

## Seeking help for perinatal psychological distress: a meta-synthesis of women's experiences

### Abstract

#### Background

Women may not seek help for perinatal psychological distress, despite regular contact with primary care services. Barriers include ignorance of symptoms, inability to disclose distress, others' attitudes, and cultural expectations. Much of the evidence has been obtained from North American populations and may not, therefore, extrapolate to the UK.

#### Aim

To understand the factors affecting women's decision to seek help for perinatal distress.

#### Design and setting

Meta-synthesis of the available published qualitative evidence on UK women's experiences of seeking help for perinatal distress.

#### Method

Systematic searches were conducted in accordance with PRISMA guidelines. Databases searched were PubMed, Scopus, PsycINFO, PsycARTICLES, CINAHL, and Academic Search Complete. Searches of grey literature and references were also conducted. Studies were eligible for inclusion if they reported qualitative data on UK women's experiences of perinatal distress and contact with healthcare professionals. The synthesis was conducted using meta-ethnography.

#### Results

In all, 24 studies were eligible for inclusion. Metasynthesis identified three main themes: identifying a problem, the influence of healthcare professionals, and stigma. These themes build on current understanding of help seeking by identifying the need for women to be able to frame their experience, for healthcare professionals to educate women about their roles, the need for continuity of care, and the way that being seen as a 'bad mother' causes women to self-silence.

#### Conclusion

Perinatal care provision needs to allow for continuity of care and for staff training that facilitates awareness of factors that influence women's help seeking. Further research is required, particularly in relation to effective means of identifying perinatal psychological distress.

#### Keywords

help-seeking behaviour; perinatal care; postnatal depression; psychological distress; seeking help, stigma.

### INTRODUCTION

Women are vulnerable to a variety of psychological difficulties during the perinatal period. Such women may be reluctant to access health care and to disclose their mental health symptoms, potentially adversely affecting the development of their child and the wellbeing of their partner.<sup>1</sup> To address this situation, a greater understanding of what influences women's behaviour is needed. The existing literature focuses predominantly on North American populations rather than perinatal populations in the UK, where perinatal health care is more easily accessible. Therefore, this study reports a meta-synthesis of the qualitative literature on what influences women's help-seeking behaviour for perinatal distress in the UK.

The concept of perinatal psychological distress is not well defined in the literature, but is closely linked to stress and coping. Although some stressors may be adaptive, psychological distress, generally, involves a maladaptive psychological response to a demand. This creates an adverse emotional state, which may be reflected in a person's behaviour, possibly causing them 'harm', for example, by adversely affecting interpersonal relationships.<sup>2</sup> It encompasses a range of psychological symptoms, such as anxiety, stress, and depression, arising from a variety of stressors.<sup>3</sup>

The concept of 'help seeking' is discussed in the general health literature. It is viewed as a decision-making process, where action is preceded by recognising a problem and a conscious decision to do something about it.<sup>4</sup> It includes seeking both professional and non-professional sources of help.<sup>5</sup>

Help seeking is affected by an individual's health beliefs and expectations — particularly beliefs about control over their symptoms, how long symptoms might last, and negative consequences.<sup>6</sup> It is also affected by stigma — both personal beliefs (self-stigma) and others' perceptions. Stigma is one of the primary barriers to seeking help for mental health concerns, particularly among men, young people, those from ethnic minority or military backgrounds, and health professions.<sup>7</sup> Although many distressed people seek informal help for their symptoms, only around 40% of these seek professional help.<sup>8</sup> Perception of positive consequences may increase the likelihood of seeking help.<sup>9</sup> This may be influenced by a person who has previously sought help themselves or who recommends such an action.<sup>8</sup> Cultural factors influence choice of help-seeking strategy, for example, the use of a traditional healer. Primary care services are often used following informal consultation with another person.<sup>10</sup>

Barriers to help seeking for perinatal psychological distress include the woman's inability to disclose her feelings, cultural

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### How this fits in

Psychological distress and problems are common in pregnant women and new mothers, but very few women access treatment. Awareness of women's experiences is important to inform primary healthcare practitioners of how best to help women with perinatal distress. The authors reviewed qualitative studies of women's experiences of seeking help for psychological distress in the UK. Findings showed that women's help seeking is influenced by identifying something is wrong, their experience with healthcare professionals, and stigma.

obstacles, ignorance about symptoms of postnatal depression (PND), and/or how to obtain help, and the attitudes of family, friends, and healthcare professionals (HCPs).<sup>11</sup> However, research has focused almost exclusively on PND in non-UK samples and is concerned with treatment preference rather than help-seeking *per se*. In the UK, services are structured differently. Access to help for perinatal distress is usually through primary care services, such as the GP, midwife, or health visitor, and is provided free at the point of delivery. Furthermore, UK guidance regarding perinatal mental health suggests that women should be screened on first contact with health services to identify those

who may need further assessment. It also recognises that women may choose not to disclose their distress.<sup>12</sup> This review focuses on help seeking in women experiencing perinatal psychological distress in the UK, where systematic, structural barriers to accessing help are reduced due to care being provided free at the point of delivery.

### METHOD

#### Search strategy

Searches were conducted in accordance with the PRISMA statement,<sup>13</sup> in Academic Search Complete, CINAHL, PsycARTICLES, PsycINFO, PubMed, and Scopus. Boolean search terms combined help-seeking terms with perinatal and mental health terms, and returned 10 954 articles (Figure 1). A search of the grey literature and back-searching identified 26 additional articles. Duplicates were removed ( $n = 1886$ ). Titles and abstracts were screened, and 37 full-text articles were examined for eligibility.

#### Eligibility

Articles were eligible if they presented primary research evidence from the UK concerning women seeking help for psychological distress experienced during pregnancy or the first year postpartum. Articles were excluded if they concerned only non-UK populations, did not report evidence regarding help-seeking, if participants had not experienced distress, or if they did not present primary data. A total of 24 studies met these criteria.

#### Quality assessment

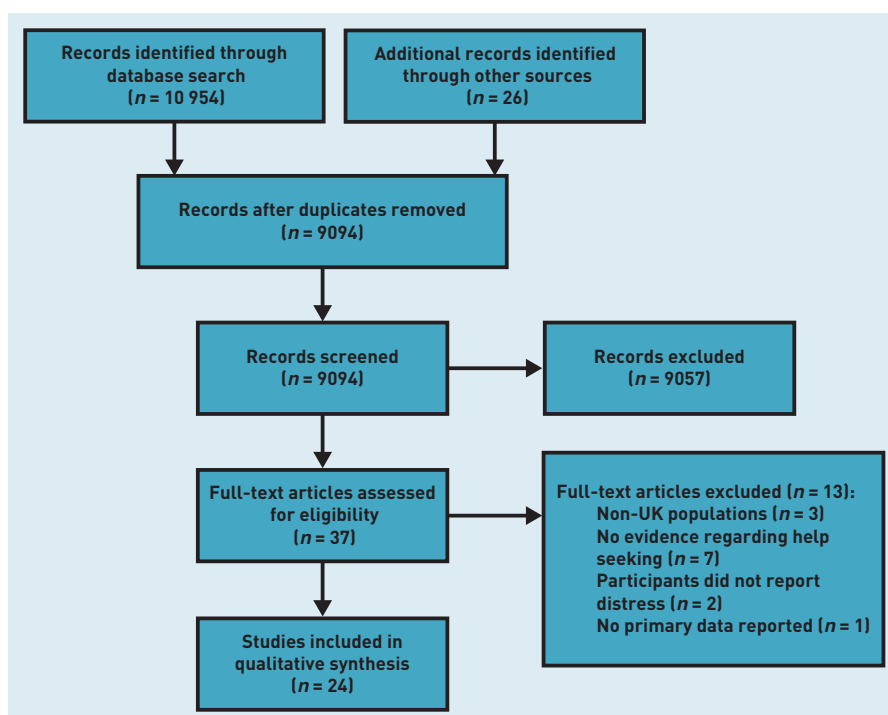
The quality of the studies was assessed using the Critical Appraisal Skills Programme guidelines.<sup>14</sup> Quality varied from good to very good (range 0.5–0.85, further information available from the author on request). No studies were excluded on grounds of quality.

#### Analytic strategy

The meta-synthesis was performed by two researchers independently using a meta-ethnographic approach.<sup>15</sup> This allows data from different studies to be synthesised, preserving the terminology of the original studies and, therefore, the meaning.<sup>16</sup> Articles were read and key themes extracted. Each theme was tabulated and illustrated with first- and second-order constructs:<sup>17</sup> specifically, direct quotes from participants (first order) and authors' analysis of interview content (second order).

Common themes emerged through the process of reciprocal and refutational translation.<sup>15</sup> The meta-synthesis was constructed using second-order constructs.

Figure 1. Flow diagram of study selection.



First-order constructs were used to illustrate and directly support themes, while enabling them to be traced back to the original studies. Researchers subsequently created third-order constructs ('the views and interpretations of the synthesis team')<sup>17</sup> in order to generate new understandings of the data. These third-order constructs were discussed and agreed by the wider research team. First-order constructs were used to support and validate the findings.

## RESULTS

All 24 studies identified were concerned with seeking help for PND. Nine explored this concept in minority groups living in the UK.<sup>18–26</sup> Three studies had mixed samples,<sup>27–29</sup> five had predominantly white samples,<sup>30–34</sup> and seven did not report ethnicity,<sup>35–41</sup> 21 used interviews to gather data, four with focus groups.

Three key themes emerged from the meta-synthesis: identifying a problem, the healthcare experience, and stigma (Table 1).

### Identifying a problem

Identification of a problem was the first step in the help-seeking process. Some women identified for themselves that something was 'wrong' and were able to seek help:

*'That's when I thought, you know: "Something is really wrong here, I need to go to the doctors if I'm thinking about killing myself."'*<sup>31</sup>

This process was facilitated if women had previously experienced difficulties:

*'It did help a bit last time, not, you know, it wasn't fantastic, but it did help a bit. So I thought, well, OK, I'll try them again.'*<sup>35</sup>

Other women, however, felt overwhelmed, even by everyday tasks — *'Sometimes it kills me to just go to school to drop [my son] off'*<sup>27</sup> — and unable to reach out for support:

*'It's the one thing you can't do, and that's the trouble ... you want people to come to you, to show they care, but there's no way that you can go to them.'*<sup>34</sup>

Women differed in their ability to recognise or to articulate their distress. Some did not understand depression:

*'I don't know what postnatal depression is — how you're supposed to feel, look, or whatever. I don't know. I have no idea ... what exactly is postnatal depression? What are you supposed to be doing, saying, or whatever? I don't know.'*<sup>20</sup>

Women in this situation sometimes described their feelings somatically, for example, as *'pressure in the heart'* or *'restlessness in the mind'*.<sup>23</sup> Cultural beliefs also affected help seeking, especially where symptoms were perceived in religious terms:

*'All illness is coming from God — it is a punishment, and if Allah wants to do something, he can.'*<sup>25</sup>

Sometimes, concerns were raised by family, friends, or HCPs:

*'It was sort of my partner saying to me: "Right, if you don't go, I'm basically making you an appointment ... You can't just keep feeling like this."'*<sup>36</sup>

*'It usually takes a professional to say: "Look, I think you're suffering from depression." And it's quite a relief when they say it.'*<sup>35</sup>

**Table 1. Themes identified**

studies	Themes		
	Identifying a problem	The influence of healthcare professionals	Stigma
Almond <i>et al</i> , 2011 <sup>29</sup>	Yes	–	–
Boath <i>et al</i> , 2013 <sup>39</sup>	Yes	Yes	Yes
Chew-Graham <i>et al</i> , 2009 <sup>35</sup>	Yes	Yes	Yes
Cooke <i>et al</i> , 2012 <sup>27</sup>	Yes	Yes	Yes
Edge <i>et al</i> , 2004 <sup>21</sup>	–	Yes	Yes
Edge, 2006 <sup>20</sup>	Yes	Yes	Yes
Edge, 2008 <sup>19</sup>	–	Yes	Yes
Edge <i>et al</i> , 2010 <sup>22</sup>	–	Yes	Yes
Edge, 2011 <sup>18</sup>	–	Yes	–
Gardner <i>et al</i> , 2014 <sup>26</sup>	–	–	Yes
Hall, 2006 <sup>30</sup>	Yes	Yes	Yes
Hanley <i>et al</i> , 2006 <sup>38</sup>	Yes	Yes	Yes
Hanley, 2007 <sup>25</sup>	Yes	Yes	–
Hannan, 2016 <sup>32</sup>	Yes	Yes	Yes
Iles <i>et al</i> , 2015 <sup>31</sup>	Yes	Yes	Yes
McIntosh, 1993 <sup>40</sup>	–	Yes	Yes
Mauthner, 1997 <sup>33</sup>	–	Yes	Yes
Mauthner, 1999 <sup>34</sup>	Yes	Yes	Yes
Parvin <i>et al</i> , 2004 <sup>23</sup>	Yes	Yes	–
Patel <i>et al</i> , 2013 <sup>41</sup>	–	–	Yes
Raymond <i>et al</i> , 2009 <sup>28</sup>	–	Yes	Yes
Shakespeare <i>et al</i> , 2003 <sup>37</sup>	Yes	Yes	Yes
Slade <i>et al</i> , 2010 <sup>36</sup>	Yes	Yes	Yes
Templeton <i>et al</i> , 2003 <sup>24</sup>	–	–	Yes

Being screened for psychological distress evoked a range of reactions. It was seen as a less 'personal' means of disclosure:

*'It's much easier to do this than to actually look somebody in the face.'*<sup>37</sup>

It provided women with reassurance: (*'Relieved in a way ... seeing the questions I thought: "Well, I'm not going mad."*'<sup>29</sup>) and an opportunity to admit that they needed help:

*'When I started to fill in that form I knew I couldn't lie about how I felt anymore.'*<sup>38</sup>

However, other women found it of limited value:

*'There's so much more that you want to say, rather than just answering quite closed questions.'*<sup>37</sup>

They described the questions as 'daft' and 'patronising',<sup>37</sup> and a poor substitute for face-to-face contact:

*'You can tell when somebody's lying, can't you, if you talk to them properly. Whereas ... you could just lie on the form, and there's nothing to say that you were lying.'*<sup>37</sup>

### The healthcare experience

Women's help seeking was influenced by their expectations and experience of healthcare professionals and by structural factors inherent in the healthcare system. Structural factors predominantly inhibited help seeking, including waiting times: *'[There is a] 7-month waiting list for counselling'*,<sup>19</sup> lack of childcare facilities: *'You have to have someone to look after your baby so who am I going to get to look after [baby]?''*<sup>19</sup> and English-language proficiency: *'Bengali girls don't come with [sic] the midwife, we don't understand what they say. We just sit there staring at their faces.'*<sup>23</sup> Similarly, women reported that services did not recognise their cultural needs:

*'You need someone who's on the same wavelength as you, who shares the same cultural experiences as you, which sometimes isn't available.'*<sup>19</sup>

Women's knowledge and experiences of health care influenced their expectations around help-seeking behaviour after birth. Women who had negative experiences of care during childbirth could be deterred from seeking help postnatally:

*'You're thinking, "What's the point in going back?" It [negative experience during pregnancy and labour] just doesn't give you any confidence to think they'll be sympathetic.'*<sup>18</sup>

Women were unsure of the role of professionals in providing support:

*'I don't really know what their job is. Nobody gave me, like, the parameters of this role of the health visitor and, so, I think if that happened then you'd ... be able to use them better.'*<sup>36</sup>

They believed that available help was ineffective and inappropriate:

*'There is nothing else available. No GP, no health visitor. They're there, but not in a helpful sense, sort of like.'*<sup>35</sup>

Medication was seen as the likely, but unwanted, treatment on offer (*I knew she would just write a prescription and send me away ... that wasn't what I wanted'*<sup>32</sup>), and women expressed concerns about addiction: *'I just didn't want to go onto antidepressants, because obviously I've heard people get addicted to them and then you're stuck on them and you have a vicious circle,'*<sup>35</sup> and its viability as a long-term solution: *'What is the point? If I take these tablets, when I stop, what am I going to do, go back into this depression?'*<sup>20</sup>

Familiarity with HCPs was important. Women were hesitant to approach professionals they did not know:

*'You have to go to the health visitor first and do a scale and see how you come out, but I didn't, because I haven't really seen the health visitor. I don't know who she is.'*<sup>39</sup>

Furthermore, women highlighted the importance of continuity of care:

*'It was the not having to start explaining again to someone new which was so great.'*<sup>28</sup>

The response from HCPs had an important influence on help-seeking behaviour. Women were concerned about the negative consequences of disclosure. They emphasised the value of a non-judgemental approach:

*'She takes you as you are, she listens. She doesn't condemn you for it happening.'*<sup>33</sup>

*'It's good having someone that you can talk*

*to about how you really feel ... she is not critical in any way.*<sup>36</sup>

Women were more likely to discuss their concerns with professionals who appeared caring and genuinely interested in their wellbeing:

*'She asked how I was. As soon as she said it, you know, "How you feeling?", I just cried.*<sup>35</sup>

*'My health visitor, she's brill, she is always there for me at the end of the phone.*<sup>39</sup>

Healthcare professionals did not always recognise an attempt to seek help:

*'I purposely circled the things 'cos I'm struggling ... the health visitor didn't get back to me, which I'm really disappointed about.*<sup>37</sup>

In some cases, this invalidated women's view that there was something wrong:

*'I did ask for support, but I didn't really get any. And the health visitor's response — "Well you seem like you're doing all right" — which kind of closes it off, doesn't it, then?'<sup>36</sup>*

Women were also deterred from seeking help when professionals seemed too busy to provide support:

*'The health visitor said something like: "You know, in this community we have to look after a thousand and something babies." And that instilled in me the feeling, like: "Oh, they are very busy these people, and I don't have to be bothering them all the time."*<sup>18</sup>

Women also believed professionals focused on the baby's health to the detriment of women's wellbeing:

*'I thought that the care would be more round care, as opposed to just being about my baby's weight, which is basically all it's ever been about.*<sup>27</sup>

### Stigma

Psychological distress was viewed in negative terms:

*'There's a huge stigma about feeling depressed, particularly postnatal.*<sup>37</sup>

Stigma manifested itself in several ways: self-judgement, concern about others' judgements, symptom normalisation,

external attribution, and anxiety around consequences of stigmatisation. This stigma deterred women from seeking help.

Women judged themselves harshly. They felt under pressure to conform to ideal standards of motherhood, many of which were internalised (*'Mothers are supposed to be rock solid aren't they?'<sup>28</sup>*), and seen as informing others' opinions (*'With my health visitor, I try not to let too much out, because then she won't think I am a bad mum.*<sup>35</sup>)

Distress was perceived as a sign of weakness, and a challenge to a woman's self-identity:

*'I felt angry, that I, a woman who had held a responsible post in work, was not capable of looking after my own child.*<sup>38</sup>

'Coping' was entwined with perceptions of 'good' mothering.

*'I'm quite independent, and I just like to think and show people that I can cope.*<sup>34</sup>

*'I felt like I was a bad mother, and I couldn't cope with it all.*<sup>30</sup>

Sociocultural values contributed to the perceived pressure to cope:

*'It's quite a matriarchal society, and therefore you've got to cope. You've got to sort your family out, and so therefore you are not allowed to be depressed.*<sup>20</sup>

Women were deterred from seeking help by these pressures to conform to ideals of motherhood:

*'I couldn't tell anybody, because I felt like I'd let everyone down. I wanted to do really well.*<sup>33</sup>

Rather than face the potential stigma of admitting distress, they remained silent:

*'When the health visitors come round: "Any problems?" "No, everything's fine." It's the attitude of women and how we've been brought up not to make a fuss.*<sup>33</sup>

Some women rationalised their symptoms as justifiable reactions to difficult circumstances:

*'I thought it was just lack of sleep and this heavy cold. I thought that after a good night's sleep it would get better, and I would be able to manage again.*<sup>38</sup>

This process of normalising symptoms

also justified the failure to seek help on the grounds that HCPs could not resolve the circumstances that had brought about the problem:

*'What could the doctor do? He can't sort out my man or any of my other problems.'*<sup>40</sup>

Women were also deterred from seeking help by the perceived consequences of being diagnosed with a stigmatised condition. Black women expressed specific concerns about the relationship between ethnicity and diagnosis:

*'I'm very much aware that black people are more likely to be labelled as having psychiatric problems and, therefore, I don't want people labelling me [with postnatal depression], and then saying later on: "Well, you've also got this [more serious mental illness] cos you're prone to it."*<sup>20</sup>

More generally, women were concerned about their children being taken into care:

*'Because of the fear of postnatal depression and the taboo of social services and having your children taking [sic] away from you, I wasn't going to admit anything to anyone.'*<sup>31</sup>

## DISCUSSION

### Summary

There were three clear factors affecting whether women seek help for perinatal distress: identifying a problem, the healthcare experience, and stigma. These are important for effective identification and treatment of women in primary and community health settings.

From 'identifying a problem' it is clear that women may not understand the significance of their symptoms. This may explain why women do not seek help for perinatal psychological distress.<sup>1</sup> In the UK, women are screened for PND at around 6 weeks postpartum. This review confirms not all women find screening helpful,<sup>12</sup> and some misrepresent their symptoms on the screening tool. Women may conceal symptoms and only seek help once they reach 'crisis point'. Furthermore, some women are unable to communicate how they feel; either because they do not understand their symptoms, or because they do not have the vocabulary to articulate them. This is consistent with the notion that help seeking requires the recognition of a problem and a conscious decision to address it,<sup>4</sup> but goes further in identifying that women need to frame their experience in a way that others can also understand

and support. That support may differ according to women's cultural, religious, and social contexts. The evidence suggests that women who receive help for perinatal mental illness achieve better outcomes for both themselves and their babies,<sup>42</sup> although the impact for women experiencing less severe symptoms of psychological distress is unclear. One difficulty, potentially, is deciding when to intervene. Some level of distress may be inevitable, such as that associated with sleep deprivation. In these instances, women may not require formal intervention, but practical and emotional support. However, women still need to feel able to ask for that help.

Results are consistent with previous studies highlighting how relationships with HCPs influence help seeking,<sup>27,35</sup> especially in terms of the need for staff to be open, non-judgemental, and accepting of women's accounts of their feelings and experiences. Such findings are consistent with evidence of the negative impact that inflexible attitudes seen in HCPs have on the HCP-patient relationship.<sup>43</sup> This review extends the evidence by identifying that help seeking is negatively influenced by women's lack of understanding of HCPs' roles, suggesting that HCPs need to discuss this with the women in their care. Furthermore, poor continuity of care may negatively influence help seeking. This is consistent with evidence identifying that provision of care by the same HCP over time is the desired clinical model in maternity services.<sup>44</sup>

Consistent with the wider literature, the perceived stigma of mental illness deterred women from seeking help.<sup>6</sup> This meta-synthesis also identified that women felt under pressure to be 'good mothers' and that 'failure' impacted negatively on their mental health and their likelihood to seek help. This is consistent with other reports of the relationship between mental wellbeing and 'being a good mother',<sup>45</sup> and that the fear of failure may cause women to 'self-silence'. This includes deliberately misrepresenting how they truly feel to HCPs involved in their care. The combined fear of stigma and the high expectations that women have of themselves further undermine their self-worth, increasing distress.<sup>46</sup> More understanding of this process by HCPs may help improve how they approach and interact with new mothers.

Perinatal care services need to be developed in a way that meets women's needs for continuity of care, and for staff training to increase awareness of factors that might impact on the likelihood of



seeking help. More research is needed in this area, particularly in relation to improving detection of perinatal psychological distress.

### Strengths and limitations

This review has highlighted that women do not always understand their symptoms and, even if they identify that there is something wrong, may not be able to articulate how they feel. Furthermore, the fear of being seen as a 'bad mother' and of being stigmatised for not being able to cope can lead to women 'self-silencing'. This includes deliberately misrepresenting how they truly feel to HCPs involved in their care.

The meta-synthesis was confined to evidence from the UK, published in English. It captures the diversity of UK society, but much of the UK literature focuses on traditional minority groups, such as Afro-Caribbean and Bengali populations, while neglecting others. Furthermore, the literature is primarily concerned with PND, despite evidence that women and men experience mental illness during pregnancy, not just after birth, and may commonly suffer from anxiety disorders as well as depression. There is clearly a need for increased primary evidence around help seeking in relation to antenatal psychological distress, including for minority groups and fathers. Researchers aimed to reduce subjectivity of data interpretation by conducting independent analysis, but recognise that subjectivity cannot be completely avoided in qualitative work.

### Implications for research and practice

Although a large number of studies were included in this review, the focus was on seeking help for PND only. The authors' understanding of seeking help for other

types of perinatal distress, such as anxiety or traumatic birth, is therefore limited. Future research needs to explore help seeking in these other conditions, and culturally changing attitudes to mental illness and reducing stigma.<sup>47</sup>

HCPs need to understand that help seeking involves recognition of a problem and a conscious decision to address it. Therefore, educating women and their partners about perinatal mental health and the roles of the different HCPs should form part of routine antenatal care. Furthermore, the importance of continuity of care and trusting relationships for help seeking suggests that consideration should be given to both service structure and staff training. One strategy may be for women to receive crossover care from a dedicated midwife and health visitor, working closely with the woman's GP, during the third trimester/early postnatal period. This would increase continuity and facilitate timely access to care. This would require careful consideration of the caseload implications for HCPs, who are often overworked. Furthermore, greater consideration needs to be given to the NICE recommendations about screening women, including how stigma and interactions with HCPs affect this, and whether the current model is fit for purpose. It is important to identify methods that elicit women's confidence in disclosing how they feel, combined with increasing HCPs' ability to detect and manage situations where women avoid disclosure. There also needs to be further investigation of the impact of seeking help on outcomes for women experiencing less severe forms of psychological distress, and the most appropriate means of educating HCPs to meet women's needs.

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### Competing interests

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