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A meta-synthesis of women's experiences of online forums for maternal mental illness and stigma

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### **Conflict of interest**

Author DM, Author ND and Author SA declare that they have no conflict of interest.

### **Ethical considerations**

We have been respectful in our use of the data from all the studies included for review. REB approval was not needed as the study used previously published research which has had ethical approval and is also entirely in the public domain. No additional data were sought by us or were provided to us for analysis by the original authors. As such our study did not require ethical approval by our host institution, City, University of London, nor is there any regulatory or legal requirement for such work to require ethical approval in the UK.

## **Abstract**

**Purpose:** Perinatal mental illness affects 15% of women, however, only half of these women access treatment. Some women with untreated perinatal mental illness may continue to suffer with mental illness after the perinatal period. Evidence suggests one barrier to accessing treatment is stigma. Forums may provide an acceptable place for women to converse about the stigmatised symptoms of maternal mental illness. Reducing stigma may increase treatment uptake. This study aimed to review and synthesise the qualitative research on maternal mental illness forums and stigma, so that stigma can be addressed, and treatment improved.

**Methods:** A meta-synthesis was conducted to describe and interpret qualitative studies regarding forum use and maternal mental illness stigma. A systematic search of seven electronic databases and Google Scholar was performed. Additional references were collected through screening references of the identified studies. Five studies were identified that reported women's experiences of online forums for maternal mental illness and stigma.

**Results:** The synthesis identified four key themes: (1) a safe place to talk; (2) virtual support; (3) stigma and identity; (4) repair of the mother identity. Stigma maybe reduced by forum discourse that reconceptualises what is to be a "good mother" and separates stigma and maternal identity.

**Conclusions:** This synthesis provides a novel and more detailed framework for the stigma of maternal mental illness and forum use. This suggests forums may enable women to explore their dual identity and repair their maternal identity and this may reduce stigma. Healthcare providers could discuss forum use with their clients.

## Introduction

Perinatal mental illness (PMI) is a common health condition with a prevalence of approximately 15% and may be higher in lower income countries (Fisher et al. 2012; Giardinelli et al. 2012; Leung and Kaplan 2009; Ross and McLean 2006). It includes depression, anxiety, and post-traumatic stress disorder (Moore et al. 2016). PMI is often left untreated resulting in detrimental outcomes for women and their families and women may continue to have mental health issues beyond this period (WHO 2009; Letourneau 2013). This paper uses the term maternal mental illness (MMI) to refer to mood disorders in pregnancy and any time after childbirth.

Women often do not disclose to others or seek help because they are concerned about considering themselves and/or being viewed by others as an inadequate mother (Bilszta et al. 2010). Women may have the stigma associated with mental illness, and having a mental illness and being a mother. This “double stigma” can have increased consequences for an individual’s identity because women not only have the negative repercussions of having a mental illness, but also of being a mother with a mental illness (McLoughlin 2013). This stigma has been recognised in the literature as a key barrier to treatment (Dennis and Chung-Lee 2006; McLoughlin 2013).

McLoughlin (2013) identified the notion of a “bad mother” as a common theme among women with postnatal depression. She postulated that for some women, the illness was irreconcilable with a positive maternal identity, as “good mothers” were thought to not have depression, therefore some women adopted a “bad mother” identity (Bilszta et al. 2010; Edwards and Timmons 2005; McCarthy and McMahon 2008; Shakespeare et al. 2003). This “bad mother” identity sometimes included concerns that others would think they were incapable of fulfilling their maternal role (Bilszta 2010; Edge 2006). It is argued that some

women take on the discourse of the media construction of a “good mother” who is not depressed and a “bad mother” who is depressed and a threat to her child (Bilszta 2010; McCarthy and McMahon 2008; Buultjens and Liamputtong 2007; Patel et al. 2013). Many women may worry about being judged as a “bad mother”, losing custody of their child and social services involvement. Some symptoms of MMI are highly stigmatised and propagate guilt and shame, for example suicidal ideation and thoughts of child abuse. These concerns often lead women with MMI to conceal their illness from others, especially healthcare providers (McLoughlin 2013).

Online forums may be a more acceptable form of support for people with stigmatised conditions because they allow anonymous disclosure of potentially taboo experiences thus circumventing possible negative outcomes associated with stigma (Rains 2014). Forums may reduce stigma (Breuer and Barker 2015; Parikh and Huniewicz 2015) and potentially challenge stigma by enabling users to connect with similar others and converse about stigma concerns. This may reduce stigma by providing emotional and informational support, promoting empowerment, giving hope of recovery, reducing isolation, and validating and normalising symptoms (Bartlett and Coulson 2011; Evans et al. 2012; Malik and Coulson 2008; Naslund et al. 2016; Scrandis 2005).

Forums for MMI may challenge the stigma associated with MMI, and the conceptualisation of a “good mother” as being incompatible with MMI. One study showed that posts on a forum shared positive experiences of disclosure and treatment and challenged some women's beliefs that healthcare providers would think of them as an unfit mother or social services would take their baby (Moore, Ayers and Drey 2016). Therefore, forums may assist women with MMI who want to discuss stigma issues. However, there is limited theoretical understanding on this pertinent topic.

Qualitative research is particularly relevant in exploring these areas as it enables detailed consideration of women's experiences of sensitive issues concerning MMI stigma and forum use. There is no meta-synthesis of the existing qualitative literature. This study aimed to develop a new theoretical understanding of how forum use may influence the stigma some women with MMI experience.

## Method

### Search methodology

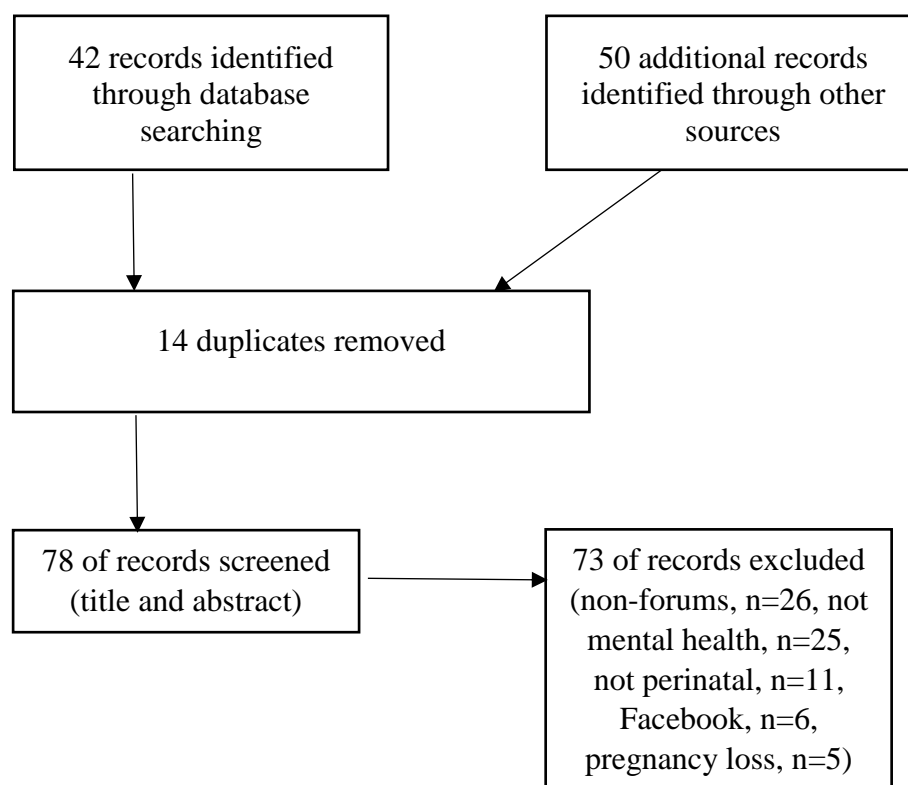
A systematic search was performed in August 2018 using computerised databases chosen for their inclusion of journals from the fields of medical science, nursing, psychiatry and psychology. The systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, and Altman 2009). Inclusion criteria were that papers reported qualitative data on online forums for MMI and stigma or contained substantial sections regarding these topics. MMI was defined as mood disorders in pregnancy and any time after childbirth.

Search terms included key words related to women, which were combined with terms related to online forums and further combined with terms related to perinatal and crossed with terms related to mental illness and finally combined with terms related to stigma (for a full list of search terms and an example of a search see Appendix 1 and 2). Seven databases were utilised; Embase, Medline, OVID, PubMed, PsycheARTICLES, PsycheINFO, and Web of Science. The first five pages of results using Google Scholar were assessed for inclusion. References from the final papers selected for inclusion were reviewed to identify further studies.

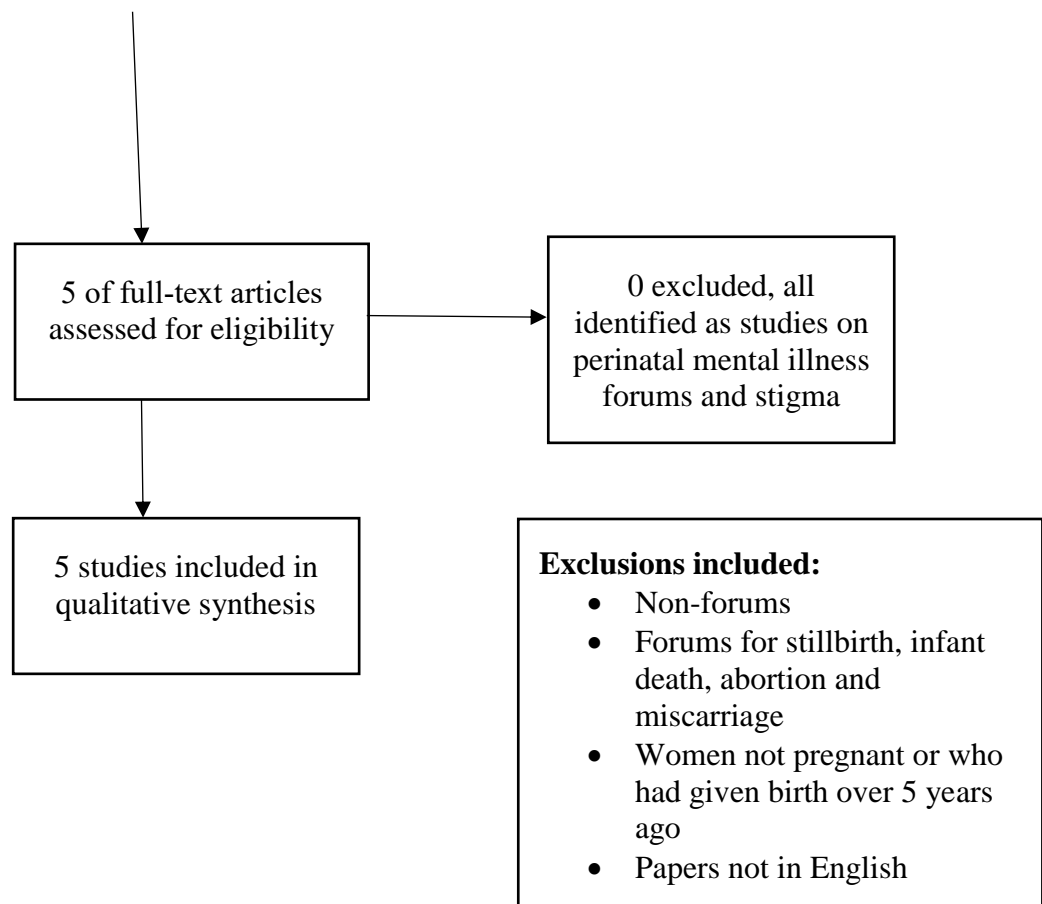
### Search outcome

Figure 1 shows the flow diagram of the results of the searches. The initial search yielded 92 papers, of which 14 duplicates were removed yielding 78 papers for inclusion. Each title was reviewed for relevance and then the abstracts were further examined for suitability for inclusion. Papers included focused on women's experiences of online forums for MMI and stigma or contained substantial sections regarding this topic. Papers excluded did not fulfil this criterion or included research on other online environments such as twitter. Papers were excluded if the focus of the forum was mental illness after stillbirth, infant death, abortion, and miscarriage. Papers that did not contain women in the perinatal period or were not in English were excluded. This inclusion and exclusion criteria yielded five suitable papers. Their references were screened for potential studies for inclusion; yielding no further studies.

The principle researcher (DM) read all papers, decided eligibility and reasons for exclusion. Uncertainties regarding inclusion were discussed by all authors until a consensus was achieved.







**Figure 1 Summary of literature search, adapted from PRISMA (Moher et al., 2009)**

### Quality assessment

There is no agreed measure of determining quality of qualitative studies and there is no consensus as to whether quality should be reported in synthesis (Atkins et al. 2008; Dheensa et al. 2013); we therefore excluded no studies due to a low-quality score because valuable findings might otherwise be excluded (Sandelowski et al. 1997). The authors used a checklist to give a description of the quality of studies to be able to emphasise findings from the more rigorous papers whilst not excluding less robust investigations, but not giving them undue weight. The quality of the

studies was assessed by the first researcher (DM) using an adapted checklist by Atkins et al. 2008; a reputable measure used to determine the quality of qualitative studies. The checklist and results are provided in Table 2. No new themes were accepted and included in the results if they were only identified in a study with lower quality score.

## **Data analysis**

The meta-synthesis was conducted using the seven-step process proposed by Noblit and Hare (1998) for meta-ethnography. This aimed to generate new insights from combining the selected studies most prevalent findings and by applying a novel interpretation, rather than summarising or reducing data (Walsh and Downe 2005). A meta-synthesis brings together interpretations from different qualitative studies to provide a new understanding of a phenomenon and develops new theories, reconceptualise already existing theories and provides a broad description of the phenomenon (Walsh and Downe 2005).

This seven-step process includes three-steps of analysis: the first is termed “reciprocal” and entailed searching the data for “metaphors” or phrases, representations and themes that occurred throughout the data sets (Noblit and Hare 1998). The second step is termed “refutational” and involved a detailed identification of phrases, representations and themes that contradicted the developing patterns in the data. The third step is termed the “line of argument synthesis” and summarised the combined patterns that emerged from all studies. Narrative discussion is used to describe the results and participant quotations are used to link concepts to the original data and explore advanced interpretations of the combination of themes.

Data were extracted from the studies. We ordered all emergent themes in a table using three levels of understanding. We moved from the first level of understanding: first order construct i.e. the view of the participant; to the second order construct: the interpretation by the authors; and then to the third order construct: a synthesis of views; and generated themes into a new understanding produced by all authors of this study (Malpass et al. 2009). Findings were first coded by reading and re-reading all the papers and then coded into themes. Characteristics of the papers included such as author, year, country, aims, sample (number and antenatal or postnatal), definition of MMI used, data collection method and method of analysis was also noted.

## Results

A description of the included studies is shown in Table 1. Studies were conducted in the USA, UK, Australia and Canada. Four studies analysed forum posts (n=102-1546) and one study interviewed women who used forums (n=15). Methods included content analysis, discourse analysis, online ethnography and thematic analysis. Quality ratings ranged from 7 to 11, with most studies having high quality (n=4) and remaining sites having lower quality (n=1, see Table 2).

Analysis identified four key themes or second order constructs: (1) a safe place to talk; (2) virtual support; (3) stigma and identity; and (4) repair of the mother's identity. Table 3 shows the key themes and subthemes present in the studies (see Appendix 3 for the key themes and subthemes in each specific study). The three concepts developed from interpreting and synthesising the second order constructs suggest stigma reduction through a discourse that negotiates maternal identity. The third order constructs are environment, understanding and identity.

## Safe place to talk: a “sanctuary for honesty”

*Safe place to talk* was a theme represented in all studies. Women described how they abstained from talking to others offline about their stigmatised symptoms and instead valued online forums for providing a safe place to disclose. Many forums offered a “sanctuary for honesty” where women could reveal their most intimate feelings (Evans et al. 2012, p. 407). Women’s maternal identity was protected by anonymous disclosure to a non-judgemental audience:

“I don’t want to share with my co-workers about my emotional issues of crying and feeling like an incompetent mom” (Kantrowitz-Gordon 2013, p. 877)

All studies showed that many women considered forums a valued platform to converse anonymously about stigmatised symptoms:

“they could put it on there because of anonymity nobody really knows who you are” (Moore & Ayers, 2016, p. 3)

The non-judgemental and sympathetic forum audience enabled women to express negative aspects of motherhood in a protective environment (Alang and Fomotar 2015; Evans et al. 2012; Kantrowitz-Gordon 2013; Moore and Ayers 2016; Moore et al. 2016). This buffered against fears that others would judge them as unfit mothers and assisted honest disclosure:

“I don’t like the baby and that I am not cut out to be a mother and that I am just simply done. . . I wish I could run away” (Evans et al. 2012, p. 407)

## Virtual Support: “you’re not alone”

*Virtual support* was a theme in four of the five studies. It encompasses virtual support forum members gave each other and may have reduced feelings of internal stigma. This included sharing personal stories with others who faced similar experiences, normalising and validating stigmatised symptoms, reducing isolation, and providing emotional support. (Evans et al. 2012; Moore and Ayers, 2016).

“everyone who’s obviously on there has postnatal depression so there’s no stigma because you’re all suffering” (Moore and Ayers, 2016, p. 3)

“Just reading some of the stories of recovery on this board makes me feel better. It is a great tool to have as you are recovering” (Evans et al. 2012, p. 407)

Sharing stories helped women to develop relationships and sometimes promoted feelings of belongingness which reduced isolation:

“I was looking for reassurance to know that somebody else is going through the same thing as you and you realise that you’re not alone because when I first got diagnosed I kind of felt like I shouldn’t tell my friends because I’m the only person in the world to have gone through this” (Moore and Ayers 2016, p. 3)

Two of the studies showed how some women benefit from using forums without posting; simply reading posts reduced their feelings of isolation:

“it does make you feel like part of a community and not on your own” (Moore and Ayers 2016, p. 3)

Studies recognised the virtual emotional support and unique empathy that made some women feel cared for and accepted despite their counter-cultural experiences of motherhood. Often women conveyed “physical” emotional support, for example, in the form of a virtual hug.

## Stigma and identity: “I am not a good mother”

*Stigma and identity* was represented in all studies. Studies showed that women frequently reported feeling inadequate as a mother because their symptoms were incongruent with their own expectations of motherhood and what they thought others expected of a proficient mother. Concerns centred on disclosing their illness and consequences for their maternal identity.

Maternal identity was expressed in a “good mother” discourse; women conceptualised what it was to be a good mother (Kantrowitz-Gordon 2013; Moore et al. 2016). This often comprised of women’s expectations of motherhood and feelings of internal stigma for not meeting these standards. They often used the words “good mother,” “bad mother,” “failure,” and “guilt”:

“I am not a good mother. My partner is better at this. I am happy that we have her, but I feel grossly incompetent” (Alang and Fomotar 2015, p. 31)

This internal stigma extended to how women believed others would appraise them if they disclosed their symptoms:

“I have seen the perinatal team and dr previously but kind of played down my feelings as I am scared that if I show I am not coping with my moods then they might look down on me, see me as an unfit mother and pass me over to social services” (Moore et al. 2016, p. 4)

Concerns were often about the consequences of disclosure to others as they might hold stigmatised attitudes and included loss of child custody, social services involvement, needing treatment and having to leave their child, job loss, social disapproval and labelling:

“Telling my doctor what I feel, my bad thoughts and the things I do may get me a diagnosis- and let’s face it, it will affect my life forever. Job prospects, respect, etc.” (Alang and Fomotar 2015, p. 29)

Some women found that using forums challenged external stigma. External stigma concerns were often met with replies that outlined positive experiences with healthcare providers and aimed to dispel worries that there would be negative consequences to disclosure:

“If you are seeking help and trying to sort it that's good. There's no reason to take your baby. I was honest with my GP. Nothing bad happened. I got better” (Moore et al. 2016, p. 4)

Only one study reported negative experiences of disclosure:

“My midwife said, and I quote, 'if you suffer from psychosis we could take your child away'. For someone feeling vulnerable this was really scary and I have not been able to relax with the pregnancy” (Moore et al. 2016, p. 4)

**Repair of the mother identity: “You are not a bad parent!!!”**

*Repair of the mother identity* was present in all studies and encapsulated the discourse that sought to repair maternal identity by challenging stigma (Kantrowitz-Gordon 2013, p. 879). Dialogue reconciled that one can have stigmatised symptoms and still be a good mother. Forums provided a unique space for women to express that they are good mothers despite having MMI and enabled women to separate their illness from their maternal identity.

Forums were valued by some women as they presented a dialogue about motherhood that was unavailable offline or was marginalised by the dominant discourse of “good mother” (Moore et al. 2016; Kantrowitz-Gordon 2013):

“I seriously was thinking if this happens to other people but now I know it’s just something that is not talked about” (Alang and Fomotar 2015, p. 27)

This allowed women a place to negotiate their maternal identity by expressing feelings that were opposed to cultural expectations and may have offered some women a cathartic release:

“My partner knows I am depressed but she does not know that I am thinking of hurting myself, or that I sometimes spank our daughter. Then I also feel like my baby is going to stop breathing. I am going insane over everything. I don’t know what I am asking here. Writing it out seems to help though” (Alang and Fomotar 2015, p. 26)

Some women were able to use forums to repair their identity as a good mother despite stigmatised symptoms. Some women explained that they had the qualities of a good mother despite being ill. Others described their stigmatised thoughts, but this did not impair their ability to parent (Kantrowitz-Gordon 2013):

“Most of the time I was genuinely a good mother and I loved holding him” (Kantrowitz-Gordon 2013, p. 879)

Some women may have visited forums to ease stigmatised feelings in other ways, for example, some separated the illness from the women’s maternal identity. Symptoms were conceptualised as part of MMI and therefore not indicative of parental capabilities. Internal stigma may have been diminished by shifting the blame off of women and onto the illness:



“I felt this huge relief that somebody else had gone through this. I guess it made me feel like I’m not just a complete failure, it was an illness” (Moore and Ayers 2016, p. 3)

Rhetoric often removed blame from the individual by endorsing a biological aetiology:

“All I can say is get help and talk to someone. You are not a bad parent!!! It is a chemical hormonal imbalance your brain and body go through after delivery” (Kantrowitz-Gordon 2013, p. 879)

“I’m not very compassionate towards myself or accepting of the fact that I was ill (rather than just being crap)” (Moore et al., 2016, p. 3)

This biomedical discourse was extended to include the belief that women were good mothers if they got treatment. One study showed that women were concerned about the stigma attached to treatment, especially medication. Concerns included guilt for taking medication that would potentially damage the baby, feelings of “weakness” for relying on medication and feeling incapable of being a good mother without medication. Responding posts targeted internal and external stigma and encouraged women to disclose to healthcare providers and engage with treatment:

“And don’t worry about not being a good mum, the very fact that you posted what you did and are worried about the possible effects on the baby show that you’re already a very caring mum” (Moore et al. 2016, p. 4)

#### 1.4.5 Third order synthesis

Forums in these studies provided a fertile *environment* that women used to communicate in a safe and supported way. This enabled women to explore an individual understanding and engage in a group understanding of MMI.

Interpretation of the synthesis showed an exploration through lived experiences of being a mother with MMI in which women negotiated and re-negotiated their individual *understanding* of MMI. Internal and external stigma were deliberated and reconciled by a group *understanding* that one can be a good mother despite having MMI.

This group *understanding* was enhanced by a sense of belonging to and being part of a group that was “expert” (through experience). It is theorised that women could not only reconceptualise their own maternal *identity*, but also incorporate a larger collective *identity* of belonging to the group of mothers with MMI. It emerged that there was a process of repairing the maternal identity through this collective *identity* that reconceptualised what is to be a “good mother” and separated stigma and maternal identity.

**Table 1 Study characteristics**

Study	Aim	Participants			Data Collection	Analysis
		N	Definition of perinatal mental illness	Location		
Evans et al. (2012)	To examine the perceived value and types of social support on postnatal depression online discussion groups.	512 messages	Postnatal depression	Unknown	Online forum posts.	Content analysis based on the typology of social support.
Kantrowitz-Gordon (2013)	To examine how women fashioned their accounts of postnatal depression as confessions.	102 messages	Postnatal depression	Unknown	Online forum posts.	Discourse analysis.
Alang and Fomotar (2015)	To identify the functions and perceived benefits of the group, and to	1,421 messages	Postnatal depression	USA, Canada,	Online forum posts.	Online ethnography (netography) and content analysis.

	investigate shared experiences among lesbians with postnatal depression			UK and Australia		
Moore et al. (2016)	To examine stigma and disclosure in forums and describe any potential disadvantages of forum use	1546 messages	Antenatal and postnatal depression and anxiety disorders, posttraumatic stress disorder after childbirth, and adjustment disorders.	UK	Online forum posts.	Thematic analysis.
Moore and Ayers (2016)	To explore online social support for postnatal mental illness, how women experience stigma and potential disadvantages of using forums	15 women	Postnatal depression and PTSD	UK	Interviews.	Thematic analysis.

**Table 2 Quality appraisal**

Study	Are the research questions clear?	Is the qualitative approach appropriate for the research question?	Is the study context clearly described?	Is the role of the researcher clearly described?	Are the following clearly described?			Are the following appropriate to the research question?			Are the claims made supported by sufficient evidence?	Total /11
					Sampling	Data collection	Analysis	Sampling	Data collection	Analysis		
Evans et al. (2012)	1	1	1	0	1	1	1	1	1	1	1	10
Kantrowitz- Gordon (2013)	1	1	1	0	1	1	1	1	1	1	1	10
Alang and Fomotar (2015)	1	1	1	1	1	1	1	1	1	1	1	11
Moore et al. (2016)	1	1	1	1	1	1	1	1	1	1	1	11
Moore and Ayers (2016)	1	1	1	0	0	0	0	1	1	1	1	7

**Table 3 Subthemes in the meta-synthesis organised under the principle themes**

<b>Theme 1</b>	<b>Theme 2</b>	<b>Theme 3</b>	<b>Theme 4</b>
<b>Safe place to talk</b>	<b>Virtual support</b>	<b>Stigma and identity</b>	<b>Repair of the mother identity</b>
Avoided talking offline	Similar others	Internal stigma	Negotiating identity online
Safe to disclose stigmatised symptoms online	Normalising and validating symptoms	External stigma	Good mother despite illness
Anonymous	Reducing isolation	Consequences of disclosure	Separate illness from mother identity
Non-judgemental	Encouragement/hope	Challenged external stigma	
	Virtual emotional support	Negative experience of external stigma	

## Discussion and Conclusions

This meta-synthesis of the qualitative literature on women's experiences of online forums for MMI and stigma, identified a new framework to understand how forum use might reduce stigma. An overarching synthesis identified four key themes: (1) a safe place to talk; (2) virtual support; (3) stigma and identity; (4) repair of the mother identity. Three constructs emerged from interpreting and synthesising: (1) environment; (2) understanding; (3) identity. We have drawn these together to

suggest a novel and deeper understanding than previous research when considering how forum use might reduce stigma. Women can explore a dual identity and may experience a repair of their maternal identity, potentially increasing treatment uptake.

Forums provided a conducive *environment* for women to explore individual *understanding* and engage in group *understanding* of MMI. Women negotiated and re-negotiated stigma through their individual *understanding* and a group *understanding* that being a good mother is compatible with having MMI. We theorise that women could reconstruct their own maternal identity, and may also incorporate a collective *identity* of the forum group. It emerged that there was a process of repairing the maternal identity through this group *identity* that reconceptualised a “good mother” and disconnected stigma from maternal identity.

This study supports and extends previous literature that identified women feeling like a “bad mother” (Bilszta et al. 2010; Edwards and Timmons 2005; McCarthy and McMahon 2008; Shakespeare et al. 2003). It builds on the “bad mother” identity and extends our understanding of how women are experiencing stigma (McLoughlin 2013). Findings show that forums specifically for MMI may help reduce stigma for some users as well as previously investigated health conditions (Bartlett and Coulson 2011; Evans et al. 2012; Malik and Coulson 2008; Naslund et al. 2016; Scrandis 2005). It is consistent with previous research that suggests that stigma is an important reason many women choose to conceal their illness (McLoughlin 2013). New insights are gained into the maternal identity, how this may be a dynamic process of conceptualisation and negotiation in forums and the potential for MMI forums to reduce stigma.

This meta-synthesis is the first study to synthesise qualitative studies of MMI forums that include stigma to increase understanding about how women use these forums and theorise relationships between maternal identity and stigma. There are some limitations that limit the generalisability of the findings. The samples in the studies are limited to women who use forums, therefore, the findings should not be extended to women with MMI who do not use forums. Studies included few types of forums that were mostly focused on depression and postnatal populations.

Research is needed to investigate women who do not use forums, and include a wider range of forums, especially those with antenatal populations and should include anxiety and post-traumatic stress disorders. Research has mostly focused on analysing posts from forums and our knowledge might be enriched through a mixed methods approach that incorporates analysis of forum messages and the first-hand experiences of women who use the forums. Future work is required to explore this new framework as research suggests internal stigma of MMI may mediate between forum use and disclosure (Moore, Ayers and Drey 2017).

Healthcare providers could discuss forum use with their clients and the pros and cons of using them. The NHS Direct website already has links to a MMI forum ([pni.org.uk](http://pni.org.uk)). Healthcare providers could consider the use of forums to help women recognise and explore issues of internal stigma.

## **Conclusions**

This study provides a new theoretical framework that highlights how individual and group understanding of MMI and stigma is negotiated online. Women can explore a dual identity and may experience a repair of their maternal identity. Healthcare



providers could discuss the use of forums with their clients as well as providing support to those diagnosed with MMI.

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