



Overcoming obstacles in perinatal Obsessive-
Compulsive Disorder: the search for screening
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Psychiatric disorders in the perinatal period are often debilitating for patients. Obsessive compulsive disorder (OCD) in the perinatal period is frequently undetected, misdiagnosed or untreated for a multitude of reasons. OCD is an anxiety disorder that is thought to affect 1 -2% of the population¹. It is characterised by intrusive and recurrent thoughts, with or without compulsions. Compulsions are ritualistic behaviours that patients perform to prevent or alleviate stress caused by intrusive thoughts². Perinatal OCD describes OCD that occurs during pregnancy or postnatally.

The psychological distress caused by OCD should not be underestimated. In the perinatal period, OCD often manifests as intrusive thoughts about deliberate or accidental harm to the baby, for instance fears of inappropriately touching the baby or harming the baby by contamination. Intrusive thoughts about harming the baby via contamination may lead to behaviours such as diet restriction in pregnancy; excessive handwashing before touching the baby; excessive bathing or nappy changing; avoiding contact with playgroups; or avoidance of the child altogether^{3,4}. Likewise, intrusive thoughts about deliberate harm to the baby may lead patients to perform mental rituals to remove disturbing thoughts, or may result in complete avoidance of the child. These symptoms can cause profound psychological distress, difficulties with day-to-day activities, persistent detrimental effects on the cognitive-behavioural development of the infant and on the mother-child relationship. This can also have knock-on effects on relationships with other family members, and – where OCD is not treated and resolved – chronic OCD that may affect quality of life^{5,6}.

There is evidently a pressing need for better understanding, awareness, detection, diagnosis and treatment of OCD in the perinatal period. Here, I will discuss the four hurdles facing OCD in the perinatal period: (1) awareness, (2) detection and diagnosis, (3) misdiagnosis, and (4) treatment. To improve services for these women and prevent misdiagnosis, these hurdles need to be discussed and addressed in full.

The first hurdle: recognition of perinatal OCD

Perinatal OCD is often poorly recognised and, to compound this problem, there is a lack of research into its prevalence and associated symptoms. Studies suggest that there is increased prevalence of OCD in the perinatal period compared with OCD in non-gravid populations. A systematic review of multiple retrospective studies indicated that up to 40% of childbearing OCD outpatients experienced onset of their OCD during pregnancy, and up to 30% experience onset of their OCD in the puerperal period^{5,7}. A recent metanalysis also demonstrated higher prevalence of OCD during pregnancy (2.07%) and the postpartum period (2.43%) compared to the general population (1.08%)⁸. Postpartum OCD has almost always been reported in mothers rather than fathers^{5,9}. In the general population, OCD typically affects women and is most commonly diagnosed in patients who are in their 20s⁴. Women are at heightened risk of OCD and healthcare practitioners are typically unaware of the increased prevalence of OCD in the perinatal period⁶.

To add to this evidence, analysis of the prevalence of OCD in a group of 78 women identified new onset OCD in 32.1% of women in the perinatal period (15.4% in pregnancy, 14.1% in postpartum and 1.3% following miscarriage)¹⁰. Exacerbation of OCD symptoms was observed in 34.1% of pregnancies; 22.0% noted improvement in OCD symptoms; whereas 43.9% did not observe a change in pre-existing OCD¹⁰. While the aetiology of perinatal OCD is unclear, there is a discernible impact of pregnancy on new onset OCD symptoms. In women who have pre-existing OCD, the impact of the perinatal period on OCD is less clear.

Despite evidence for the increased prevalence of OCD in the perinatal period, the existence of perinatal period OCD (ppOCD) as a distinct subtype of OCD has not been firmly established and the evidence to support the existence of ppOCD as a separate condition is mixed¹¹. Although perinatal OCD is not formally recognised as a separate diagnosis, there is consensus that perinatal OCD has distinct symptoms and a distinct illness course. Moreover, DSM-V recognises that “peripartum onset” of the illness may cause “onset or exacerbation of OCD, as well as symptoms that can interfere with the mother–infant relationship”^{12,13}.

There are further difficulties with the detection of OCD in the perinatal population. As with other psychiatric disorders, patients may not seek help for various reasons. Patients may feel shame and stigma about their condition, and may have thoughts of deliberately harming their child, which they often find deeply disturbing. Especially in pregnancy or postpartum, patients may worry about being labelled “unfit” for parenthood by their healthcare practitioners and may fear involvement of social services. Lack of awareness amongst healthcare practitioners may also lead to misdiagnosis with other psychiatric disorders, such as postpartum psychosis. It is important to differentiate OCD from postpartum psychosis as the treatment of OCD is markedly different. OCD patients may not receive adequate treatment and may be unnecessarily admitted to hospital. Admission to hospital can further reinforce OCD-related thoughts, such as fears of being harmful to the child. Misdiagnosis is associated with poor quality of life, impaired physical health and damaged social relationships⁴.

To overcome this hurdle, primary care clinicians and health visitors should actively screen women for symptoms of OCD during pregnancy and in the postpartum period. This can be achieved through clinical interview, which can help to identify intrusive thoughts and diagnose perinatal OCD. Several screening questions have been suggested, including “It’s not uncommon for new mothers to experience intrusive, unwanted thoughts and perform repetitive acts as a result of concerns of causing harm to their baby. Have you ever had these thoughts or performed these repetitive acts?”^{5,14}, “do you have unpleasant thoughts, urges or images that repeatedly enter your mind?” or “do you feel driven to perform certain behaviours or mental acts over and over again?”^{5,13}. Alternative methods include (1) the Edinburgh Depression Scale, combined with an additional risk questionnaire⁵, or (2) methods of screening for OCD such as the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) or, more recently, the perinatal obsessive-compulsive scale (POCS)¹⁵. Patients who have a positive screening result should receive a thorough psychiatric assessment for OCD and comorbid disorders, including depression. A diagnosis of OCD can often be relieving for patients, as it provides an explanation for their thoughts and behaviours. If perinatal OCD is suspected, mothers should be managed using the NICE guidelines and referred for CBT or specialist perinatal services.

The second hurdle: assessment and diagnosis of perinatal OCD

We urgently need good screening tools for OCD in perinatal populations. Leung et al. (2017) compared the prevalence of DSM Axis I disorders obtained on the PDSQ with (1) the prevalence of these disorders in previous studies of pregnant and postpartum women, and (2) scores from the Edinburgh Postpartum Depression Scale and Symptom Checklist-90-Revised (SCL-90R) anxiety scale¹⁶. While the PDSQ revealed higher levels of social phobia, alcohol disorder, OCD and psychosis than statistics reported in the literature, comparison of the PDSQ revealed results that were poorly concordant with the EPDS and the SCL-90R scales¹⁶. The poor concordance of these scoring systems indicates that these scales may not be suitable for pregnant populations. As evidenced here, there are difficulties in screening for and recognising OCD, and we need concerted efforts to identify adequate screening and diagnostic methods for perinatal populations.

Another review assessed the accuracy of the most commonly used and/or recommended screening tools for perinatal anxiety disorder, including the EPDS and its anxiety subscale (EPDS-3A) and the Generalised Anxiety Disorder 7 and 2-item scales (GAD-7 and GAD-2) alongside a clinically derived alternative, the Anxiety Disorder-13 (AD-13)¹⁷. To evaluate the efficacy of these scoring methods, 310 Canadian women completed mood and anxiety questionnaires at 3-months postpartum, and the accuracy of each scale was assessed via ROC analyses. The results indicated that EPDS/EPDS-3A and GAD-7/GAD-2 did not meet the standards for a clinically useful screening measure, and only the AD-13 met the standard for a useful screening measure¹⁷. As previously mentioned, Lord et al. (2011) piloted a perinatal obsessive-compulsive scale (POCS), a self-assessment scale that documents the severity of perinatal obsessions and compulsions. The POCS was compared with the Yale-Brown Obsessive-Compulsive Scale (Y-BOCS) and demonstrated properly representative items, high internal consistency, good concurrent validity and discriminative ability¹⁵. The POCS allowed for identification of common obsessions, such as the baby being unhealthy at birth, contamination of the baby, or the baby being taken away; and common compulsions, such as repetitive rituals, asking for reassurance, excessive checking and cleaning the baby. The POCS also gave women the chance to discuss any concerns or issues concerning symptoms of OCD. So far, there is limited evidence to support the use of the POCS; however, the POCS may prove useful as a screening tool in the future.

In addition to problems with screening tools, there is poor appreciation for the prevalence of OCD. Using the OCI-R and EPDS, Chaudron et al. (2010) highlighted the prevalence of OCD in a prospective longitudinal study of 44 women between 30 and 37 weeks of pregnancy¹⁸. In the third trimester, 32% of women reported high levels of anxiety and/or depressive symptoms (EPDS \geq 10 and/or OCI-R \geq 15). Following interview, 29% of these patients met the criteria for OCD. At 1 month postpartum, 12.5% had new OCS (classified as a Y-BOCS \geq 8) and 25% had new high levels of depressive symptoms (classified using EPDS \geq 10)¹⁸. OCD and OCS may be of greater prevalence during the perinatal period than previously recognised. As evidenced by these studies, we need greater research into psychiatric disorders in the postpartum period, including OCD. We need a good understanding of their symptomology and features in order to form good detection tools, diagnostic aids and treatment pathways.

The third hurdle: failure to treat and misdiagnosis

The accurate identification and diagnosis of perinatal OCD poses a problem: women commonly remain untreated or, in some cases, are misdiagnosed. There is a widespread lack of recognition of perinatal OCD amongst the public and among healthcare professionals. In addition, practitioners are comparatively more aware of postpartum psychosis, which can lead to misdiagnosis of perinatal OCD. Without widespread recognition of perinatal OCD amongst the general public, there is also difficulty in encouraging patients to seek help when needed. For women who are pregnant or have recently given birth, obsessive thoughts – especially disturbing thoughts about harming the baby – can cause immense psychological distress and patients may be reluctant to share these thoughts with family, friends or their healthcare team.

Untreated OCD has long-term and severe consequence for mothers and children. For mothers, OCD has severe detrimental effects on quality of life; for children, there are reports of increased rates of internalising disorders^{5,6} and problems with mother-infant interactions. Challacombe et al. (2016) characterised some of the effect of OCD on patients: postpartum patients were troubled by their symptoms for 9.6 hours/day on average; and reported (1) lack of confidence, (2) more marital distress, (3) less social support and were (4) less likely to breastfeed. Obsession and compulsions were also reported in the healthy group, but these did not interfere with patients' daily activities¹⁹. While the outcomes of postnatal OCD have not been properly investigated, the course of untreated OCD during

pregnancy and puerperium has been investigated in several small studies that have provided mixed results. Reported statistics were variable: outcomes indicated that 8% to 50% of women with pre-existing OCD reported worsening of symptoms^{5,20,21}; 31% to 69% reported no change^{5,20-22}; and 10% to 69% reported improvements in their symptoms^{5,20-22}. Furthermore, major depressive disorder is the most common comorbidity in patients with OCD in the general and perinatal population, and pregnant women with OCD could have increased susceptibility to postpartum depression 2 to 3 weeks after their initial OCD symptoms^{5,14}.

Misdiagnosis of OCD in the postpartum period also has serious repercussions. A case study described how OCD-affected mothers were classified “high risk” and admitted to a specialist mother and baby unit. Admission to this unit led to restricted interactions between mother and infant. In OCD patients, admission to hospital can potentially exacerbate OCD (as it reinforces OCD-related thoughts of being harmful to the child), and have detrimental effects on mother-infant interactions⁴. There are currently no case reports of women with perinatal OCD who intentionally harm their infants. OCD patients typically have good insight into their obsessions and recognise the impact on their lives. These patients need support and well-tailored treatment to prevent harm to the mother-child relationship, and improve quality of life.

Perinatal OCD would benefit from advocacy from patient groups and amongst healthcare professionals. As an example, awareness of cervical cancer screening was augmented by the so-called Jade Goody effect. When Jade Goody was diagnosed with cervical cancer, the effect her diagnosis and death was far-reaching in the UK. It encouraged (1) awareness of cervical cancer, and (2) measurably improved uptake of cervical smears^{23,24}. The importance of advocacy and high-profile cases of illnesses cannot be understated. For OCD in the postnatal period, we need a combination of (1) public advocacy to improve awareness about the signs and symptoms of OCD in the perinatal period, and awareness of its increased prevalence; and (2) improved awareness amongst healthcare practitioners, namely general practitioners and health visitors, who are able to routinely screen for psychiatric conditions during clinical interviews.

The silver lining: treatment of perinatal OCD

Therapies for perinatal OCD have only been trialled in a handful of studies, but there is evidence for its positive effects. Marchesi et al. (2016) identified selected evidence to support the use of cognitive-behavioural therapy (CBT) for OCD, and panic disorder (PD) in pregnancy and postpartum. Where fluvoxamine (up to 300 mg/day) was used to treat postpartum patients, 65% of patients demonstrated an improvement in their OCD symptoms ($\geq 30\%$ decrease in the total Y-BOCS score)^{13,25}. Selective serotonin reuptake inhibitor (SSRIs) were associated with significant improvement in OCD and panic disorder (PD) in pregnancy and the postpartum period, and minimal side effects were observed in babies. Furthermore, Marchesi et al. observed that SSRIs and tricyclic antidepressants (TCAs) remediated panic symptoms and also led to healthy outcomes for babies²⁵. While large population-based studies have not found increases in congenital malformation or long-term behavioural problems in infants exposed to SSRIs or atypical antipsychotic medications^{5,26-28}, antidepressants in pregnancy are associated with small increases in the risk of spontaneous abortion^{5,29,30} and prematurity^{5,31}. Late exposure to SSRIs has also been linked to poor neonatal adaptation symptoms, such as difficulty feeding and breathing, and neonates near should be closely monitored for at least 48 hours after birth⁵.

CBT has been suggested as first-line treatment in pregnant and postpartum women^{4,5,13}. In one small study, CBT was trialled in six cases of postpartum OCD over a 2-week period. Mothers were evaluated by self-reported OCD symptoms, alongside measurements performed by the clinician, and noted

improvements in their OCD symptoms. These improvements observed were sustained at 3–5-month follow-up⁶. It is important to acknowledge problems with heterogeneity and study design, as these studies recruited patients from specialist centres or included very few participants. However, this study offers hope for remission when patients are correctly diagnosed and treated.

Conclusions

Perinatal OCD poses a problem for psychiatrists, midwives and general practitioners alike. There is poor recognition of the increased prevalence of OCD in the perinatal period, and also poor screening and poor knowledge of treatment options. The cornerstone of improvement in perinatal OCD is improved awareness and recognition of the condition. The first step for improvement is advocacy for awareness of the condition – both within the NHS and amongst the public. Improved awareness should facilitate (1) better education about the condition, (2) improved screening for the condition at healthcare check-ups during the postnatal period, and (3) better knowledge of referral pathways and treatment options. The problems that face perinatal OCD are multifaceted, and improving awareness and treatment of perinatal OCD requires a synchronised approach. At present, the screening questionnaires available are not fit for diagnosis of perinatal OCD and, furthermore, do not have a rigorous evidence-base to support their use. Likewise, the treatment options for perinatal OCD do not have a rigorous evidence-base for their use. We need a combination of large-scale research programs to (1) introduce tools that can effectively identify perinatal OCD and (2) introduce effective treatment pathways for perinatal OCD. We need advocacy for perinatal OCD amongst the public. Through a multipronged and carefully coordinated approach to increase awareness and improve treatment of perinatal OCD, it may be possible to put perinatal OCD on the map and, more importantly, help prevent misdiagnosis and steer patients in the right direction.

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