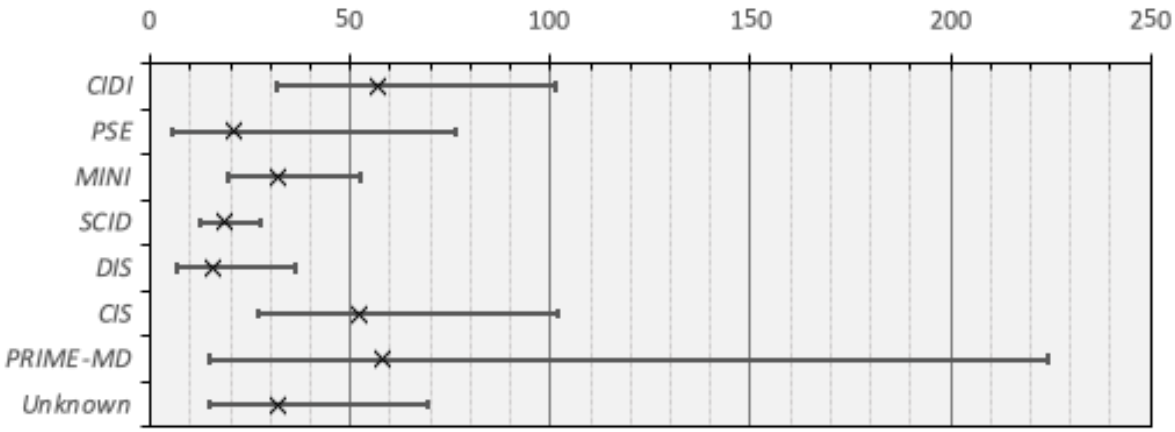
Reference test

The diagnostic odds ratios and associated confidence intervals of the different types of diagnostic interview references standards were compared (Figure 11). The MADRS diagnostic interview was unable to be included in this subgroup analysis due to one study employing this reference standard. There was not a significant difference noted in the effects between studies that employed the CIDI (n= 4) (DOR= 56.768, 95% CI 31.793-101.363), PSE (n=2) (DOR= 20.559, 95% CI 5.528-76.467), MINI (n=14) (DOR= 32.047, 95% CI 19.539-52.561), SCID

(n=23) (DOR= 18.587, 95% CI 12.503-27.633), DIS (n=5) (DOR= 15.413, 95% CI 6.548-36.277), CIS (DOR= 52.134, 95% CI 26.654-101.971), PRIME-MD (n=2) (DOR= 57.726, 95% CI 14.862-224.219) and those that did not state the reference standard used (n=10) (DOR= 31.779, 95% CI 14.617-69.093). The diagnostic odds ratios of studies employing the SCID had the smallest variability, whilst those employing the PRIME-MD, CIDI and CIS had the largest variability.

Figure 11

Subgroup analysis of the diagnostic odds ratios and confidence intervals for the different diagnostic interview reference standards

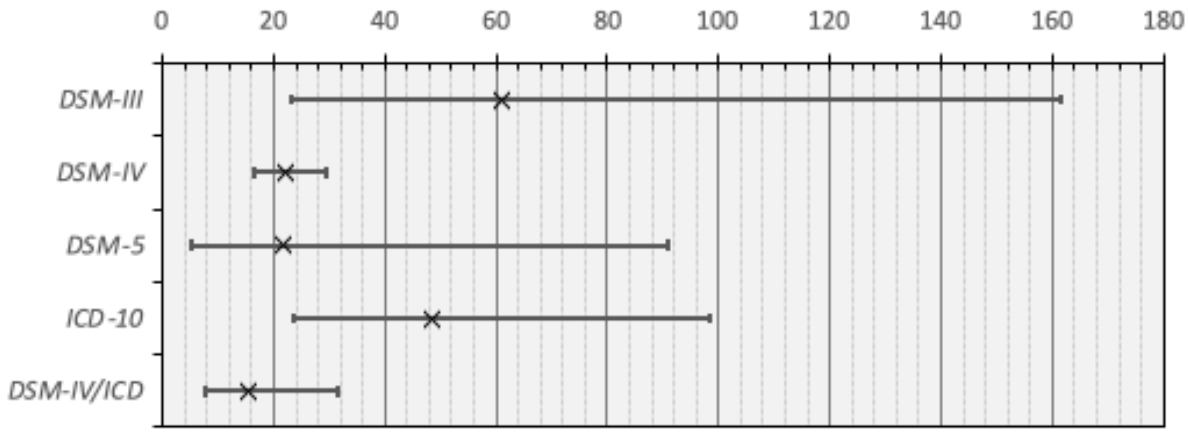


In addition to exploring the type of diagnostic interview, diagnostic odds ratios and their associated confidence intervals were explored for the different types of diagnostic framework utilised (Figure 12). There were no significant differences in the effects between studies using the DSM-III (n=7) (DOR= 61.022, 95% CI 23.064-161.447), DSM-IV (n=39) (DOR= 21.995, 95% CI 16.444-29.422), DSM-5 (n=4) (DOR= 21.746, 95% CI 5.213-90.708),

ICD-10 (n=10) (DOR= 48.380, 95% CI 23.753-98.540) and studies that used both the ICD-10 and DSM-IV (n=4) (DOR= 15.465, 95% CI 7.626-31.365).

Figure 12

Subgroup analysis of the diagnostic odds ratios and confidence intervals for the different diagnostic frameworks

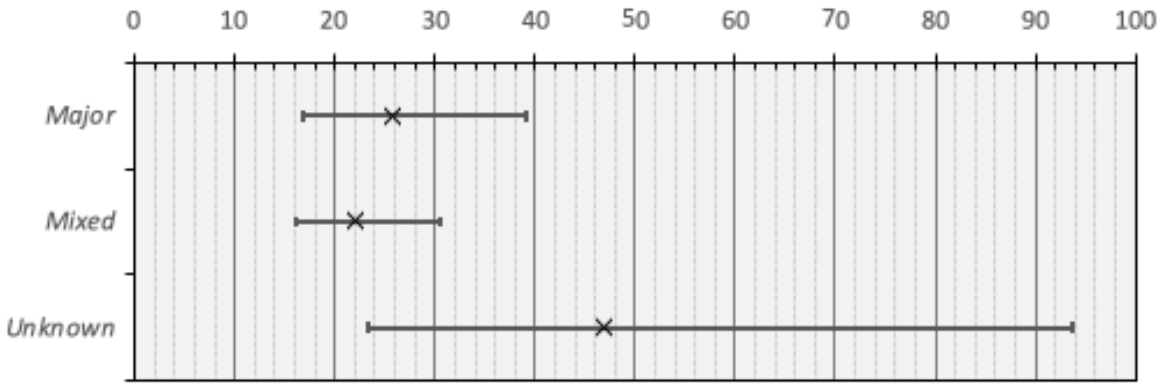


Type of depression

A further subgroup analysis explored the diagnostic odds ratios and confidence intervals of the different severities of depression examined in the studies (Figure 13). There were no significant differences between the effects of those examining major depression (DOR= 25.699, 95% CI 39.187), mixed depression (i.e. minor and major depression) (DOR= 22.12, 95% CI 23.383-93.693). The effect and the variability were noted to be highest in studies that did not state the type of depression examined, but this subgroup also had the lowest number of studies (n=9) compared to those examining major (n=21) and mixed depression (n=34).

Figure 13

Subgroup analysis of the diagnostic odds ratios and confidence intervals for the different types of depression examined



Cut-off of EPDS

Previous research has suggested that a cut-off of 12/13 on the EPDS is indicative of major depression and a cut-off of 9/10 for minor depression (Cox et al., 1993; Murray & Carothers, 1990; Zelkowitz & Milet, 1995). Given the cut-offs identified through previous research, subgroup analyses were carried out by combining similar cut-off scores into one category. Table 11 demonstrates the cut-offs grouped together and the associated diagnostic odds ratios and confidence intervals within each group, for both antenatal and postnatal samples. Table 12 and 13 present the diagnostic accuracy of the EPDS at different cut-off groups for antenatal and postnatal samples respectively.

Table 11

Overview of validity data of included papers at different groups of EPDS cut-offs

Cut off score	No. of studies	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)	Diagnostic odds ratio (95% CI)
6-8.5	12	4.004 (3.079-5.207)	0.268 (0.218-0.330)	14.853 (10.350-21.315)
9-10	25	5.736 (4.394-7.486)	0.254 (0.212-0.304)	25.092 (16.394-37.069)
11-11.5	9	6.375 (3.850-10.555)	0.194 (0.155-0.242)	38.718 (23.404-64.053)
12-13	13	7.586 (4.968-11.585)	0.238 (0.177-0.319)	39.740 (19.062-82.848)
14-16	4	5.643 (2.848-11.181)	0.237 (0.089-0.628)	20.866 (4.777-91.142)

Table 12

Overview of validity data of antenatal samples at different groups of EPDS cut-offs

Cut off score	No. of studies	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)	Diagnostic odds ratio (95% CI)
6-8.5	2	3.059 (1.266-7.391)	0.202 (0.115-0.354)	13.925 (6.745-28.745)
9-10	11	4.639 (3.118-6.902	0.288 (0.230-0.360)	18.508 (10.231-33.481)
11-11.5	3	5.046 (2.258-11.274)	0.241 (0.142-0.410)	15.276 (7.385-31.600)
12-13	5	8.025 (5.008-12.859)	0.301 (0.228-0.396)	31.990 (12.906-79.292)
14-16	2	4.928 (3.627-6.696)	0.161 (0.100-0.260)	31.366 (17.071-57.631)

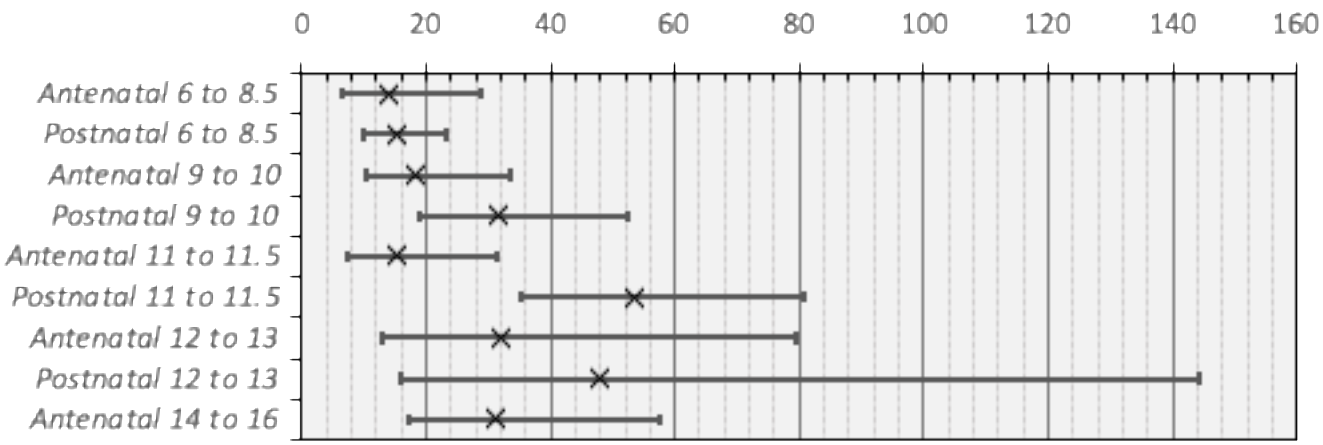
Table 13

Overview of validity data of postnatal samples at different groups of EPDS cut-offs

Cut off score	No. of studies	Positive likelihood ratio (95% CI)	Negative likelihood ratio (95% CI)	Diagnostic odds ratio (95% CI)
6-8.5	10	4.612 (3.538-6.014)	0.280 (0.225-0.350)	15.253 (10.011-23.240)
9-10	15	8.403 (5.546-12.731)	0.233 (0.180-0.302)	31.702 (18.835-53.361)
11-11.5	6	7.296 (3.476-15.313)	0.188 (0.149-0.239)	53.380 (35.230-80.880)
12-13	8	8.320 (4.915-14.085)	0.186 (0.115-0.302)	48.096 (16.043-144.191)
14-16	2	Unable to calculate due to small number of studies		

Figure 14

Subgroup analysis of the diagnostic odds ratios and confidence intervals for the different cut off scores of the EPDS in antenatal and postnatal samples

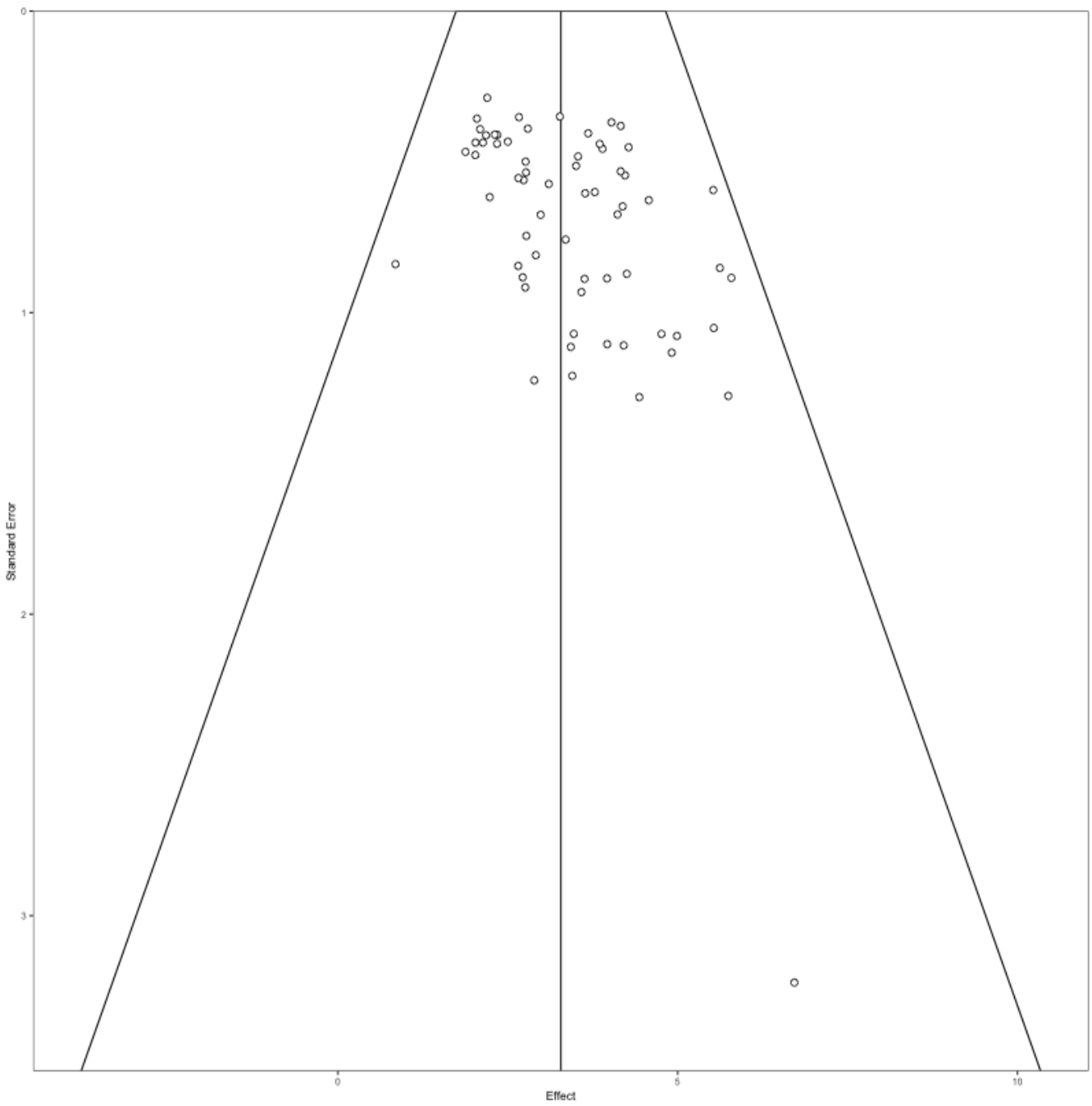


Publication bias

The funnel plot in Figure 15 below shoes the relationship between diagnostic odds ratio (effect) and the standard error of studies. The log diagnostic odds ratio is plotted on the horizontal x-axis and the standard error of the log diagnostic odds ratio is plotted on the y-axis. The 95% confidence interval of the effect sizes of the studies is depicted by the triangular zone on the funnel plot. These lines show the expected distribution of studies in the absence of heterogeneity or selection bias. A symmetrical distribution of studies across the funnel plot is expected if there are no concerns of bias. The funnel plot in Figure 15 shows a relatively symmetrical distribution of study diagnostic odds ratios ('effect') and associated standard error, suggesting minimal publication bias of studies.

Figure 15

Funnel plot of study diagnostic odds ratios ('effect') and associated standard errors



Discussion

Summary of findings

This present meta-analysis aimed to examine the diagnostic accuracy of the Edinburgh Postnatal Depression Scale (EPDS) in detecting depression during the perinatal period, both in men and in women. A total of 73 datasets, reported from 66 primary studies were identified and analysed. It was noted that nine studies reported substantially large effects (near 100% sensitivity and specificity) and therefore the decision was made to exclude these studies from the remainder of the analyses, resulting in 64 datasets forming the final analyses. Of these datasets, 43 were formed of postnatal samples and 21 were antenatal samples. The majority (n=61) examined the diagnostic accuracy of the EPDS in women during the perinatal period and only three examined the accuracy in men during this period. The results of the univariate meta-analysis indicated that the EPDS is an accurate measure at detecting depression in the perinatal period, with a pooled diagnostic odds ratio of 26.597 (95% Confidence Interval [CI] 20.681-34.206), a positive likelihood ratio of 5.686 (95% CI 4.844-6.674) and a negative likelihood ratio of 0.242 (95% CI 0.216-0.271). The bivariate meta-analysis allowed a better estimate of diagnostic accuracy by accounting for sensitivity and specificity simultaneously to produce an area under the curve value which equalled 0.873 and a SROC curve showing good diagnostic accuracy.

The diagnostic accuracy of the EPDS was further explored by subgroup analyses to explore whether the accuracy differed upon factors such as time in perinatal period (antenatal vs postnatal) and gender. Results indicated that the diagnostic odds ratio was greater in the postnatal samples (DOR= 30.393, 95% CI 21.669-42.91) than the antenatal samples (DOR= 21.441, 95% CI 14.973-30.703). However, this difference was not significant and furthermore there were over twice as many studies contributing to the postnatal than antenatal samples.

There were no noted significant differences within the subgroup analyses of type of gold standard diagnostic interview and framework and type of depression. Further subgroup differences were explored according to gender, but due to there only being three male studies compared to 61 female studies it was not possible. Unfortunately, a subgroup analysis of language of administration of the EPDS and country of use was not possible due to too few studies under each different language and country.

The quality assessment of the included studies indicated mixed quality. Quality rating indicated a substantial amount of unclear bias in flow and timing that arose due to studies not explicitly stating the amount of time between administration of the EPDS and the gold standard diagnostic interview. There was also significant high risk of bias in selection concerns, with many providing insufficient information on recruitment and many used a cut-off score on the EPDS to enter diagnostic interview and only selected a subsample of participants scoring below this cut-off, which often lead to unevenly distributed number of participants in each group.

Comparisons to other reviews

To the best of the author's knowledge, this is the first review to carry out a quantitative analysis of the evidence base of the diagnostic accuracy of the EPDS. Therefore, it is difficult to make comparisons to previous reviews that have qualitatively analysed the validity of the EPDS. Furthermore, no previous reviews have included any studies examining the diagnostic accuracy of the EPDS in both men and women in the perinatal period.

Similar to previous reviews, the current meta-analysis demonstrated a high level of heterogeneity in the design of the studies that examine the diagnostic accuracy of the EPDS. The results of the present meta-analysis demonstrated the varied use of cut-off scores of the EPDS across studies, which is something that has been shown in previous reviews (e.g. Gibson et al., 2009). This review differed to previous reviews in that it selected the cut-off score of the

EPDS that has the optimum sensitivity and specificity in studies, as opposed to selecting the same cut-off score from each study. This may explain why there was less heterogeneity noted in this review compared to previous ones.

There was agreement between this review and previous reviews in highlighting the need for higher quality studies to be able to draw conclusions about the diagnostic validity of the EPDS.

Strengths and limitations of current review

The current review set strict inclusion criteria to allow focus on high quality studies (e.g. including only studies that utilised a recognised formal diagnostic interview and diagnostic criteria [Diagnostic and Statistical Manual or International Classification of Diseases], and no longer than two weeks between diagnostic interview and EPDS administration). Not only was this the first review to conduct a quantitative analysis on the diagnostic accuracy of the EPDS, it also utilised a bivariate random effects model analysis that allowed consideration of sensitivity and specificity simultaneously, which is considered to be an optimum way to meta-analyse the diagnostic accuracy of a test (Chu et al., 2010).

It is important to note that a possible methodological limitation arises in that only one person, the author, extracted the data and conducted the quality ratings for the included studies. It is therefore possible that this may have introduced bias. However, given that the present review was conducted as part of a doctoral thesis, there were limitations in the capacity to recruit a second author to extract data and review studies.

There was a high level of heterogeneity within the identified eligible studies, for example different studies found different cut-offs points to be optimal, different administration methods and different languages of administration. This resulted in data extraction rules being set to allow consistent extraction of data, such as selecting the cut-off of the EPDS with optimal

identified diagnostic accuracy. Although there was low reported heterogeneity in terms of diagnostic odds ratios and positive and negative likelihood ratios, it is important to acknowledge the potential impact of extracting heterogeneous data from the included studies. Unfortunately, due to the small number of studies in different subgroups, subgroup analyses were unable to be conducted to examine the potential impact of domains such as different language administrations, which limits the conclusions that can be drawn about the diagnostic accuracy of the EPDS.

This review aimed to evaluate the diagnostic accuracy of the EPDS throughout the whole perinatal period, however there was nearly double as many papers that studies the postnatal population than there were antenatal. Similarly, although an aim of the review was to evaluate the diagnostic accuracy with men and women in the perinatal period, very few studies examined the use in men. Unfortunately, this made it difficult to conduct subgroup analyses to examine whether the diagnostic accuracy of the EPDS differed between different time points in the perinatal period or if it differed between genders.

A further limitation of this review is the methodological quality of the included studies, which limits the conclusions made. There were many studies rated as high or unclear risk on the Quality Assessment of Diagnostic Accuracy Studies-2 (QUADAS-2), particularly in the domains of flow and timing, selection bias and index test bias.

Implications for clinical practice

This review indicates good diagnostic validity of the EPDS in detecting depression in the perinatal period, therefore suggesting it to be a useful instrument to use in the screening of depression in clinical practice. However firm conclusions of the applicability of the EPDS to groups other than English speaking perinatal women are unable to be made due to being unable to draw conclusions about whether diagnostic accuracy differs by factors such as gender or

language. Further difficulties arise in using the EPDS as a screening tool for depression in clinical practice due to the heterogeneity of the cut-off scores used within the included studies in this meta-analysis, which therefore makes it hard to conclude the optimal cut-off to use in clinical practice.

Future research

This review has identified the need for further high-quality studies that examine the diagnostic accuracy of the EPDS, particularly studies that reduce the risk of bias in flow and timing, meaning the EPDS and diagnostic interview are administered within 24 hours of each other. It is also important that future studies reduce the risk of bias by administering the EPDS and diagnostic interview to all participants in the study, instead of using participants' scores on the EPDS to determine whether they are administered a diagnostic interview. Given the high proportion of unclear risk of bias ratings, it would be helpful for future studies to ensure that sufficient information is provided on domains such as recruitment methods, sample, order of index test and reference test administration and time between EPDS and diagnostic interview.

Future research would benefit from examining the diagnostic accuracy of the EPDS across different language administrations and country of use. Given the significant impact that culture can have on presentation of mental health difficulties, it is important to ascertain whether the EPDS is a tool that still shows good diagnostic accuracy outside of Western English-speaking cultures.

Given the increased recent focus on paternal mental health, it is important that there is a valid and reliable screening tool to aid identification of depression within men during the perinatal period. This review identified few studies examining the diagnostic accuracy of the EPDS in men and it would therefore be useful for future research to focus on examining the diagnostic accuracy of different depression screening tools currently utilised to identify

paternal depression (e.g. Patient Health Questionnaire-9, Kroenke et al. (2001) and the Beck Depression Inventory, Beck et al, (1996)).

Conclusion

The current review demonstrates sound diagnostic accuracy of the EPDS in detecting depression in the perinatal period. Conclusions can be more firmly drawn regarding the diagnostic accuracy in postnatal women due to the significantly larger number of studies that have studied this group, whilst further research would be beneficial for antenatal samples and male samples. Further research with clearer reporting of methodology information and stricter methodology would reduce the risk of bias and therefore improve upon the existing literature presented in this review.

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Empirical Paper: A qualitative study exploring the experience of women receiving a psychiatric diagnosis during the perinatal period

Abstract

Background

Past literature has demonstrated the experience of receiving a psychiatric diagnosis as entailing both positive and negative experiences. Research detailing the experience of perinatal psychiatric diagnosis is more limited and has often focussed on the experience of living with a particular diagnosis, and in either the postnatal or antenatal period. Given the complexity of the perinatal period, it is important to develop insight into how women experience receiving a psychiatric diagnosis during this time. This study therefore aimed to develop an improved understanding into the experience of women receiving a psychiatric diagnosis during the perinatal period, both antenatally and postnatally.

Method

Six women were interviewed regarding their experience of receiving a psychiatric diagnosis during the perinatal period. Interviews were analysed using Interpretative Phenomenological Analysis.

Results

Four superordinate themes were identified through the analysis and presented: 'The perinatal period as unique', 'Power imbalances', 'The complex role of others' and 'The psychological processes of diagnosis'. These themes illustrate the complexity of understanding and receiving a psychiatric diagnosis during the perinatal period. Women noted imbalances they experienced in their relationships with professionals and between physical and mental health. The importance of connection with others was emphasised, but the difficulties experienced in achieving this were highlighted. Women noted the complexity of the emotional experiences surrounding diagnosis and further recovery.

Conclusion

The results of this study illustrate a range of ways in which services could improve support for women receiving a psychiatric diagnosis during the perinatal period, for example collaboration and transparency from professionals.

Introduction

Perinatal mental health

The perinatal period is considered as the time from conception to the end of the first postnatal year. This period signifies a time of significant change for women and is associated with heightened levels of emotions and psychological state (Lee, 2000). The perinatal period is therefore linked with an increased vulnerability for the onset or relapse of mental health difficulties (Smith et al., 2011). Perinatal mental health difficulties affect between 10% and 20% of women during pregnancy and the first-year post birth (Bauer et al., 2014). The most common perinatal mental health difficulties are depression and anxiety (O'Hara & Wisner, 2014), which an estimated 12-13% of women experience during pregnancy and 15-20% of women experience in the first-year post birth (National Institute for Health and Care Excellence [NICE], 2014).

In addition to the impact of perinatal mental health difficulties on the mother, research has also demonstrated the potential adverse impact on the child and family (Boath et al., 1998; Moore Simas et al., 2019). Research has demonstrated adverse child outcomes such as preterm birth (Smith et al., 2011) and emotional, behavioural and cognitive problems (Grace et al., 2003; O'Connor et al., 2002), as well as an impact on mother-baby interactions and attachment (Carter et al., 2000).

The impact of perinatal mental health is also apparent by the significant economic burden on society that it presents. Research estimates the long-term economic and social cost as £8.1 billion per annum of births in the UK (Bauer et al., 2014). This constitutes the economic cost to the mothers, but also the significant economic cost to the child in the longer term, which is considered to be about three-quarters of this cost (Bauer et al., 2014).

Identification and diagnosis of mental health difficulties during the perinatal period

Given the documented incidence and impact of perinatal mental health noted above, it is imperative that mental health difficulties during the perinatal period are identified and treated promptly. Research has demonstrated improved outcomes for women and their families with the early detection of perinatal mental health difficulties (Yawn et al., 2012).

Perinatal mental health has received an increased focus within the National Health Service (NHS) over recent years. The 'Five Year Forward View for Mental Health' of the NHS indicated a plan for the development of specialist perinatal mental health services by 2020/21 (NHS England, 2014). Aspects of the strategic document on the transformation of perinatal mental health services emphasise the importance of early identification and diagnosis of any mental health difficulties within the perinatal period, the importance of specialist assessment and delivery of evidence-based treatments in accordance with NICE guidelines (The Perinatal Mental Health Care Pathways, NHS England, 2018). It is therefore clear that there is an important emphasis placed upon assessment and diagnosis of perinatal mental health difficulties, and thus facilitating the delivery of evidence-based treatment.

Although the importance of assessment, diagnosis and treatment of mental health difficulties in the perinatal period is clear, there are many barriers which prevent women from accessing the necessary care. A recent meta-synthesis has been conducted by Smith et al. (2019) that explored the barriers for women with perinatal mental health difficulties in accessing mental health care. This study found barriers on an individual level for women (e.g. stigma and lack of knowledge), the organisational level (e.g. inadequate resources), the sociocultural level (e.g. language barriers) and the structural level (e.g. unclear policies, such as assessment policies).

Psychiatric diagnosis

Psychiatric diagnosis proves important in mental health services worldwide, providing a way for mental health clinicians to identify mental health symptoms and classify these using a structured guide. The two most commonly used diagnostic guides are the Diagnostic and Statistical Manual (DSM) (current edition: DSM-5; American Psychiatric Association, APA, 2013) and the International Classification of Diseases (ICD) (current edition: ICD-11; World Health Organisation, WHO, 2018). This enables a shared understanding of an individual's mental health symptoms among clinicians (Craddock & Mynors-Wallis, 2014). Psychiatric diagnosis also provides a guide for making decisions about intervention (Craddock & Mynors-Wallis, 2014). For example, NHS guidelines from the NICE provide information for mental health professionals and the general public on the evidence-based treatments for different classifications of mental health difficulties, e.g. the clinical guidance on psychosis (NICE, 2014). In some mental health services worldwide, psychiatric diagnoses facilitate service users' access to services and treatment (Pitt et al., 2009).

Despite the merits of psychiatric diagnosis, it also presents challenges. Research has demonstrated limitations in the validity and reliability of psychiatric diagnosis (e.g. Frances, 2013; Kirk & Kutchins, 1994). Challenges arise in fitting the complexity of human behaviour and mental health difficulties into distinct categories based upon biomedical explanations (Widiger & Samuel, 2005). The high percentage of comorbidity (when a person is diagnosed with more than one psychiatric disorder) across mental health difficulties (Kessler et al., 2005) demonstrates some of the challenges in the validity of this categorisation system. Psychological literature has critiqued the reductionist approach of relying only on biomedical explanations, discussing how this minimises the importance of a person's social context in understanding their mental health difficulties (Johnstone, 2018). Psychological formulation provides an alternative or adjunct to psychiatric diagnosis, which aims to make sense of a person's

difficulties taking into account the wider context, for example their social circumstances, life events and cultural system (Johnstone, 2018).

Service users' experience of psychiatric diagnosis

Despite the prominence and advantages of psychiatric diagnosis, qualitative research has been conducted indicating that the experience of service users receiving a psychiatric diagnosis is varied. Research has indicated a significant impact on individuals (Perkins et al., 2018; Rose & Thornicroft, 2010), with both positive and negative experiences of service users documented.

Positively, psychiatric diagnosis has been described as helpful in aiding service users' understanding of their experiences and validating (Andersen & Larson, 2012; Delmas et al., 2011; Dinos et al., 2004; Hayne, 2003). Service users have also reported a sense of relief following psychiatric diagnosis (Proudfoot et al., 2009) and a sense of hope for the future and recovery (Bilderbeck et al., 2014; McCormack & Thomson, 2017). Psychiatric diagnosis has also been described as helping relationships between the service user and mental health services, and aiding individuals to access mental health services (Pitt et al., 2009).

The negative experience of psychiatric diagnosis has also been documented in the literature. The experience has been linked with feelings of fear (Cleary et al., 2010), external stigma and self-stigma (Corrigan et al., 2006; Yang et al., 2015), frustration (Proudfoot et al., 2009) and invalidation (Hagen & Nixon, 2011). Service users have also reported finding their diagnosis hard to believe (Gallagher et al., 2010) and have expressed difficulties in accepting diagnoses (Delmas et al., 2011). Research has also demonstrated the lack of understanding that service users can have about the meaning of their diagnosis (Horn et al., 2007) and service users' uncertainty about the diagnosis being correct or fitting with their experience (Delmas et al., 2011).

A recent review by Perkins et al. (2018) indicates that a variety of factors mediate the impact psychiatric diagnosis has on an individual. For example, this review indicated when insufficient information was provided to individuals upon diagnosis, it was viewed more negatively, compared to a more positive experience if they felt sufficiently knowledgeable. Furthermore, choice about being informed of the diagnosis (Bilderbeck et al., 2014; Cleary et al., 2010) and the way in which a diagnosis is communicated have also been found to be important factors (Pitt et al., 2009). The inclusion of the service users in the diagnostic process through collaboration has also been shown to be an important mediator in their experience of diagnosis, with more collaboration linked with a more positive view (Hackman et al., 2019).

Service users' experience of psychiatric diagnosis during the perinatal period

Although the impact of an individual receiving a psychiatric diagnosis has been well documented in the research, papers focusing on psychiatric diagnosis during the perinatal period are sparse. This is interesting, given the acknowledged vulnerability and significant change experienced during this period (Lee, 2000). Qualitative studies have been conducted that have focussed on individual's experience of perinatal mental health difficulties, but this research largely focuses on the experience of living with the mental health difficulty, rather than the experience of diagnosis. Some research has focussed on women's experience of specific mental health difficulties, such as women's experience of postnatal depression (Bilszts et al., 2010; Chan et al., 2002), postpartum anxiety (Ali, 2018) and postpartum psychosis (Doucet et al., 2012). This research has highlighted feelings of loss, guilt and frustration (Ali, 2018), and failure and stigma (Bilszts et al., 2010) in women experiencing mental health difficulties during the perinatal period. Research such as Highet et al. (2014) has looked at women's experience of mental health difficulties more widely in the perinatal period. This

study explored experience of self-reported postnatal depression and/or anxiety, and similarly found common feelings of loss, frustration and dissatisfaction with the experience of motherhood. A meta-synthesis review of 39 studies exploring women's experience of mental health in the perinatal period has been carried out by Megnin-Viggars et al. (2015). They identified themes of 'stigma', 'the need for information', 'a focus on the babies rather than mothers', 'the need for collaborative care and service user involvement in treatment decisions', 'the difficulties in having their psychological needs met' and 'the importance of compassionate and non-judgemental support'.

A small number of studies have explored women's experience of receiving a psychiatric diagnosis during the perinatal period. Oddy et al. (2009) explored women's experience of all psychiatric diagnoses during the postpartum period only. They found women felt that diagnosis positively improved their access to health care, but some also had concerns with the impact it had on others' perception of their mothering ability. This research was however conducted through postal surveys rather than interviews, which limits the richness of data gathered.

Although the described studies have deepened our understanding of the experience of particular perinatal mental health difficulties, they do not help us understand in depth the experience of receiving a psychiatric diagnosis during the perinatal period. There is therefore an absence of qualitative research that explores the experience of a range of psychiatric diagnosis during the perinatal period as a whole (pregnancy to one-year post-birth).

The present study

Given the documented experience of individuals receiving a psychiatric diagnosis, it is important to understand how this experience may be further impacted by the already challenging perinatal period. The present study therefore aims to use Interpretative Phenomenological Analysis (Smith & Shinebourne, 2012) to develop an insight into the

experience of women receiving a psychiatric diagnosis during the perinatal period. Deepening our understanding of the experience of women receiving a perinatal psychiatric diagnosis provides an opportunity to identify and develop appropriate support and care for this difficult, potentially challenging period. Tailored support informed from first-hand experience could also provide an opportunity to lessen the adverse impact of perinatal psychiatric illness.

Method

Design

The design of the present study is a qualitative interview design, which uses Interpretative Phenomenological Analysis (IPA) methodology and analysis. Participants were interviewed using a semi-structured interview (Appendix 8) in order to gather rich data on the experience and perspective of women receiving a psychiatric diagnosis during the perinatal period.

Rationale for use of Interpretative Phenomenological Analysis

IPA was adopted in this study as the approach allows for examination of a person's lived experience. IPA is a method that aims to understand how individuals make meaning of their life experiences, rather than formulating an objective account (Smith et al., 2009). Therefore, IPA was selected as the form of analysis as it provided the opportunity for in-depth qualitative understanding of women's experience of receiving a psychiatric diagnosis during the perinatal period. IPA takes a double hermeneutic stance, which allows the participant to interpret their own experience whilst the researcher explores and makes sense of this experience (Smith et al., 2009). IPA is most commonly carried out on data from semi-structured interviews (Smith et al., 2009), which fits with the design of the present study.

Procedure

Ethical approval

This research study received sponsorship from the University of Birmingham (Appendix 1). Ethical approval was obtained from the South Birmingham NHS Research Ethics Committee (Appendix 2), the Health Research Authority (HRA) (Appendix 3) and by

the Research and Development Teams from the participating NHS Trusts. A non-substantial amendment was submitted following initial ethical approval for a change of Principal Investigator (Appendix 4).

Recruitment

Participants were recruited using a purposive sampling method. Potential participants were identified by clinicians within perinatal community mental health teams across two NHS Trusts. Participants were approached by clinicians if they met the inclusion criteria of the study (Table 14 and 15) and were provided with brief details about the research. If the participant expressed interest in participating in the research, they were asked to sign a 'consent to contact' form (Appendix 5) and their names and contact details were passed onto the author. The author then contacted potential participants and provided them with the participant information sheet (Appendix 6) and consent form (Appendix 7), and participants were given the opportunity to ask questions about the research. Participants were given three days to look over the research information and were then contacted by the author, and if they wished to participate, an interview was arranged. Inclusion and exclusion criteria for participants can be found below in Tables 14 and 15.

Table 14

Inclusion criteria for participants

Inclusion criteria	Rationale
Women aged 18+ who have received a psychiatric diagnosis within the perinatal period (conception to one-year post-birth).	The aim of this study was to explore the experiences of women of receiving the psychiatric diagnosis within the perinatal period.
Psychiatric diagnosis must be based on a structured or semi-structured diagnostic interview.	A formal diagnosis was required so that women would be able to share their experience of this process.
Under the care of a community mental health team whilst participating in study	To ensure that there were procedures in place should any issues with risk arise or any distress from the interview, and participants were able to access support from their mental health team.
Psychiatric diagnosis to have been received over 6 weeks prior to recruitment to the study.	To ensure that women had a period of adjustment following diagnosis, a time period of 6 weeks post-diagnosis was required.
No previous significant mental health difficulties.	This study aimed to understand the experience of women receiving a psychiatric diagnosis for the first time during the perinatal period, so those with previous significant mental health difficulties were excluded.

Table 15

Exclusion criteria for participants

Exclusion criteria	Rationale
Current high risk of self-harm or suicide or current high risk to others.	To ensure the safety of participants and the researcher, those with current risk issues were excluded.
Previous history of a formal psychiatric diagnosis.	This study aimed to understand the experience of women receiving a psychiatric diagnosis for the first time during the perinatal period, so those with a previous diagnosis were excluded.
Previous input from secondary mental health services.	This study aimed to understand the experience of women receiving a psychiatric diagnosis for the first time during the perinatal period, so those with previous engagement with secondary mental health services were excluded.
Requirement of an interpreter to be able to take part in the research interview.	Due to the qualitative nature of the project and the limits of this project being conducted as part of a degree, it was not possible to use of interpreters for non-English speaking participants.

Interview procedure

Semi-structured interviews were conducted by the author. Interviews took place in participants' home addresses and were conducted between January and March 2020. Interviews were recorded using an encrypted Dictaphone. Interviews lasted between 40 and 77 minutes (mean= 52 minutes). An interview topic guide was used (Appendix 8), which focused on six broad topic areas: the experience of being told a mental health diagnosis, self-recognition of symptoms, information provided at diagnosis, sharing the diagnosis with others, adjustment to diagnosis and ideal care/support. These topic areas were developed from researching the evidence base on qualitative research around experience of diagnosis. Example questions under each topic area can also been seen in Appendix 8, but questions were flexible depending on the content of the interview. Following the interview, participants were provided with a document that detailed various perinatal mental health resources (Appendix 9).

Risk

As part of the consent process, participants were required to agree that the author would contact their responsible mental health team if any concerns of risk arose during the interview. Furthermore, if there were any concerns about participants' distress during the interview, this was also shared with their mental health team.

As the interviews were carried out at participants' home addresses, risk to the author was also important to consider. Participants were required to be assessed as low risk to others by their responsible clinician in order to take part in the study (Tables 14 and 15). A lone worker policy was followed; the Principal Investigator for the study was made aware of the date, time, and location of interviews. The author made the Principal Investigator aware of their arrival to the participants' address and then again when they had left at the end of the interview.

Ethical considerations and information storage

Participants were informed that they could withdraw from the study without needing to give a reason and withdrawal would not affect the care they received from their mental health team. Participants were informed that they were allowed to withdraw from the study at three different time points: before interview, during interview and after interview. Due to difficulties in withdrawing data once it has been analysed, participants were set a time frame of two weeks post-interview in which they could withdraw from the study and not have their data included in the analysis.

Research data was anonymised by the allocation of pseudonyms to participants upon entering the study. The interviews were transcribed by the author and following transcription, interview recordings were destroyed. Transcripts were stored using the pseudonym only. Participants were informed that any quotes from interview transcripts used would not be identifiable.

Participants' pseudonyms and their corresponding names and contact details were stored on a password protected secure database at the University of Birmingham that only the researchers involved in the study were able to access. Personal identifiable information obtained on paper (e.g. consent forms) was stored in a locked filing cabinet at the University of Birmingham and was only accessible to the researchers involved in the study. Research data and personal identifiable information will be stored for 10 years following completion of the study, which is in line with University of Birmingham policies.

Participants

Six participants took part in the study and the age of the sample ranged from mid-20s to mid-40s (mean= 34). Participant specific ages are not presented here to ensure anonymity.

Information on participants' demographic and interview information can be found below in Table 16.

Table 16

Participant demographic and interview information

Participant number	Participant pseudonym	Ethnicity	Age	Time since birth/number of weeks pregnant	Perinatal diagnosis	Length of interview (minutes)
1	Chen	Chinese	Mid-30s	6 months postnatal	Perinatal Depression (antenatal and postnatal)	75
2	Sarah	White British	Mid-20s	11 months postnatal	Postnatal PTSD, OCD, and Depression	59
3	Liz	White British	Early-30s	18 months postnatal	Postnatal Depression	55
4	Rachel	White British	Mid-40s	2 years postnatal	Postnatal PTSD	77
5	Zara	White British	Mid-30s	1 year postnatal	Antenatal OCD and Anxiety (not specified)	71

Participant number	Participant pseudonym	Ethnicity	Age	Time since birth/number of weeks pregnant	Perinatal diagnosis	Length of interview (minutes)
6	Priyanka	Indian	Mid-30s	39 weeks antenatal	Antenatal Depression and Anxiety (not specified)	40

Data analysis

The IPA data analysis first involved transcribing the interviews onto a computer. The five steps of IPA set out in Smith et al. (2009) were then followed, which are described in Table 17. Examples of steps 2-5 of the analysis are shown in the Appendices and detailed below.

Following initial noting of one participant's transcript (Appendix 10), initial themes were identified (Appendix 11) and then written on pieces of paper. Themes were then cut up and arranged to identify connections across themes and create superordinate themes (Appendix 12). A thematic structure was created detailing superordinate and subordinate themes with corresponding quotes (Appendix 13). This process was then repeated for each participant. Following completion of this process for each participant, the thematic structure tables for each participant were printed and cut up. This then allowed connections across the thematic structures of each participant to be explored (Appendix 14), identifying similarities and differences between participants. The final step involved the development of an overall thematic structure for all participants, which detailed superordinate and subordinate themes, and corresponding participant quotes in support of these (Appendix 15). Throughout the initial steps of coding and development of emergent themes, the author focussed on the data in hand

as opposed to the research question to allow in-depth meaning making of the participant's accounts. As the analysis progressed, the author revisited the research question to examine how much the data answered the research aims and question. Given the richness of the accounts provided by the participants and a wish to encapsulate participant's experiences fully, a decision was made to not only focus theme development on the experience of being told the mental health diagnosis, but to focus on the participant's account as a whole.

Table 17

Steps taken in IPA data analysis, adapted from Smith et al (2009)

Step number	**Step name**	**Process**
1	Reading and re-reading	Transcripts were read and re-read alongside audio recording to become familiar with participants' accounts.
2	Initial notes	On each transcript, initial notes, thoughts and reflections were made. Notes were made relating to content (what was said), language (the language used and the way something was spoken) and concepts (initial thoughts on interpretations on what was being said).
3	Development of emergent themes	Initial notes were reviewed and combined to identify emergent themes.
4	Identifying connections between themes	Connections between emergent themes were explored to identify superordinate and subordinate themes, creating a thematic structure.
		Steps 1-4 repeated for each transcript

Step number	Step name	Process
5	Identifying connections and patterns across transcripts	In this step the thematic structures for each participant were printed and superordinate themes cut up. Similar themes were clustered together to create superordinate and subordinate themes.

Credibility and validity

The process of triangulation was used throughout the analysis phase in order to enable alternative interpretations and perspectives on participants' accounts, and thus increasing the validity and credibility of the analysis (Smith, 2011). This process involved the coding of transcripts and emerging themes being discussed in supervision and in IPA support workshops with fellow colleagues conducting IPA analysis. This helped ensure that interpretations and themes were grounded in the research data.

Reflective statement

In qualitative research, it is important for the researcher to consider their own theoretical positioning through reflexivity (Morse et al., 2002). Reflexivity refers to being actively involved in the process of the research (Lambert et al., 2010). Two important types of reflexivity in research have been identified by Willig (2013), personal and epistemological. Personal reflexivity refers to the process of reflecting on one's own values, life experiences and beliefs, and considering how these influence the research. On the other hand, epistemological reflexivity refers to the consideration of various theoretical assumptions and perspectives, and the impact of these on the findings of the research. The author took a 'critical

realist' epistemological stance, assuming that there is reality that exists outside the author, but it cannot be known with any certainty.

The author used a reflective diary throughout the research process, to allow reflection on the process and content of interviews and the analysis process. This, alongside the use of triangulation, helped the author ensure consideration of their own personal positioning in relation to the research and how this could impact on the interpretation of the research data. In considering the author's position in this research, there was awareness of not being a parent and not having personal experience of receiving a psychiatric diagnosis. The author has an interest in perinatal mental health that has developed throughout their career in clinical psychology and this research project was developed as a way of pursuing this interest.

Results

Four superordinate themes were identified through the analysis: 'The perinatal period as unique', 'Power imbalances', 'The complex role of others' and 'The psychological processes of diagnosis'. Within these superordinate themes, 10 subordinate themes were identified. A structure of the themes can be found below in Table 18. Each of these themes are described in detail below and example participant quotes are used to illustrate them.

Table 18

Overview of superordinate themes and subordinate themes identified through analysis

Superordinate themes	**Subordinate themes**	**Participants contributed**
The perinatal period as unique	The perinatal period as complex	1,2,3,4,5,6 (all)
	Worry about my child	1,2,3,4,5,6 (all)
	A mother's needs are easily forgotten	2,4,5
The complex role of others	The importance of connection	1,2,3,4,5,6 (all)
	Self vs others	1,2,3,4,5,6 (all)
Power imbalances	Imbalances in therapeutic relationships	1,2,3,4,5,6 (all)
	Mental health as hidden compared to physical health	1,2,3,4,5,6 (all)
The psychological processes of diagnosis	Pre-diagnosis	1,2,3,4,5,6 (all)
	Post-diagnosis	1,2,3,4,5,6 (all)
	Recovery	1,2,3,4,5

Theme 1: The perinatal period as unique

This superordinate theme demonstrates the women's experience of the uniqueness of the perinatal period. Reflected in this theme is the complexity of the perinatal period, where one has competing demands to consider, and mental health difficulties during this time can be difficult to appreciate and understand.

The perinatal period as complex

There was a strong sense of women communicating what a challenging time the perinatal period presented, where one experiences a significant amount of change physically and emotionally. This was illustrated by Rachel *"going through pregnancy and birth, you just go through so many mental changes, your life is completely changing, you're having to constantly adjust"*. It was also communicated how many competing demands are experienced during the perinatal period and how experiencing mental health during this time is another demand to contend with, illustrated by Chen:

> *"…and then I had no energy to sort this issue because errm I don't feel I had the erm the the the sufficient energy, the positive way to deal with things, so I'm trying to deal with what I'm facing now, with my situation, my medication and then looking after her [baby]"*

Several women spoke about the difficulty in understanding perinatal mental health, particularly in questioning if perinatal mental health is distinct to 'normal' or 'non-perinatal' mental health. The following quote by Chen illustrates this: *"Erm well there are many questions still left in my mind, so what would be the difference between the postnatal depression and the normal depression"*. There was also a sense of some difficulties with mood and anxiety

being a normal part of motherhood, illustrated by Sarah: *"Obviously some anxieties as a new mum are normal, you've got this baby to protect for the first time ever"*.

There were several examples of women speaking about how postnatal depression is the most widely known and spoken about perinatal mental health difficulty, with little known about other difficulties. The following quote from Rachel illustrates this point: *"because I think when people think about you giving birth, they automatically think of postnatal depression"*. This then contributed to the women questioning what was going on for them, as they didn't feel they fitted with what they understood of postnatal depression:

> *Sarah: "you hear you know people have postnatal depression or whatever, which is the only one you really hear about, that they don't love their baby, or they don't connect with their baby. Well I had the opposite, I almost loved her too much that I couldn't cope with everyone else"*

Whilst the complexity of the demands and change of the perinatal period was emphasised, there was a particular focus on how women considered their child's needs when experiencing perinatal mental health difficulties, as discussed in the next subtheme.

Worry about my child

All women spoke about their experience of worry for their child and this impacted their desire to protect their child. The most common worry identified by women was about the potential negative impact of taking psychotropic medication on their child's health, discussed by Priyanka, Zara and Chen.

> *Priyanka: "*Participant: *I was worried about the err side effects of the medicine.* Interviewer: *In terms of for yourself or..* Participant: *No in terms of for the kid…. I was like a little hesitant to take the medicine."*

Zara: "I wanted to have as little, as few and natural chemical influences on the processes that should be happening as the baby was developing. So that's why I didn't want to take the medication"

Liz and Zara also spoke of the negative impact on taking psychotropic medication on their ability to look after their children due to medication side effects, noting aspects including fatigue and dizziness. Liz also expressed some guilt about how the medication impacted on her ability to care for her child due to the sedating impact of the medication.

Liz: "I felt that that made me unable to care for my son when I took it [medication]"

Liz: "I felt very guilty that I wasn't waking up at night when he [baby] was upset, and my husband would get up"

Given these strong worries about the impact of medication on their children, it was clear that for some women this impacted their engagement with the treatment, with some not taking medication due to the fear of negative impact on their baby.

Priyanka: "So GP already prescribed me a medicine, so when I went for the appointment with the Psychologist they just said I should, I should take the medicine. I wasn't taking it because I was worried about the err side effects of the medicine"

Rachel spoke about how she worried that her child would be taken away from her if she went to seek help for her mental health and how the intensity of this thought impacted how able she felt to seek help for her mental health:

Rachel: "I had sort of got in my head that if I even sort of said that I was struggling, would they take him away from me, and that was very very strong in my mind. I know it's like an irrational fear, but that doesn't stop it being strong and affecting how you feel"

Sarah also spoke about how she felt this was a common fear for women seeking help for mental health during the perinatal period, noting that some of her friends had experienced this worry "*She [friend] thought, you know having these thoughts, would mean social services would be involved and they would take her baby away*".

Though women spoke of their own worry for their child and consideration of their child's needs, there was also an emphasis on how their own needs may not have be considered in the same way, as reflected in the next subtheme.

A mother's needs are easily forgotten

Women spoke about how their individual needs as a mother were forgotten and not addressed by others, and instead the focus lays on their baby. This appeared to be both in terms of others around them such as peers, but also by professionals. There was a sense of this being hurtful to the women and how this could also in turn negatively impact the baby, as a mother's good health is needed to be able to care for a baby (Rachel). Sarah and Rachel's quotes below illustrate how they felt their needs were *"sidelined" (Rachel)*:

> *Sarah: "Whereas I felt like because I had a baby, no one cared how I was feeling, everyone only cared that [baby] was lovely, and she is lovely, but like I am a human as well *laughs*".*
>
> *Rachel: "as soon as the baby is born you're sort of side-lined, but without you there's nobody there to do the job for the baby. So the mother has to be in the right headspace for the sake of the baby, if they're not then you're going to have all sorts of repercussions, but they're never seen as a joint thing, it's always the baby the baby the baby"*

In addition to women highlighting a mother's needs as forgotten by others, Zara spoke about how her needs were "*were very much at the bottom of the pile"* because of the other demands she had within the perinatal period, such as taking care of the house and her children.

Overall, this superordinate theme illustrates the challenges of experiencing and understanding mental health during the perinatal period, particularly in juggling competing needs and demands whilst their own needs may not be prioritised. This links with the next superordinate theme, where women discuss the impact of their relationships

Theme 2: The complex role of others

This superordinate theme reflects the complexity of the relationships around the women and how these impact on their mental health. The need for emotional connection with others is discussed, alongside the challenges they felt in doing this, which at times then results in isolation from others.

The importance of connection

The importance of feeling a sense of connection with others was clear across participants, primarily in the key relationships around them but also in how they connect with professionals. There were several aspects in participants' narratives that illustrated the importance of connection. Firstly, there was a sense of how important emotional support was, even if it only came from a few people, illustrated here by Rachel and Sarah:

> *Rachel: "that has been great that I have got him [husband] to be able to talk to erm because I think it would have been very very hard if I hadn't have had him and I think I would have felt completely cut adrift"*
>
> *Sarah: "…when I told my 2 best friends what had happened during birth…they were both in tears and that's when I thought 'wow, you guys like really care'. Like because*

we all just had a little cry together, that's what I needed, I just wanted someone 'oh my god, she's amazing, but how are you' as well. Like we had a little cry together and I felt fine once I had opened up to them and we had had our like little moment, it was all about {baby} then and that was fine because I felt listened to"

The importance for an emotional connection was also suggested to be needed in women's relationships with professionals, illustrated here by Zara:

Zara: "I struggled with the psychiatrist because she was very clinical and very facts based and not particularly personable and I just felt like 'I'm just sat here pouring my heart out to you and you're just sitting and looking at me and writing"

Secondly, there was an emphasis on how important it was to feel like others had similar difficulties, and how connecting and sharing with others can help you realise that you are not alone in your experiences, thus normalising their experiences with mental health:

Sarah: "when you start to realise you have problems, you realise other people have had problems, but as I say, it's such a taboo"

Zara: "It helped to realise that I wasn't unique erm and to support other people as well was really valuable to me"

Though the importance of connection is highlighted, women experienced many challenges in being able to gain a sense of connection with others, reflected in the next subtheme.

Self vs others

There was a real sense of fear of judgement from others amongst the women and how others would respond if they were to share their mental health difficulties. For example, Sarah described a sense of shame about sharing and worry of how people would view her:

> *"Once I was better I was advised to talk about it, but like at the time, I was really embarrassed because I didn't want people looking at me all the time thinking 'is she alright today, is she not alright today' or like looking for signs or symptoms themselves. I didn't want to feel like a patient"*

Several women spoke about how they *"put on a front" (Liz)* to others by not sharing their mental health experiences or feelings, which appeared to serve varying purposes for different women. For some, keeping their feelings to themselves protected them against difficult and hurtful reactions from others when sharing and for others it served to protect them in terms of the fear of judgement they had about others. For example, Rachel described telling a couple of close friends but *"they did not know how to react"* so she did not tell anyone else:

> *"it never went beyond that because I think the reaction was enough to make you think 'well we won't progress talking about that'"*

Other women described keeping their feelings and experiences to themselves as a way to protect others, suggesting there may have been a fear of burdening others in sharing:

> *Zara: "I was nervous about telling them, not because of them judging me, but yeah to protect them"*
>
> *Liz: "I didn't want to burden people or to put people off being a friend *laughs*"*

Although keeping their feelings to themselves served some protection, some women noted that this resulted in isolation as it meant they withdrew from others and thus lost a sense of connection:

Liz: "It just took too much energy that I didn't have the drive to be able to put that front on anymore, so I did start pulling back from seeing people and doing things"

Women spoke of some of the difficult reactions they experienced when sharing their mental health difficulties and diagnoses with others around them. There was a sense of others struggling to understand what they were going through and this meant that many women had experienced difficult reactions from others, such as anger (Zara) and shock (Sarah). The difficult reactions from others appeared to have a negative impact on women's relationships and also contributed to feelings of isolation:

Rachel: "People just don't know how to react to it, which is really, that makes it quite hard and isolating, because sometimes you just, sometimes you just want to cry and you just feel like you're keeping it in because of other people really and other people's reactions"

*Sarah: "...his [fiancé's] mum kept saying to him 'oh it's normal, it's normal, it's normal'. So there's a bit of conflict because he was saying that I was saying 'I'm not well' and she was saying 'no, it's normal' and I was like *more raised voice* 'it's not normal' *laughs* so yeah"*

Chen: "Now, when we are talking, I can conclude for myself that I feel, apart from you professionals, no one else understands how it feels"

Cultural differences in the understanding and awareness of mental health were emphasised by Priyanka and Chen. Both participants spoke about the stigma attached to mental health in their home cultures, India and China:

> *Chen: "And my Chinese friends, including my parents, were very negative, it feels like they couldn't even speak the word [depression], it feels this word is so embarrassing or ashamed or whatever negative, that they couldn't even speak about it"*
>
> *Priyanka: "You know in India you don't speak about it so openly, mental health is a very taboo thing in India, if you say you have mental health problems in India they just think you're crazy and you'll be sent to the mental asylum *laughs*"*

The cultural stigma these participants experienced appeared to impact how responsible the women felt about making others understand their difficulties, as their narratives reflected a real sense of personal responsibility:

> *Priyanka: "If people don't understand then it's all well and good, if they don't you'll have to make them understand"*

In summary, this superordinate theme demonstrates the complexity of the women's relationships. This complexity is further demonstrated in the next superordinate theme, where there was a particular emphasis on power imbalances in relationships.

Theme 3: Power imbalances

This superordinate theme reflects the real sense of power imbalances that came across in the narratives of all participants, particularly in the relationships between the women and professionals. Some women named how imbalanced the relationships felt with some professionals, for example Zara spoke about the relationship with her Psychiatrist being

"incredibly imbalanced", whereas with other women power was implied in their statements. Several women also spoke about the imbalances between physical and mental health in society.

Imbalances in therapeutic relationships

Across participants there was a consistent narrative around professionals having access to, and holding on to, knowledge and understanding about their diagnoses. The importance of transparency from professionals is emphasised by participants, illustrated here by Liz:

> *Liz: "I think that if someone had said a bit earlier on 'you have got postnatal depression, you're struggling with this, but it's ok' *laughs* 'and we can help' then I think I might have understood it much earlier"*

Women spoke about how helpful it would have been to be provided with concrete information about their diagnoses and treatment, often stating the physicality of something as potentially helpful:

> *Zara "if there had been some, a leaflet or something, then we could have sat together and gone 'ok this actually how you're feeling, this is what is going on, this is how you're feeling, yeah that does sound, that sounds like what it's been this week, so ok yeah maybe that does make sense then'"*
>
> *Priyanka: "Yeah it was more clear you know, I got the bigger picture of what will happen if I take the medicine, what will happen if I don't take the medicine and you know how the baby might be affected" [info from perinatal team vs GP]*
>
> *Rachel "that was really where my knowledge was coming from [reading herself], it wasn't provided by anyone, even as I say, the diagnosis was given but nothing else"*

Women also spoke about how information and knowledge regarding their diagnoses could have facilitated them sharing information with others around them to help them understand their difficulties:

Chen: "Things for them to read, a leaflet for just family and friends maybe not for me. Then I can simply let them take a look and then what they, what the professionals suggest family and friends should understand more about the issue"

Participants also spoke about an imbalance between them and professionals in regard to decision making, suggesting an absence of collaboration in their treatment:

Zara: "she [the psychiatrist] didn't explain the decisions she was making, that would have a massive help, massive massive massive help"

Several women felt that they were not given a choice in the type of treatment they received, which could suggest them feeling a sense of powerlessness, as illustrated by Priyanka and Zara:

Priyanka: "I really think I would have gone for the alternate options instead of taking medicine if I had one"

Zara: "I am a talker and that's one of the reasons why I was so distraught when she sent me off with medication because I wanted talking therapy"

This sense of powerlessness was also demonstrated in Rachel's narrative, where she had felt particularly failed and dismissed by healthcare professionals when attempting to seek help for her mental health:

"I went to see the GP and erm I was told to just go and pick up a leaflet in reception about referring myself, which I was shocked about to be honest, because I know how I

was feeling but I don't know how another person could make the judgment call that I wasn't in a very serious position where I could have been suicidal and it seemed very dismissive in terms of the approach"

As well as the power imbalances noted within professional relationships, several women also spoke about their experience of a power imbalance between physical and mental health, reflected in the following subtheme.

Mental health as hidden compared to physical health

Women spoke about how the physical impact of the perinatal period is often considered in the types of information shared and disseminated with the public, whereas the same focus is not given to psychological wellbeing.

Sarah: "like 'count the kicks' and all that stuff, there's so many campaigns about you know if your baby stops moving and you know what to do and all that stuff, but there's nothing about mum, and yeah erm I think. It's the same with cancer and things, like check your breasts and if you find a lump, this is the process to follow and it's like everyone knows there's a process, whereas with like with mental health I don't really feel like there is"

Women also spoke about the disparity between physical and mental health services, reflecting that mental health services felt more hidden and harder to access:

Chen: "The mental health is really different than GP. You know you can go back to the GP, but mental health is very behind everything, you don't know where it is and I feel like if I'm not having the depression, the issue, during the pregnancy, I probably wouldn't ever know that it was out there and wouldn't even had any treatment".

Sarah spoke of perinatal mental health services being even more difficult to access, highlighting *"GPs don't know to refer into perinatal mental health"*.

In summary, this superordinate theme shows the imbalances the women experienced in their relationships with professionals and in the disparity between physical and mental health. The final superordinate theme moves away from considering power imbalance to focussing on their experience of the power in the diagnostic process.

Theme 4: The psychological processes of diagnosis

This superordinate theme reflects the psychological processes surrounding diagnosis, including prior to diagnosis, post-diagnosis and the longer-term recovery following diagnosis.

Pre-diagnosis

Several participants spoke about how consuming being unwell felt to them, suggesting almost an embodiment of 'the illness'. For example, Chen described being *"under those depression feelings for quite a long time"*, suggesting a heavy presence of depression. In addition, Liz describes depression feeling like part of her:

> *"I always thought that it was me, that there was just something wrong me *emphasis on word* me, rather than being ill *laughs* which are 2 different things, well I saw them as 2 different things"*

All but one participant discussed recognising that something was 'not right' in themselves prior to receiving a psychiatric diagnosis. For example, Priyanka explained *"I think we [husband and her] both knew somewhere that it's there, yeah so but we both knew it was coming [the diagnosis]"* and Sarah *"I knew, I knew I wasn't right after I had her [her baby]"*. In contrast, Zara spoke about *"not knowing that I was poorly"*. Although there was recognition

of something ‘not being right’, some participants found it difficult to understand what exactly was going on and this meant they often searched for meaning for their experiences:

Sarah: “I felt like I didn’t have postnatal depression, so you know what was sort of going on”

Chen: “I don’t know why every time I got the kicking [from the baby] I felt the depression”

The recognition of things ‘not being right’ but not having received a diagnosis yet appeared to have a significant emotional impact on women. Liz spoke about how without a name to put to her experiences, she felt in denial of ‘being unwell’ and Rachel similarly pushed her feelings away in an attempt to cope:

Liz: “I was maybe in denial because I didn’t really, I didn’t really have that name to put to what I was feeling I suppose”

Rachel: “I think I was just trying to push it, push it further away”

There was also a sense from one participant that not having an understanding of what they were experiencing was frightening:

Liz: “yeah really scary, really terrifying that I didn’t really understand what was happening to me or why I felt like I did”

Some participants like Rachel began to consider particular diagnoses themselves, from doing their own research, which could suggest some desire and desperation to understand what was going on:

Rachel: “I was thinking ‘I I can’t have PTSD’ you know and it’s just this constant dialogue in your head over it errm I was thinking ‘no, don’t be daft’”

Post-diagnosis

There was a mixture of emotional reactions noted amongst participants post-diagnosis and for some participants it appeared they went through several stages of these. Some women spoke of shock at the actual psychiatric diagnoses itself, but also the severity of the diagnoses communicated by professionals and the treatment offered:

> *Zara "so I was just like a big crumpled biscuit in lots of pieces and lots of crumbs all over the place"*
>
> *Chen "...and because I was already shocked to be told a medium level err depression, it was definitely a bit unbelievable about medication..."*

This shock at the severity of the diagnoses also related to some women feeling that they needed to *"take it more seriously now" (Chen and Priyanka)*, suggesting a real sense of the significance of diagnosis. The power of diagnosis was also illustrated by some women's narrative suggesting it felt quite overwhelming and a lot to take in, illustrated by Zara *"I wasn't in the place where I could hear it or remember it"* and Chen *"So it's like lots of new things and its very errrm yeah, lots of new thinking.."*.

For some participants, acceptance of the diagnosis was difficult, particularly in the early stages post-diagnosis and their narrative suggested a period of denial, as illustrated by Liz:

> *Liz: "I kept saying 'well that's not me, that's other people who are struggling with that, I can't be struggling with that I'm just, it's just me, it's not depression' *laughs*"*

However, it appeared that with time, these women moved from a denial stance towards acceptance, illustrated by Zara *"I don't think it was until a good few weeks later that I fully appreciated and acknowledged that I was unwell"*.

Though there were more difficult emotions connected with diagnosis discussed above, women also spoke about positive feelings. The majority of women spoke about a sense of relief in receiving a diagnosis, since the diagnosis helped them feel validated and listened to by professionals, illustrated by Rachel *"it felt relief in a way, that somebody had seen there was a problem"* and Sarah *"...a sense of relief that someone understood how I was feeling erm yeah that was good"*. Gratitude for the diagnosis was also noted in participant's narratives, particularly relating to the diagnosis as facilitating treatment that women found helpful, as explained by Chen *"I feel definitely grateful for the diagnosis because of the [positive] impact of the treatment"*.

Recovery

As part of women's longer-term recovery post-diagnosis, there was a noted desire to understand their mental health experiences among many of the women, for example wishing to understand why they experienced the mental health difficulty. Some women explained how psychological therapy helped them make sense of their experiences more:

> *Sarah: "and definitely the way she [Psychologist] explained it to me, she didn't just say this what you've got blah blah blah, but she really went through the motions of explaining how it works, why it happens, and that was really helpful"*
>
> *Rachel: "'right your brain is doing this' or 'this is what is happening', if it's explained in those terms 'so right you've got this hormone which will start creating this, so you might experience this', if it's done in those terms I think it's more palatable isn't it and people don't, people won't see it as a taboo, it won't be seen as a negative thing, because it's a physical thing because whichever way you look at it, whatever is going on with you is physical"*

However, Priyanka spoke about how her understanding of why she experienced anxiety and depression is still outstanding following her treatment of medication:

Priyanka: "if it is up to me, I would really like to explore the other side to know the real like reason for it"

Women spoke about a journey of self-development they have been through, both from the mental health treatment they received and from going through the experience of being unwell. There was a sense of treatment being transformational for some women, reflected here by Sarah:

"And slowly I was like, I just don't feel the same anymore, it was literally like it took a blanket off my head. It was like I was suffocating under this blanket, constantly trying to waft it away from my face, and then it was just gone"

With regards to self-development through lived experience, many women spoke about how it has changed and shaped how they now interact with others. There was a particular sense of women wishing to provide help and support to others who experience mental health, demonstrated here by Zara:

Zara: "actually my lived experiences meant that I could be more empathic to other people, more understanding to other people, maybe give them some tips if they wanted them or guidance"

Several women spoke about recovery from mental health being a complex journey, reflecting on the length of recovery and also some worries for what the future holds with their mental health:

Liz: "I suppose it's shocked me how long of a journey it is, that you get ill normally and it's quite, you have a recovery time that will, you know you have appendicitis and

they say 'oh in 4 week's time you'll be able to walk around and it'll be healed and you'll be better'....I look back to where I was a year ago and where I am now, and how long it's taken me to get back to where I am"

Chen: "So I feel a bit erm maybe not panicked, but something like that, my feet are not on the ground. So erm ok I be super happy to know that I am well and discharged, but I think I will be left a bit worried, I don't know how to look after myself afterwards"

There was also a sense of recovery being a complicated journey in terms of them finding the right treatment that met their needs, illustrated by Rachel:

"this has felt far more structured [current therapy] erm, I just felt as though the talk therapy [previous counselling] was just very, it was very emotional and very draining, but never seemed to go anywhere, there never seemed to be a resolution. This it seems that there's purpose to it and the treatment seems as though it's more focussed and this has been a more positive experience"

In summary, this superordinate theme illustrates the psychological processes the women experienced pre and post diagnosis, and around the recovery journey. Emotional reactions to the diagnosis differed and there was a clear sense of the diagnosis eliciting both positive and negative emotions, such as both shock and relief. Recovery was considered to be a transformational but complex process for many women; helping them to develop an explanation of their experiences and changing their outlook on life.

Discussion

Summary of findings

This study used Interpretative Phenomenological Analysis (IPA) to explore the experience of women receiving a psychiatric diagnosis during the perinatal period. Four superordinate themes were identified: 'The psychological processes of diagnosis', 'The perinatal period as unique', 'Power imbalances' and 'The complex role of others'. Although the present study aimed to understand more about women's experience of receiving a perinatal psychiatric diagnosis, the results have also provided insight into the women's experience of both seeking help, and living with, a mental health difficulty during the perinatal period.

Research findings in context

Psychological processes surrounding diagnosis

The present study found that psychiatric diagnosis during the perinatal period evoked both positive and negative emotions, which is consistent with previous research surrounding the experience of diagnosis in perinatal and non-perinatal populations The majority of women recognised a psychological difficulty, and many also had difficulty in making sense of their experiences. In line with previous research, some women viewed the perinatal period as a further complicating factor in understanding their experiences (Bilszta et al., 2010), as they questioned what was 'normal' and 'not normal' emotionally during this period. For some women, diagnosis appeared to offer a framework to understand their experiences, providing them a sense of validation and relief, which has been demonstrated in previous postnatal depression literature (Hanley & Long, 2006; Patel et al., 2013).

Though the process of diagnosis proved beneficial, some women noted a sense of shock at the diagnosis itself and the severity of disorder suggested by professionals, feeling like it

'came out of the blue'. This is in line with what has been found in previous research exploring experience of psychiatric diagnosis non-perinatally (Gallagher et al., 2010). There was also a sense of the diagnosis being a lot to take in for women, which suggests the importance of women needing time to process a psychiatric diagnosis. A further stage of denial of the diagnosis was noted by some women, that appeared to shift towards a journey of acceptance, something that has again been noted in non-perinatal research (Delmas et al., 2011).

The psychological process of acceptance has been outlined in the literature surrounding psychological adjustment to grief (Kubler-Ross, 1969), where five sequential stages have been suggested: denial, anger, bargaining, depression and acceptance. A process of psychological adjustment following diagnosis has also been well documented in research surrounding chronic physical illness (Telford et al., 2006). Whilst some of these adjustment stages within the grief model (Kubler-Ross, 1969) have been noted in the current study, for example denial, it is evident that participants went through an individual path in adjusting to the diagnosis. This fits closely to the work of Paterson (2001) around adjustment to chronic illness, where adjustment is noted as a complex and individual experience that is ongoing, as opposed to a predictable, linear process. The complex and unique nature of adjustment to psychiatric diagnosis has been noted in non-perinatal literature, for example in adjustment to a bipolar disorder diagnosis (Inder et al., 2011). The findings therefore suggest the importance of considering uniqueness to an individual's psychological adjustment to a psychiatric diagnosis in the perinatal period.

The experience of health services

The present study provides important insights into the women's experience of seeking help from health care services. In accordance with previous literature (Bilszta et al., 2010; Megnin-Viggars et al., 2015), a common theme was worry for their child. There was an emphasis on the potential negative impact of taking psychotropic medication during the

perinatal period and the worry of having their child 'taken away' should they seek help for their mental health. Women therefore felt that they needed to protect them, which at times negatively impacted on their engagement with treatment, for example delaying them seeking help.

Importantly, the findings suggest a lack of information and transparency shared by professionals about their diagnosis and treatment options. This could be understood to reflect a sense of imbalance between the women and professionals. Unfortunately, a lack of information shared by professionals has been consistently noted previously in the perinatal mental health literature (Chew-Graham et al., 2009; Hall, 2006; Slade et al., 2010). Some women noted that psychotropic medication felt like the only option, which has also been noted in previous research (Chew-Graham et al., 2009; Turner et al., 2008; Turner et al., 2010). It is interesting to note that some women were unsure if the decision to prescribe medication was made for the convenience of the professionals, as opposed to for the women's needs. The women's perception of an absence of shared decision-making and collaboration is vitally important, given the emphasis on these aspects in healthcare (Elwyn et al., 2010) and that they have been linked with more positive feelings when receiving a psychiatric diagnosis (Hackman et al., 2019). The presence of power imbalance within professional relationships could also significantly impact how able women feel to seek help and how much benefit they receive from services. For example, if women do not comprehensively understand the use of psychotropic medication in the perinatal period, it could negatively impact their adherence (Boath et al., 2004; Turner et al., 2008).

The experience of living with a perinatal mental health difficulty

The treatment the women received proved transformational for some, for example Sarah described her transformation through psychological therapy: "*suffocating under this*

blanket, constantly trying to waft it away from my face, and then it was just gone". An important component of treatment and recovery appeared to be professionals helping the women to understand why they were experiencing psychological and emotional distress, which was achieved through psychological therapy for many women. This could suggest how a psychological formulation that aims to help women understand their difficulties in more depth could benefit women's recovery, for example understanding the link between their life experiences and the development of mental health difficulties (Johnstone, 2018; Johnstone & Boyle, 2018). Psychological formulation can also provide a sense of collaboration (Johnstone, 2018), potentially removing some of the challenges that can occur with power imbalances in therapeutic relationships which have been noted in the present study. Previous qualitative studies have demonstrated the reliance perinatal women can feel on professionals helping them to understand their psychological and emotional difficulties, again suggesting the possibility of imbalance in the relationship and highlighting the benefit of collaboration (Edge, 2007; Edge, 2008).

The present study emphasised the difficulty women felt in getting psychological and emotional needs met during the perinatal period. It was noted that physical health needs and the needs of the baby are more fully considered by professionals and society than the mother's psychological needs, as also demonstrated in previous literature (Bilszta et al., 2010; Raymond, 2009; Turner et al., 2010). Some women also felt it was difficult to get their own needs met in their personal relationships, for example the focus of family and friends was on their child at a time when they needed support. This finding adds to the research by increasing insights into the difficulties that mothers can experience in having their psychological needs met.

The role of stigma and a lack of understanding about perinatal mental health was emphasised in the current study, as also highlighted in a recent review by Smith et al. (2019). Women spoke about a fear of judgement from others, particularly around their parenting ability,

which is something that has been demonstrated consistently in previous literature (e.g. McLoughlin, 2013). This linked with women keeping their feelings to themselves and not sharing information about their mental health with others. There was also a sense of concern that sharing with others would be burdening them, potentially illustrating a sense of guilt or shame in sharing with others. Many women felt a sense of isolation given some of these challenges, which is worrying given the imperative role that social support has been shown to have in mental health recovery (Wang et al, 2018).

A particular emphasis was placed upon cultural stigma towards mental health by the two participants from a non-White British culture in the present study. A recent systematic review (Watson et al., 2019) in minority ethnic groups has emphasised the important role of culture in perinatal mental health, supporting themes that were also found in the two non-White British participants in this study, including a cultural lack of awareness about mental health and stigma.

The majority of women spoke about a sense of self-development through their experience of treatment and/or their lived experience of mental health. This finding could be considered in the context of post-traumatic growth literature, which has suggested that positive change can occur following the experience of a challenging life event, such as mental health difficulties (Tedeschi & Calhoun, 2004). As a consequence of their own lived experience, many women spoke of wishing to support and help other women who experience perinatal period mental health difficulties. This highlights the importance of connection for these women and emphasises the power in connecting with those with similar experiences in validating one's own experiences, noted by Nicole et al. (2007) in women with postnatal depression.

Summary

As discussed above, much of the present study's results were supported by past literature, however they also provide understanding beyond past research. Past perinatal mental health research has been dominated by postnatal depression, as demonstrated in recent meta-syntheses of the experience of seeking help for perinatal mental health difficulties (Megnin-Viggars et al., 2015; Smith et al., 2019). In contrast, this study offers unique insight into women's experience across various depression and anxiety diagnoses over the entire perinatal period. Although there were nuances in the individual experiences of the women interviewed, it is clear that there were shared common experiences among the sample, potentially suggesting some common shared experiences among those struggling with perinatal mental health difficulties.

Strengths and limitations of study

It is important to consider the strengths and limitations of the current study. Firstly, the use of IPA methodology presents both strengths and limitations. IPA allowed in-depth analysis of rich, detailed data to gain a detailed sense of participant's experiences. IPA is however interpretative in stance, which means the interpretations of the data are influenced by the researcher's own experiences and narratives. A number of measures were put in place to ensure validity and credibility of interpretations, including a reflective diary, and credibility checks of themes with the use of workshops with fellow colleagues and supervision. However, it is still possible the author's own experiences and assumptions may have influenced the interpretations made from the data.

The present study recruited a small, targeted sample of six women, which was beneficial in allowing the researcher to conduct a detailed IPA analysis of each participant's experience. As small sample sizes entail limitations in the generalisability of results, the present

study does not attempt to conclude that the results represent the experience of all women receiving a psychiatric diagnosis during the perinatal period. Instead, it focuses on making sense of the six participant's experiences.

The range of depression and anxiety diagnoses and the mix across the antenatal and postnatal period represented within the recruited sample is a strength of the current study. There was a noted absence of more severe and enduring diagnoses, such as postpartum psychosis and bipolar disorder, which could limit the conclusions drawn from the results. However, increasing the number of participants recruited in an attempt to include women with these diagnoses would have presented challenges in conducting such a detailed analysis.

An additional methodological consideration to take into account is how representative the women recruited are of the general perinatal population receiving psychiatric diagnoses. The women were recruited on a voluntary basis, bringing to question whether the sample represents only women who were willing to speak about their experiences of receiving a perinatal psychiatric diagnosis, perhaps wishing to reflect a particularly positive or negative experience. However, it is important to note that a range of experiences were discussed within the interviews and women spoke with a balanced view of diagnosis and health services.

Implications for clinical practice

This research has identified a number of things which can be done to help improve and support women who receive a psychiatric diagnosis during the perinatal period.

Perinatal mental health awareness

As highlighted in this study, women felt there was emphasis on physical health during the perinatal period, whereas there was a lack of information and awareness on mental health. For example, it was highlighted that campaigns such as the 'Kicks count' charity

(https://www.kickscount.org.uk/) demonstrate the importance of physical health and monitoring during the perinatal period, but comparable campaigns do not exist for perinatal mental health. Providing information on mental health as part of standard practice when women enter maternity services offers an opportunity to empower women to recognise and understand their own mental health. For example, perinatal mental health information could be included in the 'red book' that women receive entering maternity services, which currently details information on a baby's health and is added to at medical appointments. This could in turn improve early detection and thus improve clinical outcomes (Yawn et al., 2012), providing key information to reduce women's anxiety about seeking help, such as dispelling the worry of losing custody of their child. This is supported by 'The Framework for Preparation for Birth and Beyond' developed by the Department of Health (2011), which emphasises the importance of preparing mothers for the perinatal period.

In providing more information on perinatal mental health through avenues such as campaigns, there is an opportunity to increase awareness and reduce stigma around perinatal mental health within society. Furthermore, it would also provide an opportunity for society to understand more about perinatal mental difficulties other than postnatal depression, as highlighted in the current findings.

Therapeutic relationship

The findings of this study have emphasised the important role of the therapeutic relationship for women during the perinatal period and it is essential to consider how power imbalances within these relationships can be lessened. This highlights the need for professionals to hold in mind the potential power imbalances in their relationships with clients, and also suggests the need for ongoing supervision and training around this topic.

It is essential that therapeutic relationships are built upon collaboration and transparency to reduce power imbalances. For example, ensuring collaboration in decision making around treatment and transparency in why professionals may be making certain recommendations for treatment.

Connection with others

The importance of connection found in the present study suggests that helping women link in with others, such as through support groups, could be beneficial. For example, providing a leaflet similar to that in Appendix 9 could be helpful. It will be important for services to provide opportunities for women who have experienced perinatal mental health difficulties to be involved in the ongoing development of perinatal mental health services, providing opportunities for co-production and helping others. Co-production allows empowerment for the individual, thus reducing the feeling of power imbalance, but also has positive impacts on the quality of services (McKeown et al., 2016). Preliminary evidence into the use of peer support workers in antenatal depression (Carter et al., 2019) suggests a possible benefit of connecting perinatal women experiencing mental health difficulties with other women who have gone through similar experiences in order to provide support.

Process of delivering diagnosis

The psychological processes surrounding diagnosis demonstrated in the present study suggest importance in considering how professionals communicate a psychiatric diagnosis during the perinatal period. Given the strong feelings experienced by the women, such as shock and denial, it is important that diagnoses are communicated in an empathetic and sensitive manner. Following diagnosis, it is key for professionals to listen and understand how an

individual may be feeling, whilst allowing time to normalise and acknowledge these feelings that may have been evoked.

It is imperative that concrete information is shared by professionals, both in terms of the diagnosis and treatment. The provision of physical information (e.g. an information leaflet) on diagnosis and treatment would enable women to process this information in their own time, which could be beneficial given the possible strong emotional reactions to diagnosis. This could also facilitate women sharing this information with others, lessening the burden on them in providing an explanation to others at a time when they may be struggling to process their feelings.

Future research

Future research would benefit from focussing on a wide range of mental health difficulties, particularly capturing the experience of women receiving more severe and enduring psychiatric diagnoses during the perinatal period. Further research exploring the role of culture in the experience of receiving a psychiatric diagnosis during the perinatal period would also be beneficial. Given the emphasis of the importance of relationships and the 'complex role of others' identified in this study, further research conducted with the partners of women who have received a psychiatric diagnosis during the perinatal period may provide valuable insights into the experience of the wider system around women.

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LITERATURE REVIEW PRESS RELEASE

The Edinburgh Postnatal Depression Scale could provide an important role in screening for perinatal depression

The Edinburgh Postnatal Depression Scale (EPDS) could provide a helpful, quick way to detect perinatal depression, a meta-analysis from the University of Birmingham shows.

The perinatal period, which refers to the time from conception to one-year post-birth, is a challenging time increased vulnerability for the onset or relapse of mental health difficulties (Smith et al., 2011). An investigation into perinatal mental health and its costs to society suggests that about half of cases of perinatal depression and anxiety go undetected (Bauer et al., 2014). The EPDS is the most widely used screening tool for perinatal depression and is recommended for use by the National Institute of Health and Care Excellence (NICE, 2014), which is the body that sets out recommendations for health and care in England. Previous research reviewing the accuracy of the EPDS in detecting depression perinatally is limited due there only being a systematic summary of the available evidence without statistical analysis. Furthermore, previous research only reviewed the use of the scale in either pregnancy or postnatally, rather than considering the perinatal period as a whole. This was therefore the first meta-analysis to date, which involved a statistical analysis of the evidence base using the EPDS to detect perinatal depression.

Lead researcher Caroline Caddy and colleagues at the School of Psychology, University of Birmingham conducted a meta-analysis of the accuracy of the EPDS in detecting depression during the perinatal period. They evaluated 73 datasets from 66 published research papers, involving more than 14,152 adults from 1967 to July 2019. They looked at studies that compared the results from the EPDS to a 'gold standard' diagnostic interview for depression in perinatal men or women over the age of 18.

The meta-analysis demonstrated the EPDS is an accurate measure at detecting depression in the perinatal period, as the results showed a good level of accuracy in diagnosis. Lead researcher Caroline Caddy says: “stronger conclusions can be drawn about the diagnostic accuracy of the EPDS in postnatal women, as 61 studies used postnatal women. It would be helpful for further research to be conducted exploring the effectiveness of the EPDS in detecting depression in pregnant women and in perinatal males. There is also a need for further research with higher quality methodology to be conducted.”

In considering the implications of these results to clinical practice, Caroline Caddy says: “this review indicates the EPDS could be a useful instrument to use in the screening of perinatal depression in clinical practice, particularly in postnatal women”.

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EMPIRICAL PAPER PRESS RELEASE

It's not just the baby that's important, mothers have needs too!

Women receiving a psychiatric diagnosis during the perinatal period face significant challenges and need additional support, a new study from the University of Birmingham shows.

The perinatal period refers to the time from conception to one-year post-birth. This is a challenging time for women, involving a heightened level of emotions and psychological state (Lee, 2000) and an increased vulnerability for the onset or relapse of mental health difficulties (Smith et al., 2011).

Perinatal mental health difficulties impact between 10% and 20% of women during pregnancy and the first-year post birth (Bauer et al., 2014). The experience of perinatal mental health difficulties can have a significant negative impact on the woman, child and wider family (Moore Simas et al., 2019) and cost the NHS a staggering £1.2 billion per annum (Bauer et al., 2014).

Little in depth research has been carried out into the experience of women receiving a psychiatric diagnosis across the perinatal period. Lead researcher Caroline Caddy says: "The perinatal period is a time of significant change and it is important that we understand how the experience of receiving a psychiatric diagnosis may further impact this already challenging time".

Researchers at the School of Psychology, University of Birmingham explored the experiences of six perinatal women using interviews to find out more about their experience of receiving a psychiatric diagnosis during the perinatal period.

The findings of the research illustrated the complexity of making sense of and receiving a psychiatric diagnosis during the perinatal period. The women reported finding it difficult to understand their mental health difficulties, often questioning what may be 'normal' and 'not normal' to experience perinatally given the complexity of this period. It was often difficult for

them to understand what they may be experiencing as postnatal depression was described as the only perinatal mental health difficulty well known in society.

The women felt their own psychological needs were often not prioritised by themselves and others, which resulted in them experiencing difficulties in their relationships with others and impacted their recovery. There was an importance of relationships and shared experience emphasised by the women, but sadly many people found it difficult to understand what they were going through, leading to them feeling isolated from others.

Women spoke of not feeling like they had a good enough understanding of their mental health difficulties, alluding to a lack of collaboration and transparency from professionals. Both positive and negative emotions were voiced by the women regarding receiving a psychiatric diagnosis. Many felt that the diagnosis provided an understanding for them of their difficulties and helped them feel listened to. However, this also came with more difficult feelings such as shock and denial for some women.

Lead researcher Caroline Caddy says: "Our results have important implications for how mental health services could improve support for women receiving a psychiatric diagnosis during the perinatal period. It is important that there is an increased awareness of perinatal mental health in society and that mental health information is more easily accessible to women in the perinatal period, particularly with difficulties other than postnatal depression. The findings also illustrate the importance of women's relationships with healthcare professionals. It is important for professionals to work alongside women and provide clear, concrete information."

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Appendix 1: University of Birmingham Sponsorship Letter

UNIVERSITY OF BIRMINGHAM

FINANCE OFFICE

Miss Caroline Caddy
School of Psychology
University of Birmingham

25 February 2019

Dear Caroline

Project Title: **Experience of Perinatal Mental Health**
IRAS ID: **252763**
Sponsor Reference: **RG_18-270**
UoB Ethics Reference: **ERN_18-1844**

Under the requirements of UK Policy Framework for Health and Social Care Research, the University of Birmingham agrees to act as Sponsor for this project. Sponsorship is subject to you obtaining a favourable ethical opinion, HRA approval and NHS R&D management approval where appropriate.

As Chief Investigator, you must ensure that local study recruitment does not commence until all applicable approvals have been obtained. Where a study is or becomes multi-site you are responsible for ensuring that recruitment at external sites does not commence until local approvals have been obtained.

Following receipt of all relevant approvals, you should ensure that any subsequent amendments are notified to the Sponsor, REC, HRA and relevant NHS R&D Office(s), and that an annual progress report is submitted to the Sponsor, REC and NHS R&D departments where requested.

Please ensure you are familiar with the University of Birmingham Code of Practice for Research (http://www.birmingham.ac.uk/Documents/university/legal/research.pdf) and any appropriate College or School guidelines.

Finally please contact researchgovernance@contacts.bham.ac.uk should you have any queries.

You may show this letter to external organisations.

Yours sincerely

[redacted]

Dr Birgit Whitman
Head of Research Governance and Integrity

cc: Dr George Johnson (Academic Supervisor)

University of Birmingham Edgbaston Birmingham B15 2TT United Kingdom
w: www.finance.bham.ac.uk

Appendix 2: NHS Research Ethics Committee Favourable Opinion Letter

NHS
Health Research Authority

West Midlands - South Birmingham Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0207 104 8115

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

25 March 2019

Miss Caroline Caddy
Trainee Clinical Psychologist
University of Birmingham
Department of Clinical Psychology, School of Psychology
University of Birmingham, Pritchatts Road
Birmingham
B15 2SA

Dear Miss Caddy

Study title:	**What is the experience of women receiving a psychiatric diagnosis during the perinatal period?**
REC reference:	**19/WM/0089**
Protocol number:	**RG_18-270**
IRAS project ID:	**252763**

The Research Ethics Committee reviewed the above application at the meeting held on 19 March 2019. Thank you for attending to discuss the application along with Dr George Johnson.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the

date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The participant information sheet should be amended as follows:
   a) The term 'perinatal period' should be explained.
   b) A sentence should be added to the 'purpose' section to explain the study is being conducted as part of a Doctorate in Clinical Psychology degree study.

2. Reference to video recording should be removed from the consent form.

   Recommendations (not required in order to receive a favourable opinion)

   It is recommended the wording used to exclude those who do not speak English be revisited, so that it is clear only those who would require translators are excluded. This can be updated in the protocol, but it is not necessary to update the IRAS form.

   The applicants are strongly encouraged to register the study on a public database, such as the university website.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Extract of the meeting minutes

Social or scientific value; scientific design and conduct of the study

It was noted this was an interesting study with the potential to be very worthwhile. Members observed the perinatal period from conception to one year after birth was quite a long period. They queried why this period had been chosen. *The applicants explained that previous research had focused mostly on the post-natal period, however, there was a prevalence of mental health diagnoses from conception onwards, and so they would be looking at the wider period from the time women often entered the service. This should encompass a wide range of people, enabling the IPA method to explore what sense they have made of receiving their diagnosis.*

Recruitment arrangements and access to health information, and fair participant selection

The Committee noted an exclusion criterion was patients for whom English was not their first language. They queried whether there was any particular reason those for whom English was a second language could not participate, as long as they did not need a translator. *The*

applicants informed they were happy to change the wording to reflect that those who would need translators could not participate. They added this had become a standard form of wording used in research as late, but perhaps it should be revisited by the organisation. The Committee noted this, and it was further noted that only 8 participants would be recruited.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

Members queried whether they would be checking pregnancy outcomes, and still engaging with patients who may have had miscarriages, traumatic births or still births. *The applicants explained all potential participants would be identified by their responsible clinicians, and so they would take their advice on whether it was appropriate to include them, based on their circumstances and whether it would be too challenging emotionally.*

The Committee sought clarification regarding the risk of distress during interviews, and how this would be handled. *The applicants explained that patients would be given the information sheet to consider in their own time, and so should have had time to think about how they felt. If they decided to participate, it would be clear they could pause the interview at any time in order to have a break or a drink. Most of the interviews would take place in the participants' homes. They could also terminate the interview at any time and withdraw their data from the study. If there were any concerns the applicants would follow up with the patient's responsible clinician, so that they could carry out a follow up call and provide additional support.* The Committee noted the response.

Members queried whether the applicant would be working to a Lone Worker Policy, given she would be visiting patients at home. *The applicant confirmed she would follow the Lone Worker Policies for each of the two Trusts involved. She would let her Academic Supervisor know the time and location of each meeting, and would 'check in' with him after each meeting.* The Committee noted this.

The Committee noted the list of mental health resources provided, and queried how the links and contact details had been chosen. *The applicants explained that they had tried to make it as broad as possible, whilst also providing some condition specific resources. They hoped they could use the websites to look up useful information and that this would meet the needs of a range of different service users.* The Committee noted this.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

It was noted the study would not be registered on a public database; members queried why this was the case. *The applicants informed that REC that this was the way things were set up academically at the University, however, they could consider finding a suitable public registry, such as the university public library.* The Committee encouraged them to do so. *The applicants add the study would be available publicly after completion.*

Informed consent process and the adequacy and completeness of participant information

Prior to the applicants' arrival, it was noted that the term 'perinatal period' was not a lay term, and should be explained for context.

Members commented that there was reference to video recording in the consent form, but this was not mentioned elsewhere in the application. *The applicants confirmed there would be no video taken, only audio using an encrypted Dictaphone.* The Committee noted this,

and asked that the reference be removed. They also asked that the information sheet mention the study was being carried out as part of a Doctorate in Clinical Psychology degree.

Before leaving the applicants informed they had been asked to make a number of changes as part of the Assessment of the study, and asked whether they could submit these alongside their response to the REC. The Committee confirmed they responses could be submitted together.

Please do not hesitate to contact me if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Letter]		25 February 2019
GP/consultant information sheets or letters [GP Notification Form]	1.0	22 January 2019
Interview schedules or topic guides for participants [Interview Topic Guide- Version 1.0]	1.0	06 February 2019
IRAS Application Form [IRAS_Form_25022019]		25 February 2019
Letter from sponsor [Sponsor Letter]		25 February 2019
Other [Participant Resource Leaflet]	1.0	07 February 2019
Participant consent form [Participant Consent Form]	1.0	22 January 2019
Participant consent form [Participant Consent to be Contacted Form]	1.0	22 January 2019
Participant information sheet (PIS) [Participant Information Sheet-Version 1.2.]	1.2	22 February 2019
Research protocol or project proposal [Research Protocol]	1.1	07 February 2019
Summary CV for Chief Investigator (CI) [Chief Investigator (Caroline Caddy)-CV]	1.0	22 January 2019
Summary CV for supervisor (student research) [Academic Supervisor CV]	2	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/WM/0089	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]PP

Professor Paula McGee
Chair

E-mail: NRESCommittee.WestMidlands-SouthBirmingham@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Dr Birgit Whitman*

Appendix 3: Health Research Authority Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Caroline Caddy
Trainee Clinical Psychologist
University of Birmingham
Department of Clinical Psychology, School of Psychology
University of Birmingham, Pritchatts Road
Birmingham
B15 2SA

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

28 May 2019

Dear Miss Caddy

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

Study title:	**What is the experience of women receiving a psychiatric diagnosis during the perinatal period?**
IRAS project ID:	**252763**
Protocol number:	**RG_18-270**
REC reference:	**19/WM/0089**
Sponsor	**University of Birmingham**

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 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 **252763**. Please quote this on all correspondence.

Yours sincerely,
Lauren Allen

Email: hra.approval@nhs.net

Copy to: *Dr Birgit Whitman*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Letter]		25 February 2019
GP/consultant information sheets or letters [GP Notification Form]	1.0	22 January 2019
HRA Schedule of Events	1.1	08 March 2019
HRA Statement of Activities	1.1	08 March 2019
Interview schedules or topic guides for participants [Interview Topic Guide- Version 1.0]	1.0	06 February 2019
IRAS Application Form [IRAS_Form_25022019]		25 February 2019
Letter from sponsor [Sponsor Letter]		25 February 2019
Other [Participant Resource Leaflet]	1.0	07 February 2019
Participant consent form [Participant Consent to be Contacted Form]	1.0	22 January 2019
Participant consent form [Participant Consent Form]	1.1	27 March 2019
Participant information sheet (PIS) [Participant Information Sheet]	1.3	27 March 2019
Research protocol or project proposal [Research Protocol]	1.2	27 March 2019
Summary CV for Chief Investigator (CI) [Chief Investigator (Caroline Caddy)-CV]	1.0	22 January 2019
Summary CV for supervisor (student research) [Academic Supervisor CV]	2	

Appendix 4: Health Research Authority Amendment Confirmation Email

Amendment Categorisation and Implementation Information

Dear Miss Caddy

IRAS Project ID:	**252763**
REC Reference:	**19/WM/0089**
Short Study Title:	**Experience of Perinatal Mental Health**
Date complete amendment submission received:	**25/10/2019**
Sponsor Amendment Reference Number:	**NSA 1**
Sponsor Amendment Date:	**18 October 2019**
Amendment Type	Non Substantial
Outcome of HRA and HCRW Assessment	**This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything further.**
Implementation date of Category B elements in NHS organisations in England and/or Wales	35 days from date amendment information together with this email, is supplied to participating organisations **(providing conditions are met)**
For NHS/HSC R&D Office information	
Amendment Category	**B/C**

Thank you for submitting an amendment to your project. We have now categorised your amendment and please find this, as well as other relevant information, in the table above.

Please note that elements of this amendment have been categorised as **Category B** (where specific sites are impacted and should be given time to consider its implementation) and elements as **Category C** (where no sites are impacted and you can implement as soon as all regulatory approvals are in place). You should therefore read the below instructions carefully in order to implement the amendments appropriately.

Please note that you may only implement changes described in the amendment notice.

What should I do now and when can I implement the Category B elements of this amendment?

The category B elements of this amendment are change to a PI.

Please read the information in IRAS, which provides you with information on how and when you can implement the category B elements of your amendment at NHS/HSC sites in each nation, and what actions you should take now.

If you have participating NHS/HSC organisations in any other UK nations that are affected by this amendment please note that **we will** forward the amendment submission to the relevant national coordinating function(s).

What should I do now and when can I implement the Category C elements of this amendment?

The **remainder of this amendment has been categorised as Category C**. You should follow the information below in order to implement this change at all participating NHS/HSC organisations.

You should now inform participating NHS/HSC organisations of the amendment.

- For NHS organisations in England and/or Wales, this notification should include the NHS R&D Office, LCRN (where applicable) as well as the local research team.

You may implement the category C elements of this amendment **immediately**.

Who should I contact if I have further questions about this amendment?

If you have any questions about this amendment please contact the relevant national coordinating centre for advice:

- England – hra.amendments@nhs.net
- Northern Ireland – research.gateway@hscni.net
- Scotland – nhsg.NRSPCC@nhs.net
- Wales – HCRW.amendments@wales.nhs.uk

Additional information on the management of amendments can be found in the IRAS guidance.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please do not hesitate to contact me if you require further information.

Kind regards

Mr Ali Hussain
Workflow Administrator
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.hra.amendments@nhs.net
W. www.hra.nhs.uk

Appendix 5: Consent to Contact Form

IRAS ID: 252763

UNIVERSITY OF BIRMINGHAM

[redacted]

CONSENT TO CONTACT FOR RESEARCH PURPOSES

Title of Project: What is the experience of women receiving a psychiatric diagnosis during the perinatal period?

Researchers: Caroline Caddy, [redacted] Dr George Johnson

You are being invited to give consent for Caroline Caddy (Chief Investigator) to contact you regarding the project 'What is the experience of women receiving a psychiatric diagnosis during the perinatal period?'

If you consent to be contacted, the research team will provide you further information on the project. You are not agreeing to take part in the study at this stage. You can make that decision once you receive the full information and have the opportunity to ask any questions.

We will require your name, telephone number and email address to be able to contact you.

1. I confirm that I am willing to receive information about the project. ☐
2. I agree that my Responsible Clinician can disclose my name, contact telephone number and email address to the research team for the purpose of being contacted. ☐
3. I understand that I am not consenting to take part in the project, only to receive further information. ☐

Patient's Signature: _____

Date: _____

Clinician's Name: _____

Version 1.1 18 October 2019

Appendix 6: Participant Information Sheet

IRAS ID: 252763
Participant Identification Number for this trial:

UNIVERSITY OF BIRMINGHAM

[redacted]

PARTICIPANT INFORMATION SHEET

Title of Project: What is the experience of women receiving a psychiatric diagnosis during the perinatal period?

Researchers: Caroline Caddy, [redacted], Dr George Johnson

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it would involve for you. Please read this information carefully and contact us if you have any questions. Our contact information is included on the final page. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The aim of this research project is to better understand the experience of women receiving a psychiatric diagnosis during the perinatal period. This study is being conducted as part of Caroline Caddy's Doctorate in Clinical Psychology.

Why have I been invited to take part?

You have been invited to take part as you have been identified as meeting the criteria for participation in this research study. We are recruiting individuals who have received a psychiatric diagnosis during the perinatal period and did not experience any significant mental health difficulties prior to this. This means not having received a psychiatric diagnosis or accessed any secondary mental health services previously. The perinatal period refers to the time from conception to one year post-birth.

What will happen to me if I agree to take part?

If you agree to take part in the study, you will be provided with a consent form which is to be signed. Once you have consented to take part in the study, a time, date and location for an interview will be made. The interview can take place at your home address, but if you would prefer we can try to arrange for it to take place at a local NHS establishment. The interview will last between 45 to 90 minutes and will involve being asked questions that have been set before interview and will be asked to all participants. The interview will also allow time for us to explore any new ideas generated.

Who will know I am taking part in the study?

We will inform your General Practitioner and Responsible Clinician at your mental health team that you are participating in the research, but they will not be made aware of the content of what is discussed within the interviews. However, if we have any concerns about your safety or the safety of others during the course of the study, then we will make your Responsible Clinician at your mental health team aware. This is to ensure that you are safe and that you receive any support you need.

What will happen with the information I give?

The University of Birmingham is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you take part in the interview, you will have two weeks after the date of interview where you can withdraw from the study and all your research data can be destroyed. If you decide to withdraw after this two week period, we will be unable to destroy your data as it is likely to have been included in analysis already.

The University of Birmingham will keep your name and contact details confidential and will not pass this information on to any other organisation. The University of Birmingham will use this information as needed, to contact you about the research study and to make sure relevant information about the study is recorded to oversee the quality of the study. Individuals from regulatory organisations may look at these research records to check the accuracy of the research study. The people who analyse the information will not be able to identify you and will not be able to find out personal information such as your name or contact details. The University of Birmingham will keep identifiable information about you on a secure server for 10 years after the study has finished.

You can find out more about how we use your information by contacting Mrs Carolyn Pike, Data Protection Officer at the University of Birmingham on dataprotection@contacts.bham.ac.uk.

What will happen with the results of the study?

The findings of the study will be written up as part of Caroline Caddy's Doctorate in Clinical Psychology. It is expected that the results will also be written up for publication in a peer reviewed journal. Quotes from interviews may be used in write up, but these will be anonymised. There will be no personally identifiable information in research reports and publications.

Do I have to take part?

Taking part in the study is completely voluntary. The purpose of this information sheet is to give you more information on the study to help you make your decision. If you decide to take part now in the study but later change your mind, you can withdraw from the study. If you choose not to take part in the study, or if you withdraw, this will not have any impact on the care you receive from your mental health team.

If you take part in the interview, you will have two weeks after the date of interview where you can withdraw from the study and all your research data can be destroyed. If you decide to withdraw after this two week period, we will be unable to destroy your data as it is likely to have been included in analysis already.

What are the potential benefits of taking part?

By taking part in the study and sharing your experience, it will help us deepen our understanding of how women experience psychiatric diagnosis during the difficulty perinatal period. This will help us to make recommendations for the future development of services so that appropriate support can be offered to women going through this experience.

What are the potential disadvantages and risks of taking part?

Taking part in the study will involve talking about your experience of receiving a psychiatric diagnosis, which you may find upsetting. If you become upset during the interview and you feel that you do not want to continue participating in the research, you can withdraw from the study. If you become very upset during the interview and the researcher has concerns about your safety, they will contact your Responsible Clinician at your mental health team. This is to ensure that you are safe and that you receive any support you need.

Will I receive any payment for participating in the study?

Participants will not be paid to participate in this study.

What happens if I have any further concerns?

If you would like to discuss any aspect of this research or have any concerns you would like addressing then please do not hesitate to contact me:

[redacted]

If you have any concern or would like to make a complaint about the research, then you can contact the Academic Supervisor of this project, Dr George Johnson:

[redacted]

You may also contact the Patient Advice and Liaison Service (PALS) of your local NHS Trust if you have any concerns or complaints about the research:

[redacted]

Appendix 7: Participant Consent Form

UNIVERSITY OF BIRMINGHAM

IRAS ID: 252763

Centre Number:

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: What is the experience of women receiving a psychiatric diagnosis during the perinatal period?

Name of Researcher: Caroline Caddy Please initial box

1. I confirm that I have read the information sheet dated 18 October 2019 (Version 1.4) 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 until two weeks after the date of my interview, without my medical care or legal rights being affected.

3. I understand that if the researcher has any concerns for my safety or the safety of others they will contact my Responsible Clinician.

4. I agree to audio recording and the use of anonymised quotes in research reports and publications.

5. I agree to my General Practitioner being informed of my participation in the research study.

6. I would like to be sent a summary of the research once completed.

7. I agree to take part in the above study.

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

Version 1.2 18 October 2019
When completed: 1 for participant; 1 for researcher site file.

Appendix 8: Interview Topic Guide and Example Questions

Interview Topic Guide

Topic	Example Questions
Experience of being told mental health diagnosis	What do you remember about being told your diagnosis? Do you remember who told you your diagnosis? What was it like to realise you had this diagnosis?
Self-recognition of symptoms	Did you expect to hear the diagnosis that you were told? Did you feel that the diagnosis fitted with your experience? Did the diagnosis alter in any way how you perceived your difficulties?
Information provided	Can you tell me what explanation was given to you about the diagnosis? Do you remember any words that were used to explain the diagnosis to you?
Impact on relationships/sharing diagnosis	How did you go about telling others about your diagnosis? What was it like sharing with others your diagnosis? Do you think the diagnosis had any impact on your relationships?
Adjustment to diagnosis	How has the diagnosis impacted your life? Did the diagnosis alter in any way how you felt about the future? Did your feelings change over time about your diagnosis?

Ideal care/support	What support did you receive when you received the diagnosis? What was your experience of the support you received? What support would you have liked to have received when you were given the diagnosis?

Appendix 9: Perinatal Resource Leaflet

UNIVERSITY OF BIRMINGHAM

PERINATAL MENTAL HEALTH RESOUCRES

This leaflet includes information on helpful organisations, websites and literature that are aimed at helping you, or those you are close to, understand perinatal mental health problems.

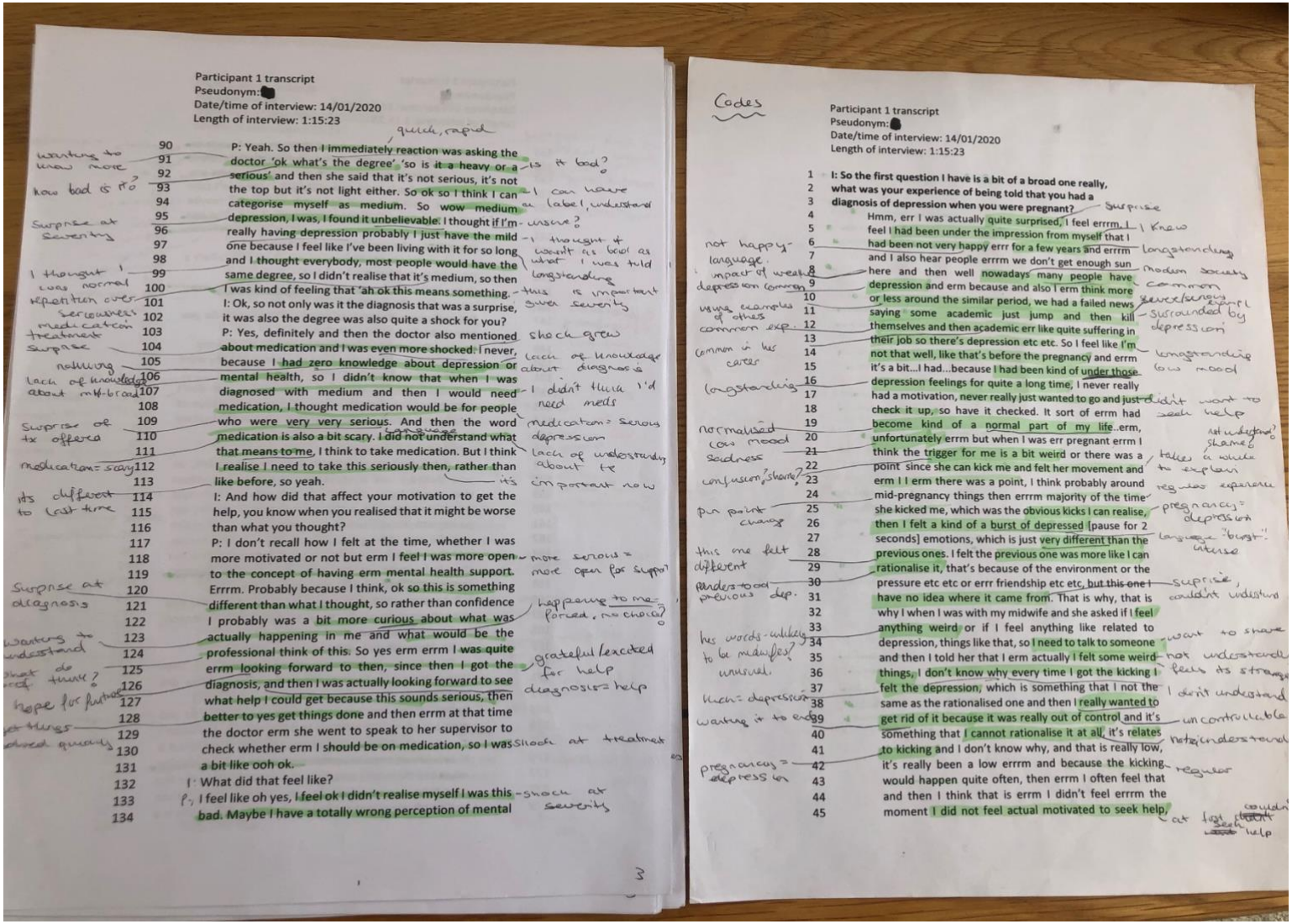
Useful Organisations

- **Action on Post-Partum Psychosis: Provides help and support for mothers experiencing psychosis or bipolar during the perinatal period.**
  https://www.app-network.org
- **Maternal OCD: Provides help and support for mothers experiencing OCD.**
  https://maternalocd.org
- **Association for Post Natal Illness:**
  https://apni.org
  0207 386 08 68
- **Birth Trauma Association: Provides help and support for mothers who have experienced birth trauma.**
  http://birthtraumaassociation.org.uk
- **Maternal Mental Health Alliance:**
  https://maternalmentalhealthalliance.org
- **PANDAS: Provides help and support for parents experiencing a perinatal mental health difficulty.**
  http://www.pandasfoundation.org.uk
- **NCT: Provides practical and emotional support in all areas of pregnancy, birth and early parenthood.**
  http://nct.org.uk
  0300 330 0770
- **Home Start: Provides local support networks for families with young children.**
  http://home-start.org.uk
  0800 068 63 68
- **Family Lives: Provides confidential information and advice for parents.**
  http://familylives.org.uk
  0808 800 2222

Useful Resources

- **Mind:**
  https://www.mind.org.uk/information-support/types-of-mental-health-problems/postnatal-depression-and-perinatal-mental-health/about-maternal-mental-health-problems/
- **The Royal College of Psychiatry:**
  https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/perinatal-mental-health-toolkit.aspx

Appendix 10: Step 2 of Analysis: Initial Noting



Participant 1 transcript
Pseudonym: [redacted]
Date/time of interview: 14/01/2020
Length of interview: 1:15:23

90 P: Yeah. So then I immediately reaction was asking the
91 doctor 'ok what's the degree' 'so is it a heavy or a
92 serious' and then she said that it's not serious, it's not
93 the top but it's not light either. So ok so I think I can
94 categorise myself as medium. So wow medium
95 depression, I was, I found it unbelievable. I thought if I'm
96 really having depression probably I just have the mild
97 one because I feel like I've been living with it for so long
98 and I thought everybody, most people would have the
99 same degree, so I didn't realise that it's medium, so then
100 I was kind of feeling that 'ah ok this means something.
101 I: Ok, so not only was it the diagnosis that was a surprise,
102 it was also the degree was also quite a shock for you?
103 P: Yes, definitely and then the doctor also mentioned
104 about medication and I was even more shocked. I never,
105 because I had zero knowledge about depression or
106 mental health, so I didn't know that when I was
107 diagnosed with medium and then I would need
108 medication, I thought medication would be for people
109 who were very very serious. And then the word
110 medication is also a bit scary. I did not understand what
111 that means to me, I think to take medication. But I think
112 I realise I need to take this seriously then, rather than
113 like before, so yeah.
114 I: And how did that affect your motivation to get the
115 help, you know when you realised that it might be worse
116 than what you thought?
117 P: I don't recall how I felt at the time, whether I was
118 more motivated or not but erm I feel I was more open
119 to the concept of having erm mental health support.
120 Errrm. Probably because I think, ok so this is something
121 different than what I thought, so rather than confidence
122 I probably was a bit more curious about what was
123 actually happening in me and what would be the
124 professional think of this. So yes erm errm I was quite
125 erm looking forward to then, since then I got the
126 diagnosis, and then I was actually looking forward to see
127 what help I could get because this sounds serious, then
128 better to yes get things done and then errm at that time
129 the doctor erm she went to speak to her supervisor to
130 check whether erm I should be on medication, so I was
131 a bit like ooh ok.
132 I: What did that feel like?
133 P: I feel like oh yes, I feel ok I didn't realise myself I was this
134 bad. Maybe I have a totally wrong perception of mental

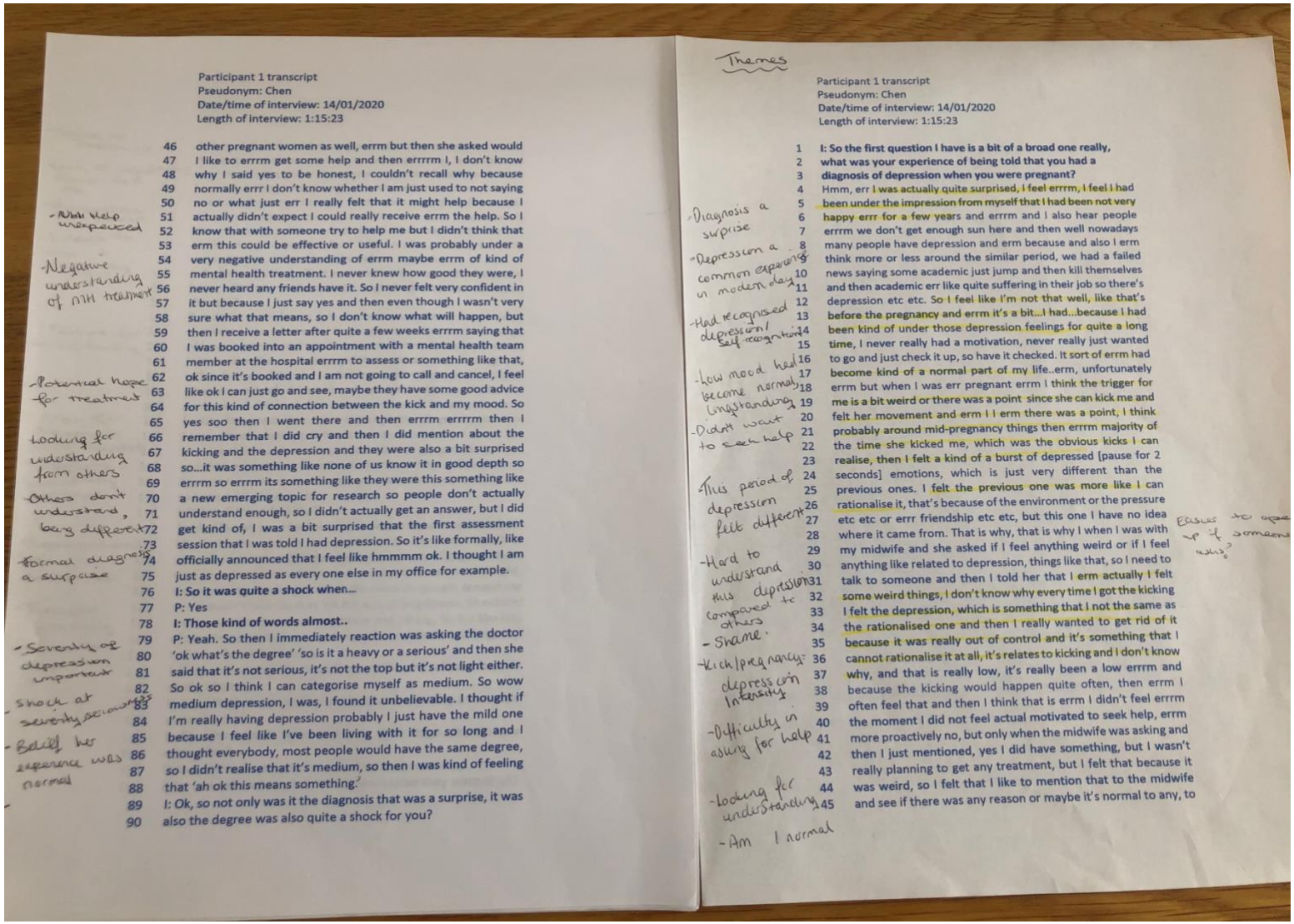
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Codes

Participant 1 transcript
Pseudonym: [redacted]
Date/time of interview: 14/01/2020
Length of interview: 1:15:23

1 I: So the first question I have is a bit of a broad one really,
2 what was your experience of being told that you had a
3 diagnosis of depression when you were pregnant?
4 Hmm, err I was actually quite surprised, I feel errrm, I
5 feel I had been under the impression from myself that I
6 had been not very happy errr for a few years and errrm
7 and I also hear people errrm we don't get enough sun
8 here and then well nowadays many people have
9 depression and erm because and also I erm think more
10 or less around the similar period, we had a failed news
11 saying some academic just jump and then kill
12 themselves and then academic err like quite suffering in
13 their job so there's depression etc etc. So I feel like I'm
14 not that well, like that's before the pregnancy and errm
15 it's a bit...I had...because I had been kind of under those
16 depression feelings for quite a long time, I never really
17 had a motivation, never really just wanted to go and just
18 check it up, so have it checked. It sort of errm had
19 become kind of a normal part of my life..erm,
20 unfortunately errm but when I was err pregnant errm I
21 think the trigger for me is a bit weird or there was a
22 point since she can kick me and felt her movement and
23 erm I I erm there was a point, I think probably around
24 mid-pregnancy things then errrm majority of the time
25 she kicked me, which was the obvious kicks I can realise,
26 then I felt a kind of a burst of depressed [pause for 2
27 seconds] emotions, which is just very different than the
28 previous ones. I felt the previous one was more like I can
29 rationalise it, that's because of the environment or the
30 pressure etc etc or errr friendship etc etc, but this one I
31 have no idea where it came from. That is why, that is
32 why I when I was with my midwife and she asked if I feel
33 anything weird or if I feel anything like related to
34 depression, things like that, so I need to talk to someone
35 and then I told her that I erm actually I felt some weird
36 things, I don't know why every time I got the kicking I
37 felt the depression, which is something that I not the
38 same as the rationalised one and then I really wanted to
39 get rid of it because it was really out of control and it's
40 something that I cannot rationalise it at all, it's relates
41 to kicking and I don't know why, and that is really low,
42 it's really been a low errrm and because the kicking
43 would happen quite often, then errm I often feel that
44 and then I think that is errm I didn't feel errrm the
45 moment I did not feel actual motivated to seek help,

Appendix 11: Step 3 of Analysis: Development of Emergent Themes



Participant 1 transcript
Pseudonym: Chen
Date/time of interview: 14/01/2020
Length of interview: 1:15:23

other pregnant women as well, errm but then she asked would I like to errrm get some help and then errrrm I, I don't know why I said yes to be honest, I couldn't recall why because normally errr I don't know whether I am just used to not saying no or what just err I really felt that it might help because I actually didn't expect I could really receive errm the help. So I know that with someone try to help me but I didn't think that erm this could be effective or useful. I was probably under a very negative understanding of errm maybe errm of kind of mental health treatment. I never knew how good they were, I never heard any friends have it. So I never felt very confident in it but because I just say yes and then even though I wasn't very sure what that means, so I don't know what will happen, but then I receive a letter after quite a few weeks errrm saying that I was booked into an appointment with a mental health team member at the hospital errrm to assess or something like that, ok since it's booked and I am not going to call and cancel, I feel like ok I can just go and see, maybe they have some good advice for this kind of connection between the kick and my mood. So yes soo then I went there and then errrrm errrrm then I remember that I did cry and then I did mention about the kicking and the depression and they were also a bit surprised so...it was something like none of us know it in good depth so errrm so errrm its something like they were this something like a new emerging topic for research so people don't actually understand enough, so I didn't actually get an answer, but I did get kind of, I was a bit surprised that the first assessment session that I was told I had depression. So it's like formally, like officially announced that I feel like hmmmm ok. I thought I am just as depressed as every one else in my office for example.

I: So it was quite a shock when...

P: Yes

I: Those kind of words almost..

P: Yeah. So then I immediately reaction was asking the doctor 'ok what's the degree' 'so is it a heavy or a serious' and then she said that it's not serious, it's not the top but it's not light either. So ok so I think I can categorise myself as medium. So wow medium depression, I was, I found it unbelievable. I thought if I'm really having depression probably I just have the mild one because I feel like I've been living with it for so long and I thought everybody, most people would have the same degree, so I didn't realise that it's medium, so then I was kind of feeling that 'ah ok this means something.'

I: Ok, so not only was it the diagnosis that was a surprise, it was also the degree was also quite a shock for you?

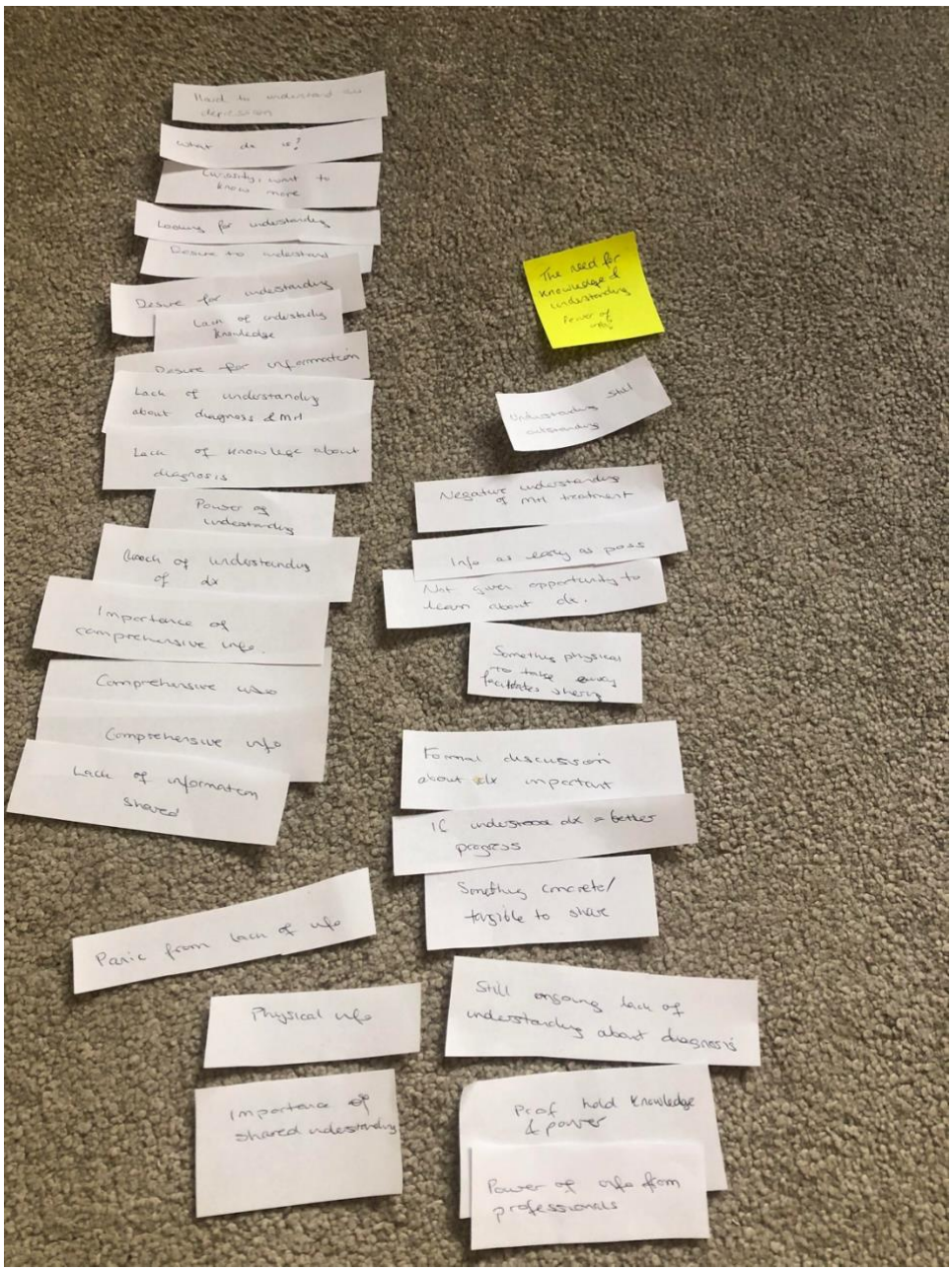
Themes

Participant 1 transcript
Pseudonym: Chen
Date/time of interview: 14/01/2020
Length of interview: 1:15:23

I: So the first question I have is a bit of a broad one really, what was your experience of being told that you had a diagnosis of depression when you were pregnant?

Hmm, err I was actually quite surprised, I feel errrm, I feel I had been under the impression from myself that I had been not very happy errr for a few years and errrm and I also hear people errrm we don't get enough sun here and then well nowadays many people have depression and erm because and also I erm think more or less around the similar period, we had a failed news saying some academic just jump and then kill themselves and then academic err like quite suffering in their job so there's depression etc etc. So I feel like I'm not that well, like that's before the pregnancy and errm it's a bit...I had...because I had been kind of under those depression feelings for quite a long time, I never really had a motivation, never really just wanted to go and just check it up, so have it checked. It sort of errm had become kind of a normal part of my life..erm, unfortunately errm but when I was err pregnant errm I think the trigger for me is a bit weird or there was a point since she can kick me and felt her movement and erm I I erm there was a point, I think probably around mid-pregnancy things then errrm majority of the time she kicked me, which was the obvious kicks I can realise, then I felt a kind of a burst of depressed [pause for 2 seconds] emotions, which is just very different than the previous ones. I felt the previous one was more like I can rationalise it, that's because of the environment or the pressure etc etc or errr friendship etc etc, but this one I have no idea where it came from. That is why, that is why I when I was with my midwife and she asked if I feel anything weird or if I feel anything like related to depression, things like that, so I need to talk to someone and then I told her that I erm actually I felt some weird things, I don't know why every time I got the kicking I felt the depression, which is something that I not the same as the rationalised one and then I really wanted to get rid of it because it was really out of control and it's something that I cannot rationalise it at all, it's relates to kicking and I don't know why, and that is really low, it's really been a low errrm and because the kicking would happen quite often, then errm I often feel that and then I think that is errm I didn't feel errrm the moment I did not feel actual motivated to seek help, errrm more proactively no, but only when the midwife was asking and then I just mentioned, yes I did have something, but I wasn't really planning to get any treatment, but I felt that because it was weird, so I felt that I like to mention that to the midwife and see if there was any reason or maybe it's normal to any, to

Appendix 12: Step 4 of Analysis: Identifying Connections Between Themes



Appendix 13: Example of Overall Thematic Structure for Participant 1

Participant 1 (Chen) Thematic Structure

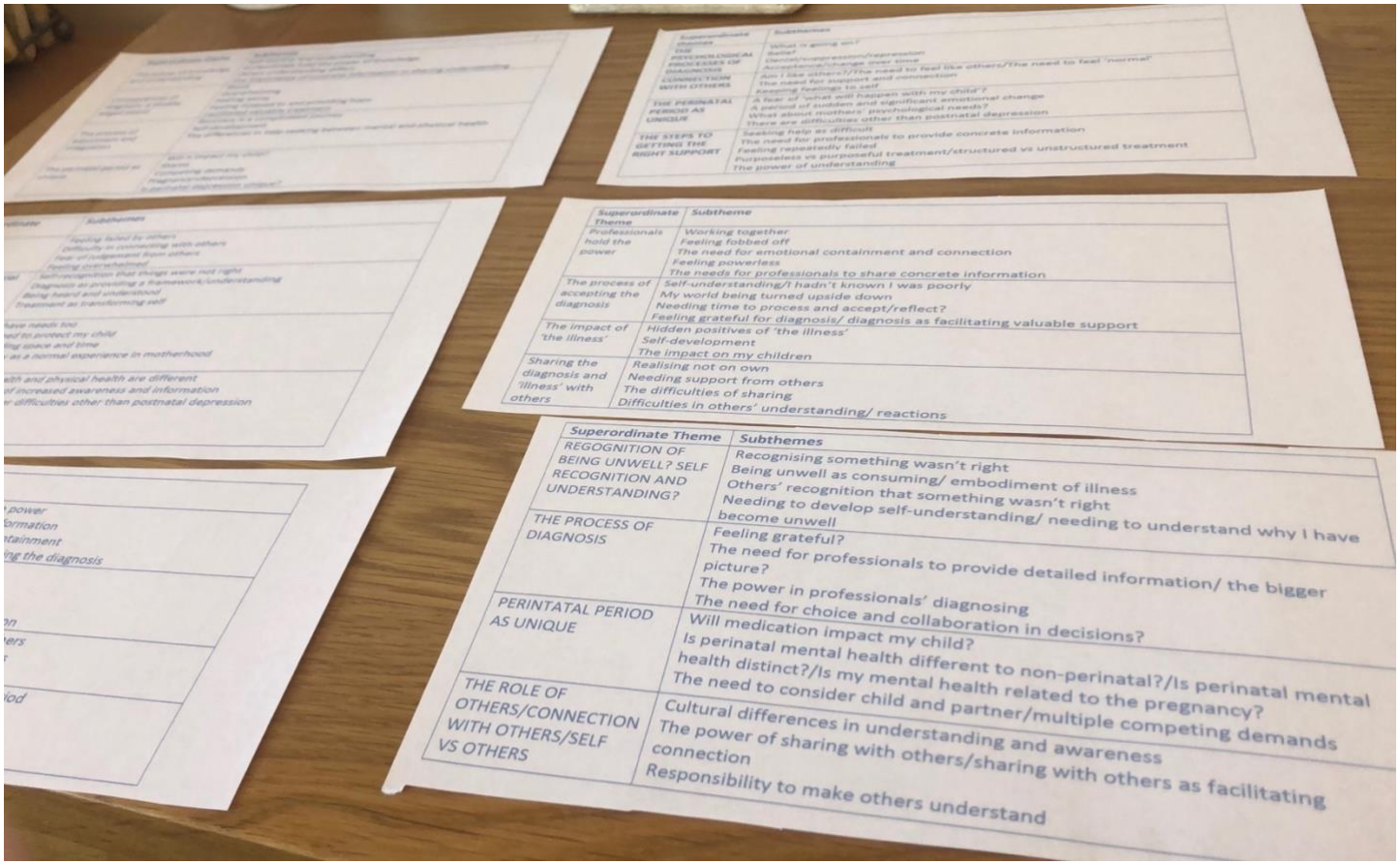
The importance of concrete information in sharing information	"But I feel that I have something tangible to share with...like for example, if I tell my cousin 'ok how good this, how about you go to seek mental health'..."	854-857
	"Things for them to read, a leaflet for just family and friends maybe not for me. Then I can simply let them take a look and then what they...what the professionals suggest family and friends should understand more about the issue"	933-936
	"...and then it's possible to take away something for erm people, friends and families, that would still be very good..even though the treatment is finished" [information on diagnosis to take away]	951-953
	"I think was too shocked to think what I needed. But definitely I was like quite bad? because it was out of my *baby crying* expectation. But now looking back I would really appreciate if they can give me something that I can simply take away and I can actually talk to my family and explain to them errm what PND means and what it covers so..."	894-899
SUPER-ORDINATE THEME: CONSEQUENCES OF DIAGNOSIS- A DOUBLE EDGED SWORD		
Shock	"...I was actually quite surprised.."	4
	"...I was a bit surprised that the first assessment session that I was told I had depression"	72-73
	"...so wow medium depression, I was like, I found it unbelievable"	82-83
	"...and then the doctor also mentioned about medication and I was even more shocked"	91-92
	"I think I realise I need to take this seriously then, rather than like before..."	98-99
	"...I feel ok I didn't realise myself I was this bad"	117
	"So I was definitely not feeling that is exactly makes sense to me, erm particularly the degree of it, I think 'woah really'..."	213-215
	"...and because I was already shocked to be told a medium level err depression, it was definitely a bit unbelievable about medication..."	231-233
	"...and then I realise that OCD is part of that. So it's like surprises, surprises, surprises..."	354-355
	"I would really love to share with as many friends as possible about what I experienced, because it's definitely a big shock, it's just really turned my world upside down"	570-572
Overwhelming	"Errrm. I think at that time, I was too overwhelmed by just these things, together with life, with the actual depression itself, so I didn't really have the space to actually think of these questions"	306-307
	"So it's like lots of new things and its very errrrm yeah, lots of new thinking.."	123-124
Feeling alone	"just a bit errrrm desperate because I was left, no one was there during that window"	309-310

5

Participant 1 (Chen) Thematic Structure

Superordinate theme	Subthemes
The power of knowledge and understanding	Self-identity and understanding Professionals hold the power of knowledge Others understanding differs The importance of concrete information in sharing understanding
Consequences of diagnosis: a double-edged sword	Shock Overwhelming Feeling alone Feeling listened to and providing hope Facilitated valuable treatment
The process of adjustment and integration	Recovery is a complicated journey Self-development The differences in help seeking between mental and physical health
The perinatal period as unique	Will it impact my child? Shame Competing demands Pregnancy=depression Is perinatal depression unique?

Appendix 14: Step 5 of Analysis: The Process of Identifying Connections and Patterns Across Transcripts



Superordinate Theme	Subtheme
Professionals hold the power	Working together Feeling fobbed off The need for emotional containment and connection Feeling powerless The needs for professionals to share concrete information
The process of accepting the diagnosis	Self-understanding/'I hadn't known I was poorly My world being turned upside down Needing time to process and accept/reflect? Feeling grateful for diagnosis/ diagnosis as facilitating valuable support
The impact of 'the illness'	Hidden positives of 'the illness' Self-development The impact on my children
Sharing the diagnosis and 'illness' with others	Realising not on own Needing support from others The difficulties of sharing Difficulties in others' understanding/ reactions

Superordinate Theme	Subthemes
RECOGNITION OF BEING UNWELL? SELF RECOGNITION AND UNDERSTANDING?	Recognising something wasn't right Being unwell as consuming/ embodiment of illness Others' recognition that something wasn't right Needing to develop self-understanding/ needing to understand why I have become unwell
THE PROCESS OF DIAGNOSIS	Feeling grateful? The need for professionals to provide detailed information/ the bigger picture? The power in professionals' diagnosing The need for choice and collaboration in decisions?
PERINTATAL PERIOD AS UNIQUE	Will medication impact my child? Is perinatal mental health different to non-perinatal?/Is perinatal mental health distinct?/Is my mental health related to the pregnancy? The need to consider child and partner/multiple competing demands
THE ROLE OF OTHERS/CONNECTION WITH OTHERS/SELF VS OTHERS	Cultural differences in understanding and awareness The power of sharing with others/sharing with others as facilitating connection Responsibility to make others understand

Appendix 15: An Extract from the Overall Thematic Structure of Participants

Superordinate themes	Subthemes	Quotes
The perinatal period as unique	Worry about impact on my child/needing to protect my child	***Chen*** "...not knowing what is going to happen and not knowing how that will errrm influence her {baby's name} ..." [regarding medication] ***Sarah*** "I was like 'right, only I can look after this baby' *laughs* 'nobody understands, nobody cares'" ***Liz*** "I felt that that made me unable to care for my son when I took it" [medication] ***Rachel*** "I had sort of got in my head that if I even sort of said that I was struggling, would they take him away from me, and that was very very strong in my mind. I know it's like an irrational fear, but that doesn't stop it being strong and affecting how you feel" ***Zara*** "I wanted to have as little, as few and natural chemical influences on the processes that should be happening as the baby was developing. So that's why I didn't want to take the medication" ***Priyanka*** "P: I was worried about the err side effects of the medicine. I: In terms of for yourself or P: No in terms of for the kid.... I was like a little hesitant to take the medicine."
	The perinatal period as complex	***Chen*** "...and then I had no energy to sort this issue because errm I don't feel I had the erm the the the sufficient energy, the positive way to deal with things, so I'm trying to deal with what I'm facing now, with my situation, my medication and then looking after her {baby}" "...I think one thing that to me is very special about postnatal depression, is that this is actually impacting on baby. At least that's how I perceive it. Unlike the other people with depression" "Erm well there are many questions still left in my mind, so what would be the difference between the postnatal depression and the normal depression..." ***Liz*** "Yeah because you feel like you lose any ability to do anything other than be a mum I suppose *laughs*" ***Sarah*** "Obviously some anxieties as a new mum are normal, you've got this baby to protect for the first time ever" "...you hear you know, people have postnatal depression or whatever, which is the only one you really hear about..." "because the only thing you hear about is postnatal depression, you don't hear about anxiety, you don't hear about OCD, there is not enough around on it"