

Review article

How women with obsessive compulsive disorder experience maternity care and mental health care during pregnancy and postpartum: A systematic literature review

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ABSTRACT

Introduction: Obsessive Compulsive Disorder has a higher prevalence in pregnancy and postpartum than in the general population. Experiences of maternity care and mental health care can impact the health and wellbeing of perinatal women. The aim of this review was to synthesize evidence on the experiences of maternity care and mental health care for women with OCD during pregnancy and postpartum.

Methods: Studies were systematically reviewed by two independent reviewers after identification in MEDLINE, Embase, PsycINFO, Global Health, CINAHL, the Cochrane Library, Web of Science and grey literature searches (last searched October 2021). Papers meeting pre-specified inclusion criteria were extracted using a pre-determined extraction sheet and were quality assessed. Thematic synthesis was conducted.

Results: 19 papers reporting 18 studies describing 33 participants were included. Three descriptive themes were found: experiences of barriers to treatment and care, experiences of treatment/care decision making and experiences of treatment and care. Three analytic themes were found demonstrating tensions: keeping baby healthy vs keeping mother healthy, keeping baby safe vs keeping mother safe, and normal perinatal experience vs not normal perinatal experience.

Limitations: Despite an inclusive search strategy, available data was limited. 17 of the studies were case studies that were poor in quality. Synthesis and subsequent findings were limited.

Conclusions: There were significant literature gaps for all aspects of care but particularly around experiences of maternity and pharmacological care. Tensions that could impact the experience of care need to be carefully balanced to ensure that women with OCD get the care that they need.

1. Introduction

Experiences of maternity services and mental health services can have positive or negative effects on the emotional wellbeing and health for pregnant and postpartum women (Henderson et al., 2018; Makregiorgos et al., 2013; Redshaw et al., 2019). Women with mental health disorders may face additional barriers when accessing maternity care services (Makregiorgos et al., 2013). Several issues have been previously identified for some women accessing perinatal mental health services, including lack of knowledge from care providers and poor approachability (Viveiros and Darling, 2019). There is also fragmentation between maternity services and mental health services (Sambrook Smith

et al., 2019) that can cause problems for women requiring mental health services during the perinatal period, including baby centred care (Viveiros and Darling, 2018), poor knowledge of perinatal mental health disorders among maternity care givers and lack of continuity of care (Sambrook Smith et al., 2019). Postnatal depression has, historically, been the main focus of scientific enquiry (Higgins et al., 2018) despite evidence suggesting that women are also at increased risk of developing anxiety disorders (including obsessive compulsive disorder) during pregnancy and postpartum (Fawcett et al., 2019; Uguz et al., 2019). Obsessive compulsive disorder (OCD) is a mental health disorder that has a prevalence of approximately 1.08 % in the UK population (Russell et al., 2013). The prevalence of OCD is higher in the pregnant and

Abbreviations: OCD, Obsessive compulsive disorder; ppOCD, Perinatal obsessive compulsive disorder.

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postpartum populations, 2.1 % and 2.4 % respectively (Russell et al., 2013) and more recent studies suggest that prevalence could be as high as 7.8 % and 16.9 % during pregnancy and postpartum respectively (Fairbrother et al., 2021).

Perinatal OCD (ppOCD) refers to OCD that occurs during pregnancy or postpartum; this can include the new development OCD or the exacerbation of existing OCD (Challacombe and Wroe, 2013). Despite evidence of increased prevalence and vulnerability, ppOCD is under researched (Higgins et al., 2018) and is frequently poorly understood and under recognised in maternity settings (Higgins, 2017). Various studies have demonstrated that the perinatal period is associated with an increased risk of developing OCD or the exacerbation of existing OCD. (Abramowitz et al., 2003; Forray et al., 2010; Guglielmi et al., 2014). Left untreated, ppOCD can cause significant distress and reduce the mother's quality of life (Gezginç et al., 2008). There is also evidence of increased risk of poor long term emotional and social functioning for the babies of affected women (Weinberg and Tronick, 1998) and stress associated with mental health disorders during pregnancy has been shown to impair infant development (Wenzel, 2014). Little is known about the maternity care and mental health care experiences of women with OCD during pregnancy and postpartum.

A systematic literature review is needed to understand what is currently known, to highlight research gaps and to provide a foundation for future research into this area. Therefore, the aim of this review was to explore how women with OCD experience mental health care and maternity care during pregnancy and postpartum.

2. Methods

A systematic literature review was conducted following the guidelines of the Preferred Reporting Items for systematic review and Meta-Analyses (PRISMA) (Page et al., 2021). The study was registered with the International Prospective Register of Systematic Reviews (PROSPERO) prior to beginning the review (registration number: CRD42020219016).

2.1. Searches

A search strategy was developed in collaboration with Nia Roberts and Eli Harriss, expert librarians at the Bodleian Health Care Libraries (supplementary materials Fig. 1). The search was conducted in November 2020 (and updated in October 2021) using the following databases: MEDLINE, Embase, PsycINFO, Global Health, CINAHL, the Cochrane Library and Web of Science. OpenGrey, PsycEXTRA and Google Scholar were searched to identify articles in journals not indexed on the databases listed to identify grey literature. For the Google Scholar searches, the results of the first twenty pages were screened, which represented 200 papers, based on the assumption that there are unlikely to be additional relevant results after twenty pages (Haddaway et al., 2015). Finally, a manual search of the reference lists of all primary studies included in the review and forward citation searching was carried out to identify any further eligible studies. Key authors were also contacted for grey literature.

2.2. Studies to be included

Inclusion criteria:

- Any quantitative or qualitative study that included information about mental health or maternity care/treatment experience for women with OCD during pregnancy and postpartum
- Any study design (except for animal studies)
- Any language
- Any date
- Any country
- Any mental health care or maternity care setting

2.3. Data extraction (selection and coding)

The titles and abstracts of the identified publications were uploaded into Covidence (Veritas Health Innovation) to manage the evidence

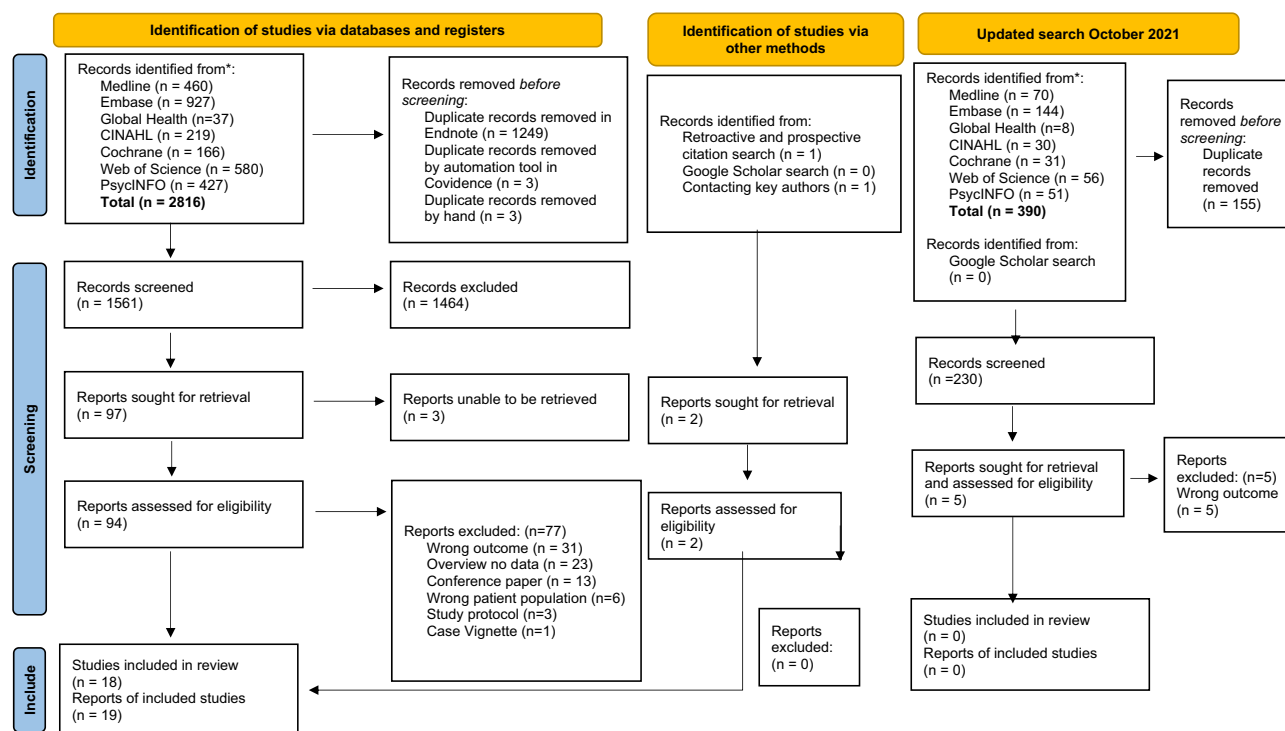


Fig. 1. PRISMA flow chart demonstrating the process of identification of studies to the final included studies

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: <https://doi.org/10.1136/bmj.n71>. For more information, visit: <http://www.prisma-statement.org/>

synthesis. All identified articles were screened and then independently screened again by a second reviewer (LP) using the predefined inclusion criteria. A study specific data extraction form was set up in excel to extract the data (Supplementary materials Table 1). Data extraction was conducted independently by HB and LP. Qualitative patient experience was extracted using NVIVO (QSR International Pty Ltd., 2020). Any discrepancies between the reviewers were discussed, and where agreement could not be reached, discussions with the wider research team took place.

2.4. Quality assessment

Two independent quality assessments of the included papers were conducted (second reviewer: LP). Papers were assessed using the CASP qualitative tool (Critical Appraisal Skills Programme, 2018) and a modified version of Murad et al. (2018) tool for evaluating the methodological quality of case reports and series. This tool was adapted (Supplementary materials Table 2) to include further information provided by Murad et al., (Murad et al., 2018) and guidelines written by the Case Reporting Guidelines (CARE) (Riley et al., 2017). The adapted tool was used to assess case studies, case series and personal narratives. The study by Challacombe (2014) was also assessed using the adapted Murad et al. (2018) tool, as this study describes a qualitative case series collected ahead of a clinical trial. Any discrepancies in the assessment between reviewers were discussed, and if no consensus could be made, the papers were discussed with the wider research group.

2.5. Strategy for analysis and synthesis

The studies were summarised in tables outlining the main features of the design and characteristics of the included studies following the extraction sheet in supplementary materials Table 1. This included the date of publication, country, study design and methods, number of participants, main outcome measures, and main findings. Extracted data concerning experience was analysed within NVIVO; this included direct quotes, summary statements on experience and commentary from authors of case reports. A thematic synthesis was conducted using the methods proposed by Thomas and Harden (2008). This approach is recommended by the Cochrane Qualitative Review Methods Group and can be used with ‘thin’ data (Noyes and Lewin, 2011). First, the included studies were read and re-read, then the studies were coded for any descriptions of the experience of care including treatment, using descriptive codes that came from the data rather than pre-determined themes. Similarities, differences, and patterns were looked for between the descriptive codes in each paper, which led to the development of descriptive themes. Higher order themes were created to synthesize these descriptive themes across all of the papers, which Thomas and Harden (2008) refer to as “analytic themes”. These analytic themes allowed the synthesis of these findings to go “beyond” the descriptive themes, allowing interpretations of these descriptive themes and the development of a narrative to describe all of the papers collectively. Thomas and Harden (2008) coded their papers line by line, however as there was unrelated information in the included studies, this did not occur in this current review; only relevant information was coded. The majority of the included papers were case studies, so there were no pre-existing themes in these studies. However, there were pre-existing themes in a single qualitative study, which were not collected or extracted in the current review. All papers were analysed, and then a second reviewer (FA) conducted an independent analysis of the extracted data. Any discrepancies in the analysis between the two independent reviewers that could not be resolved were discussed with the wider research group. Planned subgroup analyses by timing of onset and timing of diagnosis were planned but not feasible due to insufficient data.

3. Results

The results are presented in the PRISMA flow chat (Fig. 1) (Page et al., 2021). The systematic search of the databases identified 2816 records. After deletion of duplicates, 1561 papers were screened using their title and abstract. This process excluded 1464 papers and therefore 97 papers were sought for retrieval. Texts could not be retrieved for three papers. Therefore 94 papers were assessed for their eligibility. Seventy-seven papers did not meet the inclusion criteria leaving a total of 17 papers that came from the database searches. One paper was identified through prospective and retrospective searching and one through contacting key authors. In total there were 19 papers included, which described 18 studies.

The table of study characteristics can be seen in Table 1. The review included three personal narratives, thirteen case studies/series, one case series collected ahead of a clinical trial and one qualitative interview study. In total, these eighteen studies reported on the experiences of 33 women. The majority of participants were white, highly educated and, where reported, all had singleton births. The three personal narratives contained three participants' experiences, two of which were presented under the original author's name (Benfield, 2018; Beraz, 1996), and the third was presented under the authorship of a doctoral student in clinical psychology (Darling, 2014). Thirteen case studies/series were included (Ahuja, 1979; Blakey and Abramowitz, 2017; Burt and Rudolph, 2000; Buttolph and Holland, 1990; Chelmon and Halfin, 1997; Christian and Storch, 2009; Fang et al., 2018; Flosnik and Khin, 2012; Gershkovich, 2019; Hertzberg et al., 1997; Hudak and Wisner, 2012; Kalra et al., 2005; Puryear and Treece, 2020), which were reported in 14 papers (Blakey and Abramowitz (2017) and Abramowitz and Fairbrother (2008) report the same participant case study). These 13 studies described the experiences of 14 participants, as two participants included within the paper by Buttolph and Holland (1990) had relevant experience information. One case series of pre-trial information was collected ahead of a clinical trial consisting of 34 women. However, only 14 women had relevant experience information (Challacombe, 2014). One qualitative study was included that consisted of five participants' experiences (Burton, 2020).

4. Quality assessment of included studies

A quality assessment was carried out on all included studies (Tables 2 & 3). Seventeen of the studies were analysed using Murad et al. (2018)'s tool for analysing case studies or series (Table 2), and the remaining single qualitative study was analysed (Table 3) using the Critical Skills Appraisal Programme's checklist for qualitative studies (Critical Appraisal Skills Programme, 2018). Overall, the quality of the studies was relatively low. The three personal narratives (Benfield, 2018; Beraz, 1996; Darling, 2014) contained rich information from the participant's perspective. However, participant and birth characteristics and assessment of OCD were missing from all three studies.

Challacombe (2014) was a unique case series as it was taken from unanalysed pre-trial treatment data ahead of a clinical trial completed as part of a PhD Thesis. There was limited data summarised from the researcher's perspective; however, OCD diagnoses were ascertained clearly. This study only enrolled women who had not had previously successful OCD treatment which reduces generalisability of the sample.

The remaining thirteen case studies or series were mixed in quality. Only one study contained direct quotes from their participant (Gershkovich, 2019), and six studies contained minimal patient perspective (Ahuja, 1979; Buttolph and Holland, 1990; Fang et al., 2018; Flosnik and Khin, 2012; Hertzberg et al., 1997; Kalra et al., 2005). Eight studies did not clearly assess OCD (Ahuja, 1979; Blakey and Abramowitz, 2017; Burt and Rudolph, 2000; Fang et al., 2018; Flosnik and Khin, 2012; Hertzberg et al., 1997; Hudak and Wisner, 2012; Puryear and Treece, 2020). Only one case study explained how they selected their participant (Buttolph and Holland, 1990) and in the majority of studies it was

Table 1

Table of characteristics of included studies.

Author (date)	Country	Number of participants	Timing of Diagnosis Onset of OCD Time of collection or writing (TOC)	Time period of experience covered	Treatment	Maternal demographics and birth characteristics
Personal Narratives Benfield (2018)	UK	1	Diagnosis: 2 years postpartum Onset: OCD since childhood. Written: 5 years postpartum	Postpartum	CBT and antidepressants on and off for 3 years.	Age: NR Relationship status: NR Education: NR Ethnicity: NR Parity: NR Pregnancy characteristics: NR Birth: NR Baby characteristics: NR Mental Health other than OCD: NR
Beraz (1996)	US	1	Diagnosis: Diagnosed during the postpartum of her first pregnancy Onset: During her 20s Written: whilst second infant was a baby	Pre-conception, pregnancy and postpartum	Preconception: Antidepressants (SSRI) Pregnancy: No medication or therapy Postpartum: Waiting to finish breastfeeding before returning to SSRI	Age: NR Relationship status: married Education: NR Ethnicity: NR Parity: Second child Pregnancy characteristics: NR Birth characteristics: NR Baby characteristics: NR Mental Health other than OCD: NR
Darling (2014)	US	1	Diagnosis: unclear Onset: postpartum Written: 3 years postpartum	Pre-conception, pregnancy and postpartum	Preconception: Antidepressants, and therapy for depression Pregnancy: Meds were tapered off during her final trimester of pregnancy due to clinicians worries about baby. Postpartum: Antidepressant (SSRI)	Age: 33 Relationship status: married Education: Higher education Ethnicity: NR Parity: first child Pregnancy characteristics: uncomplicated Birth characteristics: emergency c section. No further detail except healthy daughter. Mental health other than OCD: depression since early teenage years
Case studies/series Ahuja (1979)	UK	1	Diagnosis: 7 months postpartum Onset: 6 weeks prior to baby's birth TOC: 6 weeks after diagnosis.	Postpartum	Prior to postpartum referral: unsuccessful group therapy sessions and antidepressants (tricyclic) discontinued during treatment. Therapy (flooding)	Age: 26 Relationship status: Married Education: Higher education Ethnicity: NR Parity: NR Pregnancy characteristics: NR Birth characteristics: NR Baby characteristics: NR Mental Health other than OCD: History of Anorexia at 19, treated in an inpatient psychiatric unit.
Blakey and Abramowitz (2017) (This case is also reported in Abramowitz and Fairbrother, 2008)	US	1	Diagnosis: 2 months postpartum Onset of OCD: Unclear TOC: ongoing from 2 months postpartum	Postpartum	Postpartum: CBT	Age: 28 Relationship status: Married Education: NR Ethnicity: NR Parity: NR Pregnancy characteristics: Uncomplicated Birth characteristics: Uncomplicated Baby characteristics: NR Mental Health other than OCD: No previous psychiatric history, secondary depression postpartum.
Abramowitz and Fairbrother (2008)	US	1	Diagnosis: 2 months postpartum Onset of OCD: Unclear TOC: Ongoing from 2 months postpartum	Postpartum	Postpartum: CBT	Age: 27 Relationship status: Married Education: NR Ethnicity: NR Parity: NR Pregnancy characteristics: Uncomplicated Birth characteristics:

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Table 1 (continued)

Author (date)	Country	Number of participants	Timing of Diagnosis Onset of OCD Time of collection or writing (TOC)	Time period of experience covered	Treatment	Maternal demographics and birth characteristics
Burt and Rudolph (2000)	US	1	Diagnosis: 4 years prior to first pregnancy. Onset: Childhood TOC: Ongoing from 2 years prior to first pregnancy	Preconception, pregnancy and postpartum	Preconception antidepressants (SSRI) and therapy (CBT and ERP) Pregnancy: same antidepressant (SSRI) and benzodiazepines Postpartum: same antidepressant (SSRI)	Uncomplicated Baby characteristics: NR Mental Health other than OCD: No previous psychiatric history, secondary depression postpartum. Age: 26 Relationship status: Married Education: Higher education Ethnicity: Orthodox Jewish Parity: She gave birth to three singleton babies during the reporting time, and she miscarried twins after her first pregnancy Pregnancy characteristics: Complicated by Hyperemesis during each pregnancy (except for the miscarriage) Birth characteristics: All uncomplicated Baby characteristics: Gestations, 39.5, full term, full term. Weight, 3203 g, 3487 g, 3373 g Mental health other than OCD: Secondary depression during each pregnancy believed to be due to hyperemesis and anxiety.
Buttolph and Holland (1990)	US	2 relevant cases out of 27 participants	Case 1: Diagnosis: during pregnancy Onset: Unclear TOC: during pregnancy Case 2: Diagnosis: 13 years postpartum Onset: Immediately after birth of first child TOC: 13 years postpartum	Case 1: Pre- pregnancy pregnancy Case 2: postpartum	Case 1: Pregnancy: Behaviour therapy Case 2: 13 years postpartum: antidepressant (SSRI) and benzodiazepines and behaviour therapy	Case 1: Age: 25 Relationship status: NR Education: NR Ethnicity: NR Parity: NR Pregnancy characteristics: NR Birth characteristics: NR Baby characteristics: NR Mental health other than OCD: scored 24 on Beck Depression scale indicating moderate depression Case 2: Age: 42 Relationship status: divorced Education: NR Ethnicity: NR Parity: first child Pregnancy characteristics: NR Birth characteristics: NR Baby characteristics: NR Mental health other than OCD: scored 26 on the Beck Depression scale indicating moderate depression
Chelmon and Halpin (1997)	US	1	Diagnosis: During first pregnancy Onset: During first pregnancy TOC: from 8 weeks gestation of third pregnancy	Pre pregnancy, pregnancy and postpartum.	Preconception: antidepressant (tricyclic) then enrolled onto a drug trial for SSRI for 2 days, discontinued due to pregnancy Pregnancy: no medication or formal therapy, but used “thought stopping” Postpartum: initially no medication, but due to worsening symptoms started back on antidepressant (tricyclic) breastfeeding Postpartum: Hospitalised involuntarily for one night and	Age: 28 years old Relationship status: Divorced Education: Higher education Ethnicity: White Parity: Third child Pregnancy characteristics: NR Birth characteristics: healthy baby Gestation, 47 1/7 weeks Weight, 3350 g Mental health other than OCD: Developed a secondary depression postpartum
Christian and Storch (2009)	US	1	Diagnosis: 5 months postpartum	Postpartum		Age: 29 years old Relationship status: Married

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Table 1 (continued)

Author (date)	Country	Number of participants	Timing of Diagnosis Onset of OCD Time of collection or writing (TOC)	Time period of experience covered	Treatment	Maternal demographics and birth characteristics
			Onset: OCD symptoms since childhood TOC: from 5 months postpartum		prescribed antidepressant (SSRI), and CBT Discontinued antidepressant after therapy, in consultation with psychiatrist. Relapse 3 months later: CBT and SSRI.	Education: Higher education Ethnicity: White Parity: NR Pregnancy characteristics: NR Birth characteristics: NR Mental health other than OCD: She did not meet criteria for any other mental health disorder though she did endorse moderate depressive symptoms secondary to the OCD.
Fang et al. (2018)	US	1	Diagnosis: Prior to pregnancy, unclear when Onset: childhood TOC: 6 weeks postpartum	Pregnancy and postpartum	Preconception: antidepressant (SSRI) Pregnancy: no medication or therapy Postpartum: Reinitiated on same antidepressant (SSRI) and an antipsychotic while an inpatient which she continued to take after release with CBT	Age: 31 Relationship status: Married Education: Higher education Ethnicity: Chinese Parity: First child Pregnancy characteristics: NR Birth characteristics: Uncomplicated Mental health other than OCD: History of recurrent major depressive episodes and childhood trauma, history of emotional and physical abuse from her parents
Flosnik and Khin (2012)	US	1	Diagnosis: 27th week of pregnancy Onset: A few years prior TOC: from 27 weeks	Pregnancy and postpartum	During pregnancy and postpartum: CBT and antidepressant (SSRI). Therapy was suspended for one month after delivery	Age: 31 Relationship status: Married Education: NR Ethnicity: White Parity: NR Pregnancy characteristics: NR Birth characteristics: NR Mental health other than OCD: No history of psychiatric disorder diagnosis
Gershkovich (2019)	US	1	Diagnosis: 4 months postpartum Onset: close after birth TOC: from 4 months postpartum	Postpartum	Postpartum: when misdiagnosed with psychotic postpartum depression she had unsuccessful psychodynamic therapy with non-behavioural approaches. then CBT	Age: 29 Relationship status: Married Education: Higher education Ethnicity: Hispanic Parity: First child Pregnancy characteristics: Uncomplicated Birth characteristics: Uncomplicated Mental health other than OCD: No history of psychiatric disorder diagnosis
Hertzberg et al. (1997)	US	1	Diagnosis: Unclear Onset: 4 months before her first baby was born 3 years prior. TOC: 2 weeks postpartum of her second baby	Pregnancy, postpartum	First pregnancy: benzodiazepine Postpartum of her first pregnancy: psychiatric hospitalisation, SSRI and benzodiazepine, and relaxation training. Tapered off the SSRI at 9 months postpartum. Second postpartum: Initially, benzodiazepine. Presented at psychiatric emergency room, and was prescribed antidepressant (SSRI) and plan to follow up in a week, however she presented at the ER again in 2 days and hospitalised Discontinued SSRI and resumed tricyclic and benzodiazepine discharged after a week. Benzodiazepine discontinued.	Age: 28 Relationship status: Married Ethnicity: NR Education: Higher education Parity: Second child Pregnancy characteristics: First pregnancy was complicated by OCD, the second was not, only postpartum Birth characteristics: Uncomplicated births Mental health other than OCD: No psychiatric history before pregnancy. Diagnosed with generalised anxiety disorder during the 5th month of her first pregnancy.
Hudak and Wisner (2012)	US	1	Diagnosis: 11 weeks postpartum Onset: a few days postpartum	Postpartum and pregnancy and pre- pregnancy,	First Postpartum: Initially treated with antidepressant (SSRI) Referred to specialised OCD intensive ERP outpatient	Age: 32 Relationship status: Married Education: NR Ethnicity: White

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Table 1 (continued)

Author (date)	Country	Number of participants	Timing of Diagnosis Onset of OCD Time of collection or writing (TOC)	Time period of experience covered	Treatment	Maternal demographics and birth characteristics
			TOC: from 11 weeks postpartum	postpartum of second pregnancy.	for targeted treatment. Second pregnancy: antidepressant (SSRI) Postpartum: brief course of benzodiazepine	Parity: First and second child Pregnancy characteristics: Uncomplicated Birth characteristics: First baby, uncomplicated Second baby, gave birth via c-section Mental health other than OCD: Previous history of only panic disorder for which she responded well to paroxetine and had not taken any medication in the 2 years prior to pregnancy. She did not meet the criteria for depression.
Kalra et al. (2005)	Australia	1	Diagnosis: 4 months gestation Onset: 3 months gestation TOC: from 4 months gestation to one year postpartum.	Pregnancy and postpartum	Pregnancy: Pharmacotherapy declined. "Thought stopping" therapy. One month after initial presentation antidepressant (SSRI). Stopped antidepressant during 8th month due to advice from family member.	Age: 30 Relationship status: NR Education: NR Ethnicity: NR Parity: First child Pregnancy characteristics: NR Birth characteristics: NR Mental health other than OCD: no history of psychiatric illness
Puryear and Treece (2020)	US	1	Diagnosis: 2 months postpartum of her second child Onset: Unclear, but OCD symptoms during postpartum of her first child 3 years previously. TOC: From 2 months postpartum to one year postpartum.	Postpartum of her second child	Postpartum: Antidepressant (SSRI) and benzodiazepine and sessions with cognitive behaviourally orientated clinical psychologist involving psychoeducation and ERP	Age: 32 Relationship status: Married Education: Higher education Ethnicity: NR Parity: Second child Pregnancy characteristics: NR Birth characteristics: NR Mental health other than OCD: History of untreated depressive episode and a level of baseline anxiety that she felt she had good control of it. Described checking and rechecking her eldest child for up to three hours a night. Denied OCD symptoms in childhood or at any time before her first pregnancy, but described herself as a generally anxious person who liked things in a certain way and tended to see herself as a perfectionist. She was diagnosed with major depressive disorder that is recurrent and of mild to moderate severity, with a peripartum onset specifier and anxiety disorder not otherwise specified.
Qualitative Study Burton (2020)	UK	5	Diagnosis: 2 prior to pregnancy, 3 during postpartum Onset: 3 childhood, 1 adolescence and 1 late 20s TOC: 10 months to 3 years postpartum	Pre-pregnancy, pregnancy and postpartum	All participants were currently receiving therapy/medication or previously had received therapy/medication	Mean age (range) years: 33.6 (26–40) Ethnicity: All white British Relationship status: Married, 3 Cohabiting, 1 Single, 1 Education: All higher education Parity: First child, 2 Second child, 1

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Table 1 (continued)

Author (date)	Country	Number of participants	Timing of Diagnosis Onset of OCD Time of collection or writing (TOC)	Time period of experience covered	Treatment	Maternal demographics and birth characteristics
Case series from a clinical trial Challacombe (2014)	UK	In total 34, however only 14 had experience information. These 34 were randomised into two groups. 17 were given CBT and 17 were given TAU	Diagnosis: NR Onset: CBT: 26.82 (9.96) years TAU: 24.18 (6.20) years Timing of collection: 6 months postpartum	Unclear, but primarily postpartum.	The 14 participants that had experience information available varied in treatment options: Tricyclic: 2 SSRI: 5 Antipsychotic: 1 Benzodiazepine: 1 Declined medication: 5 CBT: 3 Group therapy: 1 OCD support group: 1 Mindfulness group: 1	Third child, 2 Pregnancy characteristics: NR Birth characteristics: 1 postpartum haemorrhage, 4 relatively positive experience of labour and delivery Baby characteristics: NR Mental Health other than OCD: NR Not possible to separate the participants with experience information from the 34. Mean age years: 32 Ethnicity: 29 white Relationship status: 0 single parents Education: 23 higher education Parity: 21 first time parent Pregnancy characteristics: NR Birth characteristics: NR Mental Health other than OCD: History or current diagnoses of depression, panic disorder, social phobia, agoraphobia, simple phobia and generalised anxiety disorder

CBT = Cognitive behavioural therapy; ERP = Exposure Response Prevention; NR = Not recorded; SSRI = Selective Serotonin Reuptake Inhibitor; TAU = Treatment as usual.

not possible to know if these participants were seen as typical cases or if they were unusual in presentation. Three studies did not contain sufficient participant characteristic information ([Ahuja, 1979](#); [Blakey and Abramowitz, 2017](#); [Buttolph and Holland, 1990](#)). Eight studies did not contain sufficient birth characteristic information ([Ahuja, 1979](#); [Blakey and Abramowitz, 2017](#); [Buttolph and Holland, 1990](#); [Christian and Storch, 2009](#); [Fang et al., 2018](#); [Kalra et al., 2005](#)). Treatment was poorly described in three papers ([Buttolph and Holland, 1990](#); [Flosnik and Khin, 2012](#); [Kalra et al., 2005](#)). When not written from the participants' perspective, these case studies were written from the perspective of a mental health clinician or similar, and there was no perspective from maternity care health professionals included.

Within the qualitative study by [Burton \(2020\)](#), there was substantial information from the individual participants' perspectives and direct quotes. However, OCD was only ascertained through self-report and triangulation with dimensional obsessive compulsive scale scores, which is not the gold standard method for identifying OCD.

5. Descriptive themes

Three descriptive themes were identified within the data: "Experience of barriers to diagnosis and care", "Experience of decision making in treatment and care", and "Experience of treatment and care". Illustrative quotations for each theme can be found in [Table 4](#).

5.1. Theme 1: experiences of barriers to diagnosis and care

Experiences of barriers to diagnosis and care were mentioned in fourteen studies. Some of these barriers stemmed from the participants themselves, including how they viewed themselves and how they thought family members and wider society might view them. Some of these barriers came from health professionals involved in maternity

care, psychiatric care or primary care. Sometimes these barriers resulted in reduced access to timely and accurate treatment and care.

5.1.1. Subtheme 1.1: personal barriers

Eleven of the studies described personal barriers that hindered the participants from accessing a diagnosis or treatment. Five participants across four studies ([Benfield, 2018](#); [Burton, 2020](#); [Challacombe, 2014](#); [Chelmow and Halfin, 1997](#)) were stated to have not confided in or disclosed to their primary care or maternity care professional about their OCD symptoms. It is unclear why the participants in [Challacombe \(2014\)](#) and [Chelmow and Halfin \(1997\)](#) did not disclose or wish to disclose their symptoms; however, [Benfield \(2018\)](#) and one participant in [Burton \(2020\)](#) noted that they were concerned that their babies would be taken away if they were to tell a professional about their thoughts. Some participants were also worried about how family and wider society may see them.

5.1.1.1. Being afraid that their baby would be taken away. The fear that their baby would be taken away was shared by five participants across four studies ([Benfield, 2018](#); [Burton, 2020](#); [Gershkovich, 2019](#); [Puryear and Treece, 2020](#)). These participants all expressed concern that their babies and older children would be taken away if they told anyone about the nature of their intrusive thoughts. This worry was primarily about telling health professionals, and occasionally partners or family members. This fear prevented the participants from seeking care and sometimes made it harder for participants to disclose the nature of their symptoms during assessment/treatment, particularly when the thoughts involved taboo topics ([Burt and Rudolph, 2000](#); [Puryear and Treece, 2020](#)).

5.1.1.2. Concern about how family members would see them. Three participants in three studies mentioned concerns about how family

Table 2

Quality assessment of personal narratives and case studies/series using a modified version of [Murad et al. \(2018\)](#) Tool for evaluating the methodological quality of case reports and series.

Author (year)	1.Does the patient(s) represent the whole experience of the investigator (centre) or is the selection method unclear to the extent that other patients with similar presentation may not have been reported?	2a. Is the intended purpose of the selected case report clearly stated?	2b. does the case report fit with this purpose?	3. Was OCD adequately ascertained?	4. Was treatment/care adequately ascertained?	5. Was experience adequately ascertained?	6. Is the case(s) described with sufficient details to allow other investigators to replicate the research or to allow practitioners to make inferences related to their own practise?	Overall decision about quality.
Ahuja (1979)	No	Yes	Yes	No	Yes	No	No	Low
Benfield (2018)	Yes	Yes	Yes	No	No	Yes	No	Medium-Low
Beraz (1996)	Yes	No	No	No	Yes	Yes	No	Medium-Low
Blakey and Abramowitz (2017)	No	Yes	Yes	No	Yes	Yes	Mixed	Medium-Low
Abramowitz and Fairbrother (2008)	No	Yes	Yes	No	Yes	Yes	Mixed	Medium-Low
Burt and Rudolph (2000)	No	Yes	Yes	No	Yes	Yes	Yes	Medium
Buttolph and Holland (1990)	Mixed	Yes	Yes	Yes	No	No	No	Low
Chelmow and Halfin (1997)	No	No	No	Yes	Yes	Mixed	Yes	Medium
Christian and Storch (2009)	No	Yes	Yes	Ye	Yes	Yes	Mixed	Medium
Darling (2014)	Yes	Yes	Yes	No	No	Yes	No	Medium-Low
Fang et al. (2018)	No	Yes	Yes	Mixed	Yes	Mixed	Yes	Medium-low
Flosnik and Khin (2012)	No	Yes	Yes	No	Mixed	No	No	Low
Gershkovich (2019)	No	Yes	Yes	Yes	Yes	Yes	Yes	Medium – High
Hertzberg et al. (1997)	Yes	Yes	Yes	No	Yes	No	Yes	Low
Hudak and Wisner (2012)	No	No	No	No	Yes	Mixed	Mixed	Medium-Low
Kalra et al. (2005)	Yes	Yes	Yes	Yes	No	No	Mixed	Low
Puryear and Treece (2020)	No	Yes	Yes	No	Mixed	Yes	Mixed	Medium-Low
Challacombe (2014)	No	Yes	Yes	Yes	No	No	No	Low

members would view them or worried about the impact of telling their family members ([Beraz, 1996](#); [Blakey and Abramowitz, 2017](#); [Gershkovich, 2019](#)). The participant in [Blakey and Abramowitz \(2017\)](#) expressed worry that her family would see her as an evil monster; other participants expressed similar worries that they would be labelled as “crazy”, so they hid their thoughts and behaviour from their partners.

5.1.1.3. Concerns about wider social and cultural barriers. The importance of acknowledging the potential impact of religious and cultural beliefs and the importance of discussing these in relation to OCD symptoms, care and treatment was highlighted in two studies ([Burt and Rudolph, 2000](#); [Fang et al., 2018](#)). In [Fang et al. \(2018\)](#), the participant's concerns about cultural perceptions impeded disclosure. The participant's reluctance to seek help was discussed within the context that she and her husband are Chinese and how shame around mental illness is particularly prevalent within Chinese culture. [Burt and Rudolph \(2000\)](#) highlighted the importance of nuance and sensitivity when people who

have specific religious or cultural beliefs or are from minority ethnic groups are treated or assessed. The participant in this study declined referral to an intensive behavioural programme due to fears of judgment about her obsessions' religious aspects, which she felt discomfort disclosing.

5.1.2. Subtheme 1.2: health professional barriers

Experience of health professional barriers was included in nine of the 18 studies, from the personal narratives, case studies and the case series from the clinical trial. These barriers impeded the ability to access an accurate and timely diagnosis and included misdiagnosis, missing opportunities to pick up a diagnosis and lack of knowledge by a health professional.

5.1.2.1. Misdiagnosis. Seven participants across four studies ([Challacombe, 2014](#); [Darling, 2014](#); [Gershkovich, 2019](#); [Hudak and Wisner, 2012](#)) were misdiagnosed with generalised anxiety disorder, or more

Table 3

Quality assessment of [Burton \(2020\)](#) using Critical Skills Appraisal Programme tool qualitative checklist.

Question	Yes/No/ Unclear
Section A:	Yes
1. Was there a clear statement of the aims of the research?	Yes
2. Is the qualitative methodology appropriate?	Yes
3. Was the research design appropriate to address the aims of the research?	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes
5. Was the data collected in a way that addressed the research issue?	Yes
6. Has the relationship between researcher and participants been adequately considered?	Yes
Section B:	Yes
7. Have ethical issues been taken into consideration?	Yes
8. Was the data analysis sufficiently rigorous?	Yes
9. Is there a clear statement of findings?	Yes

often, postpartum depression. These misdiagnoses led to delays in accurate diagnoses for these participants, leading to further delays in implementing appropriate treatment.

5.1.2.2. Lack of Knowledge. Eleven participants in eight studies ([Benfield, 2018](#); [Buttolph and Holland, 1990](#); [Challacombe, 2014](#); [Chelmsow and Halfin, 1997](#); [Christian and Storch, 2009](#); [Darling, 2014](#); [Gershkovich, 2019](#); [Hudak and Wisner, 2012](#)) ([Benfield, 2018](#); [Challacombe, 2014](#)) were impacted by a lack of knowledge about OCD by health professionals. Four of these studies identified the health professional who lacked knowledge. In [Challacombe \(2014\)](#), three participants were impacted by a lack of knowledge of OCD; after birth, one participant was told that "everyone feels like this; get on with it" by her health visitor. Similarly, another participant was told by their general practitioner that "everyone had OCD" and she "should get on with it". The third participant was told by her general practitioner that she should either choose to be hospitalised or be strong and fight off the thoughts, she was also told by her health visitor that her intrusive thoughts resulted from her not being busy enough. A psychiatrist was involved in a delay in treatment due to lack of knowledge in [Christian and Storch \(2009\)](#) and in [Hudak and Wisner \(2012\)](#). A primary care physician/general practitioner was involved in the delay for the participant in [Gershkovich \(2019\)](#). In the four further studies ([Benfield, 2018](#); [Buttolph and Holland, 1990](#); [Chelmsow and Halfin, 1997](#); [Darling, 2014](#)) it was not clear what type of health professional was responsible for the impacted care due to a lack of knowledge. [Benfield \(2018\)](#) argued in her personal narrative that the health professionals she came into contact with during the first two years after her son's birth failed to identify her symptoms as OCD because they were impeded by their lack of knowledge of the condition. Although there were opportunities for OCD to be identified, it was not, and there was a focus on assessment for other postpartum psychiatric disorders. To mitigate these barriers Benfield explained how she "refused to stop pushing for help".

5.1.2.3. Missed opportunities to be identified. Two personal narratives described instances of missed opportunities where OCD could have been identified ([Benfield, 2018](#); [Darling, 2014](#)). The participant in [Darling \(2014\)](#) reported that her 6-week postpartum check-up was not scheduled, so she had reached 10 weeks postpartum without a follow-up. This issue is further illustrated by [Darling \(2014\)](#) and [Blakey and Abramowitz \(2017\)](#), where someone other than their primary health care provider identified the participant's symptoms. The participant in [Darling](#) stated that it was her lactation consultant who discerned that she was unwell. The participant in [Blakey and Abramowitz \(2017\)](#) mentioned feeling "down" most of the day and that she was afraid of interacting with her son to her paediatrician, who recognised this could be a sign of a postpartum psychiatric disorder.

Table 4

Illustrative quotes organised by theme and subtheme.

Theme	Sub theme	Quote
1. Experiences of barriers to diagnosis and care	1.1 Personal barriers	"I would never admitted, would have [er] admitted the, the thoughts that I was having because of the concern that they would take the baby away (Gina)." (Burton, 2020).
		"She had also been concealing the content and frequency of her obsessions from others (including her husband) for fear that they would think she was "an evil monster." (Blakey and Abramowitz, 2017).
		"she did not seek treatment due to shame...we learnt that Mrs. A. is reluctant to seek help, given her "fear of disgracing her family if she were deemed mentally unstable." (Fang et al., 2018).
	1.2 Health professional barriers	"The diagnosis given to Mrs. M in the emergency department was generalized anxiety disorder with panic attacks, with a differential diagnosis of obsessive-compulsive disorder This assessment overlooked the patient's primary concern—namely, her obsessions—which resulted in a delay in implementing a more focused intervention" (Hudak and Wisner, 2012).
2. Experience of decision making in treatment and care		"Sadly, along the way, my recovery was impeded by a lack of knowledge about the condition, and the myriad ways in which it can manifest. My progress is thanks in no small part to me, and my refusal to stop pushing for help. None of the medical professionals I met within my first year of motherhood identified my symptoms as OCD. I was assessed for postnatal depression and psychosis, but postnatal OCD was never mentioned." (Benfield, 2018).
	2.1 Impact of pregnancy on treatment and care decision making	"But that was another reason why I did stop taking my medication because I had known there were certain cases of [um] women who had taken [name of medication] being pregnant and it had caused, like, heart defects and I was really worried that, and I was thinking, I can't be selfish. Yes, I know, realistically I need the medication to function properly but then I can't cause something that's going to impact on my baby's life (Rosie)." (Burton, 2020).
		"Each week, my doctor and I discussed starting on meds, again, and each week, we managed to "delay it.. until next visit" Somehow it helped

(continued on next page)

Table 4 (continued)

Theme	Sub theme	Quote
	2.2 Impact of breastfeeding on treatment and care decision making	<p>just to acknowledge that the symptoms were there.” (Beraz, 1996).</p> <p>“She is thriving on my breast milk, so medication must stand in line. Baby comes first” (Beraz, 1996).</p> <p>“Given the history of exacerbation of symptoms in the two previous postpartum periods, restarting clomipramine immediately after delivery was recommended. However, the patient wanted to breast-feed without the baby’s exposure to medication” (Kalra et al., 2005).</p> <p>“Ana elected not to breast-feed. Her reasons included uneasiness regarding the paucity of data on the subject and the fact that sleep deprivation exacerbated her OCD symptoms” (Burt and Rudolph, 2000).</p> <p>“Lauren, who did not experience exacerbation of her OCD, was able to maintain her own health throughout pregnancy with the use of medication and CBT, and ongoing support from her partner and doctor. She had a positive perinatal experience.” Burton (2020).</p> <p>“Her ability to care for her new baby as well as her two other children was severely compromised, and the patient decided that she could be a better mother with resumption of medication and a reduction in symptoms even if she was not breast-feeding. She discontinued breast-feeding and restarted clomipramine, increasing her dose to 125 mg per day with excellent relief of her symptoms”. (Chelmow and Halfin, 1997).</p>
	2.3 Putting mother's mental health first	
	2.4 Informed decision making	<p>“They were given a full discussion of the risks and benefits of medication during pregnancy, and Mrs. M decided to maintain her citalopram at 80 mg/day. During the 19th week of her pregnancy, the Food and Drug Administration released a warning about citalopram dosages over 40 mg/day. Mrs. M decided to maintain her medication after obtaining normal results in an ECG” (Hudak and Wisner, 2012).</p>
3. Experiences of treatment and care	3.1 Maternity care experience	<p>“I remember saying I was scared—could they slow down and explain what was happening to me. “No. We don’t have time,” was his gruff response. I remember asking for my husband—where was</p>

Table 4 (continued)

Theme	Sub theme	Quote
		<p>he? Why wasn’t he here? Why isn’t he allowed to be in the room with me now? I demanded” (Darling, 2014).</p> <p>“while she was still in hospital and learning from nurses how to care for her infant. She was instructed that she needed to scrub and use sterile techniques, such as using a fingernail brush and antiseptic to clean her hands before touching her child. She was also instructed not to touch the telephone, the bed rail and or any of her personal items before touching her baby” (Buttolph and Holland, 1990).</p> <p>“Because of the success of the treatment that followed... I too was rediscovering life. I realize how blessed I was to have found treatment in time to enjoy her early years and to continuously gain strength from the multiple joys of motherhood and mental and emotional wellness”. (Beraz, 1996)</p> <p>“I’m not certain how much the Zoloft [sertraline] helped, but what really seemed to help in the end was, awful as it may sound, earplugs and selective use of sedatives to help me sleep.... Eventually, through re-regulating my system with sleep, and through getting back on an antidepressant, the anxiety lessened. The thoughts stopped. The gory images halted. Eventually, around month five, she stopped crying so much, too”. (Darling, 2014).</p> <p>“Her primary physician again prescribed lorazepam (0.5 mg tid) [benzodiazepine]. She then worried about transmitting fragments of the lorazepam from her fingers to the new born..... Fear of medication transmission to clothing, utensils, and furniture led to compulsive laundering and cleaning” (Hertzberg et al., 1997).</p>
	3.2 Experiences of pharmacological treatment	
	3.3 Experience of therapy	<p>“She was quite receptive to the cognitive aspect of treatment; she related that she had never considered that certain beliefs which she held strongly may not be accurate. She also reported that challenging such beliefs reduced her anxiety and made her feel hopeful about treatment.” Christian and Storch (2009).</p> <p>“She attributed this improvement largely to psychoeducation – specifically, to understanding that her intrusive thoughts did not</p>

(continued on next page)

Table 4 (continued)

Theme	Sub theme	Quote
		reflect her actions or even her desires.” Fang et al. (2018).
		“The initial normalization of intrusive thoughts was especially helpful to Anna. She was comforted to learn that these thoughts were not unique to her and did not mean that she was a “bad person”. To make this form of psychoeducation specific to normalizing postpartum intrusive thoughts, the therapist provided Anna with research articles showing how common these thoughts are in new parents. The therapist provided Anna with a list of commonly reported cognitive intrusions among new parents, and Anna was amazed and relieved that her own thoughts were so similar to those experienced by other new moms (and dads).” Gershkovich (2019).
		“Jane’s mother had warned Jane about the likelihood of postpartum intrusive thoughts as Jane’s mother, although she did not have OCD, had experienced intrusive thoughts during and after her pregnancies. Jane suggested that if she had not known that intrusive thoughts were normal she would be even more disturbed and worried about ‘what was wrong with her’.” Burton (2020).
		“Anna: I understand the rationale for doing exposures. I’m just not sure if I’ll be able to do this. I can imagine myself doing some of the things we talked about, like reading news articles, but being around my baby and holding a knife is just so different. I just don’t know if I can commit to doing that.” Gershkovich (2019).
	3.4 Involvement of family members in treatment	“Jenny’s thoughts about sexual molestation were particularly distressing to her and were difficult for her therapist to address” Puryear and Treece (2020). “Both Ana and her husband felt more hopeful and optimistic. Her husband felt included in the treatment process, and Ana felt less isolated.” Burt and Rudolph (2000).

5.2. Theme 2: experience of decision making in treatment and care

Experience of decision making within treatment and care was mentioned in twelve of the eighteen studies across all four design types (Beraz, 1996; Blakey and Abramowitz, 2017; Burt and Rudolph, 2000; Burton, 2020; Buttolph and Holland, 1990; Challacombe, 2014;

Chelmow and Halfin, 1997; Darling, 2014; Fang et al., 2018; Gershkovich, 2019; Hudak and Wisner, 2012; Kalra et al., 2005). Many different facets were involved in decision making. Three subthemes were identified including impact of pregnancy on treatment and care decision making, impact of breastfeeding on treatment and care decision making and putting mothers' mental health first.

5.2.1. Subtheme 2.1: impact of pregnancy on treatment and care decision making

Six participants in six studies (Beraz, 1996; Burton, 2020; Challacombe, 2014; Darling, 2014; Fang et al., 2018; Kalra et al., 2005) stopped taking antidepressant medication during or ahead of pregnancy due to concerns about how the medication may affect their unborn baby. Two participants in two papers reported that they stopped taking their medication due to their concerns about the effect it could have on their unborn baby without the support of their doctor or against their doctors' advice (Burton, 2020; Kalra et al., 2005). In Kalra et al. (2005) the participant was advised to start on medication after being diagnosed with OCD during pregnancy, and she declined. The participant eventually started taking medication during pregnancy. However, after what is reported as input from a family member, she stopped taking them during the final month of gestation against the advice of her doctors, which led to a resurgence of her OCD symptoms. The participant in Burt and Rudolph (2000) also expressed concern about the impact of taking antidepressants during pregnancy. After research and consultation with her doctors, she decided it was in her best interests to prioritise taking her medication due to the rapid return of symptoms when she had tried to discontinue her medication previously. Two participants in Burton (2020) were aware of the impact that poor mental health might have on their developing baby which led to anxiety and guilt. Two further participants in two studies reported cessation of antidepressants where it is unclear if this decision was supported by doctors (Challacombe, 2014; Fang et al., 2018). Fang et al. (2018) also pointed out that their participant mistakenly stopped attending psychopharmacological appointments when she stopped taking her antidepressants which presented a challenge for continuing adequate care. The final two participants who stopped medication were supported by their doctors in their decisions. The participant in Darling (2014) was supported by her doctors to taper off her medication in her third trimester due to concerns from her obstetrician about the impact of medication on her unborn baby. Similarly, Beraz (1996) described stopping her medication ahead of becoming pregnant with the support of her doctors. Despite stopping her medication, Beraz continued to have appointments with her doctors about her medication. These appointments allowed her to delay treatment whilst having her symptoms monitored regularly.

5.2.2. Subtheme 2.2: impact of breastfeeding on treatment and care decision making

Similarly, to the previous subtheme, four participants decided not to start taking antidepressants while they were breastfeeding (Beraz, 1996; Blakey and Abramowitz, 2017; Chelmow and Halfin, 1997; Gershkovich, 2019), all of these participants, except Beraz (1996), opted for cognitive behavioural therapy (CBT). There were no cases of participants discontinuing medication due to breastfeeding intentions. A prominent aspect of decision-making during breastfeeding (and pregnancy) was based on the potential impact medication may have on their developing baby. Breastfeeding was prioritised by some participants, sometimes at great expense to their mental health. Though some participants decided not to breastfeed to allow them to continue taking their medication (Burt and Rudolph, 2000).

5.2.3. Subtheme 2.3: putting mother's mental health first

There were five cases (Burt and Rudolph, 2000; Burton, 2020; Chelmow and Halfin, 1997; Darling, 2014; Hudak and Wisner, 2012) where participants put their mental health first, sometimes with the aim of ‘being a better mother’ (Chelmow and Halfin, 1997). Even though

their mental health was being put first, there was always still a focus on the benefits of this for their baby due to acknowledging that being unwell could impact their baby.

There were cases where mental health was put first initially, often in pre-conception plans (Burt and Rudolph, 2000; Burton, 2020; Hudak and Wisner, 2012), always with much consideration and discussion with doctors and personal research. There were two studies where two participants resolved to take medication for the sake of their baby after finding their symptoms intolerable. The participants in Chelmon and Halfin (1997) and Darling (2014) decided to start medication because they were so unwell, deciding that being pharmacologically treated would help them 'be a better mother', even if it was at the expense of discontinuing breastfeeding or a trace amount of drug being transferred through their milk, as a trade-off for better mental health.

In three of the studies that mentioned making maternal mental health a priority, there was a clear emphasis on informed decision making. (Burt and Rudolph, 2000; Darling, 2014; Hudak and Wisner, 2012). Informed decision making was also mentioned in Beraz (1996); the author stopped her medication ahead of pregnancy and described knowing that she had an informed decision helped her worry less. Informed decision making involved discussing the risks and benefits to continuing or starting medication, which was facilitated by doctors or by personal research for example contacting top OCD researchers, reading studies and talking to other women with OCD. The importance of this was demonstrated by the reporting that the participant and her husband in Burt and Rudolph (2000) were educated about clinical decision making in case she needed to start pharmacological treatment.

5.3. Theme 3: experience of treatment and care

Twelve of the eighteen studies included information about the experience of treatment and care (Ahuja, 1979; Benfield, 2018; Beraz, 1996; Burton, 2020; Buttolph and Holland, 1990; Challacombe, 2014; Christian and Storch, 2009; Darling, 2014; Fang et al., 2018; Gershkovich, 2019; Hudak and Wisner, 2012; Puryear and Treece, 2020). Three subthemes were identified: maternity care experience, experience of pharmacological treatment and experience of therapy.

5.3.1. Subtheme 3.1 maternity care experience

Overall, the information available about maternity care experience was extremely limited and OCD was rarely explicitly taken in to account in maternity care descriptions. Four participants within four studies (Burt and Rudolph, 2000; Burton, 2020; Buttolph and Holland, 1990; Darling, 2014) provided limited information on maternity care experience. Two participants described the experience of having an emergency during birth which led to fear and confusion (Burton, 2020; Darling, 2014). The participant in Darling (2014) described being excluded from understanding what was happening to her and her body during an emergency birth as the health professionals had no time to discuss what was happening to her. This lack of communication and not knowing what was happening to her made the experience more traumatic. The participant in Burton (2020) described having a postpartum haemorrhage that she found very frightening as she did not have any control over what was happening or what the outcome might be. In Buttolph and Holland (1990), one participant recalled an experience that affected her negatively, reporting that she had been given specific cleaning instructions including not touching her bedframe before touching her baby. It is unclear what was said to the participant at the time as this is not in keeping with usual advice, but this was her memory from the event over 13 years later. One positive experience of maternity care was recorded, involving the collaboration between obstetrician and therapist; a participant in Burt and Rudolph (2000) reported asking for a meeting between herself, her therapist, and her obstetrician to appraise the obstetrician of her OCD diagnosis and her wishes to remain on medication during pregnancy.

5.3.2. Theme 3.2 experience of pharmacological treatment

Pharmacological experience was mentioned in three studies (Beraz, 1996; Darling, 2014; Hertzberg et al., 1997). Though there was limited information about actual experience of pharmacological care.

Beraz (1996) described her previous experience of starting on medication after the birth of her first child. The participant reported in Darling (2014) described how a combination of sertraline and sleeping medication helped her. The participant in Hertzberg et al. (1997) presented at the psychiatric emergency room and was prescribed a standard dose of antidepressant (SSRI) with a planned follow up in a week. However, two days later, she returned unable to wait for the follow up due to the severity of her symptoms and was hospitalised. There was very little information about her experience aside from the information that she could not wait until the follow-up appointment, and her treatment was escalated. There were two examples where pharmacological treatment became an obsession itself (Beraz, 1996; Hertzberg et al., 1997), for example, Beraz (1996) described having "what if" intrusive thoughts about taking medication, which prevented her from taking them while she was pregnant and the participant in Hertzberg et al. (1997) developed an obsession that she would transmit fragments of her medication from her fingers to her baby.

5.3.3. Theme 3.3 experience of therapy

Twelve participants across eleven studies described the experience of therapy (Ahuja, 1979; Benfield, 2018; Blakey and Abramowitz, 2017; Burton, 2020; Challacombe, 2014; Chelmon and Halfin, 1997; Christian and Storch, 2009; Fang et al., 2018; Flosnik and Khin, 2012; Gershkovich, 2019; Hudak and Wisner, 2012; Puryear and Treece, 2020). The majority of these participants took part in cognitive behavioural therapy except Ahuja (1979), where flooding was used, and behavioural therapy with "thought stopping" was prescribed to the participant within Chelmon and Halfin (1997).

Some participants reported finding cognitive behavioural therapy helpful and that these techniques reduced their symptoms. Psychoeducation played a significant role in many of the participants' therapy experiences. Psychoeducation was described by nine participants in eight studies (Benfield, 2018; Blakey and Abramowitz, 2017; Burton, 2020; Chelmon and Halfin, 1997; Fang et al., 2018; Flosnik and Khin, 2012; Gershkovich, 2019; Hudak and Wisner, 2012). It was regularly described as helpful and as bringing relief. Participants often attributed their improvement in symptoms to psychoeducation. Psychoeducation was particularly useful when framed around typical perinatal experience and perinatal OCD (Gershkovich, 2019; Hudak and Wisner, 2012; Puryear and Treece, 2020). One participant (Gershkovich, 2019) found it helpful when her husband was involved in treatment, as he revealed that he also had intrusive thoughts and did not think that it was odd that she did too. The participant's husband learnt how to help support her without providing inappropriate reassurance in response to OCD symptoms and was given an opportunity to discuss how he felt treatment was progressing. The participant found this self-disclosure helpful, and both the participant and her husband found the session to be beneficial. Though the knowledge did not come from a health professional, one participant in Burton (2020) was told about intrusive thoughts by her mother highlighting the value of knowledge and education more broadly. This participant found it helpful to know that other new parents have harm thoughts about their babies.

Some participants were hesitant to start CBT due to not understanding that this would not put their baby at risk (Gershkovich, 2019; Hudak and Wisner, 2012); the participant in Ahuja (1979) also expressed concern that their flooding therapy might put her baby at risk. One participant in Challacombe, 2014 was reported to have declined CBT previously because she was too anxious. Initial lack of understanding that intrusive thoughts did not mean they would act on them, and that exposure response prevention therapy would not put their babies in danger led to hesitancy in beginning treatment. However, this was relieved through psychoeducation.

The taboo nature of some intrusive thoughts made it difficult for some participants to discuss them with the person treating them (Burt and Rudolph, 2000; Puryear and Treece, 2020). Three participants in two studies (Challacombe, 2014; Christian and Storch, 2009) were viewed as high risk to their children by health professionals. In Christian and Storch (2009), the participant was involuntarily hospitalised by her psychiatrist despite being willing to be voluntarily hospitalised and then discharged 24 hours later. She said this experience increased her fear and it provided further evidence to support the participant's mistaken belief that she was actually a threat to her baby. When describing unhelpful/negative reactions to disclosure of symptoms in her study population, Challacombe (2014) noted that three participants were

previously deemed as an increased risk to their infant by their health care professionals. Two of these participants were reported to social services. One participant was reported to social services without her knowledge by her health visitor and whilst it was not clear who reported the second participant, she was not allowed to be alone with her baby whilst she was a patient on a mother and baby unit due to being deemed a high risk. These experiences link to theme 1.1 where there was a barrier to accessing care due to fear that their babies would be taken away from them if they told anyone their intrusive thoughts; the fact that some women have been seen as high risk to their babies demonstrates that the concern about telling health professionals about their intrusive thoughts is not entirely unfounded.

Table 5

To demonstrate how the descriptive themes and the analytic themes intersect.

		Analytic themes		
		Keeping baby healthy vs keeping mother healthy	Keeping baby safe vs keeping mother safe	Normal experience vs not normal experience
Descriptive themes	Theme 1: Experiences of barriers to diagnosis and care			
	Subtheme 1.1 Personal barriers		Participants afraid that their baby would be taken away	Participants afraid that they would be seen as crazy for having intrusive thoughts
	Subtheme 1.2 Health professional barriers	Misdiagnosis, lack of knowledge and missed opportunities to be identified leading to delayed treatment for mother	Misdiagnosis, lack of knowledge and missed opportunities to be identified leading to women being seen as a danger to their baby	Potential impact of religious and cultural beliefs Misdiagnosis, lack of knowledge and missed opportunities to be identified leading to over normalisation of OCD experience.
	Theme 2: Experience of decision making in treatment and care			
	Subtheme 2.1: Impact of pregnancy on treatment and care decision making	Participants ceasing antidepressants use during or ahead of pregnancy Deciding to continue medication during pregnancy		
	Subtheme 2.2: Impact of breastfeeding on treatment and care decision making	Participants being concerned that being mentally unwell might impact their unborn baby Participants declining to start antidepressants while they were breastfeeding Participants deciding not to breastfeed to allow them to continue taking their medication Participants taking antidepressants whilst breastfeeding due to trace amounts having a minimal impact		
	Subtheme 2.3: putting mother's mental health first	Participants putting their mental health first pre-conception or early on in pregnancy Participants resolving to take medication for the sake of their baby		
	Theme 3: experience of treatment and care			
	Subtheme 3.1 Maternity care experience	Emergency birth intervention making communication with mother difficult	Participant recalled being given excessive cleaning instructions	
	Theme 3.2 Experience of pharmacological treatment	Medication helping manage and improve symptoms	Pharmacological treatment becoming an obsession e.g., worrying about the transfer of medication to baby through touch	
Descriptive themes	Theme 3.3 Experience of therapy	Therapy (particularly psychoeducation) leading to improvement of symptoms	Participants being concerned that therapy might put baby at risk Therapist finding it difficult to address taboo topics e.g., sexual molestation Participants being reported to social services without their knowledge or being involuntarily hospitalised increasing fear and demonstrating that they are a risk to their baby.	Psychoeducation teaching participants that most people experience intrusive thoughts, without over normalising the experience. Psychoeducation in non-clinical setting i.e., participant's mother discussing intrusive thoughts with her

5.4. Analytical themes

The data was synthesised into three analytical themes that demonstrate a series of tensions that cut across the descriptive themes. These were tensions between “keeping baby healthy vs keeping mother healthy”, “keeping mother safe vs keeping baby safe” and “normal perinatal experience vs not normal perinatal experience”. Table 5 shows how the analytical themes intersect with the descriptive themes.

5.4.1. Analytical theme 1: keeping baby healthy vs keeping mother healthy

Tensions between keeping the baby healthy and the mother healthy influenced the experience of care and treatment decision making during pregnancy and postpartum and during emergency births. Resolving these tensions was managed by both medical professionals and the mothers themselves, and risks and benefits were assessed in different ways. There were various examples of participants putting more emphasis on the health of their babies when deciding to continue or stop medication during pregnancy and postpartum, which for some, meant that their OCD symptoms were made worse during this time. Some participants felt guilty that their poor mental health might impact their developing baby. Similarly, those that continued medication during pregnancy were typically doing so to protect their infants, as they recognised the impact their poor mental health could have on their infants. This tension not only affected pharmacological choices; in some cases, participants were hesitant to start CBT or other therapies fearing that it might put their infant at risk due to not understanding what the therapies would involve. Misdiagnosis and delayed diagnosis may exacerbate this tension by increasing the length of time until appropriate treatment is accessed.

5.4.2. Analytical theme 2: keeping baby safe vs keeping mother safe

Another cross cutting analytic theme was the tension experienced between keeping baby and mother safe. Several participants were worried about being seen as a threat to their baby, and a few participants were classed as high risk to their baby by the health professionals treating them. This classification as high risk sometimes led to restricted contact with their infant and referral to social services without their knowledge. Concern about being seen as a threat to their child or concern that they may actually be a threat is understandable when pre-diagnosis women may not know that they have a mental health disorder or that their intrusive thoughts are not reflective of what they want. Some participants also feared being seen as “crazy” or as an “evil monster”. Misdiagnosis and lack of knowledge by health professionals may also increase the risk of health professionals seeing women as a threat to their infant so may exacerbate this tension and the taboo nature of some intrusive thoughts e.g. sexual molestation were difficult to address between some therapist and participant dyads. Some participants also worried that treatment may put their baby in danger e.g. there was hesitancy about starting CBT and flooding for some participants, which was resolved through psychoeducation and one participant developed an obsession that her medication would transfer via clothing to harm her baby.

5.4.3. Analytical theme 3: normal perinatal experience vs not normal perinatal experience

The third analytic theme reflects the constant tension between the need to normalise intrusive thoughts so as not to pathologize the normal experiences of pregnant and postpartum women without over-normalising it so that women with OCD are missed or their experiences trivialised. For example, the experience of one participant in Challacombe (2014) who was told that ‘everyone feels like this; get on with it’ by her health visitor, created a barrier to care access. A helpful way of resolving the conflict between appropriate normalisation and over normalisation was through psychoeducation. During psychoeducation, the participants were taught that many people experience these thoughts and that having intrusive thoughts is a normal

experience, particularly during the perinatal period, and that their intrusive thoughts did not mean they would act on them or harm their baby, without trivialising these experiences. This came as a relief to some of the participants and was helpful in their recovery.

6. Discussion

This review summarises the published literature on the experience of maternity care and mental health care of women with OCD in the perinatal period, and highlights gaps in the current research literature. There was limited good quality research identified. Three descriptive themes were found across these 18 studies: “Experience of barriers to diagnosis and care”, “Experience of decision making in treatment and care”, and “Experience of treatment and care”. Further synthesis of the data identified three cross-cutting analytic themes that described tensions between “keeping baby healthy vs keeping mother healthy”, “keeping mother safe vs keeping baby safe” and “normal perinatal experience vs not normal perinatal experience”.

There were significant research gaps in the experience of maternity care and experience of pharmacological care experience. There was also limited evidence concerning information sharing between medical professional and participant. There was no indication of co-production or service user involvement. A lack of research in this area may partially account for the poor knowledge and recognition of OCD during pregnancy and postpartum identified in the review themes. Postpartum depression has historically received the most focus in perinatal mental health research (Higgins et al., 2018). However there is growing awareness that women are at increased risk of both mood disorders and anxiety disorders during pregnancy and postpartum (Uguz et al., 2019) which will hopefully lead to an increase in research into anxiety disorders.

Concerns around medication use, and the tension between keeping mother healthy and keeping baby healthy, are similar to findings from focus groups of a wider perinatal population of women that take prescription medication who expressed concern about foetal development (Lynch et al., 2018). Women in the Lynch et al. (2018) study also described concerns about the impact that their own poor mental health could have on their developing babies, these participants also stated that if they did not know the risks associated with a medication they would not take the medication. These similar experiences highlight the importance of providing women with OCD clear resources and information, including risks and benefits of treatment, to make informed decisions about their medication. In addition, continuity of care, irrespective of the approach to treatment is key to experiences of decision making and care. Delayed diagnosis created barriers that exacerbated the difficulties in keeping mother and baby healthy, as delayed treatment or inappropriate treatment can further the risk of anxiety, fear and, in some cases, lead to depression (Bruce et al., 2018).

Keeping both baby and mother safe was sometimes in tension in the data. Some participants experienced feeling like they would be seen as “crazy” or as an “evil monster”, which created a barrier for disclosure. In the general OCD population, many people feel like they are “going crazy” or that they might act on their intrusive thoughts (Keyes et al., 2018) before psychoeducation. Therefore, prior to diagnosis, many of the participants in this review may have seen themselves as a threat to their baby and might also assume that others would too. The fear that some participants in the current systematic review shared that they would be seen as a threat was not unfounded, especially considering some participants were reported to social services without their knowledge. Similar fears also extend to the non-perinatal OCD population, where people experiencing taboo intrusive thoughts, e.g. paedophilic obsessions or harm obsessions, are concerned about disclosing their symptoms due to fears of being reported to the police, which can affect help seeking behaviours and disclosure (Newth and Rachman, 2001). Harm obsessions are particularly prevalent during the perinatal period for women with OCD, where many intrusive thoughts focus on

harming their infant (Zambaldi et al., 2009), so this may be a particular problem during the perinatal period for women with OCD.

There are two particular problems that need to be highlighted, firstly that a mother may be mistakenly perceived as a risk to her infant by care provider. Secondly, that the mother may fear that she is a danger to her infant, fears that are then maintained by OCD behaviours and in some cases by health professionals reporting new mothers to social services. Some health professionals may be at risk of seeing women with OCD as a risk to their babies due to lack of knowledge about or experience of perinatal OCD. They may be unable to recognise the difference between people with OCD, who are therefore experiencing unwanted intrusive thoughts, and those who actually want to harm their children. Veale et al. (2009) noted that the real risk to infants is the secondary risks that occur as a consequence of untreated OCD and the unintended consequence of acting on compulsions e.g., a mother's avoidance of being alone or changing their infant's nappy, rather than a mother's obsessions being the risk to their infant's safety. However, this is not well understood by some health professionals. There have also been other reports of women with OCD experiencing ego-dystonic, distressing intrusive thoughts about harming their babies, who were not recognised as having OCD and subsequently classified as 'high risk' of harming their children, leading to admission onto specialist mother and baby unit which exacerbated OCD (Challacombe and Wroe, 2013). This can exacerbate OCD symptoms as it mistakenly confirms the fear to the mother that she is a danger to her child. Misdiagnosis may also exacerbate the risk of being misclassified as high risk. Misdiagnosis is also not unusual within the general OCD general population (Bruce et al., 2018; Fenske and Petersen, 2015), particularly when symptoms involve harm obsessions (Glazier et al., 2015) and symptoms that do not fall within the stereotypical understanding of OCD (i.e. cleaning hands and needing things to be 'just right') (Rasmussen and Eisen, 1992). Misdiagnosis may exacerbate secondary risks to mother and baby e.g. avoiding spending time with baby alone (Veale et al., 2009) and can lead to the inappropriate involvement of child protective services (Challacombe and Wroe, 2013). The lack of knowledge of some health professionals in this current review is supported by the finding in a survey study of 829 nurses in Ireland that their self-reported knowledge of OCD was poorer than knowledge of anxiety, depression, the impact on baby and risk factors (Higgins, 2017). Further training to improve identification of OCD and what constitutes intrusive thoughts is required for health professionals in contact with women during pregnancy and the postpartum period. The cognitive model of OCD as developed by Salkovskis et al. (1998) proposes that obsessional problems occur due to the misappraisal of intrusive thoughts as meaningful, and as a consequence of the significance a person attaches to the intrusive thought. Fairbrother and Abramowitz (2007) suggest that the perinatal period lowers the threshold for the development or exacerbation of OCD due to a sudden increase in responsibility for their vulnerable baby, which encourages the misinterpretation of normally occurring intrusive thoughts as significant and meaningful, leading to covert and overt obsessional behaviours developing in response to these intrusive thoughts and thereby maintaining the obsessions. As pregnancy and postpartum is a period when the majority of new parents experience the onset of intrusive thoughts concerning the health and safety of their new baby (Fairbrother and Woody, 2008) it is consistent that the perinatal period is a particular time when new mothers are at risk of developing or experiencing an exacerbation of their OCD. It is important that health professionals understand firstly, that there is an increased risk in the development/exacerbation of OCD during this time, and secondly, what the processes are that maintain OCD. Health care professionals should also be aware of the increased risk of harm intrusive thoughts and the potential for misappraisal of them during this time.

The tension between what is a normal perinatal experience and what is not a normal perinatal experience is most evident in relation to intrusive thoughts. As stated previously, many new parents experience the onset of intrusive thoughts during pregnancy and postpartum

(Fairbrother and Woody, 2008). It is important that this typical experience is acknowledged but still taken seriously and queried to understand if these thoughts are causing distress or significant interference. This highlights the importance for health professionals to make it clear that many new parents have intrusive thoughts and to discuss them openly without trivialising the experience. Whilst being aware that if these thoughts are causing new parents' distress that further investigation may be necessary. Lack of knowledge, fewer skills and less training has been found to be associated with more negative attitudes among nurses toward people with mental health disorders (van der Kluit and Goossens, 2011) and knowledge about OCD among health professionals is poor (Glazier et al., 2013; Glazier et al., 2015) which may exacerbate this tension. Nuanced health professional training focussing on intrusive thoughts may be useful to help reduce misdiagnosis, the lack of recognition and understanding of intrusive thoughts and potentially unnecessary escalation to social services.

7. Strengths and limitations

This current review benefited from a robust and exhaustive search strategy that used a broad search, without limits on time of publication, language, or type of design. It was also broadly inclusive, demonstrated by the inclusion of case studies and grey literature. The review was completed systematically by two independent reviewers and involved a wider team to resolve conflicts. A limitation of this review was that there were small numbers of studies available for analysis. The studies that were identified were often of low quality. The high proportion of case studies, with their inherent methodological limitations, including selection bias, means the subsequent synthesis and its findings were limited.

7.1. Implications for further research and practice

7.1.1. Implications for further research

The limited data found in this review indicates significant research gaps in this field. A better understanding of the treatment and care routinely offered to women with OCD during pregnancy, and postpartum is needed and in-depth qualitative research into the experiences of mental health and maternity care would substantially increase our understanding of the experiences of women with OCD. In the UK, there are several key points of access during the perinatal period, including antenatal appointments, health visitor visits and a primary care check at six weeks postpartum which offer opportunities to assess maternal mental health. It is important to know if health professionals are successfully engaging with women at these key time points and whether women with OCD are receiving appropriate care.

7.1.2. Implications for methodological quality and reporting of case studies

The findings of this review also highlighted the need for more rigorous reporting of case studies. In particular, CARE Case reporting guidelines (Riley et al., 2017) suggest including patient perspectives on the treatment that they received, which was regularly missing from the case studies included in this systematic review. An increased focus on maternity characteristics and maternity care information would also be pertinent for case studies involving pregnant or postpartum women.

7.1.3. Implications for practice

This systematic review demonstrated the importance of discussing intrusive thoughts as a normal and typical perinatal experience to all perinatal women, while simultaneously recognising that if these intrusive thoughts are causing distress or are disabling that OCD needs to be considered. Therefore, further medical professional training about the nuances of intrusive thoughts may help identify women who are currently being missed and improve health professionals' confidence in supporting women with OCD. Improved communication, multi-disciplinary team working, and involvement of perinatal mental

health services may also be vital for improving access.

8. Conclusion

Overall, the current review identified three analytic themes that demonstrated tensions that impacted experience. In some cases, these tensions were exacerbated by barriers, such as misdiagnosis or the fear of escalation to social services, that delayed diagnosis and treatment for OCD during pregnancy and postpartum. Multi-disciplinary team working and further training for health care professionals about nuances in intrusive thoughts to differentiate between typically occurring intrusive thoughts and OCD is needed. Improved communication and involvement of perinatal mental health services is vital to help reduce misdiagnosis and ensure that women are getting the treatment and care that they need. Co-production in future research would also be an important step in helping to address significant gaps in the literature around experiences of maternity and mental health care in the perinatal period.

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CRediT authorship contribution statement

Burton, Alderdice, Carson and Salkovskis designed the study. Burton and Pickenhan reviewed the studies, extracted data and completed the risk of bias assessment. Burton and Alderdice analysed the findings. Alderdice and Carson resolved discrepancies in the reviewing process. Burton wrote the manuscript and Alderdice and Carson participated in editing the manuscript. Salkovskis also provided clinical experience with regards to the interpretation of the results and writing of the discussion. All authors contributed to and have approved the final manuscript.

Conflict of Interest

The study by Burton (2020) included in the systematic literature review was authored by Burton. Burton declares no other conflicts of interest. All other authors declare that they have no conflicts of interest.

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Appendix A. Supplementary data

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