

## A hidden problem:

consequences of the misdiagnosis of perinatal obsessive-compulsive disorder

### WHAT IS PERINATAL OBSESSIVE-COMPULSIVE DISORDER?

Obsessive-compulsive disorder (OCD) is characterised by: recurrent and persistent thoughts, impulses, or images that are experienced as intrusive and that cause marked anxiety or distress; and compulsions, which are behaviours or mental acts aimed at preventing or reducing distress or preventing some dreaded event or situation. Avoidance can also feature prominently. In women, OCD commonly starts in the early 20s, and is often chronic; thus it coincides with the typical childbearing years for many women and pregnancy and/or birth is a consistently cited triggering factor.<sup>1</sup>

Perinatal OCD is OCD that occurs in pregnancy or postnatally. It may be a new and sudden onset in those with no previous history or an exacerbation of existing OCD. Symptoms commonly orientate around the baby and caregiving. Pregnancy onset has been more associated with fears of accidentally harming the baby by contamination (for example, 'my hands may be contaminated'), with related compulsions including excessive washing, restriction of diet and, postnatally, avoidance of activities and contact with others such as playgroups, and minimal child handling, reducing mother-child interaction. Postnatal onset has been more associated with fears of deliberately harming the baby (for example, 'I could touch my baby inappropriately'), associated with avoidance of tasks such as bathing and nappy changing, and mental rituals to cancel out thoughts.<sup>1</sup> These symptoms can cause significant burden and distress, particularly as daily life is dominated by caregiving activities at this point.

Research shows that the experience of intrusions regarding deliberate or accidental harm occurs in 80% of the general population and even more commonly in new parents.<sup>2</sup> These thoughts are usually easily dismissed; people

with OCD differ in that they give undue importance and meaning to the intrusions, which to them signal that they are capable of causing harm. It is essential to note that people with OCD do not act on their thoughts of deliberate harm; however, high levels of preoccupation and distress are caused by the symptoms.<sup>1</sup>

### TREATMENT

National Institute for Health and Clinical Excellence guidelines for treating OCD recommend cognitive behavioural therapy (CBT) and medication (with little specific evidence available for perinatal OCD). Many women prefer not to take medication in the perinatal period due to the possible impact on the child *in utero* or via breastfeeding. CBT helps the person understand that while their thoughts are normal, their reactions are excessive, and maintain the problem. Patients are encouraged to drop unhelpful behaviours and challenge their fears using exposure and response prevention.

### PREVALENCE

OCD is thought to affect 1.2% of the general population at any one time, while the few extant studies suggest that postnatal OCD is much more prevalent, at 4–9%.<sup>3</sup> A conservative estimate is one perinatal OCD case to a full-time GP per annum.

### BARRIERS TO DETECTION

Detection and help-seeking for all perinatal problems is low relative to the prevalence and this is particularly true of anxiety,<sup>4</sup> although little evidence exists regarding OCD. In perinatal OCD, the shame of disclosing difficulties is often compounded by fears of being misunderstood by professionals and being judged a potentially harmful parent. Parents themselves may not make sense of their experiences as OCD, particularly if they have no previous history. This may be particularly true of those experiencing thoughts of deliberate

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harm who often fear they are 'going mad'.

Lack of awareness of perinatal OCD may also mean that other diagnoses such as postnatal depression are made. Research indicates a small to moderate association between severity of intrusions and depressive symptoms among mothers, that is, that OCD is a distinct problem (rates of comorbidity are not known).<sup>1</sup> In severe cases, perinatal OCD can be misdiagnosed as postpartum psychosis. Therefore secondary care health professionals need to be skilled in differentiating perinatal OCD from severe depressive disorders and psychosis with actual risk of harm.

## MISDIAGNOSIS

Untreated perinatal OCD is associated with poor quality of life due to the symptoms described above, which cause restricted functioning, impaired physical health, and damaged social relationships (effect size >0.8).<sup>5</sup> Failure to detect perinatal OCD is likely to result in persistence of these problems. Misdiagnosis may lead to inappropriate, ineffectual, or potentially damaging treatment. It is crucial then that primary care health professionals, for example, GPs and health visitors, are able to identify symptoms of perinatal OCD, and refer to secondary care in a timely manner.

The authors recently worked with two women who presented with intrusive, ego-dystonic, and distressing thoughts of harming their children. Unfortunately OCD was not recognised and instead the women were classified as 'at high risk' of harming their children, and admitted to specialist mother and baby units. Contact with their babies was severely restricted and child protection proceedings were initiated. This reinforced the mothers' own fears that their symptoms meant they may harm their babies, thereby severely exacerbating the OCD and impairing the mother-baby relationship. Both were successfully treated with CBT following discharge.

## IDENTIFICATION BY GPs

Clinical interviews assessing the experience of and reaction to intrusive thoughts of harm can help diagnose perinatal OCD. When less anxious, parents with OCD are clear they would not act on their thoughts and/or are aware their compulsions such as cleaning are excessive.

Screening questions for OCD from the Psychiatric Diagnostic Screening Questionnaire<sup>6</sup> have a good detection rate; further research is required to develop 'easy-to-use' questions for use in primary

care. Patients are often hugely relieved to receive a diagnosis of OCD.

As with other perinatal mental health difficulties, if perinatal OCD is suspected, the parent should be managed as per NICE guidelines and referred to a CBT or specialist perinatal service, that will also be well placed to confirm diagnosis and assess risk.

## LEARNING POINTS

- OCD is increased during the perinatal period, and may present as fear around harming the baby.
- CBT is effective for treating postnatal OCD.
- Lack of awareness of perinatal OCD can lead to failure to diagnose, or misdiagnosis, and inappropriate treatment, which causes distress and potential disruption of mother-infant relationships.

## Provenance

Freely submitted; not externally peer reviewed.

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