Aimee McGinn BSc (Hons)

EXPLORING WOMEN'S EXPERIENCES OF SEEKING HELP FOR MENTAL HEALTH DIFFICULTIES IN THE PERINATAL PERIOD

Section A: What are the barriers and facilitators to seeking help for anxiety and depression in the perinatal period? A review of the literature.

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Section B: What helps and hinders mothers with OCD in disclosing unwanted infant-related harm thoughts to a health care professional?

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Summary

Section A

The systematic literature review explored the barriers and facilitators of help seeking among women experiencing perinatal anxiety and depression and anxiety in the UK. Given the relative neglect of anxiety in previous reviews, the inclusion of anxiety was an important addition. Following quality appraisal, a thematic synthesis of 10 included papers identified four themes: stigma, making sense of experiences, relational factors and structural barriers. Clinical implications focused on the domain of staff training, with a potential role for clinical psychology in providing reflective spaces to staff working with new mothers. Future research implications were also discussed.

Sections B

This study explored “What helps and hinders mothers with OCD in disclosing unwanted infant-related harm thoughts to a Health Care Professional?” Semi-structured interviews were conducted with 10 participants and data analysed using reflexive thematic analysis. A thematic map was created with six themes. Themes suggested a number of factors that have the potential to act as barriers or facilitators to disclosure, providing new insights for mothers with obsessive compulsive disorder as well as echoing existing literature for post-natal depression. Findings are discussed in relation to relevant theory and research. The limitations, implications for clinical practice and future research were discussed.

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Section A

Title: What are the barriers and facilitators to seeking help for anxiety and depression in the perinatal period? A review of the literature.

Word Count: 7146 (388)

Abstract

Background: Perinatal mental health is an important public health concern. In the context of the UK, there is a need to better understand help seeking for depression and anxiety in the perinatal period.

Aim: This review aimed to carry out a systematic search of the literature to understand the barriers and facilitators to help seeking for depression and anxiety in the perinatal period from the perspective of mothers in the UK.

Design: A systematic search of existing qualitative literature contained within Psychinfo, PsycArticles, Medline, CINAHL and ASSIA was conducted in February 2022. A total of 10 studies met the inclusion criteria for this review. A thematic synthesis was then conducted.

Findings: Four themes were identified: stigma, making sense of experiences, relational factors and structural barriers. Each theme described barriers and/or facilitators related to help seeking for anxiety or depression in the perinatal period.

Clinical and research implications: Useful clinical implications centred primarily on the domain of staff training and space for reflection. Recommendations for future research were also made.

Key words: systematic review, perinatal mental health, help seeking, qualitative methods

Introduction

Prevalence of Perinatal Anxiety and Depression

Guidance co-created by the National Health Service (NHS) in the UK defines the perinatal period as pregnancy and the first 12 months after childbirth (NHS England et al., 2018). The perinatal period has been described as a time in women's lives that involves significant physiological and psychological changes and adjustment (Garcia & IIona, 2017; Chen et al., 2021). Such changes can include hormonal and body changes, sleep disturbances and adjusting to new roles, responsibilities and identities as a pregnant and new mother.

It has been suggested that these changes may contribute to some women experiencing increased vulnerability to experiencing anxiety and depression in the perinatal period (Wenzel & Stuart, 2011). Approximately 10-20% of women experience anxiety or depression in the perinatal period (National Institute for Health and Care Excellence (NICE), 2014) and it has been estimated that perinatal mental health difficulties carry a cost to society of around £8.1 billion for each annual cohort of births (Bauer et al., 2014).

Impact of Perinatal Anxiety and Depression

Beyond the economic impact on the NHS, mental health difficulties in the perinatal period are an important public health concern as they can be associated with an increased risk of a range of negative effects, for both the mother and child. Problems with the mother's mental health may have an effect on pregnancy outcomes, compromise caregiving, and have become a leading cause of maternal death (Grigoriadis, et al., 2013; Field, 2010; Knight, et al., 2021).

A review of the data on women who died during or up to one year after pregnancy between 2017 and 2019 in the UK found that maternal suicide remains the leading cause of direct deaths occurring within a year after the end of pregnancy (Knight, et al., 2021). This report also highlighted the stark disparity in maternal mortality rates between women belonging to minoritised ethnic groups and White women, with Black women four times more likely to die in pregnancy or childbirth than White women for all causes.

Perinatal mental health difficulties can impact a mother's ability to bond with their baby and influence their attachment relationship (Slomian et al., 2019; McNamara et al., 2019; Göbel et al., 2018). According to attachment theory (Bowlby, 1969), the attachment relationship a child develops with their primary caregiver sets the template for later relationships and plays an important role in a child's psychological, cognitive and social development.

Mental Health Services in the UK

In 2008 the UK government introduced a large-scale, publicly funded programme for Improving Access to Psychological Therapies (IAPT) for adults experiencing anxiety disorders and depression within the NHS across England. This has dramatically increased the availability of evidence-based psychological therapies as a result of the IAPT model of access through self-referrals as well as referrals by general practitioners (GP) and its systematic implementation, with over 200 IAPT services across England (Wakefield et al., 2021).

Access to help for perinatal distress in the UK is usually through primary care services, such as GP, midwife or health-visitor. The UK differs from health care provision in most other countries due to services being provided free at the point of delivery. According to NICE guidelines on antenatal and postnatal mental health, pregnant women should be asked depression identification questions during their first contact with primary care (NICE, 2014.) However, a survey carried out in 2017 found that only 31% of respondents reported to have been asked by a GP about their mental well-being and whether additional support was needed (Royal College of Obstetricians and Gynaecologists, 2017).

The Five Year Forward View of Mental Health recommended that 30,000 more women each year should be supported to access evidence-based specialist mental health care during the perinatal period (Mental Health Taskforce, 2016). With this in consideration, the Perinatal Mental Health Care Pathways guidance highlights how specialist services fit within a wider system, including primary care and IAPT services as they are commissioned to provide evidence based psychological therapies to individuals during the perinatal period experiencing anxiety or depression, and the importance of partnership working (NHS England et al., 2018).

Ensuring all women receive access to the appropriate support during the perinatal period is seen as necessary to reduce the impact of perinatal mental health difficulties on maternal mortality, as well as on infant mental health and future adolescent and adult mental health (Public Health England, 2021; Howard & Khalifeh, 2020).

Help Seeking in the Perinatal Period

Following a review to investigate how help seeking for mental health difficulties has been conceptualised in the literature, Rickwood and Thomas (2012) concluded that no single definition existed. Instead, they proposed that help seeking for mental health difficulties could be defined as “an adaptive coping process that is the attempt to obtain external assistance to deal with mental health concerns” (Rickwood & Thomas, 2012, p. 180) and therefore is considered an important step towards improving quality of life. The authors further categorised sources of support as formal, informal or self-help (Rickwood & Thomas, 2012).

A number of theories have been applied to help seeking for mental health difficulties but no one theory has been widely accepted (Gulliver et al., 2012). Rickwood and colleagues (2005) developed a framework of the help seeking process for young people with mental health ‘problems’ and conceptualised seeking help as both a multi-step process and a social transaction between the personal domain of the internal world of thoughts and feelings and the interpersonal domain of social relationships. The framework maintains that help seeking begins with the individual's development of an awareness of difficulties and appraisal of having a problem that may need support, followed by the expression of the problem and a need for help to others, the availability of sources of help, and finally, the willingness of the individual to seek out and disclose to the potential source of help (Rickwood et al., 2005).

There are many factors that can influence an individual's help seeking, especially in terms of formal help. A systematic review of research examining the impact of the stigma associated with 'mental illness' on help seeking found that stigma has a clear, but small to moderate, detrimental impact on mental health related help seeking (Clement, 2015). This stigma has been distinguished by two dimensions: public stigma and self-stigma (Corrigan, 2004). Corrigan described public stigma as the harm that occurs when the general population agree with the negative stereotypes about 'mental illness', and self-stigma as the harm that occurs when an individual internalises these negative beliefs. Individuals can experience losses of self-esteem and self-efficacy through self-stigma (Bathje & Pryor, 2011), and shame, fear and embarrassment have been identified as common emotional responses for those affected (Link et al., 2004). It has been suggested that people who feel stigmatised may reduce their social contacts in order to avoid these negative experiences and decide not to seek diagnosis or treatment to avoid the label of 'mental illness' (Corrigan, 2004; Bathje & Pryor, 2001). This aligns with mental health disclosure theoretical models which explore how individuals with 'mental illness' try to manage the effects of stigma through disclosure-related decision-making (Chaudoir & Fisher, 2010; Pahwa et al., 2017).

Previous reviews focused on help seeking for depression, which might suggest a need for a review on anxiety alone. However, a preliminary search into help seeking in the perinatal period for anxiety yielded an insufficient number of papers to conduct a review on anxiety alone and to the author’s knowledge there are currently no reviews into help seeking in the perinatal period for anxiety. Research into help seeking in the perinatal period has focused on postnatal depression in non-UK samples and largely examines treatment preferences (Button et al., 2017). Button and colleagues (2017) carried out a review to understand the factors affecting women’s decision to seek help for perinatal distress in the UK in 2017. They identified three main themes: identifying a problem, the influence of healthcare professionals, and stigma. Their findings highlighted that continuity of care and trusting relationships with HCPs were important factors in help seeking and that the fear of being seen as a ‘bad mother’ and of being stigmatised for not being able to cope resulted in mothers ‘self-silencing’ (Button et al., 2017). While the scope of their review included the broad term of perinatal distress, the studies included focused only on PND and studies before the implementation of IAPT, ranging from 1993 to 2015. The authors called for future research to explore help seeking in other ‘conditions’, such as ‘anxiety disorders’.

Given the frequent co-occurrence of anxiety and depression, and the potential for some common difficulties in seeking help, there is a rationale to consider both types of mental health difficulty in a single review. By focusing on qualitative papers on perinatal anxiety as well as depression that have been carried out since the inception of IAPT services, this review offers a more comprehensive review of the literature as it relates to help seeking in the UK in the last 14 years. Qualitative literature contributes to understanding the experiences of individuals or groups and the context in which these experiences are situated (O'Brien et al., 2014) and aims to provide a rich, contextualised understanding of some aspects of experience (Polit & Beck, 2010). As this review aimed to get a better understanding of help seeking from the perspective of mothers, qualitative papers were most appropriate to address the aims.

Currently, no similar recent reviews exist. Papers from Button and colleagues' (2017) review that met the inclusion criteria were included due to the different purposes of the present review and it allowed for a systematic review of existing literature.

Aims

With the above in mind, this review considers the following question:

1) What does research suggest are the barriers and facilitators of help seeking for perinatal anxiety and depression from the perspective of mothers in the UK?

Methods

A preliminary search was carried out using Google Scholar and an initial review of the literature found that multiple terms were used for 'help seeking' and 'perinatal' and that there were limited papers examining help seeking for anxiety in the perinatal period. An electronic database search was then conducted in February 2022, which included searches of five databases: Psychinfo, PsycArticles, Medline, CINAHL and ASSIA. The search terms used were: ("help-seek*" OR "help seek*" OR "seek* treatment" OR "seek* help) AND ("anxiety" OR "depression" OR "OCD" OR "obsessive compulsive disorder" OR "panic" OR "phobia") AND ("perinatal" OR "post partum" OR "postpartum" OR "prenatal" OR "antenatal" OR "maternal"). Truncation symbol (*) was utilised to ensure papers were not missed as a result of various terms.

Due to the nature of the review, databases were searched since 2008 to capture the most up-to-date papers and papers since the introduction of IAPT services. Although categorised as an 'anxiety disorder', papers focusing on post-traumatic stress disorder (PTSD) were not included in this review. As PTSD often follows a psychologically traumatic event and therefore can have a recognisable point of onset (Shalev, 2009), health care practitioners (HCPs) may be more aware of the triggering events and it was therefore excluded because of this potential influence over HCPs' detection of distress and mothers' help seeking.

Initial results from the database search produced 314 papers. Papers were exported to RefWorks in order for duplicate records to be removed, although some were not removed by the automated database function but removed manually later in the review process, of which there were 81 in total. Papers were screened through a process of screening titles, abstracts and then full texts using the inclusion and exclusion criteria. Reference lists of identified papers were hand-searched and an additional 5 papers were found. Relevant papers from the review by Button et al (2017) were included in the review. The search process has been illustrated in Figure 1 (based on PRISMA; Page et al., 2020) and a summary of the papers included has been provided in Table 1.

Inclusion and exclusion criteria

The inclusion criteria consisted of:

- Papers available in English
- Published in a peer reviewed journal and conducted in the UK
- Papers that focused on perinatal women (pregnant and/or women who had given birth in the last 12 months at the time of the study) experiencing anxiety or depression
- Papers that reported on mental health help seeking for women experiencing perinatal anxiety/depression
- Mothers who were at least 18 years of age or older
- Qualitative papers

The exclusion criteria consisted of:

- Papers that did not report the proportion of mothers experiencing anxiety and/or depression or where mothers experiencing anxiety and/or depression were less than 50% of the sample
- Papers that focused on psychological distress more broadly or other perinatal mental health difficulties e.g. post-traumatic stress disorder (PTSD).
- Papers were excluded if they did not discuss or report evidence regarding help seeking or if participants had not experienced distress.
- Quantitative papers
- Papers out of the date range
- Reports of studies conducted outside of the UK
- Papers that did not focus on the mothers' perspectives e.g. the fathers' or HCPs'
- Commentaries, theoretical papers and news pieces.

Figure 1

PRISMA Diagram of Search Strategy

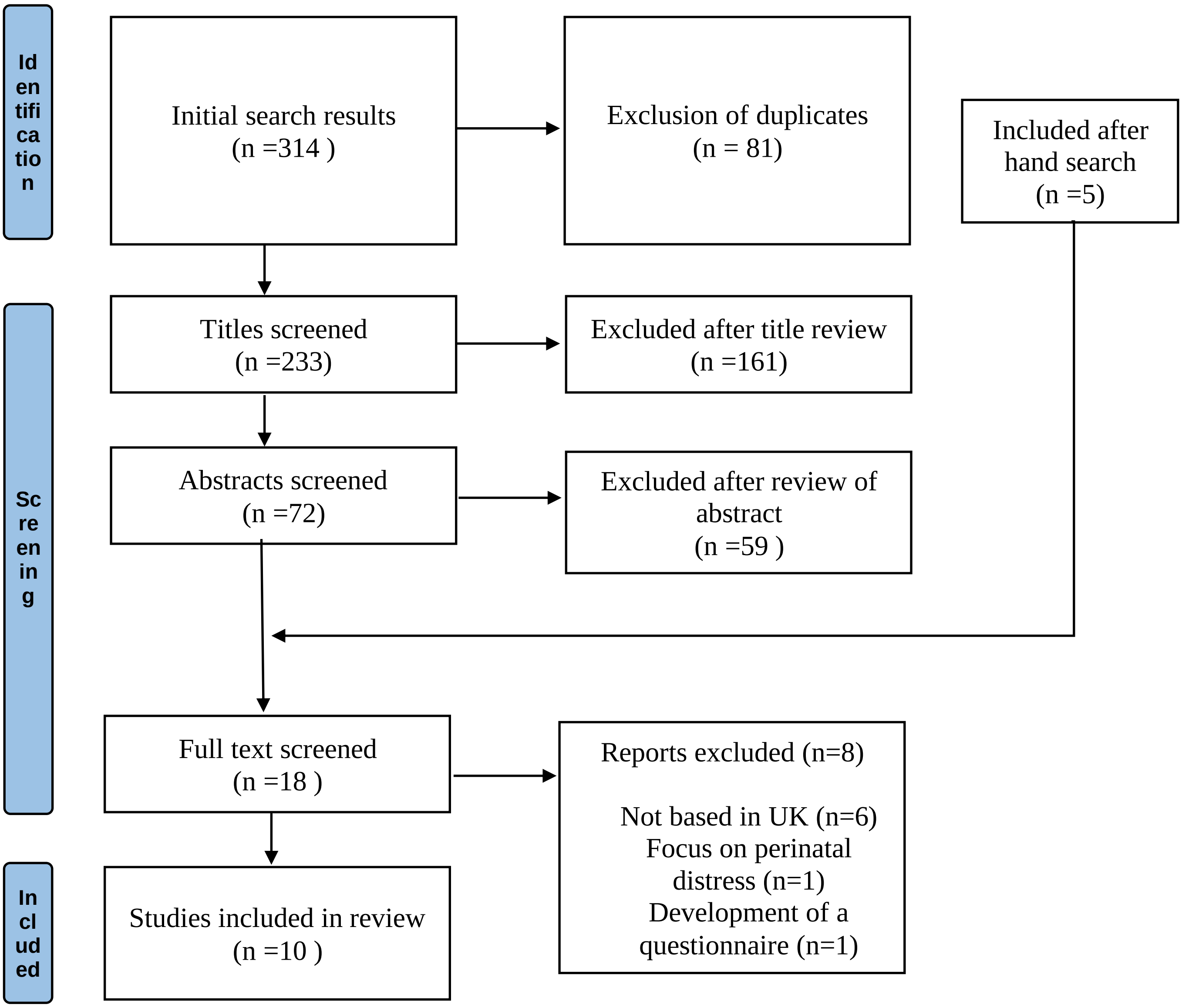

Table 1

Summary of study characteristics

Authors, date	Title	Participants	Measures, analysis	Mental health difficulty	Findings relevant to review	Limitations
(Burton, 2021)	How women with established obsessive compulsive disorder experience pregnancy and postpartum: an interpretative phenomenological analysis	**Participants:** 5 women aged between 26 to 40 (M= 33.6). All white British. All women had been pregnant within the last three years. **Sampling strategy:** Opportunistic sampling through Facebook OCD support groups and Twitter	**Measures:** Demographic information. Dimensional Obsessive Compulsive Scale (DOCS) (Abramowitz, et al., 2010) Semi-structured interviews. **Analysis:** Interpretive phenomenological analysis (IPA) (Smith, 1996)	All were diagnosed with OCD. All currently receiving therapy/medication or previously had received therapy/medication	Seeking professional help was difficult Participants did not trust that their doctor would understand; some were fearful that their child(ren) would be taken away	Reliance on participant self-report for diagnosis. Did not screen for other mental health difficulties. Analysis not verified by a second researcher. Sensitive and stigmatised topic: potentially vulnerable women who were acutely distressed may not have participated. Findings cannot be generalised as the study used a small homogenous self-selected sample of highly educated, white British women. Retrospective and

						relied on accurately recalling feelings and experiences up to 3 years previous.
(Oh, et al., 2020)	Exploring women's experiences of identifying, negotiating and managing perinatal anxiety: A qualitative study.	**Participants:** 17 women aged between 25 to 42 years (M= 33). Ethnicity not provided. **Sampling strategy:** Opportunistic sampling through social media platforms (Twitter and Facebook), maternal support groups, community-based services in local NHS trust, public libraries and children's centres.	**Measures:** Demographic information. Semi-structured interviews **Analysis:** Constant comparative analysis method (Fram, 2013)	Self-reported anxiety during pregnancy and/or up to 12 months after birth	Two of the three main themes were concerned with help-seeking; barriers to disclosing PNA and help-seeking for PNA. Participants reported stigma (with internal and external sources) and missed opportunities as factors preventing disclosure of mental health concerns Participants reported having their concerns dismissed by others as a factor preventing disclosure. Participants reported to perceive maternal depression as more acceptable Decisions to seek help were initiated	Lack of demographic information. Reported lack of diversity. Those experiencing acute distress may have been reluctant to self-identify. Majority were members of local support groups so were already linked into support systems.

					following the realisation that anxiety was impacting daily life, childcare responsibilities or after experiencing physical symptoms. Double stigma Lack of continuity of care limited the extent to which participants could develop positive relationships with clinicians. Other factors that supported a positive relationship with HCP included giving time to explore concerns, displayed compassion and empathy.	
(Harrison, Moore, & Lazard, 2020)	Supporting perinatal anxiety in the digital age; a qualitative exploration of stressors and support strategies	**Participants:** 23 women aged between 25 to 45 years (M= not provided). Pregnant or had had a baby in the last 12 months. Ethnicity: White British (N=16), White New Zealander (N=2), White European (N= 3), White & Black	**Measures:** Focus groups using semi-structured interviews **Analysis:** Inductive thematic analysis from a realist stance (Braun and Clarke, 2006)	Self-reported anxiety in perinatal period. Rated anxiety from 1 to 5 (none, mild, moderate, severe, extremely severe)	Internal and external stigma acted as a barrier to help-seeking. Many felt reluctant to disclose symptoms to HCP due to fear of being seen as a bad mother and that there may be negative consequences (e.g.,	Findings may not be generalisable due to lack of diversity. Participants self-selected through online adverts so may have more motivation to explore online support for PNA.

		African (N=1), Black African (N=1). **Sampling strategy:** Convenience sampling through advertising on social media and relevant forums (e.g., MumsNet) and via local mum and baby groups.		(M=2.65); and (2) how much this distressed them (1 = not at all; 5 = severely) (M=2.52).	that their baby may be taken away). Women felt that prenatal support from HCPs was generally good, but that there was little support postnatally. It was thought that postnatal mental health screening measures were focused on PND. Lack of knowledge about PNA and maternal mental health as a barrier to seek support.	
(Hore, Smith, & Wittkowski, 2019)	Women's experiences of anxiety during pregnancy: An interpretative phenomenological analysis	**Participants:** seven women aged 28 to 39 (M= 32), all White, employed and living with a partner or husband. **Sampling strategy:** Opportunistic sampling with women attending antenatal clinics and through online advertisements (Twitter, Facebook and pregnancy forums).	**Measures:** Semi-structured interviews **Analysis:** IPA (Smith, Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology, 1996)	Self-reported anxiety during current pregnancy	All women commented on the importance of building a relationship with just one mid-wife to establish trust. Not knowing the midwife acts as a barrier for the disclosure of anxieties. Having one midwife allowed for conversations about mental health to develop rather than be a 'tick box' question.	Findings may not be generalisable due to a lack of diversity.

(Hannan, 2016)	Older mothers' experiences of postnatal depression	**Participants:** Four women aged 30 to 35 years (M= not available), all White, middle-class, highly educated and married. **Sampling strategy:** Opportunistic via social media platforms of PND support organisations (details not provided).	**Measures:** Interviews on two separate occasions **Analysis:** IPA (Smith, Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology, 1996)	Self-reported depression within four weeks of giving birth to the child and had now recovered.	Participants were aware of stigma attached to mothers with PND and had mixed feelings about letting other people know of their difficulties.	Findings may not be generalisable due to the lack of diversity of the sample.
(Gardner, Bunton, Edge, & Wittkowski, 2014)	The experience of postnatal depression in West African mothers living in the United Kingdom: A qualitative study	**Participants:** Six Black West African mothers aged 22 to 36 years. **Sampling strategy:** Convenience sampling through NHS team.	**Measures:** Semi-structured interviews The Edinburgh Postnatal Depression Scale (EPDS; Cox, Holden, & Sagovsky, 1987) The depression module of the non-patient version of the Structural Clinical Interview for DSM-IV (SCID) (Spitzer, Williams, Gibbon, & First, 1992) **Analysis:** IPA (Smith & Osborn, 2008)	Score of 10 or above on the EPDS (Cox, Holden, & Sagovsky, 1987)	Participants stated that their cultural background made it difficult to disclose feelings of depression thus adversely influencing help-seeking. Conceptualisation of PND may be different in West African women compared with Western views; women may not recognise their experiences as an illness that they need help for. Participants described distrust of others and they	Participants had received treatment, involvement with services may have influenced participants' experiences. Although the EPDS has been validated in West African populations (Uwakwe & Okonkwo, 2003), there may be some difficulties in accurately detecting 'PND' symptoms.

					therefore could have chosen not to present emotional problems to health professionals for fear of being stigmatized The West African tradition of the extended social network caring for the mother and baby was not experienced in the UK, yet services could be viewed as ‘maternal African figures’, replacing this level of support. If the level of care did not meet expectations, it led to cultural dissonance in expectations of services and can intensify feelings of being let down.	
(Patel et al., 2013)	An exploration of illness beliefs in mothers with postnatal depression	**Participants:** 11 women aged between 22 to 35 years (M= 29.4), all white British. **Sampling strategy:** purposive sampling through two perinatal services.	**Measures:** Demographic information Semi-structured interviews EPDS (Cox et al., 1987)	Women diagnosed with depression who scored over 10 on the EPDS (Cox et al., 1987), and with babies	Mothers described reaching a crisis point before seeking help, and disclosed their difficulties to their most accessible HCP where these were ‘medicalised’. The delay in	EPDS has been criticised for not detecting PND accurately. Findings may not be generalisable due to the lack of diversity of the sample.

			Analysis: Grounded Theory (Charmaz, 2006)	up to 24 months old.	seeking help seemed to be due to the risk of being a ‘bad mother’ and others thinking badly of them or judging them.	
(Edge & MacKian, 2010)	Ethnicity and mental health encounters in primary care: help-seeking and help-giving for perinatal depression among black Caribbean women in the UK.	**Participants:** 12 women ages between 18 to 43 years, all Black Caribbean **Sampling strategy:** Purposive and theoretical sampling through a larger study who were recruited at community clinics and a teaching hospital.	**Measures:** Interviews **Analysis:** Constant comparison (Glaser, 1978)	Women with a range of depression scores as measured by the EPDS	Only when self-reliance and social networks failed to meet their needs did they seek help from formal healthcare providers. Only two of the 12 women sought help from services. Reluctance to engage with services was often based on previously negative interactions with healthcare providers. Cultural factors as powerful barriers to help-seeking (emphasis on self-efficacy, fear of stigmatisation and social imperatives to be ‘Strong-Black-Woman’. More likely to seek help from spiritual and religious sources. Sought help from	Limited sample size, use of a single ethnic group and inner-city population may affect generalisability

					services as a last resort but then faced with structural barriers (long waiting lists and unavailability of culturally competent therapists)	
(Slade et al., 2010)	Postnatal women's experiences of management of depressive symptoms: a qualitative study	**Participants:** 30 women. No information about ethnicity. **Sampling strategy:** Purposive sampling through a larger study who were recruited by their HV at GP practices participating in the study.	**Measures:** Semi-structured interviews **Analysis:** Template Analysis (King, 1998)	Women with an EPDS score ≥18, indicating a high probability of clinical depression.	Three processes seemed to influence help-seeking; 1) recognising difficulty and acting on this, 2) seeking help indirectly e.g. presenting a concern about the infant, 3) responding to advice from others that they needed help. **Barriers:** women found the help seeking process difficult, especially 'admitting' to needing help and the implication of failure. Women were afraid that their infant might be taken away from them. Perception of the HV as someone they could not	No information about participant ethnicity. No participant validation.

					relate to emotionally or what was not well known to them acted as a barrier.	
(Edge, 2008)	We don't see Black women here': an exploration of the absence of Black Caribbean women from clinical and epidemiological data on perinatal depression in the UK	**Participants:** 12 women age between 18 to 43 years, all Black Caribbean **Sampling strategy:** Purposive from a larger quantitative study on the basis of theoretical sampling, through a teaching hospital.	**Measures:** Interviews **Analysis:** Constant Comparative Approach (Glaser, 1978)	Women with an EPDS score ≥12	Identified social, structural and personal barriers Unfamiliarity with depression in general and perinatal depression in particular makes it unlikely that women will recognise their symptoms and unlikely be able to explain to HCP. HV's focus on their babies gave little scope for dealing with women's needs.	Generalisability of findings

Results

Quality Appraisal of Papers

The quality of the final papers was appraised using the Critical Appraisal Skills Programme (CASP) Qualitative checklist (CASP, 2018). The CASP tool is a commonly used checklist for quality appraisal in health and social care-related qualitative evidence syntheses (Dalton et al., 2017) and was designed for appraising the strengths and limitations of qualitative literature. The checklist was not designed as a scoring system and was used as a way of reflecting on the studies and the conclusions that were drawn. A summary checklist of quality appraisal for each paper can be found in Table 2.

The search yielded 10 papers. Most papers addressed a majority of the CASP criteria, with notable limitations in describing ethical considerations and consideration of the relationship between researcher and participants. Despite these limitations, all 10 papers presented direct quotations in their results and were considered to be of sufficient quality to be included in the review.

Aims and Method

All 10 were appraised to have clearly stated their aims and appropriately chosen a qualitative method to answer the research aims.

Research Design

The research designs chosen to address the aims of the research, while appropriate, were not consistently strong, with only four studies clearly justifying how they decided which method to use (Oh et al., 2020; Harrison et al., 2020; Gardner et al., 2014; Patel et al., 2013).

Sampling and Data Collection

The three main sampling strategies used were opportunistic, convenience and purposive and most studies either met or partially detailed how and why a certain participant was selected. These strategies limit the transferability of the findings. Sampling and self-selection biases may arise from recruiting participants through social media sources.

Data collection processes were described in varying detail, with two papers providing no information about the interview schedule or setting (Patel et al., 2013; Hannan, 2016), some papers describing the broad areas that interview schedules covered (Hore et al., 2019; Gardner; Edge & MacKian, 2010; Edge, 2008) and three studies providing the interview schedule (Oh et al., 2020; Harrison et al., 2020; Slade et al., 2010).

Reflexivity and Ethical Considerations

Papers were mixed in their reporting of researcher reflexivity. Six papers made no reference to the relationship between the researcher and participants, therefore, the impact of researcher bias is unclear. Of the papers that did report on researcher reflexivity, one paper partially met the criteria (Burton, 2021) by stating that the author remained reflexive throughout the interview process but did not explain how this was achieved. One paper outlined how the authors used techniques of bracketing and self-reflection to reflect on their personal and professional experiences to mitigate how this might influence the analysis (Harrison et al. 2020). Two papers outlined how the research team similarly reflected on their backgrounds and how this might influence the research process. One of these papers also clearly described how this might have impacted the analysis for one author more (e.g. one author (Hore et al., 2019) was a man with no experience of pregnancy or parenting who may have brought a potentially different perspective, as well as professional knowledge of anxiety as a clinical psychologist) and less so for the others authors (Hore et al., 2019), the other paper provided a clear description of the author who analysed the data (Patel et al., 2013).

Ethical issues were at least partially addressed for all papers. All papers stated that ethics approval was obtained from a relevant ethics committee and informed consent processes were referenced. Only one paper described offering debriefing following participation and mentioned a risk protocol in the event of risk disclosure (Oh et al., 2021) and one paper offered participants a contact sheet with numbers to contact if they felt upset by the interview (Burton, 2021).

Data Analysis and Findings

All papers clearly stated their findings in relation to the aims of the research and discussed the limitations. Several forms of analysis were used (see Table 1). IPA was the most common analysis (four papers), followed by thematic analysis (two papers), constant comparative analysis (two), grounded theory (one) and template approach (one). At least partial fulfilment for rigour of analysis was met for all papers and fully met for two (Patel et al., 2021; Harrison, 2020). All 10 studies outlined their analysis process, with only two studies providing an in-depth description (Hore et al., 2019; Slade et al., 2010). All of the studies gave samples of verbatim text to demonstrate their findings but the majority of the studies did not examine the influence of the researcher during analysis.

Value of Research

According to the CASP framework (2018), the value of research is appraised upon three main criteria: whether the findings further existing knowledge or understanding; whether recommendations for future practice or research are suggested; and whether the findings may be transferred to other populations has been addressed. All of the studies addressed at least two of these areas, most often discussing the findings in relation to current practice and/or relevant research or by commenting on the limited transferability of findings. When discussing the limited transferability of findings, studies referenced the use of small homogenous samples, the healthcare system in the UK and intensity of symptoms (Burton, 2021; Harrison et al., 2020; Patel et al., 2013; Edge & MacKian, 2010; Edge, 2008; Hore, 2019; Slade et al., 2010). Three studies did not suggest recommendations for future practice or research (Burton, 2021; Hore; 2019; Edge, 2008).

Table 2

CASP checklist for qualitative studies

Paper	CASP Criteria									
	Clear Aims?	Qualitative methodology appropriate?	Research design appropriate?	Recruitment strategy appropriate?	Data collection appropriate?	Relationships considered?	Ethical issues considered?	Data analysis rigorous?	Clear findings?	Valuable contribution?
Burton, 2021	Yes	Partially	Partially	Partially	Partially	Partially	Yes	Partially	Yes	Partially
Oh, et al., 2020	Yes	Yes	Yes	Partially	Yes	No	Yes	Partially	Yes	Yes
Harrison, Moore, & Lazard, 2020	Yes	Yes	Yes	Yes	Yes	Yes	Partially	Yes	Yes	Yes
Hore, Smith, & Wittkowski, 2019	Yes	Yes	Partially	Yes	Partially	Yes	Partially	Partially	Yes	Partially
Hannan, 2016	Yes	Yes	Partially	Yes	No	No	Partially	Partially	Yes	Yes
Gardner, Bunton, Edge, & Wittkowski, 2014	Yes	Yes	Yes	Partially	Partially	No	Partially	Partially	Yes	Yes
Patel et al., 2013	Yes	Yes	Partially	Yes	No	Yes	Partially	Yes	Yes	Yes

Edge & MacKian, 2010	Yes	Yes	Partially	Yes	Partially	No	Partially	Partially	Yes	Yes
Slade et al., 2010	Yes	Yes	Yes?	Yes	Yes	No	Partially	Partially	Yes	Yes
Edge, 2008	Yes	Yes	Partially	Yes	Partially	No	Partially	Partially	Yes	Partially

Synthesis of findings

Approach to Synthesis of Findings

Following quality appraisal, a thematic synthesis was conducted using the qualitative findings of the 10 studies following the method outlined by Thomas and Harden (2008). In an attempt to synthesis qualitative research, Thomas and Harden describe a three-stage process which was adhered to in the present review. First, all relevant data from the results/findings section of each of the 10 studies were extracted and imported into NVivo Qualitative Data Analysis Software. Line-by-line coding was then used and the resulting codes were reviewed for similarities and differences in order to develop descriptive themes that remained 'close' to the original texts. The third stage involved the development of analytical themes, through a degree of researcher interpretation.

Synthesis of Findings

Four themes were developed from the analysis: stigma, making sense of experiences, relational factors and structural barriers. Each theme described barriers and/or facilitators related to help seeking for anxiety or depression in the perinatal period. A full description of themes developed with example quotations is presented in appendix A. Synthesised findings are described below with subthemes in bold.

Four papers examined anxiety, of which one focused on OCD, and six papers examined depression (as outlined in table 1). Two papers did not report the ethnicities of the participants, five papers recruited participants who were all or mostly White and three papers purposively recruited Black Caribbean or west African participants (also outlined in table 1). Table 3 presents the themes and subthemes and the papers in which they were found and a more detailed table can be found in appendix A.

Table 3

Summary of themes and subthemes

Theme	Subtheme	Burton (2021)	Oh et al., 2021	Harrison et al., 2020	Hore et al., 2019	Hannan, 2016	Patel et al., 2013	Slade et al., 2010	Edge, 2008	Gardner et al., 2014	Edge & MacKian, 2020
Stigma	External	*x*	*x*	*x*	*x*	*x*	*x*	*x*	*x*	*x*	*x*
	Internal	*x*	*x*	*x*		*x*		*x*			
	‘bad mother’			*x*	*x*	*x*	*x*	*x*			
Making sense of experiences	Lack awareness of PMH	*x*	*x*	*x*	*x*			*x*			
	Conceptualisation of depression								*x*	*x*	*x*
Relational factors	How HCPs respond		*x*		*x*	*x*		*x*	*x*		*x*
	Relationship with HCP		*x*		*x*	*x*		*x*	*x*		*x*
Structural barriers	NHS systems			*x*	*x*				*x*		*x*
	Culturally sensitive services								*x*	*x*	*x*

Theme 1: Stigma

The theme ‘stigma’ described how the women experienced different forms of stigma and its role as a barrier to help seeking.

The impact of **external stigma** on help seeking was described in all of the papers. Women in all 10 papers expressed a fear that they would be judged negatively if they discussed their mental health with a HCP (‘Women were reluctant to openly discuss their mental health concerns with HCPs for fear of being judged’ – Oh et al., 2021). In three of the papers, external stigma manifested in a fear that their baby would be taken away if they shared their mental health difficulties (“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.” – Burton, 2021).

The impact of **internal stigma** as a barrier to help seeking was described in five papers. Some women shared experiencing feelings of shame, embarrassment and guilt and how this acted as a barrier to seeking help as it influenced them to conceal their difficulties (“[I told] few of my close friends, but no, not really because you sort of hide it, don’t you? You’re just, like, embarrassed." – Oh et al., 2021).

The stigma associated with mental health appeared to be heightened for some of the mothers and incompatible with their idea of a ‘good mother’, resulting in fear that they would be seen as a **‘bad mother’** if they shared their difficulties with a HCP. This was described in six of the papers and manifested in denial and concealment of symptoms and delayed help seeking (“I felt like I couldn’t talk to anyone about it, because I didn’t think it was normal and I felt like it was me not being a good mum – Harrison et al., 2020) and was linked to a sense of failure (“Women found the help seeking process difficult, especially ‘admitting’ to needing help and the implication of failure – Slade et al., 2010).

The findings for this theme were similar across papers looking at different kinds of mental health difficulties.

Theme 2: Making sense of experiences

The theme ‘making sense of experiences’ described how some of the mothers’ lack of ‘awareness’ of certain ways of understanding difficulties and their conceptualisations of depression acted as a barrier to help seeking.

Four of the papers reported that **mothers lacked awareness about perinatal mental health.** Lack of awareness was said to present a barrier to the mothers in all the papers examining anxiety and one paper examining depression in making sense of their experiences and seeking help. This was particularly reported for the mothers who had experienced perinatal anxiety, as there seemed to be some awareness of PND (“I kept reading the books… and one page was on postnatal depression. I was like I haven’t got any of the symptoms, if anything I’m really happy but I’m not.” – Harrison et al., 2020).

Three papers suggested that **conceptualisations of depression** for mothers within different cultural contexts resulted in an additional barrier to seeking help within the NHS: ‘Although participants [from Black West African origin] experienced symptoms of PND, their conceptualisations differed to Western views, attributing it to social stress instead.’ (Gardner et al., 2014). Three papers suggest that Black Caribbean and West African mothers may not use the language of ‘depression’ to describe their experiences and therefore HCPs may not be aware of the culturally appropriate terminology that these mothers might use when seeking help. The papers focusing on PNA recruited mainly White British participants and did not comment on the mothers’ conceptualisation of anxiety.

Theme 3: Relational factors

The theme ‘relational factors’ described how relationships with HCPs could influence help seeking.

In terms of **how HCPs respond to mental health** with mothers, seven papers described how their conversations and responses could act as a barrier for seeking further support. Some mothers who had experienced anxiety highlighted that mental health had been discussed with them in a ‘tick box’ way (“I mean they ask me about it in general terms (sighs) when I go to an appointment. They have sort of a ‘tick box’ they do every now and again.” – Hore et al., 2019). Other mothers described how their initial concerns about their mental health had been dismissed by HCPs ("You daren’t say when you’re shot down the moment you speak up. You can’t then go on to how bad you’re feeling […] because people say, ‘Oh no, no, it’s the norm. It’s the norm.’ And they just shoot you down." – Oh et al., 2021).

Mothers in five papers also talked about the role of **how HCPs respond** in facilitating help seeking. Having a non-judgemental approach, being empathic and giving mothers time and space to talk about their concerns were identified as ways that HCPs had responded and supported them to disclose mental health concerns (“She could tell there was something wrong. Because when I went in I wasn’t crying when I actually went in but she could tell there was something wrong and she got talking to me then. So she was quite nice.” – Hore et al., 2019).

The **relationship with HCPs** appeared to have the potential to both facilitate and act as a barrier to help seeking. Mothers in three of the papers described how continuity of care with the same HCP provided the opportunities to build trust, which facilitated disclosure of their mental health concerns (“‘I always ask to speak to [health visitor] because I know her and it’s easier really if you know somebody.’ – Slade et al 2010). Having the same HCP also seemed to allow conversations about mental health to develop and therefore prevent the previously mentioned ‘tick box’ experience. In three papers mothers discussed the HCP’s focus on the baby and how this made them feel invisible and that there was little space for their needs to be considered (‘It seems the women became objectified as mothers and lost their own personhood and identity. The prioritising of the child overshadowed the needs of the woman herself, who became lost in the process.’ – Hannan, 2016).

Mothers in four papers discussed how the **relationship with HCPs** acted as a significant barrier to help seeking, or rather the lack of a relationship. When continuity of care was not experienced, mothers reported that it was difficult to build a relationship with the HCP and this was similar across mental health difficulties. As a result, mothers felt unable to disclose their difficulties and seek help ("I didn’t want help from someone I didn’t know, like I didn’t know my Health Visitor, I didn’t know my Midwife, cause that’s the thing with like, it’s just the way with the NHS now, you don’t know the person that’s taking care of you, you don’t build a relationship with them, so why am I going to talk to that person?" – Oh et al., 2021). In one paper the majority of mothers discussed how previous negative interactions with HCPs impacted on their willingness to seek help in the future (“…And from then on, I just don’t go ... I just don’t go. If I’m ill, I really do not go to the doctors. I’d rather sit here in pain” – Edge & MacKian, 2010).

Theme 4: structural barriers

The theme ‘structural barriers’ described the organisational and systemic barriers to help seeking. Mothers in six of the papers made comments that could refer to **NHS systems** and **culturally sensitive services**.

Mothers in several papers commented on aspects of **NHS systems** that made help seeking more difficult. This included long waiting lists, appointments feeling ‘rushed’, having to be proactive in seeking help and limited opportunities for continuity of care ("I'd had my initial appointment with the midwife or health visitor, whoever it was, but it was so rushed. They didn't get it. I had to contact my GP myself to ask, y'know, to be put on the mental health service lists… but y'know, nobody contacted me. I waited for like 3 weeks…" – Harrison, 2020).

Mothers in the majority of papers were White British, although three papers were interested in the experiences of West African and Black Caribbean mothers. The mothers in these papers shared concerns about the ability to access **culturally sensitive services**. Some mothers shared concerns about being allocated a therapist from outside their ethnic or cultural group and how helpful their responses might be ("And that's the bottom line. It's about having someone who you can chat to who understands where you're coming from" – Edge, 2008).

Discussion and Limitations

This review aimed to synthesise the findings of papers that investigated factors that acted as barriers or facilitators to help seeking among women experiencing perinatal anxiety and depression in the UK. This was achieved by performing a systematic literature search, quality appraisal and thematic synthesis. Four themes emerged: *stigma, making sense of experiences, relational factors* and *structural barriers*. Key findings are discussed in relation to existing literature, followed by strengths and limitations of the review. Finally, the implications for practice and research are discussed.

The themes of stigma, making sense of experiences, relational factors and structural barriers were consistent with previous research. In seeking help for depression, Button et al. (2017) placed an emphasis on the role of stigma, relationships with HCPs and structural factors inherent in the NHS, and similarly described stigma as influencing women to worry about being judged by others, to judge themselves and deter them from seeking help. Continuity of care, culturally sensitive services and the importance of HCPs demonstrating a non-judgemental approach in facilitating help seeking were also replicated findings, and extended to anxiety, which was not covered in Button et al. (2017).

As there are no reviews of help seeking for anxiety in the perinatal period, the findings in the current study add to our understanding of the barriers and facilitators and suggest some similarities and differences to those seeking help for depression. In terms of mental health presentations, the four themes were common across papers examining depression and anxiety and stigma was the only theme present in all papers, reported as a barrier to help seeking in its different forms. All the papers cited external stigma as a key barrier to help seeking, with women choosing to not discuss their experiences of mental health difficulties for fear of being judged negatively and/or fear that their baby would be taken away. Differences between mental health presentations were found within the subtheme internal stigma, as three of the four papers that focused on anxiety difficulties cited internal stigma as a barrier as women judged themselves harshly and concealed their experiences from HCPS and others in their network. The subtheme of lack of awareness about perinatal mental health was also found in all papers focusing on anxiety and only one paper focusing on depression.

The theme of stigma was consistent with previous research and the subthemes of external and internal stigma fit with Corrigan’s (2004) dimension of public and self-stigma. Stigma has been reported as a reason for not seeking help for mental health difficulties among numerous populations including groups from minoritised ethnicities (Gary, 2005; (Mantovani et al., 2016). Unrealistic, idealised expectations of motherhood are widely acknowledged as contributory factors for women who experience mental health difficulties to perceive themselves as ‘bad mothers’ (McLoughlin, 2013). Some mothers in the studies referred to feeling under pressure to live up to the image of a ‘perfect mum’ as often portrayed by social and mainstream media (Harrison et al., 2020, p. 5) and correlated their mental health difficulties with a sense of failure and an indication that they were not ‘good enough’ mothers.

It is well documented that anxiety in the perinatal period has received limited research attention compared to depression (Field, 2018; Loughnan, et al., 2018). The findings in the current review suggest that while mothers struggling with anxiety in the perinatal period have some awareness of depression, they struggled to make sense of their experiences as ‘symptoms’ of anxiety and experienced feelings of shame, embarrassment and guilt. ‘Mental health literacy’ was discussed in one paper as a barrier to help seeking for anxiety (Harrison et al., 2020). This has been described as the knowledge and beliefs about mental health difficulties which can aid their recognition, management and prevention (Jorm et al., 2006). It has been suggested as a factor that can decrease an individual’s self-stigma (Crowe et al., 2018) and the majority of public health interventions have aimed to promote mental health literacy (Griffiths et al. 2014; Mehta et al., 2015). However, recent research suggests that internal stigma may decrease or increase depending on the different discourses around ‘mental health literacy’ (Van Beveren, et al., 2020). Van Beveren and colleagues (2020) examined the media portrayal of ‘mental illness’ in six European countries and how this related to different understandings of mental health literacy. They highlighted that the promotion of the biomedical approach to mental health difficulties through increased mental health literacy does not necessarily lead to an increase in social acceptance (Van Beveren et al., 2020) but can instead perpetuate perceptions of ‘dangerousness’ and unpredictability (Read et al., 2016).

The theme of relational factors as both a barrier and facilitator to help seeking was consistent with previous research. Continuity of care has previously been identified as a facilitator to help seeking in the perinatal period (Vivieros et al., 2018) and has been promised in the NHS Long Term Plan (NHS England, 2019) having been reported as the single biggest request of women during the National Maternity Review (NHS England, 2016). The findings of this theme are also consistent with evidence of the negative impact that dismissive attitudes and baby-centredness have on help seeking (Viveiros & Darling, 2018).

The theme of structural barriers to help seeking was consistent with previous research. It has been argued that the NHS is stretched in terms of finances, staffing and facilities following the longest period of austerity in its history and the consequences of Brexit, and more recently the coronavirus pandemic (Paton, 2022), although the papers reviewed gathered data before the pandemic. Austerity has led to longer waiting lists across the NHS (O'Dowd, 2017), with waiting times for psychological therapies through IAPT services commonly reported as 18 weeks (Punton et al., 2022). Inadequate resources including limited service provision and staff shortages have previously been identified by HCPs as barriers to providing support for women with perinatal MH difficulties (Sambrook Smith et al., 2019).

Disparities exist in access to mental health services for people from minoritised backgrounds in the UK (Memon et al., 2016). Such disparities have been attributed to factors such as perceived discrimination and prejudices (Chen & Yang, 2014), with unequal access to care (Ajayi, 2021) and are in the context of disproportionate rates of admission to mental health inpatient units (HM Government, 2021). Given this background, extra attention is warranted to understand the additional barriers that mothers from minoritised backgrounds may face when needing help, such as HCPs holding different conceptualisations of mental health difficulties.

The quality of papers varied according to the CASP (2018) tool, with some papers providing a clear and in-depth analysis of mothers' experiences, and others lacking in clarity of researcher reflexivity, methodology and sampling strategies that may have introduced biases to the findings. However, findings tended to be similar across papers of different quality. Although these papers highlight barriers and facilitators to help seeking for anxiety and depression in the perinatal period, only small samples were used, which may not fully represent this population of mothers in the UK. However, the goal of qualitative studies is not to produce generalisable findings but rather to provide a rich, contextualised understanding of some aspects of experience (Polit & Beck, 2010).

Limitations and strengths

The number of papers included in this review (10) is small. While three of the papers focused on minoritised groups (Black Caribbean and West African) there are many other minoritised groups in the UK whose voices were not included.

Qualitative quality appraisal tools have been critiqued for being based on broad criteria that do not account for important differences between methodological approaches (Williams et al., 2021). It may have been useful to consider the use of a modified CASP tool to appraise the papers' theoretical underpinnings (Long et al., 2020). The CASP tool can also be criticised for not taking into account whether an adequate description of the sample has been provided. However, as previously mentioned, it is the most widely used checklist for quality appraisal in health and social care-related qualitative evidence syntheses (Dalton et al., 2017) and broadly captures key aspects of the strengths and limitations of any qualitative research methodology (Long et al., 2020).

While the thematic synthesis methodology offers a transparent process for the synthesis of studies, it is worth noting that thematic synthesis involved some re-interpretation of the authors' interpretation of their findings. It is possible this introduced a degree of bias to the findings. To mitigate this, the use of direct quotations was prioritised. Additionally, the themes developed through the thematic synthesis of secondary data may reflect the biases of the original papers. The sampling strategies used limit the transferability of the findings to women who are active on social media.

Despite these limitations, this review provides the first qualitative synthesis of research into help seeking in the perinatal period to include studies on anxiety. As a result, this review facilitated the identification of overlapping themes between individual papers and across mental health difficulties.

Implications

Clinical implications

The findings of the review offer some useful implications for clinical practice. Help seeking was found to be affected by the way HCPs respond to mothers and the relationship between HCPs and mothers. Continuity of care has been identified as a facilitator in developing this relationship. In addition. given that when women did seek help, it was with their midwife, health visitor or GP, it would be important for these professionals to be aware of the ways they can engage with mothers that could build rapport and help to facilitate help seeking. The Maternity Workforce Strategy (2019) recommends upskilling for the workforce to deliver continuity of carer, a model of delivering maternity care from the same midwifery team, and training in generic therapeutic skills, such as active listening, empathy and responding with a non-judgemental approach to emotional content to support HCPs to better support mothers experiencing mental health difficulties. Clinical psychologists could play a role in training and supporting these staff groups to develop their skills in responding compassionately to and supporting women with anxiety and depression, as suggested in one of the papers (Hore et al., 2019), and to emphasise to HCPs the importance of continuity of care wherever possible**.**

Some mothers expressed concerns about the cultural competence of HCPs from a different background than themselves. Research on cultural differences between service users and providers has found that people from Black and minoritised ethnic backgrounds who have experienced racial discrimination in healthcare prefer to work with HCPs from a similar ethnic background (Mallat et al., 2010). However, the research is not consistent on the issue of service user-provider concordance and service user preferences, as some studies have found no benefit to shared ethnicity between service user and provider (Coats et al., 2018). The review findings suggest that it would be important to upskill the workforce to better understand the social construction of mental health difficulties within different communities to ensure the delivery of culturally sensitive care to service users in racially discordant HCP relationships.

As previously mentioned**,** the NHS is under considerable pressure following years of austerity, the ramifications of Brexit and the coronavirus pandemic. The review highlights to service providers the potentially negative impact of structural factors, such as stretched resources and long waiting lists, on help seeking. There could be a further role for clinical psychology in offering reflective spaces to HCPs working with mothers to consider the impact of working in teams that are restrained by such structural barriers, to help 'contain the containers' (Rifkind, 1995). More controversially, where applicable, clinical psychologists might assist in awareness-raising about the effect of national policies and support non-violent forms of social action to influence change.

Research implications

Several papers reported limited participant demographic information. Future research in this area could ensure fuller descriptions of demographic information are collected to help contextualise and better understand the experience of help seeking, and to carry out research with more diverse groups.

Further research is warranted in relation to structural barriers, both to better understand them and their possible role in helping and hindering HCPs in developing relationships with mothers and responding to mothers in a way that facilitates help seeking.

Given the limited number of papers that focused on anxiety, more research is needed in this area. Future studies should explore awareness and understanding of perinatal anxiety among women and HCPs. Stigma was the common theme across all papers described as a barrier to women seeking help and internal stigma was reported as common for anxiety disorders. The complex task of addressing the stigma associated with mental health, motherhood and help seeking may also be important to be addressed by future research. The voices of mothers could be centred in research to support the development of HCP training that is acceptable and responsive to their needs. Research could then examine relationship quality and whether further support is sought when training interventions have been provided to HCPs.

Conclusions

Despite a growing interest in mental health difficulties in the perinatal period, relatively few papers have explored help seeking in the UK and even fewer for anxiety disorders. This review explored the potential barriers and facilitators to help seeking for depression and anxiety in the perinatal period in the UK. Given the relative neglect of anxiety in previous reviews, the inclusion of anxiety was an important addition. Ten papers were identified and a thematic synthesis of these papers identified four themes related to help seeking: stigma, making sense of experiences, relational factors and structural barriers. Within each theme, subthemes further suggested factors that could help or hinder mothers in seeking help from HCPs. To facilitate help seeking, services could adapt their practices to prioritise continuity of care. Roles for clinical psychology are suggested in providing training for HCPs working with mothers in generic therapeutic skills and cultural competence, as well as in providing reflective spaces. Future research could explore in depth specific themes that arose from this review, and especially focus on hearing more from mothers concerning help seeking in relation to anxiety.

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Section B

What helps and hinders mothers with OCD in disclosing unwanted infant-related harm thoughts to a Health Care Professional?

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Abstract

Introduction: Unwanted intrusive infant-related harm thoughts are a common experience for new mothers. When such thought are particularly distressing and interpreted as threatening and significant for mothers they may receive a diagnosis of 'obsessive compulsive disorder (OCD)'. The existing perinatal mental health literature focuses on postnatal depression (PND) and highlights many barriers for disclosure and help seeking. However, to the researcher's knowledge there is no research that has sought to understand the perceived barriers and facilitators to disclosing unwanted infant-related harm thoughts in mothers with OCD.

Method: Semi-structured interviews were held with 10 participants. This study used reflexive thematic analysis to explore perceptions of mothers with OCD diagnosis of what might help and hinder disclosing infant related harm thoughts to a health care professional.

Results: Six themes were developed; fear of consequences, sense of safety in the relationship, empathic communication, access and availability, understanding OCD and dilemma of disclosure.

Discussion: Despite the study's limitations, the findings contribute to this area of research by offering overlapping themes with the PND literature and identifying a barrier that is particularly relevant for mothers with a diagnosis of OCD. The results are considered alongside existing literature. Clinical implications and recommendations for future research are outlined.

Key words: perinatal mental health, obsessive compulsive disorder (OCD), disclosure, reflexive thematic analysis

Introduction

‘Obsessive Compulsive Disorder’

‘Obsessive compulsive disorder’ (OCD) is the term that describes the presence of obsessions, defined as unwanted intrusive thoughts, images or urges that repeatedly enter a person’s mind and that are associated with marked anxiety or distress; and/or compulsions, which are behaviours or mental acts that the person feels driven to perform (APA, 2013).

It has been suggested that ‘OCD’ is a “hidden” anxiety problem (Welkowitz et al., 2000). It is thought that only a minority of individuals who experience obsessions and/or compulsions seek help for these experiences (Fullana et al., 2009) and there is often a considerable delay in seeking treatment (Pinto et al. 2006, Torres et al. 2007). Robinson et al. (2017) carried out a qualitative study that offers insights into the reasons for delayed help seeking in adults experiencing obsessions and/or compulsions. They identified a range of factors that can act as barriers and enablers and concluded that “internal/cognitive” factors such as reluctance to admit that there may be a problem and stigma are important barriers, with individuals reporting fear of the reaction of their GPs, friends, families and employers, and fear of criminalisation.

OCD in the Perinatal Period

A meta-analysis of studies reporting the rate of OCD diagnosis in pregnant and postpartum women found evidence that women during this period are at greater risk of receiving a diagnosis of OCD compared to the general population (Russel et al., 2013). Women in the perinatal period (during or after pregnancy) may be given a diagnosis of ‘Perinatal OCD’ (pOCD) and Challacombe and Wroe (2013) highlight that the experiences commonly centre around the baby and caregiving. The findings from a more recent study suggested that OCD postnatally may affect as many as 9% of mothers (Fairbrother, et al., 2021). Research suggests that receiving a diagnosis of OCD in the perinatal period may be associated with reduced quality of life, and with difficult experiences of parenting and mother-infant interactions (Gezginc et al., 2008; Challacombe et al., 2016; Nicol-Harper et al., 2007).

A lack of timely access to good quality perinatal mental health care is estimated to cost the NHS £1.2 billion for each annual cohort of births in the UK (Bauer et al., 2014). The ‘1001 Critical Days’ cross-party manifesto (Leadsom et al., 2013) placed an emphasis on early intervention, with a focus on the first 1001 days of a child’s life. This influenced the NHS Long-Term Plan (NHS, 2019) which outlines a commitment to expanding support for perinatal mental health conditions, including the increased availability of specialist perinatal mental health services from preconception to 24 months after birth. The National Institute for Clinical Excellence guidelines (NICE, 2014) also recognised that anxiety disorders, in which it included ‘OCD’, were under-recognised during pregnancy and the postnatal period and recommended primary care givers to consider asking about anxiety in the initial contacts.

Unwanted infant related harm thoughts

There is growing evidence that it is common for women in the perinatal period to experience unwanted intrusive thoughts related to harming their infant, either accidentally or intentionally (Fairbrother & Woody, 2008). Fairbrother and Woody (2008) found that all of the 98 women in their study, who were recruited through maternity settings, reported intrusive thoughts of accidental harm towards their child and half of the women reported thoughts of intentional harm. Such thoughts have been shown to be more intense for first-time parents than for experienced parents (Kim et al., 2013). However, unwanted infant related harm thoughts are often not talked about and many mothers and HCPs are not aware of the prevalence of these types of thoughts (Brok et al., 2017).

A recent qualitative study explored how new mothers experienced intrusive infant related harm thoughts (Boyd & Gannon, 2019). They interviewed a non-clinical sample of eight women who had experienced intrusive, infant related harm thoughts and found these thoughts to be extremely distressing for participants. In addition, none of the women had shared these thoughts with healthcare professionals (HCPs), and they limited disclosure when they shared these thoughts with a partner or friend. Fears of being perceived as a risk to their baby and having their child removed by statutory services were reported to influence the participants' decision to not share their thoughts with HCPs. Participants reported limiting disclosure in an attempt to maintain an image of a "good mother" (Boyd & Gannon, 2019).

Such thoughts can be particularly distressing for some mothers who have received a diagnosis of OCD, as in line with the cognitive behavioural hypothesis of OCD they may misinterpret them as threatening and significant (Abramowitz et al., 2003), leading to an inflated sense of responsibilty for the thought (Salkovskis, 1996).

Disclosure.

Disclosure has been described as a fundamentally social activity that occurs in the context of social relationships (Rice et al., 2009) and disclosure of distress as one step in the pathway to treatment (Prevatt & Desmarais, 2018). As mental health difficulties can be categorised as concealable stigmatised identities (Cooper et al., 2020) the decision to disclose is a complex one. It has been associated with the risk of experiencing negative outcomes mostly associated with the stigma of mental health difficulties, such as social rejection and discrimination (Mayer et al., 2021). However, the continued concealment has also been associated with being stressful (Smart & Wener, 1999) or feelings of guilt for the individual about not sharing with others (Derlega et al., 1993). Disclosure has also been associated with positive outcomes for some people such as increased social support and reduced feelings of isolation (Garcia & Crocker, 2008).

The Disclosure Decision Making-Model (DD-MM) suggests that decision-making involves making multiple assessments of factors on individual and relational levels that contribute to the process of disclosure (Greene et al., 2009) and has been adapted to understand the factors associated with the disclosure of mental health difficulties (Pahwa et al., 2017). According to this model, the disclosure process involves assessing information when deciding to disclose (including individual factors such as stigma, symptoms, perception of social support) and assessing the potential receiver (including relational factors such as relationship type, quality, length and availability).

The Disclosure Process Model (DPM) (Chaudoir & Fisher, 2010) provides a theoretical framework to understand when and why disclosure might be beneficial for individuals with concealable stigmatised identities. The model suggests that disclosure is an ongoing process rather than a singular event, and that the outcome of a single disclosure event can affect subsequent disclosure processes (Chaudoir & Fisher, 2010). It suggests that approach vs. avoidance goals (antecedent disclosure goals) underlie disclosure behaviour and that these may moderate the effect of disclosure on various individual and dyadic outcomes. This differs from previous research which has highlighted the importance of confidant reaction and acceptance in determining the outcomes of disclosure (Rodriguez & Kelly, 2006).

The Coordinated Management of Meaning (CMM) theory views communication as a complex circular process where meaning is co-created by the participants involved (Pearce & Cronen, 1980) and helps to make sense of disclosure by exploring the multiple levels of embedded contexts (Pearce, 2005). CMM posits that the meaning of communication occurs in multiple contexts and pays attention to culture, episode, relationship and self. Consideration of contexts for HCPs and mothers encourages exploration of the multiple conversations occurring in different contexts. For example, for HCPs this could involve foregrounding conversations with a supervisor about safeguarding and risk.

Help seeking in the perinatal period

There is growing recognition in the literature that research into postnatal anxiety disorders has received less attention compared to postnatal depression (Field, 2018; House et al., 2016; Goodman et al., 2016). Research on help seeking for depression in the perinatal period indicates women may experience barriers to disclosure and help seeking (Button et al., 2017). Findings from a systematic review highlighted that continuity of care and trusting relationships with HCPs were important in enabling help seeking and that the fear of being seen as a ‘bad mother’ and of being stigmatised for not being able to cope resulted in mothers ‘self-silencing’ (Button et al., 2017).

It may be as a result of the limited research attention that anecdotal reports suggest that a lack of awareness of pOCD and how to respond among health care professionals (HCPs) have contributed to a misdiagnosis of ‘postpartum psychosis’ or women being classified as ‘high risk’ of harming their child, referrals to social services and admittance to specialist mother and baby units (Challacombe & Wroe, 2013). Failing to correctly identify OCD in the perinatal period is likely to contribute to the worsening of mental distress for mothers and prevent them from accessing the appropriate support. Research by Glaziers and colleagues (2015) found doctors misdiagnosed OCD 50.5% of the time when presented with OCD vignettes and those who misdiagnosed OCD were less likely to recommend an empirically supported treatment like CBT.

Rationale

Despite the evidence indicating the increased likelihood of obsessive/compulsive experiences in the perinatal period and prevalence of experiencing infant related harm thoughts, there is limited research into this phenomenon with a recent qualitative study in the UK focusing on non-clinical samples (Boyd & Gannon, 2019).

Research is needed to better understand the barriers and what might enable the disclosure of unwanted infant related harm thoughts to HCPs. It was anticipated that this research would have clinical implications by providing evidence for how HCPs can be better enabled to support new mothers experiencing this phenomenon. Furthermore, it is important to the field of clinical psychology given the potential for unintended harm for mothers if they are misdiagnosed or inappropriately referred to social services when normal intrusive thoughts are misinterpreted by HCPs as risky.

Aims

This study aimed to focus on the following research question:

- What do participating mothers with an OCD diagnosis believe helps and hinders them in disclosing unwanted infant-related harm thoughts to a HCP?

To understand the perceived processes, this study focused on exploring and creating a thematic understanding of mothers' experiences and views of the disclosure process.

Methods

Design

This study used a qualitative design and one-off semi-structured interviews were conducted via online video platforms (Microsoft Teams or Zoom) with participants. Semi-structured interviews are commonly used in a healthcare context and are useful when exploring participants' thoughts, experiences and beliefs related to a topic, particularly regarding personal and sensitive issues (DeJonckheere & Vaughn, 2019).

A critical realist epistemological stance was adopted, acknowledging that our experiences and understandings of reality are mediated by language and culture (Willig, 2013). This approach is congruent with reflexive thematic analysis methodology as discussed by Braun and Clark (2021). Reflexive thematic analysis, from a critical realist approach, provides access to situated, interpreted realities, not decontextualised truths (Braun & Clarke, 2021).

Participants

Convenience sampling was used to recruit participants through advertising on social media and relevant forums (e.g. OCD Action, Maternal OCD). Initially, the aim was to recruit two groups of participants; mothers with OCD who had the experience of disclosing or difficulty disclosing unwanted infant related harm thoughts to a HCP and Health Visitors (HV) who had experienced a mother with OCD disclosing such thoughts. Due to recruitment difficulties it was not possible to recruit HVs, see detail in procedure. Inclusion criteria included being a mother who was 18+ years, living in the UK, having had the experience of disclosing or difficulty disclosing unwanted infant related harm thoughts to a HCP and a diagnosis of OCD. Recruiting mothers who had their child in the last two years was considered important to aid memory of the experience. However, difficulties with recruitment meant this inclusion criterion was relaxed to no time limit since the disclosure experience. Potential participants were asked to self-exclude on the basis of the information sheet if they anticipated that discussing their experiences would be distressing. Additional exclusion criteria involved not having a support system and not providing contact information for GP or a trusted person. Participants were reimbursed £10 for their time.

Ten participants took part in the study. Participant information is shown in Table 1. All participants were women and (where it was provided) were aged between 25-44 years. Three participants did not provide their age. All had received a diagnosis of OCD in adulthood, antenatally or postnatally. All of the women had experienced the dilemma of whether to disclose their unwanted harm thoughts to a HCP between 10 months to 7 years ago (M= 3.24 years). All were White British. Eight out of the ten participants had delayed disclosure and two did not disclose.

A debrief sheet was provided to one potential participant who was 'excluded' from the research for not living in the UK and not having a support network in place. This included an explanation for the exclusion and recommendations for online support should they wish to access it.

Table 1

Participant information

Participant number	Age ranges in years	Sexuality	Religion	Age of child in years	When diagnosis received	Disclosed to HCP?
1	40-44	Heterosexual	None	4.5	Since becoming a parent	Yes
2	30-34	Heterosexual	Jewish	2years 2 months	Before becoming a parent	Yes
3		Bisexual	None	7	Since becoming a parent	Yes
4	35-39	Heterosexual	None	7	During pregnancy	Yes
5		Heterosexual	Christian	2.5	During pregnancy	No
6		Heterosexual	Jewish	2	Since becoming a parent	Yes
7	30-34	Heterosexual	Christian	17months	Before becoming a parent	Yes
8	25-29	Heterosexual	None	2	Since becoming a parent	Yes
9	30-34	Heterosexual	None	10 months	Before becoming a parent	No
10	35-39	Heterosexual	None	3	Since becoming a parent	Yes

Procedure

The author consulted with a founder of the Maternal OCD charity on the design of the study and the interview schedule. An advertisement for the mothers' group was shared on social media and relevant forums (e.g. OCD Action, Maternal OCD), which briefly outlined the study and provided contact details of the researcher. An advertisement for HVs was promoted in the Institute of Health Visiting's monthly newsletter and via the research consultants' colleagues. However, there was no response to the advertisement for HVs and the research design was amended as a result to only recruit mothers and the research method was changed. Please see details of methods change in data analysis.

People who expressed an interest to the researcher via email were then sent a link to the participant information sheet (Appendix B), consent form (Appendix C) and screening questionnaire (Appendix D) which were hosted by Qualtrics, along with a PDF file copy of the information sheet, and offered the chance to ask any further questions about participating in the study. Eligible participants were then invited to interview via secure video call platforms (Zoom or Microsoft Teams). Interviews were recorded and transcribed verbatim. Data were analysed using reflexive thematic analysis as outlined by Braun and Clarke (2019; 2021).

Interview

Semi-structured interview schedules were utilised to explore participants' experiences of disclosing unwanted harm thoughts to a HCP (Appendix E). These interview schedules were developed in collaboration with the research supervisor and through consultation with a lived experience consultant. Before the interview, participants were reminded of the limits of confidentiality and their right to withdraw at any time. Each participant was interviewed individually and interviews lasted between 28 and 62 minutes (M=44minutes). During the interviews, the researcher remained attentive, curious and flexible to allow participants to fully express their experiences without feeling constrained by the structure of the interview schedule. At the end of the interviews, participants were offered the opportunity to debrief and ask questions. Interviews were recorded on the researcher's secure password protected laptop. Interviews were transcribed verbatim and anonymised to protect participants' confidentiality.

Data Analysis

To the researcher’s knowledge there are no studies exploring mothers’ experience of the process of disclosure of unwanted infant related harm thoughts to a HCP, therefore this research is exploratory. In considering the most suitable method for this research, grounded theory was initially chosen in view of its aim to be inductive and for the potential to also recruit HCPs and triangulate their experiences. Interpretative phenomenological analysis (IPA) was also considered. This method was not chosen as the study planned to recruit two groups and IPA favours data from a reasonably homogenous group (Smith & Fieldsend, 2021). Due to difficulties with recruiting participants, in particular being unable to recruit any HCPs and the resulting time constraints, the decision to analyse data using grounded theory was abandoned. Thematic analysis was then deemed appropriate to enhance understanding due to the exploratory nature of this method and its aim to identify patterns across the data-set (Braun & Clarke, 2006).

The data were analysed using a reflexive thematic analysis methodology (TA), following the procedures outlined by Braun and Clark (2019; 2021), and based within a critical-realist epistemological stance. An inductive approach was undertaken in attempting to develop themes that were strongly linked to the data (Patton, 1990). However, Braun and Clarke (2006, p. 84) highlight that even with an inductive approach, data are not coded in an ‘epistemological vacuum’.

Quality Assurance

A bracketing interview (Appendix F) was held with the lead supervisor prior to the researcher carrying out interviews. This allowed the researcher to reflect on some of her own assumptions and biases, which included an assumption that conversations about mental health experiences with professionals can be helpful. As a result, the researcher was able to hold these in mind to ensure that the findings were grounded in the data rather than the researcher’s assumptions. During analysis, a section of data was independently coded by the research supervisor and differences in coding were discussed. Throughout this study the primary researcher kept a reflective research diary (Appendix G) and memos (Appendix H). As a relative novice to reflexive TA, the researcher followed guidance from Braun and Clarke (2021) to try to ensure methodological rigour.

Respondent validation questionnaires including the themes and sub-themes were sent to all participants who gave their consent to be contacted to participate in this exercise (Appendix I). Nine out of 10 participants consented to participate, and five out of nine questionnaires were returned. Those who responded agreed with the themes and sub-themes and commented on areas that felt important, including the fears and difficulty finding someone to talk to who understands.

Ethical Considerations

Ethical approval was gained through the Salomons Ethics Panel (Appendix J). Participants were reminded of their right to withdraw from the research at any time and their choice to not answer any questions without the need to give an explanation. They were provided with an opportunity to debrief after the interview and were also encouraged to contact the researcher if they had any questions following the interview.

Although considered unlikely, the potential for safeguarding issues to arise such as participants disclosing risk information related to themselves or others, was considered and a plan established. In the event that risk might have been disclosed, the researcher would discuss contacting the GP or trusted person indicated in the screening questionnaire or relevant service with the participant. No risk was disclosed.

An additional information sheet outlining support services was developed so that it could be emailed to any participants if they needed further support. (Appendix K).

Results

Six themes and 20 subthemes were developed from the thematic analysis (see Table 2). Each theme is discussed with verbatim interview quotes. Rather than presenting a list of barriers and facilitators, the data did not lend itself to an exact match of these categories, so the themes have been presented as they were developed from the data.

Table 2

Themes and Subthemes

Theme	Subtheme
Fear of consequences	Baby will be taken away I will be taken away My parenting will be judged
Dilemma of disclosure	Shared with partner first Limiting disclosure It was just too much Online research
Sense of safety in the relationship	Build up a relationship Someone you can trust
Empathic communication	Validating and normalising Non-judgemental Dismissive and invalidating
Access and availability	Good long conversations Lack of privacy Perinatal services are different in different places
Understanding OCD	Why am I thinking that? Knowing doesn’t make it easy HCPs not having any understanding That’s not OCD Specialism in this type of thing

Fear of consequences

This was a central theme that describes a barrier to disclosure for all participants. Three subthemes describe the different consequences the participants feared would happen if they disclosed the thoughts they were experiencing: *baby will be taken away, I will be taken away, my parenting will be judged***.**

Baby will be taken away. The majority of participants expressed experiencing a fear that if they shared their experience of unwanted harm thoughts with a HCP it would lead to social services involvement and their baby being taken away.

> “I was absolutely convinced (pause) if it went any further than me and him [husband] (pause) they’d be knocking on the door and that would be it… And they’d just come and take them away (pause)” (P8)

> “Because you, you just think (pause) if I tell anyone about these thoughts, they're gonna take my baby away” (P10)

I will be taken away. Some mothers indicated that a fear of being sectioned or arrested prevented them from disclosing their thoughts to a HCP.

> “I just kept saying ‘I know they’re gonna take me away I know they’re gonna take me away’” (P8)

> “Would they (pause) would I be taken into an institution?” (P1)

My parenting will be judged. Mothers indicated that they either feared or expected that their ability to parent would be judged negatively if they shared with HCPs, suggesting a dichotomy of being a good/bad mother.

> “Erm or (long pause) people would just start questioning my mental capacity as a parent…” (P7)

> “Would they worry about (pause) whether I could look after her?” (P1)

> "And it was so nice [after disclosure] that people… weren't judging me and weren't saying 'oh you're a horrible mum for this or you're terrible'." (P4)

Dilemma of disclosure

This theme represents the process leading up to disclosure. For some mothers this involved speaking with their partners first, limiting disclosure with HCPs, carrying out online research and reaching a point where the distress they were experiencing was just too much.

Shared with partner first. Half of the mothers explained that the first person they disclosed their thoughts to were their partners.

> "So I shared it with my partner first, he was the one that said I need to talk about it with someone." (P2)

> "Yeah I remember sitting him down one night and saying you know (pause) telling him (pause) and I, I remember the look on his face, he was he wasn't shocked (laughs). He was like 'its okay' like 'we'll, we'll work through it it's fine, we'll get you what you need'" (P8)

Limiting disclosure. Mothers shared that when they did start to talk to a HCP about the unwanted infant related harm thoughts, they would refrain from sharing the full details of their experience.

> "I kind of only told her that I had obsessive compulsive disorder, and I kind of kept it to the briefest, very minimum, very (pause) smallest amount of information" (P7)

> "mm because I told them I was having some intrusive thoughts but I didn't go into detail (pause)" (P8)

It was just too much. Half of the mothers spoke about reaching the resolution to their dilemma as a result of feeling they could not continue as things were. This was considered a negative enabler of disclosure.

> "And then it got to a point that I think it was just too much." (P3)

> "I think for me it was the feeling that I was absolutely at the point where I just couldn't, just couldn't cope with the way we were going." (P6)

> "Um but I didn't really tell anyone until probably about June, because that's when I returned to work and it was just too much." (P2)

Online research. Some mothers spoke about how the research they carried out online and their involvement in parenting groups provided them with valuable information that offered them the reassurance they needed to speak to a HCP about their experience.

> "I like looked up on Mind and I kind of saw a few things and just thought, 'well maybe they'll be okay about it…more, more…'." (P4)

> "Yeah, I think luckily it was either that morning that I sort of read this post or the day before… I I acted on it really, like (pause) I'm gonna go, so I, I mean, baby clinic used to be on a Tuesday morning. So potentially I read that post Tuesday morning (pause) and thought I could go and speak to someone and I like (pause) went and did it there and then (pause)" (P10)

Sense of safety in the relationship

This central theme from participants' accounts describes how the relationship between the mother and HCP had the potential to act as a facilitator or barrier to disclosure and the factors that contributed to feeling safe in this relationship.

Build up a relationship. Mothers shared that they eventually felt able to speak to a HCP once they had developed a relationship over time. Not having a good enough relationship with a HCP was also identified as a barrier to disclosure.

> "I think that's the big problem, is that you don't have health visitors or anyone that you can trust, that you can build up that relationship with so that you can talk about it." (P4)
>
> "You've got a text number, a number you can text if you've got a problem but it's a different person each time. Mm… So even when I did go for help it was my GP that I went to because I, that's the person that I…knew" (P4)
>
> ""just always had that because I have met her before, just there's like, a connection there to sort of, a bit of empathy, you know, she she showed always showed so (pause) yeah" (P10)
>
> "I do just think that had (pause) had my relationship been better with her or I trusted her more I might have been more willing to do it" (P7)

Someone you can trust. Mothers shared the importance of feeling that they could trust the HCP and this was closely linked with building a relationship over time.

> "cos I'd already, I'd already built up that level of trust with him by this point" (P2)
>
> "And luckily, the doctor that I went to was also a doctor that I'd got to know quite a bit mm (pause) and sort of trusted, because he'd always been really good with everything." (P4)
>
> "I do just think that had (pause) had my relationship been better with her or I trusted her more I might have been more willing to do it" (P7).

Empathic communication.

This theme recognises the importance of HCPs expressing empathy to mothers experiencing distress. Three subthemes helped describe the different ways empathy was or was not expressed.

Validating and normalising. Mothers spoke about the importance of HCPs validating and normalising their experience when they did begin to share their experiences.

> “Mm (pause) I think she validated the way I was feeling. And she sort of made it feel like it was okay to feel this way… And (pause) made it all seem (pause) a lot more normal.” (P3)

> “ I remember going to the doctor, cus I was feeling really down and not having a great time and he just prescribed me some stuff and just let me go, he didn't really talk to me or anything like that (pause) so I didn't actually go and get the prescription cus I didn't feel like it was validated” (P10)

Non-judgemental. One mother shared how the HCPs non-judgemental approach made her feel relief after disclosing.

> “Cus it’s, you’ve you told her and she hasn’t (pause) she hasn’t reacted (pause) she’s just taken it in and carried on, you know. Mm so I definitely felt relief when I told her” (P8)

Dismissive and invalidating. Mothers shared how dismissive and invalidating their interactions with HCPs could feel.

> “I can remember telling the midwife that I was feeling really anxious and just being completely dismissed… And she was very dismissive and I mentioned it on a few antenatal appointments and she didn’t really seem too fussed.” (P3)

> “I think she just felt very dismissive” (P5)

> “Before she came I just couldn’t stop crying and I was just crying and crying and crying and I was like hyperventilating and (pause) all this sort of thing and then she came in and she was really like ‘oh you know, it’s okay, you know, we think, you know, the baby’s fine and you know you’re just, you know, a bit low and if it carries on you know contact the GP but we’re discharging you’ and I was thinking ‘ughh’ like ‘now I’m left, now we’re on our own” (P8)

Access and availability

This theme describes how opportunities to access HCPs in the postnatal period influenced disclosure.

Good long conversations. Mothers shared that when HCPs were able to make time and space to talk with them this facilitated disclosure.

> “So it was all very (pause) and I just had a really good long conversation with her and it went from there really.” (P2)

> “She, we were, I was the last person left, she took me aside and we sat and talked and (pause) and everyone had gone, it was well after the end of the (pause) clinic” (P6)

Lack of privacy. One mother shared how the environment could act as a barrier to disclosure as she felt others might hear what is talked about.

> “you’re usually queuing up with other mothers standing there that can probably hear what you’re talking about (pause) (pause) I didn’t, there weren’t any any opportunities for me to say ‘I’m having really bad, you know, thoughts …I didn’t really feel like there were opportunities to raise those concerns cus of the settings that you’re (pause) pushed to or that are available to you, you know (sighs)”. (P1)

Perinatal services are different in different places. Mothers shared how the quality of care in perinatal services were different in different places in the country.

> “Unless you call, unless you call them with a problem here. I think it’s different in every, in different places in the country.” (P4)

> “erm (pause) I’m in [town] (laughs) and it’s not great (pause) the like, they’ve, first of all they forgot I was pregnant and then they said ‘oh you’re still pregnant’” (P9)

> “we’re really fortunate in [county] (pause) we are literally on the border and I'm so glad because (pause) the [another county] health visiting team whatever they are called, but that whatever they are, they're not doing visits, they're not doing weigh-ins, nothing” (P10)

Understanding OCD

This theme regarded the role that both the mothers own understanding of OCD and that of others, both at a societal and practitioner level, played in creating or reducing barriers to disclosure.

Why am I thinking that? Mothers shared the difficulty they experienced in making sense of why they were having unwanted thoughts of harm about their child.

> “I started getting these strange thoughts and I thought, ‘ooh’, you know (pause) or ‘ I don’t want to think about that, why am I thinking that?’ (P8)

> “I wasn’t really sure how normal it was (pause) whether everyone had that when they had a baby because I hadn’t had that before.” (P3)

Knowing doesn’t make it easy. One mother who had received a diagnosis of OCD before having her baby shared how understanding OCD did not make it easier to experience the thoughts.

> “one of the things that I remember the day after he was born was (pause) I was in a hospital bed next to a window and I remember thinking ‘God do I wanna just chuck him out the window?’ and (pause) I was thinking god this is so silly I know what this is (pause) but it doesn’t make it easy still” (P9)

HCPs not having any understanding. Some mothers spoke about their perception of HCPs not having any understanding about OCD and the types of thoughts they were experiencing. There was also a sense that health visitors in particular were not well versed in mental health and were only familiar with PND. This was experienced as a barrier to disclosure.

> “I knew I wasn’t gonna tell her (pause) because I thought she’s a GP (pause) and if it is what we think it is, she’s not gonna have any understanding” (P8)

> “Mm (pause) so (pause) I thought th (pause) people would just think (pause) that I was, yeah, that I was just gonna hurt them and (pause) that it was something very unusual… It was I was worried that that was going to happen. It was very hard to explain that, and I didn’t think people would understand that.” (P4)

> ““‘and mm they they touch upon (pause) you know, postnatal depression but literally in a box ticking kind of way.” (P1)

That’s not OCD. Some mothers expressed their perception that the experience of OCD has been minimised in society and this has impacted on how people understand it.

> “Anxiousness is thrown around so loosely now (pause) and I do get that (pause) umm and I really hate that the term ‘I'm really OCD about that’ when someone's talking about their being cans being turned right around like I get that, I get that that annoys you, but that's not OCD.” (P10)

> “something like OCD which has, which people think is just having things in order you know, there’s still this ‘I’m a little bit OCD’ about this (pause) which is actually, you know, really damaging.” (P9).

Specialism in this type of thing. Some mothers indicated that they benefited from HCPs who had experience of working with OCD.

> “yeah, but like it was more the kind of (pause) mm the way you would kind of ask questions it just came out. I didn’t think about the fact that I was telling him” (P2)

> “I know not everyone can be trained about everything […]. I definitely think there should be one allocated worker in a trust that has a specialism in this type of thing […] because (pause) maybe if my first health visitor had that and I felt that she had been more (pause) supportive and understanding and understood the (pause) the whole situation, then maybe I would have been able to talk to her a bit more” (P7)

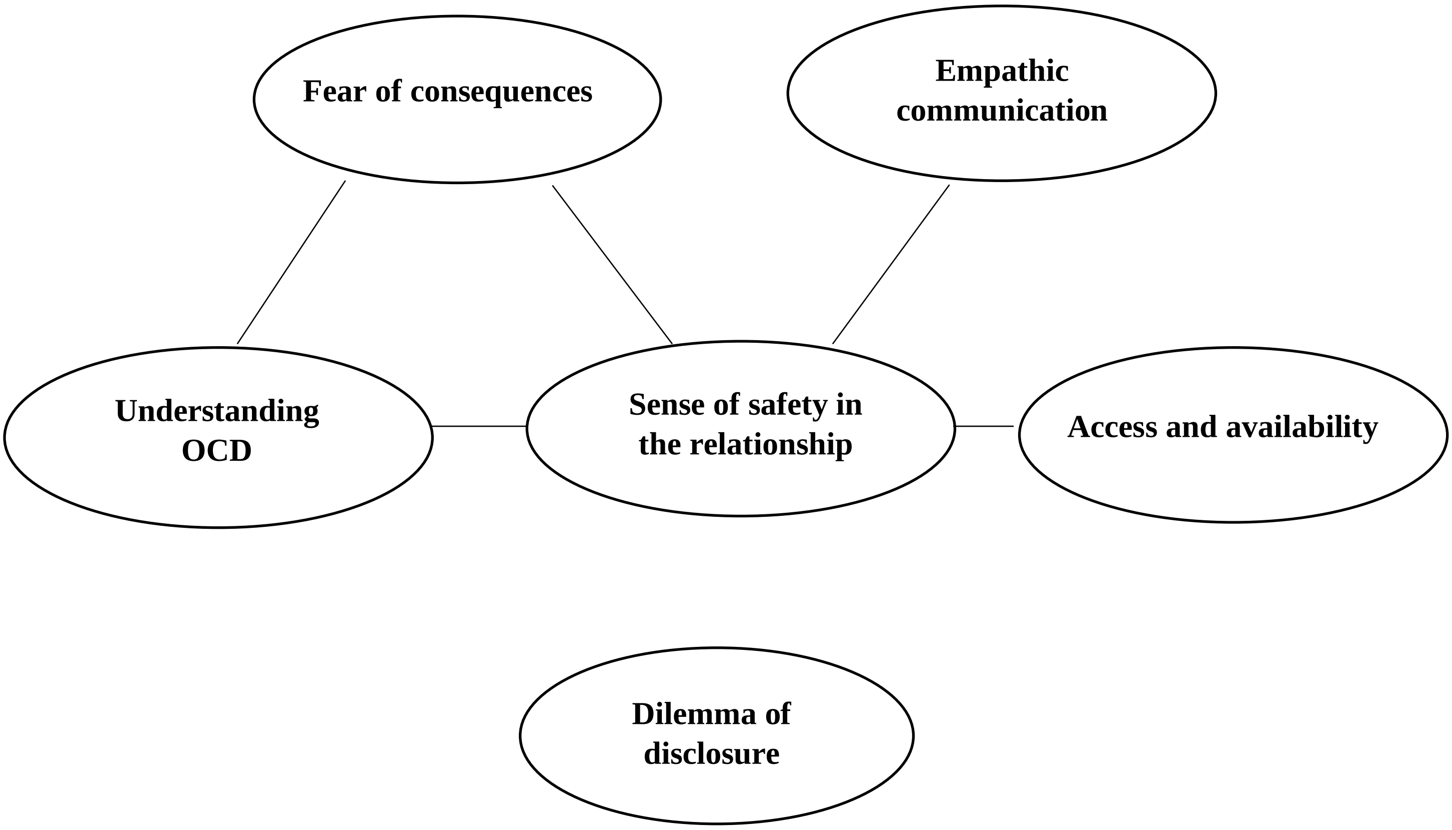
> ““when I first had CBT with a psychologist (pause) I couldn’t, it was such a relief to have somebody know what I was talking about umm that therapists, you know, and I’m talking general, and counsellors, you know, they don’t know.” (P1)

Thematic summary

Figure 1 presents a thematic map of the findings (see appendix L for themes, subthemes and illustrating quotations). The fear of consequences seemed to be the central theme that illustrated the perceived barriers for mothers in disclosing their unwanted harm thoughts to HCPs and was linked to understanding OCD. There were a number of themes that focused on factors that could act as both a barrier and facilitator to disclosure, such as empathic communication, understanding of OCD and access and availability, and were associated with having a sense of safety in the relationship. The theme regarding the dilemma of disclosure provided some context to how the mothers tried to manage the distressing experience of not knowing whether to disclose to a HCP.

Figure 1

Thematic map of themes



Discussion

Setting the Findings in the Context of Previous Literature

The most prominent theme mentioned by participants about delaying disclosure to HCPs was a fear of the consequences. This theme is aligned with theories of stigma (Corrigan, 2004) and replicates the findings of previous research that indicate stigma is an important barrier to seeking help (Button et al., 2017) within the population of mothers with OCD. However, the finding that mothers also feared that they might be taken away if they disclosed their thoughts and that 'OCD' is misunderstood at a societal level adds to the literature as this was not found to be a barrier to seeking help for PND (Button et al., 2017). It is possible that this is particularly relevant for OCD in the perinatal period when experiencing infant related harm thoughts. The reported fear that their parenting will be judged fits with the findings of Boyd and Gannon (2019) and the PND literature (McLaughlin, 2013). Unrealistic dominant discourses of the "good mother" have been recognised as influencing the "double stigma" associated with mental health difficulties and having mental health difficulties as a mother (McLoughlin, 2013). Relevantly, the CMM model highlights that cultural stories influence an individual's actions and give meaning to them.

For some participants their perception that HCPs would not understand and therefore misinterpret their thoughts as indicating intent to harm their child acted as a barrier to disclosure. Uncertainty about HCPs' level of understanding of OCD aligns with previous research that suggests HCPs' understanding of anxiety disorders in the perinatal period is variable and training programmes have limited or inconsistent inclusion of perinatal mental health issues (Silverwood et al., 2019). These findings also support the anecdotal reports of Challacombe and Wroe (2013) who suggest the fear of being misunderstood by professionals and being judged as a potentially harmful parent as a barrier to detection and help seeking.

The relationship with the HCP and the perceived nature of the interactions with the HCP appeared to be key mediators when navigating disclosure, having the potential to facilitate or discourage it. This is consistent with previous research into help seeking for PND, which has suggested a trusting relationship and continuity of care as facilitators of help seeking (Button et al., 2017; Jones, 2019). It also lends support to previous disclosure research which emphasised the role of the reaction of the receiver of the disclosure (Rodriguez & Kelly, 2006). The DD-MM helps to understand this finding as it emphasises the role of relational factors, such as relationship quality, length and availability in the disclosure process.

Some participants experienced what could be described as poor quality care, where HCPs were perceived to be dismissive, invalidating or not having adequate time to engage in meaningful communication. This may be considered in the context of pressures on the NHS and staff burnout. There has been a long-term decline in the number of nurses and HVs working in the NHS (Buchan et al., 2019) and the COVID-19 pandemic has worsened the existing maternity staffing crisis (Cordey et al., 2022). High levels of burnout have been reported in HCP groups such as GPs (Hall et al., 2019) and research has identified that 36% of doctors working in obstetrics and gynaecology in the UK suffered from burnout (Bourne et al., 2017). Their findings suggested an association between burnout and higher levels of defensive medical practice, such as the avoidance of working with 'difficult cases' (Bourne et al., 2017). Burnout has also been associated with negative work attitudes and threatens the quality of patient care (Spence & Leiter, 2006). According to Menzies-Lyth's (1988) work on social defence systems in healthcare, the healthcare system may function as a defence against the stress of closeness to people who are suffering, leading to dehumanising practices. Psychoanalytic theory suggests that the institution (in this case the NHS) potentially plays an important role in containing the anxiety engendered by the work (Bion, 1961) and that a lack of proper containment of these anxieties can lead to a defensive system (Hinshelwood & Skogstad, 2000).

HVs work in partnership with colleagues to safeguard and protect vulnerable children and identify those at risk. A disclosure of unwanted infant-related harm thoughts requires a HV to distinguish these thoughts from those that should trigger safeguarding proceedings. There is currently limited guidance for HCPs on the screening and assessment of these thoughts (Lawrence et al., 2017). Sensitive exploration following disclosure could include normalising this experience and explicit discussion that their occurrence is not automatically indicative of risk to aid in developing the therapeutic relationship, as part of a risk assessment (Department of Health, 2009).

The finding that half of the participants disclosed to their partners first and that some sought to make sense of their experience through online research supports previous research that mothers may seek informal sources of support before seeking support from HCPs (Edge & Mackain, 2010). Online forums may provide a more acceptable route to seeking help for people with stigmatised ‘conditions’ as they enable the anonymous disclosure and sharing of experiences and therefore avoid the possible feared outcomes of disclosure (Rains, 2014). Research suggests online forums for perinatal mental health difficulties provide a space to “test out” disclosure and where stigma and dominant “good mother” discourses can be challenged (Moore, Ayers, & Drey, 2016). This finding aligns with the DPM, which suggests that disclosure is an ongoing dynamic process. If a disclosure event to a partner or anonymously in an online forum creates positive outcomes and enhances well-being, it may serve to increase the likelihood of future disclosure (Chaudoir & Fisher, 2010). However, most mothers did not share how they experienced disclosing their unwanted harm thoughts to their partners. The findings also lend some support to the DD-MM, as both individual and relational factors associated with disclosure were highlighted in the themes of ‘access and availability’, ‘empathic communication’, ‘sense of safety in the relationship’ and ‘fear of consequences’.

Limitations

Despite this study offering useful insights, there are limitations that need to be acknowledged. One is the sampling strategy. Mothers who may have been able to overcome the barriers to disclosure and who felt more comfortable talking about their experiences may have been more likely to participate than mothers who were struggling to disclose. That said, no participants disclosed easily and all described considerable dilemmas.

Another limitation is the lack of diversity in the sample. The researcher approached the administrators of social media groups offering an online community to mothers of minoritised racial groups to promote the study within their communities in an attempt to ensure the voices of mothers from different backgrounds were included in the research. However, all of the participants identified as White British.

As a result of difficulties with recruitment, the inclusion criteria were relaxed to no time limit since the disclosure experience and the mean time since disclosure was 3.24 years. This may have impacted participants' memory retrieval. Even so, the material from all participants was rich enough to use in the analysis.

Although quality assurance measures were put in place, including the use of a bracketing interview, memos, a research diary, respondent validation questionnaire and coding comparisons, the researcher will have likely influenced the process of interview and analysis. Through monitoring my internal responses during interviews and while reflecting afterwards I noticed my bias towards wanting to defend what I perceived to be HCPs poor quality care by considering the current context of the NHS as overstretched and under-resourced. This was an important reflection as I was able to hold this in mind when analysing data to try to ensure the themes were not presented in a more positive light.

Clinical implications

The present study highlighted the factors that have the potential to act as barriers and/or facilitators to disclosure for mothers with OCD who experience unwanted infant related thoughts. There could be a role for clinical psychology in training HCPs who work with women in the perinatal period and their partners, particularly around psychoeducation and assessment of unwanted infant related harm thoughts, in having explicit conversations around risk that may alleviate some of the feared consequences of disclosure and in developing a better relationship to support disclosure through the facilitators identified in this research. Pregnant women and partners need to be informed about the nature of these thoughts through routine sensitive discussion, screening and the development of written materials.

This study also indicated that half of the participants disclosed their thoughts to their partners first. This emphasises the need to include significant others in their care and therefore it may be beneficial for HCPs to adopt more of a systemic lens when working with mothers and explore women's access to social support. It may also be useful for HCPs to consider signposting to online support forums. This may be particularly relevant when working with single parents who may have access to other sources of social support (Luthar & Ciciolla, 2015).

Future research

Future research needs to be carried out to further explore this area to provide evidence for NICE guidelines as current guidance for perinatal mental health does not reference screening for unwanted infant-related harm thoughts. Research could consider the views of groups whose voices were not heard in this research, such as single-parents, mothers from minoritised ethnic backgrounds and same-sex couples. Additionally, future research could aim to understand this experience of disclosure from the perspective of HCPs and their understanding of these thoughts to inform staff training. Research could also evaluate HVs' ability to distinguish between unwanted infant-related harm thoughts and thoughts that could indicate potential risk and skills in empathic communication.

It would also be important to hear from partners/fathers to understand their perception of the experience and the impact on their own mental health, which is in line with the NHS Long Term Plan (2019).

Conclusion

This study aimed to understand what mothers with a diagnosis of OCD believe helps and hinders them in disclosing unwanted infant-related harm thoughts to a HCP. Using reflexive thematic analysis, six themes were developed: fear of consequences, sense of safety in the relationship, empathic communication, access and availability, understanding OCD and dilemma of disclosure. The findings suggest that the presence or absence of a sense of safety in a relationship with a HCP, empathic communication from a HCP and opportunities to access HCPs could act to both help or hinder participants' disclosure. Understanding of OCD in relation to that of the participants, HCPs and at a societal level also had the potential to act as a barrier and facilitator. Three consequences that participants feared would happen if they disclosed to a HCP acted to hinder them in disclosing. The dilemma of disclosure suggests that there are different ways that participants managed the distress they experienced with these types of thoughts. The findings have implications for clinical practice, highlighting a role for clinical psychology in supporting HCPs working with women in the perinatal period through training. Future research would benefit from exploring this area further through the experiences of HCPs and partners/fathers and with mothers from diverse backgrounds.

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Section C: Appendices of supporting information

Appendix A

Themes, subthemes, codes and illustrative quotes

Theme	Subtheme	Code	Number of Papers	Quote
Stigma	External Stigma	Fear of being judged	8	‘The majority of participants expressed concern about how loved ones may view them, and two participants expressed feelings of isolation and secrecy surrounding their OCD.’
		Fear of being treated differently	1	“... it’s just that you don’t want to be labelled...I certainly haven’t told other people ... because I don’t want them to label me. They treat you differently and I think that makes you worse.”
		Fear of baby being taken away	2	‘“…. 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.”
	Internal stigma	Shame or embarrassment	4	“[I told] few of my close friends, but no, not really because you sort of hide it, don’t you? You’re just, like, embarrassed."
		Guilt	1	‘The women were aware that their mental health might affect their baby’s development which led to guilt and anxiety for two participants.’
	‘Bad mother’	‘bad mother’	3	“I felt like I couldn’t talk to anyone about it, because I didn’t think it was normal and I felt like it was me not being a good mum” “Me too. Yeah, exactly. I thought people might think I was an awful mother.”
		Sense of failure	2	‘Women found the help seeking process difficult, especially ‘admitting’ to needing help and the implication of failure.’
Making sense of experiences	Lack of awareness about perinatal mental health	Lack of awareness about PNA	4	“I knew I didn’t have postnatal depression… and I did those questions with the health visitor, and she seemed to think I was ok. But then I couldn’t stop worrying about (the baby). I’d constantly check on her. And I didn’t want to go out in case something bad happened. And that’s not right. I didn’t know what it was, but I didn’t feel depressed.”

		Lack of awareness about PND	1	“‘I didn’t really know much about it to be honest.” ‘There were variations in how well informed women were about postnatal depression, ranging from having extensive information and good understanding, to having no information at all,’
	Conceptualisations of depression	Non-medical conceptualisation of PND	2	‘Although participants [from Black West African origin] experienced symptoms of PND, their conceptualisations differed to Western views, attributing it to social stress instead.’
		Different conceptualisation of PND to HCPs	1	‘Unfamiliarity with perinatal depression not only makes it unlikely that women would recognise depressive symptoms and self-refer for diagnosis and treatment, but also suggests that they were unlikely to know how to conceptualise and explain their feelings to healthcare professionals. In this context, women relied heavily on the ability of healthcare professionals to translate their feelings into symptoms in order to make diagnoses and offer appropriate interventions.’
Relational factors	How HCPs respond	MH a tick box exercise	1	“I mean they ask me about it in general terms (sighs) when I go to an appointment. They have sort of a ‘tick box’ they do every now and again.”
		MH concerns dismissed by HCP	4	You daren’t say when you’re shot down the moment you speak up. You can’t then go on to how bad you’re feeling […] because people say, ‘Oh no, no, it’s the norm. It’s the norm.’ And they just shoot you down."
		HCP had a judgemental approach	1	“[At the booking appointment] I had an absolute breakdown again and it really knocked me, I felt terrible, I was anxious, you don’t know if you're going to carry the child, so some of the questions that she [the midwife] was asking me and I can’t remember the name of the questions, it’s just like a brief three or four questions about if you’ve had, not suicidal thoughts, if you’ve had like maybe low thoughts and you’ve felt like it would be better off if you weren’t here, those kind of questions. And I answered yes to two of them and she looked at me and went, ‘really?’ and she just instantly broke any kind of rapport."
		Giving time and space	2	“You just want someone to say “It’s alright, sit down and I’ll listen to what you’ve got to say”.
		Non-judgemental approach	2	‘Antenatal professionals need to be confident in discussing anxiety with women in a non-judgemental and empathic way, to normalise and validate experiences’
		Compassionate	3	“She [The GP] was really understanding […] asked me lots of questions about

		response		what I was feeling. She also signposted me to lots of groups as well."
		Important to normalise and validate experiences	2	“‘It was just nice to open up and just tell somebody all the panics that I had got into… Somebody who understood why you were saying it and somebody who was reminding you that it was an illness and not to feel guilty about it.”
	Relationship with HCPs	Continuity of care important	5	“‘I always ask to speak to [health visitor] because I know her and it’s easier really if you know somebody.’”
		Factors that support positive relationship	1	‘Key factors that supported positive relationships were described, including compassion, empathy and giving time to explore concerns’
		Focus on the baby	3	‘It seems the women became objectified as mothers and lost their own personhood and identity. The prioritising of the child overshadowed the needs of the woman herself, who became lost in the process.’
		Difficult to build a relationship	2	"I didn’t want help from someone I didn’t know, like I didn’t know my Health Visitor, I didn’t know my Midwife, cause that’s the thing with like, it’s just the way with the NHS now, you don’t know the person that’s taking care of you, you don’t build a relationship with them, so why am I going to talk to that person?"
		Negative experiences with HCPs in the past	1	‘Of the 12 women interviewed, 10 spontaneously expressed dissatisfaction with aspects of their previous interactions with healthcare professionals and spoke about the negative impact of such encounters on their willingness to seek help from professionals thereafter.’ “…And from then on, I just don’t go ... I just don’t go. If I’m ill, I really do not go to the doctors. I’d rather sit here in pain”
Structural barriers	NHS systems	Rushed appointment	1	“I’d had my initial appointment with the midwife or health visitor, whoever it was, but it was so rushed. They didn’t get it. I had to contact my GP myself to ask, y’know, to be put on the mental health service lists… but y’know, nobody contacted me. I waited for like 3 weeks…”
		Long waiting lists	2	“…I had to contact my GP myself to ask, y’know, to be put on the mental health service lists… but y’know, nobody contacted me. I waited for like 3 weeks…”
		Stretched NHS resources	1	‘Women expressed frustration and dejection with the ante-natal healthcare system at times, acknowledging the system was stretched in terms of resources…’
		Inadequate childcare	2	“You have to have someone to look after your baby... So who am I going to get to look after [baby]? You know, my family aren’t here she’s being breast fed as well…”
	Culturally	Concerns about	2	“you need someone who’s on the same wavelength as you, who shares the same

	sensitive services	therapists' cultural competence		cultural experiences as you, which sometimes isn't available…and that's the bottom line. It's about having someone who you can chat to who understands where you're coming from"
		Mismatch with cultural expectations of services	1	'Services can be seen as replacing this maternal figure, helping to provide support in caring for new-borns by providing time, expertise and care. A lack of this support can be viewed as a mismatch with cultural expectations and can intensify feelings of being let down.'

Appendix B

Participant Information Sheet

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

What might help and hinder mothers with OCD in disclosing unwanted harm thoughts about their infant to a healthcare professional?

Hello. My name is Aimee McGinn and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. It can be helpful to talk to someone you trust about taking part in the study.

Part 1 explains the purpose of this study and what will happen if you chose to take part.
Part 2 gives you more detailed information about the conduct of the study

What is the purpose of the study?
It is common for new mothers to experience unwanted, intrusive thoughts about harm coming to their infant but limited research has been carried out to understand this in mothers with OCD. This project aims to understand the barriers and facilitators to mothers disclosing these thoughts to their health visitor.

We hope that the outcome of this research will help to provide guidance to healthcare professionals working with new mothers in the UK.

Why have I been invited?
You have been invited because you responded to an advertisement put out via Maternal OCD Charity/social media/children's centres. We are interested in speaking to mothers who have experienced postnatal OCD, specifically intrusive thoughts of infant-related harm, and either disclosed these thoughts or felt unable to disclose these thoughts to a healthcare professional. We hope to interview 10 mothers for this study.

Do I have to take part?
It is up to you to decide whether to join the study or not. As already mentioned, it can be helpful to speak with someone you trust about whether you want to take part. I will send a follow up email 24 hours after you have received this information sheet and you can reply to this email to let me know if you agree to take part. I will then ask you to sign an online consent form. Please know, you are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?
The research initially involves completing a short online questionnaire that will help us to determine whether/when to invite you for an interview. This will include questions such as your age, sex, marital status, and questions about your experience, for example, whether you are a first time mother. You might then be asked to participate in an online interview that will last up to an hour. The interview will be audio-recorded and will finish with a short debriefing of the study and the opportunity to ask any questions.

If you take part in the interview, you will also be invited to review the themes from the analysis of the interviews to check that I've accurately made sense of your experiences. This is optional and to ensure that my results are trustworthy.

We can schedule the interview at a time that is convenient for you and it is important that you are in a quiet and private space for the interview. This is so you can speak openly without anyone else in the room with you, and where it is quiet enough to hear and audio record the interview.

Expenses and payments
You will receive a £10 Amazon voucher as reimbursement for your time in taking part in this study.

What will I be asked to do?
You will be asked to attend an online interview with me, Aimee, at a time that is convenient for you. During the interview you will be asked open-ended questions that will explore your experience of disclosing unwanted harm thoughts to healthcare practitioners, including your thoughts and feelings related to this. You can choose what questions you want to answer or not.

What are the possible disadvantages and risks of taking part?
Given the sensitive nature of this topic, it is possible you may get distressed if you are discussing something you find difficult or emotional. If you think talking about your experience will cause you a lot of distress, it is recommended that you do not take part. If you do not expect to be distressed but find you are becoming upset during the interview, we can take breaks and you can discuss how the interview felt at the end. You can also let me know if you would like to stop taking part at any point. I can also provide you with the contact details of local support groups, if necessary.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we gather from this study will help to improve our understanding of how healthcare professionals can support mothers with OCD who experience unwanted harm thoughts.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed and can be raised with me at any time during the study. Alternatively, you can contact the Salomons Research Director to raise any concerns or make a complaint. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?
Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time by leaving a message on the 24-hour voicemail number (01227927070) or emailing me (am1321@canterbury.ac.uk). If you choose to withdraw before the study has been submitted as part of a Major Research Project contributing towards the lead investigator's doctoral degree, we would like to use the data collected up to your withdrawal. If you do would prefer that your data is withdrawn after interview, we ask that you inform us within 2 weeks of completing the interview.

What if there is a problem?

Any complaints made by you will be taken very seriously and reviewed by me, and if necessary, Canterbury Christ Church University.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for Aimee McGinn and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology – fergal.jones@canterbury.ac.uk

Will information from or about me from taking part in the study be kept confidential?

All information which is collected from or about you during the course of the research will be kept strictly confidential. The information below explains how this will be done:

- The data you provide will be kept in electronic format in a password protected folder on the researcher's computer.
- Names of participants will be replaced with false names and identifying information anonymised when I type up the interview.
- Your anonymous data would be kept securely at the Salomons Institute for Applied Psychology for 10 years, after which time it will be destroyed.
- The lead researcher will be the only person who has access to any personally identifiable information.
- The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else. I would not do this just as a result of you talking about unwanted harm thoughts.
- You have the right to check the accuracy of data held about you and correct any errors.

What will happen to the results of the research study?

The data collected will be reported anonymously in my Major Research Project and also submitted for publication in the Journal of Reproductive and Infant Psychology. This may include anonymised quotes from your interview. If you would like, you can be provided with a summary sheet of the findings and link to the results after publication, via email.

Who is sponsoring and funding the research?

This study was organised by the lead researcher (Aimee McGinn) with input from a lead supervisor (Dr.Sue Holttum) and external supervisor (Dr.Janice Rigby), as part of the lead researcher's Clinical Psychology doctoral training at Canterbury Christ Church University. The university has funded this research.

Who has reviewed the study?

This study has been reviewed and been approved by The Salomons Ethics Panel, Salomons Institute for Applied Psychology, Canterbury Christ Church University.

Should you wish to take part, you will be given a copy of this information sheet to keep for your records in addition to a signed consent form.

Further information and contact details

If you would like to speak to me and find out more about the study of have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me (Aimee McGinn) and leave a contact number so that I can get back to you. Alternatively, you can also contact me via email at: a.mcginn1321@canterbury.ac.uk

If you would like to speak to the member of the research department who is supervising the study, please contact Sue Holttum at: sue.holttum@canterbury.ac.uk

Finally

Thank you for considering taking part in this research project, it is very much appreciated.

Appendix C

Participant Consent Form

Canterbury
Christ Church
University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: V:\075\Ethics\2020-21
Version number: 1
Participant Identification number for this study: TBC

CONSENT FORM

Title of Project: What might help and hinder new mothers in disclosing unwanted harm thoughts about their infant?

Name of Researcher: Aimee McGinn

Please initial box below:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I understand that should I withdraw, the researcher would like to use my anonymous data up until the point of withdrawal in the write-up of the study and in any further analysis that may be conducted by the researcher. I understand that I can withdraw my data up to two weeks after participating in the interview. ☐

4. I understand that data collected during the study may be looked at by the lead supervisor, Dr Sue Holttum. I give permission for this individual to have access to my anonymised interview data. ☐

5. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings ☐

6. I agree to the use of audio-recording during the interview. ☐

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

Additional options:

8. I agree to be contacted after the interview data has been analysed to check that the themes that the researchers have formed fit with my experience. ☐

9. I would like to be provided with a summary sheet of the findings and link to the results after publication, via email. ☐

Appendix D

Screening Questionnaire

1) What is your age?

○ 18-24
○ 25-29
○ 30-34
○ 35-39
○ 40-44
○ 45-49
○ 50-59
○ 60-64
○ 65 and over

2) What is your ethnic group?

○ White (Welsh/English/Scottish/Northern Irish/British)
○ White (Irish)
○ White (Gypsy or Irish Traveller)
○ White (Any other White background, please describe)
○ Mixed/Multiple ethnic groups (White and Black Caribbean)
○ Mixed/Multiple ethnic groups (White and Black African)
○ Mixed/Multiple ethnic groups (White and Asian)
○ Mixed/Multiple ethnic groups (Any other Mixed/Multiple ethnic background, please describe)
○ Black/African/Caribbean/Black British (African)
○ Black/African/Caribbean/Black British (Caribbean)
○ Black/African/Caribbean/Black British (Any other Black background, please describe)
○ Asian/Asian British (Indian)
○ Asian/Asian British (Pakistani)
○ Asian/Asian British (Bangladeshi)
○ Asian/Asian British (Chinese)
○ Asian/Asian British (Any other Asian background, please describe)

○ Other ethnic group (Arab)
○ Other ethnic group (Any other ethnic group, please describe)

3) Do you consider yourself to belong to a religious group? If yes, please indicate below:
○ Christian
○ Buddhist
○ Hindu
○ Jewish
○ Muslim
○ Sikh
○ Any other religion (please describe)_________
○ No religion

4) Which of the following best describes your sexual orientation?
○ Straight/Heterosexual
○ Lesbian or Gay
○ Bisexual
○ Other sexual orientation (please describe_______)
○ Prefer not to say

5) What is the name of your nearest town/borough/county?
____

6) How many children do you have?
○ 1
○ 2
○ 3
○ 4+

7) Have you ever received a diagnosis of OCD? If yes, please indicate when this was:_________________________________

8) Are you receiving any treatment for OCD?
○ Yes

- ○ No

9) Have you ever considered sharing with your health visitor that you have experienced infant-related harm thoughts but decided not to? For the purpose of this study, it does not matter whether you actually did share this information or not. If yes, please indicate when this was below.

- ○ Yes, I have considered sharing but decided not to. Please indicate below when this was: ____
- ○ No, I have not considered sharing with my health visitor

11) Have you ever shared with your health visitor that you have experienced infant-related harm thoughts? For the purpose of this study, it does not matter whether you actually did share this information or not. If yes, please indicate when this was below.

- ○ Yes I have shared with my health visitor. Please indicate when this was: ____________________________________
- ○ No, I have not shared with my health visitor

12) Who lives in your household?

____

13) What support system(s) do you have available?

____

14) What is the name and address of your GP or another person you trust?*

____

* They will not be informed automatically of your participation in the study, but it is a safeguard in case you or the researcher should later feel a need to contact them.

Appendix E

Semi-Structured Interview schedule

Introduction

Introduce self and reminder of the purpose of the study.
Reminder of the approximate interview length and debrief opportunity at the end.
Check that there is no one who might be able to overhear the interview.
Give example of infant related harm thoughts, brief research information regarding the common occurrence of these thoughts among new mothers and that these thoughts in themselves are not indicative of risk.
Reminder of the limits of confidentiality
Offer opportunity to answer any questions.
Reminder that participants can decline to answer a question without giving a reason or stop participating at any time.
Check in on how participants are finding the interview intermittently

Semi-structured interview questions

- Could you share when you first remember experiencing harm thoughts?
- What was the situation/going on in your life at the time?
- Would you feel comfortable sharing whether these were thoughts of deliberate/accidental harm [If disclosed]
- How did you make sense of these thoughts?

If disclosed:

- You indicated on the questionnaire that you have shared your experience of unwanted harm thoughts to your health visitor. Could you share your experience of disclosing these thoughts of harm to your health visitor?
- (prompt: can you tell me a bit more about that?)
- What was it like to talk about these thoughts? How did you feel before disclosing? What did you think afterwards?
- What led to your decision to disclose these thoughts?
- Who, if anyone, influenced your actions? Tell me about how they influenced you
- Tell me about your thoughts and feelings after you disclosed.
- Have your views/actions regarding disclosure changed since this experience? [If yes] How have they changed?
- After having this experience, what advice would you give to someone who has started to experience similar thoughts?
- Is there anything else you think I should know to understand this experience better?
- Is there anything you would like to ask me?

If not disclosed:

- You indicated on the questionnaire that you have not shared your experience of unwanted harm thoughts to your health visitor – could you share a time you have spoken to a health visitor after experiencing infant related thoughts of harm and not disclosed these thoughts to them?
- (prompt: can you tell me a bit more about that?)
- Can you describe the events that led up to/followed this situation?
- Tell me about your thoughts and feelings after the situation you described.
- What led to your decision to not disclose these thoughts?
- Who, if anyone, influenced your actions? Tell me about how they influenced you.
- Have your views/actions regarding disclosure changed since this experience? [If yes] How have they changed?
- After having this experience, what advice would you give to someone who has started to experience similar thoughts?
- Is there anything else you think I should know to understand this experience better?
- Is there anything you would like to ask me?

Debrief

- How did you find the interview?
- How are you feeling now?
- Provide information about the dissemination of findings
- Provide additional information sheet, if appropriate.

Appendix F

Bracketing Interview

Themes from bracketing interview reflections:

- Reflected on my interests relevant to this research - previous experience working with pregnant women in an IAPT setting prior to training. This increased my awareness of how anxiety provoking the adjustment to motherhood can be, the range of emotional distress that can be experienced during perinatal period and the need to prioritise maternal mental health. Experiences where their wellbeing has not been discussed in appointments. I also hope to work in a perinatal mental health team in the future.
- Useful to spend time thinking about the themes that could potentially influence my capacity to listen to participants. I noticed that I held an assumption that talking about distress or mental health difficulties to a HCP can be a helpful and validating experience that can lead to change. This has been shaped by my professional roles, however these have been in mental health settings and it was helpful to acknowledge that staff in maternity settings will have different professional backgrounds and training experiences. Recognised I can take for granted skills of listening and responding to people in distress but need to be sensitive that this may not be the case for other HCPs. What drives HCPs misunderstanding an expression of distress as a risk of harm to the infant and moving to action and safeguarding- anxiety/lack of confidence? I also noticed an assumption that participants will seek help from an NHS service however this may not be the case.
- Reflected on my Social GRACES and family background and how this may influence this research. Thought about power imbalances – power in my position as researcher and the questions asked but also power in participants ability to not answer questions. Will they feel able to utilise this power? Reflected on the participants' gender and how power may operate in their lives.
- Thought about my hopes and anxieties about this research. Hope the interview is a validating experience for participants and to hear about both barriers and facilitators. That the findings can lead to mothers feeling more supported with their mental health in the perinatal period. Also hope the findings can be used by services to support HCPs better in their work with mothers. Worries around the “role conflict” while moving from trainee role to a researcher role during the interviews, how to manage the interview to ensure the participants speak about what’s important for them while also needing to address the research questions. What if I hear about poor or unsafe HCP practice? Or a mother is particularly distressed talking about her experiences?

Appendix G

Extracts From Research Diary

March 2021:

Received feedback from the ethics review today and feeling very relieved at the outcome (full approval), although there were four comments to be considered. The comments feel useful but I'm not sure about the fourth comment that refers to 'women harming their children' rather than thoughts of, which is what this project will focus on. I wondered whether this comment highlights how unwanted infant related harm thoughts are often misinterpreted. It will be good to discuss the comments with Sue.

April 2021:

Research adverts are live! No one has been in touch yet but hopefully start to hear from potential participants soon… The health visiting charity have requested money for putting the advert in their newsletter. Unfortunately I did not budget for this so can't agree the amount they request and feeling pretty desperate to recruit. I've emailed Sue for advice.

May 2021:

I was able to negotiate I reduced price to promote my research with the health visiting charity so the research advert for health visitors is finally in their newsletter and social media sites. Feeling very relieved this has been resolved as I think I will struggle to recruit health visitors without access to the members of this charity. I had a bracketing interview with Sue and found it really useful to spend some time thinking about the assumptions I was holding and where these might have come from.

June 2021:

Had a joint meeting with Sue and Janice to discuss recruitment difficulties as I've still not recruited any participants… We reviewed the research poster and decided to make some amendments to make the poster for mothers (hopefully) more inviting. We agreed it would be useful to get back in contact with the consultant at Maternal OCD to see if she has any feedback on the poster. Getting a bit stressed about this but feeling more hopeful after this meeting

July 2021:

Finally had an enquiry from a mother about participating in the study but they didn't meet the inclusion criteria and are based outside of the UK. I've emailed Margie to review my exclusion email and will amend my inclusion criteria to include being based in the UK.

September 2021:

Met with Sue to discuss whether to consider next steps if I do not recruit any participants soon and amending the research proposal. It doesn't seem likely that I will be able to recruit any health visitors. I proposed changing the proposal to continue to try and recruit only mothers and wondered about the most appropriate methodology going forward.

October 2021:

Finally interviewed my first participant!!! I noticed it felt quite difficult to get a balance of asking the questions I hoped to ask and allowing the participant to say all that she wanted to say. Felt grateful that she had been so open in sharing her experiences with me. Struck by how debilitating this experience was for her and the lack of discussion about her wellbing from health care professionals and how alone she felt in general.

December 2021

I've now conducted two interviews and started to transcribe an interview. Transcribing is taking a lot longer than I anticipated and I also had my QIP assignment due near the start of the month. I've been reflecting on the two interviews so far and any similarities/differences in their experiences. I found it interesting that both participants had sought private therapy and wondered what about this experience that led to seeking help outside of the NHS. Both also talked about their relationship with their therapist being an important factor in their disclosure, with one making a deliberate decision to disclose and the other describing the disclosure as a more natural outcome of the conversation.

January 2022

It's been a busy and successful month interview wise. Three more this month so five in total! Relieved that there is some momentum gathering with interviews and transcribing. I've also started to explore the literature with the aim of coming up with a research question for my part A. Interested in thinking about what is currently known about the prevalence and impact of maternal OCD/assessment and intervention. Also exploring more broadly into existing review of the literature on anxiety disorders in the perinatal period.

February 2022:

Met with Sue to make a new timeline of deadlines with the July deadline in mind. I felt quite disappointed going into the meeting about not making the April deadline and it was helpful to reflect on the impact that covid has had on training and having to complete the QIP outside of the typical timeline. Feel more confident about what to focus on going forward.

May 2022:

Met with Sue after the viva briefing and feeling more motivated to make the July Deadline. Discussed some provisional theme ideas: fears about disclosure, HV provision in different areas, opportunities to get to know a HCP, the tone of HCP interactions, reaching a breaking point, influence of work experiences and specialist knowledge of OCD. I found Sue's suggestion to read a whole transcript through again helpful as I have found myself getting stuck on trying to capture everything in the dataset.

Appendix H

Example memos

October 2021

Conducted first interview today. Initial thoughts:

- Physical challenges while adjusting to motherhood (sleep deprivation, pain, hormones mentioned)
- Carried out own research online to learn about OCD
- Something about reaching a breaking point before seeking help
- Interesting that participant was able to disclose to CBT therapist, something about having an understanding of OCD helped to facilitate this.
- HV talk about PND, experienced this conversation as a tick box exercise
- No opportunity to disclose to HV at drop in clinic
- Scared of response if disclosed to HCP
- Struck by participants comment of HCP checking in with baby rather than her, more checks needed after initial 8 weeks.
- Relationship with GP important factor in decision whether to disclose to them.

19th November 2021

Conducted second interview today with a mother who disclosed to a private therapist. Initial thoughts:

- Feeling like reaching breaking point as a precursor to sharing with partner. The partner then encouraged to seek professional help
- Talked about difficulties more broadly but not disclose content of thoughts to HV
- Disclosed to partner first, valuing partners opinion
- Selective about who can discuss these thoughts with, took a long time to disclose
- Fear of being judged negatively as a parent – is this about the ability to parent?
- Relationship with HCP is important – what is it about the relationship?
- Disclosure was not planned in advance
- Wondering now about the women who are unable to seek private support

January 2022

I conducted my third interview today with a mother who was diagnosed with OCD postnatally. Initial thoughts:

- Described experiencing anxiety during pregnancy and intrusive thoughts following birth. This was an intense and constant experience.
- Fear of negative consequences/being separated from baby as a barrier to disclosing to midwife/HV – worried about social services taking the baby away or being sectioned
- Shared thoughts to husband first - would have been useful to find out how long before she shared thoughts to husband.
- Difficult to remember details from initial disclosure to GP
- Participant got to a point where it all felt too much as a precursor to sharing with GP

- Initial support received not seen as helpful e.g. being offered medication. Sense that that participant wanted therapy and not viewed medication as a solution.
- Validation important
- Found therapy and peer support helpful
- I am wondering how she coped while on the waiting list for talking therapies.

January 2022

I conducted my fourth interview today with a participant who was diagnosed with OCD postnatally. Initial thoughts:

- Really difficult to disclose these thoughts because of the fear of social services taking the baby away and judging her ability to parent
- Getting to know the HCP (GP in this case) was really important.
- As was providing reassurance, validation and helping her to realise that she was not alone.
- Lack of understanding/awareness of maternal OCD/anxiety. The main focus for maternal mental health that was talked about by HCPs was around ‘baby blues’.
- Limited opportunities to build relationship with health visitor due to infrequency of contact? Or because of the responsibilty on the mother to seek out meetings?
- Positive experience of disclosure with GP led to feelings of relief, and built up confidence to disclose to others.
- Did she know this at the time or is this since having an understanding of OCD? – about the thoughts not meaning she would act on them.
- Unrealistic expectations for motherhood
- Online research provides reassurance/confidence/normalises?

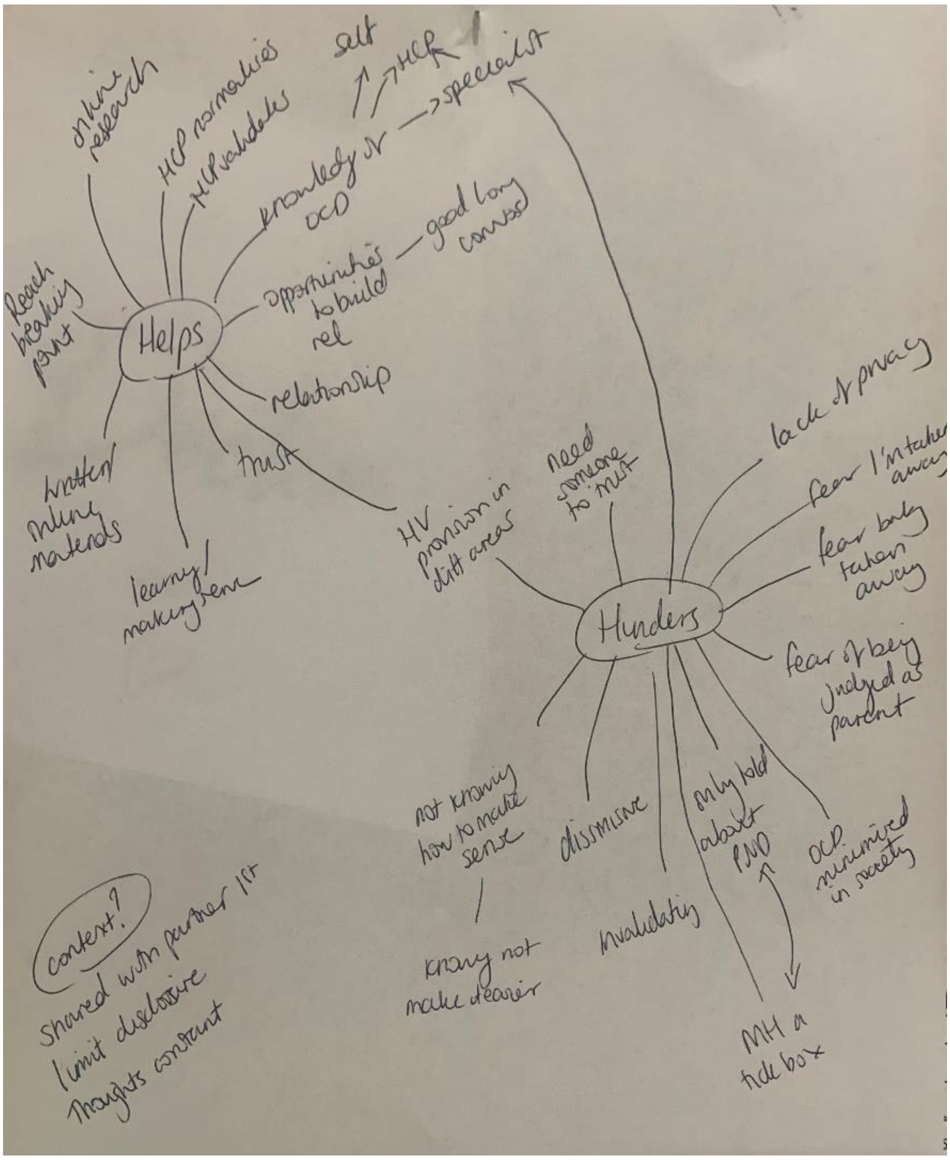
April 2022

Conducted my tenth interview today with a participant who was diagnosed with OCD postnatally. Initial thoughts:

- Participant unaware of OCD until it was introduced by HV
- Emotional experience to make sense of thoughts as OCD
- Online mental health websites and parenting groups an important resource, useful to read about other people having similar experience and also to reference when talking to HCP
- HV knew about intrusive thoughts and postnatal anxiety and was able to provide psychoeducation
- Again fear of being judged or baby being taken away were barriers that delayed disclosure
- Stress and anxiety building up contributed to seeking help
- Decided not to take medication that had been prescribed because she felt the GP did not validate her feelings – importance of validation

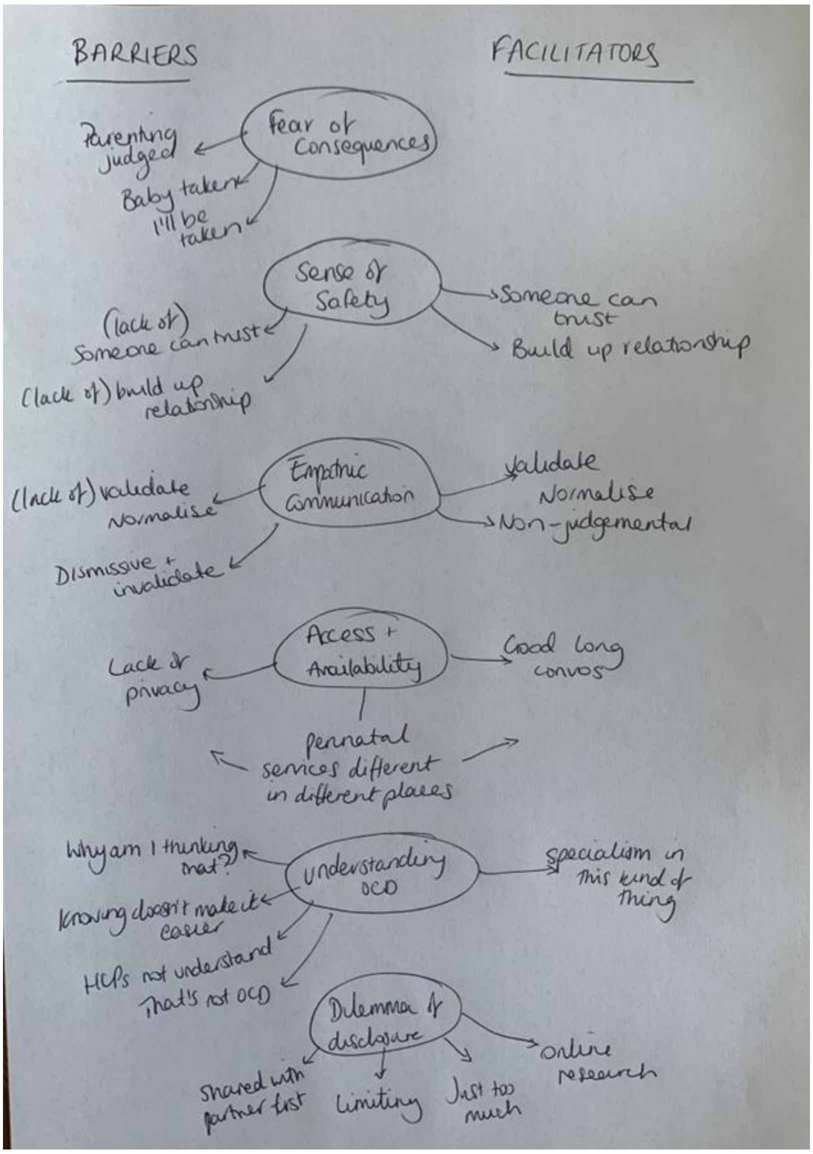
June 2022

Developing themes around barriers and facilitators and maybe something about the context. Noticing some connection/repetition between themes that I’ve clustered with both.



August 2022:

Refining themes and have been looking back to the codes and data. Thematic mapping has been useful for this process. Looking back at the data again there’s a developing shift from maps where themes were clustered around barriers and facilitators.


BARRIERS
FACILITATORS
Fear of Consequences
Parenting judged
Baby taken
I'll be taken
Sense of Safety
(lack of) Someone can trust
(lack of) build up relationship
Someone can trust
Build up relationship
Empathic Communication
(lack of) validate Normalise
Dismissive + invalidate
Validate Normalise
Non-judgemental
Access + Availability
Lack of privacy
Good long convos
perinatal services different in different places
Understanding OCD
Why am I thinking that?
Knowing doesn't make it easier
HCPs not understand That's not OCD
specialism in this kind of thing
Dilemma of disclosure
shared with partner first
Limiting
Just too much
online research

Appendix I

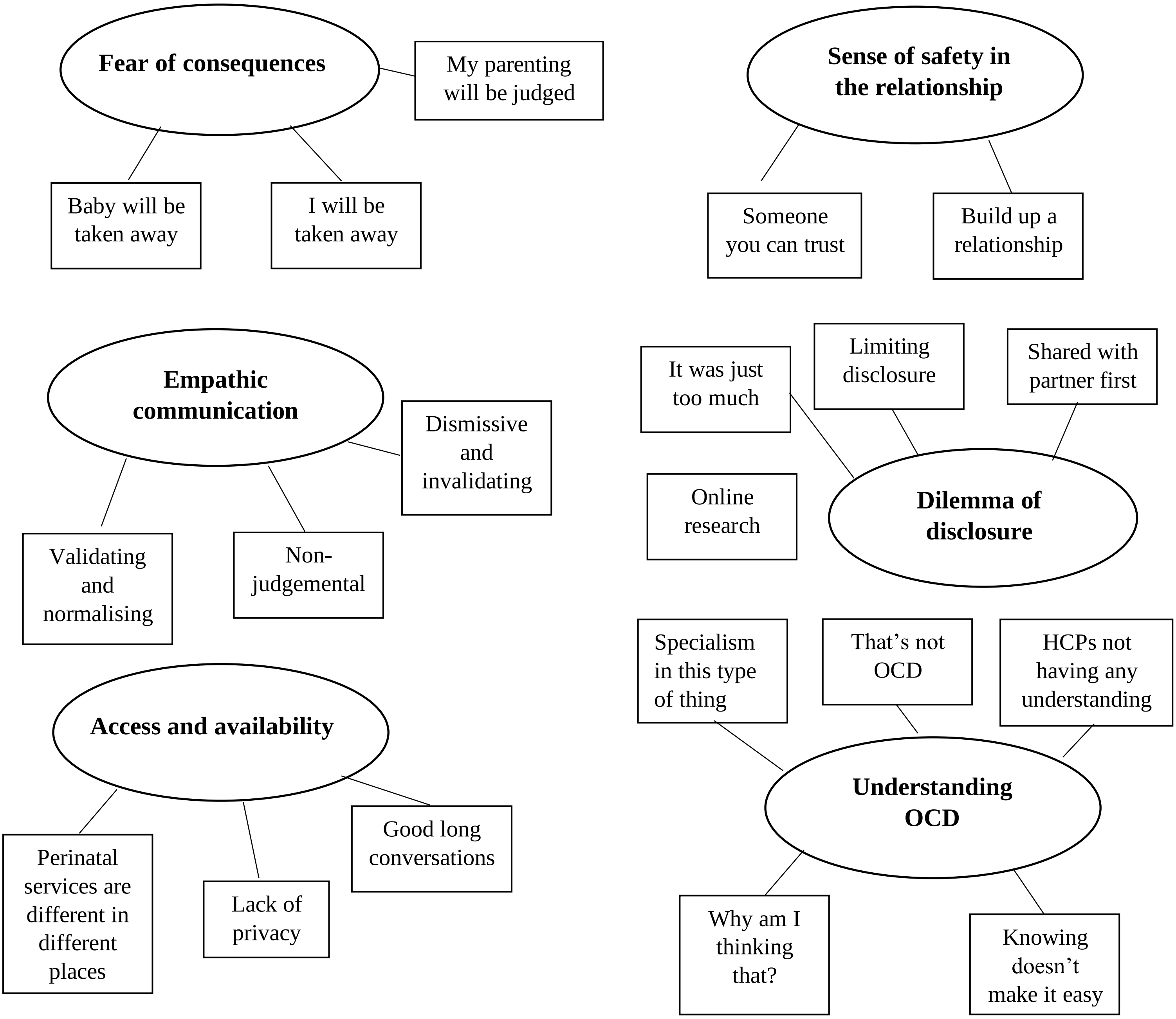
Respondent Validation Questionnaire

Feedback questionnaire

Project title: What helps and hinders mothers with OCD in disclosing thoughts of unwanted infant related harm to a health visitor/health care practitioner.

Thank you for agreeing to review the themes developed from the analysis. I will present the themes below and ask that you complete the questionnaire on the final page to let me know if the findings fit your experience.

Six themes and 20 sub-themes were developed from the analysis:



Summary of the themes

This section provides a summary of the themes and an example of a quote that illustrates each theme and sub-theme.

Fear of consequences

This was a central theme that describes a barrier to disclosure for all participants. Three subthemes describe the different consequences the participants feared would happen if they disclosed the thoughts they were experiencing.

Baby will be taken away. The majority of mothers expressed experiencing a fear that if they shared their experience of unwanted harm thoughts with a health care professional (HCP) it would lead to social services involvement and their baby being taken away.

> "Because you, you just think (pause) if I tell anyone about these thoughts, they're gonna take my baby away" (Participant 10)

*I will be taken away***.** Some mothers indicated that a fear of being sectioned or arrested prevented them from disclosing their thoughts to a HCP.

> "I just kept saying 'I know they're gonna take me away I know they're gonna take me away'" (Participant 8)

My parenting will be judged. Mothers indicated that they either feared or expected that their ability to parent would be judged negatively if they shared with HCPs, suggesting a dichotomy of being a good/bad mother.

> "Erm or (long pause) people would just start questioning my mental capacity as a parent…" (Participant 7)

Sense of safety in the relationship

This central theme from participants' accounts describes how the relationship between the mother and HCP had the potential to act as a facilitator or barrier to disclosure and the factors that contributed to feeling safe in this relationship.

Build up a relationship. Mothers shared that they eventually felt able to speak to a HCP once they had developed a relationship over time. Not having a good enough relationship with a HCP was also identified as a barrier to disclosure.

> "I think that's the big problem, is that you don't have health visitors or anyone that you can trust, that you can build up that relationship with so that you can talk about it." (Participant 4)

Someone you can trust. Mothers shared the importance of feeling that they could trust the HCP and this was closely linked with building a relationship over time.

> "cos I'd already, I'd already built up that level of trust with him by this point" (Participant 2)

Empathic communication.

This theme recognises the importance of HCPs expressing empathy to mothers experiencing distress. Three subthemes helped described the different ways empathy was or was not expressed.

Validating and normalising. Mothers spoke about the importance of HCPs validating and normalising their experience when they did begin to share their experiences.

> "Mm (pause) I think she validated the way I was feeling. And she sort of made it feel like it was okay to feel this way… And (pause) made it all seem (pause) a lot more normal." (Participant 3)

Non-judgemental. One mother shared how the HCPs non judgemental approach made her feel relief after disclosing.

> "Cus it's, you've you told her and she hasn't (pause) she hasn't reacted (pause) she's just taken it in and carried on, you know. Mm so I definitely felt relief when I told her" (Participant 8)

Dismissive and invalidating. Mothers shared how dismissive and invalidating their interactions with HCPs could feel.

> "I can remember telling the midwife that I was feeling really anxious and just being completely dismissed… And she was very dismissive and I mentioned it on a few antenatal appointments and she didn't really seem too fussed." (Participant 3)

Access and availability

This theme describes how opportunities to access HCPs in the postnatal period influenced disclosure.

Good long conversations. Mothers shared that when HCPs were able to make time and space to talk with them this facilitated disclosure.

> "She, we were, I was the last person left, she took me aside and we sat and talked and (pause) and everyone had gone, it was well after the end of the (pause) clinic" (Participant 6)

Lack of privacy. One mother shared how the environment could act as a barrier to disclosure as she felt others might hear what is talked about.

> "you're usually queuing up with other mothers standing there that can probably hear what you're talking about (pause) (pause) I didn't, there weren't any any opportunities for me to say 'I'm having really bad, you know, thoughts … I didn't really feel like there were opportunities to raise those concerns cus of the settings that you're (pause) pushed to or that are available to you, you know (sighs)". (Participant 1)

Perinatal services are different in different places. Mothers shared how the quality of care in perinatal services were different in different places in the country.

> "erm (pause) I'm in [town] (laughs) and it's not great (pause) the like, they've, first of all they forgot I was pregnant and then they said 'oh you're still pregnant'" (Participant 9)

Understanding OCD

This theme regarded the role that both the mothers own understanding of OCD and that of others, both at a societal and practitioner level, played in creating or reducing barriers to disclosure.

Why am I thinking that? Mothers shared the difficulty they experienced in making sense of why they were having unwanted thoughts of harm about their child.

> "I wasn't really sure how normal it was (pause) whether everyone had that when they had a baby because I hadn't had that before." (Participant 3)

Knowing doesn't make it easy. One mother who had received a diagnosis of OCD before having her baby shared how understanding OCD did not make it easier to experience the thoughts.

> "one of the things that I remember the day after he was born was (pause) I was in a hospital bed next to a window and I remember thinking 'God do I wanna just chuck

> him out the window?' and (pause) I was thinking god this is so silly I know what this is (pause) but it doesn't make it easy still" (Participant 9)

HCPs not having any understanding. Some mothers spoke about their perception of HCPs not having any understanding about OCD and the types of thoughts they were experiencing. There was also a sense that health visitors in particular were not well versed in mental health and were only familiar with PND. This was experienced as a barrier to disclosure.

> "Mm (pause) so (pause) I thought th (pause) people would just think (pause) that I was, yeah, that I was just gonna hurt them and (pause) that it was something very unusual… It was I was worried that that was going to happen. It was very hard to explain that, and I didn't think people would understand that." (Participant 4)

That's not OCD. Some mothers expressed their perception that the experience of OCD has been minimised in society and this has impacted on how people understand it.

> "something like OCD which has, which people think is just having things in order you know, there's still this 'I'm a little bit OCD' about this (pause) which is actually, you know, really damaging." (Participant 9).

Specialism in this type of thing. Some mothers indicated that they benefited from HCPs who had experience of working with OCD.

> "when I first had CBT with a psychologist (pause) I couldn't, it was such a relief to have somebody know what I was talking about umm that therapists, you know, and I'm talking general, and counsellors, you know, they don't know." (Participant 1)

Thank you for reviewing the themes and sub-themes. I would appreciate any feedback on the questionnaire (please see next page).

Questionnaire

Do the themes and sub-themes, as I have described them, fit your experience of disclosing unwanted infant related harm thoughts to a health care professional? Please tick one of the boxes below:

Yes☐

Partly☐

No☐

Are there any particular ways in which your experience has not been shown in the themes? If so could you briefly say what is missing or what you wish to be taken into account?

Is there anything else you would like to say?

Thank you for taking part in the research project looking at what helps and hinders mothers with OCD in disclosing their unwanted infant related harm thoughts to a health care professional.

Appendix J

Ethics Approval Letter

This has been removed from the electronic copy.

Appendix K

Additional Information Sheet

List of support services

Peer support:

○ ***Maternal OCD***

Maternal OCD are currently taking a peer support sabbatical but their website has useful information and resources: https://maternalocd.org/resources/

○ ***OCD Action***

OCD Action's helpline and email service operates between 9.30-5 Monday to Friday and volunteers are also able to call people back during the evenings. It is a confidential and unbiased service offering help, information and support for people with OCD, carers and anyone who is concerned that they, or their friends or relatives, may have OCD or a related difficulty.
You can contact the helpline on 0845 3906232 or email support@ocdaction.org.uk

OCD Action Skype/Phone Support Group: On the second Tuesday of the month at 7pm & fourth Thursday of the month at 7pm there is a Perinatal OCD Support Group run by OCD Action's 'Even Better Together' project.

For further details please email sign-up@ebtsupportgroups.co.uk

Psychological wellbeing:

○ ***The Samaritans***

Confidential service offering 24 hour emotional support to those in need.
Tel: 116 123 (this is a free telephone number and will not appear on the phone bill)
Web: www.samaritans.org
Email: jo@samaritans.org

○ ***Family Lives*** (formerly Parentline)

Confidential and free helpline service for families offering emotional support, information, advice and guidance on any aspect of parenting and family life.
Tel: 0808 800 2222
Web: www.familylives.org.uk
Email: askus@familylives.org.uk

○ ***Home Start***

Offers support for families with young children.
Tel: 0800 068 63 68
Web: www.home-start.org.uk

○ ***British Association for Counselling and Psychotherapy (BACP)***

Provides information and advice for those considering counselling.
Tel: 01455 883300

Web: www.bacp.co.uk

General:

- ***National Childbirth Trust (NCT)***

The UK’s leading charity for parents. Support line offering practical and emotional support in all areas of pregnancy, birth and early parenthood.
Tel:0300 330 0700
Web: www.nct.org.uk

Appendix L
Themes, Subthemes and example quotations

Theme	Subtheme	Code	Example Quote
Fear consequences of disclosure	Baby will be taken away	Fear of baby being taken away	All I would be worried about is the fear of being judged and having my baby taken (pause) rather than actually getting help [P9]
		Fear of social services	Either which was ex, was one of two extremes, either she'd just say 'oh okay we'll just keep monitoring that' or she'd go 'well yeah well we're gonna have to talk to the GP and get social services involved and that's really awful, and like I don't know if he can stay with you' [P7]
	I will be taken away	Fear of being sectioned	I didn't know what (pause) would happen, you know, would they (pause) would I be taken into an institution? What sort of intervention…does that then flag? [P1]
		Fear of being arrested or sectioned	And I just kept saying 'you know I'm a good person, you know I'm a good mum' and I just kept saying 'I know they're gonna take me away I know they're gonna take me away.' [P8]
	My parenting will be judged	Fear of being judged as a bad mother	Expected to be judged as a bad mother and it was so nice that people (pause) weren't judging me and weren't saying 'oh you're a horrible mum for this or you're terrible'. [P4]
		Fear of being judged as a dangerous parent	Um (pause) and I guess, it's one of those things where you fear that telling them, they may think that you are a danger to yourself or your children. [P2]
		Fear of capacity to parent being judged	Would they worry about (pause) whether I could look after her? You know, I was, that's, and I'm sure you'll probably hear that quite a lot, I was (pause) I didn't want to admit it to anyone. [P1]
		Reassuring self of being a good mum	And I just kept saying 'you know I'm a good person, you know I'm a good mum… [P8]

		Being a parent does not mix with mental health difficulties	You tell someone that you’re struggling mentally (pause) and then throw kids into the mix as well, and then tell them that those thoughts relate to your children (pause) it just (pause) yeah. [P2]
Dilemma of disclosure	Shared with partner first	Non-judgemental response from partner	Yeah I remember sitting him down one night and saying you know (pause) telling him (pause) and I, I remember the look on his face, he was he wasn’t shocked (laughs). He was like ‘its okay’ like ‘we’ll, we’ll work through it it’s fine, we’ll get you what you need’[P8]
		Partner supportive after disclosure	So I shared it with my partner first, he was the one that said I need to talk about it with someone.” [P2]
	Limiting disclosure	Only share minimum amount of information	I kind of only told her that I had obsessive compulsive disorder, and I kind of kept it to the briefest, very minimum, very (pause) smallest amount of information [P7]
		Talk about experience more broadly	No, so I shared that I was having a difficult time with my health visitor… um but I didn’t actually share about the thoughts that I was having. [P2]
	It was just too much	Reach a breaking point	And then it got to a point that I think it was just too much. [P3] Um but I didn’t really tell anyone until probably about June, because that’s when I returned to work and it was just too much. [P2]
		No longer able to cope	I think for me it was the feeling that I was absolutely at the point where I just couldn’t, just couldn’t cope with the way we were going. [P6]
	Online research	Reassurance from online research	I like looked up on Mind and I kind of saw a few things and just thought, ‘well maybe they’ll be okay about it…more, more…’.” [P4]
		Parenting groups an important resource	Yeah, I think luckily it was either that morning that I sort of read this post or the day before… I I acted on it really, like (pause) I'm gonna go, so I, I mean, baby clinic used to be on a Tuesday morning. So potentially I read that post Tuesday

			morning (pause) and thought I could go and speak to someone and I like (pause) went and did it there and then (pause) [P10]
Sense of safety in the relationship	Build up a relationship	Relationships are important	I think (pause) it's too much (pause) unless there was a, you know, a therapist that you had a good relationship with (pause) I don't think it would be easy at all. [P9]
		Relationship develops over time	Just always had that because I have met her before, just there's like, a connection there to sort of, a bit of empathy, you know, she she showed always showed so (pause) yeah [P10] Our local NHS trust had put into place umm pregnancy visits with health visitors or pregnancy phone calls with health visitors whereas with [1st son] that wasn't in place, you just had contact with your midwife (pause) so our trust had changed that and I thought that was really great, so I spoke to her a couple of times when I was pregnant… I know that (pause) lots of people were having issues with even seeing a GP or getting in to see the same midwife to have continuity of care (pause) and yet she was, she was actively coming into my house [P7]
		Need a better relationship to disclose	The end of our conversations were always 'if you've got a problem you know where I am, you're welcome to call me at any point' etcetera etcetera (pause) but I just didn't feel that (pause) there was yeah that relationship to (pause) to be able to do that (pause) yeah… I do just think that had (pause) had my relationship been better with her or i trusted her more I might have been more willing to do it. [P7]
	Someone you can trust	Trust in HCP before disclosure Lack of trust in HCP	Cos id already, id already built up that level of trust with him by this point. [P2] So a lot of the support I got from her was around his weight and the decline in weight and the, the feeding support and stuff like that, to help my OCD from that perspective rather than (pause) anything else because, I didn't I didn't trust her…I do just think that had (pause) had my relationship been better with her or i trusted her more I might have been more willing to do it. [P7]
Empathic communication	Validating and normalising	Validation of feelings important	Mm (pause) I think she validated the way I was feeling. And she sort of made it feel like it was okay to feel this way… And (pause) made it all seem (pause) a lot

			more normal. [P3]
		Important to normalise experience	I think I felt quite good and (pause) especially because she reassured me, as someone who's totally normal, it's absolutely normal, it's natural, let me get you this piece of paper, like (pause) and it was almost like it wasn't a big deal, it was, I didn't feel brushed off, but that was how she was doing it. [P10]
	Non-judgemental	Not reacting to disclosure	Cus it's, you've you told her and she hasn't (pause) she hasn't reacted (pause) she's just taken it in and carried on, you know. Mm so I definitely felt relief when I told her. [P8]
	Dismissive and invalidating	Not acknowledging concerns about anxiety	I can remember telling the midwife that I was feeling really anxious and just being completely dismissed… And she was very dismissive and I mentioned it on a few antenatal appointments and she didn't really seem too fussed. [P3]
		Not acknowledging distress	"Before she came I just couldn't stop crying and I was just crying and crying and crying and I was like hyperventilating and (pause) all this sort of thing and then she came in and she was really like 'oh you know, it's okay, you know, we think, you know, the baby's fine and you know you're just, you know, a bit low and if it carries on you know contact the GP but we're discharging you' and I was thinking 'ughh' like 'now I'm left, now we're on our own" [P8]
Access and availability	Good long conversations	HCP made time to talk	She, we were, I was the last person left, she took me aside and we sat and talked and (pause) and everyone had gone, it was well after the end of the (pause) clinic. [P6]
	Lack of privacy	Role of setting	You're usually queuing up with other mothers standing there that can probably hear what you're talking about (pause) (pause) I didn't, there weren't any any opportunities for me to say 'I'm having really bad, you know, thoughts … I didn't really feel like there were opportunities to raise those concerns cus of the settings that you're (pause) pushed to or that are available to you, you know (sighs). [P1]
	Perinatal services are different in different places	Sense of luck in access to HV team	We're really fortunate in [county] (pause) we are literally on the border and I'm so glad because (pause) the [another county] health visiting team whatever they are called, but that whatever they are, they're not doing visits, they're not doing weigh-ins, nothing. [P10]

Understanding OCD	Why am I thinking that?	Trying to make sense of why having these thoughts.	I started getting these strange thoughts and I thought, ‘ooh’, you know (pause) or ‘ I don’t want to think about that, why am I thinking that?.[P8]
	Knowing doesn’t make it easy	Understanding OCD does not make the experience easier	One of the things that I remember the day after he was born was (pause) I was in a hospital bed next to a window and I remember thinking ‘God do I wanna just chuck him out the window?’ and (pause) I was thinking god this is so silly I know what this is (pause) but it doesn’t make it easy still. [P9]
	HCPs not having any understanding	Belief that HCPs would misinterpret thoughts	Mm (pause) so (pause) I thought th (pause) people would just think (pause) that I was, yeah, that I was just gonna hurt them and (pause) that it was something very unusual… It was I was worried that that was going to happen. It was very hard to explain that, and I didn’t think people would understand that. [P4]
	That’s not OCD	OCD is minimised in society	Anxiousness is thrown around so loosely now (pause) and I do get that (pause) umm and I really hate that the term ‘I'm really OCD about that’ when someone's talking about their being cans being turned right around like I get that, I get that that annoys you, but that's not OCD. [P10]
	Specialism in this type of thing	Specialist clinicians questions feel conversational	Yeah, but like it was more the kind of (pause) mm the way you would kind of ask questions it just came out. I didn’t think about the fact that I was telling him. [P2]

Appendix M

Sample coded transcript

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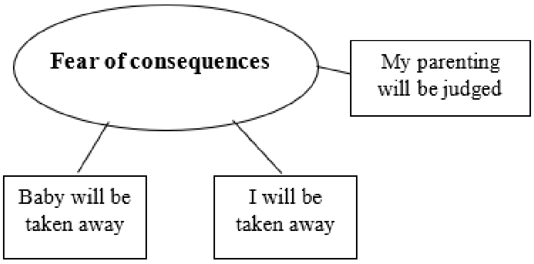
Appendix N

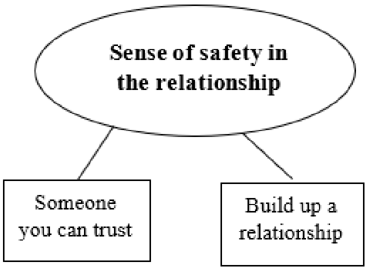
Summary report for ethics panel

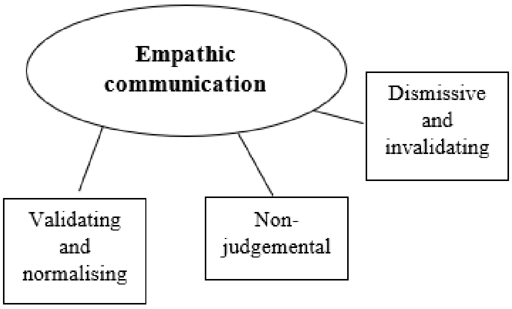
Background: Unwanted intrusive infant-related harm thoughts are a common experience for new mothers. When such thought are particularly distressing and interpreted as threatening and significant for mothers they may receive a diagnosis of 'obsessive compulsive disorder (OCD)'. The existing perinatal mental health literature focuses on postnatal depression (PND) and highlights many barriers for disclosure and help seeking. However, to the researcher's knowledge there is no research that has sought to understand the perceived barriers and facilitators to disclosing unwanted infant-related harm thoughts to a health care professional (HCP) in mothers with OCD.

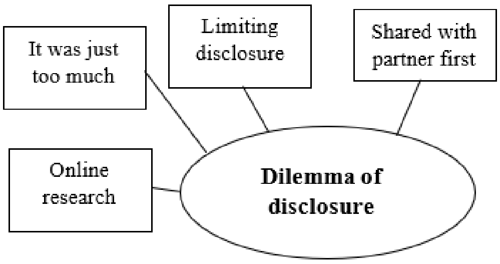
Method: This qualitative study used reflexive thematic analysis to explore and create a thematic understanding of mothers' experiences and views of the disclosure process. 10 participants were recruited through advertising on social media and relevant forums and participated in a semi-structured interview about their experiences. Interviews were completed online using a video platform. Participants were asked to read a participant information sheet, a screening questionnaire and sign a consent form prior to the interview.

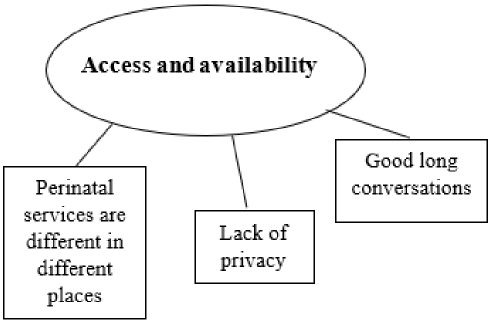
Results: Six themes and 20 sub-themes were developed from the analysis:

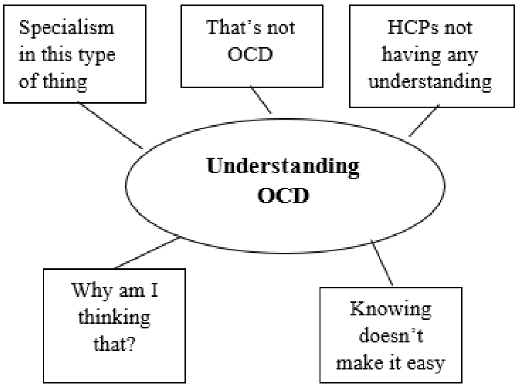












Fear of consequences- This was a central theme that describes a barrier to disclosure for all participants. Three subthemes describe the different consequences the participants feared would happen if they disclosed the thoughts they were experiencing.

Sense of safety in the relationship - This central theme from participants' accounts describes how the relationship between the mother and HCP had the potential to act as a facilitator or barrier to disclosure and the factors that contributed to feeling safe in this relationship

Empathic communication - This theme recognises the importance of HCPs expressing empathy to mothers experiencing distress. Three subthemes helped described the different ways empathy was or was not expressed

Access and availability - This theme describes how opportunities to access HCPs in the postnatal period influenced disclosure.

Understanding OCD - This theme regarded the role that both the mothers own understanding of OCD and that of others, both at a societal and practitioner level, played in creating or reducing barriers to disclosure.

Implications: The findings suggested a number of factors that have the potential to act as barriers or facilitators to disclosure, providing new insights for mothers with OCD as well as echoing existing literature for PND. There could be a role for clinical psychology in training HCPs who work with women in the perinatal period and their partners, particularly around psychoeducation of unwanted infant related harm thoughts, in having explicit conversations around risk that may alleviate some of the feared consequences of disclosure and in developing a better relationship to support disclosure through the facilitators identified in this research. Future research needs to be carried out to further explore this area and could consider the views of groups whose voices were not heard in this research, such as single-parents, mothers from minoritised ethnic backgrounds and same-sex couples. It would also be important to hear from partners/fathers to understand their perception of the experience and the impact on their own mental health.