Perinatal depression: Factors affecting help-seeking behaviours in asylum seeking and refugee women. A systematic review

Amanda Firth a,*, Melanie Haith-Cooper b, Josie Dickerson c, Andrew Hart b

a University of Huddersfield, Queensgate, Huddersfield, West Yorkshire HD1 3DH, UK
b University of Bradford, UK
c Bradford Teaching Hospitals NHS Foundation Trust, Bradford Institute for Health Research, UK

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ABSTRACT

Purpose: Perinatal depression is one of the most commonly diagnosed mental health conditions in the general maternity population but whilst the prevalence is thought to be much higher in asylum seeking and refugee (AS&R) women, it is less frequently identified and diagnosed by health care professionals.

Method: A systematic review was undertaken to address ‘what factors influence help-seeking behaviours in asylum seeking and refugee women with symptoms of perinatal depression’. The review focussed on women accessing care in high income countries. 12 studies met the eligibility criteria and a narrative synthesis was undertaken resulting in two main themes: women’s perceptions of depression and access to healthcare and support services.

Results: Findings indicated that many of the influences on help-seeking were also present in the general population and women from ethnic minority populations, with the exception of migration experiences; but that women from a AS&R background may experience more of these barriers, exacerbating inequality in access to and engagement with healthcare.

Conclusion: Further research is needed to provide more detailed insight into the experiences of asylum seeking and refugee women to identify ways that barriers in help-seeking can be addressed.

Introduction and background

Perinatal depression is the most commonly diagnosed perinatal mental health condition, affecting up to 20% of pregnant women and new mothers in the general population (NICE, 2014). In migrant women prevalence is estimated to be around 42%, more than twice that of the general population; and rates are thought to be higher still in forced migrant women such as refugees and those seeking asylum (Brown et al., 2015; Collins et al., 2011). Evidence suggests that AS&R women accessing maternity care in high income countries have poorer experiences than the country’s general population (Frank et al., 2021). This review concentrates on perinatal mental health, specifically perinatal depression; exploring the factors which influence help-seeking behaviours in AS&R women accessing maternity care in high income countries.

Perinatal depression is defined as depression occurring during pregnancy or up to the first year following birth (NICE, 2014). Clinical guidance in the UK states that symptoms include persistent low mood, apathy, lethargy, change in appetite, withdrawal from social situations, feelings of inadequacy, shame, guilt and hopelessness (NICE, 2014). However, women from different cultural backgrounds or ethnicities may also express somatic symptoms such as aches and pains, which are symptoms that are not acknowledged within UK clinical guidance (Lansakara et al., 2010; NICE, 2014; Parvin et al., 2004). Research suggests that ethnicity itself is a risk factor for perinatal depression and that rates may be higher in women from ethnic minority groups (Gavin et al., 2005). There are also socio-economic and demographic factors...
risk factors to consider; with those who experience poverty, social isolation, unplanned pregnancies, unsupportive relationships or without a partner having a higher risk of developing perinatal depression (Beck, 2008; Hickey et al., 2005; Lancaster et al., 2010). The implications of untreated perinatal mental health conditions have a significant individual and societal cost. It suggested that untreated perinatal mental health problems carry a societal cost of £8.1 billion per year, with almost three quarters of this sum relating to the long term impact on the child and wider family (Bauer et al., 2014).

Migration is frequently defined in research simply as movement from one country to another, without consideration of whether it was forced or voluntary movement (Balaam et al., 2017). Within this systematic review an asylum seeker is defined as a person seeking sanctuary from harm or persecution, who submits an application for refugee status on arrival at the host country (IOM, 2016). A refugee is someone who has formal recognition that their life would be endangered if they returned to their home country, and in light of this they are awarded a form of humanitarian protection known as refugee status (IOM, 2016). Their experiences will be different to a voluntary migrant woman who have relocated for reasons such as marriage, study and career opportunities (IOM, 2016).

A&R women are likely to experience the socio-economic risk factors noted above, but also additional factors associated with forced migration. Some risk factors are pre-migratory in origin, with many women fleeing war, persecution, sexual violence and slavery within their home country or during their migration journey (Correa-Velez and Ryan, 2012; Zimmerman et al., 2009). Other risk factors are post-migratory and may include unstable migration status, poverty, language barriers, social isolation, discrimination, a perceived lack of protection from government agencies, detention and dispersal (Brown-Bowers et al., 2015; Feldman, 2013; Latif, 2014).

Childbearing A&R women are more likely to experience fragmented maternity care and be less satisfied with the care that they received, with women reporting a lack of effective communication and cultural awareness from clinicians (Phillimore, 2016; Sharma et al., 2020). It is argued that maternity services are not sufficiently designed to meet the needs of many migrant women, including those who are refugees or seeking asylum (Briscoe and Lavender, 2009). UK health guidelines themselves acknowledge that there is not enough robust evidence to suggest how to most effectively care for the maternity and mental health needs of this population (NICE, 2010).

A&R women have an increased number of risk factors for developing perinatal depression and they are less likely to have their symptoms recognised by a health care professional. It is apparent that service improvements are needed but this must also consider the voices of women who will use the services. The objective of this review is to amplify the voices of women so that their narratives are heard when considering future service improvement. This systematic review asks the question ‘what factors influence help-seeking behaviours for A&R women with symptoms of perinatal depression?’.

Methods

The review was conducted using the steps suggested by Cochrane (CRD, 2009). A scoping exercise confirmed no other literature reviews answering the review question, but also highlighted the difficulty in retrieving relevant papers due to global differences in migration vocabulary or definition of key terms. When searching poorly defined terms or concepts it is preferable to undertake a broader search, with fewer search terms and a greater emphasis on hand-sifting for relevant studies (CRD, 2009; Enticott et al., 2018). Search terms were simplified, and the scoping exercise was repeated until authors could confirm that relevant papers were being retrieved. The final search terms used are documented in Table 1.

ASSIA, CINAHL, Medline and PsycINFO electronic databases were searched in addition to handsearching and grey literature searching to reduce publication bias (Godin et al., 2015; Neale, 2008). Author contact was made when there was uncertainty in the proportion of refugee and asylum seeking women in a paper’s sample.

Search results and screening decisions were documented within a PRISMA diagram (Fig. 1) and Endnote (bibliographic software) was used to remove duplicate papers (Page et al., 2021). All papers were screened against the eligibility criteria (Table 2). The search retrieved a large proportion of irrelevant papers but also minimised selection bias (Aveyard, 2018). All papers were critically appraised using the relevant Critical Appraisal Skills Programme (CASLP) tool (Table 3).

Data were extracted by a single researcher (AF) using a self-designed and piloted electronic form to ensure standardisation of the information extracted (Higgins and Green, 2011). Data were discussed with corresponding authors throughout the extraction process and a narrative synthesis was undertaken. Narrative synthesis aims to preserve the integrity of the individual studies; theory-building rather than theory-testing (Harden, 2010; Pope et al., 2006). Preliminary synthesis was undertaken by reading the papers multiple times; coding the data, re-checking data, sharing and discussing this with the other authors and together developing links between the codes which eventually became categorised as themes (Liamputtong, 2009).

Results

A total of 12 papers met the criteria for inclusion in the review. No papers were excluded following critical appraisal because it important not to exclude findings from smaller studies or the third sector when researching under-represented populations (Enticott et al., 2018). A summary of the included papers can be seen in Table 4.

A total of 12 qualitative papers were reviewed from Canada, (n = 6), UK (n = 2), Australia (n = 3) and Sweden (n = 1). The studies represent the experiences of 110 refugee, 46 asylum-seeking and 40 voluntary migrant women. Four Canadian papers describe data from the same study and these participants are only counted once in the numbers above (O’Mahony and Donnelly, 2012; O’Mahony et al., 2012a, 2013, 2012b). Eight out of 12 papers had mixed samples and at times it was difficult to extract the voices of refugee or asylum seeking women; a factor which is discussed later in the review.

A narrative synthesis resulted in two overarching themes with sub-themes (Table 5). Review findings demonstrated that women’s help seeking behaviors were influenced by their perceptions of depression and their access to healthcare and support.

| Theme: women’s perceptions of depression |

Conceptualising depression

Many women did not understand the concept of perinatal depression or identify with Western symptoms which was a barrier to help-seeking. Some women believed that depression was rare, did not exist within their home country or that it was not considered a medical issue within their culture (Ahmed et al., 2017; O’Mahony et al., 2012a, 2013; Skoog et al., 2018).
In my culture, they don’t believe in postpartum depression. They say, “Everybody feels it, but they come out of it...” (O’Mahony et al., 2012a, p.739)

Some women who scored highly on a depression screening tool did not recognise depressive symptoms within themselves.

“Sometimes you feel bored. It’s not depression, it’s just that I might be bored and my mood will change and this is something normal. But depression means being sick and requiring a treatment.” (Ahmed et al., 2017, p.6)

AS&R women (70% of the sample) in a Swedish study remarked that questions on depression screening tools, such as those enquiring about self-harm, described a Western sign of depression which was irrelevant to their culture (Skoog et al., 2018). This was echoed in another paper where women did not understand the word ‘harm’ and how this related to depression (Willey et al., 2020). Some women referred to depression as a reactive state to a specific significant trigger such as the death of a baby, fear of birth and separation from family members (Ahmed et al., 2017).

Stigma

The stigma of mental illness influenced help-seeking behaviour. Women were reluctant to disclose symptoms of depression or access help, fearing that their children would be taken into care (Ahmed et al., 2008; O’Mahony et al., 2012a, 2013; Russo et al., 2015; Skoog et al., 2018).

“If we answer that question like this, maybe they will take our baby away...” (O’Mahony et al., 2013, p306)

Negative adjectives such as ‘crazy’, ‘mad’ and ‘embarrassing’ were used by women to describe how their family or community may label someone with mental illness (Ahmed et al., 2017; Ahmed et al., 2008; O’Mahony et al., 2012a, 2013; Russo et al., 2015; Willey et al., 2020).

The influence of family

For some women, there was a dissonance between advice from family members versus medical advice which may affect the likelihood...
of help-seeking from official services (Ahmed et al., 2008; Russo et al., 2015).

“...and I was thinking, should I listen to my mum, or to my doctor? I think, my mum is uneducated, doctor is educated, what should I do?” (Russo et al., 2015, p.5)

A fear of negative reactions from family members or bringing dis-honour to a family was prominent consideration for women (Ahmed et al., 2017; O’Mahony et al., 2012a, 2012b; Stapleton et al., 2013; Willey et al., 2020).

“The way we are taught back home there, since you are a young girl, that you obey your husband. . . The husband is everything . . . to answer these questions could make your husband part of it. . . Your husband later to [be] blamed for all these sort of things.” (Stapleton et al., 2013, p.652).

**Self-management of symptoms**

Some women felt that they had developed ways of managing symptoms of depression without medical intervention. Religion and faith were important to many women, who stated that reading scripture and praying gave them hope, calmed their anxieties and helped them to manage their emotions (Ahmed et al., 2017; Fellmeth et al., 2018; O’Mahony et al., 2013; Russo et al., 2015; Skoog et al., 2018).

“I believe in God, I prayed a lot. Really I am proud of myself ... I came all the way from Africa to live here and have family. I keep that successful. So that gives me more strength, I say “wow ... I did it,” ‘I’m thankful because all the time God was with me to help me”’. (O’Mahony et al., 2013, p.309)

Some women coped by keeping close contact with distant family using phone calls and social media (Skoog et al., 2018). Others accessed social support from neighbours or new friends (Ahmed et al., 2017). For some, it was important to seek people from similar communities as they could both communicate more easily and culturally identify with them (McLeish, 2002; O’Mahony et al., 2013; Russo et al., 2015). Women in one study actively sought out opportunities to learn the new language so that they could participate more fully in life in the new country (Russo et al., 2015). A minority of women took up a hobby such as weaving or embroidery or embraced Western concepts of self-care and relaxation (Russo et al., 2015).

Women also discussed trying to intentionally change their attitudes and expectations, leaving the past behind them, setting goals and embracing opportunities in the new country (Ahmed et al., 2008; McLeish, 2002; O’Mahony et al., 2013).

“You have to accept that this is it, who is here now, you have to relate to them. One of our community friends, she was a bit older than me...My mother said, ‘Now I cannot help you out, whoever is nice to you, that is your kind of mother’...so I accepted this.” (Russo et al., 2015, p.8)
### Table 4
Summary of included papers.

| Details of paper | Study Aims | Sample Characteristics | Study Characteristics | Data Analysis | Findings |
|------------------|------------|------------------------|----------------------|--------------|----------|
| Ahmed et al. (2008) | To increase understanding of women’s experiences and attributions of depressive symptoms and experiences of health care that facilitate or hinder help-seeking behaviours. | N = 9 (1 Asylum seeker, 2 refugees and 7 other migrant women) | Semi-structured telephone interview with the woman in her chosen language. | Constant comparative approach | Themes: attributions/ causes of depression, experiences of health care, use of support services, barriers to asking for help. |
| McLeish (2002) | To explore the maternity experiences of asylum seeking women in England | N = 31 (24 asylum seekers and 7 refugees) | Interviews | Not stated | Women discussed their mental health in context of their whole maternity experience. Women experienced sadness, anxiety and described symptoms of depression but no participants had been formally diagnosed as depressed but reported to describe symptoms of depression. |
| Russo et al. (2015) | Explore the experiences of Afghan women through pregnancy, birth and early childhood and gain an insight into experiences that positively and negatively affect their wellbeing. | N = 38 refugee Afghan born women. | Focus group discussions and in-depth interviews | Thematic analysis | Experiences within formal maternity care settings & experiences within the context of relationships, home and community. |
| Stapleton et al. (2013) | To explore staff and interpreters experiences of using a depression screening tool with refugee women | N = 33. (18 refugee women and 15 staff) | Mixed methods including qualitative data from focus groups and quantitative data from medical records. | Thematic analysis | Women value being screened in the same way as general population – feeling confirmed as a society member. Women experienced stigma, anxiety and described symptoms of depression but no participants had been formally diagnosed as depressed but reported to describe symptoms of depression. |

(continued on next page)
Language barriers

Women’s inability to speak the language of the new country or communicate clearly was a barrier to formally seeking help with their mental health (Ahmed et al., 2008; McLeish, 2002; O’Mahony et al., 2012a; 2013). Issues with interpreting were also raised. The presence of male interpreters was awkward and presented a barrier to authentic communication or disclosure for women (Skoog et al., 2018). Use of interpreters from within a woman’s own community was a concern, with women reporting that they could not trust them to uphold confidentiality, deterring them from discussing mental health concerns (Ahmed et al., 2017; McLeish, 2002; Stapleton et al., 2013).

“If you speak with a psychiatrist, you would speak normally, but if there is an interpreter as a mediator, and this person might speak about what you said, and now like you have told your story to this and may be this mediator will tell everybody.” (Ahmed et al., 2017, p.8)

Migration status

A woman’s migration status influenced the likelihood of disclosure and ability to access support for symptoms of depression, particularly for asylum-seeking women who feared deportation, or disclosure of poor mental health having a negative effect on their migration application (Feldman, 2013; McLeish, 2002; O’Mahony et al., 2012a).

“I feel very stressed these days, because I hear all the people saying they will send us back, and I think about what will happen to us, what they will do to us” (McLeish, 2002, p.57)

Refugee women in one study did not want to disclose mental health issues for fear of appearing ungrateful for the humanitarian protection they had been granted (Skoog et al., 2018).

Being held in detention led to barriers accessing maternity care is discussed by women in Feldman et al.’s (2013) UK report. Asylum-seeking women in the paper were frequently blocked from seeing any kind of medical care due to the attitudes of detention staff, who acted as gatekeepers to health services, which negatively impacted women’s mental health. Women who had been in detention were subsequently less knowledgeable about healthcare services available to them. Dispersal to a new area in pregnancy meant women were frequently forced to re-book maternity care in multiple cities, were unable to attend scheduled maternity appointments or develop a trusting relationship with a midwife which would reduce the likelihood of confiding in midwives or accessing services (Feldman, 2013).

Women’s migration status also created practical barriers to engaging with services. A lack of transport to attend appointments, no money to pay travel costs and no childcare for existing children influenced women’s engagement with maternity and mental health services (Feldman, 2013; McLeish, 2002; O’Mahony et al., 2012a, 2013).

Discussion

The aim of this review was to identify the factors affecting help-seeking behaviours of AS&R women with symptoms of perinatal depression. The review findings suggest that AS&R women may conceptualise perinatal depression differently and that this may influence whether they sought medical help for any symptoms. Mental health stigma meant that women were more fearful of seeking help or disclosing symptoms, especially when this went against family beliefs, with many women motivated to self-manage their symptoms. Women’s help-seeking behaviours were also influenced by previous experiences with healthcare systems or clinicians. Language barriers impeded women’s likelihood of disclosure, as did migration status, which presented physical and practical barriers to help seeking.

Most of the factors influencing help seeking behaviours in AS&R women are seen in other sectors of the maternity population. AS&R women described difficulties conceptualising perinatal depression...
because there was no equivalent word for it within their own culture. Frequently, women did not recognise Western symptoms of depression and were more likely to describe their feelings as boredom, tiredness or somatically as aches and pains. Similarly, existing literature suggests that ethnic minority women may demonstrate symptoms of depression but that the equivalent vocabulary or concept may not exist within their own language and culture (Jain and Levy, 2013). Gavin et al. (2005) suggest that being from an ethnic minority may itself be a risk factor for perinatal depression. A meta-ethnography by Schmied et al. (2017) had similar findings with women associating the depression with their status as a migrant woman as well as ethnic minority identity. Although it is impossible to distinguish between forced and voluntary migrant women in Schmied et al.’s study, it evidences that being a migrant woman increases perceptions of personal vulnerability which correlates with findings from this review. Additionally, if a woman does not identify with Western symptoms of depression or feels vulnerable because of her migration status this may affect her help seeking behaviour.

The findings from this review indicate that there is significant stigma around the experience of mental illness. Other research supports this, suggesting that stigma is not unique to AS&R women. Women in the general population (including women from ethnic minorities) report the same fears suggesting that the stigma is a societal or cultural phenomenon rather than a direct link to being a refugee or asylum seeker (Dennis and Chung-Lee, 2006; Schmied et al., 2017). Similarly, additional barriers to help seeking experienced by AS&R women are also experienced by other women from ethnic minorities, with practical barriers such as childcare, finance and transportation issues identified in existing literature; as are using coping mechanisms such as faith, accessing social support or taking up a new hobby (Wittkowski et al., 2017).

Previous negative encounters with staff displaying discriminatory attitudes, giving inaccurate advice or lacking cultural awareness have been experienced by other ethnic minority women using Western maternity services too. Women often perceive that they have received substandard care due to midwives’ lack of understanding about their cultural needs and preferences (Jomeen and Redshaw, 2013; Lyons et al., 2008). In addition, literature suggests that cultural influences on migrant women’s mental health are not fully recognised by clinicians, who have a tendency to trivialise, dismiss or pathologise traditional and cultural practices (Collins et al., 2011; Philimore, 2016).

Most factors affecting help-seeking behaviours are not unique to this population, yet AS&R women are more likely to experience multiples of these factors in addition to the complexities surrounding their migration experiences. A post-colonial feminist perspective would argue that mental illness cannot be attributed solely to one of these factors, contending instead that the intersectionality of issues such as gender, ethnicity, social class or politics and their influence on women’s health must be taken fully into account (Anderson, 2002; O’Mahony and Donnelly, 2010). Incrementally, AS&R women experience many of the same factors affecting help-seeking behaviours as the general population, with the addition of those associated with ethnic minority backgrounds and also women’s migration experiences. Women with precarious migration status may have less control over their access to health services due to factors such as detention, dispersal, restricted finances, social isolation and unfamiliarity with the host country’s healthcare system. Therefore, it is essential that further research is undertaken to recognise and respond to the barriers to mental health help-seeking behaviour experienced by women from a AS&R background.

Strengths and limitations of the review

A strength of this of this review is the robust definition and application of the terms ‘asylum seeker’ and ‘refugee’ and the attempts made to contact authors to confirm the terms used within included papers. The review also considers publication and selection bias by ensuring that grey literature was thoroughly searched and that the voices of women within charity funded reports were included.

A limitation is the lack of universality in migration vocabulary or formal recording of migration status in the country of publication which means that some relevant papers may have been inadvertently discounted due to the inability to confirm a refugee or asylum seeking population, particularly in Canadian papers. This is an acknowledged issue in maternity migration research and it is argued that a more systematic conceptualisation should be used to better identify forced migrant women in future research (Balaam et al., 2017).

Papers by O’Mahony et al. (2012a, 2012b, 2013) and O’Mahony and Donnelly (2012) only segregated some data for refugee and asylum seeking women, consequently it cannot be guaranteed that the voice of the woman has been differentiated from the voice of a voluntary migrant women. Nonetheless, as discussed in this review, papers with exclusive AS&R participants had very similar findings to those of the general migrant and ethnic minority population of women. These issues are acknowledged by other researchers and evidence the invisibility of this population within current research.

Conclusion

These review findings demonstrate that most factors affecting help-seeking behaviours in AS&R women are similar to those of other ethnic minority and migrant women. However, in addition to elements associated with migration status and experience, being a AS&R woman may exacerbate or increase the likelihood of experiencing multiple barriers to help-seeking.

Although this review highlights some of the factors affecting help-seeking behaviours of AS&R women, women in the papers reviewed are frequently part of a mixed homogenous migrant sample. Future research needs to consider AS&R women as a unique sample so that their voices are more audible within maternity research. The themes discussed are the visible tip of the iceberg and each theme merits further research to explore the issues in more depth.

Declarations

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Conflicts of interest

None declared.

Ethics approval

Ethical approval not required as this is a literature review.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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