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

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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 & 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, PsychInfo, PsychArticles, Cinahl and Academic Search Complete. Searches of grey literature and references were also conducted. Papers 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: Twenty-four papers were eligible for inclusion. Metasynthesis identified three main themes: identifying a problem, the influence of healthcare professionals, and stigma. These themes build upon 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: perinatal, psychological distress, postnatal depression, seeking help, help seeking, stigma.

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 health care practitioners of how to best help women with perinatal distress.
 - We 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.
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NICE guidelines (1) recognise that women are vulnerable to a variety of psychological difficulties during the perinatal period; such women may be less likely to access health care and reluctant to disclose their mental health symptoms, potentially adversely affecting the development of their child and the wellbeing of their partner. In order to address this situation, a greater understanding of what influences women's behaviour is needed. The existing literature focusses predominantly upon North American populations rather than perinatal populations in the United Kingdom (UK), where perinatal healthcare is more easily accessible. Therefore this paper reports a meta-synthesis of the qualitative literature on seeking help for perinatal distress in the UK.

What is perinatal psychological distress?

The concept of perinatal psychological distress is not well defined in the literature, although appears to be closely linked to stress and coping. Whilst there is evidence that some stressors may be adaptive, there is a recognition that psychological distress, generally, involves a maladaptive psychological response to a demand (acopia). This creates an adverse emotional state, which may be reflected in a person's behaviour, possibly causing them 'harm', e.g. by adversely affecting interpersonal relationships (Ridner, 2004). In this way, it encompasses a range of psychological symptoms arising from a variety of stressors (Doc's Ref).

What is help seeking?

The concept of 'help seeking' is most discussed in the general health literature. Here, it is viewed as a decision-making process, where the decision to act is preceded by both recognition of a problem and a conscious decision to do something about it (2). It includes seeking both professional and non-professional sources of help (3).

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 (4). 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 amongst men, young people, those from ethnic minority or military backgrounds or health professions (5). Many of those experiencing distress seek informal help for their symptoms, but only around 40% of these will seek professional help (6). Perception of positive consequences may increase the likelihood of seeking help (7). This may be influenced by a person who has previously sought help themselves or who recommends such an action (6). Cultural factors influence choice of help-seeking strategy, e.g. use of traditional healer. Primary care services are more likely to be used following informal consultation with another person (8).

Perinatal help seeking

Barriers to help seeking for perinatal psychological distress include the woman's inability to disclose her feelings, cultural obstacles, ignorance about symptoms of postnatal depression (PND) and/or how to obtain help and the attitudes of family, friends and health care professionals (HCPs) (9). However, research has focused almost exclusively on PND in non-UK samples and is concerned with treatment preference rather than help-seeking per se. This presents a challenge when applying evidence to UK women as services are structured differently. In particular, access to help for perinatal distress is usually through primary care services such as the GP, midwife or health visitor. Furthermore, the UK guidance regarding perinatal mental health suggests that women should be screened upon first contact with mental health services in order to identify women who may need further assessment; the guidance also recognises that women may choose not to disclose their distress (10). This review focusses upon help seeking in women experiencing perinatal psychological distress in the UK, where systematic, structural barriers to accessing help are minimised due to care being provided free at the point of delivery by the National Health Service.

Method

Search Strategy

Searches were conducted in accordance with the PRISMA statement (11), in Academic Search Complete, Cinahl, PsychArticles, PsychInfo, PubMed, and Scopus. Boolean search terms combined help seeking terms with perinatal and mental health terms returned 10,954 articles (Figure 1). A search of the grey literature and back-searching identified 26 additional articles. Duplicates were removed (n=1,886); titles and abstracts were screened and 37 full text articles were examined for eligibility.

- insert Figure 1 here -

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 papers was assessed using the Critical Appraisal Skills Programme guidelines (12). Quality varied between good to very good (range 0.5-0.85; see Supplementary material). No papers were excluded on the basis of quality.

Analytic strategy

The meta-synthesis was performed by two researchers independently using a meta-ethnographic approach (13). Articles were read and key themes extracted. Each theme was tabulated and illustrated with first and second order constructs (14): 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 (13). The metasynthesis was constructed using second order constructs. First order constructs were used to illustrate and directly support themes, whilst enabling them to be traced back to the original papers. Researchers subsequently created third order constructs ["the views and interpretations of the synthesis team", (14), p.158] 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 papers identified were concerned with seeking help for postnatal depression. Nine explored this concept in minority groups living in the UK (15-23). Three studies had mixed samples (24-26), five had predominantly White samples (27-31) and seven did not report ethnicity (32-38). Twenty-one used interviews to gather data, four with focus groups.

Three key themes emerged from the metasynthesis: identifying a problem; the influence of HCPs; and stigma (Table 1).

- insert Table 1 here -

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” (28). 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, okay, I’ll try them again’* (32). Other women, however, felt overwhelmed even by everyday tasks - *‘Sometimes it kills me to just go to school to drop [my son] off’* (24) – 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’* (31).

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’* (17). Women in this situation sometimes described their feelings somatically, for example as *‘pressure in the heart’* or *‘restlessness in the mind’* (20). 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’* (22).

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”’* (33); *‘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’* (31).

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’* (34). It provided women with reassurance [*‘Relieved in a way... seeing the questions I thought, “Well I’m not going mad”’* (26)] 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’* (35). 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’* (34). They described the questions as *‘daft’* and *‘patronising’* (34) 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'* (34).

The healthcare experience

Women's help-seeking was also influenced by their expectations and experience of healthcare professionals (HCPs) 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'* (16), 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]?' (16)*, 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'* (20). 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'* (16).

Women's knowledge and experiences of healthcare 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'* (15). 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'* (33). 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'* (32). 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'* (29)] 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' (32), 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?'* (17).

Familiarity with HCPs was an important factor. 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'* (36). 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'* (25).

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'* (30); *'It's good having someone that you can talk to about how you really feel... she is not critical in any way'* (33). 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'* (32); *'My health visitor, she's brill, she is always there for me at the end of the phone'* (36).

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'* (34). 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 alright", which kind of closes it off doesn't it then?'* (33).

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” (15). Women also believed professionals focussed 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’* (24).

Stigma

Psychological distress was viewed in negative terms: *‘There’s a huge stigma about feeling depressed particularly postnatal’* (34). 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?’* (25)] 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’* (32)]. 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’* (35)]. ‘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’* (31), *‘I felt like I was a bad mother, and I couldn’t cope with it all’* (30). 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’* (17). 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’* (30). 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’* (30). 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'* (35). This process of normalising symptoms also justified the failure to seek help on the grounds that HCPs could not resolve the circumstances which had brought about the problem: *'What could the doctor do? He can't sort out my man or any of my other problems'* (37).

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"'* (17). 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 away from you I wasn't going to admit anything to anyone'* (28).

Discussion

This meta-synthesis identified 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 are not always aware of the significance of their symptoms. This may explain why women do not seek help for perinatal psychological distress (1). In the UK, women are screened for PND at around six weeks post-partum. This review suggests not all women find screening helpful, 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. These findings are consistent with the notion that help seeking requires both the recognition of a problem and a conscious decision to address it (2), but go further in identifying the need for an appropriate means for women to frame their experience in a way that others can understand and support. The evidence suggests that women who receive help for perinatal mental illness achieve better outcomes for both themselves and their babies (39), 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 [e.g. (24, 32)], 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 upon the HCP-patient relationship (Ref). This review adds to this literature by identifying that help seeking is also negatively influenced by women's lack of understanding of HCPs' roles, suggesting that HCPs need to discuss this with the women in their care. In addition, lack of continuity of care may negatively influence help seeking. This is consistent with recent evidence identifying that continuity of care, where a patient is cared for by the same HCP over time, is the desired clinical model in maternity services (40).

Consistent with the wider literature, the perceived stigma of mental illness deterred women from seeing help (4). This metasynthesis also identified broader factors regarding women's perceived pressure to be 'good mothers' and the impact that perceived failure had upon their mental health and their likelihood to seek help. This finding is consistent with other reports of the

relationship between mental wellbeing and 'being a good mother' (41) and that the fear of failure may cause women to 'self-silence'. The combined fear of stigma and the high expectations that women have of themselves further undermine their self-worth, compounding stress (Ref). More understanding of this process by HCPs may help improve how they approach and interact with new mothers.

Implications for Research

Although a large number of studies were identified and included in this review, the focus was upon seeking help for postnatal depression. Our understanding of seeking help for other types of perinatal distress, such as anxiety or traumatic birth, is therefore limited. Future research needs to explore the mechanisms associated with different forms of distress, who is best place to identify perinatal distress, and whether the likelihood of seeking help changes during the course of pregnancy and the first twelve months postpartum. Outcomes associated with these mechanisms should be evaluated carefully and should be reviewed against factors such as culturally changing attitudes to mental illness and reducing stigma (42).

Clinical Implications

HCPs need to understand that help seeking involves recognition of a problem and a conscious decision to address it. Therefore, educating women about perinatal mental health 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 structuring of services and staff training. One strategy may be for women to be allocated a dedicated midwife and health visitor. These would provide some cross-over care in the third trimester and early postnatal period to allow continuation of relationships, and work closely with the woman's GP in order to facilitate timely access to care. Such a model would require careful consideration of the caseload implications for HCPs, who are often overworked. Furthermore, greater consideration needs to be

given to the process of 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 when women may be avoiding disclosure and manage the situation effectively. There also needs to be further investigation of the impact of seeking help upon the outcomes for women experiencing less severe forms of psychological distress and the most appropriate means of educating HCPs to meet women's needs.

Strengths and Limitations

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 upon traditional minority groups such as Afro-Caribbean and Bengali populations whilst neglecting others. Furthermore, the literature is primarily concerned with PND, despite evidence that women experience perinatal 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.

Conclusions

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

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Competing interests

The authors have no competing interests.

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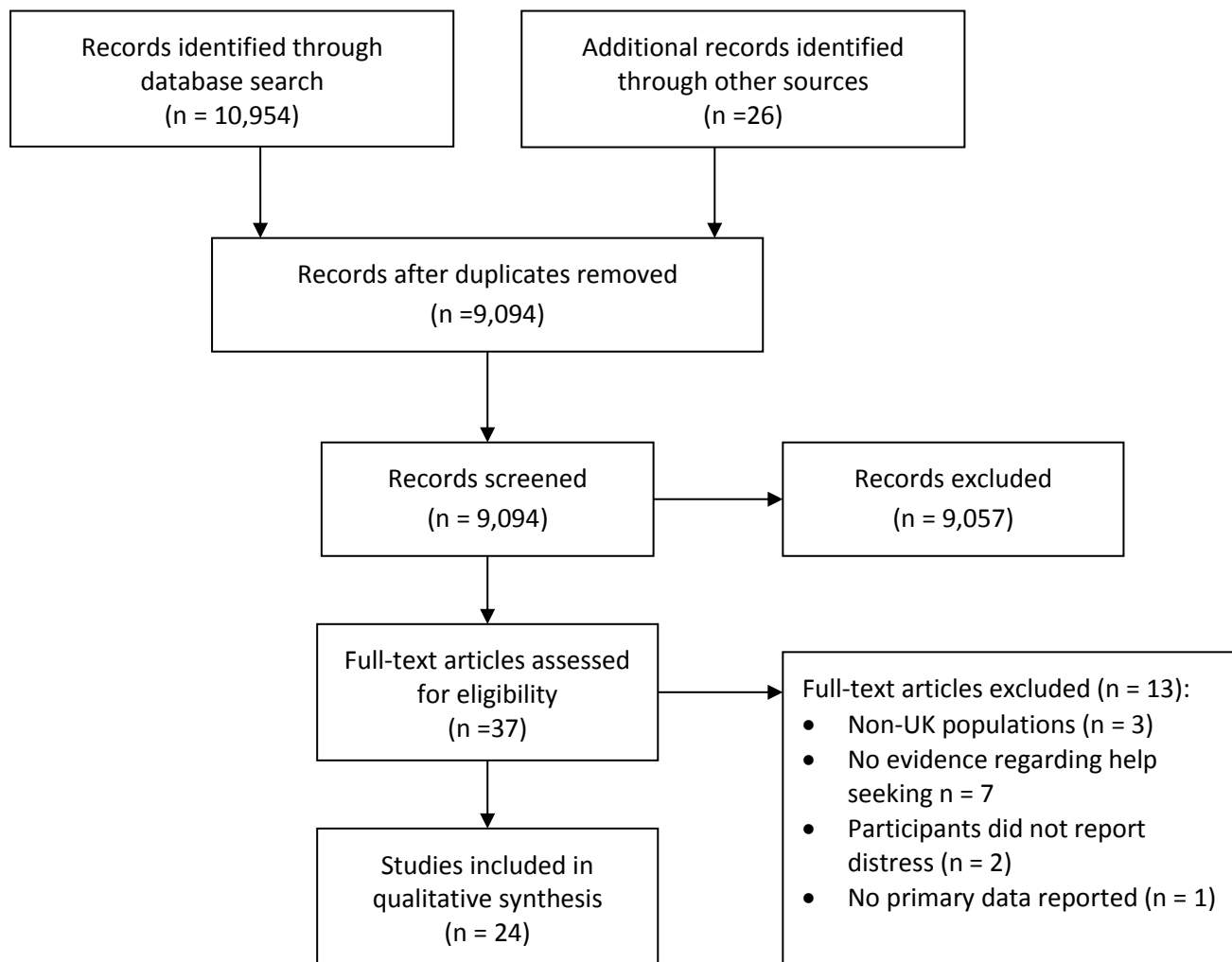
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Table 1. Themes identified

Themes Papers	Identifying a problem	The influence of healthcare professionals	Stigma
Almond et al 2011 (26)	Yes	-	-
Boath et al 2013 (36)	Yes	Yes	Yes
Chew-Graham et al 2009 (32)	Yes	Yes	Yes
Cooke et al 2012 (24)	Yes	Yes	Yes
Edge et al 2004 (18)	-	Yes	Yes
Edge 2006 (17)	Yes	Yes	Yes
Edge 2008 (16)		Yes	Yes
Edge et al 2010 (19)	-	Yes	Yes
Edge 2011 (15)	-	Yes	-
Gardner et al 2104 (23)	-	-	Yes
Hall 2006 (27)	Yes	Yes	Yes
Hanley et al 2006 (35)	Yes	Yes	Yes
Hanley 2007 (22)	Yes	Yes	-
Hannan 2016 (29)	Yes	Yes	Yes
Iles et al 2015 (28)	Yes	Yes	Yes
McIntosh 1993 (37)	-	Yes	Yes
Mauthner 1997 (30)	-	Yes	Yes
Mauthner 1999 (31)	Yes	Yes	Yes
Parvin et al 2004 (20)	Yes	Yes	-
Patel et al 2012 (38)	-	-	Yes
Raymond et al 2009 (25)	-	Yes	Yes
Shakespeare et al 2003 (34)	Yes	Yes	Yes
Slade et al 2010 (33)	Yes	Yes	Yes
Templeton et al 2003 (21)	-	-	Yes

Figure 1. Flow diagram of study selection



Supplementary Material. Methodological quality ratings for studies (0-1)

Author & Year	Methodological Rating (CASP)
Edge (2011)	0.6
Edge & MacKian (2010).	0.65
Edge, Baker & Rogers (2004)	0.6
Edge (2006)	0.6
Edge (2008)	0.75
McIntosh (1993)	0.5
Parvin, Jones & Hull (2004)	0.65
Shakespeare, Blake & Garcia (2003)	0.85
Mauthner (1997)	0.75
Templeton, Velleman, Persuad & Milner (2003)	0.65
Hanley (2007)	0.6
Cooke, Smith, Turl, Arnold & Msetfi (2012)	0.7
Slade, Morrell, Rigby, Ricci, Spittlehouse & Brugha (2010)	0.85
Raymond (2009)	0.8
Chew-Graham, Sharp, Chamberlain, Folkes & Turner (2009)	0.6
Hanley & Long (2006)	0.55
Mauthner (1999)	0.7
Almond & Lathlean (2015)	0.7
Boath, Henshaw & Bradley (2013)	0.75
Hannan (2016)	0.65
Iles & Pote (2015)	0.6
Patel, Wittowski, Fox & Wieck (2013)	0.6
Gardner, Bunton, Edge & Wittowski (2014)	0.65
Hall (2006)	0.7