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**ONLINE RESOURCES FOR PERINATAL MENTAL ILLNESS AND
STIGMA**

Thesis submitted for the degree of Doctorate of Philosophy

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January 2017

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Declaration

The middle chapters of this thesis consist of distinct articles written for publication in peer-reviewed journals (Chapters 2-7). The first and the final chapter present overviews and discussions of previous literature and the research in this thesis. References for all chapters are at the end of the thesis.

All of the papers in this thesis have been accepted or submitted for publication in peer-reviewed journals and presented in this thesis as the final published or submitted manuscripts (see Appendix 8 for copies of the published articles). The articles are my own work with guiding involvement from the second author and for some articles a third author. I wrote the first draft and took the lead on all subsequent revisions including those suggested as part of the peer-review process. Full references are detailed below:

Chapter 2 is submitted for publication in the Journal of Affective Disorders as: Moore, D., Drey, N., & Ayers, S. A meta-synthesis of women's experiences of online forums for perinatal mental illness and stigma. *Computers in Human Behaviour* (submitted for publication).

The author contributions are as follows: Donna Moore wrote the protocol, undertook the literature searches, data analysis and interpretation of results and drafted the manuscript. Nick Drey and Susan Ayers participated in the design, data analysis and drafting of the manuscript.

Chapter 3 is published in the Archives of Women's Mental Health as:

Moore, D., & Ayers, S. (2011). A review of postnatal mental health websites: Help for healthcare professionals and patients. *Archives of Women's Mental Health, 14*(6), 443-452. doi: 10.1007/s00737-011-0245-z

The author contributions are as follows: Donna Moore initiated the design, carried out the website ratings, data analysis and interpretation and drafted the manuscript. Susan Ayers participated in the design, reporting the data and drafting of the manuscript. Rose Coates was an additional website reviewer for a selection of websites. Richard de Visser (my second supervisor at the University of Sussex) advised on reporting the findings.

Chapter 4 is published in Psychology, Health and Medicine as:

Moore, D., & Ayers, S. (2016). Virtual voices: Social support and stigma in postnatal mental illness Internet forums. *Psychology, Health and Medicine, 1-6*. doi: 10.1080/13548506.2016.1189580

The author contributions are as follows: Donna Moore designed the study, wrote the protocol, carried out the interviews, analysed and interpreted the data and drafted the manuscript and redrafted for publication. Susan Ayers contributed to the design of the study, interpretation and drafting the manuscript. Ylva Parfitt completed additional coding for a selection of the interviews.

Chapter 5 is published in the Journal of Medical Internet Research as:

Moore D, Ayers S, & Drey N. (2016). A thematic analysis of stigma and disclosure for perinatal depression on an online forum. *Journal of Medical Internet Research*. doi:10.2196/mental.5611

The author contributions are as follows: Donna Moore contributed to the protocol, design, analysis and interpretation of data and drafted the manuscript. Susan Ayers participated in the design, data analysis and drafting of the manuscript. Nick Drey participated to subsequent drafts of the manuscript.

Chapter 6 is published in the Journal of Infant and Reproductive Psychology as:
Moore, D., Drey, N., & Ayers, S. (2017). The City MISS: The development of a scale to measure stigma of perinatal mental illness. *Journal of Infant and Reproductive Psychology*, 35(3), 273-275. doi: 10.1080/02646838.2017.1313967

The author contributions are as follows: Donna Moore contributed to the conceptualisation and design of the study, online survey development, participant recruitment, data analysis and interpretation, and drafted the manuscript and redrafted for publication. Nick Drey contributed to the conceptualisation and design of the study, data analysis and interpretation, subsequent drafts of the manuscript. Susan Ayers contributed to data analysis and subsequent drafts of the manuscript.

Chapter 7 is published in the Journal of Medical Research as:

Moore, D., Ayers, S., & Drey, N. (2017). Use of forums for perinatal mental illness, stigma and disclosure: an exploratory model. *Journal of Medical Internet Research*, 4(1): e6. doi:10.2196/mental.5926.

The author contributions are as follows: Donna Moore contributed to the conceptualisation and design of the study, online survey development, participant recruitment, analysed and interpreted the data, and drafted the manuscript. Susan Ayers contributed to data analysis and interpretation, and drafts of the manuscript. Nick Drey contributed to the design of the study, data analysis and drafting the manuscript.

I hereby declare that this thesis has not been, and will not be, submitted in whole or in part to another University for the award of any other degree.

Donna Moore

January 2017

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List of Abbreviations

APA American Psychological Association

BPS British Psychological Association

City MISS City Mental Illness and Stigma Scale

CFA Confirmatory factor analysis

CI Confidence interval

DSM Diagnostic and Statistical Manual

EFA Exploratory factor analysis

HADS Hospital Anxiety and Depression Scale

PND Postnatal Depression

PNI Postnatal Illness

PMI Perinatal Mental Illness

PTSD Post-traumatic Stress Disorder

TPB Theory of planned behaviour

WDT Web Depression Tool

WHO World Health Organisation

WWW World Wide Web

City University London

Donna Kate Moore

Thesis submitted for the degree of Doctorate of Philosophy

**ONLINE RESOURCES FOR PERINATAL MENTAL ILLNESS AND
STIGMA**

Summary

Perinatal mental illness is a global health issue with detrimental outcomes for women and their families if left untreated. Unfortunately, many women do not get the treatment they need for many reasons, one often acknowledged reason is that the stigma some women experience inhibits disclosure of their needs to healthcare providers. This thesis looked at Internet resources for women with perinatal mental illness, in particular online forums. It examined how forums might affect stigma and thus disclosure behaviour.

This thesis is by prospective publication. Article 1 aimed to describe and interpret qualitative studies regarding forum use and perinatal mental illness stigma. A meta-synthesis of five studies identified four key themes: a safe place to talk; virtual support; stigma and identity; and repair of the mother identity (Moore, Ayers & Drey, under review). Article 2 aimed to identify what websites about postnatal mental illness were available and assess them for content and quality. A systematic review of 114 websites evaluated accuracy of information, resources and website quality. Results showed information was largely incomplete and difficult to read; resources were limited and website quality was variable (Moore & Ayers, 2011). Article 3 aimed to determine how women with perinatal mental illness use web-

based resources. A qualitative interview study (n= 15) found that the anonymity and non-judgemental social support on forums may have made it an acceptable way to challenge internal stigma and that most women described forums as providing a space to discuss stigma and test out disclosing about their illness to others (Moore & Ayers, 2016). Article 4 therefore aimed to identify whether forums for perinatal mental illness reduce stigma and facilitate disclosure. Thematic analysis of 1546 posts over six months on a forum for postnatal mental illness suggested that forum discourse reconstructed ideology of motherhood as compatible with perinatal mental illness. Many women overcame stigma and posted that they had taken advice and disclosed to a healthcare provider (Moore, Ayers, & Drey, 2016).

The final article developed and tested a hypothesised model of the relationship between stigma and disclosure about perinatal mental illness. Study 5 developed a questionnaire measure of stigma for perinatal mental illness in order to test the model. Questionnaire items were completed online by women with perinatal mental illness (n=279). Psychometric testing suggested it was a valid scale with three subscales: external, internal and disclosure stigma (Moore, Ayers, & Drey, 2017). Study 6 tested a hypothesised model that stigma would mediate the relationship between forum use and disclosure to healthcare providers. An online survey of women with perinatal mental illness (n=200) who had used forums provided partial support for this hypothesis, with internal stigma mediating the relationship between length of forum use and disclosure (Moore, Drey, & Ayers, 2017).

This research highlights the importance of considering the stigma associated with perinatal mental illness and its role in online forum use and disclosure. Overall, findings suggest that forums may facilitate recognition of stigma, which may in turn lead to greater disclosure of symptoms to healthcare providers. However, the

relationship between forum use, stigma and disclosure may be more complex than our initial model proposed. Similarly, most participants in these studies were white, well-educated and actively participated in the forums. Future studies would benefit from testing these relationships using longitudinal designs with more representative samples.

1 Background

1.1 Introduction

Pregnancy and motherhood are seen as positive life events, however, some women can experience psychological distress at this time. Women can experience a variety of affective disorders in the antenatal and postnatal period, such as depression, anxiety, obsessive compulsive disorder, and post-traumatic stress disorder (O'Hara, Wisner, & Asher, 2014). These illnesses will be referred to as perinatal mental illness throughout the thesis. Perinatal mental illness has an approximate prevalence of 15% and the World Health Organisation stresses that it is a global health concern (Giardinelli et al., 2012; Leung & Kaplan, 2009; Ross & McLean, 2006; WHO, 2008, 2014).

Perinatal mental illness can result in detrimental outcomes for women, infants and families if left untreated (Letourneau et al., 2012). However, many women fail to get the treatment they need to recover (Dennis & Chung-Lee, 2006). One often cited reason for this is that the stigma associated with perinatal mental illness can be a barrier to women disclosing symptoms and seeking help (Bilszta et al., 2010). Some researchers have described how some women may experience a two-fold stigma that involves receiving negative appraisals from other people both in terms of having a mental illness and in being a mother with a mental illness (McLoughlin, 2013). Thus, some women might avoid disclosure to healthcare providers because they do not want to be considered a "bad mother".

Online forums may be an acceptable aid to people with stigmatised conditions as they can use them anonymously, therefore circumventing possible negative outcomes associated with stigma (Rains, 2014). Forums for perinatal mental illness

have shown potential for providing places for women to discuss and challenge stigma and get encouragement to disclose to healthcare providers (Alang & Fomotar, 2015; Evans et al., 2012; Kantrowitz-Gordon, 2013). Therefore, more research is needed to investigate if forums challenge perinatal mental illness stigma and potentially facilitate women disclosing. Forums might provide a beneficial intervention to assist disclosing symptoms to healthcare providers, thus making the first step towards recovery from their illness.

This thesis aimed to explore how women with perinatal mental illness use online resources, in particular, online forums and how this relates to stigma and disclosure of symptoms to healthcare providers. This chapter provides an overview of the current research on perinatal mental illness, the concept and theory of stigma, and of the online forums for perinatal mental illness. There are four sections in this chapter. The first section presents relevant research on perinatal mental illness considering diagnosis, prevalence, outcomes and barriers to care. The second section looks at the concept and theory of stigma and mental health, and summarises research on stigma for perinatal mental illness. The third section addresses online forums for perinatal mental illness and stigma. The fourth section outlines the aims of the thesis and gives a brief description of each study included.

1.2 Perinatal mental illness

1.2.1 Diagnosis

Women can experience a variety of perinatal mental illnesses, such as depression, anxiety, post-traumatic stress disorder and puerperal psychosis. These illnesses can occur either in the antenatal or postnatal period and or in both timeframes, with the exception of puerperal psychosis which only occurs after birth. Conditions may be

comorbid, for example, an individual might present with both depression and anxiety.

A fundamental issue regards how perinatal mental illness is conceptualised and the pros and cons of diagnostic or symptom approaches (Coates, de Visser & Ayers, 2015). Using an internationally recognised system for classifying disorders, for example, the Diagnostic and Statistical Manual for Mental Disorders, enables identification of people who need treatment and comparisons of different populations' prevalence, incidence and prognosis. Perinatal mental illness is thus defined by meeting diagnostic criteria or exceeding a specified threshold measurement on a screening scale (O'Hara, Wisner & Asher, 2014). However, a diagnostic approach uses categorical classification on the presence or absence of symptoms, rather than a more encompassing approach that recognises symptoms on a continuum (diFlorio & Meltzer-Brody, 2015). Therefore, women who experience distress but do not meet criteria for a diagnosis may fail to be included in research or treatment programmes (McKenzie-McHarg et al., 2015).

The most well-recognised and researched perinatal mental illness has been perinatal depression, in particular, postnatal depression. The Diagnostic and Statistical Manual for Mental Disorders, the fifth edition (DSM-5) defines postnatal depression as a major mood disorder that starts after childbirth. Symptoms of postnatal depression are similar to those of depression experienced in other times of life and primary symptoms include a persistent low mood and/or lack of motivation to do things that were previously regarded as enjoyable (Lee & Chung, 2007; Wee et al., 2011). Other symptoms include fatigue, irritability, suicidal ideation, change in appetite, and sleep disorders (Lee & Chung, 2007). Antenatal depression has similar symptoms, but presents during pregnancy. Possible consequences of depression in

the perinatal period include lack of interest in the baby, intense feelings of inadequacy as a mother, difficulty bonding with their baby, and worry that they will not be able to cope when the baby is born (O'Mahen et al., 2012; Tommy's, 2013).

Anxiety can occur in the perinatal period and there is increasing evidence that it may be more prevalent than depression (Glasheen, Richardson, & Fabio, 2010). Anxiety conditions include Generalised Anxiety Disorder (GAD), Obsessive-Compulsive Disorder (OCD), panic disorder and phobias (Brockington, 2004). General Anxiety Disorder is characterised by persistent and excessive worry or anxiety for more than six months that interferes with daily functioning (American Psychiatric Association, APA, 2013). Symptoms include catastrophizing, restlessness, and sleep disturbances. Possible consequences of anxiety in the perinatal period include fear that the baby will be harmed and hypervigilance over the baby (Abramowitz, Schwartz, & Moore, 2003).

Obsessive Compulsive Disorder is characterised by distressing and unwanted thoughts, images or impulses that repeatedly enter an individual's mind (APA, 2013). The individual can develop repetitive behaviours or mental acts such as counting, checking and thinking "neutralising" thoughts to counter the obsessive thoughts in an attempt to alleviate the unpleasant feelings these thoughts produce (APA, 2013). In the perinatal period, symptoms often revolve around the well-being of the fetus or infant, for example, excessive restriction of what they eat while pregnant in an attempt to protect the fetus' health or excessive washing and/or cleaning due to fears of contaminating the fetus or baby (Uguz et al., 2007).

Panic disorder is characterised by reoccurring panic attacks and symptoms include heart palpitations, sweating, shortness of breath, and fear of losing control or

dying (APA, 2013). Phobias can be specific to the perinatal period, for example, fear of childbirth; tokophobia (Hofberg & Brockington, 2000). Consequently, women might try to terminate a pregnancy, elect for a caesarean section or avoid getting pregnant (Hofberg & Brockington, 2000).

Post-traumatic stress disorder (PTSD) was classified in DSM-IV as an anxiety disorder but has since been reclassified as a "trauma- and stressor-related disorder" in DSM-5 (APA, 2000; APA, 2013). The DSM-5 defines the disorder as occurring after exposure to actual or threatened death, serious injury or sexual violation (APA, 2013). There is increasing research showing a proportion of women have PTSD in pregnancy and that this disorder can also occur as a result of trauma during childbirth (Grekin & O'Hara, 2014; Seng et al., 2010). Symptoms are described in DSM-5 as comprising of four symptom clusters: intrusion, avoidance, negative alterations in cognitions and mood, and alterations in arousal and reactivity. Firstly, intrusion involves re-experiencing of the event (e.g., nightmares and flashbacks of the event). Secondly, avoidance refers to distressing memories, thoughts, feelings or external reminders of the event (e.g., sex or hospital). Thirdly, negative alterations in cognitions and mood is marked by a range of behaviours (e.g. hypervigilance, irritability, difficulty concentrating and dissociation from others). Fourthly, reactivity is characterised by the "flight" feature of PTSD and aspects include aggressive, reckless or self-destructive behaviour, sleep disturbances, and hypervigilance. Symptoms must last more than a month after the event and cause significant distress and impairment to functioning (APA, 2013).

1.2.2 Prevalence

Perinatal mental illness is a global health concern (World Health Organisation; WHO, 2009). It is difficult to identify the overall prevalence of perinatal mental

illness but it has been estimated as an approximate prevalence of 10-20% (Gavin et al., 2005). Discrepancies between the prevalence reported by studies is due to a variety of factors. Firstly, studies differ in terms of how they define and measure the illness, for example, some might only measure postnatal depression and others include postnatal depression and anxiety (O'Hara, Wisner & Asher, 2014). Secondly, studies differ in the instruments used to measure symptoms: some use self-report questionnaires like the Edinburgh Postnatal Depression Scale (EPDS) where others use a clinical interview like the Structured Clinical Interview for DSM-5 (SCID-5) (O'Hara et al., 2014). Studies also differ in measurement cut off scores used to classify disorders, some may include mild levels of the illness or only include moderate to severe cases or rely on the terms used by the women themselves to describe their illness (Paulson & Bazemore, 2010).

Thirdly, there are other factors that affect prevalence and include differences between samples, including number of participants, ethnicity, level of risk, and if the country is developed or not (O'Hara et al., 2014). Researchers may differ in how they define the illness and the period of time in the gestational or postnatal period women can experience perinatal mental illness (O'Hara et al., 2014). Sometimes women may experience two or more illnesses and prevalence rates may or may not include these comorbid conditions (Falah-Hassani, Shiri, & Dennis 2016). Finally, many women suffer from symptoms associated with mental illness without detection because they do not conform to all the diagnostic criteria (McKenzie-McHarg et al., 2015). Therefore, there may be some women who experience substantial distress, and even impaired daily functioning, but are not included in perinatal mental illness prevalence rates.

Anxiety might be more prevalent than previously thought in the perinatal period and even exceed depression rates (Fairbrother, Janssen, Antony, Tucker, & Young, 2016; Glasheen et al., 2010). Anxiety affects 3 to 37% of pregnant women and 4 to 20% of mothers in the postnatal period (Leach, Poyser, & Fairweather-Schmidt, 2015). Fairbrother et al. (2016) conducted diagnostic interviews with 115 women who scored above the cut offs for depression and anxiety measures. Results showed that 2.6% of the sample experienced generalised anxiety disorder in pregnancy and 3.2% after birth. Obsessive compulsive disorder affected 2.9% of pregnant women and 3.6% of new mothers. Panic disorder was less common, affecting 1.7% of pregnant women and 0.7% after childbirth. Phobia disorders were present in 7.4% of women before and after birth.

Post-traumatic stress disorder occurs in 3.2% of mothers and affects over 15% of women in high risk groups, such as women with depression or a history of psychopathology (Grekin & O'Hara, 2014). A recent systematic review of 59 studies has shown that PTSD affects 3.3% of pregnant women in community samples and 18.9% in high-risk samples (Dikmen, Ayers & Phillips, 2016). The review showed the prevalence of PTSD in the first year after birth is 4.0% in community samples and 18.5% in high risk samples.

1.2.3 Outcomes

A range of possible detrimental outcomes have been identified for mothers who experience perinatal mental illness and their children and families if the illness is not treated (Patel & Wisner, 2011). The most researched perinatal mental illness is depression and a range of negative outcomes have been documented for the child. For example, antenatal depression is associated with delayed fetal growth, and increased risk of premature birth and low birthweight (Field, Diego, & Hernandez-

Reif, 2006; Field, 2011). Obstetrics complications are more likely, for example, pre-birth complications including preeclampsia, miscarriage and increased pain relief during labour and post-birth complications, such as high neonatal cortisol levels at birth (Alder, Fink, Bitzer, Ho-Sli, & Holzgreve, 2007; Olivier et al., 2015). Perinatal mental illness can not only affect early child development, evidence suggests its impact can extend through to the adolescence and adulthood of the offspring (Hay et al., 2010; O'Hara & McCabe, 2013). Infants of women with postnatal mental illness are at significantly greater risk of behavioural, cognitive and social problems, such as impaired language development and IQ (Letourneau et al., 2013, 2012; Narayanan & Nærde, 2016; Brand & Brennan, 2009; Grace, Evindar, & Stewart, 2003). Some studies have shown adolescent outcomes to include mood disorders and social problems (Halligan, Murray, Martins, & Cooper, 2007), yet other research is conflicting. Sanger, Iles, Andrew, & Ramchandani (2015), for example, reviewed 16 longitudinal studies and found the most consistent findings were for cognitive deficits but evidence for psychopathology was conflicting. It should also be noted that perinatal mental illnesses might be comorbid with other conditions and occur in both the antenatal and postnatal period as well as re-occurring throughout the lifespan, possibly resulting in cumulative negative consequences for the mother and child (Grace et al., 2003; Hay, Pawlby, Waters, & Sharp, 2008).

Other psychological disorders in the postnatal period have been less researched, but offspring of women with anxiety disorders have been shown as potentially having similar deficits as those with depression, such as behavioural, cognitive and social problems (Glasheen, Richardson & Fabio, 2010). Possible adverse outcomes for the mother include poor self-care, suicide and negative coping behaviours such as smoking, alcohol and drug use (Bonari et al., 2004; Gressier et

al., 2017). Antenatal mental illness also puts a woman at higher risk of postnatal affective disorders, such as depression and anxiety, in the postnatal period (Field, 2011). Postnatal mental illness can sometimes impair the mother-infant relationship and the woman's parenting capabilities (Alder et al., 2007; Letourneau et al., 2012). Family relationships can suffer and partners are more likely to develop depression (Rominov, Pilkington, & Whelan, 2016). Moreover, these outcomes for both woman, child and family mean that there can be a significant economic cost to both the individual and society, in particular, to the public sector (Bauer et al., 2016). Given the possible negative impact on the mother, child, family and society, it is critical research looks at alternative support women might access outside of the health service.

1.2.4 Barriers to care

Many women with perinatal mental illness do not receive treatment despite the high prevalence of perinatal mental illness and its associated negative outcomes for the whole family, such as delayed child development (Letourneau et al., 2013). There are many obstacles facing women trying to access appropriate healthcare for perinatal mental illness and this can prevent treatment uptake even where mental health services are available (Dennis & Chung-Lee, 2006). Logistical barriers include lack of childcare or transportation (Goodman, 2009), constraints of infant napping and feeding schedules and stigma (Goodman, 2009; O'Mahen & Flynn, 2008; O'Mahen et al., 2015), cost of treatment (O'Mahen et al., 2015), being unable to get time off work, and language difficulties (Kopelman et al., 2008). Institutional barriers may include ineffective screening, insufficient training for healthcare providers, lack of available resources, and healthcare providers not having confidence to diagnose clients (Byatt et al., 2012; Olson et al., 2002). Kingston et al.

(2015) conducted a survey of 460 pregnant women in Canada that identified barriers to screening for mental health issues. The four most common barriers were family and friends normalising their symptoms, not knowing if their emotions were normal or not, wanting to deal with their feelings on their own and preferring to talk to significant others rather than healthcare providers. Women were reluctant to seek professional treatment and preferred to cope individually with any problems. The authors theorised that this could be in part due to issues of stigma and pointed to online help as a viable alternative for support for this subset of women.

Individual causes that prevent treatment uptake and adherence include lack of education, therefore women may not seek help simply because they do not recognise they have a problem (Gardner et al., 2014). Concerns about treatment options may also hinder access to care (Byatt et al., 2013). Other reasons that inhibit use of mental healthcare services include beliefs that psychopharmacological treatment during pregnancy and whilst breastfeeding is unacceptable; mistrust of healthcare providers; lack of social support; and cultural factors, such as beliefs that problems should only be discussed within the family (Abrams, 2011; Byatt et al., 2012; Dennis & Chung-Lee 2006; Edge, 2004, Flynn et al., 2010; Goodman, 2009). Symptoms themselves may be a barrier to care: depression can involve social withdrawal, ambivalence and chronic tiredness which all make initiating and engaging with healthcare appointments difficult.

Disclosure of symptoms to a healthcare provider is the first step in accessing treatment and promoting recovery. However, a major barrier to disclosing to healthcare providers is stigma. A systematic review of 144 studies that were both qualitative and quantitative showed that stigma reduced seeking help for mental health conditions with concerns about disclosure being the most cited barrier to care

(Clement et al., 2015). Byatt et al. (2012) conducted focus groups with healthcare providers who described women with perinatal mental illness as reluctant to disclose symptoms because they were anxious about stigma. Women's concerns included their child being taken away, being seen as an unfit mother and being institutionalised. Healthcare providers were concerned that this stigma resulted in a failure to attend healthcare appointments and receive treatment. The theme of stigma is common in the literature surrounding disclosure of perinatal mental health problems to healthcare providers (McLoughlin, 2013).

A recent UK survey of 1547 women with perinatal mental illness (diagnosed or self-diagnosed) and 1801 healthcare providers (health visitors, midwives, family nurse practitioners and others) revealed that the majority of women attributed their illness to trying to live up to unrealistic expectations and a lack of support (Tommy's, 2013). The biggest barrier to accessing care was reluctance to talk about their feelings. Less than a fifth of women reported that they had been completely honest with their healthcare providers and many chose to only disclose just enough to get help and avoid negative consequences of disclosure. Nearly a third had never told a healthcare provider they had perinatal mental illness symptoms. More than a quarter reported that this was because they thought their baby would be taken away. Many women thought that their symptoms were indicative of failure as a mother, which hindered disclosure because women were concerned about being judged as an inadequate mother.

1.3 Perinatal mental illness stigma

This section outlines some important conceptual issues regarding stigma such as external, internal and disclosure stigma. Key components of stigma theory are then

considered and how they might apply to perinatal mental illness. Finally, this section extends considerations of theory and current research to consider perinatal mental illness stigma and how it is unique from stigma associated with other mental illnesses including depression.

1.3.1 Conceptualisation of stigma

Stigma is a complex and multi-faceted phenomenon. It is a set of negative, and often, unfair beliefs society or a group of people may have about something. An individual or group can be stigmatised because of a characteristic which is often related to race, ethnicity, obesity, gender, culture, socio-economic status illness or disease. The term “stigma” dates back to the ancient Greeks who referred to the branding of criminals and slaves to identify them as tainted. A key theorist in stigma literature; Goffman (1963), defined stigma as the extreme disapproval of someone or a group of people because they have a certain attribute that is perceived as highly undesirable. Many definitions of stigma have two essential components; the recognition of difference and devaluation (Dovidio, Major, & Crocker, 2000). Definitions also recognise the social nature of stigma, often considering it as occurring in a social context (Crocker, Major, & Steele, 1998; Hebl & Dovidio, 2005).

Stigmatised conditions are not always obvious to others, for example, leprosy is a visually recognisable stigmatised illness whereas mental illnesses and other illness such as HIV are often not visually apparent. Indeed, individuals with mental illness may be able to conceal their condition and thus avoid identification and consequent discrimination. Goffman (1963) theorised that some individuals will conceal their stigmatised status in order to be accepted by others, or out of concern that others would discredit them.

There are several theoretical approaches to the stigma and discrimination of mental health that emphasise social cognitive concepts, such as stereotypes, prejudice and discrimination (Corrigan, 2004; Thornicroft, 2006). A stereotype is a negative belief about a group, for example, people with mental illness are dangerous. Prejudice is an agreement with a stereotype and/or negative emotional reaction, for example, fear. Discrimination is the behavioural response to prejudice, for example, avoidance (Rusch, Angermeyer & Corrigan, 2005). Internal stigma presents similarly, but stereotypes are applied to the self, for instance, the stigmatised individual believes that they are dangerous (Rusch et al., 2005). Prejudice is also applied to the self and can result in low self-esteem. Resultant discrimination could be seen in a stigmatised individual not pursuing housing or career opportunities because of feelings of worthlessness.

These social-cognitive models recognise that stigma can be external and/or internal (Thornicroft, 2006). Stigma can be said to be external when the general public holds a stigmatising attitude. Stigma can also present as internal when the stigmatised individual subscribes to the prejudicial beliefs of the external stigma and applies it to themselves. It can also occur if the stigmatised individual does not necessarily agree with the external stigma, but they devalue themselves regardless because they have the stigmatised characteristic (Corrigan et al., 2011). This is known as internal stigma and sometimes referred to as “self-stigma” (Rusch et al., 2005). However, not all stigmatised individuals present with internal stigma as their reaction may depend on a number of factors, for instance, they may not even be aware of the stigma or are simply unaffected by it (Corrigan & Watson, 2002). When individuals view the stigma as erroneous, they may react with anger or indifference depending on how much they identify with the stigmatised group. Anger or

indignation may result in behaviour that seeks to counter stigma, for example, joining advocacy groups (Rüsch, Lieb, Bohus, & Corrigan, 2006). Stigmatised individuals could also suffer by simply believing others hold a stigmatised attitude (known as perceived external stigma).

Stigma has also been conceptualised in sociological terms where theories suggest that self-identity is socially constructed. Labelling theory was developed by sociologists in the 1960s and proposes that an individual's identity and behaviour is shaped by the language used to describe them. Deviance is viewed as not necessarily inherent to an act or state, but socially constructed. Stigmatised individuals are seen as deviant from the majority and labelled with derogatory terms that exclude them from the cultural norms or "normals". This is closely linked to the "us" and "them" point of view separating the normal and deviant group and placing inferior labels on the minority which are damaging to both social and self-identity.

Research has highlighted that the general public often equate mental illness with violence despite the fact that people with mental illness are more likely to be victims of violence than perpetrators (Stuart, 2003). The stigmatised individual may be labelled as deviant or inferior and this is associated with negative stereotypes, some studies have shown the popularity of derogatory terms used by the general public to describe people with mental illnesses, for example, "crazy", "nuts" and "psycho" (Rose, Thornicroft, Pinfold, & Kassam, 2007). In an online survey of 596,712 respondents, from 229 countries; 70% percent of replies from developed countries felt that people with a mental illness were more violent (Seeman, Tang, Brown, & Ing, 2016). A UK survey in 2011 showed that 85% of respondents believed people with mental illness experience stigma and discrimination (The Health and Social Care Information Centre, 2012).

1.3.2 Stigma outcomes

Today, stigma towards mental illness is still widespread (Crisp et al., 2000). A global study measured stigma and discrimination through self-reports (the Discrimination and Stigma Scale; DISC) and interviews with 732 people in 27 countries (King et al., 2007). Findings suggested that stigmatised attitudes and discrimination are high across countries. Respondents frequently reported negative discrimination regarding making or keeping friends, keeping and finding a job, in intimate relationships and discrimination by family members.

There are many cultural considerations associated with stigma of mental illness, such as beliefs about its aetiology and societal expectations that need to be taken into account. For example, in Nigeria it is common for both physicians and the general population to attribute mental illness to supernatural causes (Ukpong & Abasiubong, 2010). In Asia, mental illness is highly stigmatised, families are ashamed of members if they have a mental illness and therefore delay seeking medical advice or avoid diagnosis (Lauber & Rössler, 2007). Thus it appears that mental illness can be associated with not meeting cultural expectations and sufferers have lowered self-worth and feel guilt at failing to meet family obligations (Hsiao et al., 2006). Therefore, beliefs about mental illness, and consequent stigmatising attitudes, vary from country to country and between ethnicity groups. For example, Jordanian women living in Australia described how their culture expected new mothers to not be sad as sadness was seen as indicative of inadequate parenting (Nahas & Amasheh, 1999).

Internal stigma is also high and has been identified in approximately a third of people with severe mental illnesses in Western countries (Crisp et al., 2000; West,

Yanos, Smith, Roe, & Lysaker, 2011). There are well-documented negative outcomes for individuals with mental illness because of external stigma, with consequences including, social exclusion, discrimination, and fewer life opportunities (Corrigan et al., 2011). Internal stigma has been linked to low self-esteem, reduced disclosure to healthcare providers, and hesitancy in seeking treatment (Corrigan et al., 2011; Rodrigues et al., 2013). Furthermore, perceived external stigma correlates with detrimental physical and mental health outcomes (Leach et al., 2015; Pascoe & Richman, 2009). Studies have shown that the effects of this stigma are further amplified by belonging to additional stigmatised groups, such as homosexuals and ethnic minorities (Alang & Fomotar, 2015, O'Mahen et al., 2011).

External stigma, perceived external stigma and internal stigma of perinatal mental illness could potentially contribute to stigma associated with disclosure. This thesis defines this as “disclosure stigma”; the anticipated negative judgement and/or anticipated negative behaviour towards the stigmatised individual if they were to disclose to others. Therefore, stigma could be a crucial component when an individual decides whether or not to disclose their symptoms of mental illness or distress. Indeed, when a mental illness such as depression can be concealable, many people choose to hide their illness as they fear being judged by others as responsible for being ill, losing their job, disapproval, being seen as “weak” or inferior, and labelled as mentally ill (Griffiths et al. 2006). Recently research has shown conflicting evidence regarding the impact of negative attitudes, anticipated discrimination and experienced discrimination on the rate at which people seek professional help and take treatment (Clement et al., 2015).

1.3.3 Applying stigma theory to perinatal mental illness

There are important considerations when applying theories of stigma to perinatal mental illness, including the concepts of “spoiled identity” and labelling. Goffman (1963) developed the notion of a “spoiled identity”; an individual’s identity that was discredited as a consequence of stigma. The undesirable characteristic taints the individual’s sense of who they are, how society views them and ultimately affects their feelings of self-worth. This damage to identity or a “spoiled identity”, can lead to the individual concealing their illness in an attempt to protect their social and self-identity.

Stigmatised individuals may want to appear “normal” and choose to hide symptoms and avoid disclosing diagnosis to others. Individuals can also be concerned with protecting their vulnerable identity from themselves, by avoiding disclosure to healthcare providers they can avoid a professional diagnosis. Receiving a diagnosis could mean that an individual has to accept their status as having a spoiled identity. A systematic review and meta-synthesis of 39 studies examining barriers to care in the antenatal and postnatal period revealed that some women avoided a mental illness diagnosis as they viewed it as a threat to their self-concept and the image they wanted to present to others (Megnin-Viggars, Symington, Howard, & Pilling, 2015). However, other studies have suggested that some women find a diagnosis beneficial, for example, qualitative interviews with 10 women with postnatal depression described how some felt relief when they were diagnosed as it allowed them to be ill without guilt (Hanley & Long, 2006)

Some women may take on the diagnosis of the illness meaning they have a “label”, for example, “depressed” or “schizophrenic”. This may also mean that their

identity becomes entangled with conceptions about what it means to have a particular illness and, in the case of perinatal mental illness, what it means for their identity as a mother with a mental illness (a detailed consideration of this can be seen in the next section).

Labelling theory can be applied to perinatal mental illness stigma, some researchers have indicated that many women with postnatal depression view the role of a “good mother” as incompatible with their illness (McLoughlin, 2013). For example, in an interview study by Bilstza et al., (2010), women often described their concern with being labelled with postnatal depression. They frequently reported that they felt the stigma of being labelled as a “bad mother” was worse than being labelled as depressed (p. 48). Women expressed how they did not want to be viewed by others as inadequate, this was often expressed as not wanting to “be seen as a failure” or “as being different from others” (p. 48). They described external and internal stigma as their own and others expectations of motherhood and how this reinforced their ideas of not fitting in with other mothers and guilt for feeling like they were a “failure as a parent” (p. 49). The two groups stipulated in labelling theory (“us” and “them”) could be applied to the identity of a “good mother” juxtaposed to the identity of a “bad mother”. The women in Bilstza et al.’s. study repeatedly explained that they felt the need to keep up appearances in order to show they were part of the “good mother” group.

1.3.4 Unique aspects of perinatal mental illness

Research into perinatal mental illness stigma suggests that perinatal stigma might differ from stigma associated with mental illness at other times of life. Women with perinatal mental illness have the stigmatised condition of a mental illness and

also the stigmatisation of being a mother with a mental illness. Some researchers have argued that some women believe society holds the belief that mothers with a mental illness cannot fulfil the role of mother (O'Mahen et al., 2015). This can be conceptualised as a "double stigma" (O'Mahen et al., 2015). There are specific cultural expectations of mothers, such as being caring, nurturing and an assumption that the ability to be a mother comes naturally (Beck, 2002, Bilstza et al., 2010). Some researchers have argued that society perpetuates the "myth of motherhood" that being a mother is characterised by complete fulfilment and joy (Buultjens & Liamputtong, 2007; Mauthner, 1999).

These pressures can all contribute to women's concerns that they would be labelled as a failed mother if they cannot live up to an unrealistic and idealised version of motherhood (McLoughlin, 2013). It can be deeply connected to how women believe they fulfil the expectations of others in their role as a mother, and women's concerns include others seeing them as a "bad mother", for example, some qualitative interviews with women reveal that they believe that some people think mothers with perinatal mental illness do not love their babies or even pose a threat to their babies (Bilszta, 2010; McCarthy & McMahan, 2008; Buultjens & Liamputtong, 2007; Patel et al., 2013). This could also include how women think the media portray mothers with perinatal mental illness, for example, news reports of extreme cases of perinatal mental illness and infanticide.

In addition to external pressures, women have their own expectations of becoming a mother and what it means to be a "good mother". They can experience distress when there is discrepancy between their anticipated and actual experience of parenthood, especially if their experience involves mental illness (Dennis & Chung-Lee, 2006, O'Mahen et al., 2015). O'Mahen et al. (2015) conducted 17 interviews

with women with postnatal depression as part of a larger online intervention study. Thematic analysis extracted themes regarding motivations and barriers to treatment adherence that contributed to a sense of loneliness. They identified six barriers to treatment, two of which are particularly relevant to perinatal mental illness stigma and include “unrealistic expectations of motherhood” and “double stigma”. The unrealistic expectations of motherhood theme outlined how some women felt disappointment that their hoped for experience of motherhood was marred by having postnatal depression. These women explained bonding difficulties, not feeling the anticipated excitement of motherhood, or meeting their imagined proficiency at parenting. Double stigma referred to women’s recognition of postnatal depression and included negative media representation which led to feelings of “secrecy” and “shame” (p. 87). Feelings of stigma resulted in mixed reactions to the online intervention, some women preferred the anonymity of the treatment and found that it reduced stigma while others found that concerns about stigma interfered with engagement with the treatment.

Other studies support O’Mahen et al.’s (2015) findings that suggest some women with perinatal mental illness feel that their illness affects their parenting ability and therefore contributes to stigma (Abrams & Curran, 2011; McLoughlin, 2013). The signs and symptoms associated with perinatal mental illness may be taken by society, and the stigmatised individual, as a reflection of them as a mother, for instance, the illness may cause women to experience feeling that they are not coping, are having bonding difficulties or thoughts of harming or leaving their child, thoughts of self-harm, suicidal ideation, feeling that their psychological problems had decreased time spent with their child, feeling at fault for risk of future mental illnesses and feeling like they are a burden to their family (Abrams & Curran, 2011;

Beck, 2002; Bilszta et al., 2010; Buultjens & Liamputtong, 2007; Byatt et al., 2012; Edge, 2006; Edwards & Timmons, 2005; Gardner, Bunton, Edge, & Wittkowski, 2014; Hanley & Long, 2006; Mauthner, 1999; McCarthy & McMahon, 2008; McLoughlin, 2013; Patel et al., 2013; Price & Bentley, 2013; Shakespeare et al., 2003). Such factors can all build up internal stigma; when women think less of themselves as a person and mother due to their perinatal mental illness. For example, if a consequence of perinatal mental illness presents as difficulty bonding with the infant, this can lead a woman to feel guilty that they are not a perfect mother or do not love their baby as they would like to (Tommy's, 2013).

In the case of perinatal mental illness, disclosure stigma is a woman's anticipation of the discrimination they feel they would encounter if they disclosed their feelings, symptoms or diagnosis to others. Potential consequences of disclosure to a healthcare provider include loss of custodial rights, hospitalisation, social service involvement and being judged as an "unfit" mother (Byatt et al., 2012; Edwards & Timmons, 2005; Hanley & Long, 2006). Also, women may believe that disclosure could lead to pharmacological treatment which they may regard as stigmatised especially if they are pregnant or breastfeeding, however, evidence is mixed (Battle et al., 2013; Patel & Wisner, 2011; Price & Bentley, 2013; Stepnauk, Fisher, Wittmann-Price, Posmontier, & Bhattakaya, 2013). Both external and internal stigma play a part in how a woman understands her identity as a mother and many describe perinatal mental illness as incompatible with being a "good mother" (Bilszta et al., 2010; Edwards & Timmons, 2005; McCarthy & McMahon, 2008; Shakespeare et al., 2003). However, it may be best to not view this as a static state, but rather a continuous one that may change throughout a mother's lifetime. It is possible that maternal identity may undergo a process, maturing as a woman

develops in her role as a mother alongside growing in understanding and coping with her illness. Goffman's (1963) idea of the "moral career" of a stigmatised individual may be applicable here. The moral career refers to the process of transformation the stigmatised individual's identity can undergo over time, especially as they learn more about their condition. Therefore, as a woman learns more about perinatal mental illness stigma, and identifies with others who have the stigma, there is the possibility for stigma reduction (McLoughlin, 2013). A woman may feel less stigmatised because she may realise she is not alone in her condition and may come to understand her diagnosis as an illness rather than a mark of disgrace (Kantrowitz-Gordon, 2013).

It is likely that women differ in how they deal with their identity, for instance, Abrams and Curran's (2011) in depth interview study of 19 women with low income suggested that they reconciled their symptoms with a positive maternal identity by framing their "authentic" identity as that of a good mother, namely one who is a competent parent and enjoys mothering. They associated their depression as an identity outside of this core identity, so they could regard themselves as a good mother with a mental illness. Conversely, some women in an online survey of 100 women with antenatal or postnatal depression were unable to reach this reconciliation, instead they accepted treatment for their illness in order to make themselves feel like a good mother (Patel & Wisner, 2011).

It is also important to consider individual differences that may bring additional complexities to how women negotiate their identity, for example low income, single motherhood, ethnicity, child illness and sexual orientation (Abrams & Curran, 2011; Alang & Fomotar, 2015; Gardner et al., 2014). Receiving a diagnosis of perinatal mental illness can compound an already existing label-based stigma of

ethnicity (Shakespeare et al., 2003; Edge, 2006). Hanley and Long's (2007) study showed that some women welcomed the label of having a mental illness because it meant they could justify withdrawing from employment, thus reconciling the additional stigma of having perinatal mental illness and belonging to a low socioeconomic group. Also, Black women with perinatal mental illness symptoms may be less likely to seek help from healthcare providers potentially because of their own stigma and also the stigma they may face from their community (O'Mahen, Henshaw, Jones, & Flynn, 2011). O'Mahen et al. (2011) measured mood and stigma of 532 pregnant women using two subscales of the Link stigma scale (Link, 1987; LSCS) that were modified to represent attitudes about depression (O'Mahen & Flynn, 2008). Black women in the study had more stigmatised attitudes to depression than White women, regardless of whether they had experienced depression, whereas, White women's stigma levels were associated with personal experience. O'Mahen et al. (2011) suggested that their findings supported previous research that stipulated individuals may be more aware of stigma if they have experienced or anticipated discrimination.

Disclosure stigma can result from either wanting to avoid judgment from others or reluctance to reveal a damaged identity as a mother. Receiving a diagnosis could mean women are faced with confronting their feelings and a new status of a "spoiled identity" (Bilszta et al., 2010; Goffman, 1963). Although, there is some evidence that obtaining a diagnosis can improve this conflict by identifying the condition as an illness rather than a reflection of parental capability (Edwards & Timmons, 2005; Hanley & Long, 2006). Thus diagnosis may externalise the locus of causality and therefore lessen feelings of guilt and shame.

In summary, both the perceived and experienced external stigma and internal stigma women experience contributes to their decision to disclose or not to disclose to a healthcare provider. Women may be concerned about healthcare provider attitudes towards them as a mother with a mental illness. This includes anticipated discrimination, such as appraising them as an inadequate mother. This can provoke concerns about consequences of disclosure, such as loss of child custody or social services involvement. Also, disclosing to a healthcare provider may mean that women receive a diagnosis. Some women may want to avoid a “label”, because it would further damage their self-worth and add to feelings of internal stigma. Stigma and mental illness can form a vicious cycle as stigma contributes to mental distress which can exacerbate mental illness symptoms and thus increase stigma.

1.4 The Internet as an adjunct to treatment

1.4.1 Internet interventions

Unfortunately, many women with perinatal mental illness fail to get the help they need despite it being available. One frequently cited reason for this is stigma (Dennis & Chung-Lee, 2006). The Internet could be a useful tool in helping women to access the help they need as they can use it anonymously thus avoiding any possible negative consequences associated with stigma (Rains, 2014). It might be the first place some women look for information and support when experiencing distress. The Internet could provide information on symptoms, risk factors and potential outcomes of untreated perinatal mental illness. This could help women self-diagnose and encourage help-seeking behaviour and disclosure to healthcare providers. The Internet could also provide self-help tools and peer support prior to treatment, or as an adjunct to treatment.

1.4.2 Online forums for stigmatised conditions

Online forums are online discussions where users can have conversations with others by posting and replying to messages. Online forums for mental health have seen a rapid growth in recent years, allowing individuals to receive, as well as offer, support from others who have or have had a similar health condition. They have potential to be an acceptable aid to people with stigmatised conditions, such as mental illness. Some research suggests that forums may help people cope with, or assist recovery from, various stigmatised or embarrassing conditions, such as HIV, irritable bowel syndrome and infertility (Chung, 2014; Malik & Coulson, 2011; Mo & Coulson, 2013). Research has largely relied on self-report measures, e.g. online surveys or observation of forum posts, for example, Malik & Coulson (2011) conducted an online questionnaire with open ended questions and used inductive thematic analysis to reveal the perceived benefits of using online support groups for infertility.

Explorative research suggests that forums offer users social support for a variety of stigmatised health conditions and opportunities to communicate experiences with others who share their illness, express emotions, gain a group identity, and possibly become empowered and diminish isolation (Bartlett & Coulson, 2011; Bauer et al., 2016; Malik & Coulson, 2008; Pendry & Salvatore, 2015). Benefits have also been reported by both active users (visitors who post on forums) and so called “lurkers” (visitors who only read forum messages and do not post). However, some evidence suggests lurkers may not benefit as much as active users (Coulson, 2015; Setoyama et al., 2011). It is estimated that most visitors are lurkers, with reports of between 45% and 90% of visitors lurking (Bishop, 2007; van Mierol, 2014).

There is less empirical evidence for the effectiveness of online forum use, however, some research suggests that long-term forum use may be associated with improved mental health. For example, a randomised control trial compared four groups; depression Internet support group, automated depression Internet training program, combination of the Internet support group and Internet training program, and a control group that had delayed access to an e-couch website after six months (Griffiths et al., 2012). The Internet support group and the Internet training program showed reduced depressive symptoms at six and 12 months compared to the control group, but not at three months.

Some theorists suggest that stigma can be reduced as people learn about it and identify with others with the same stigma (Goffman, 1963). There is some evidence that shows individuals who have contact with stigmatised individuals experience a reduction in previously held stigmatised beliefs (Thorncroft et al., 2016). For example, Couture and Pen (2003) reviewed 22 studies and showed that contact with individuals with mental illness reduced stigmatised beliefs of people with mental illness in both Western and non-Western populations. Thorncroft et al. (2016) conducted a narrative review of eight systematic reviews and 8143 quantitative studies and showed that interventions to reduce stigma through social contact only have short term effects. In particular, interventions that targeted individuals with mental illness self-stigma benefited from contact with others with mental illness.

Online forums could give women the unique opportunity to connect with others who they might otherwise be unable to find in their community or feel able to talk to face-to-face. Theoretically, using the Internet may protect stigmatised individuals' spoiled identity through anonymity, it may be easier for individuals'

who suffer with social isolation due to the barrier symptoms present, such as social avoidance and difficulties in face-to-face interactions (Berger, Wagner, & Baker, 2005, Wright & Bell, 2003). For example, Berger et al. (2005) conducted a US survey and showed that individuals with a stigmatised psychiatric illness are more likely to seek help online than those with non-stigmatised psychiatric illnesses (n=7014). However, a systematic review of 38 studies failed to show any effect of online forum use for peer-to-peer support on mental health and social support outcomes (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Eysenbach et al. (2004) noted that this did not necessarily indicate online forums have no effect, but rather pointed to a lack of robust evidence to show any significant effects. Overall, research indicates that forums may potentially benefit users with stigmatised conditions by reducing stigma, but more research is needed (Blank, Schmidt, Vangness, Monteiro, & Santagata, 2010).

1.4.3 Online forums for perinatal mental illness and stigma

There are many online forums for perinatal mental illness which are often popular, as indicated by their large number of visitors e.g. the website *Mumsnet* has a forum for postnatal and antenatal depression that displays hundreds of messages and displays how many replies and views each have had (<http://www.mumsnet.com>). However, there has been little research on forums for perinatal mental illness. Some research suggests postnatal mental illness forums may offer social support to women. Evans et al. (2012) conducted a directed content analysis of 512 posts on a forum for postnatal depression over six months. They analysed posts using the typology of social support (emotional, informational and instrumental) to explore women's experiences of postnatal depression. Findings revealed that posts primarily offered emotional support (41.6%) and then informational support (37.5%).

Instrumental support was much rarer (20.9%). Emotional support encompassed giving hope of recovery, providing a place to discuss issues honestly, and a resource of affection and empathy. Informational support was characterised by posters seeking and providing reassurance that their experiences of postnatal depression were valid and this often normalised symptoms. There were some “peer experts” that answered questions and provided experiential knowledge on coping strategies and treatment that frequently encouraged engagement with healthcare providers (p. 408). Posts also provided experiences of treatment, which was largely discussed in terms of medication.

Finally, instrumental support centred on practical ideas for coping with the pressures of childcare and promoted self-care. The forum was viewed by posters as a non-judgmental “sanctuary” where they could disclose “unspeakable” thoughts without fear of stigma (p. 407). This allowed a discussion of motherhood that included negative experiences which may have been difficult for women to talk about offline. There was no evidence that posts contained derogatory comments or supported harmful behaviour. Evans et al. (2012) concluded that this forum offered a safe place to support women with postnatal depression and more research is needed into the role of forums in assisting women recover and if there are any possible risks of use.

In another study, Alang and Fomotar (2015) conducted an online ethnographic and content analysis of a forum for lesbians with postnatal depression. The study aimed to identify the main purposes and perceived benefits of the group and explore lesbian mothers’ shared experiences. A total of 1421 posts were assessed on a daily basis over three months. Analysis comprised of a directed content analysis (posts were coded in accordance with the research questions) and conventional

content analysis techniques (posts were coded by more specific concerns and experiences). Analysis identified the function of the forum as a form of social support that included allowing women to disclose experiences and struggles with isolation and many used the forum to share experiences of coping with postnatal depression. Similar to the forum in the Evans et al. study, women appreciated this supportive environment with access to others who had similar experiences that validated their own feelings. Nearly 17% of message content discussed ways of coping with the illness. Themes from the content analysis suggested that this virtual community exemplified belongingness, strengthened self-esteem and sought to counteract social isolation.

Alang and Fomotar (2015) reported a range of specific concerns, including reluctance to seek treatment with three sub-themes; child well-being, public perceptions about motherhood abilities and stigma of mental illness. These sub-themes centred on feeling bad about themselves as mothers because they had postnatal depression. Some worried about how the treatment would impact their baby, for example, one woman worried that treatment might mean she had to go into hospital and leave her child. Some women had intense concerns regarding disclosure of their symptoms, they thought others would see them as unfit mothers and they would lose custody of their infant. Posts often challenged these anxieties and advocated that disclosure to healthcare providers was indicative of a good mother. Discourse strongly rejected that notion that having postnatal depression was a sign of being an unfit mother. Building on this, some women who were reluctant to seek treatment explained that they did not want to be labelled as having a mental illness.

There are additional complications for lesbians, firstly, the decision to reproduce is nearly always intentional and this may add additional pressures when

experiencing postnatal depression because motherhood was a planned and welcomed event. Secondly, women may have concerns over discrimination due to homophobia. There may be a double stigma of not just having a mental illness (“crazy” p. 30), but being a lesbian with a mental illness (“crazy lesbian” p. 30). Findings supported those of Evans et al. (2012) and showed that the forum provided a space for women to discuss negative aspects of motherhood including postnatal depression experiences, for example, suicidal ideation, not wanting to be a mother, trauma of childbirth and specific issues of being part of a sexual minority and having postnatal depression.

Kantrowitz-Gordon (2013) examined posts on a forum for postnatal depression to explore how women constructed their stories as “confessions”. They used this to see whether Foucault’s theory that confession is a common means to construct truth applies in Western society. They used discourse analysis from a social constructivist stance to analyse 102 posts over six years. Results suggested that women benefited from being able to share their experiences of depression through admitting online what they could not talk about or had no one to talk to about, offline. This comprised two key themes: the language of difficult confessions and discursive explanations of postnatal depression. The first theme described how women expressed feelings of incompetency as a mother, and frequently expressed feelings of shame and embarrassment as they unfolded their stories. The forum provided a platform to acknowledge symptoms that included thoughts of highly stigmatised behaviours, such as suicide or child abuse. A prominent feature of the storytelling involved the broken relationship between mother and infant. Women expressed distress at bonding difficulties; feeling hatred or indifference towards the

infant. The distress women experienced was often magnified by their disappointment at not meeting the expectations of motherhood.

The second theme regarded the different discourses women used to explain their depression. Interestingly, this included a discourse of “good mother” that extended women’s feelings of failure at being a mother. This self-critical discourse was characterised by concepts such as “good mother”, “bad mother”, “failure” and “guilt” (p. 879). They felt bad about wanting their life to go back to how it was before the birth, they felt inadequate compared to an idealised version of what it means to be a mother and sometimes blamed themselves for being ill. Many women attempted to repair their identity as a mother by giving examples of how they were trying to love their baby as they should. Biomedical discourse was another prominent discourse that extracted the blame for their illness onto physical or situational causes, such as hormones or poverty. This lessened guilt and self-stigma by externalising the aetiology of their illness and reconciled their postnatal mental illness identity with that of an idealised mother.

The above studies are the only ones to date that have explored online forums for postnatal depression and issues of stigma. The exploratory findings suggest that forums have the potential to benefit women through social support and challenging perinatal mental illness stigma. Forums may provide an acceptable and anonymous platform to discuss sensitive issues regarding stigma that would otherwise be difficult to do offline. Findings point to the possibility that forums encourage a discourse that enable users to negotiate the maternal identity and perinatal mental illness stigma online. However, research is still preliminary and would benefit from including analysis of other forums, interviews with users and quantitative measurement of forum use and stigma attitudes. Each of the three studies looked at

one online forum and had small samples, which limits how far findings can be generalised to other populations. Evans et al. (2012) and Kantrowitz-Gordon (2013) failed to clearly describe the role of the researcher in their studies which limits the conclusions. Future research needs to examine the potential of online forums for stigma reduction that has replicable methodology, multiple data collection methods, different and larger samples and a variety of analysis techniques.

Despite the potential benefits of online forum use, it is important to note that some recent research, on forum use for other health conditions, suggests online support groups may not challenge stigma enough to affect or change help-seeking behaviour (Chung, 2013). Also, recent research outlines some concerns regarding forum use, for example, it might be a form of social avoidance and enable excessive dependency (Chung, 2013; Lawlor & Kirakowski, 2014). Vulnerable people may be susceptible to addiction (Prizant-Passal, Shechner & Aderka, 2016) and forums may also enable negative behaviours, such as pro-anorexic forums (Chang & Bazarova, 2016). There have been very few documented negative outcomes for women who use perinatal mental illness forums. However, there has been very little research to date and some women are concerned that healthcare providers will not understand, or social services will become involved or take their baby away (McLoughlin, 2013), hence women are potentially vulnerable to posts that reinforce these anxieties. There is little research examining the potential of forum use to adversely impact healthcare decisions. Therefore, future studies should also consider if there are any potential disadvantages when engaging with forums.

In summation, there is very little research on forums for perinatal mental illness, but what is available provides some evidence that engagement with forums for perinatal mental illness could have the potential to reduce stigma (Alang &

Fomotar, 2015; Evans et al., 2012; Kantrowitz-Gordon, 2013). Forums may be a valuable resource for women who do not have others to talk to or feel unable to discuss highly stigmatised symptoms face-to-face. They could find relief from disclosing unspeakable feelings and knowing that others have similar feelings can validate and normalise their feelings. Women could benefit from the opportunity to anonymously discuss sensitive and highly stigmatised aspects of perinatal mental illness stigma, such as anxieties over child custody, bonding and the double stigma of being a mother with a mental illness. Women could also reconcile their identity as a mother with perinatal mental illness and resolve their disappointment of being ill compared to their anticipated experience of motherhood. Forum discourse may challenge stigma, provide strategies on coping with stigma, provide a safe place to test out disclosing symptoms and converse about stigma surrounding mental health and motherhood. Theoretically, these factors could reduce stigma and positively influence disclosure to healthcare providers, and consequently increase recovery rates. However, future work should consider potential disadvantages of forum use, such as posts that may discourage disclosure by describing negative experiences with healthcare providers.

1.5 Summary, Rationale and Aims

In summary, empirical evidence shows that perinatal mental illness is common and has many potentially detrimental outcomes for women and families if left untreated. Many women do not get the treatment they need to recover because there are barriers to care, in particular, stigma. Stigma is a severe disapproval of someone or group of people because they have a characteristic that is considered as highly undesirable and discrediting. Pregnant women and new mothers may believe others have stigmatised attitudes towards perinatal mental illness (perceived external

stigma), stigmatise themselves for having the symptoms or diagnosis (internal stigma) and may associate disclosing their symptoms or diagnosis with external and internal stigma (disclosure stigma).

Previous research into perinatal mental illness suggests that many women experience feelings of stigma and thus do not disclose, partially disclose, or are late in disclosing to healthcare providers. The Internet may be a more acceptable means of seeking information and support for stigmatised illnesses. Goffman's (1963) theory of stigma, in particular, the concept of a "spoiled identity" provides a useful framework to evaluate women's experiences of being a mother with a mental illness and applies to how they negotiate this online. There are many websites for perinatal mental illness and online resources with a high number of visitors. Online forums are increasingly popular and provide peer-to-peer support. There is theoretical support, and some preliminary, evidence that online forums for perinatal mental illness could affect the stigma some women with the condition experience. This could have important implications for increasing treatment uptake and recovery, as well as providing additional support. Forums could potentially influence perinatal mental illness stigma and thus promote disclosure to healthcare providers.

1.5.1 Research aims and objectives

The overall objectives of this thesis were:

1. To explore Internet resources for women with perinatal mental illness and how they are used by women

- 1.1 What information and resources are available for women with perinatal mental illness on the Internet?
- 1.2 How do some women with perinatal mental illness use Internet forums for perinatal mental illness?
2. To examine the relationship between Internet forum use, stigma and disclosure to healthcare providers
- 2.1 What are the experiences of stigma and disclosure for women who use online forums for perinatal mental illness? Are there any disadvantages of forum use?
- 2.2 Do women discuss stigma issues on Internet forums, and if they do, how do they conceptualise perinatal mental illness stigma through online communication?
- 2.3 Do women manage or reduce feelings of perinatal mental illness stigma through online forum communication?
- 2.4 Does online forum use affect levels of perinatal mental illness stigma and in turn promote disclosure of symptoms to healthcare providers?

These objectives were addressed through the research studies shown in Table 1.

Table 1. Overview of research questions and studies

Research questions	Study	Article	Chapter
2.2, 2.3	Meta-synthesis	1	2
1.1	Website review	2	3
1.2, 2.1	Interview	3	4
2.1	Thematic analysis	4	5
2.2, 2.4	Online survey (stigma scale)	5	6
2.3, 2.4	Online survey (mediation model)	6	7

Ethical approval was not required for the first and second projects. Ethical approval was given by The University of Sussex for the third project and by City, University of London for the final projects (see Appendix 4.2, 5.1 and 6.1), following the transfer of the PhD study to City, University of London. The following guidelines were adhered to; BPS (2006) Report of the Working Party on Conducting Research on the Internet: Guidelines for ethical practice in psychological research online, BPS (2009) Code of Ethics and Conduct, BPS (2011) Code of Human Research Ethics, BPS (2013) Conducting Research on the Internet: Ethics Guidelines for Internet-Mediated Research. The details on the procedures, measures and analysis methodology applicable to each study are outlined in each chapter. Further ethical considerations are documented in Appendix 5.2.

The website review formed the basis of up-to-date knowledge about what information and resources are available on the Internet by describing and rating website content. An interview schedule was designed from this knowledge to retrieve initial information about how some women were using Internet forums and revealed the potential for forums to challenge stigma. This qualitative approach was also particularly relevant in exploring the second overall research aim as it enabled detailed consideration of women's experiences of sensitive issues concerning perinatal mental illness stigma.

The interview study informed and led to the thematic analysis study that sought to expand understanding and develop the conceptual framework surrounding the nature of perinatal mental illness stigma and how women were negotiating their stigma online. This enabled the development of the concepts external, internal and disclosure stigma regarding perinatal mental illness. This conceptualisation was translated into a scale that demonstrated these aspects of perinatal mental illness

stigma as theoretical constructs and attempted to quantitatively measure this stigma. From this work, the final study was able to address the second research objective and test a model that hypothesised that perinatal mental illness stigma mediates the relationship between forum use and disclosure.

Conceptualisation of perinatal mental illness is considered and defined in each article. The meta-synthesis defines perinatal mental illness as depression, anxiety, and PTSD in the perinatal period and included studies that used women's own self-reported diagnosis (Article 1). The website review focused on postnatal mental illnesses, because at the time, antenatal mental illness information was largely absent on the Internet (Article 2). The qualitative interview and thematic analysis included women's own reporting of the professional diagnosis they received or how they regarded their own mental health (Articles 3 & 4). In the interview study, women were encouraged to use terms they felt appropriate to describe their condition and distress, this enabled them to explore their feelings in a way that was comfortable for them. This approach encouraged maximum disclosure to the researcher. Measures of depression anxiety using the Hospital Depression and Anxiety Scale (HADS) were included in the descriptive statistics. It was not possible to verify the present diagnosis of women who posted on the forum in the thematic analysis and was determined by information women disclosed in their posts. Women could post on the forum without a diagnosis or even consultation with a healthcare provider, this was important because research included a consideration of how women decided to disclose or not to healthcare providers.

Both the interview study and the thematic analysis allowed women to talk about their illness in their own terms and explore their own conceptualisation of perinatal mental illness. It was important to give women this freedom of expression

to ensure detailed information retrieval especially as research concerned issues of stigma and other potentially sensitive topics. The stigma scale and the mediation model studies (Articles 5 & 6) used self-reported perinatal mental illnesses including depression, anxiety, PTSD and women with a combination of these conditions. The Hospital Anxiety and Depression Scale (HADS) was chosen again as the measure for perinatal mental illness as it includes items for both depression and anxiety and was thought to be a better representation of symptoms than other measures such as the Edinburgh Postnatal Depression Scale (EPDS) which mainly accounts for depressive symptoms (Cox, Holden & Sagovsky, 1987). Classifying perinatal mental illness this way allowed for maximum coverage of the various types of perinatal mental illnesses to be included in the model.

2 A meta-synthesis of women's experiences of online forums for perinatal mental illness and stigma (Article 1)

Moore, D., Drey, N., & Ayers, S. A meta-synthesis of women's experiences of online forums for perinatal mental illness and stigma. *Computers in Human Behaviour* (submitted for publication).

2.1 Abstract

Background: Perinatal mental illness is a common health concern, but unfortunately many women do not seek help because of stigma. Forums may provide an acceptable place for women to disclose and converse about the stigmatised symptoms of perinatal mental illness and other stigma issues. The current study is the first to present a review of the current qualitative research on perinatal mental illness forums and stigma.

Method: A meta-synthesis was conducted to describe and interpret qualitative studies regarding forum use and perinatal 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 perinatal 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. Women in these studies may have benefited from having an acceptable and anonymous place to converse about stigma, and exchange social support, and thus enabled to negotiate their maternal identity. Notably, women might have been able to recover a positive identity as a mother with perinatal mental illness.

**The full text of this article has been
removed for copyright reasons**

3 A review of postnatal mental health websites: help for healthcare professionals and patients (Article 2)

Moore, D., & Ayers, S. (2011). A review of postnatal mental health websites: help for healthcare professionals and patients. *Archives of Women's Mental Health, 14*(6), 443-452. doi: 10.1007/s00737-011-0245-z

3.1 Abstract

Purpose The Internet offers an accessible and cost-effective way to help women suffering with various types of postnatal mental illnesses and also can provide resources for healthcare professionals. Many websites on postnatal mental illness are available but there is little information on the range or quality of information and resources offered. The current study therefore aimed to review postnatal health websites and evaluate their quality on a variety of dimensions.

Methods A systematic review of postnatal health websites was conducted. Searches were carried out on four search engines (Google, Yahoo, Ask Jeeves and Bing) which are used by 98% of web users. The first 25 websites found for each key word and their hyperlinks were assessed for inclusion in the review. Websites had to be exclusively dedicated to postnatal mental health or have substantial information on postnatal mental illness. Eligible websites ($n = 114$) were evaluated for accuracy of information, available resources and quality.

Results Results showed that information was largely incomplete and difficult to read; available help was limited and website quality was variable.

Conclusions The top five postnatal mental illness websites were identified for (1) postnatal mental illness sufferers and (2) healthcare professionals. It is hoped these

top websites can be used by healthcare professionals both for their own information and to advise patients on quality online resources.

3.2 Introduction

For many women and their families, pregnancy and birth are a time of excitement and great joy. Unfortunately, some new mothers suffer beyond the typical concerns of parenthood and experience varying degrees of antenatal and postnatal mental health problems. Studies show that 10-15% of new mothers are diagnosed with postnatal mental illnesses, and potentially 1 in 4 women may have significant distress without meeting criteria for a disorder (Baker, Kamke, O'Hara, & Stuart, 2009a; Czarnocka & Slade, 2000). There are many different types of psychological disorders associated with the postpartum period (Brockington, 2004). Historically, the majority of research has focused on postpartum depression (PPD), which has a prevalence of 10-15% (Baker et al., 2009a). However, there is now increasing evidence that anxiety disorders are also prevalent in between 3 and 43% of women in the postpartum period (Glasheen et al., 2010). Postpartum anxiety disorders can include generalised anxiety disorder, panic, obsessive compulsive disorder and post-traumatic stress disorder (PTSD) (Brockington, 2004). Both anxiety and depressive disorders are associated with negative impacts on women, their infant and families (Glasheen et al., 2010; Reissland, 2006; Burke, 2003). It is therefore essential that research continues to investigate new ways of treatment and education.

One issue that is relevant to treatment is how postpartum psychological disorders are conceptualised. First, it is important to note that there are no diagnostic categories specific to the postpartum period in the two main classification systems –

the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR American Psychiatric Association, 2000) or ICD-10 (WHO, 1993). The term postpartum or postnatal depression is often used by the general public and health professionals to describe the array of mood disturbances in the postpartum. Moreover, classifications of postpartum disorders can be confusing, as they can be co-morbid with each other and other illnesses. For example, studies show that most women with PTSD following childbirth also have depressive symptoms (Alcorn et al., 2010), and women with depression often have anxiety problems (Matthey et al., 2003). In addition, many women may experience debilitating symptoms synonymous with one or more disorders, yet fail to meet all the diagnostic criteria. For example, Czarnocka and Slade (2000) reported that 24.2% of their sample of mothers showed significant symptoms in one of the three main symptom clusters of PTSD. Therefore, potentially 1 in 4 women could be suffering mental distress after childbirth but might not be identified by healthcare providers because they do not fit criteria for a 'disorder'. The way in which postpartum psychological illnesses are classified therefore has implications for screening and treatment. Hence, the current paper uses the term postnatal mental illness to cover PPD, postpartum anxiety disorders, PTSD after childbirth and postpartum psychoses.

Indeed, there are other reasons women often fail to get the help or treatment they require. Despite increased awareness about postnatal mental illness, many women feel it still retains much of its stigma and consequently are less likely to report any negative feelings after birth and avoid treatment (Wisner et al., 2002; Shakespeare et al., 2003). Other barriers to reporting postnatal mental illness include concern about being regarded as a bad mother (McCarthy & McMahon, 2008),

symptoms being dismissed by healthcare providers and family and problems accessing services (Dennis & Chung-Lee, 2006). In light of this, it is important to consider whether postpartum interventions and treatments are regarded as acceptable by women. If the treatment is seen as acceptable then the patient is more likely to seek help and adhere to treatment offered.

Given the popularity and accessibility of the World Wide Web (WWW), it may be a viable and cost-effective way to offer information and help to women suffering various types and levels of postnatal mental illness, many of whom would not otherwise receive the treatment (Christensen & Griffiths, 2004). Indeed, evidence shows that web users who frequently search for health information for themselves tend to be women (Atkinson et al. 2009). Women can easily access information and self-help on postnatal illness while retaining their anonymity. Christensen and Griffiths (2004) found that increased knowledge of depression and interventions delivered via the Internet were associated with reduced depressive symptoms. Furthermore, many studies support the efficacy of online interventions (Andersson & Cuijpers, 2008; Barak et al., 2008) and online support for depression (Griffiths et al., 2009). The WWW could have the potential to help women self-diagnose, seek support and empower them to be an active participant in overcoming their condition.

The WWW is therefore potentially a valuable resource for women with postnatal mental illness in terms of providing them with information, support and occasionally online interventions. However, women and healthcare professionals need information on which websites are reliable. Research has shown that patients are more likely to trust websites recommended by their physicians (Griffiths & Christensen, 2006). The WWW is also a potential resource for healthcare

professionals in terms of building knowledge of postnatal mental illness, accessing screening and treatment skills. However, health information on the WWW tends to be unevenly dispersed and users can struggle to find, understand, and use the information (Benigeri & Pluye, 2003). Research on the quality of information on depression is conflicting, but there is a general consensus that more evidence-based information and advanced tools for assessing websites are needed (Griffiths & Christensen, 2000).

Research into the quality of websites for postnatal mental illness is extremely limited. Heringhausen and Montgomery (2002) selected four websites on PPD for review that they regarded as the best resources available for healthcare professionals. All websites were reported as easy to navigate, up-to-date, readable, informative, and had unique features to help consumers and healthcare professionals. Summers and Logsdon (2005) found that Google listed 83,600 websites when the term “postnatal depression” was entered. This term was entered into 11 search engines and the first 10 websites were assessed for inclusion. Thirty-four of the 36 websites found were assessed for content, technology and readability. Nearly a third of websites contained an unacceptably small quantity of information on postpartum depression and only 14.7% provided more than 75% accurate information as assessed by the web depression tool (WDT). Moreover, 11.8% of websites included misleading information, such as advocating herbal treatments over medical care. The technology of websites was generally poor with out of date links, poor graphics, no references and disorganised or overwhelming information. The Flesch-Kincaid Grade Level score found that all websites had eight-grade or higher readability. This means that for many users information would be difficult to comprehend. This study is the most comprehensive review of websites for PPD to date. However, websites

were assessed only for information on depression and not other types of postnatal mental illness. The rapidly expanding nature of the Internet also means many more websites are likely to have been created since this review in 2005.

The WDT comprises of 33 content questions with yes or no answers, for example, “Depression is treatable” and 11 technology questions on a scale from not applicable to strongly agree, for example “the information contained in the site is presented in a clear manner”. As Summers and Logsdon note, the WDT has serious shortcomings when evaluating web-based information specific to postnatal mental health. To date, there is no web tool that measures postnatal mental health sites specifically for postnatal mental illness information. This study aimed to develop a new rating system using evidence-based research and current thinking on postnatal mental illness. Furthermore, both accuracy of information and technology of sites were considered separately, unlike the WDT that adds scores together. This study extends the work of Summers and Logsdon (2005) by (1) carrying out a more recent review of websites and (2) using a more extensive, multidimensional rating scale.

In conclusion, there is a need for an up-to-date, systematic review of websites on postnatal mental illness that uses clear rating criteria and is evidence based. Also, little is known about self-help, online support services and resources for sufferers and this could be a useful adjunct to treatment. This study therefore conducted a systematic review of websites on postnatal mental illness. Information specific to postnatal mental illness was evaluated including symptoms, risk factors and impact of the illness. In addition, the study looked at screening and treatment resources for healthcare professionals and support services, self-help and further resources for mothers. Website technology was rated on attributes considered to be important for usability and accuracy. They were *authority*, *contact-ability*, *up-to-date*, *navigation*,

presentation, advertisements, and accessibility (Kapoun, 1998). Results provide the top five websites recommended for (1) postnatal mental illness sufferers and (2) healthcare professionals.

3.3 Method

To identify relevant websites, a search of the WWW was conducted using the top four search engines (Google, Yahoo, Ask Jeeves and Bing) which are used by 98% of web users (SEO Consultants Directory, 2009). The key words “postnatal depression”, “postnatal illness”, “postpartum depression” and “postpartum illness” were entered into each search engine. The first 25 websites found for each key word and their hyperlinks were assessed for inclusion in the review.

Inclusion criteria were that websites had to be exclusively dedicated to postnatal mental health or have substantial information on postnatal mental illness (defined as >500 words). Blogs were excluded from review as they are typically maintained by one individual presenting an online diary. Of the 117 websites that met criteria for assessment, two had expired and one was under construction. This resulted in 114 websites being available for review. Websites were evaluated between November 2009 and April 2010 for accuracy of information, available help and website quality. All websites were reviewed again at the end of the evaluation period to check for updates. Five websites were noticeably different in data or presentation and were rated again.

3.3.1 Measures

Rating scales were devised to measure accuracy of information, available resources and quality of websites. These are described below and given in full in Appendix 3.1.

3.3.1.1 Accuracy of information

Information on symptoms, risk factors and impact of postnatal mental illness was assessed using a combination of DSM-IV-TR (American Psychiatric Association 2000), existing high quality postnatal mental illness websites (www.step-ppd.com) and current literature on postnatal mental illness. In addition to DSM-IV-TR criteria for major depressive disorder, the STEP_PPD website lists symptoms specific to postnatal mental illness. A total score for information was calculated (range 0 - 76) on the basis of the subscales below. Means of subscales were used to determine the frequency and distribution of information.

Websites were scored for information presented, with three subscales: (1) symptoms, (2) risk factors and (3) impact. *Symptoms* examined whether information was given about common symptoms of depression, anxiety, puerperal psychosis and post-traumatic stress disorder. Websites that listed a symptom scored 1 point per symptom with a range of 0-15 for depression, 0-6 for anxiety, 0-7 for puerperal psychosis and 0-2 for post-traumatic stress disorder. Thus, the range for all symptoms was 0-30.

Risk factors comprised of psychosocial, medical history and additional considerations in predisposition to postnatal mental illness. Websites that listed a risk factor scored 1 point per risk factor with a range of 0-12 for psychosocial, 0-8

for medical history and 0-6 for additional considerations. Thus, the range for all risk factors was 0-26.

Impact was divided into mother, infant and partner/family. Websites that listed an impact scored 1 point per impact with a range of 0-19. Impact on mother ranged 0-9, impact on infant ranged 0-5 and impact on partner/family ranged 0-5.

Treatment and screening information was recorded as a simple yes/no as the majority of websites had limited or no information. In this area, websites that had inaccurate or unsafe information that advocated alternative treatments over medical help were scored negatively (-1).

Additional resources for healthcare professionals was noted yes/no. For websites to be included in top ranking for healthcare professionals they had to include correct information on *treatment, screening* and *additional resources*.

Further points of interest were noted as a yes/no, such as, encouragement to seek professional help, assurance of recovery, prominent information on what to do if experiencing thoughts of harming themselves or their infant, prevalence, and recognising that fathers can also experience postnatal mental illness.

Readability was assessed using the Flesch-Kincaid Grade Level score for each website. This is a widely used, reliable measure of the literacy level needed for a person to understand a specific text. The first paragraph of the website homepage was imported into Microsoft Word. Flesch 2.0 for windows was used to assess the text for reading age (Flesch 2007).

3.3.1.2 Available resources

Websites were also scored on the number of support resources offered for mothers and comprised of *self-help tools for mothers*, *support for mothers* and *additional resources*. *Self-help tools for mothers* refers to self-help information for mothers, such as how to seek help, letters to doctors and coping strategies. Websites were awarded 1 point for each tool and scored out of 16. *Support for mothers* referred to online and offline support and included email counselling, helplines and group meetings. *Additional resources* were classed as any other resource that might assist mothers and included links, book reviews and leaflets. These categories were compiled through an initial assessment before the review commenced. Any extra tools, support or additional resources that were observed during the review were added to the criteria. Subsequently, all previously reviewed websites were re-assessed on this criterion.

3.3.1.3 Website quality

Websites were rated on website quality, examining attributes important to usability and accuracy. There were seven subscales; *authority*, *contact-ability*, *up-to-date*, *navigation*, *presentation*, *advertisements*, and *accessibility*. *Authority* of the site was scored according to whether the creators of the websites were specified or not, with 1 point if websites acknowledged site creators and 0 for non-specified. *Contact-ability* referred to whether users could contact the site owner. Websites scored 1 point if contact details were presented.

Up-to-date referred to the website being maintained regularly; websites were scored on working links, date of information and cited sources. Websites scored 1 if

all links worked. When information was dated on most pages the site scored 1. When sources were cited websites were awarded 1 point.

Navigation referred to the ease with which users could navigate a site.

Websites with a clear index on the home page that linked to all pages on the site were awarded 2 points. Websites that were relatively easy to navigate, but needed several clicks from the home page to access all pages scored 1. Websites were rated poor and scored 0 when it was very difficult to navigate the site, due to no index, confusing or hidden links, or requiring the viewer to use the search option to find all the information.

Presentation referred to the visual presentation of the website. Websites with clear text, uncluttered and a picture on most pages were awarded 2 points. Mediocre websites where information was well presented, but less clearly than top websites and had little if any pictures scored 1 point. Poor websites that were confusing with too much information on a single page, had disorganised layouts and no pictures scored 0.

Advertisements can affect *navigation* and *presentation* and also distract or mislead viewers. Two points were awarded to websites without any advertisements, 1 point to mediocre websites that had relevant advertisements and poor websites had advertisements that were irrelevant to postnatal mental illness or made it difficult to navigate and/or in the way of the text scored 0.

Accessibility referred to how much of the site was readily accessible to users. Websites that required no fees or special software to access information were awarded 1 point.

To ensure the reliability of ratings, approximately 10% of websites were rated by an independent researcher. Using a random number generator programme, 11 random websites were selected and rated using the same rating system and instructions (Daniels, 2010). A kappa test showed a moderate agreement ($\kappa=0.46$, $p<0.001$). Discrepancies between ratings were largely due to poor site navigation which meant the independent rater missed information on some sites. In some cases, whole sections of sites were missed as there was no link from the “home page”, instead, sections were found by following various hyperlinks on different pages or using the search feature. There were also minor discrepancies due to raters rating sites at different times.

3.4 Results

The most frequently occurring sites using Google were www.pni.org.uk, www.apni.org and www.patient.co.uk.

3.4.1 Accuracy of information and available help

Figure 3.1 shows the distribution of scores for information on symptoms, risk factors and treatment given by websites. Seventy-five percent or more of sites reported ≥ 9 symptoms (range of 0-26, $M=13.05$, $SD=5.71$). Most frequently mentioned symptoms on sites were depressive ($M=8.65$, $SD=3.55$) with tearfulness being reported by 82.5% of sites and sleep disturbances reported by 76.3%. There were noticeably fewer instances of anxiety symptoms being described ($M=2.19$, $SD=1.48$) or puerperal psychosis symptoms ($M=2.03$, $SD=2.01$). The majority of sites (86.8%) did not mention PTSD symptoms ($M=0.18$, $SD=0.51$).

Seventy-five percent or more of sites listed ≥ 2 risk factors ($M=4.73$, $SD=3.28$). Only one site included all the risk factors and 19.3% of sites had none.

The most common risk factors listed were personal or family history of psychiatric disorders (66.7%), lack of social support (62.3%), and recent stressful life events (53.5%). Psychosocial factors accounted for most results ($M=2.74$, $SD=2.07$), closely followed by medical history (1.75 , $SD=1.52$). Additional risks were largely absent with 83.3% of sites not reporting any ($M=0.24$, $SD=0.72$). One website was a notable outlier that covered a lot of risk factors, www.postpartumdads.org.

Impact was the least occurring type of information with 38.6% of sites failing to report anything about the impact of postnatal mental illness on mothers, infants or the family ($M=1.95$, $SD=2.36$). One or more impacts on the mother was recognised by 43.9% of sites ($M=0.92$, $SD=1.31$); 30.7% of sites recognised ≥ 1 impact on the infant ($M=0.61$, $SD=-1.08$); and 28.9% of sites recognised ≥ 1 impact on the family ($M=0.41$, $SD=0.75$). The most frequent impacts mentioned were delayed infant development of cognitive skills, social skills, and expressive language (26.3%) and increased instability in marital and family relationships (20.2%). Outliers for impact were most notably www.mededppd.org, www.birthtraumaassociation.org.uk and www.medicinenet.com (see Figure 3.1). Overall, the range of information given by websites was low. Total score for information was the sum of symptoms, risk factors and impact and had a possible range of 0-76. However, actual range observed was 0-40 ($M=19.73$, $SD=8.39$).

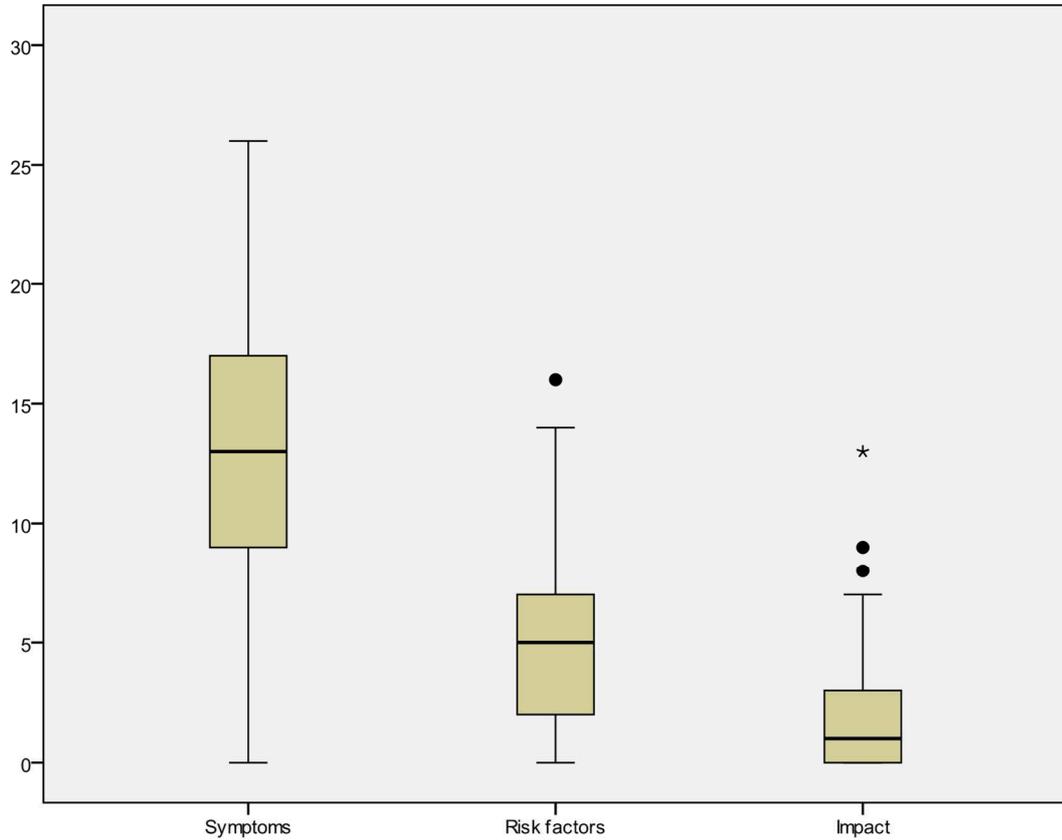


Figure 3.1 Boxplots for information on postnatal mental illness symptoms, risk factors and impact

A range of help was provided for postnatal mental illness. These included 15 different types of tools for mothers (e.g. screening tests, how to access medical notes, advice, relaxation, coping strategies), 8 support services (e.g. forums, chat rooms, telephone helplines, support groups, home visits) and 9 additional resources (e.g. links, downloads, podcasts, book recommendations, information leaflets). Full details of tools found are given in the appendix (Appendix 3.1). The range and median number of tools provided by websites is shown in Figure 3.2. In *tools for mothers*, $\geq 75\%$ of sites reported ≥ 2 tools for mothers out of 16 ($M=3.10$, $SD=2.31$). The predominant tool was standard self-help (58.8% of sites). Outliers were

www.postpartumstress.com, www.patient.co.uk and www.panda.org.au. In *support for mothers* $\geq 75\%$ of sites offered ≥ 1 support out of 8, with 54.4% having 0 services (M=0.89, SD=1.20). Telephone support was the predominant support (28.9%). In *additional resources*, $\geq 75\%$ of sites offered ≥ 1 resources out of 10 (M=2.08, SD=1.5), with *links* being the most frequent (59.6%). Total score for available help was the sum of mothers' tools, mother support and additional help (M=6.06, SD=3.65). There were two outliers, www.patient.co.uk and www.panda.org.au.

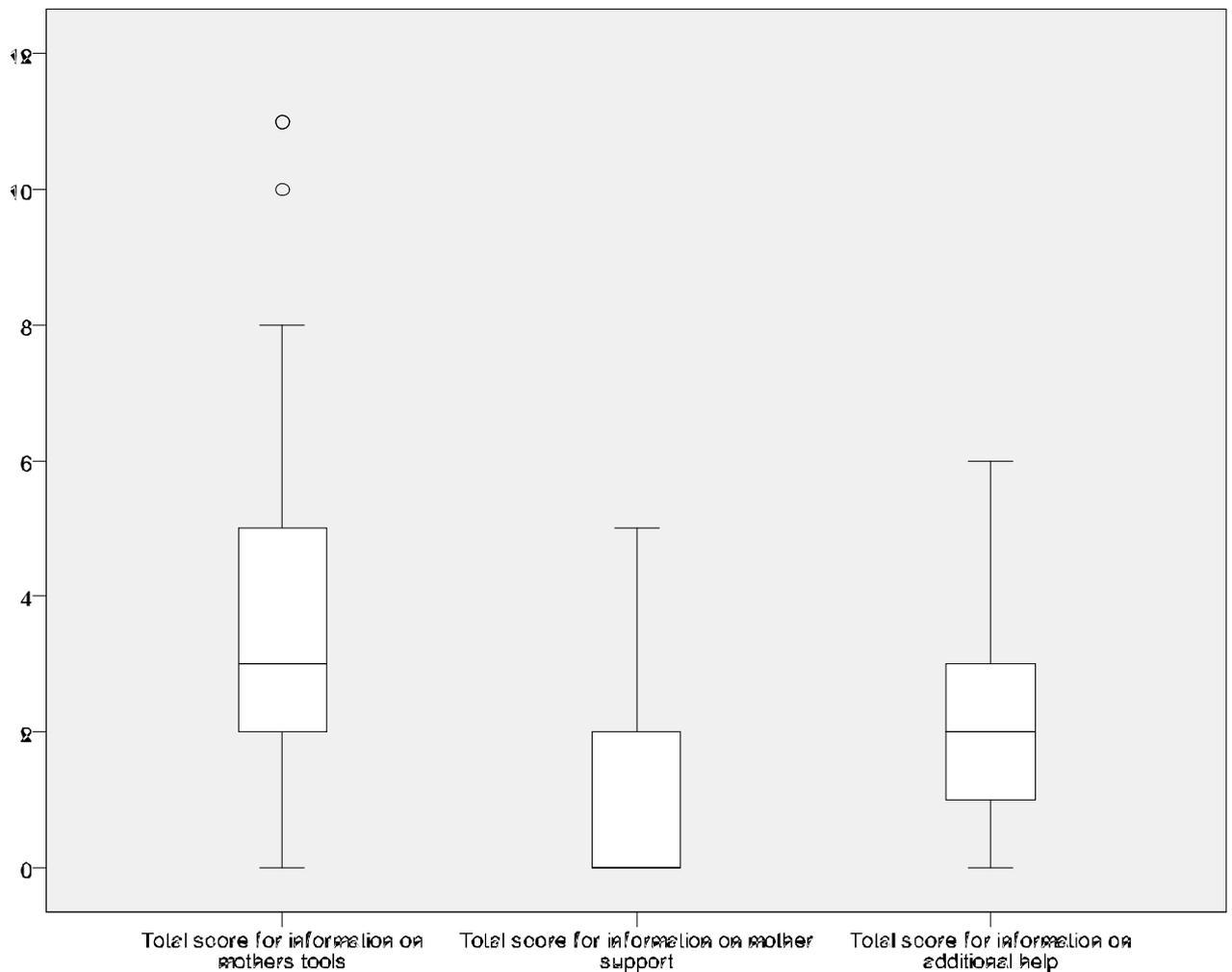


Figure 3.2 Boxplots of self-help tools, support and additional help offered by websites

3.4.2 Website quality and additional considerations

Most sites scored high on website quality, *authority*; 91.2%, *contact-ability*; 98.2%, *navigation*; very good 56.1% (mediocre 28.1% and poor 15.8%), *advertisements*; very good 67.5% (7% adverts and 25.4% inappropriate/in the way) and *accessibility*; 91.2%. Sites tended to score lower on *Up-to-date* quality; 17.5% (links working 60.5%; info dated 53.5%; sources cited 28.9%); *presentation*; very good 27.2% (mediocre 57% and poor 15.8%). The top 25% and 50% of sites scored 9 out of 11 (M=8.18, SD=1.93). Outliers with poor quality were www.mededppd.org and www.babyworld.co.uk.

Many sites had information on treatment (71.9%); 16.7% had screening information and 22.8% had additional resources for healthcare professionals. Only one site had inaccurate information (www.answers.com), which was due to user-generated content. Many sites encouraged users to seek professional help (80.7%) and assured users of recovery (75.4%). However, few had prominent information on what to do if thinking of harming self or infant (9.6%). Eighty-four percent of sites stated the prevalence of postnatal mental illness but this ranged from 10 to 50%. Two sites were aimed exclusively at fathers who had postnatal mental illness, or whose partners had postnatal mental illness (www.postpartumdads.org and home.comcast.net/~ddklinker/mysite2/Welcome_page.htm). These were separate sites but had largely identical information. Reading level ranged from 5.54 to 24.08 and had a mean of 12.86 (SD 4.71). Only 10.5% of sites had a reading level of 8 or below as recommended by health education experts (Freda, 2004).

3.4.2.1 Top websites

To be rated as a top website for healthcare professionals, sites had to rank in the top 25% for information, top 25% for website quality and also include information on assessment, treatment and additional resources for healthcare professionals. Only two sites met these criteria, so sites without assessment, treatment or additional resources were then included. To be rated as a top site for women suffering with postnatal mental illness, websites had to rank in the top 25% for information, website quality, tools for mothers, support for mothers and additional resources. Top websites are given in Table 3.1.

To check the reliability of website rankings, results were scored again with slightly different criteria, where presentation was given a stronger weighting. Results showed only a small variation from the top websites initially identified thus lending support to the validity of the rating scale (see Appendix 3.2).

Table 3.1 Top five websites for healthcare professionals and mothers with postnatal mental illness

	Healthcare professionals	Mothers with postnatal mental illness
1	www.postpartum.net	www.panda.org.au
2	www.postpartumhealthalliance.org	www.hapis.org.uk
3	www.babybluesconnection.org	www.postpartumhealthalliance.org
4	www.postpartumsupport.com	www.postpartum.net
5	www.postpartumeducationandsupport.com	www.pnsa.co.za

3.5 Discussion and conclusion

This review identified over a hundred websites on postnatal mental illness, although the content and quality of websites varied widely. Information on most websites was incomplete and focused on symptoms, rather than risk factors or impact. Few websites had tools, support or additional resources for mothers. Many websites had information on treatment, but it was generally superficial. Moreover, websites infrequently presented screening and additional resources for healthcare professionals. Most websites assured users of recovery and encouraged seeking medical help, nonetheless sites rarely had prominent information on what the user should do if they have thoughts of harming themselves or their infant.

Half of the websites reviewed were of good technological quality, but not always good for information or support services. There were many useful websites on postnatal mental illness, but no one website was found that covered everything i.e. accurate and detailed information, support and website quality. This study highlights those current websites that would be most useful for healthcare professionals and sufferers. Healthcare professionals can use the recommended websites to increase their understanding of postnatal mental illness and advise patients on quality online resources.

Information was often incomplete and tended to be about symptoms, predominantly depressive symptoms, such as tearfulness. Coverage of other symptoms of anxiety, puerperal psychosis or PTSD was minimal. This could reinforce the misconception that postnatal mental illness is solely depression or simply an extension of the “baby blues”. Information for healthcare professionals

and women self-diagnosing should also present anxiety and PTSD symptoms which also affect many sufferers. Accurate information on all symptoms is essential for healthcare professionals screening for postnatal mental illness and sufferers and their families deciding whether to get help.

Information on risk factors and impact could help with screening and prevention of postnatal mental illness. Unfortunately, websites did not commonly include information on risk factors and this could have repercussions for antenatal populations looking for information on prevention. Impact was even more infrequent, which means websites are failing to inform users of the consequences of untreated postnatal mental illness. For example, information on the detrimental effect of postnatal mental illness on the mother, infant and family may make women more likely to seek help. Similarly, the level of resources for healthcare professionals was poor, information on treatment was generally superficial and screening and additional resources were infrequent. Encouragingly, most websites assured users of recovery and encouraged seeking medical help.

Websites often presented basic information on self-help. This type of self-help was usually advice on self-care e.g. sleep whenever possible, eat healthily, exercise, and rest. There were some sites with potentially more useful information - these provided practical help and tools for mothers to actively tackle their illness. Practical help included online tests, letters to healthcare professionals, how to gain access to/understand medical notes, what to say to healthcare professionals, how to seek help, tips for family and prevention. Other tools included relaxation techniques, coping strategies and positive thinking. Future research should explore if and how such tools help women. For example, research could examine how women use true stories, myths of motherhood and stigma information. Research could also explore if

and how information on the myths of motherhood help women develop a more realistic idea of what a “good mother” is and what role information on stigma plays in encouraging women to seek professional help and help from friends and family.

Nearly half of websites offered one or more support services, with telephone support predominating. Referrals, home visits, personal messaging and chat were largely absent. Nearly a quarter of websites offered group meetings and a few offered forums and email/letter support. Online support was mostly run by volunteers from professional and personal postnatal mental illness experience backgrounds. Given the disabling nature of postnatal mental illness, the WWW has the potential to inform and support sufferers in their own homes, provide anonymity and is readily accessible. There is a striking need for more online support, although one obstacle is cost. During the study one site stopped their services due to lack of funding. However, given the cost of postnatal mental illness to the health service, the WWW has the potential to be a cost-effective means of treatment. Further research is needed into the efficacy of online tools and support.

Many websites scored high on website quality, but were not always accompanied by high quality content. Some websites that scored highly for information and resources had to be excluded from recommendation due to poor website quality. For example, MedEdPPD had outstanding information and unique multi-media resources for healthcare professionals, including slide libraries, patient videos, interactive case studies, screening tools and teleconferences. However, it scored exceptionally low for website quality. Interestingly, the site was divided into two sections; professional information and mothers and others. The ‘Mothers and others section’ would most likely be confusing and discouraging for sufferer’s due to poor navigation, presentation, some dead links and advertisements that hinder use.

The professional section had easier navigation, but still scored poorly on quality. Despite not being recommended on the basis of poor quality, healthcare professionals who do not mind overcoming the technology difficulties could benefit from its features and resources. Future research should examine the purpose of sites and their intended audience.

Another site that could have been in the top five was STEP_PPD, the site used for its up-to-date evidence based knowledge of postnatal mental illness and top-quality website technology. The site did not meet criteria as it did not present in the search engine results. In fact, further investigation showed it was not present in the first 60 pages of Google search when the search terms were entered. However, the site had outstanding information and resources for healthcare professionals. If the creators have not already done so, it is recommended that they register their site with the top search engines, ask similar websites to link to their page, and write articles for other websites that would provide a link back to their site to increase hits. Search Engine Optimisation (SEO) should also be considered. Search engines determine the results of a search based on the relevance of pages to the search terms entered. SEO means that to optimise the volume of traffic a site gets, namely by presenting in the top results of a search, sites have to register relevant keywords.

Summers and Logsdon found 83,600 websites when entering “postnatal depression” into Google search. The same search in this study yielded 1,360,000 results. Therefore, the Internet and interest in postnatal mental illness has grown considerably. Nevertheless, the findings of the present review broadly confirm Summers and Logsdon’s findings that information was incomplete and had problems with technology. Interestingly, Postpartum Support International (www.postpartum.net) was one of the top-rated websites in both Summers and

Logsdon's study and the current review. Furthermore, in the present review only one site presented misleading information compared to four in the Summers and Logsdon study. Further research into sufferer's experiences of using the Internet and website resources will reveal if this increased choice is helpful or makes searching and choosing websites even more daunting.

The recommended reading age for health information for the general public is 13-14 years, yet 89.5% of the websites exceeded this (Freda, 2004). Indeed, the majority of websites required the reader to have college graduate or higher literacy skills. These results have striking implications in that many readers would find these websites incomprehensible.

Before drawing conclusions, a number of limitations must be considered. The first is that the WWW is constantly changing and expanding (Berland, 2001). Therefore, this review provides information on websites that are likely to change over the next few years. Recommendations of top websites may therefore date quickly and regular updates will be necessary. Related to this is the second limitation, which was the moderate inter-rater reliability for ratings of websites. This was mostly due to poor navigation of some sites and minimal attribution to websites being further developed or modified in the time between the researchers and the external rater evaluating them.

Other minor limitations are that websites were scored for support services offered, but the quality of these services was not investigated. Also, the country of origin was not considered in scoring and some support services are area specific. Sponsored articles, such as information that promoted drug companies, were not accounted for. Only the first 25 results from the Internet search were included and

these results are based the algorithms used in the search engine and are thus influenced by the previous searches made on the computer. This means that search results will differ between users. This study tried to minimise any search bias by using a “neutral” public computer. However, it should be noted that women using the Internet may access a variety of different sites that may not be included in this study. Future research should address these limitations and provide a detailed account of services offered and how users utilise website features. For instance, there has been no investigation into the search terms mothers with postnatal mental illness use or how the use of search engines might vary with demographics.

Research in the future using the web tool we developed would be advised to address other considerations in its refinement. Given that there is little research supporting the efficacy of using online support, should a measure of whether a website encourages user to access local services over Internet resources be included? Can sites be scored specific to symptom severity and advice offered? How should sites that are interact be measured? What are important features of sites that address antenatal mental health or perinatal mental health as a whole? Would it be helpful to list symptom-specific sites, i.e. for PTSD? Furthermore, it would be interesting to compare the WDT and our rating scale.

The strengths of this review are that it examined a large sample of websites, scored information specific to postnatal mental illness, and was the first to examine available help for sufferers and healthcare professionals. The top five websites for healthcare professionals and sufferers have been recommended. Key findings were that information was largely incomplete and difficult to read, available help was limited and website quality variable. Websites need to be created with accurate and

more detailed information, support and website quality. These websites should also be constructed around knowledge of how sufferers use web resources.

4 Virtual voices: Social support and stigma in postnatal mental illness Internet forums (Article 3)

Moore, D., & Ayers, S. (2016). Virtual voices: Social support and stigma in postnatal mental illness Internet forums. *Psychology, Health and Medicine*, 1-6. doi: 10.1080/13548506.2016.1189580

4.1 Abstract

Many women with postnatal mental illness do not get the treatment they need and this is often because stigma prevents disclosure. The purpose of this study was to explore online social support for postnatal mental illness, how women experience stigma and potential disadvantages of using Internet forums. Interviews were conducted with fifteen participants who had suffered postnatal mental illness and had used forums. Systematic thematic analysis identified common themes in relation to social support, stigma and disadvantages of using forums. Most women felt they benefited from visiting forums by developing a shared understanding and discourse about their illness. Findings suggest future research should investigate if women benefit from using online social support provided by forums, if use challenges stigma and further explore potential concerns about using forums.

4.2 Introduction

Postnatal mental illness is a global health concern with well-documented negative effects of postnatal mental illnesses on the infant and mother (Almond, 2009; Letourneau et al., 2012). The most common disorders are depression and anxiety disorders, which affect between 10 and 20% of women (Ayers & Shakespeare, 2015). Stigma can delay help-seeking and many women feel postnatal mental illness is stigmatised and do not want to be seen as a “bad mother” and this is often cited as a barrier to care (Dennis & Chung-Lee, 2006; McLoughlin, 2013; Weiss, Ramakrishna, & Somma, 2006). Stigma can be external or internal. External stigma is the extreme disapproval of a person or a group of people due to a characteristic that is considered abnormal or highly undesirable by society (Goffman, 1963). Internal stigma occurs if the stigmatised individual agrees with the external stigma and applies the negative appraisal to themselves thus internalising the stigma (Corrigan, Rafacz, & Rüsçh, 2011).

Online social support via forums could offer an opportunity for stigma reduction through education and identification with other people with the same stigma (Crabtree, Haslam, Postmes, & Haslam, 2010). Reduced stigma correlates to increased help-seeking behaviour often through increased disclosure, normalising, and framing the problem as an illness (Clement et al., 2015; Makkarala, O’Brian & Siegel, 2016). There are hundreds of websites offering information on postnatal mental illness and some provide forums (Moore & Ayers, 2011). Some research suggests that women may benefit from the social support from forums for postnatal depression (Alang & Fomotar, 2015; Evans, Donelle, & Hume-Loveland, 2012). Furthermore, some research suggests that women may overcome stigma by posting on forums and this in turn leads to disclosure to healthcare professionals

(Kantrowitz-Gordon, 2013, Moore, Ayers & Drey, 2016). Sometimes forums may provide misinformation or enable social avoidance (Chung, 2013; Lawlor & Kirakowski, 2014). This study aimed to explore women's experiences of social support and stigma and possible disadvantages when utilising a forum for postnatal affective disorders.

4.3 Method

A qualitative study using semi-structured interviews to explore women's experience of using forums when they had postnatal mental illness. Women were recruited by advertising on parenting websites and inclusion criteria included; self-reported postnatal distress, they had used forums for social support and were a UK resident. There was no inclusion criteria for number of children or time since birth to maximise the sample. The interview schedule was designed to explore forum use and experience of postnatal distress (see Appendix 4.1 for the interview schedule). Current symptoms were assessed using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Ethical approval was acquired from the University Research Ethics Committee (Appendix 4.2). Interviews were conducted between 07/2011 and 12/2011 and lasted between 30 and 100 minutes.

Transcripts were analysed using thematic analysis to identify the main themes emerging from the interviews (Braun & Clarke, 2006). Transcripts were coded by the first researcher in collaboration with a senior researcher (SA) and themes were generated and defined in relation to the research aims. Themes were then reviewed and refined with the senior researcher to create a coding schedule. The coding schedule defined each theme, provided notes on how to identify when the

theme occurred and gave examples. All interviews were then coded again using this coding schedule. The qualitative data analysis was conducted using computer software NVivo (QSR International Pty Ltd. 2010).

4.4 Results

4.4.1 Sample

Eleven participants reported that they were diagnosed with postnatal mental illness (depression, n=6; post-traumatic stress, n=5). Four participants stated that they were not professionally diagnosed, but believed they experienced postnatal distress. Most participants had recovered by the time of the interview, only one women reported moderate symptoms of depression. All participants were White and most were married (n=13), had a graduate or postgraduate level of education (n=10) and reported accessing forums two or more times a week (n=13). Women's ages ranged from 20-48 years of age (M=32.6, SD=6.7) and the time since they had their child ranged from six months to 10 years (M=28.3 months, SD=34.4). Participants are identified by their number and diagnosis.

4.4.2 Thematic analysis

To check reliability of coding, 10 themes and 5 quotes for each were coded by a third researcher trained in thematic analysis (YP). This found a percentage agreement between coders of 94%. Two major themes were identified: Social support and stigma; and Disadvantages of forum use.

4.4.2.1 *Social support and stigma*

The majority of mothers described how forums provided social support and suggested an online community of sufferers and survivors actively and passively engaging in a shared voice in cyberspace. This theme comprised of two sub themes (i) anonymous and non-judgemental support and (ii) not alone.

4.4.2.1.1 *(i) anonymous and non-judgemental support*

The majority of women visited forums to reduce their feelings of inadequacy and perceived stigma from others:

they could put it on there because of anonymity nobody really knows who you are and everyone who'd obviously on there has postnatal depression so there's no stigma because you're all suffering (16; depression)

the best thing about the Internet is you can research a lot of these things and nobody knows you're doing it (9; PND)

For some women, this was the first step in enabling offline disclosure:

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 'cause when I first got diagnosed I kind of felt like I shouldn't tell my friends 'cause I'm the only person in the world to have gone through this (10; depression)

I didn't even go to the doctor originally because I just thought you know it's just me it's only by going online looking up you know sort of symptoms and looking up PND and things and it made me realise oh it's not just me it's actually a real problem and not just something in my head (9; PND)

4.4.2.1.2 (ii) not alone

As women identified with others they developed an understanding of their symptoms as an *illness*. This enabled them to challenge internal stigma that they were to blame for being ill, thus lessening feelings of guilt and promoting help seeking behaviour. Women often gained a new understanding of themselves as having a *real* condition with hope of recovery:

you can actually feel quite isolated but if you look on the Internet there are actually a lot of people out there who have been through a lot and it it's actually sounds horrible but it's quite nice to that there are other people there who are going through it as well...and certainly the ones about the medication I wouldn't have taken, I wouldn't have taken it if I'd not read more about it (5; PTSD)

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 (11; depression)

Many women felt supported even if they did not actively participate on forums. One woman who did not interact on forums described how she still felt part of the community:

it does make you feel like part of a community and not on your own (5; post-traumatic stress)

4.4.2.2 Disadvantages of forum use

There were two instances of negative experiences and three women expressed that there were times when using forums may do more harm than good. This comprised two sub themes (i) forum moderators and (ii) knowing when to use forums.

4.4.2.2.1 (i) forum moderators

One negative experience occurred because the forum was not moderated:

I had one very negative experience on my own site not long after I had set it up actually I think I got quite an abusive message left one day on, I can't remember what i'd put on the page that day but I got an abusive message left on it saying I ought to be disgusted with what i'm doing (10; depression)

Women described how they chose forums that provided an atmosphere that was trustworthy, non-judgemental and monitored.

[it] could get negative if you start talking to the wrong person, who sort of offended you or wasn't very sensitive, that could be disastrous (14; post-traumatic stress)

One mother describes how she was discerning in choosing a forum:

I just felt they were judgemental, it didn't feel a safe place to go, it felt like you couldn't be sure that anybody there would be understanding, and actually if somebody did write something horrible to you that it would be stopped (1; depression)

4.4.2.2.2 (ii) knowing when to use forums

A few women described how sometimes forums made them feel worse.

These women described how they managed this by recognising when forums help and when to avoid them.

it's a double-edged sword really, you find that people are going through the same thing as you and having similar experiences, but sometimes that almost makes you wallow...it can add to your negative thoughts, and then it doesn't necessarily help you especially if you're having a really bad day (2; depression)

when you read through other peoples' experiences and it's like written in the first person it's quite sad to see that they've been through something as bad as what you've been through and um although you want to know the end result and that it is all gonna be okay at the end of it (pause) it's quite depressing to have to kind of read stuff like that and I had to make sure that I'd got time to do that cause I try not to think about it too much because I just find the more I pondered on it then, the worse my feeling would be for that day (13; depression)

4.5 Discussion

The majority of women suggested that their internal stigma was challenged by social support in forums that expressed an alternative discourse about postnatal mental illness. The anonymity and non-judgemental social support may have made it an acceptable way to challenge internal stigma through normalisation, validation and separating the illness from their identity as a mother. Most women reported that engaging either actively or passively with this virtual "voice" empowered them to disclose offline. A minority of women explained negative experiences.

The findings are consistent with literature suggesting that members benefit from forums and they may lessen internal stigma (Crabtree, 2010). This exploratory study points towards some ways that forums may challenge the stigma women with postnatal mental illness may experience. Findings extend previous research by providing a unique perspective of the interactions of women engaging in a collective shared "voice". Unlike previous studies, some possible risks to women have been highlighted. It may be important for women in this sample to recognise times when

reading forums can be of benefit and times when it can be detrimental rather than issues with overuse (Lawlor & Kirakowski, 2014).

There are reasons the sample may not be representative; sample size was small, self-selected, White, mostly educated and women may have been more proactive in seeking social support. However, findings prepare the way for research that explicitly examines if there is an online conceptualisation of postnatal mental illness that reduces stigma and if so, how women engage with it. There may be concerns about using forums for postnatal mental illness which should be explored further.

5 A thematic analysis of stigma and disclosure of perinatal depression on an online forum (Article 4)

Moore, D., Ayers, S., & Drey, N. (2016). A thematic analysis of stigma and disclosure for perinatal depression on an online forum. *Journal of Medical Internet Research*. doi:10.2196/mental.5611

5.1 Abstract

Background: Perinatal mental illness is a global health concern; however, many women do not get the treatment they need to recover. Some women choose not to seek professional help and get no treatment because they feel stigmatised. Online forums for various health conditions, including perinatal mental health, can be beneficial for members. Little is known about the role that online forums for perinatal illness play in reducing stigma and subsequent disclosure of symptoms to healthcare professionals and treatment uptake.

Objective: This study aimed to examine stigma and disclosure in forums and describe any potential disadvantages of forum use.

Methods: An online forum for mothers was examined and 1546 messages extracted from 102 threads from the antenatal and postnatal depression section. These messages were subjected to deductive systematic thematic analysis to identify common themes regarding stigma and disclosure of symptoms and potential disadvantages of forum use.

Results: Two major themes were identified: *stigma* and *negative experiences of disclosure*. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma. Many women were concerned about feeling like a “bad” or “failed” mother and worried that if they disclosed their symptoms to a healthcare professional they

would be stigmatised. Posts in response to this frequently encouraged women to disclose their symptoms to healthcare professionals and accept professional treatment. Forum discourse reconstructed the ideology of motherhood as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment. Many women overcame stigma and replied that they had taken advice and disclosed to a healthcare professional and/or taken treatment.

Conclusions: Forum use may increase women's disclosure to healthcare providers by challenging their internal and external stigma and this may strengthen professional treatment uptake and adherence. However, a few posts described negative experiences when disclosing to healthcare professionals.

5.2 Introduction

Perinatal mental illness is a global health concern and includes antenatal and postnatal depression and anxiety disorders, posttraumatic stress disorder after childbirth, and adjustment disorders. Perinatal depression has a prevalence of 12%-20% (Leung & Kaplan, 2009) and perinatal anxiety affects 2.6%-39% of women (Leach, Poyser, & Fairweather-Schmidt, 2015). Posttraumatic stress disorder after childbirth affects 3.17% of new mothers and 15% in high-risk groups (Grekin & O'Hara, 2014). If these illnesses are not treated, there are well-documented adverse outcomes for women, infants, and families (Letourneau et al., 2014). Detrimental maternal outcomes include substance abuse and suicide (Bennett et al., 2004) and untreated antenatal depression is associated with postnatal depression (Grekin & O'Hara, 2014). Negative infant outcomes include developmental and cognitive delays (Field, 2001; Bergman, Sarkar, Glover, O'Connor, 2010), preterm delivery (Ding et al., 2004), and an increased risk of behavioural and attachment problems (Stevenson-Hinde, Shouldice, & Chicot, 2011).

Women with perinatal mental illness often fail to receive treatment despite treatment being available (Dennis & Chung-Lee, 2006). Often this is because women choose not to disclose and seek help from their healthcare provider. Poor knowledge of medical conditions is one reason some people may be less likely to recognize they are ill and therefore less likely to seek help (Jorm, Christensen, & Griffiths, 2006). Some women have poor health literacy about perinatal mental illness and problems relating professional health information to how they experience the illness (Tommy's, 2013). In addition, there can be a misconception about what perinatal mental illness is, and women may find it difficult to distinguish what is a healthy

emotional reaction to the transition to motherhood and what emotions may indicate a mental illness (Bilszta et al., 2010). These issues can contribute to stigma.

Stigma is an extreme disapproval of someone or group of people because of a certain characteristic; it can present as external stigma where the general public holds a stigmatising attitude. It can also present as internal stigma where the stigmatised individual believes this negative appraisal and applies it to themselves. There are high levels of external stigma in the general population and internal stigma has been identified in approximately a third of people with severe mental illnesses (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; West, Yanos, Smith, Roe, & Lysaker, 2011). There are well-documented negative outcomes for individuals with mental illness because of external stigma such as social exclusion, discrimination, and fewer life opportunities (Corrigan, Druss, & Perlick, 2014). Similarly, internal stigma has been associated with low self-esteem, reduced disclosure, and reluctance to seek treatment (Corrigan et al., 2014; Rodrigues et al., 2013).

Thus, some women may think others will view them negatively for having a mental illness (external stigma) and may also feel bad about themselves for having a mental illness (internal stigma). Stigma is a major barrier to disclosure and help-seeking in the perinatal period (Bilszta et al., 2010; Maloni, Przeworski, & Damato, 2013). Some women feel stigmatised not only because they have a mental illness but principally because they are a mother with a mental illness. This two-fold stigma means they are concerned about feeling like, and being seen by others as, a “bad mother” (McLoughlin, 2013). Women with perinatal mental illness have unique concerns related to their maternal identity; they may worry that having a mental illness would result in negative consequences such as social services involvement, loss of custodial rights, and hospitalization (Byatt et al., 2012; Edwards & Timmons,

2014; Hanley & Long, 2006). These features of stigma can contribute to reluctance to disclose symptoms (Kingston et al., 2015). A systematic review and meta-synthesis identified stigma and concerns about child custody as a key barrier to care for postnatal women (Megnin-Viggars, Symington, Howard & Pilling, 2015). Many women avoided disclosing symptoms to healthcare providers, as they did not want to be diagnosed as having a mental illness. They wanted to be seen as coping and were worried they would lose custody of their child should they disclose.

People suffering from stigmatised illnesses are more likely to turn to the Internet for help (Berger, Wagner, & Baker, 2005; Millard & Fintak, 2002). Studies have detailed the benefits of using online social support for a variety of health issues (Mo & Coulson, 2002; van Uden-Kraan, 2008). The Internet could provide a unique avenue to reduce stigma in terms of knowledge and attitude. It could provide information about perinatal mental illness that women could relate to. This could aid disclosure by increasing women's health literacy about perinatal mental illness and enable them to recognize that they have a problem.

There are thousands of websites dedicated to perinatal mental health and many online support groups or forums, but little is known about how members engage with them (Moore & Ayers, 2011; Teaford, Goyal, & McNeish, 2015). A content analysis by Evans et al. (2012) of an online support group for postnatal depression reported it was non-judgmental. The forum provided emotional, informational, and some instrumental support. Posts encouraged users to contact a healthcare provider and take medication; there were no posts containing negative experiences with healthcare providers. Similarly, another content analysis documented how online support forums for lesbians with postnatal depression provided social support (Alang & Fomotar, 2015). Many women were reluctant to

disclose and seek help because of the stigma of being seen as an unfit mother and fear of the child being taken away. In addition to the stigma around their mental illness, women felt stigmatised because they were homosexual. The dichotomy of “good mother” “bad mother” deterred help-seeking behaviour; it is plausible that this may be because it increases internal and external stigma. To some women the idea of a “good mother” is not compatible with mental illness; similarly, having symptoms of perinatal mental illness such as bonding problems or thinking of harming your child can make women feel like a “bad mother” (McLoughlin, 2013).

A discourse analysis of an online forum for postpartum depression reported how it provided a place for mothers to confess their shame about having perinatal mental illness (Kantrowitz-Gordon, 2013). This enabled many women to overcome the stigma of being mentally ill and not meeting the expectations of a good mother. Women found that no one talked about this offline, so they constructed an online dialogue with other forum users that expressed negative feelings around motherhood. Nevertheless, it is important to note that some recent research suggests online support groups may not challenge stigma enough to affect or change help-seeking behaviour (Chung, 2013). Excessive participation in online support groups could also be a form of social avoidance and prevent disclosure and foster over reliance on forums (Lawlor & Kirakowski, 2014). Internet forums for perinatal mental health have yet to be researched to see how using forums may increase disclosure of symptoms and help-seeking behaviour. Forums may challenge stigma by providing a unique source of experiential information and a space for women to disclose and seek advice anonymously without fear of being stigmatised. Posts on forums may challenge stigma and provide positive discourse about perinatal mental health. Posts

may also provide encouragement for women to seek and adhere to professional treatment by challenging external stigma.

This study aimed to investigate if and how perinatal mental illness forums might overcome the barriers stigma presents to some women with perinatal mental illness when seeking help from healthcare professionals and to see if there are possible disadvantages of using forums regarding disclosure and stigma.

5.3 Method

5.3.1 Sample

Forums were identified using the three most popular UK search engines (Google, Bing, and Yahoo) that are used by 98.83% of Web users (SEO Consultants Directory, 2010). The text searches were “postnatal depression,” “postnatal forum,” “postnatal anxiety,” and “birth trauma” and entered into each of the search engines. The first 25 websites and their hyperlinks were assessed for inclusion in the study. Inclusion criteria were as follows: (1) they had a forum or message board dedicated to antenatal and/or postnatal mental health, (2) they had been active for the last 6 months, (3) the forum had more than 50 members, (4) messages could be viewed by non-members of the group, and (5) moderators gave permission to research their forums. Nine forums were contacted but only 1 forum moderator gave permission to research posts. The forum moderator was from “Mumsnet,” one of the largest websites for parenting advice and has active forums with between 1.2 and 1.7 million members (<http://www.mumsnet.com>). There were 28 “talk topics” that contained between 1 and 273 forums. The forum section for antenatal and postnatal

depression was dedicated to perinatal mental health and was used to draw the data for analysis.

5.3.2 Procedure

Nineteen forum moderators were contacted and written permission from 1 moderator was obtained. Visitors were informed of the nature of the research and their right to withdraw their data via a prominent disclaimer on the forum. A link from the site provided details about what data were taken from the site and how the information was used. The study was retrospective to avoid influencing the participants' interactions. Confidentiality was maximized by ensuring the anonymity of participants by replacing their user names with pseudo names.

5.3.3 Data Selection

All messages on the antenatal and postnatal forum between January 2013 and June 2013 were included for analysis. This comprised of 1546 messages retrieved from 102 threads. The average number of posts in a thread was nearly 28. These threads and messages were copied into Microsoft Word files and stored securely for data protection purposes and because forums can terminate at any time.

5.3.4 Ethical considerations

The study received ethical approval from the School of Health Sciences Research Ethics Committee, City University London (Appendix 5.1). Precautions

were taken to ensure the safety, dignity, and rights of participants in accordance with the 2007 “Guidelines for Ethical Practice in Psychological Research Online” as outlined by the British Psychological Society (The British Psychological Society, 2007). Consideration was given to the nature of online private and public spaces, anonymity, confidentiality, valid consent, and the right to withdraw from the study (Moore & Drey, 2014, see Appendix 5.2).

5.3.5 Analysis

Discussion threads were examined using deductive systematic thematic analysis from a realist stance (Braun & Clarke, 2006). Threads were copied into the qualitative data analysis computer software NVivo 10 and threads were read and reread before generating initial codes (QSR International Pty Ltd. 2012). Themes were generated from patterns in the codes and were included when they were frequent, appeared important to posters, and were related to the research aims. The principal researcher had experience in qualitative analyses and met regularly with a senior health researcher (SA) to discuss analysis, thus increasing reliability of codes and themes. The whole dataset was recoded when themes were defined and codes were organized to address the research questions of stigma, disclosure, and messages that could potentially hinder women seeking help. The principal researcher developed the interpretation of themes and final interpretations were agreed by consensus of all authors.

5.4 Results

Two major themes were identified: stigma and negative experiences. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma.

5.4.1 Stigma

The majority of women disclosed their symptoms on their first post and often sought advice on diagnosis, on whether they should contact a healthcare professional, and on healthcare providers' attitudes to illness and treatment. Nearly all the replying posts urged women to contact their healthcare providers and often reassured women who had concerns about approaching healthcare professionals. Women were frequently encouraged to honestly disclose their symptoms to healthcare professionals and take professional treatment offered. This theme comprised 3 subthemes: (1) internal stigma, (2) external stigma, and (3) treatment stigma. Messages that started a thread are labelled (I) for initial post and it includes subsequent posts in the thread made by the initial poster. Posts labelled (R) are replies to the initial poster and posts that addressed other posters in a thread.

5.4.1.1 *Internal Stigma*

Internal stigma was coded when women wrote about their stigmatised attitudes towards themselves, such as feelings of inadequacy as a mother. Many women used the forum to disclose shameful feelings often hidden from others such as feeling like a failure as a mother, wanting to leave the baby or family, intrusive

thoughts of self-harm and child-abuse. They felt that there was no place offline to talk about the negative side of pregnancy and motherhood and valued the non-judgmental space offered by forums. Replies were often reassuring and challenged internal stigma by stressing that these feelings were part of the illness and not indicative of failure as a mother:

I'm not very compassionate towards myself or accepting of the fact that I was ill (rather than just being crap). [R]

You haven't failed!!! The illness is making you think this way. [R]

5.4.1.2 External Stigma

External stigma comprised the concerns many women had about how healthcare professionals would think that they were inadequate mothers if they disclosed symptoms. Members perpetuated a strong culture of advice that urged women to contact a general practitioner, midwife, or health visitor even if they did not ask for it. Half of all women who had not disclosed to a healthcare professional when they first posted replied that they had sought professional help following others' encouragement (n=15):

Thank you have rung the doctor. Think I just needed someone else to tell me to do it.

[I]

Nearly half of the women who posted did not reply to say if they had taken members' advice, and one woman refused to disclose to a healthcare professional. Women were often reluctant to disclose to their healthcare professionals, as they feared being seen as a *bad mother* and that their baby would be taken away or social services would intervene:

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. [I]

Anyone got any experience with this - what did u say to the DR? What was their approach? Were you made to feel like a bad mum/mum to be? Were you strictly monitored/referred to social services after? [I]

Most replies to these posts were reassuring, shared positive experiences of disclosing, and stressed getting help from a healthcare provider was the best course of action:

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. [R]

5.4.2 Treatment Stigma

Treatment stigma was related to women's concerns about seeking and adhering to professional treatment. It extended concepts of internal and external stigma described above.

Often posters emphasized the importance of professional help in recovery; women who started threads and posed questions were often reassured that they had *done the right thing* when they had disclosed to healthcare professionals.

It is the people who are not seeking help and not being honest with themselves that are in the most danger, You are doing the right things, you are being objective, and seeking help. [R]

Treatment was largely discussed in terms of antidepressants. Some women felt like a failure for having to take medication, which added to feelings of *weakness* for having a mental illness and being a *failure* as a mother. This stigma often centred on guilt for thinking they would harm the baby, inability to cope as a mother, and needing to rely on medication.

I still feel guilty and worried I am causing my baby harm and being selfish if I ask for drugs - did any of you guys who have taken meds struggle with this before asking? [I]

Replies were embedded in a dialogue of social support and most were pro-antidepressants and encouraged women to work with healthcare professionals. These

posts often challenged stigma by promoting an alternative “good mum” discourse that challenged external and internal stigma. Posts reconceptualised what a good mother is, namely, a good mother gets help and takes 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. [R]

I feel like there's a stigma attached to taking meds for a mental illness, which doesn't exist for physical illnesses...And I don't think I'm going to do DD (darling daughter) any favours by trying to prove I can be a good mum off my medication. [R]

5.4.3 Negative Experiences

Negative experiences with healthcare professionals included disclosure and treatment experiences. This theme extended feelings of internal and external stigma and the majority of subsequent posts challenged stigma by promoting healthcare professionals and treatment.

Very few posts outlined any negative experiences when women disclosed to healthcare providers (n=3). One woman who started a thread rebuked replies encouraging help-seeking as she had previous negative experiences with the social services and did not trust healthcare providers. Two women started threads to talk about bad events with healthcare providers:

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. [1]

Subsequent posts condemned the midwife's approach and said how there are good and non-judgmental healthcare professionals. Replies to unhelpful healthcare professional experiences strongly urged women to engage with healthcare professionals and stressed that treatment was essential for recovery.

5.5 Discussion

5.5.1 Principal findings

This study increases our knowledge of the stigma women with perinatal mental illness may experience. In particular, it offers unique insights into how women are expressing different types of stigma on an online forum, online discourse that challenged this stigma, and the potential outcomes for help-seeking behaviour. Women frequently expressed internal stigma and were concerned about external stigma from healthcare providers. Both were noteworthy barriers to help-seeking behaviour and reply posts often challenged this stigma by sharing positive experiences of disclosure and treatment. Posts challenged some women's beliefs that healthcare providers would think of them as an unfit mother or social services would take their baby. Women were consistently encouraged to seek professional help.

Treatment stigma was often expressed as stigma about having a mental illness and having a mental illness as a mother. Some women felt they had failed at

their role as a mother because they had to rely on medication to cope and feared treatment would harm their unborn child. Subsequent posts challenged this stigma promoting a different discourse that advocated good mothers seek help and take treatment. Many women who sought advice on whether they should disclose to a healthcare professional reported that they followed the advice of reply posts and sought help. There were 3 instances of negative experiences when disclosing symptoms to healthcare providers.

5.5.2 Comparisons With Prior Work

Consistent with previous studies (Megnin-Viggars et al., 2015; Bishop, 2007), the stigma attached to mental illness was a salient barrier to treatment and women were able to “test out” disclosing symptoms and concerns in online conversations. Like previous research, many women spoke about the stigma attached to antidepressants that contributed to a reluctance to engage in treatment (Turner, Sharp, Folkes, & Chew-Graham, 2008). This study extends our knowledge of how a forum provided an anonymous place where women could explore their understanding of perinatal mental illness and where they got encouragement to seek help and accept treatment. If women recognize that they may have a mental illness, they may be more motivated to seek help like many women in this study. Women frequently expressed internal and external stigma often describing feeling like and/or being seen as a “bad mother,” an “unfit mother,” or a “failure.”

Internal, external, and treatment stigma discourse was met by replies of encouragement to get help and praised acts of disclosure to healthcare providers. Posts often promoted a “good mother” discourse that included the ideas that a good

mother discloses and gets treatment and healthcare providers will not think them inadequate or take their baby away. These posts challenged the distressing dissonance between the concept of a good mother, and that of a bad mother, present in some mothers' posts and thus reconciled that a "good mother" can have perinatal mental illness.

Unlike previous research on perinatal mental health forums, there were 3 posts that shared negative experiences of disclosing to healthcare providers (Evans et al., 2012; Alang & Fomotar, 2015; Kantrowitz-Gordon, 2013). Despite the vast majority of posts presenting positive experiences, the potential effect of negative posts should be considered. Some women who experience stigma can suffer with intense feelings of inadequacy and worry that healthcare providers will not understand or social services will become involved (McLoughlin, 2013). Future work should investigate if negative posts reinforce these anxieties and if in turn this inhibits disclosure and help-seeking behaviour. The culture of discussions and attitudes to disclosure may be very different in other online communities; for example, a birth trauma support group may include many posts describing negative experiences with healthcare professionals. This group gives women an opportunity to voice their concerns that they may not be able to do offline; however, there is potential for conversations to negatively affect healthcare decisions. Concerns are warranted, especially if the forum is unmoderated and lacks encouragement to engage with healthcare professionals.

5.5.3 Clinical Implications

This study provides further insights into the stigma women with perinatal mental illness may experience and how they communicate online. This could be used to develop targeted interventions to help women disclose to professionals and get treatment; for example, forums could be developed to offer this support to at-risk women and their subsequent disclosure could be measured against a control group. Future theoretical models could draw on this evidence and investigate if online forum use for perinatal mental illness affects the stigma experienced by some women and if this affects disclosure to healthcare professionals.

5.5.4 Conclusions

Forum posts often expressed internal and external stigma from healthcare providers and treatment stigma as major barriers to disclosure and help-seeking behaviour. Forum replies challenged this stigma and provided a place to discuss stigma. Forum discourse reconstructed the idea of a good mother as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment. The vast majority of posts encouraged women to engage with and trust in healthcare providers, and consequently some women sought help and engaged in treatment. This study showed that this forum has the potential to increase women's disclosure to healthcare providers and strengthen professional treatment uptake and adherence. However, there are possible concerns when using forums. Healthcare providers should exercise discernment when directing their clients to online forums.

6 The City MISS: The development of a scale to measure stigma of perinatal mental illness (Article 5)

Moore, D., Drey, N., & Ayers, S. (2017). The City MISS: The development of a scale to measure stigma of perinatal mental illness. *Journal of Infant and Reproductive Psychology*, 35(3), 273-275. doi:10.1080/02646838.2017.1313967

6.1 Abstract

Objective: This study aimed to develop and validate a scale to measure perceived stigma for perinatal mental illness in women.

Background: Stigma is one of the most frequently cited barriers to seeking treatment and many women with perinatal mental illness fail to get the treatment they need. However, there is no psychometric scale that measures how women may experience the unique aspects of perinatal mental illness stigma.

Method: A draft scale of 30 items was developed from a literature review. Women with perinatal mental illness ($n = 279$) were recruited to complete the City Mental Illness Stigma Scale. Concurrent validity was measured using the Internalized Stigma of Mental Illness Scale. Factor analysis was used to create the final scale.

Results: The final 15-item City Mental Illness Stigma Scale has a three-factor structure: perceived external stigma, internal stigma and disclosure stigma. The scale accounted for 54% of the variance and had good internal reliability and concurrent validity.

Conclusion: The City Mental Illness Stigma Scale appears to be a valid measure which provides a potentially useful tool for clinical practice and research in stigma and perinatal mental illness, including assessing the prevalence and characteristics of

stigma. This research can be used to inform interventions to reduce or address the stigma experienced by some women with perinatal mental illness.

6.2 Introduction

Anxiety and depression can affect many women in pregnancy and after birth. Antenatal anxiety and depression have a prevalence of approximately 7 to 25% (Banti et al., 2011; Biratu & Haile, 2015; Waldie et al., 2015). Postnatal anxiety has a prevalence of 3 to 43% and postnatal depression affects 12 to 20% of new mothers (Glasheen et al., 2010; Leung & Kaplan, 2009). Post-traumatic stress disorder occurs in 3.17% of women after childbirth and 15% of women in high risk groups (Grekin & O'Hara, 2014). Many women additionally suffer from moderate affective symptoms or distress without meeting all the diagnostic criteria (McKenzie-McHarg et al., 2015). This study uses the term perinatal mental illness to refer to affective disorders or symptoms such as depression, anxiety, obsessive compulsive disorder, psychosis and post-traumatic stress that occur in the perinatal period. Despite perinatal mental illness being a global health problem, only half of women with symptoms get professional treatment (WHO, 2009; Dennis & Chung-Lee, 2006). Existing literature frequently attributes this problem to stigma acting as a barrier to women disclosing and seeking help (Bilszta et al., 2010; Byatt 2012; Kingston et al., 2015).

The stigma associated with mental illness is well documented (Thornicroft, 2006). Stigma can be defined as the strong negative appraisal of a person or group of people because they have a characteristic that is considered undesirable (Goffman, 1963). Stigma can be held by the public, which is labelled external stigma. Internal stigma can also present when stigmatised individuals attach stigma to their own identity (Chang et al., 2016). Both external and internal stigma can have negative consequences for the stigmatised individuals' self-esteem, relationships, recovery,

social and employment opportunities, and willingness to seek and adhere to treatment (Corrigan, 2004; Corrigan & Watson, 2002, Fung et al., 2008).

Although the symptoms women with perinatal mental illness experience are similar to those of other affective disorders, the illness occurs specifically when women are transcending into motherhood (Abrams & Curran, 2011). This makes perinatal mental illness distinctive and it is possible that this stigma differs from stigma for mental illnesses at other times of life in a number of ways. Motherhood is a rite of passage where women may reconstruct their identity with a new role as a mother and new skills and behaviour (Mercer, 2004). There are many complexities involved in this change and women may experience different influences due to cultural norms, societal expectations and relationship changes. Also, perinatal mental illness affects not only the sufferer, but also the child and these factors can lead to both external, internal and disclosure stigma.

First, women may have to cope with the stigma of having a mental illness, and also of being a mother with a mental illness. Women may worry about external stigma; being seen by others as a “bad mother” because they have a mental illness (Bilszta et al., 2010; Kingston et al., 2015; McCarthy & McMahon, 2008). Specifically, they may feel that others view them as inferior for not meeting society’s expectations of what it is to be a “good mother” or meeting their own idealised expectations of motherhood (Beck, 2002).

Secondly, women may also experience internal stigma because they consider themselves as a “bad mother” or a failure for having symptoms associated with mental illness. Women may experience guilt and shame for not meeting their own expectations of motherhood potentially compromising the maternal self (Dennis & Chung-Lee, 2006, O’Mahen et al., 2012). These symptoms can be very damaging to

women's identity as mothers: women may experience intrusive thoughts, such as harming, abandoning or not loving their child. These symptoms can mean that some women berate themselves believing the symptoms are a reflection of their parental ability rather than symptomatic of an illness (Moore, Ayers & Drey, 2016).

Women may be concerned that disclosure of their symptoms would result in outcomes such as social services involvement, losing parental rights, being judged as an "unfit" mother and becoming hospitalised (Byatt et al. 2012; Edwards & Timmons, 2005; Hanley & Long, 2006). For many women, talking about their illness is uncomfortable as they feel ashamed and may not even know how to talk about it (Price & Bentley, 2013). Women may experience anxiety if they perceive others as having stigma and are therefore reluctant to disclose as it might result in others attributing stigmatised attitudes to them personally and consequent discrimination (Gardner et al., 2014). This study refers to this as "disclosure stigma".

There are added complications for women considering disclosing to healthcare professionals as disclosure might result in treatment. Women may be concerned that if they take medication there might be side effects for their unborn baby, or breastfeeding infant, which can increase feelings of guilt and reinforce internal stigma (Alvidrez & Azocar, 1999; Boath et al., 2004). Women often experience decisional conflict when comparing maternal and infant health outcomes (Walton et al., 2014). Some women may feel like a failure or see relying on medication as a "weakness" signalling their inability to cope as a mother (Moore, Ayers & Drey, 2016). Overall, there is reason to believe that external and internal stigma, as well as the stigma associated with disclosing to others is a unique phenomenon and is worthy of investigation as it may be a barrier to care for some women (O'Mahen et al., 2012).

Questionnaire scales have been developed to measure stigma for a variety of mental illnesses such as depression and anxiety (Barney et al., 2010; Griffiths et al., 2011). However, we are unaware of a validated scale that measures the stigma for perinatal mental illness. A scale is therefore needed that includes those aspects of women's experiences of stigma that may be unique to the perinatal period. Development of such a tool would have advantages for future research examining interventions for stigma reduction and identifying women at risk of not disclosing symptoms. This study aimed to develop and validate a scale of stigma for women with perinatal mental illness.

6.3 Method

6.3.1 Design

Items for the City Mental Illness Stigma Scale (City MISS) were administered as part of a larger Internet study of perinatal mental illness stigma and use of online forums. Self-report questions were derived by reviewing research that specified unique characteristics of perinatal mental illness stigma. The City MISS was evaluated for psychometric characteristics. Concurrent validity was examined by determining how scores related to the brief version of the Internalized Stigma of Mental Illness Scale (Boyd et al., 2014; ISMI-10). Because both scales claim to measure stigma related to mental illness we hypothesised a positive correlation between the scores of the two studies. Women were additionally asked if they found it hard to disclose to a healthcare professional or avoided complete disclosure and giving their reason for this. Symptoms of perinatal mental illness were identified

using the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983; HADS) and demographic information.

6.3.2 Participants and procedure

Participants were recruited by publicising on perinatal mental illness websites, baby-related websites, Facebook groups and twitter (e.g. www.birthtraumaassociation.org.uk, www.netmums.co.uk, Pandas foundation Facebook group and @PNDandMe Twitter account). Women self-identified as: over 18 years old, pregnant or having a child under 4 years old, and having experienced or experiencing perinatal distress. 403 women answered questionnaires via an online survey (Qualtrics, LLC, 2015). Women were included in the analyses if they completed all the City MISS questions and all the ISMI-10 scale questions (n =279). Seven women reported antenatal distress and 272 women had postnatal distress.

It was important to try to get participants to read and understand the participant information sheet, in particular, to ensure they understood their participation was confidential and anonymous and they had a right to withdraw their data retrospectively from the study. The first page of the survey was the participant information sheet and participants had to click a box to confirm that they consented to the study or they could not progress to the survey.

6.3.3 Ethics

Ethical approval was given by the School of Health Sciences Research Ethics Committee, City University London (Appendix 6.1). Website administrators and moderators of the forums were contacted to ask for consent to post information about the study and a hyperlink to the online survey. The participant information sheet and

the first and last page of the survey urged women to contact their healthcare provider should they feel distressed and provided details of outside organisations that offered appropriate support.

6.3.4 Measures

6.3.4.1 *The City Mental Illness Stigma Scale*

The draft of the City MISS was developed by reviewing the literature on the stigma experienced by women with perinatal mental illness. Literature was selected by searching for “perinatal depression/anxiety”, “antenatal depression/anxiety”, “postnatal depression/anxiety” AND “stigma” in SCOPUS and Medline. Papers were included if published between 1999 and 2014 and they contained information about antenatal and/or postnatal mental illness stigma. Each title was reviewed for relevance and then the abstracts were further examined for suitability for inclusion. Papers were included if they focused on women’s experiences of perinatal mental illness and stigma or contained substantial sections regarding this topic. Papers were excluded if they did not fulfil this criterion or included research that focused on mental illness after stillbirth, infant death, abortion, and miscarriage. Papers with samples that did not contain women who were pregnant or had given birth up to five years previously. Papers were also excluded if they were not in English. The application of the inclusion and exclusion criteria yielded 16 suitable papers (Abrams & Curran, 2011; Battle et al., 2013; Beck, 2002; Bilszta et al., 2010; Buultjens & Liamputtong, 2007; Byatt et al., 2012; Edge, 2006; Edwards & Timmons, 2005; Gardner et al., 2014; Hanley & Long, 2006; Mauthner, 1999; McCarthy & McMahon, 2008; McLoughlin, 2013; Patel et al., 2013; Price & Bentley, 2013; Shakespeare et al., 2003). Questions and subscales were developed by the first author in collaboration with two other senior researchers (ND & SA). Thirty

questions were derived from issues that had face validity and reflected the unique stigma associated with having a mental illness and being a mother. Responses were measured on Likert scales (1-4) from ‘strongly disagree’, ‘disagree’, ‘agree’ to ‘strongly agree’, higher scores indicating greater stigma. Reverse scoring was used for two questions; “I am as good a mother as other mothers despite having psychological problems” and “a good mother gets treatment for her psychological problems”.

Questions addressed three aspects of stigma: perceived external stigma, internal stigma and disclosure stigma.

Perceived external stigma questions (10 questions) aimed to measure participant’s beliefs about how other people think about mothers with psychological problems fulfil their role as a mother. Questions were developed from the literature capturing concerns women had about being seen as a “bad mother”, for example “people think mothers with psychological problems don’t love their babies”. This included two items to assess how participants thought the media portrayed mothers with psychological problems; “the media tends to show mothers with psychological problems as a threat to their babies”.

Internal stigma subscale (9 questions) extended the concept of a “spoiled identity”, specifically relating it to participant’s maternal identity (Goffman, 1963). The literature review suggested symptoms that exacerbate women’s feelings of maternal inadequacy were highly associated with internal stigma, so the scale was developed to capture these symptoms due to their association with a substantial risk of internal stigma. Features of these symptoms identified from the literature were: not coping,

bonding difficulties, thoughts of harming or leaving their child, thoughts of self-harm, suicidal ideation, feeling that their psychological problems had decreased time spent with the baby, feeling at fault for risk of future psychological problems, and being a burden on family. Questions were developed to ascertain if women experienced these features, for example “I find it difficult to love my baby”.

Disclosure stigma subscale (11 questions) aimed to measure participants anticipated discrimination if they disclosed their symptoms or diagnosis to others. Questions were developed from the literature and contained two items that measured how women believed others would perceive them if they disclosed their psychological problems, for example “I do not want people to know I have a psychological problem as they may think I’m a bad mother”. It contained four items that rated the potential consequences of disclosure to a healthcare professional, for example “I worry that if I told a healthcare provider about my psychological problems my baby would be taken away”. It contained four items that related to stigma associated with the treatment of perinatal mental illness, for example “A good mother gets treatment for her psychological problems”.

Face validity and acceptability were assessed by piloting the questionnaire. Six women with infants under two years who had perinatal mental illness completed the questionnaire online using a mobile phone. Following their feedback, no items were excluded, but the two media questions were rescaled to include “neither agree nor disagree”.

6.3.5 Concurrent validity

Internalised stigma of mental illness in general was measured using the brief version of the Internalised Stigma of Mental Illness scale (ISMI-10) a shorter form

of the 29-item self-report questionnaire (Boyd Ritsher et al., 2003) which has been shown to be a valid and reliable measure.

6.3.6 Perinatal mental illness symptoms

Symptoms of perinatal anxiety and depression were measured by the Hospital Anxiety and Depression Scale which is widely used to measure affective symptoms in diverse populations (Montazeri et al., 2003). It has good validity and reliability (Bjelland et al., 2002) and has seven items to measure anxiety and seven items to measure depression. Scores of eight or above indicate depression or anxiety; eight to ten are indicative of mild symptoms, 11-15 moderate symptoms and 16 or more as severe depression and anxiety.

6.4 Results

6.4.1 Sample

Participant characteristics are shown in Table 6.1. Most participants classed themselves as White and married or living with a partner (n=172, n=59). Nearly 40% (n=158) were educated to degree level and most had one child (n=135). The majority of women were diagnosed with one or more postnatal mental illnesses (66.8%, n=189) but 25.4% (n=71) of women reported postnatal mental illness but had not sought a professional diagnosis. The remaining women had a diagnosis of antenatal mental illness (2.5 %, n=7) or both antenatal and postnatal mental illness (4.3%, n=12). Based on the Hospital Anxiety and Depression Scale measure completed during this study (n = 255), 50.6% (n=129) of women had moderate or severe anxiety and 25.1% (n=64) had moderate or severe depression.

6.4.2 The City Mental Illness and Stigma Scale

All 30 items were normally distributed. Principal axis factor analysis was conducted on 30 items with oblique rotation (direct oblimin). Analysis did not specify the number of factors. Items were removed if they did not correlate well with other items, e.g. if an item had four or less factor loadings below 0.3 (n=9). Items with communalities below .40 were also removed (n=6). The final principal axis factor analysis was conducted on the remaining 15 items. These 15 questions loaded onto three components that had eigenvalues over 1 and in combination explained 54.43% of the variance. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis (KMO = .85). Items that clustered on the same factor suggested that the scale was formed of three subscales: *Perceived external stigma* (variance: 33.96%) comprising 6 items relating to the variance of the participants view of others' attitudes to women with perinatal mental illness; *Internal stigma* (variance: 11.44%) comprising 5 items relating to the variance of the participants own attitudes towards themselves regarding their perinatal mental illness; *Disclosure stigma* (variance: 9.02%) comprising 4 items relating to the variance of the participants beliefs about the stigma they would encounter if they disclosed their symptoms or diagnosis of perinatal mental illness (see Appendix 6.2 for the final scale and Appendix 6.3 for the excluded items).

The three-factor structure of the 15 item CityMISS, as identified by the above Exploratory factor analysis, was estimated using Confirmatory Factor analysis (CFA; see Appendix 5. for more detail). Overall, results suggest the model is a good fit, and support the stigma constructs in the scale. Results showed Incremental Fit Index (IFI) = 0.92, Tucker-Lewis Index (TLI) = 0.89 and Comparative Fit Index

(CFI) = 0.92, which suggests that it is a plausible model for internal, external and disclosure stigma. RMSEA was 0.08 and suggests a good model fit as scores between 0.05 and 0.08 suggest a good fit (Reeve et al., 2007).

6.4.2.1 Internal reliability and validity of the City Mental Illness Stigma Scale

Internal reliability for the final scale and subscales was good with Cronbach's alphas between .81 and .86 for subscales and an overall alpha for the total scale of .84 indicating high reliability (see Table 6.2). The City MISS was highly correlated with the ISMI-10 scale suggesting good concurrent validity ($r(277) = .56, p < .001$).

The City MISS score could be predicted by the ISMI-10 scale score and the total of the HADS score following the formula $19.05 + (0.7 \times \text{ISMI-10 score}) + (0.24 \times \text{HADS score})$. This regression model predicted 5.2% of CityMISS scores exactly and accounted for 50% of scores with a 4.38 difference or less from the actual CityMISS score. The range of point differences between predicted and actual score for the CityMISS was 0.07 to 14.69 (mean 5.03, SD 3.69).

Multiple regression was used to examine whether the total score of the City MISS predicted the total score of the ISMI-10 scale after controlling for psychological symptoms (HADS score) ($n=255$). Results showed that including the subscale of internal stigma significantly predicted the ISMI-10 score in addition to the subscales external and disclosure stigma and HADS score ($R^2= 0.33, p<0.001$ and $R^2= 0.41, p<0.001$ respectively). This indicated that the internal stigma subscale measured more than just symptoms of perinatal mental illness (see Table 6.3).

Women were asked “are there any things that make it difficult for you to talk to healthcare providers about how you feel/ felt during pregnancy and/or after birth?” at the beginning of the survey before any questions were asked about stigma. Most women replied yes and were subsequently asked to “describe the things that make it difficult to talk?” in an open text box (76%, n=212). Over half of them said that stigma was the main reason for their disclosure difficulties (52.83%, n=112). Answers were coded as stigma if they explicitly answered stigma or they used the terms guilt, shame, embarrassment or feeling bad about themselves or worried others would think badly of them.

Table 6.1 Sample demographic characteristics

		<i>N</i>	<i>%</i>
Marital status	Single	13	4.7
	Married	172	61.6
	Living with partner	59	21.1
	Divorced	1	0.4
	Separated	5	1.8
	Other	3	1.1
Ethnicity	White	242	95.7
	Mixed/Multiple ethnic groups	6	2.4
	Asian	1	0.4
	Black/African/Caribbean	2	0.8
	Other	2	0.8
Occupation	Employed	131	47
	Self-employed	23	8.2

	Out of work	13	4.7
	Homemaker	60	21.5
	Student	14	5
	Unable to work	12	4.3
Education	GCSE's ¹	22	7.9
	A levels ²	32	11.5
	Trade/vocational training	40	14.3
	Bachelor's degree	111	39.8
	Master's degree	44	15.8
	Doctorate degree	3	1.1
Number of children	1	135	73.8
	2	36	19.7
	3	10	5.5
	4	1	0.5
	8	1	0.5
Diagnosis	Antenatal depression	3	1
	Antenatal anxiety	2	0.7
	Antenatal depression and anxiety	2	0.7
	Antenatal depression and postnatal depression	12	4.3
	Postnatal depression	74	26.5
	Postnatal anxiety	11	3.9
	Post-traumatic stress disorder (PTSD)	31	11.1
	Postnatal depression and anxiety	28	10
	Postnatal depression and PTSD	21	7.5
	Three or more postnatal mental illnesses	11	3.9

Puerperal psychosis	6	2.2
Other postnatal mental illness	7	2.5
No diagnosis sought	71	25.4

Note: Total number in demographic categories do not add up to 279 as not all participants completed the demographic questions.

¹ General Certificate of Secondary Education typically taken at 16 years of age

² General Certificate of Education Advanced Level typically taken at 18 years of age

Table 6.2 Component loadings for items on the City Mental Illness Stigma Scale (City MISS)

City MISS Scale components (% variance)	Component loading	Cronbach's alpha
Perceived external stigma (33.96%)		0.86
People think mothers with psychological problems will harm their babies	0.88	
People think mothers with psychological problems will harm themselves	0.74	
People think mothers with psychological problems will kill themselves	0.73	
People think mothers with psychological problems don't love their babies	0.72	

People think mothers with psychological problems can't cope with their babies	0.64	
People think mothers with psychological problems are abnormal	0.57	
Internal stigma (11.44%)		0.81
I have thoughts of hurting myself	0.84	
I have thoughts of killing myself	0.82	
I have thoughts about leaving my baby	0.65	
I can't cope as well as I'd like with my baby	0.60	
My psychological problems have meant I have lost time with my baby	0.51	
Disclosure stigma (9.02%)		0.85
I worry that if I told a healthcare provider about my psychological problems my baby would be taken away	0.93	
I worry that if I told a healthcare provider about my psychological problems the social services would get involved	0.90	
I worry that if I told a healthcare provider about my thoughts they would think I am an abusive mother	0.75	

I do not want people to know I have	0.48
psychological problems as they may think I'm a	
bad mother	
Total Scale City MISS (54.43%)	0.84

Table 6.3 Linear model of predictors of ISMI-10 scores, with confidence intervals and standard errors

	<i>b</i>	<i>SE B</i>	β	<i>p</i>
Step 1				
Constant	14.34 (11.45, 17.22)	1.46		
External Stigma	0.48 (0.29, 0.62)	0.08	0.33	<i>p</i> = .000
Step 2				
Constant	11.36 (8.53, 14.18)	1.44		<i>p</i> = .000
External stigma	0.29 (0.13, 0.45)	0.08	0.21	<i>p</i> = .000

Internal Stigma	0.48 (0.34, 0.63)	0.08	0.38	$p = .000$
Step 3				
Constant	9.83 (7.13, 12.54)	1.37		$p = .000$
External stigma	0.13 (-0.04, 0.29)	0.08	0.09	$p = .130$
Internal stigma	0.37 (0.23, 0.52)	0.07	0.29	$p = .000$
Disclosure Stigma	0.55 (0.36, 0.73)	0.09	0.25	$p = .000$
Step 4				
Constant	8.58 (6.00, 11.16)	1.31		$p = .000$
External stigma	0.10 (0.05, 0.25)	0.08	0.07	$p = .205$
Internal stigma	0.25 (0.11, 0.39)	0.07	0.19	$p = .000$
	0.43 (0.25, 0.61)	0.09	0.27	$p = .000$

Disclosure	0.22	0.04	0.32	$p = .000$
Stigma	(0.14, 0.29)			
HADS				

Note. $R^2 = .11$ for step 1; $\Delta R^2 = .127$ for step 2 ($ps < .001$); $\Delta R^2 = .093$ for step 3 ($ps < .001$); $\Delta R^2 = .080$ for step 4 ($ps < .001$).

6.5 Discussion

This study developed the first scale to measure the stigma women with perinatal mental illness may experience. The final scale consists of 15 items that account for 54% of the variance. The scale has good internal reliability and concurrent validity, with strong correlations with a general measure of stigma for mental illness. This scale could be a useful tool to measure the unique stigma women with perinatal mental illness may experience. Qualitative findings confirm that for many women stigma is the main reason they find disclosure to healthcare professionals difficult or chose not to disclose at all (O'Mahen et al., 2012). The scale highlights the concerns women with perinatal mental illness have and could be used to develop targeted interventions to reduce stigma and promote help-seeking behaviour.

6.5.1 Strengths and limitations

The strengths of this study include that scale items were derived directly from studies of women's experiences of stigma. This new scale is specific to the stigma

women may experience in the perinatal period and contributes to the theoretical understanding and conceptualisation of stigma. It contains items that capture the concerns some women have about how others see mothers with perinatal mental illness. It also contains items that highlight their own internal stigma and feelings of maternal inadequacy. Importantly, it reveals the stigma around disclosing to others which has important implications for help-seeking behaviour and recovery. It is possible that high scores on the internal stigma subscale could be due to individually held beliefs or could be based on what individuals think others attitudes are. The complexities of both perceived external stigma and internal stigma should be teased apart in subsequent research.

There are a number of other limitations that need addressing in future research, predominantly that this analysis was based on a convenience sample which comprised mostly White women educated to A-level or above. Women with antenatal mental illnesses were under-represented. This limits the potential generalisability of the scale and more research is therefore needed examining the psychometric properties of the City MISS amongst different socio-demographic groups. Similarly, future research should be sensitive to potential additional complexities regarding stigma for example, race or sexual orientation (Alang & Fomotar, 2015).

Another possible limitation of the study is the construct validity of the internal stigma subscale. It is possible that the subscale was not measuring internal stigma, instead it may be measuring something else for example, symptom severity or identification with PMI (perinatal mental illness). If this is the case the findings could be explained by other factors and it may be that women who have more severe symptoms are more likely to disclose. To account for this, future work should

examine how internal stigma is conceptualised by considering up to date research and adjusting the internal stigma items to ensure they are measuring internal stigma. Related to this is the limitation that the study does not include another validated measure that is distinctive to compare the scale with. Future work would also benefit by including a validated measure that is different from the scale, so to extend concurrent and discriminatory validity.

6.5.2 Future directions

Unfortunately, the questions that were phrased positively were not strong enough to be included in the final questionnaire and this may mean the final scale has a negative tone. Future work could explore the use of filler questions to buffer for this. It might be worthwhile rephrasing the internal stigma questions to directly relate to women's identity as a mother. The scale would benefit from including a timeframe in the instruction, for example, "please select the amount you agree or disagree with each of the following statements in the past two weeks". This amendment would allow for measuring change in attitudes and thus assess the effectiveness of interventions.

Cut-offs for the total City MISS could be developed to detect high perinatal mental illness stigma and women at risk of perinatal mental illness. Additional research is needed to test the scale in women with different demographic characteristics and explore test-retest reliability. Furthermore, diagnoses were self-reported so it could be beneficial to test this scale with a clinical population. Future studies would also benefit by using other statistical methods to test the psychometric properties of the scale, such as Rasch analysis (Chang et al., 2015). The analysis for the validity of the City MISS suggested that external stigma may not be a significant variable in the regression model. This could be because the ISMI-10 may not be a

good measure of perceived external stigma. It would be worthwhile replicating the study including measures of stigma other than the ISMI-10.

This study was limited to the stigma experienced by women with perinatal mental illness. The stigma experienced by fathers with perinatal mental illness could be developed. The scale was developed to ascertain the stigma women perceive rather than actually experienced, therefore, future scales could be developed to account for actual experienced stigma and discrimination. Future work would benefit by comparing perceived stigma and experienced stigma.

6.5.3 Clinical implications

The scale provides a potentially useful tool for research on stigma and perinatal mental illness, including the prevalence and characteristics of stigma. This research can be used to inform interventions for reducing or addressing the stigma experienced by some women with perinatal mental illness. The scale could potentially be used to screen women for high perinatal mental illness stigma, which may assist early diagnosis of perinatal mental illness.

7 Use of forums for perinatal mental illness, stigma and disclosure: an exploratory model (Article 6)

Moore, D., Ayers, S., & Drey, N. (2017). Use of forums for perinatal mental illness, stigma and disclosure: an exploratory model. *Journal of Medical Internet Research*. 4(1): e6. doi:10.2196/mental.5926.

7.1 Abstract

Background: Perinatal mental illness is a global health concern, however, many women with the illness do not get the treatment they need to recover. Interventions that reduce the stigma around perinatal mental illness have the potential to facilitate women disclosing their symptoms to healthcare providers and consequently accessing treatment. There are many online forums for perinatal mental illness and thousands of women use them. Preliminary research suggests that online forums may promote help-seeking behaviour, potentially because they have a role in challenging stigma. This study draws from these findings and theoretical concepts to present a model of forum use, stigma and disclosure.

Objective: This study tested a model that measured the mediating role of stigma between online forum use and disclosure of affective symptoms to healthcare providers.

Method: An online survey of 200 women who were pregnant or had a child under five years of age and considered themselves to be experiencing psychological distress. Women were recruited through social media and questions measured forum usage, perinatal mental illness stigma, disclosure to healthcare providers, depression and anxiety symptoms, barriers to disclosure and demographic information.

Results: There was a significant positive indirect effect of length of forum use on disclosure of symptoms through internal stigma, $b=0.40$, BCa CI [0.13, 0.85]. Long-term forum users reported higher levels of internal stigma and higher internal stigma was associated with disclosure of symptoms to healthcare providers when controlling for symptoms of depression and anxiety.

Conclusions: Internal stigma mediates the relationship between length of forum use and disclosure to healthcare providers. Findings suggest that forums may have the potential to facilitate women recognising and revealing their internal stigma, which may in turn lead to greater disclosure of symptoms to healthcare providers.

Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to healthcare providers.

7.2 Introduction

The term perinatal mental illnesses is used throughout this study to refer to conditions that include depression, anxiety, obsessive compulsive disorder, post-traumatic stress disorder and puerperal psychosis. Perinatal mental illness is a global health concern (UNFPA/WHO, 2009). However, prevalence varies depending on a variety of factors such as the instrument used to measure symptoms, developed versus non-developed countries, time of evaluation in the gestational or postnatal period and whether the sample is high risk. Antenatal depression and anxiety occur in approximately 7 to 25% of pregnant women (Biratu & Haile, 2015; Castro et al., 2016; Waldie et al., 2015). Postnatal depression has a prevalence of 12 to 20% and postnatal anxiety affects 3 to 43% of women (Leung & Kaplan, 2009; Glasheen, Richardson, & Fabio, 2010). Post-traumatic stress disorder occurs in 3.17% of new mothers and can affect up to 15% of women in high risk groups (Grekin & O'Hara, 2014). Puerperal psychosis occurs in approximately 1-2 per 1000 women (Munk-olsen, Laursen, Pedersen, Mors, & Mortensen, 2006; Vesga-lopez, 2008). Moreover, many women suffer from symptoms associated with mental illness without detection because they do not conform to all the diagnostic criteria (McKenzie-McHarg et al., 2015).

Approximately half the women with perinatal mental illness fail to get professional treatment despite regular contact with healthcare providers (Dennis & Chung-Lee, 2006). One reason for this is the stigma associated with perinatal mental illness can be a barrier to women disclosing and seeking help (Bilszta, Ericksen, Buist, & Milgrom, 2010). External stigma is a negative attitude held by the general public towards an individual or group based on an undesirable quality, for example mental illness (Goffman, 1963). These negative social stereotypes can lead to

labelling the individual as deviant or inferior. Consequently, discriminatory behaviour can occur towards the stigmatised group for example through social exclusion and marginalisation (Corrigan & Penn, 1999). A UK survey showed that 85% of respondents believed people with mental illness experience stigma and discrimination (The Health and Social Care Information Centre, 2012). There has been noteworthy research and interventions to combat this pervasive social problem, for example, Mind and Rethink Mental Illness developed the “Time to Change” campaign (Time to Change, 2016).

Internal stigma can occur when a stigmatised individual agrees with external stigma and applies it to themselves or they may feel external stigma is unreasonable, yet still appraise themselves negatively. There are many detrimental outcomes of internal stigma including lowered self-esteem, lowered life satisfaction and avoidance of both disclosure and help-seeking behaviour (Corrigan, Rafacz, & Rüschi, 2011; Rodrigues et al., 2013). High levels of internal stigma have been identified in approximately a third of people with severe mental illnesses (West, Yanos, Smith, Roe, & Lysaker, 2011). Furthermore, it is important to distinguish between discrimination an individual experiences and external stigma the individual believes others hold without actually experiencing it (known as perceived external stigma). Perceived external stigma correlates with adverse health and mental health outcomes Pascoe & Smart Richman, 2009; Schmitt, Branscombe, Postmes, & Garcia, 2014). One consequence of perceived external stigma and internal stigma is that they can contribute to stigma associated with disclosure (Moore, Ayers, & Drey, 2016). This paper defines this as “disclosure stigma”: the anticipated negative appraisal and/or anticipated negative behaviour towards the stigmatised individual if they chose to disclose to others. This means that stigma could be a key component in

an individual's decision-making process when choosing whether or not to disclose their symptoms of mental illness.

7.2.1 Internet forums for stigmatised mental illnesses

Internet forums are online discussions where users can have conversations with others by posting messages. They have potential to be an acceptable aid to people with stigmatised conditions as they can use them anonymously, thus circumventing possible negative outcomes associated with stigma (Kendal, Kirk, Elvey, Econ, & Catchpole, 2016; Rains, 2014). Anonymity may also assist online disclosure which may otherwise be difficult offline (Bauer, Bauer, Spiessl, & Kagerbauer, 2013; Chang, 2009). Forums for mental health have shown potential for helping people manage or recover from a variety of mental illnesses, in particular, depression (Griffiths, Reynolds, & Vassallo, 2015; Highton-Williamson & Priebe 2015; Naslund, Aschbrenner, Marsch, & Bartels, 2016). They provide an opportunity to connect with similar others and share informational and emotional support (Huh, 2016). Benefits include social support, communicating experiences with others who share their illness, expressing emotions, group identity, and empowerment and can reduce isolation (Naslund et al., 2016; Bartlett & Coulson, 2011; Bauer, Knap, & Parsonage, 2016; Malik & Coulson, 2011; Moorhead et al., 2013; Pendry & Salvatore, 2015). There is some evidence from randomised control trials that forum use reduces depressive symptoms (Griffiths et al., 2012). These and other benefits have been reported by both active users (visitors who post on forums) and lurkers (visitors who only read forum messages and do not post), although some evidence suggests lurkers benefit less than active users (Coulson, 2015; Setoyama, Yamazaki, & Nakayama, 2011). It is estimated that lurkers make up the majority of forum

visitors, with reports of between 45% and 90% of users lurking (Bishop 2007; van Mierol, 2014).

There is some evidence that engagement with online forums has the potential to reduce stigma (Breuer & Barker, 2015; Parikh & Huniewicz, 2015). Online forums may challenge stigma, help cope with stigma, provide useful tools in testing out disclosing symptoms and conversing about stigma surrounding mental health. Some research suggests that online forums could challenge stigma through empowerment, giving hope of recovery and increasing knowledge of healthcare decisions (Naslund et al., 2016). Theoretically, all these factors could positively influence disclosure to healthcare providers, and subsequently increase treatment uptake and recovery rates. Disclosure may also be encouraged through social support and posts that direct posters to consult healthcare providers (Huh, 2016).

Nonetheless, it should be noted that recent research highlights concern regarding forum use and detrimental outcomes such as social avoidance, Internet addiction and enabling negative behaviours such as pro-anorexic forums (Chang & Bazarova, 2016; Chung, 2013; Lawlor & Kirakowski, 2014).

7.2.2 Online forums for perinatal mental illness and stigma

It is arguable that stigma associated with perinatal mental illness is distinct from mental illness stigma experienced at other times. There are specific concerns related to maternal identity and mental illness such as worries about social services involvement, custodial rights, and being judged by others and judging themselves as a “bad mother” (McLoughlin, 2013). This is complex as some symptoms are highly stigmatised and propagate guilt, shame and consequent concealment of their illness, for example suicidal ideation and thoughts of child abuse. Goffman’s (1963) theory of spoiled identity could be applied to understand how women may experience

stigma affecting their maternal identity. Many symptoms of perinatal mental illness are seen as incompatible with being a good mother and can exacerbate women's illness. For example, a woman with postnatal obsessive compulsive disorder might have persistent intrusive thoughts about harming her baby even though she does not act on them. This is a symptom of the illness, but it generates substantial distress and can damage her identity as a mother as these thoughts are not what she thinks a good mother should have.

Indeed, perinatal mental illness stigma could be conceptualised as multifaceted: comprising of stigma associated with mental illness and stigma associated with being a mother with a mental illness. This stigma could comprise of perceived external, internal and disclosure stigma. All facets of this stigma could contribute to a woman's reluctance to disclose symptoms to healthcare providers (Byatt et al., 2013; Kingston et al., 2015). It is vital that research and interventions target perinatal mental illness stigma to facilitate women disclosing, which is the first step to recovery.

One possible avenue for reducing stigma are online forums for perinatal mental illness. There are thousands of online forums for perinatal mental illness with a large flow of traffic indicating that they are highly used (Moore & Ayers, 2011). Some evidence highlights that perinatal mental illness forums might provide women with valuable peer support outside the hours of healthcare provider appointments (Baumel & Schueller, 2016). Moreover, some research suggests that these forums provide social support that may challenge stigma. One study found an online forum for postnatal depression to be non-judgemental and posts encouraged users to disclose and seek professional help (Evans, Donelle, & Hume-Loveland, 2012). Another study documented how online support forums for lesbians with postnatal

depression provided social support and a space to communicate stigma (Alang & Fomotar, 2015). Many women were reluctant to disclose and seek help because of stigma, they were worried about being seen as an unfit mother and concerned their child would be taken away. The dichotomy of “good mother”, “bad mother” deterred help seeking behaviour, this may be because it contributed to stigma. However, little is known about the relationships between perinatal mental illness forum use, stigma associated with perinatal mental illness and help-seeking behaviour of forum visitors.

A qualitative interview study (N=15) with women who had used forums to assist their recovery from perinatal mental illness explored how women visited forums to reduce their feelings of inadequacy as a mother and perceived stigma from others (Moore & Ayers, 2016). Benefits were reported by both active users and lurkers and women valued the anonymity provided by these forums as they could access social support without fear of judgement. Interestingly, most women suggested that forum culture normalized and validated their stigmatised symptoms and unraveled their identity as a “bad mother” with a mental illness from their identity as a “good mother”. Many women felt they were helped by visiting these forums by developing a collective understanding and discourse about their illness. They suggested that this discourse challenged their internal stigma and empowered them to disclose to others offline.

A thematic analysis of posts on an antenatal and postnatal depression forum suggested that use may increase women's disclosure to healthcare providers, possibly by reducing stigma (Moore, Ayers, & Drey, 2016). Posts provided positive experiences of disclosure to healthcare providers that challenged women's concerns about external stigma. Discourse addressed internal stigma by promoting that a

“good mother” can have perinatal mental illness and if a woman discloses and gets treatment they are a “good mother”. Forums for postnatal mental illness may therefore provide a place where women can express internal stigma and concerns about external stigma and disclosure stigma. They offer a unique opportunity to anonymously explore sensitive and highly stigmatised issues around their illness with others who may be experiencing the same problems. Potentially, these types of stigma could be challenged by women sharing positive experiences of disclosure. Forum rhetoric could reconstruct the idea of a good mother as compatible with perinatal mental illness, especially if women seek help. Thus, forum use has the potential to increase women's disclosure to healthcare providers by influencing stigma.

7.2.3 Aims

This study aimed to test a model that examined the role perinatal mental illness stigma has in mediating between forum use and disclosure to healthcare providers. It was hypothesised that perinatal mental illness stigma would mediate between online forum usage and disclosure to healthcare providers (Figure 7.1).

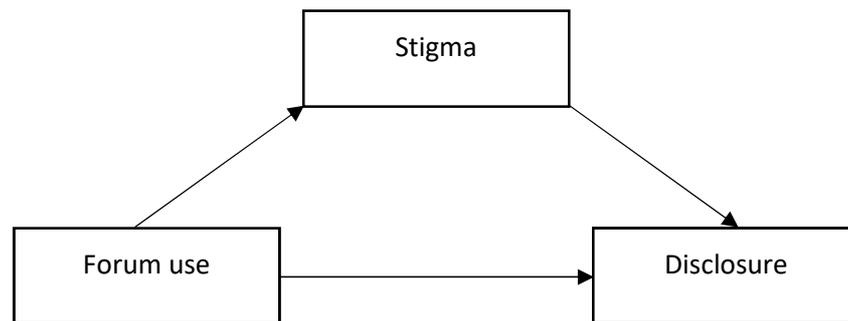


Figure 7.1 Hypothesis model

7.3 Method

7.3.1 Design

A cross-sectional online survey of forum use, stigma and disclosure in women during pregnancy and up to five years after birth who identified themselves as having some level of distress or psychological problems. Due to the sensitive nature of stigma, the information about the study did not use the term perinatal mental illness as some women might not have wanted to associate with the label, instead, the terms “psychological problems, stress and/or isolation” were used. Demographic information was collected and symptoms were also measured.

7.3.2 Participants

Respondents were recruited by advertising on perinatal mental illness websites, baby-related websites, Facebook groups and Twitter. 422 women started completing the questionnaires via an online survey and 200 had complete answers for the measures used in the model (Qualtrics, LLC, 2015). The survey questions can be found in the Appendix 7.1. Inclusion criteria stipulated that women were over 18

years old, were pregnant or had a child under five years old, were a UK resident, considered themselves to be experiencing psychological distress and had used perinatal mental illness forums.

7.3.3 Measures

7.3.3.1 *City Mental Illness Stigma Scale*

Stigma was measured using the City Mental Illness Stigma Scale a 15-item scale that measures the unique stigma women with perinatal mental illness experience (Moore, Ayers, & Drey, 2017). It was developed from a literature review of perinatal mental illness stigma and tested via an online survey with women with perinatal mental illness ($n = 279$). Factor analysis was used to create the final 15-item scale. The scale accounted for 54% of the variance in the sample and had good reliability with Cronbach's alphas between .81 and .86 for subscales and an overall alpha for the total scale of .84 indicating high reliability. The City MISS was highly correlated with a reliable measure for mental illness stigma (brief version of the Internalized Stigma of Mental Illness; ISMI-10 scale) which suggested good concurrent validity ($r(277) = .56, p < .001$).

Respondents were asked to score the extent to which they agreed with a series of statements measured on Likert scales (1-4); 'strongly disagree', 'disagree', 'agree' and 'strongly agree' with higher scores signifying greater stigma. The scale has a three-factor structure: the first concerns perceived external stigma, the second internal stigma and the third disclosure stigma.

The perceived external stigma subscale comprised of six statements that measured the respondent's beliefs about what other people think about mothers with psychological problems, for example, "people think mothers with psychological

problems will harm themselves”. The internal stigma subscale contained five questions that extend the concept of a “spoiled identity”, in this case it was specifically related to the respondent’s identity as a mother, for example “I have thoughts about leaving my baby” (Goffman, 1963).

The disclosure stigma subscale contained four questions that measured respondents’ anticipated discrimination if they disclosed their symptoms or diagnosis to healthcare providers. It contained two items that measured how they believed others would perceive them if they disclosed their psychological problems, for example “I worry that if I told a healthcare provider about my thoughts they would think I am an abusive mother”. It contained two items that rated the potential negative consequences of disclosure, for example “I worry that if I told a healthcare provider about my psychological problems the social services would get involved”.

7.3.3.2 Hospital Anxiety and Depression Scale

Current affective symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS questionnaire has 14 items; seven questions to measure depression and seven questions to measure anxiety which is widely used to score symptoms for many mental health conditions and languages (Montazeri, Vahdaninia, Ebrahimi, & Jarvandi, 2003). It has good validity and reliability. Many studies from various countries including samples with different health conditions have reported factor analysis results supporting the two factor structure; depression and anxiety and significant correlations between the two factors (Al Aseri et al., 2015; Montazeri et al., 2003). The scale has also shown correlations with other scales that measure depression and anxiety (Bjelland, Dahl, Haug, & Neckelmann, 2002).

7.3.3.3 Assessment of forum usage, disclosure, and demographic information

Forum usage was measured with questions specifically developed for the study that measured frequency and duration of forum use, frequency of writing posts and frequency of reading posts. Participation level was classified in accordance with previous literature that defined active and lurker status (Amichai-hamburger, 2016; Sun, Rau, & Ma, 2014). Women were categorised as active if they started threads and/or replied to posts and lurker if they did not contribute to forum conversations. Frequency of forum visits and duration of forum use categories were developed by all authors and subject to data analysis several times using different classifications and cut offs to see if the results were altered. All authors agreed on the final categories based on face-validity and categories with approximately equal numbers. Frequency of forum visits was measured as occasional when women reported visiting three times or less a month and frequent when reported as once or more a week. Duration of forum use was measured as long-term for members who had been visiting a year or more and short-term if under a year.

Disclosure was ascertained by participants indicating the people they had disclosed symptoms or diagnosis to e.g. health visitor, family member, midwife. Results were coded as disclosed to a healthcare provider or not disclosed to a healthcare provider.

Demographic information was collected about marital status, ethnicity, occupation, education, number of children and diagnosis.

7.3.3.4 Procedure

The survey was piloted with six women with children under three and all found it acceptable and easy to understand and answer. Ethical approval was given by City, University of London, UK (Appendix 6.1). Website and forum administrators were

contacted to ask for consent to post information about the study and a hyperlink to the survey. The participant information sheet and the first and last page of the survey urged women to contact their healthcare provider should they feel upset and provided details of outside organisations that offered support. The first page of the survey was the participant information sheet and participants had to click a box to confirm that they consented to the study before they could progress to the survey.

7.3.3.5 Data analysis

Results were included if the respondent had completed all the forum questions and the City MISS questions (n=200). Internet Protocol addresses were checked for duplication, but none were identified. The models were analysed using the statistical software package IBM SPSS 20.0 and the moderation and mediation plug in PROCESS (Software, 2016). Mediation analysis was conducted using the method suggested by Hayes (2013). This method was used because tests whether there is an indirect effect and has good power because it uses bootstrapping (Hayes; 2013; Jose, 2013). Frequency of forum visits, duration of forum use, and frequency of writing posts were entered as predictor variables. City MISS scores for subscales internal, external and disclosure stigma were entered as mediators. The outcome variable was disclosure of symptoms to a healthcare provider. HADS scores were entered as a covariate to account for potential confounding effects on the relationships between variables. The bootstrapping method was used to test the potential mediation effect using 1000 iterations. This method was chosen as it allows for multiple mediators, controls for the effects of covariates, has a higher power than the traditional Sobel test and reduces the possibility of a type I error. The bootstrapping procedure computes the confidence intervals (CIs) for the indirect path. The null hypothesis is that the indirect path does not significantly differ from zero so if the CIs do not

include zero, then the null hypothesis can be rejected and the indirect effect is significant when $p < 0.05$. Qualitative answers regarding disclosure barriers were transferred to the NVivo 10 software package and coded for external, internal and disclosure stigma (QSR International Pty Ltd., 2012).

7.4 Results

7.4.1 Sample characteristics

Participant characteristics are provided in Table 7.1. Most participants classed themselves as White ($n=191$) and married or living with a partner ($n=133$, $n=48$). Over 60% ($n=125$) were educated to degree level or above and most had one child ($n=139$). The majority of women had a diagnosis of one or more postnatal mental illnesses (71%, $n=142$) but 23% ($n=46$) of women reported postnatal mental illness, but had not sought a professional diagnosis. The remaining women had a diagnosis of antenatal mental illness (1.5%, $n=3$) or both antenatal and postnatal mental illness (4.5%, $n=9$). On the basis of the HAD measure completed during this study ($n=200$), 66.5% ($n=133$) of women had moderate or severe anxiety and 34.5% ($n=69$) had moderate or severe depression. Forum use characteristics are presented in Table 7.2. Women were almost evenly categorised as frequent/occasional users and long-term/short term users ($n=92$, $n=108$). There were nearly three times as many active users than lurkers ($n=156$, $n=44$).

7.4.2 Correlational analysis

Relationships between variables are presented in Table 7.3. The length of forum use was significantly correlated to internal stigma score (subscale of City MISS).

Frequency of forum visits was significantly correlated to participation level. Total stigma score was significantly correlated to internal stigma, external stigma, and disclosure stigma (stigma subscales of City MISS). Internal stigma score was significantly correlated to disclosure to a healthcare provider. Total affective symptoms score was significantly correlated to total stigma score, internal stigma, external stigma, and disclosure stigma. Total affective symptoms was the only variable that had significant correlations with the model variables, that is, all mediator variables. Therefore, total affective symptom score was entered as a covariate in the following analyses.

7.4.3 Stigma mediating the relationship between forum use and disclosure

There was a significant indirect effect of length of forum use on disclosure of symptoms to a healthcare provider through entering all stigma subscales as simultaneous mediators, $b=0.16$, BCa CI [0.04, 0.40]. There was no direct effect between forum variables and disclosure, $b=0.47$, $p = 0.33$ (See Appendix 7.2, Figure 7.2). Internal stigma was the only variable to show significant effect on disclosure, $b=0.15$, $p<0.00$.

There was a significant indirect effect of length of forum use on disclosure of symptoms to a healthcare provider through internal stigma, $b=0.399$, BCa CI [0.133, 0.846]. There were no other indirect effects between variables and there was no direct effect between forum variables and disclosure, $b=0.133$, $p = 0.793$ (Figure 7.2).

Table 7.1 Sample demographic characteristics

Characteristics	Subcategories	<i>N</i>	%
Marital status	Single	12	6
	Married	133	66.5
	Living with partner	48	24
	Separated	3	1.5
	Other	2	1
Ethnicity	White	191	95.5
	Mixed/Multiple ethnic groups	5	2.5
	Other	2	1
Occupation	Employed	104	52
	Self-employed	17	8.5
	Out of work	9	4.5
	Homemaker	47	23.5
	Student	11	5.5
	Unable to work	10	5
Education	GCSE's	17	8.5
	A levels	30	15
	Trade/vocational training	26	13
	Bachelor's degree	89	44.5
	Master's degree	34	17
	Doctorate degree	1	0.5
Number of children	1	139	69.5

	2	45	22.5
	3	6	3
Diagnosis	Antenatal depression	2	1
	Antenatal depression and anxiety	1	0.5
	Antenatal depression and postnatal depression	9	4.5
	Postnatal depression	53	26.5
	Postnatal anxiety	9	4.5
	Post-traumatic stress disorder (PTSD)	23	11.5
	Postnatal depression and anxiety	23	11.5
	Postnatal depression and PTSD	19	9.5
	Three or more postnatal mental illnesses	7	3.5
	Puerperal psychosis	3	1.5
	Other postnatal mental illness	5	2.5
	No diagnosis sought	46	23

Note: Total number of participants in demographic categories does not add up to 200 as not all participants completed the demographic questions.

Table 7.2 Sample forum use characteristics

		<i>N</i>	<i>%</i>
Frequency of visits	Frequent	108	54
	Occasional	92	46
Participation level	Active	156	78
	Lurker	44	22
Duration of use	Long-term	108	54
	Short-term	92	46

Table 7.3 Bivariate correlations of dependent variables, independent variables, mediators and control variable

	1	2	3	4	5	6	7	8	9
1 Disclosure	1	.060	-.004	.045	.138	.230**	.074	-.019	.019
2 Length of use		1	-.087	.043	.150*	.180*	.064	.087	-.020
3 Frequency of visits			1	.285**	.088	.065	.031	.111	.066
4 Participation				1	.058	.095	.061	-.041	.032
5 Total City MISS					1	.751**	.766**	.744**	.423**
6 Internal stigma						1	.299**	.331**	.393**
7 External stigma							1	.434**	.222**
8 Disclosure stigma								1	.339**
9 HADS									1

* correlation is significant at the .05 level (two-tailed)

** correlation is significant at the .01 level (two-tailed)

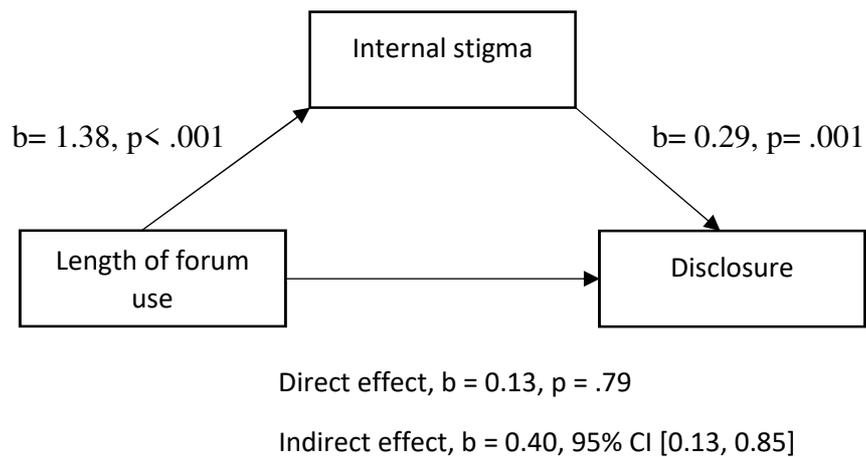


Figure 7.2 Final model

7.5 Discussion

7.5.1 Principle Results

This study tested a model based on previous research that proposed perinatal mental illness stigma mediates between forum use and disclosure. There was a significant indirect effect of length of forum use on disclosure of symptoms to healthcare providers through internal stigma. Long-term forum users reported higher internal stigma scores and higher internal stigma was associated with disclosure to a healthcare provider. There was no indirect effect of perceived external or disclosure stigma, nor was there a direct effect between length of forum use and disclosure. Qualitative findings support this as many women reported that external, internal and disclosure stigma specific to perinatal mental illness were barriers to their disclosing to healthcare providers.

There was theoretical reason to believe that increased forum use would be associated with decreased stigma and increased disclosure to healthcare providers. Also, social support offered by forum members might be empowering and play a role in disclosure. Results unexpectedly indicated that forum use was associated with

increased reported internal stigma. There are a number of possible explanations for this. It is plausible that visiting forums might have adversely affected internal stigma or it may be that women with higher internal stigma use forums for longer. However, this study advocates an alternative explanation of the findings and proposes that forum messages encouraged these women to recognise their feelings of internal stigma and this increased their self-awareness enabling them to make a fuller disclosure when completing the stigma questionnaire. Previous research suggests that forums may provide a place where women can explore their feelings, and this may have meant that implicit feelings of internal stigma could have become explicit (Moore, Ayers, & Drey, 2016). Also, women may have overcome barriers to revealing this internal stigma through forum benefits such as social support, identification with the forum group and an alternative perspective of perinatal mental illness that shifted their “spoiled identity” to an empowered identity as a good mother despite having a mental illness.

Interestingly, there was no direct effect between forum use variables and disclosure. Current research suggests that mediation can occur without results showing a direct effect (Moran, Polanin, & Wenzel, 2014; Rucker, Preacher, Tormala, & Petty, 2011). It is possible that other factors omitted from the analyses may have weakened the direct effect, also known as suppressor variables. Possible suppressor variables are individual differences such as personality traits, experience of discrimination and social support. Furthermore, there may have been an over representation of a subset of women who do not have a significant relationship between the predictor and outcome variables, and thus a direct effect would have been neutralised. Future research could measure potential suppressor variables to explore this intricate relationship.

7.5.2 Limitations

Caution should be exercised when considering generalisation from this sample as there are a number of characteristics that might not be true of the general population of forum users. The women were mostly White and educated to A-Level or above. There was also an over representation of active users, possibly because active users have a more vested interest in forum research or they have different traits which might make them more likely to post on forums and participate in online surveys (Lawlor & Kirakowski, 2014). The majority of women had experienced symptoms in the postnatal period, and thus findings might not extend to antenatal populations. The model could benefit from future modifications such as including a measure of whether women had experienced discrimination when disclosing, such as “health professional stigma” (Ahmedani, 2011). Similarly, there was no measure of other social media use that may affect stigma levels and have further implications for disclosure behaviour. The type of forum or combination of forums women used may have had an impact on the results, for example, if the forum was moderated or unmoderated. The study cannot determine the direction of causality because it was cross-sectional. It is impossible to ascertain if changes in one variable would predict changes in another, therefore it would be erroneous to conclude that forum use increases disclosure. There could be other factors that this study has not included that account for why there is a relationship between the two factors. It may therefore be that women who disclosed may be more likely to visit forums (due to any myriad of individual differences) rather than forum use in itself increasing disclosure behaviour. However, it does show that there is a relationship between the variables and future research should use experimental and longitudinal designs to be able to ascertain the direction of this potential effect and include a measure of forum type.

Future research could test the theories suggested as part of prevention and intervention studies.

It is important to consider the construct validity of the internal stigma subscale. The subscale may not measure internal stigma, rather it may be measuring something else for example, symptom severity or identification with PMI. Future investigations should take time to consider how internal stigma is conceptualised and developments in terms of theory and evidence-based measures of internal stigma.

7.5.3 Comparison with Prior Work

This study supports and extends previous research that suggests forum use may affect internal stigma and in turn lead to disclosure, however, this relationship may be more complex than our initial model proposed (Breuer & Barker, 2015; Parikh & Huniewicz, 2015). Interpretation of the findings suggest that perceived external stigma and disclosure stigma do not mediate between forum use and disclosure. This is surprising because prior studies showed that perinatal mental illness forum messages are pro-disclosure and supply positive experiences with healthcare providers (Moore et al., 2016; Evans et al., 2012; Alang & Fomotar, 2015).

Another consideration is that forums differ in their posts concerning healthcare providers. Recent research has highlighted that some forums include many negative experiences with illness symptoms and experiences with healthcare providers (Faith, Thorburn, & Sinky, 2016). Thus, some forums may contain conversations that reduce disclosure stigma and external stigma and others, albeit inadvertently, may increase external stigma and disclosure stigma. Women in this sample may have been visiting a mixture of these types of forums and they may have had different effects on perceived external stigma and disclosure stigma. Therefore,

future research should not dismiss the exploration of external stigma and disclosure stigma in forum use.

Qualitative findings confirm that stigma is a major barrier to disclosure and details the complex relationship between maternal identity and internal stigma, external stigma and disclosure stigma (Moore et al., 2016). Other studies advocated a negative effect on disclosure from an over reliance on forums, but this was not suggested in our findings (Chung, 2013; Lawlor & Kirakowski, 2014). However, it may be worth investigating whether there are forums that maintain or generate stigma, for example, through providing negative experiences with healthcare providers, such as a forum for birth trauma.

7.5.4 Conclusions

Findings suggest internal stigma of perinatal mental illness mediates between forum use and disclosure. Using forums may provide valuable social support and improve women's disclosure to healthcare providers through enabling expression of their internal stigma. Theoretical reasons for this have been discussed, in particular, it is suggested that women can explore their feelings so they become more aware of their internal stigma and are empowered to express these feelings. Also, women may be enabled to disclose by reconciling the negative impact of internal stigma on their maternal identity by agreeing with forum discourse that promoted the idea that one can be a good mother despite having perinatal mental illness. Future work could test these theories and continue to strengthen knowledge of perinatal mental illness, forum use, stigma and disclosure behaviour. Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to healthcare providers.

8 General discussion of the thesis

This thesis consists of six studies that address the overall research aims; (i) to explore Internet resources for women with perinatal mental illness and how they are used by women and (ii) to examine the relationship between Internet forum use, stigma and disclosure to healthcare providers.

Chapters 2 to 7 presented each study and discussed the findings and implications in relation to each specific aim. The first section is a summary of the findings, explaining how they link together in the context of the two overall aims of the thesis as well as the previous literature. The second section examines methodological strengths and limitations. The third section considers overall implications of these studies and identifies future investigations. The chapter ends with overall conclusions.

8.1 Summary of findings

This section will consider a summary of the combined findings of the articles in this thesis and include (1) summary of the findings, (2) main themes and (3) underlying mechanisms.

8.1.1 Summary of the combined findings

The work of the thesis started with a meta-synthesis of the current research on forums for perinatal mental illness and stigma (Article 1). This included five studies that were described and interpreted to provide new insights into the stigma of perinatal mental illness. Findings identified 18 themes across the studies which were then organised into four key themes: (1) safe place to talk; (2) virtual support; (3) stigma and identity; and (4) repair of the mother's identity. *Safe to place to talk*

encapsulated how many women in the studies were able to converse honestly about stigmatised symptoms online. Women tended to avoid disclosing offline, and for, some this was because it intensified their feelings of maternal inadequacy. Instead, online disclosure protected their maternal identity as they could disclose anonymously and the forum audience was non-judgemental. *Virtual support* was characterised by support given by forum members that may have helped reduce feelings of internal stigma. This included sharing personal stories with others who were going through similar experiences, normalising and validating stigmatised symptoms, offering hope and encouragement, and providing emotional support. *Stigma and identity* referred to how perinatal mental illness affected women's identity as a mother. 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. This was often expressed by women using a "good mother" discourse; women conceptualised what it was to be a good or ideal mother. The final theme; *repair of the mother's identity*, described the discourse that sought to repair maternal identity by challenging the stigma of being a mother with a mental illness. Forums provided a valued platform for women to converse using a "good mother discourse" and repair their damaged maternal identity through reconciling that they are good mothers despite having perinatal mental illness. Overall, findings suggested that current qualitative literature points towards forums' potential to reduce internal stigma through virtual support, space to discuss experiences of internal stigma and disentanglement of perinatal mental illness from the maternal identity.

The website review evaluated 114 websites using evidence-based information on postnatal depression, support services, self-help, website technology, treatment

and screening information (Article 2). The website review rated the available resources for women with perinatal mental illness and healthcare providers. Findings showed that websites contained information that was mostly incomplete and difficult to read. Information was mostly on symptoms, with infrequent information on risk factors and the impact of the illness on the family. Symptoms were largely discussed in terms of depression and not other potential perinatal mental illnesses.

The website review showed that there was not much available help for women in recovery and these often presented as self-help tools (for example, relaxation techniques, stigma around illness and stories about women's personal experiences of perinatal mental illness), support (for example, forums, phone and email), and additional resources for mothers (for example, downloads, links and book recommendations). Many websites had superficial information on treatment. Screening and additional resources for healthcare professionals were infrequent. Most websites assured users of recovery and encouraged seeking medical help. However, sites rarely had clear information on what women should do if they had thoughts of harming themselves or their infant.

The quality of website technology was variable, meaning that some sites were good for content, but could not be recommended because they were extremely difficult to use. Findings broadly confirmed previous research that showed information was incomplete and websites had problems with technology (Summers & Logsdon, 2005). Similarly, "Postpartum Support International" (<http://www.postpartum.net>) was one of the top-rated websites in both the study by Summers and Logsdon (2005) and the thesis review. The website review showed that only one website had misleading information compared to four in the Summers and Logsdon (2005) study. Moreover, interest in postnatal mental health had grown

considerably from 2005 to 2010, indicated by an increase in results from a Google search for “postnatal depression”, 83,600 and 1,360,000 respectively (April, 2010).

The interview study (Article 3) was conducted to explore how women with perinatal mental illness were using the aforementioned online available help tools for women in recovery. The majority of women described how forums provided social support and suggested an online community of sufferers and survivors actively and passively engaging in a shared online voice. There were two themes (1) anonymous and non-judgemental support and (2) not alone. *Anonymous and non-judgemental support* referred to the majority of women visiting forums to reduce their feelings of inadequacy and perceived stigma from others. The results suggested that social support on forums communicated an alternative discourse about postnatal mental illness that challenged their internal stigma.

Not alone was a theme that encapsulated how forums provided anonymity and non-judgemental social support. This may have made it an acceptable way to counteract internal stigma through normalisation, validation and separating the illness from their identity as a mother. Most women were empowered to disclose to family and healthcare providers through engaging either actively or passively with this virtual "voice" that encouraged them to disclose offline. Only a minority of women described negative experiences when using websites and forums.

The findings from the interview study are consistent with studies that suggested users benefit from forums, showing they may be an acceptable aid for people with stigmatised conditions (Crabtree, 2010; Rains, 2014). This exploratory study pointed towards some ways forums may have challenged perinatal mental illness stigma. Findings extended the existing literature by providing the perspective

of the interactions of women engaging in a collective shared “voice” online. In contrast to previous studies, such as Evans et al’s. (2012) website review, some potential risks to women were revealed. The women in this study were discerning when choosing a “safe” forum, especially as there are unmoderated forums that do not have safeguarding policies or individuals to monitor and ensure posts are not abusive or contain misinformation. Results suggested that some women in this sample identified times when reading forums can be of assistance and times when it can be harmful, rather than problems with overuse as previous research suggested (Lawlor & Kirakowski, 2014).

The thematic analysis of posts on a forum for antenatal and postnatal depression was conducted to further examine how women used online forums and the possible impact use had on stigma and disclosure (Article 4). Two major themes were identified (1) stigma and (2) negative experiences. Stigma had three subthemes: internal stigma, external stigma, and treatment stigma. *Internal stigma* referred to the stigmatised attitudes many women had towards themselves, such as feelings of maternal inadequacy. Many women used the forum to disclose shameful stigmatised feelings often hidden from others as they felt that there was nowhere offline to talk about the negative side of pregnancy and motherhood. Members often replied to these posts and challenged internal stigma by stressing that these feelings were part of the illness and not a reflection of parenting capabilities.

External stigma comprised the concerns many women had about how healthcare providers would think that they were inadequate mothers if they disclosed symptoms. Replies endorsed a strong culture of advice that urged women to contact a healthcare provider. Half of all women who had not disclosed to a healthcare

provider when they first posted replied that they had since pursued professional help following other members' encouragement.

Treatment stigma extended concepts of internal and external stigma by encompassing women's concerns about seeking and adhering to treatment from healthcare providers.

Often posters emphasised the importance of professional treatment in recovery; frequently reassuring women that they had done the right thing when they posted they had disclosed to healthcare providers and posters reconceptualised what the notion of good mother, namely, a good mother gets help and takes treatment.

The second major theme was *negative experiences*. Very few posts described negative experiences when disclosing to healthcare providers. These posts highlighted internal and external stigma concerns, however, the majority of subsequent posts challenged this stigma by promoting treatment as essential for recovery.

Like previous research, internal and external stigma attached to mental illness was a salient barrier to treatment and the women on the forum were able to "test out" disclosing symptoms and concerns through online conversations (Dennis & Chung-Lee, 2006; Megnin-Viggars et al., 2015; Poole, Smith, & Simpson, 2015). External stigma was often communicated in forum posts and supported previous research that described women's stigma concerns about being perceived by others as a "bad mother" (McLoughlin, 2013). Findings support previous research suggesting that women believe healthcare providers view women with perinatal mental illness as inadequate mothers and therefore in need of external assistance or, at worst, unable to care for their baby so their baby might be taken into care.

Results extended concepts from previous literature including the concept of “good mother” discourse, in this case suggesting a good mother discloses and gets treatment. Posts challenged the distressing dissonance between the idea of a good mother and that of a bad mother, present in some mothers’ posts and thus reconciled that a “good mother” can have perinatal mental illness. Unlike previous research on perinatal mental illness forums, there were three posts that described negative experiences of disclosing to healthcare providers (Evans et al., 2012; Alang & Fomotar, 2015; Kantrowitz-Gordon, 2013).

The stigma scale was developed because there was no psychometric scale that measured how women may experience the unique aspects of perinatal mental illness stigma (Article 5). Previous research highlighted how perinatal mental illness stigma is different from simply stigma associated with mental illness (Abrams & Curran, 2011; Battle et al., 2013; Beck, 2002; Bilszta et al., 2010; Bultjens & Liamputtong, 2007; Byatt et al., 2012; Edge, 2006; Edwards & Timmons, 2005; Gardner et al., 2014; Hanley & Long, 2006; Mauthner, 1999; McCarthy & McMahon, 2008; McLoughlin, 2013; Patel, 2013; Price & Bentley, 2013; Shakespeare et al., 2003).

Questions were developed on the basis of the results of the meta-synthesis, interview study, and thematic analysis and tested on an online survey of 279 women with perinatal mental illness (Articles 1, 3 & 4). The final 15-item, City Mental Illness Stigma Scale (City MISS scale) had a three-factor structure: perceived external stigma, internal stigma and disclosure stigma. *Perceived external stigma* measured what women believed other people thought about mothers with mental illness and was associated with how other people thought women fulfilled their role as a mother. *Perceived external stigma* was related to stigma concerns women had

about people perceiving women with perinatal mental illness as “bad mothers”, for example “people think mothers with psychological problems don’t love their babies”.

Internal stigma subscale extended the concept of a “spoiled identity”, specifically highlighting problems associated with perinatal mental illness that exacerbate women’s feelings of maternal inadequacy, for example, not coping or bonding difficulties. Questions were developed to ascertain if women experienced these difficulties, for example “I find it difficult to love my baby”. *Disclosure stigma subscale* measured women’s anticipated discrimination if they disclosed their symptoms or diagnosis to others, for example “I do not want people to know I have a psychological problem as they may think I’m a bad mother”.

The scale accounted for 54% of the variance and had good internal reliability and concurrent validity, with strong correlations with a general measure of stigma for mental illness. This scale extends previous research into perinatal mental illness stigma and adds a potentially useful tool for research and measurement of stigma and perinatal mental illness. This new scale contributes to existing literature on the theoretical understanding and conceptualisation the stigma women may experience in the perinatal period.

The mediation model study measured the mediating role of stigma between online forum use and disclosure of affective symptoms to healthcare providers (Article 6). An online survey measured forum usage, perinatal mental illness stigma (City MISS scale), disclosure to healthcare providers, depression and anxiety symptoms, barriers to disclosure and demographic information (n=200). Results showed that there was a significant positive indirect effect of length of forum use on disclosure of symptoms through internal stigma. Long-term forum users reported

higher levels of internal stigma and higher internal stigma was associated with disclosure of symptoms to healthcare providers when controlling for depressive and anxious symptoms.

The mediation model supports and extends previous research that suggested forum use affects internal stigma (Alang & Fomotar, 2015; Evans et al., 2012; Kantrowitz-Gordon, 2013). This model quantitatively supports that internal stigma mediates the relationship between length of forum use and disclosure to healthcare providers. Findings extend existing qualitative knowledge by suggesting that forums potentially affect internal stigma through facilitating women recognising and revealing their internal stigma, which may result in greater disclosure of symptoms to healthcare providers.

8.1.2 Main themes

This section discusses the main themes that have emerged from the work in this thesis and includes; components of perinatal mental illness stigma, good mother discourse and negative experiences of using forums.

8.1.2.1 Components of perinatal mental illness stigma

The investigation conceptualised perinatal mental illness stigma as comprising of three components; external stigma, internal stigma and disclosure stigma. Each component is discussed and their relationship with forum use and disclosure to healthcare providers is considered. Findings were used to develop an exploratory model that tested whether these components of stigma mediated between forum use and disclosure of symptoms to healthcare providers. Overall findings suggest that some women use online forums to explore concerns with stigma and disclosure of

their illness. The investigation also suggested that forum use may affect women's disclosure to healthcare providers by enabling women to recognise internal stigma, and challenge stigma through conceptualising the maternal identity as compatible with perinatal mental illness.

When conceptualising perinatal mental illness stigma it may be important to reflect on the complexities of the suggested theoretical components. For instance, it is possible that the work in this thesis conceptualised stigma in different ways according to the research aims and questions of each article. For instance, the thematic analysis study may give different weight to some elements of disclosure stigma e.g. an overemphasis of treatment stigma when compared to the stigma scale study that gave less attention to treatment in favour of concerns about disclosing stigmatised feelings to healthcare providers. Also, the different methodologies in the studies could have yielded different perspectives of the same phenomenon. Linked to this is the idea that rather than presenting different facets of the same constructs, the investigation may have actually been exploring separate constructs of stigma. Prudence may be required when conceptualising perinatal mental illness stigma, especially when interpreting and applying these findings to future theoretical development and research designs.

8.1.2.2 Good mother discourse

The investigation highlighted the “good mother” discourse used by many women who post on online forums for perinatal mental illness. Women frequently expressed internal stigma by using discourse that described their “spoiled identity” including terms such as “bad mother”, “unfit mother” and “failure” (Article 1, 3, 4 & 5). This is consistent with the literature and showed that women were able to discuss these painful and stigmatised feelings in an understanding and non-judgmental

environment (Alang & Fomotar, 2015; Evans et al., 2012; Kantrowitz-Gordon, 2013). Indeed, many women described that there was no place offline to talk about the negative side of pregnancy and motherhood and so valued using forums to disclose shameful feelings that they often hid from others. Specific concerns were not meeting parental responsibilities, wanting to leave the baby or family, intrusive thoughts of self-harm and child-abuse.

Stigmatised symptoms were often met with replies that were reassuring and challenged internal stigma. Often forum discourse conceptualised symptoms as synonymous to the illness, rather than being a reflection of their capabilities as a mother. This supported previous evidence that suggested women may separate their maternal identity from that of a “bad mother” or “spoiled identity” localising the blame outside themselves, thus reducing internal stigma (Abrams & Curran, 2011).

The findings from this investigation point towards the potential of forums to provide experiential knowledge of symptoms that may help women recognise that they have an illness, rather than just experiencing “normal” transition to parenthood difficulties, or simply being a “bad” mother. This increased knowledge, when coupled with a new understanding of themselves as a mother with a potential mental illness, may help women disclose and seek professional help. Women in the study tested out disclosing online and got encouragement to seek professional help. Findings suggest that disclosure was further enhanced by an alternative discourse which reconciled that a woman can have perinatal mental illness and still be a good mother.

The conceptualisation of a “good mother” online included the idea that a good mother discloses to healthcare providers and gets treatment. Forum discourse

displayed the mindset that a woman with perinatal mental illness can be a good mother, especially if she received treatment as this was viewed as essential for recovery. This way of thinking challenged perceived external and disclosure stigma by providing positive experiences when disclosing to healthcare providers, but, perhaps more importantly, re-conceptualised perinatal mental illness including a positive maternal identity and addressed the painful feelings associated with internal stigma.

8.1.2.3 Negative experiences

It may be important to strive towards a balanced view when considering the potential outcomes associated with forum use. The investigation sought to achieve this by also contemplating negative influences or disadvantages of forum use on stigma. Unlike previous research on perinatal mental illness forums, the findings from the work of this thesis suggest three main concerns: the impact of unmoderated forums; times when forum use may be detrimental to mood; and posts that contained negative experiences of engaging with healthcare providers.

The interview study showed that some forums are not moderated meaning that there is no-one to enforce safeguarding (Article 3). Forum moderators promote the welfare and safety of members by viewing posts and removing any harmful messages or inaccurate information. Moderators can caution and remove members who do not adhere to the forum policy and lock conversations if they become argumentative. However, policies and moderators vary from site to site and may not always be dependable. When forums are unmoderated there is the potential for harmful posts to be displayed and members may act inappropriately. This can have serious consequences for already vulnerable women who visit the sites, for example, “flaming” might damage women’s self-esteem. “Flaming” is aggressive interactions

between Internet users and can occur on forums, particularly if the forum is unmoderated. It is often characterised by the swapping of insults and it can occur when one person instigates negative posts or when a group of users target a single victim. Closely related to this is the phenomenon of “trolling”; where a person deliberately targets social communication sites with the intention of disrupting communities and upsetting individuals by posting inflammatory remarks.

The interview study also suggested that some women found that there were times when forums helped their distress and other times when they exacerbated symptoms. While the women in this study appeared to be discerning when choosing a good time to use forums, it is a concern that other forums users might not exercise such discernment and actually experience their feelings of stigma increasing. The thematic analysis revealed that although the vast majority of posts described positive experiences, there were three reports of negative experiences when disclosing to a healthcare provider. Concerns are warranted as to the potential negative outcome of reading these experiences for women. Women with perinatal mental illness are vulnerable, some feel deflated in their role as a mother and are trying to decide whether or not to disclose to others. Women may be using information about what happens to others when they tell healthcare providers about stigmatised symptoms to make this decision. Potentially, posts that describe negative experiences of disclosure could actually increase feelings of stigma and encourage women to hide their symptoms from healthcare providers.

Recent research has highlighted that some forums include many negative experiences with healthcare providers, however this was not reflected in the current findings (Faith, Thorburn, & Sinky, 2016). Nevertheless, it is important to reflect on some forums that may contain discussions that potentially reduce disclosure and

other forums that, albeit inadvertently, may increase perceived external stigma and disclosure stigma. Women in the samples may have been visiting a mixture of forums and they may have had different effects on perceived external stigma and disclosure stigma.

8.1.2.4 Underlying mechanisms

Goffman (1963) theorised that some individuals will conceal their stigmatised status because they desire to be accepted by others and/or are concerned that others will perceive them unfavourably. The work in this thesis supports this theory and suggests that women in the studies often expressed their preference for disclosing online because they could remain anonymous, compared to offline situations where they claimed that they were potentially exposed to perceived external stigma. In addition, findings suggest that offline disclosure was hindered by women's concerns about their maternal identity. They were concerned not only with being labelled by others as a "bad mother", but also disclosing offline was associated with a risk of increasing their own feelings of maternal inadequacy, or internal stigma. They felt they could safely reveal their "spoiled identity" online because forums were often described as providing social support and a non-judgmental atmosphere that encouraged an alternative dialogue about this negative side of motherhood.

Findings suggest that online forums present a good mother rhetoric that re-conceptualises what a good mother is and seeks to disarm perceived stigma and internal stigma. This suggests that it was possible for mothers to be part of the "good mother" group as maternal identity was compatible with perinatal mental illness, especially if women sought help from healthcare providers.

Surprisingly, the mediation model shows that forum use actually appeared to increase internal stigma rather than reduce it, as the model hypothesised (Article 6). One possible reason for this is that forum use may assist women in recognising their own internal stigma through discussion of stigma issues and encouragement to talk about it without attaching the stigma of the illness to the maternal identity. Therefore, women were able to reveal internal stigma concerns without necessarily taking on the role of “bad mother” and therefore feeling comfortable to disclose symptoms to others.

Drawing from Goffman’s theoretical ideas, stigma could potentially be challenged by reconstructing the maternal identity, either by separating the illness, along with the stigmatised symptoms from women’s maternal identity, or by reconciling that women can be good mothers despite having perinatal mental illness. This different understanding has potential for affecting stigma and disclosure behaviour by fixing women’s “spoiled identity” and enabling disclosure (Goffman, 1963). Women may have increased disclosure of their stigmatised symptoms, because they did not consider them synonymous with their maternal identity. Thus, long-term forum use helped women to disclose to healthcare providers by recognising and helping women cope with internal stigma.

Findings from the investigation therefore point towards the possibility that forum use may not lessen internal stigma per se, but rather encourage women to think about and discuss their feelings and experiences of internal stigma. This may have enabled women to recognise their internal stigma, and despite experiencing this stigma, were able to positively construct their maternal identity to resolve the good mother bad mother dichotomy.

Another interesting finding is that stigma and maternal identity may not only be negotiated online through interacting with other forum members, but also by users who simply read posts without posting. A few women in the qualitative interview study expressed that they felt part of the forum community even though they did not post (Article 3). These women applied the alternative conceptualisation to their identity and therefore transformed their spoiled identity to a positive one. This supports prior literature which advocates that lurkers experience similar benefits to active forum users (Coulson, 2015). There was no difference in the stigma levels between lurkers and active users in the mediation model study, which suggests that women may potentially benefit equally whether or not they actively participate in online conversations (Article 6).

In summation, this thesis suggested that forum messages may encourage women to recognise their thoughts regarding perinatal mental illness stigma, and thus increase their self-awareness which enabled them to make a fuller disclosure. Findings suggested that forums may provide a space where women can explore their feelings, and this may have meant that implicit feelings of internal stigma could have become explicit. Also, women may have overcome barriers to revealing this internal stigma through forum benefits, such as social support. Long-term visitors may have developed, through identification with other forum members, an alternative conceptualisation of perinatal mental illness that transformed their “spoiled identity” to an empowered identity as a good mother, despite having perinatal mental illness. This may have further enhanced disclosure to healthcare providers.

8.2 Strengths, limitations and future directions

The specific strengths and limitations for the individual articles in the current investigation have been addressed in each chapter (2-7). However, this section gives an overview of some important methodological issues. The section starts with a summary of the methodological strengths of the studies before considering the most important limitations and directions for future research.

8.2.1 Strengths

Strengths of each article have been discussed in each chapter. This section presents a selection of merits including; the mixed methods approach and how ethical principles were applied to online methodology.

8.2.1.1 *Mixed methods*

The work of this thesis sought to address the research questions through a mixed methods approach. Qualitative methods employed were; a meta-synthesis (Article 1), semi-structured interviews (Article 3) and thematic analysis (Article 4), and quantitative methods were; website rating scale (Article 2), and self-reported surveys (Article 5 & 6). This approach was adopted because perinatal mental illness stigma was considered to be a complex phenomenon and mixed methods was thought to satisfy the research aims and potentially yield a fuller consideration of stigma.

While it is not possible to give a comprehensive understanding of perinatal mental illness stigma, the methods were used to provide a detailed exploration from a multitude of perspectives in order to develop our understanding of stigma. Previous literature on perinatal mental illness forum use and stigma was solely qualitative, so it was considered appropriate to extend this line of exploration. Thus, initial

understanding was developed from qualitative methods before developing quantitative measures of perinatal mental illness stigma and examining a mediation model of forum use, stigma and disclosure of symptoms.

One of the main purposes of publishing articles from the investigation was to potentially inform healthcare providers regarding real world problems, for example, how to direct women to quality and useful Internet forums. Mixed methods enabled findings to have different applications to research and practice. Together qualitative and quantitative findings have developed concepts of perinatal mental illness stigma and validated a questionnaire measure that can be applied to experimental designs and clinical practice. For example, the thematic analysis is useful when constructing a theoretical framework to inform research that seeks to understand how forums might challenge stigma. The website review could be used to inform practitioners about quality resources to recommend to their clients as well as inform their own understanding and consequent discernment when selecting websites to use for information and resources.

8.2.1.2 Online ethics

The investigation presented the first study of posts on a perinatal mental illness online forum that explored stigma and disclosure and was the first study to suggest potential concerns for users (Article 4). Designing the methodology for this study was one of the major challenges of this thesis. The methodology used in this study formed the basis of an article written to assist health researchers when designing online studies (*Health Psychology Update*, Moore & Drey, 2014, see Appendix 5.2). This provided a novel and valuable contribution because there is a

wide variation, debate and challenges in how different researchers and ethics committees apply ethical principles to online environments.

The article discussed the BPS *Ethical Guidelines for Conducting Internet-mediated Research* (2013) principle 1: respect for the autonomy and dignity of persons, alongside a case study of research on online health forums (Article 4). The article gave practical examples of online ethical conundrums and suggestions for applying these ethical guidelines. This is of particular methodological importance as research is in its formative stages, which means we need to give careful consideration to how we protect participants and respect forum moderators, at the same time as facilitating high quality innovative research. The article suggested researchers should be flexible in approaching online ethics and explores working with forum moderators to help adhere to the highest ethical standards.

Researchers vary widely in how they apply ethical principles to online circumstances (Herron et al., 2011). The article explored specific challenges in interpreting and employing the BPS ethical principles in the thematic analysis and included: a consideration of the nature of online private and public spaces, anonymity, confidentiality, valid consent and the right to withdraw from a study.

One fundamental ethical disagreement amongst researchers concerns whether the information on the Internet is considered to be in the “private” or “public” domain. There are several points of view. Some researchers consider that online information is accessible to the public it is in the public domain and therefore available for research without the need for informed consent. Other researchers consider that online information might be publically available, but the author may not have anticipated its use in research and therefore informed consent would be necessary for research purposes. From this frame of reference, researchers would

need to protect against intrusive research and respect the participant's dignity in accordance with principle 1 (BPS, 2013). Another viewpoint stipulates that if a forum is only assessable by members it is clearly private, and informed consent should be sought from individual posters.

Different online circumstances present their own unique challenges, and researchers and research ethics committees display a range of views as to the best way to uphold ethical principles. Examples from the research proposal for the thematic analysis of forum posts were given to address these concerns, especially considering the views of forum contributors who may discuss sensitive topics, for example, stigma and maternal identity. In this case, several forum moderators and authors were emailed and asked for their thoughts on the research protocol. In keeping with the BPS guidelines on conducting research on the Internet (2006), forums were viewed as private and moderators were contacted regarding issues of privacy. Only publicly available posts were included in the research i.e. any forums that required membership for access were excluded; thus, confining the research to posts from women who should have been aware that their conversations were able to be viewed by the general public.

One problem was that it was impossible to gain informed consent from many forum contributors, like the ethics committee initially requested. Instead a compromise was reached and a notice was displayed on forums giving a description of the study and a link to an online "participant information sheet" that outlined women's right to withdraw, utilising an opt-out consent policy. Forum contributors could contact the researcher and ask not to be quoted in the study and instead just have their posts used in a contextual basis for the analysis. Due to these and other constraints in applying considered ethical principles it was concluded by the

researcher and ethics committee to be the best approach to make the forum posters aware of the research and seek informed consent from them. The article concluded by outlining the importance of considering individuals in online data and the need to give serious consideration when applying ethical principles to the sometimes grey area of online research.

8.2.2 Limitations

There are a number of practical and methodological limitations which have been addressed in each chapter. In this section, the following limitations and future recommendations are considered; issues of sampling and what is not said on forums.

8.2.2.1 Sampling

There are several issues regarding sampling that need to be considered when evaluating the findings of the investigation. These include a reflection on website sampling, participant sampling and forum sampling. The investigation largely focused on postnatal mental illness, in particular, depression. One reason for this was because the studies commenced at a time when the available literature on perinatal mental illness was limited, and the majority of websites concentrated on postnatal depression. Research has progressed since the start of the research for this investigation and now includes more work on other perinatal mental illnesses. Likewise, websites have advanced in number along with the resources they offer. They now include a myriad of topics, such as obsessive compulsive disorder, fathers with postnatal depression, antenatal mental illness, maternal bipolar and parents who have partners with perinatal mental illness. Therefore, results regarding websites may not be representative of all perinatal mental illnesses. Closely linked to this is the forums under examination were largely focused on postnatal depression (Article

3, 4, & 6). Future research should include a consideration of websites for all perinatal mental illnesses.

Another area warranting possible future consideration is participant sampling. The interview study sample may not be representative; sample size was small, self-selected, White, mostly educated and women may have been more proactive in seeking social support (Article 3). Also, there is a large range of time since the events of interest (6 months to 10 years). This was due to low response rates when recruiting, however, it was intended to be exploratory in nature and used to develop ideas for the subsequent studies. Likewise, the sample for the online survey for Articles 5 and 6 was self-selected and presented similar potential bias; women were mostly White and educated (Articles 4 & 5).

The issue of these convenience samples has implications for the generalisability of findings. However, it is possible that sample characteristics may be a reflection of the population that use these resources rather than a bias. Future work should examine characteristics of women who use these forums to make more informed decisions when recruiting. Also, work may benefit from using samples with different socio-demographics and to avoid self-selection bias, could include clinical samples.

Whilst the creation of a novel scale to measure perinatal mental illness stigma offers a positive contribution to research in this area, there was a disproportionate number of women who had postnatal mental illness compared to antenatal mental illness (Articles 3-6). Therefore, the scale and the mediation model may be more representative of stigma for postnatal mental illness and not antenatal mental illness or perinatal mental illness as a whole. The scale and the mediation model could be

re-tested with a more representative sample to claim validity as a measure for perinatal mental illness.

Additionally, there could be vital interactions with other facets of stigma, such as religious beliefs or obesity which have not been accounted for in the studies in this thesis. Previous literature has highlighted that women from low income populations suffer additional complications and are much less likely to receive treatment (Kozhimannil, Trinacty, Busch, Huskamp, & Adams, 2011). There has also been some research that highlights that women may suffer with stigma related to teenage pregnancy (Boath, Henshaw & Bradley, 2013). There are practical and psychological barriers to care that might make online forums a popular choice of support. In addition, women may have other illnesses that are stigmatised such as HIV, AIDS or substance abuse (Lee, Kochman, & Sikkema, 2002; Leigh & Milgrom, 2008) or belong to other stigmatised groups for example, Black or homosexual (Alang & Fomotar, 2015; O'Mahen et al., 2011).

Future research should be sensitive to these potential additional complexities regarding stigma. As Alang and Fomotar (2015) note, women in their sample were concerned with not just being seen as a “crazy” but a “crazy lesbian”. It is possible that there are cumulative effects when belonging to various minorities or members of other stigmatised groups. It is likely that given the increase in number and topics of forums that forum might advance to include combined stigma issues such as, teen mothers with postnatal depression. It would be interesting if future studies considered comparing these different forums and the effect on stigma levels.

Related to this possible sample bias is the notion of bias resulting from the type of forum women used. The thematic analysis only considered one online forum

because no other moderators gave consent for forum posts to be included in the study. However, the forum was for use by women with both antenatal and postnatal depression. Future research would benefit from investigating different forums to ensure the validity and generalizability of these findings. Also, it is possible that different forums have different consequences for stigma and disclosure. For example, a birth trauma forum may provide women with an opportunity to communicate their concerns that they may not be able to do offline. However, due to the nature of the forums topic, many posts may discuss negative experiences with healthcare providers. It would be interesting to investigate if birth trauma forum use adversely affects healthcare decisions or if given the context of experiences, it has no effect compared to general perinatal mental illness forums.

Similarly, the quantitative study did not take into account the type of forum used by women or if they used a mixture of forums (Article 6). Other features of forums that should be included in future research that were not accounted for in the current investigation are a measure of forum moderation, safeguarding policies and social media involvement. Moderation could be measured in terms of moderated and unmoderated, and could also include type of moderation, for example, moderation by peers, professionals, or both. Safeguarding policies could ensure the well-being of users by removing posts that do not comply with forum etiquette (or “netiquette”) and could attach “trigger warnings” to thread titles that identify posts which could potentially be harmful to readers, thus enabling users avoid exposure to sensitive posts that may be detrimental to their mental health. It is essential that future work considers this and includes additional measures which could have notable consequences for the results. Future work would benefit from comparing women

who use different forums to see if there is different effect of forum use on stigma and disclosure.

8.2.2.2 *What is not said on forums*

Finally, when considering what is said on forums, it might be pertinent to give thought to what is not said. This thesis suggests that there is an alternative discourse on some online forums that appears to challenge stigma and promote disclosure. However, it is unclear if this attitude is a true representation of forums and the women who use them. It is possible that posts are censored by moderators who want to encourage a particular attitude in their forum and discourse itself may marginalise women who want to talk about the pitfalls of disclosure or advocate going it alone. Given this, forum users may endorse a type of self-censorship where they feel they cannot “voice” a counter attitude to others posts, so either do not post or censor what they do post to comply with the forum culture. For example, Orgad (2006) studied online forums for breast cancer sufferers and noted that communication was often embedded in a Christian discourse. Both Christian and non-Christians participated in the forum and experiences were frequently set in the framework of Christian ideology. This had benefits for encouraging hope and support, for example, prayers, but does run the risk of excluding other types of discourse. Therefore, it may be of profit for future studies to examine what is said juxtaposed to what is not said on forums.

8.3 Implications

The current thesis has several practical and theoretical implications and these are discussed specifically in each chapter (2-7). This section highlights some key implications for the thesis as a whole, including implications for healthcare practice, research and theory.

8.3.1 Implications for healthcare practice

This thesis shows that there were a multitude of websites for postnatal mental illness with various resources for both women with postnatal mental illness and healthcare providers who care for them. With such an array of choice, it is important that healthcare providers have up-to-date knowledge of quality websites for their own use and sites that are appropriate for them to direct their clients to or even warn against. Clinicians could use the rating scale when assessing websites to use. This thesis suggests there is a need for websites that are created with accurate and detailed information, good support resources and website quality. Ideally, these websites should be built around evidence of how women use web resources.

Other considerations are warranted when recommending websites, especially when promoting forums. This research has highlights the importance of moderated forums that enable women to discuss stigma concerns and promote a discourse of “good mother” as compatible with perinatal mental illness. Forum posts could be of value to some women when they contain encouragement for women to disclose to healthcare providers, seek help and adhere to treatment. This research also highlights forums that may be detrimental to disclosure. When referring clients to web resources, clinicians should consider the possible negative effects of using forums that contain negative experiences of healthcare, whilst being sensitive individual’s needs, for example, if they feel comfortable using online support or might benefit from talking about their birth trauma.

8.3.2 Implications for research

The present investigation draws attention to the importance of perinatal mental illness stigma and further expands knowledge of this salient barrier to care. All qualitative findings (Articles 1, 3 & 4) confirm previous research that suggests

many women describe stigma as the main reason they find disclosure to healthcare providers difficult or avoid disclosing completely (O'Mahen et al., 2012). Therefore, it is important that work continues to explore stigma as many women are failing to get the help they need to recover and thus this has serious detrimental outcomes for both women and their families (Dennis & Chung-Lee, 2006; Letourneau et al., 2013).

The thesis presents the first quantitative measure of stigma for perinatal mental illness by developing a scale (City MISS) from qualitative findings of the investigation and literature review. Future research can use the tools, such as the scale, and methodology developed to further test the relationships between forum use characteristics, types of stigma and disclosure. A measure of the unique stigma with perinatal mental illness some women experience was developed and may provide a valuable tool for research. For example, it could be used to measure the prevalence and characteristics of perinatal mental illness stigma. It has potential for clinical screening and can be used to inform interventions that address the stigma experienced by some women with perinatal mental illness, for instance, forums could be developed to offer support women who are at risk of perinatal mental illness stigma and their subsequent disclosure could be measured against a control group.

Outside of this investigation, perinatal mental illness stigma has only been researched using qualitative designs. The work of the present investigation presents a mixed methods approach that develops understanding of stigma and forum use and quantitative measures of stigma and forum use characteristics. Together the findings have developed theoretical concepts and validated measures that can be applied to experimental designs. It sets out specific concerns women may experience and points

towards future investigation of these phenomenon by highlighting the most relevant and salient stigma issues. Qualitative results show that external, internal and disclosure stigma may all have a role in perinatal mental illness stigma and a quantitative study suggests that internal stigma is associated with forum use and disclosure. This is important as evidence to date has had mixed results for the impact of online support for depression and anxiety (Eysenbach et al., 2004; Griffiths et al., 2012). Future work would benefit from testing these theories including additional measures of forum use and adopting a longitudinal design and randomised control trials.

8.3.3 Implications for theory

Overall, findings suggest that perinatal mental illness stigma can be conceptualised in terms of several components; perceived external stigma, internal stigma and disclosure stigma. Quantitative findings show that forum use may not reduce internal stigma as hypothesised, but rather increase disclosure of internal stigma. Findings suggest that the alternative understanding of perinatal mental illness on forums may have helped women recognise their internal stigma and this increased women's self-awareness, enabling them to make a fuller disclosure. In addition, women may have overcome barriers to revealing this internal stigma through forum benefits, such as social support, identification with the forum group, empowerment and an alternative perspective of perinatal mental illness that shifted their "spoiled identity" to an empowered identity as a good mother despite having a mental illness.

These factors may have lessened women's feelings of distress when experiencing internal stigma, and therefore enabled them to articulate stigma feelings and lessen shame when disclosing. These findings suggest that forums are a useful

aid in assisting women to recognise and reveal their perinatal mental illness which has notable implications for promoting help-seeking behaviour and treatment uptake.

These findings may fit in with help-seeking theories which hypothesise that people take a series of steps to get the help they need for their condition. Generally, help-seeking is conceptualised as comprising of three factors; attitude towards help seeking, intention to seek help and help-seeking behaviour. Some research suggests that attitudes towards seeking help, such as beliefs and willingness, are correlated with actual help-seeking behaviour (Nam et al., 2010). Researchers have applied help-seeking theories to mental health, however, there is no one agreed upon unifying model (Gulliver et al., 2012).

One help-seeking model is Ajzen's Theory of Planned Behaviour (TPB; 1991). TPB emphasises the importance of attitude as a critical predictor of help-seeking behaviour. If the individual perceives the help-seeking behaviour as a positive thing they are more likely to do it. Likewise, the subjective norm also contributes to resultant behaviour. If a person believed significant others in their life would want them to do the behaviour they are more likely to act accordingly. Perceived behaviour control is the third and final factor in this model and purports that if an individual believes they are likely to succeed at the behaviour then they are more likely to act. This model can be preliminarily applied to the findings of this thesis.

Women who have PMI often have a negative view of their condition and concerns about disclosure to healthcare professionals. It could be theorised that women who visit forums change this attitude through re-conceptualising PMI stigma by engaging with forum discourse that reconciles a positive identity as a mother and having PMI. Women may also come to adopt the shared understanding of the forum

members that help-seeking behaviour does not have negative outcomes e.g. their baby will not be taken away. Thus, a women's attitude towards herself and disclosure becomes positive.

Women forum users often come to value the group and its subjective norms. The forum posts in these studies consistently encouraged disclosure to healthcare professionals as the best course of action and stressed to be a "good mother" it was essential to seek help. Thus, it could be argued that this subjective norm promoted help-seeking behaviour. The perceived behavioural control could be considered when women engage with an online discourse they become educated about symptoms and learn new ways to communicate their feelings. This could give women confidence when approaching healthcare professionals. Thus, all three factors could be influenced by forum use and in turn lead to an increased and fuller disclose.

This consideration is explorative and to an extent a simplistic account of the factors that might be a work in women's help-seeking behaviour. However, future research could benefit by using TPB to tease out the factors that contribute to help-seeking behaviour and examine if and how they interact.

Social identity theory may be another useful way to conceptualise how women manage the transition in their identity when they become mothers. This theory suggests that people receive social support through identifying as a member of a social group, for example, a sports team or work group (Tajfel & Turner, 1986). These groups define how people regard their sense of self and what makes them different from other groups. These group identities may lend mental resilience through imparting a sense of belongingness and connectedness (Cruwys et al. 2014; Haslam et al. 2009). There has been well-documented research showing that social

support through in-groups is beneficial for mental health (Ozbay et al., 2007). However, when women become mothers there is often a loss of group memberships, for example, she stops work and due to childcare commitments, she can no longer participate in her usual leisure activities. This loss of identity can have a negative impact on women's mental health (Jetten, O'Brien, & Trindall, 2002).

Seymour-Smith et al. (2016) examined the Social Identity Model of Identity Change and postnatal depression. They recorded changes in women's social identity and depressive symptoms (N=387). Women reported significantly decreased valued group membership after childbirth, which highlights the perinatal period as a time of great identity change. They showed that maintaining social groups was associated with lesser depressive symptoms and group losses were associated with more depressive symptoms. However, they failed to find any evidence that making new group memberships (e.g. baby groups) had any effect on mental health. This may be because of the type of new groups the women in this study joined. If the new groups had been specific to mental health in the perinatal period they might have yielded different results. Women with PMI may not identify with the group norm of "wellness".

This related to the thesis and suggests possible benefits of forum belongingness. It would be interesting to investigate if women who use Internet forums to manage their PMI utilise group membership to manage their social identity. It could be argued that women identifying as a member of the "PMI group" or "PMI forum" may regard their identity as a mother with PMI as a positive one, rather than conforming to the dominant discourse that associates PMI as a negative trait. As this thesis suggests, stigma may be negated by adopting an alternative group

discourse that socially constructs PMI as compatible with a positive maternal identity.

Another similar consideration for future research could be how social media presents the social grouping of PMI sufferers and survivors. One example of this can be seen in the recent social media and parliamentary campaign to increase mental health services for women in the UK and reduce stigma (#HopeNov20). Over 200 people met for the conference on perinatal mental health at the House of Commons on November 20th, 2017 to raise public and political awareness. Many of the delegates were forum moderators, social media campaigners, bloggers and forum users. They expressed a clear sense of group identity and a united vision for ending PMI stigma, despite it being the first time many had met in a non-virtual environment.

To conclude, the most important implications of the thesis as a whole are (i) clients may benefit from healthcare providers' recommendations of reliable and moderated online forums that facilitate communication of perinatal mental illness stigma, challenge stigma by promoting a discourse that reconciles perinatal mental illness with being a good mother and encourages disclosure to healthcare providers and (ii) findings suggest that forum use effects internal stigma and in turn disclosure and has developed potentially useful tools for future research and (iii) a new theoretical understanding of the unique stigma of perinatal mental illness has been developed, and suggests that many women experience a range of external, internal and disclosure stigma that may prevent disclosure.

8.4 Conclusions

In conclusion, the studies presented in this thesis have added to knowledge of Internet resources for women with perinatal mental illness and healthcare providers

in several important ways. In particular, the relationship between forum use, stigma and disclosure has been investigated and findings have addressed a number of gaps in the literature. Combined findings suggest that forums exhibit potential for influencing women's recognition of stigma and conceptualisation of stigma that may encourage and enable women to disclose symptoms to healthcare providers.

Findings suggested that forums may facilitate disclosure of symptoms to healthcare providers by addressing issues regarding perinatal mental illness stigma in a rhetoric of social support. Forums appear to provide a safe space to anonymously "voice" highly sensitive stigmatised feelings and symptoms. This may be of particular value to women as this space may not be available offline. Forum discourse may challenge stigma concerns and promote disclosure. It is suggested that some forums may reduce the negative feelings associated with stigma by advocating an alternative conceptualisation of perinatal mental illness that reconciles "good mother" and "bad mother" labelling that causes distress, and instead advocates that a woman can be a good mother despite their illness, especially if they disclose to a healthcare provider.

This thesis benefited from using a number of qualitative and quantitative methodologies such as meta-analysis, website review, semi-structured interviews, thematic analysis, and an online survey. The investigation has also benefited from considering how to applying ethical principles to online research. However, some caution should be exercised when considering the findings as they may not always be generalisable given the limits of the sampling. Also, findings suggest a largely positive effect of forums on stigma and disclosure. This discussion points to some issues regarding what is not said on forums and suggests prudence when applying the findings to future theory and research development.

Forums may assist women in exploring concerns regarding perinatal mental illness stigma, and thus enables them to recognise their own feelings of stigma and therefore assist their disclosure of symptoms. Preliminary results of the thesis suggest that internal stigma may mediate the relationship between long-term forum use and disclosure. This has important implications for addressing stigma as a barrier to care. Future work should continue to explore how forums may facilitate disclosure. However, results are exploratory and further work would benefit from investigating the relationships between forum use, stigma and disclosure using larger and more representative samples so findings can be generalised. Additionally, longitudinal designs might enhance understanding of the process involved in engaging with forums over time. Potential disadvantages of forum use have been suggested and warrant further investigation.

9 References

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10 Appendices

Appendix 2.1 Full list of search terms for systematic search (Article 1)

Search terms included key words related women (e.g. women, “woman”, “mother*”, “female*”), which were combined with terms related to online forums: “online support group*”, “message board*”, “online forum*”, “online communit*”; and further combined with terms related to perinatal: “postnatal”, “postpartum”, “antenatal”, “perinatal”, and crossed with terms related to mental illness: “psych*”, “mental”, “emotion*”, “problem*”, “disorder*”, “illness*”, “symptom*”, “depression”, “anxiety”, “post-traumatic stress”, “psychosis” “mood disorder*”; and finally combined with terms related to stigma: “stigma”, “stigmatiz*”, “discriminat*”, “prejudice*”, “stereotype*”, “perception*”, “label*”.

Appendix 2.2 Example of a database search (Article 1)

Searches were conducted using the database Scopus for “All Fields” and limited to the date range (inclusive) for all years to present in all subject areas.

1. “women” OR “woman” OR “mother*” OR “female*”
2. “online support group*”, OR “message board*”, OR “online forum*”, OR “online communit*” “postnatal” OR “postpartum” OR “antenatal”, OR “perinatal”
3. “psych*”, OR “mental”, OR “emotion*”, OR “problem*”, OR “disorder*”, OR “illness*”, OR “symptom*”, OR “depression”, OR “anxiety”, OR “post-traumatic stress”, OR “psychosis”, OR “mood disorder*”

4. “stigma”, OR “stigmatiz*”, OR “discriminat*”, OR “prejudice*”, OR “stereotype*”, OR “perception*”, OR “label*”
5. “#1 AND #2 AND #3 AND #4 AND #5”

Appendix 2.3 Themes from the meta-synthesis (Article 1)

Studies	Themes			
	Safe place to talk	Virtual support	Stigma and identity	Repair of the mother identity
Evans et al. (2012)	y	y	y	y
Kantrowitz-Gordon (2013)	y		y	y
Alang and Fomotar (2015)	y	y	y	y
Moore and Ayers (2016)	y	y	y	y
Moore et al. (2016)	y	y	y	y

Appendix 3.1 Rating scales for evaluating websites (Article 2)

Dimension	Subcategories	Items
Symptoms	Depression	<p>Tearfulness, feelings of sadness</p> <p>Irritability</p> <p>Decreased interest in usual activities</p> <p>Changes in appetite, inability to eat</p> <p>Sleep disturbances</p> <p>Low energy or fatigue</p> <p>Poor concentration</p> <p>Feelings of guilt or shame</p> <p>Suicidal ideation</p>
	Anxiety	<p>Anxiety</p> <p>Somatic complaints</p> <p>Obsessive thoughts (e.g. about the baby's safety)</p> <p>Ambivalent or negative feelings toward the baby. Wanting to flee</p> <p>Doubts or feelings of inadequacy about caring for the baby</p> <p>Thoughts of harming the baby or self</p> <p>Persistent, unjustified worry (e.g. about the baby)</p>

		Irritability
		Obsessive thoughts (e.g. about the baby)
		Difficulty concentrating
		Sleep disturbances
		Panic attacks
Puerperal		Restlessness, agitation
psychosis		Irritability, rapid mood swings
		Insomnia
		Disorientation
		Erratic or disorganized behaviour
		Delusional beliefs, usually regarding the baby
		Hallucinations
		Inability to distinguish reality
	PTSD	Avoidance of reminders or talking about the birth
		Disturbing images, flashbacks or nightmares about birth
Risk factors	Psychosocial	Unplanned/unwanted/mistimed pregnancy
		Unemployment, either the woman or her partner, not by choice
		Young maternal age, especially adolescence
		Lack of social support

Recent stressful life events within 2 years of pregnancy,
such as a death, divorce, or relocation

Perceived stress of parenting

Fetal anomaly or infant illness

Trauma related to the pregnancy or birth

Interpersonal violence (current or past)

Difficulty breastfeeding

History of sexual abuse

**Medical
history**

Previous postnatal illness

Symptoms or anxiety during pregnancy

Personal or family history of psychiatric disorders,
including alcoholism

History of menstrual-related mood disorders (e.g.
premenstrual dysphoric disorder)

Symptoms of mood disorders during past use of hormonal
contraceptive methods

Severe postpartum fatigue

History of miscarriage, neonatal death, stillbirth, or sudden
infant death syndrome

		History of infertility, infertility treatment and/or multiple pregnancy
	Additional considerations	Maternal low socio-economic status
		Living in rural areas
		Women from ethnic minority groups
		Mothers who partner with women
		Mothers with disabilities
		Mothers whose infants are hospitalized after birth
Impact	Impact on the mother	Difficulty fulfilling family roles
		Diminished responsiveness to infant cues
		Attachment difficulties with their baby/other children
		Fear of having another baby
		Financial worries due to inability to work
		Poor self-care, including following through with healthcare recommendations
		Increased risk of substance abuse
		Increased risk for suicidal behaviours or attempts
		Increased risk for future episodes of depression
	Impact on the infant	Feeding problems and poor weight gain
		Increased fussiness and sleep problems

Delayed development of cognitive skills, social skills, and expressive language

Problems with behaviour, conduct and attention

Poor emotional attachment

Impact on the Feelings of fear, helplessness or lack of control

partner/family Feelings of anger or resentment

Guilt over the suffering of the new mother

Increased instability in marital and family relationships

Higher risk of divorce

Available **Mothers tools** Tests (e.g. Edinburgh Postnatal Depression Scale)

help Myths about motherhood (dispelling unrealistic expectations of mothers that compound PNI symptoms such as guilt)

Letters to healthcare professionals

Stigma surrounding postnatal mental illness (i.e. confronting stigma and promoting help-seeking behaviour)

How to gain access to/understand medical notes

What to say to healthcare professionals

How to seek help

Standard self-help (i.e. limited advice on nutrition, sleep, exercise and asking others for help)

Tips for family

Relaxation techniques

Coping strategies

How to think (e.g. advice on positive thinking)

Postnatal mental illness issues

Prevention

Stories

Mothers

Forum

support

Email/letter

Chat

Personal messaging (a private message sent to another user in a forum or chat room)

Telephone

Group meetings

Home visits

Referrals

Additional

Links

resources

Downloads

Audio/visual

Podcasts

Contacts

Articles/research

Book recommendations

Quotes/poems

Leaflets

Appendix 3.2 Top five websites for healthcare professionals and postnatal mental illness sufferers when presentation was more strongly weighted (Article 2)

	1st Rating Criteria	2nd Rating Criteria
Healthcare Professionals		
1	www.postpartum.net	www.postpartum.net
2	www.postpartumhealthalliance.org	www.postpartumhealthalliance.org
3	www.babybluesconnection.org	www.babybluesconnection.org
4	www.postpartumsupport.com	www.postpartumva.org
5	www.postpartumeducationandsupport.com	www.postpartumsupport.org
Postnatal mental illness sufferers		
1	www.panda.org.au	www.panda.org.au
2	www.hapis.org.uk	www.postpartum.net
3	www.postpartumhealthalliance.org	www.pndsa.co.za
4	www.postpartum.net	www.babybluesconnection.org
5	www.pndsa.co.za	www.rcpsyche.ac.uk

Appendix 4.1 Interview schedule (Article 3)

Can you tell me about your experience of pregnancy, birth and your time until now?

Can you describe your experience of using the Internet for resources for your *?

Is that all you can tell me?

What Internet resources for postnatal health do you use?

Can you describe how you use each Internet resource?

What resource do you use most? Why?

Do you/have you used websites to help you cope with having *

Do you think using these resources on the web has benefited you in any way?

If so, how?

Do you think using these resources on the web has in any way been a negative experience for you?

If so, how?

What effect if any do you think your use of websites has had on you and your *?

What's your understanding of *?

Has using the Internet shaped how you understand your *?

If so, how?

What do you think of the information on postnatal depression or * available on the Internet?

Are there any aspects of websites that make them easy or difficult to use? If so, how?

* = use terms they use for example, illness, postnatal depression, trauma etc

Appendix 4.2 Ethical approval for the interview study (Article 3)



University of Sussex

Life Sciences & Psychology Cluster based Research Ethics Committee

10.1.1 CERTIFICATE OF APPROVAL

Reference Number:	SADM0411
Title of Project:	Women with postpartum psychological illness (PPI) who use internet resources.
Principal Investigator:	Dr Susan Ayers
Student:	Donna Moore
Collaborators:	
Duration of Approval (not greater than 4 years)	6 months
Expected Start Date:*	April 2011
This project has been given ethical approval by the Life Sciences and Psychology Cluster based Research Ethics Committee (C-REC).	

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol.

- Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects

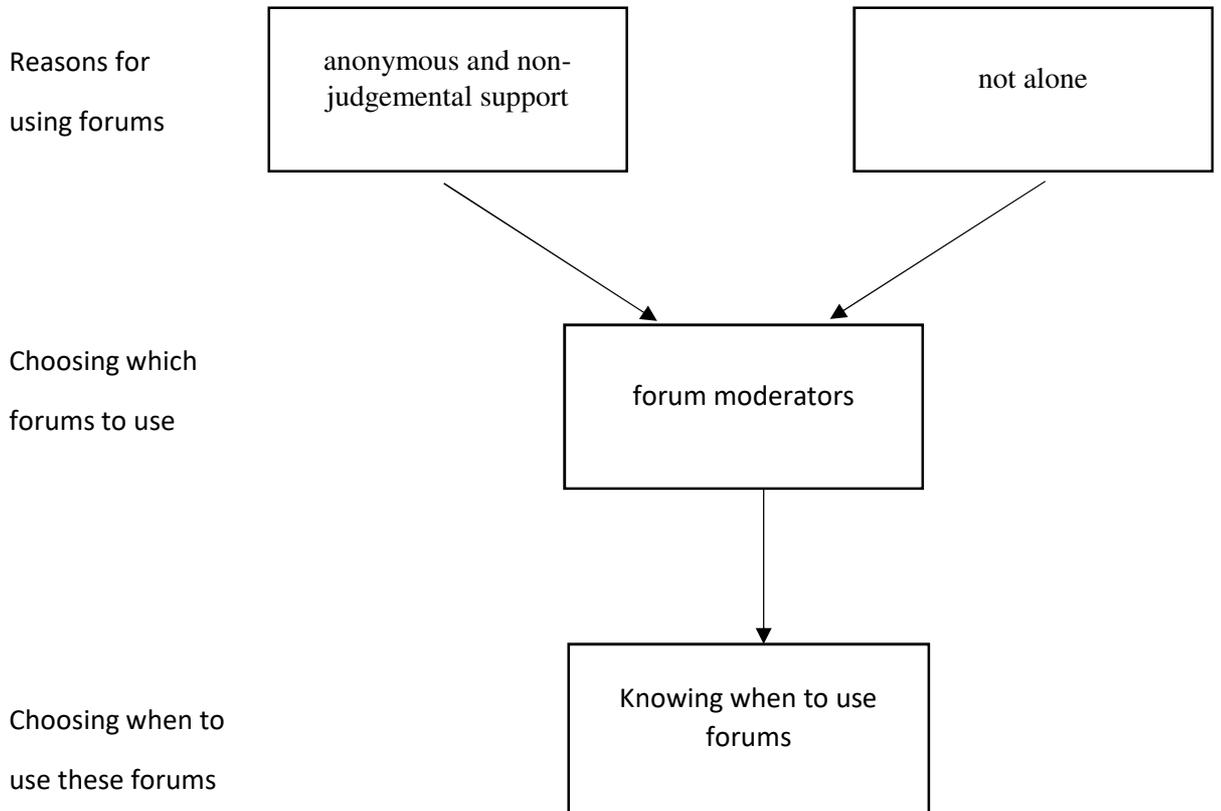
- Any incidents with ethical implications that occur during the implementation of the project must be reported immediately to the Chair of the C-REC.

The principal investigator is required to provide a brief annual written statement to the committee, indicating the status and conduct of the approved project. These reports will be reviewed at the annual meeting of the committee. A statement by the Principal Investigator to the C-REC indicating the status and conduct of the approved project will be required on the following date(s):

December
2011.....

Authorised Signature	Jennifer Rusted
Name of Authorised Signatory (C-REC Chair or nominated deputy)	Jennifer Rusted
Date	4 April 2011

Appendix 4.3 Exploratory theoretical model of forum use (Article 3)



Appendix 5.1 Ethical approval for online forum study (Article 4)

School of Health Sciences



Ref: PhD/13-14/01

Research Office
Northampton Square
London EC1V 0HB

Tel: +44 (0) 20 7040 5704

11 July 2013

www.city.ac.uk

Dear Donna / Susan

Re: A thematic analysis of online forums for postnatal mental illness

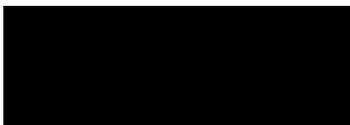
Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once the project has been completed, and may be asked to complete a brief progress report six months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely



Alison Welton
Research Governance Officer



Appendix 5.2 Journal article: Moore, D. & Drey, N. (2014). E-health and e-ethics: Some ethical and practical considerations when conducting internet research on health forums. *Health Psychology Update*, 24(1).

E-health and e-ethics: some ethical and practical considerations when conducting internet research on health forums.

Donna Moore & Nicholas Drey

Summary

There is wide variation in how different researchers and ethics committees apply ethical principles to online environments. The BPS *Ethical Guidelines for Conducting Internet-mediated Research* (2013) principle 1: respect for the autonomy and dignity of persons is considered alongside a case study researching online health forums. The lines of “public” and “private” online data are often blurred and care needs to be taken when protecting the person in electronic data. This presents unique challenges when applying BPS ethical principles of confidentiality, anonymity and informed consent. This article suggests that a thoughtful and flexible approach is adopted and demonstrates how communication with forum moderators can help ensure the highest ethical standards.

There are a myriad of websites, discussion boards and social networking groups focusing on health issues. This presents a unique opportunity for health psychologists to access patient experiences which would otherwise be difficult to obtain. However, there is wide variation between researchers in terms of how they apply ethical principles to an online environment (Herron et al 2011). This article

explores some issues in relation to the BPS *Ethical Guidelines for Conducting Internet-mediated Research* (2013) in particular principle 1: respect for the autonomy and dignity of persons. We reflect on the experiences of one researcher and an ethics committee of designing, approving and conducting research based on data from online health forums. We discuss the specific challenges in interpreting and employing the BPS ethical principles in this research, including: a consideration of the nature of online private and public spaces, anonymity, confidentiality, valid consent and the right to withdraw from a study.

There are several professional bodies with guidelines on internet mediated research, for example, the Association of Internet Researchers (AoIR 2012), but perhaps the most relevant guideline for health psychologists is the professional guidance provided by the BPS which applies ethical principles from the Society's *Code of Human Research Ethics* (2011) and the *Code of Ethics and Conduct* (2009) to research based on the internet: *Ethical Guidelines for Conducting Internet-mediated Research* (2013). However, this remains a relatively new and varied area of study in a state of flux due to the ever expanding and changing nature of the internet and advances in technology (Mann & Stewart 2000). This presents a challenge for researchers who want to be innovative in their approach to designing and conducting research whilst remaining sensitive to ethical considerations.

The first authors' research looked at the role the internet could play in helping women with postnatal mental illness; particularly how websites, social media and online forums could provide valuable information and social support. This work included researching women's posts on online forums for postnatal mental health; which raised a number of ethical issues and challenges when seeking ethical approval from our university and also in their subsequent implementation.

This experience is considered as a single case study reflecting on principle 1 of the BPS *Ethical Guidelines for Conducting Internet-mediated Research* (2013) which addresses issues of privacy, which is closely linked to notions of anonymity, confidentiality, informed consent and the right to withdraw from a study.

A key ethical dispute amongst researchers focuses on whether the information on the internet is considered to be in the “private” or “public” domain. It could be crudely simplified into three arguments. First, if the information is accessible to the public i.e. anyone can see the information, it could be argued that this is published material in the public domain and is so available for academic research without the need for informed consent, although the poster (author of the post) may not have envisaged its use in research and may even object to this use (Hudson & Bruckman 2004). A second viewpoint is that although this information might be publically available in a legal sense, this is not necessarily the understanding of the author and it follows that they may therefore be even less likely to envisage its use in research, than in the first scenario. In this case, informed consent should be sought, to protect against intrusive research and respecting the participants’ dignity in accordance with principle 1 (BPS, 2013). In the third situation a forum is clearly private and is members-only access, requiring permission to access the forum so informed consent from individual posters would be required to use the data for research purposes.

In the conduct of research matters are rarely as clear cut with different online circumstances presenting their own unique challenges, and researchers and research ethics committees displaying a range of views as to the best way to uphold the ethical principles. Some view posts on accessible internet forums as public information and take the view that forum contributors should be aware that their

posts can be seen by any user and are therefore “fair game” to be used for research. Legally speaking such archive messages in accessible forums can be analysed without permission from posters as long as this complies with copyright laws (Hookway, 2008). However, just because something may be legally permissible, does not necessarily make it ethical.

The research proposal carefully considered the views of forum contributors who may perceive their posts as private, especially when they addressed sensitive topics, for example, feeling inadequate as a mother. Several forum moderators and authors were emailed and asked for their opinion on the research protocol. In keeping with the BPS guidelines on conducting research on the Internet (2006), support groups and other interactions that included posts about sensitive issues were viewed as private and moderators were contacted regarding issues of privacy. The inclusion criteria for forums were developed after consulting a forum contributor and forum moderator. Only publicly available posts were included in the research i.e. any forums that required membership to view posts were excluded; thus confining the research to forums where contributors should have been aware that their posts were publicly available.

The BPS guidelines note that the level of control the researcher can have over data on the internet is often significantly lower than data gathered offline, because the raw data available to the researcher is identical to that available to the general public, so the researcher cannot increase the security, anonymity or confidentiality of the data. Where the researcher does have control, and thus a responsibility, is in the analysis of the data and dissemination of the results. The researcher must consider how to maximise confidentiality and anonymity and what assurances they can give participants. In this study it was thought unlikely that users would be identifiable as

thousands of posts were analysed with multiple authors and many contributors posting under a pseudonym. However, a decision was taken to publish only short quotations to minimise the possibility of internet traceability and possible identification of an individual, through commonly used internet text-based search engines, further poster's pseudonyms were also anonymised.

It was impossible to gain informed consent from many forum contributors because they no longer use the site where they posted or even the email address with which they registered. A less direct approach was adopted: a notice was displayed on forums giving a general description of the study and a link to an online "participant information sheet" outlining forum contributors right to withdraw, choosing an opt-out consent policy. Forum contributors could contact the researcher and ask not to be quoted in the study and instead just have their posts used in a contextual basis for the analysis. To avoid influencing or disrupting the online community, the study was limited to historical posts, adhering to principle 3: social responsibility (BPS, 2013).

The university research ethics committee suggested that forum contributors may well see forums as private, especially if they posted from computers in their own homes for example. Further clarification was required on the issue that some forum contributors might not see the notice about the study on the forum. In addition to the safeguards proposed, the committee requested that moderators be asked to email members of their forum with an information sheet and inform them of their right to withdraw their online contributions from the study. The result of discussions with the ethics committee concluded that as far as was practically possible every effort should be made to make the forum contributors aware of the research and seek informed consent from them.

In reality there were constraints to applying these well thought-out ethical principles and procedures, not least because some forums did not have moderators. Of those that did one consenting moderator reasoned there was no need to display a notice on their forum as all members had signed the terms and conditions of using the forum and this specified joint copyright of contributors' posts arguing strongly that they had therefore already given their consent for their posts to be used. The ethics committee was consulted again, they were concerned that users often fail to read the terms and conditions and if they had it might have been some time ago and therefore informed consent should be sought again to make sure it was current, if at all possible. The moderator explained that their forum was an open forum for anyone to use and it would be excessive for the moderator to email individual members and she was unwilling to do this contending that their intervention would be more intrusive than any academic use of the posts. As a compromise it was agreed that a new thread in the media section would be started and outline the research to increase awareness of it with current users.

This article has highlighted some of the challenges when applying principle 1 of the BPS *Ethical Guidelines for Conducting Internet-mediated Research* (2013) in relation to the first author's research. This type of research is in its formative stages which means we need to give careful consideration to how we protect participants, respect the moderators, at the same time as facilitating high quality innovative research. In addition to respecting participants' rights, we suggest that researchers remember the person in the electronic data and that they can enhance their sensitivity to ethical issues in their research by working with moderators and forum users to take account of their opinions and wishes. It may be best to adopt a flexible approach

when applying these ethical guidelines and heed the BPS cautionary “thinking is not optional” (BPS, 2011, p.4).

The Authors

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Correspondence

Donna Moore

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2011http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

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<http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf>

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Hookway, N. (2008). Entering the blogosphere: some strategies for using blogs in social research. *Qualitative Research* 8(1): 91-113.

Hudson, J. M., & Bruckman, A. (2004). "Go away": Participant objections to being studied and the ethics of chatroom research. *The Information Society: An International Journal*, (20): 2.

Mann, C. & Stewart, F. (2000). Internet communication and qualitative research: a handbook for researching online. London: Sage publications.

Top tips for researchers

- Consider the complexity of the public/private space issue with the Ethics Committee
- Email forum moderators for their written informed consent
- Put a notice on the forum briefly explaining the study, which posts will be used and posters right to withdraw
- Include a link on the notice to more detailed information of the study (i.e. participant information sheet)
- Posters can email the researcher and give their user name for the forum and any quotes from that user name will not be published

Appendix 5.3 Additional quotes for thematic analysis results (Article 4)

Theme	Subtheme	Quote
Stigma	Internal stigma	<p>I just fail at everything about being a mother. Failed at pregnancy, failed at labour, failed at feeding, failed at getting them healthy, failed at keeping other bits of them healthy. [I]</p> <p>PND and mental illness generally still have such a stigma attached don't they. First things first, I doubt very much you are anything like an utterly rubbish mother. I think it is a very big and brave decision to have another child knowing you might have to suffer PND again so well done for that. [R]</p>
	External stigma	<p>I just feel convinced that the DR/midwife will see me as an unfit mother/label me as such and seek to take my baby away. [I]</p> <p>Please seek help from your GP, medication can really help with PND and there can be lots of other support too. [R]</p>
	Treatment stigma	<p>am worried that if I tell the truth, the GP will send someone round to take my baby away :- ((Should I just leave that bit out? [I]</p> <p>Tell someone how you feel - not because you need to be medicated, but so they can give you a cuddle, tell you that you are doing a great job and make you a cuppa. [R]</p>
Negative experiences		<p>I had severe PND but because I adored my babies, the GP didn't believe it was that bad and refused to treat it on the grounds I was breast feeding and there were no drugs that were compatible (actually, apparently there was one and there are probably loads more these days, in case that's an issue.) Without treatment, it took me years to feel well (truly, years) and I only felt 100% when I did finally get some treatment. [R]</p> <p>I had a phone consultation with a doctor today he made me feel awful like i was choosing to hurt my baby! I asked if there was meds i could take that were safe and he basically said no it was all about clinical risk. Then he said i</p>

		<p>will prescribe you <i>something</i> could not tell me what nothing. [I]</p> <p>Sorry that you were treated so badly. you did the right thing asking for help and they should be helping you. [R]</p>
--	--	---

Appendix 6.1 Ethical approval for the online survey study (Article 5 & 6)



School of Health Sciences

Research Office
Northampton Square
London EC1V 0HB

Ref: PhD/14-15/03

Tel: +44 (0) 20 7040 5704

www.city.ac.uk

27 March 2015

Dear Donna /Susan

Re: Use of online forums for perinatal mental illness: an online survey

Thank you for forwarding amendments and clarifications regarding your project. These have now been reviewed **and approved** by the Chair of the School Research Ethics Committee.

Please find attached, details of the full indemnity cover for your study.

Under the School Research Governance guidelines you are requested to contact myself once

the project has been completed, and may be asked to complete a brief progress report six

months after registering the project with the School.

If you have any queries please do not hesitate to contact me as below.

Yours sincerely



Alison Welton
Research Governance Officer



Appendix 6.2 The City Mental Illness Stigma Scale (Article 5)

We use the term “psychological problems” in this questionnaire to refer to all sorts of distress mothers might experience after having a baby, for example mood problems, depression, anxiety, trauma and obsessive compulsive disorder. Please think of psychological problems to mean whatever you feel comfortable with. We appreciate that some questions may be of a sensitive nature and we thank you for your honesty in helping us better understand how you are feeling.

Please select the amount you agree or disagree with each of the following statements based on how you have been feeling the past 2 weeks.

	Strongly disagree	Disagree	Agree	Strongly agree
1. I can't cope as well as I'd like with my baby	1	2	3	4
2. I have thoughts of hurting myself	1	2	3	4
3. I have thoughts of killing myself	1	2	3	4
4. I have thoughts about leaving my baby	1	2	3	4
5. My psychological problems have meant I have lost time with my baby	1	2	3	4

6. People think mothers with psychological problems can't cope with their babies	1	2	3	4
7. People think mothers with psychological problems don't love their babies	1	2	3	4
8. People think mothers with psychological problems will harm their babies	1	2	3	4
9. People think mothers with psychological problems will harm themselves	1	2	3	4
10. People think mothers with psychological problems will kill themselves	1	2	3	4
11. People think mothers with psychological problems are abnormal	1	2	3	4
12. I do not want people to know I have psychological problems as they may think I'm a bad mother	1	2	3	4
13. I worry that if I told a healthcare provider about my psychological problems the social services would get involved	1	2	3	4

14. I worry that if I told a healthcare provider about my psychological problems my baby would be taken away	1	2	3	4
15. I worry that if I told a healthcare provider about my thoughts they would think I am an abusive mother	1	2	3	4

Appendix 6.3 Items omitted from the final scale (Article 5)

Omitted from the second analysis:

It is my fault I am more likely to have psychological problems in the future

Television and newspapers show motherhood as a happy time and mothers are not depressed

Good mothers do not have psychological problems

I am as good a mother as other mothers despite having psychological problems

A good mother gets treatment for her psychological problems

I worry that if I took medication for my psychological problems I would not know if

I got better because of my own hard work or the pills

Mothers should only talk about their psychological problems with their family

People think having a new baby is a happy time so mothers should not be depressed

Omitted from third analysis:

I would feel bad if others knew I took medication for my psychological problems

I find it difficult to love my baby

I have thoughts of harming my baby in some way

My psychological problems have made things difficult for my partner and/or family

People think mothers with psychological problems should be able to snap out of it

Television and newspapers show mothers with psychological problems as a threat to their babies

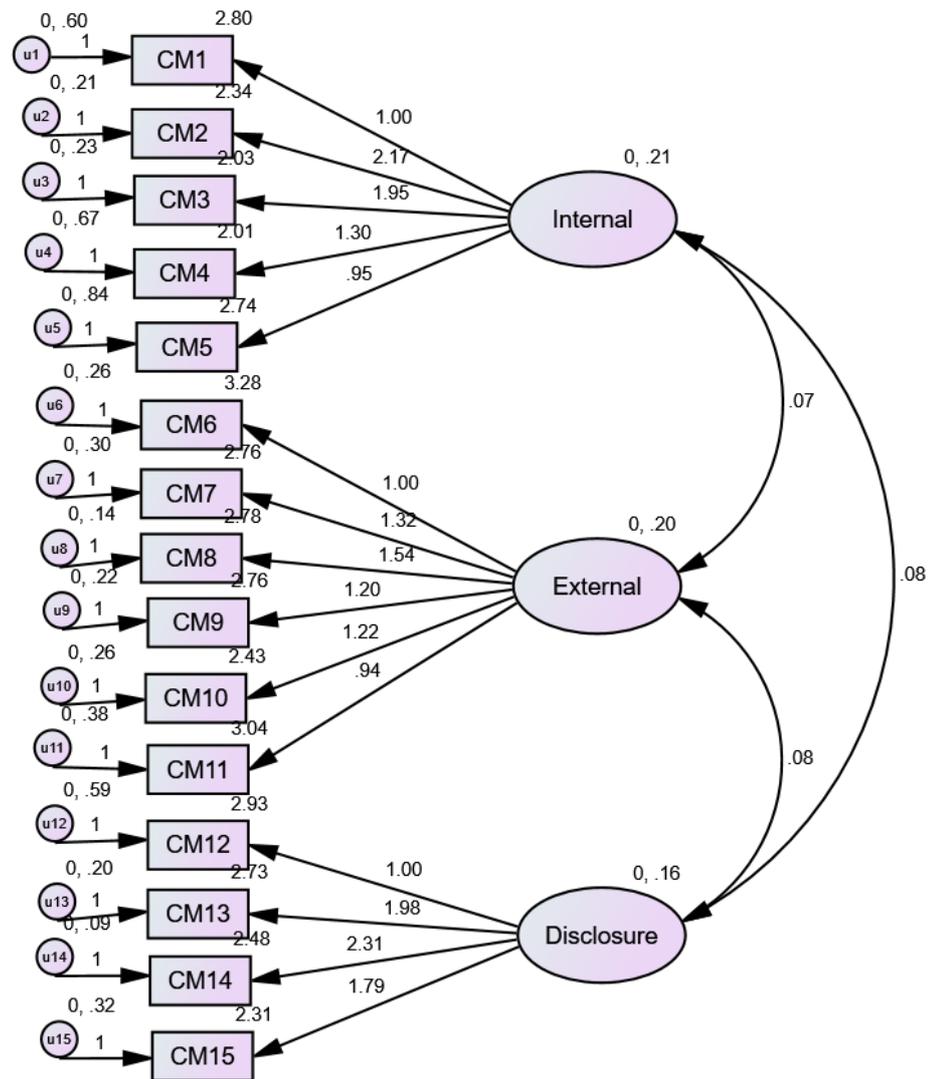
I worry that if I tell my healthcare provider how I feel I will be referred for counselling

Appendix 6.4 Confirmatory factor analysis of the CityMiss (Article 5)

The three-factor structure of the 15 item CityMISS, as identified by the Exploratory factor analysis (EFA) in article 5, was estimated using Confirmatory Factor analysis (CFA; see Figure 6.4). The model was found to have a significant chi-squared result ($\chi^2 = 250.75$, $p = 0.001$) which can indicate a poor model fit. However, this could be due to the large sample size and not necessarily indicative of a poor fitting model, thus a range of other tests were utilised to assess model fit (Byrne, 2001). Other frequently used tests of model fit include Incremental Fit Index (IFI), Tucker-Lewis Index (TLI) and Comparative Fit Index (CFI) and when scores are above 0.9 it suggests a good model fit (Hu & Bentler, 1999). Results showed IFI = 0.92, TLI = 0.89 and CFI 0.92, which suggests that it is a plausible model for internal, external and disclosure stigma. RMSEA was 0.08 and suggests a good model fit as scores between 0.05 and 0.08 show a good fit (Reeve et al., 2007).

Overall, results suggest the model is a good fit, and support the EFA results. However, the model could be improved to yield more agreement between tests of good fit. One way to improve the model fit is to consider the construct validity of the subscales of stigma. This has been discussed in the thesis, particularly in relation to the internal stigma subscale (see page 159).

Figure 6.4



Appendix 7.1 Online survey questions (Article 6)

Section 1 About you

Please rate the level of psychological problems, stress and/or isolation you had in pregnancy and/or after birth?

None

Mild

Moderate

Severe

Have you talked to any of the following people about these feelings? Please tick all that apply

Partner

Family

Friends

Family Doctor/GP

Midwife

Online forum users

Health visitor

Counsellor/therapist

other

please state

Have you been diagnosed by a healthcare professional as having a psychological problem during pregnancy and/or after birth?

Yes

No

If yes, please state what they said the problem was

Are there any things that make it difficult for you to talk to healthcare providers about how you feel/felt during pregnancy and/or after birth?

No

Yes

if yes please describe

Are you receiving or have you received any of the following treatments in the time around the birth of your child? please tick all that apply

Mother and baby unit

Counselling

Medication

Cognitive Behavioural Therapy (CBT)

Online self-help

other

please state

Section 2 What do you think about psychological problems during pregnancy and after birth?

The City Mental Illness Stigma Scale (Moore, Ayers & Drey)

We use the term “psychological problems” in this questionnaire to refer to all sorts of distress mothers might experience after having a baby, for example mood problems, depression, anxiety, trauma and obsessive compulsive disorder. Please think of psychological problems to mean whatever you feel comfortable with. We appreciate that some questions may be of a sensitive nature and we thank you for your honesty in helping us better understand how you are feeling.

Please select the amount you agree or disagree with each of the following statements.

	Strongly disagree	Disagree	Agree	Strongly agree
1. I can't cope as well as I'd like with my baby	1	2	3	4
2. I have thoughts of hurting myself	1	2	3	4
3. I have thoughts of killing myself	1	2	3	4
4. I have thoughts about leaving my baby	1	2	3	4
5. My psychological problems have meant I have lost time with my baby	1	2	3	4
6. People think mothers with psychological problems can't cope with their babies	1	2	3	4

7. People think mothers with psychological problems don't love their babies	1	2	3	4
8. People think mothers with psychological problems will harm their babies	1	2	3	4
9. People think mothers with psychological problems will harm themselves	1	2	3	4
10. People think mothers with psychological problems will kill themselves	1	2	3	4
11. People think mothers with psychological problems are abnormal	1	2	3	4
12. I do not want people to know I have psychological problems as they may think I'm a bad mother	1	2	3	4
13. I worry that if I told a healthcare provider about my psychological problems the social services would get involved	1	2	3	4

14. I worry that if I told a	1	2	3	4
healthcare provider about my				
psychological problems my baby				
would be taken away				
15. I worry that if I told a	1	2	3	4
healthcare provider about my				
thoughts they would think I am an				
abusive mother				

Section 3 What do you think about mental illness in general?

Brief Version of the Internalized Stigma of Mental Illness (ISMI) Scale (Boyd, Otilingam & DeForge, 2014)

Section 4 About using online forums

How often do you visit forums that discuss mental health in pregnancy or after birth?
For example, depression after childbirth, upsetting feelings around birth.

daily

weekly

monthly

never

Please list the forum(s) that you use most often about these issues?

When did you start using these forum(s)?

A week ago

A month ago

6 months ago

A year ago

Over a year ago

How often do you read posts on these forums?

daily

weekly

monthly

never

How often do you start a conversation/thread on these forums?

daily

weekly

monthly

never

How often do you reply to conversations/thread posted by other members?

daily

weekly

monthly

never

What are the main reasons you visit these forums?

Section 5 How you feel now

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Part 6 Tell us about yourself

What is your age?

What is your child's/children's date of birth?

Which category best describes you?

White

Hispanic or Latino

Black or African American

Native American or American Indian

Asian / Pacific Islander

Other please state

What is your country of residence?

What is your current marital status?

Single, never married

Married

Living with partner

Divorced

Widowed

Separated

other

Are you currently?

Employed for wages

Self-employed

Out of work and looking for work

Out of work but not currently looking for work

A homemaker

A student

Military

Unable to work

What is the highest level of education you have completed?

GCSEs

A levels

Trade/technical/vocational training

Bachelor's degree

Master's degree

Doctorate degree

Appendix 7.2 Path analysis with external, internal and disclosure stigma as simultaneous mediators (Article 6)

There was a significant indirect effect of length of forum use on disclosure of symptoms to a healthcare provider through the stigma subscales, $b=0.16$, BCa CI [0.04, 0.40]. There was no direct effect between forum variables and disclosure, $b=0.47$, $p = 0.33$ (Figure 7). Internal stigma was the only variable to show significant effect on disclosure, $b=0.15$, $p<0.00$

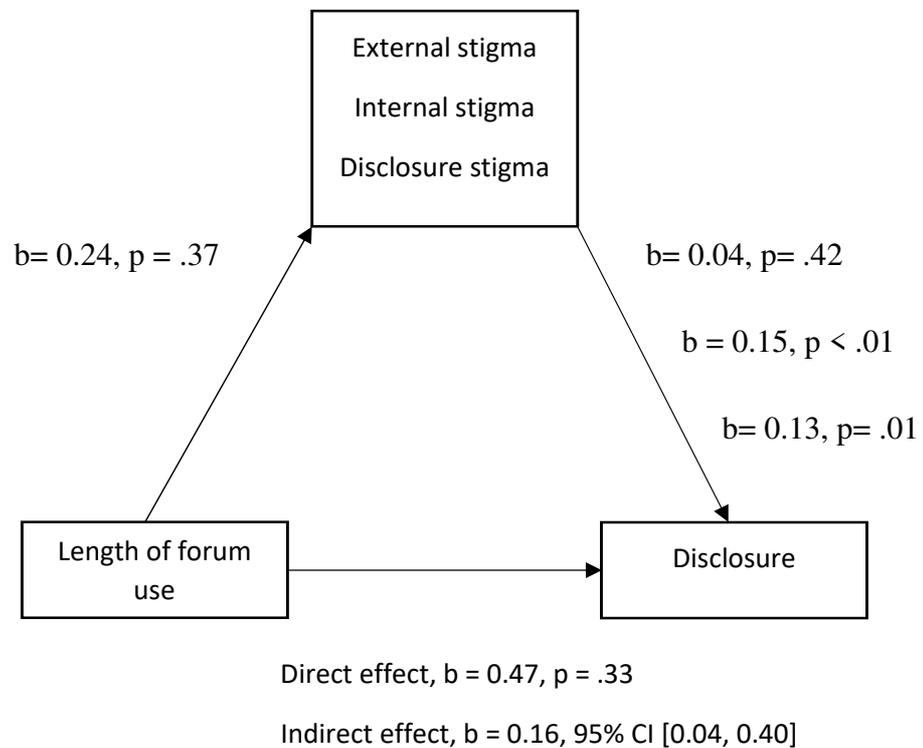


Figure 7.2 Model of length of forum use as a predictor of disclosure, mediated by relationship with external, internal and disclosure stigma

Appendix 8 Publications

**The full text of this article has been
removed for copyright reasons**

Original Paper

A Thematic Analysis of Stigma and Disclosure for Perinatal Depression on an Online Forum

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Abstract

Background: Perinatal mental illness is a global health concern; however, many women do not get the treatment they need to recover. Some women choose not to seek professional help and get no treatment because they feel stigmatized. Online forums for various health conditions, including perinatal mental health, can be beneficial for members. Little is known about the role that online forums for perinatal mental illness play in reducing stigma and subsequent disclosure of symptoms to health care providers and treatment uptake.

Objective: This study aimed to examine stigma and disclosure in forums and describe any potential disadvantages of forum use.

Methods: An online forum for mothers was examined and 1546 messages extracted from 102 threads from the antenatal and postnatal depression section. These messages were subjected to deductive systematic thematic analysis to identify common themes regarding stigma and disclosure of symptoms and potential disadvantages of forum use.

Results: Two major themes were identified: *stigma* and *negative experiences of disclosure*. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma. Many women were concerned about feeling like a “bad” or “failed” mother and worried that if they disclosed their symptoms to a health care provider they would be stigmatized. Posts in response to this frequently encouraged women to disclose their symptoms to health care providers and accept professional treatment. Forum discourse reconstructed the ideology of motherhood as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment. Many women overcame stigma and replied that they had taken advice and disclosed to a health care provider and/or taken treatment.

Conclusions: Forum use may increase women's disclosure to health care providers by challenging their internal and external stigma and this may strengthen professional treatment uptake and adherence. However, a few posts described negative experiences when disclosing to health care providers.

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KEYWORDS

perinatal; online; Internet; depression; eHealth

Introduction

Perinatal mental illness is a global health concern and includes antenatal and postnatal depression and anxiety disorders, post-traumatic stress disorder after childbirth, and adjustment

disorders. Perinatal depression has a prevalence of 12%-20% [1] and perinatal anxiety affects 2.6%-39% of women [2]. Post-traumatic stress disorder after childbirth affects 3.17% of new mothers and 15% in high-risk groups [3]. If these illnesses are not treated, there are well-documented adverse outcomes

for women, infants, and families [4]. Detrimental maternal outcomes include substance abuse and suicide [5] and untreated antenatal depression is associated with postnatal depression [6]. Negative infant outcomes include developmental and cognitive delays [7,8], preterm delivery [9], and an increased risk of behavioral and attachment problems [10].

Women with perinatal mental illness often fail to receive treatment despite treatment being available [11]. Often this is because women choose not to disclose and seek help from their health care provider. Poor knowledge of medical conditions is one reason some people may be less likely to recognize they are ill and therefore less likely to seek help [12]. Some women have poor health literacy about perinatal mental illness and problems relating professional health information to how they experience the illness [13]. In addition, there can be a misconception about what perinatal mental illness is, and women may find it difficult to distinguish what is a healthy emotional reaction to the transition to motherhood and what emotions may indicate a mental illness [14]. These issues can contribute to stigma.

Stigma is an extreme disapproval of someone or group of people because of a certain characteristic; it can present as external stigma where the general public holds a stigmatizing attitude. It can also present as internal stigma where the stigmatized individual believes this negative appraisal and applies it to themselves. There are high levels of external stigma in the general population and internal stigma has been identified in approximately a third of people with severe mental illnesses [15,16]. There are well-documented negative outcomes for individuals with mental illness because of external stigma such as social exclusion, discrimination, and fewer life opportunities [17]. Similarly, internal stigma has been associated with low self-esteem, reduced disclosure, and reluctance to seek treatment [17,18].

Thus, some women may think others will view them negatively for having a mental illness (external stigma) and may also feel bad about themselves for having a mental illness (internal stigma). Stigma is a major barrier to disclosure and help-seeking in the perinatal period [14,19]. Some women feel stigmatized not only because they have a mental illness but principally because they are a mother with a mental illness. This two-fold stigma means they are concerned about feeling like, and being seen by others as, a “bad mother” [20]. Women with perinatal mental illness have unique concerns related to their maternal identity; they may worry that having a mental illness would result in negative consequences such as social services involvement, loss of custodial rights, and hospitalization [21-23]. These features of stigma can contribute to reluctance to disclose symptoms [24]. A systematic review and meta-synthesis identified stigma and concerns about child custody as a key barrier to care for postnatal women [25]. Many women avoided disclosing symptoms to health care providers, as they did not want to be diagnosed as having a mental illness. They wanted to be seen as coping and were worried they would lose custody of their child should they disclose.

People suffering from stigmatized illnesses are more likely to turn to the Internet for help [26,27]. Studies have detailed the

benefits of using online social support for a variety of health issues [28,29]. The Internet could provide a unique avenue to reduce stigma in terms of knowledge and attitude. It could provide information about perinatal mental illness that women could relate to. This could aid disclosure by increasing women's health literacy about perinatal mental illness and enable them to recognize that they have a problem.

There are thousands of websites dedicated to perinatal mental health and many online support groups or forums, but little is known about how members engage with them [30,31]. A content analysis by Evans et al [32] of an online support group for postnatal depression reported it was nonjudgmental. The forum provided emotional, informational, and some instrumental support. Posts encouraged users to contact a health care provider and take medication; there were no posts containing negative experiences with health care providers. Similarly, another content analysis documented how online support forums for lesbians with postnatal depression provided social support [33]. Many women were reluctant to disclose and seek help because of the stigma of being seen as an unfit mother and fear of the child being taken away. In addition to the stigma around their mental illness, women felt stigmatized because they were homosexual. The dichotomy of “good mother” “bad mother” deterred help-seeking behavior; it is plausible that this may be because it increases internal and external stigma. To some women the idea of a “good mother” is not compatible with mental illness; similarly, having symptoms of perinatal mental illness such as bonding problems or thinking of harming your child can make women feel like a “bad mother” [20].

A discourse analysis of an online forum for postnatal depression reported how it provided a place for mothers to confess their shame about having perinatal mental illness [34]. This enabled many women to overcome the stigma of being mentally ill and not meeting the expectations of a good mother. Women found that no one talked about this offline, so they constructed an online dialogue with other forum users that expressed negative feelings around motherhood. Nevertheless, it is important to note that some recent research suggests online support groups may not challenge stigma enough to affect or change help-seeking behavior [35]. Excessive participation in online support groups could also be a form of social avoidance and prevent disclosure and foster over reliance on forums [36]. Internet forums for perinatal mental health have yet to be researched to see how using forums may increase disclosure of symptoms and help-seeking behavior. Forums may challenge stigma by providing a unique source of experiential information and a space for women to disclose and seek advice anonymously without fear of being stigmatized. Posts on forums may challenge stigma and provide positive discourse about perinatal mental health. Posts may also provide encouragement for women to seek and adhere to professional treatment by challenging external stigma.

This study aimed to investigate if and how perinatal mental illness forums might overcome the barriers stigma presents to some women with perinatal mental illness when seeking help from health care providers and to see if there are possible disadvantages of using forums regarding disclosure and stigma.

Methods

Sample

Forums were identified using the three most popular UK search engines (Google, Bing, and Yahoo) that are used by 98.83% of Web users [37]. The text searches were “postnatal depression,” “postnatal forum,” “postnatal anxiety,” and “birth trauma” and entered into each of the search engines. The first 25 websites and their hyperlinks were assessed for inclusion in the study. Inclusion criteria were as follows: (1) they had a forum or message board dedicated to antenatal and/or postnatal mental health, (2) they had been active for the last 6 months, (3) the forum had more than 50 members, (4) messages could be viewed by nonmembers of the group, and (5) moderators gave permission to research their forums. Nine forums were contacted but only 1 forum moderator gave permission to research posts. The forum moderator was from “Mumsnet,” one of the largest websites for parenting advice and has active forums with between 1.2 and 1.7 million members [38]. There were 28 “talk topics” that contained between 1 and 273 forums. The forum section for antenatal and postnatal depression was dedicated to perinatal mental health and was used to draw the data for analysis.

Procedure

Nineteen forum moderators were contacted and written permission from 1 moderator was obtained. Visitors were informed of the nature of the research and their right to withdraw their data via a prominent disclaimer on the forum. A link from the site provided details about what data were taken from the site and how the information was used. The study was retrospective to avoid influencing the participants’ interactions. Confidentiality was maximized by ensuring the anonymity of participants by replacing their user names with pseudo names.

Data Selection

All messages on the antenatal and postnatal forum between January 2013 and June 2013 were included for analysis. This comprised 1546 messages retrieved from 102 threads. The average number of posts in a thread was nearly 28. These threads and messages were copied into Microsoft Word files and stored securely for data protection purposes and because forums can terminate at any time.

Ethical Considerations

The study received ethical approval from the School of Health Sciences Research Ethics Committee, City University London. Precautions were taken to ensure the safety, dignity, and rights of participants in accordance with the 2007 “Guidelines for Ethical Practice in Psychological Research Online” as outlined by the British Psychological Society [39]. Consideration was given to the nature of online private and public spaces, anonymity, confidentiality, valid consent, and the right to withdraw from the study [40].

Analysis

Discussion threads were examined using deductive systematic thematic analysis from a realist stance [41]. Threads were copied into the qualitative data analysis computer software NVivo 10

and threads were read and reread before generating initial codes [42]. Themes were generated from patterns in the codes and were included when they were frequent, appeared important to posters, and were related to the research aims. The principal researcher had experience in qualitative analyses and met regularly with a senior health researcher (SA) to discuss analysis, thus increasing reliability of codes and themes. The whole dataset was recoded when themes were defined and codes were organized to address the research questions of stigma, disclosure, and messages that could potentially hinder women seeking help. The principal researcher developed the interpretation of themes and final interpretations were agreed by consensus of all authors.

Results

Two major themes were identified: stigma and negative experiences. Stigma had 3 subthemes: internal stigma, external stigma, and treatment stigma.

Stigma

The majority of women disclosed their symptoms on their first post and often sought advice on diagnosis, whether or not they should contact a health care provider, healthcare providers’ attitudes to illness and treatment. Nearly all the replying posts urged women to contact their healthcare providers and often reassured women who had concerns about approaching health care providers. Women were frequently encouraged to honestly disclose their symptoms to health care providers and take professional treatment offered.

Internal Stigma

Internal stigma was coded when women wrote about their stigmatized attitudes towards themselves, such as feelings of inadequacy as a mother. Many women used the forum to disclose shameful feelings often hidden from others such as feeling like a failure as a mother, wanting to leave the baby or family, intrusive thoughts of self-harm and child-abuse. They felt that there was no place offline to talk about the negative side of pregnancy and motherhood and valued the nonjudgmental space offered by forums. Replies were often reassuring and challenged internal stigma by stressing that these feelings were part of the illness and not indicative of failure as a mother:

I'm not very compassionate towards myself or accepting of the fact that I was ill (rather than just being crap). [R]

You haven't failed!!! The illness is making you think this way. [R]

External Stigma

External stigma comprised of the concerns many women had about how health care providers would think that they were inadequate mother if they disclosed symptoms.

Members perpetuated a strong culture of advice that urged women to contact a general practitioner, midwife or health visitor even if they did not ask for it. Half of all women who had not disclosed to a health care providers when they first

posted replied that they had sought professional help following others' encouragement (n=15):

Thank you have rung the doctor. Think I just needed someone else to tell me to do it. [I]

Nearly half of women who posted did not reply to say if they had taken members advice, and one woman refused to disclose to a health care provider. Women were often reluctant to disclose to their health care providers as they feared being seen as a bad mother and their baby would be taken away or social services would intervene:

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. [I]

Anyone got any experience with this - what did u say to the DR? What was their approach? Were you made to feel like a bad mum/mum to be? Were you strictly monitored/referred to social services after? [I]

Most replies to these posts were reassuring, shared positive experiences of disclosing, and stressed getting help from a health care provider was the best course of action:

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. [R]

Treatment Stigma

Treatment stigma was related to women's concerns about seeking and adhering to professional treatment. It extended concepts of internal and external stigma described above.

Often posters emphasized the importance of professional help in recovery; women who started threads and posed questions were often reassured that they had *done the right thing* when they had disclosed to health care providers.

It is the people who are not seeking help and not being honest with themselves that are in the most danger; You are doing the right things, you are being objective, and seeking help. [R]

Treatment was largely discussed in terms of antidepressants. Some women felt like a failure for having to take medication, which added to feelings of *weakness* for having a mental illness and being a *failure* as a mother. This stigma often centered on guilt for thinking they would harm the baby, inability to cope as a mother, and needing to rely on medication.

I still feel guilty and worried I am causing my baby harm and being selfish if I ask for drugs - did any of you guys who have taken meds struggle with this before asking? [I]

Replies were embedded in a dialogue of social support and most were pro-antidepressants and encouraged women to work with health care providers. These posts often challenged stigma by promoting an alternative "good mum" discourse that challenged external and internal stigma. Posts reconceptualized what a good mother is, namely, a good mother gets help and takes 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. [R]

I feel like there's a stigma attached to taking meds for a mental illness, which doesn't exist for physical illnesses...And I don't think I'm going to do DD (darling daughter) any favours by trying to prove I can be a good mum off my medication. [R]

Negative Experiences

Negative experiences with health care providers included disclosure and treatment experiences. This theme extended feelings of internal and external stigma and the majority of subsequent posts challenged stigma by promoting health care providers and treatment.

Very few posts outlined any negative experiences when women disclosed to health care providers (n=3). One woman who started a thread rebuked replies encouraging help-seeking as she had previous negative experiences with the social services and did not trust health care providers. Two women started threads to talk about bad events with health care providers:

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. [I]

Subsequent posts condemned the midwife's approach and said how there are good and non-judgemental healthcare providers. Replies to unhelpful health care provider experiences strongly urged women to engage with health care providers and stressed that treatment was essential for recovery.

Discussion

Principal Findings

This study increases our knowledge of the stigma women with perinatal mental illness may experience. In particular, it offers unique insights into how women are expressing different types of stigma on an online forum, online discourse that challenged this stigma, and the potential outcomes for help-seeking behavior. Women frequently expressed internal stigma and were concerned about external stigma from health care providers. Both were noteworthy barriers to help-seeking behavior and reply posts often challenged this stigma by sharing positive experiences of disclosure and treatment. Posts challenged some women's beliefs that health care providers would think of them as an unfit mother or social services would take their baby. Women were consistently encouraged to seek professional help.

Treatment stigma was often expressed as stigma about having a mental illness and having a mental illness as a mother. Some women felt they had failed at their role as a mother because they had to rely on medication to cope and feared treatment would harm their unborn child. Subsequent posts challenged this stigma promoting a different discourse that advocated good mothers seek help and take treatment. Many women who sought advice on whether they should disclose to a healthcare provider reported that they followed the advice of reply posts and sought

help. There were 3 instances of negative experiences when disclosing symptoms to health care providers.

Comparisons With Prior Work

Consistent with previous studies [25,43], the stigma attached to mental illness was a salient barrier to treatment and women were able to “test out” disclosing symptoms and concerns in online conversations. Like previous research, many women spoke about the stigma attached to antidepressants that contributed to a reluctance to engage in treatment [44]. This study extends our knowledge of how a forum provided an anonymous place where women could explore their understanding of perinatal mental illness and where they got encouragement to seek help and accept treatment. If women recognize that they may have a mental illness, they may be more motivated to seek help like many women in this study. Women frequently expressed internal and external stigma often describing feeling like and/or being seen as a “bad mother,” an “unfit mother,” or a “failure.”

Internal, external, and treatment stigma discourse was met by replies of encouragement to get help and praised acts of disclosure to health care providers. Posts often promoted a “good mother” discourse that included the ideas that a good mother discloses and gets treatment and health care providers will not think them inadequate or take their baby away. These posts challenged the distressing dissonance between the concept of a good mother, and that of a bad mother, present in some mothers’ posts and thus reconciled that a “good mother” can have perinatal mental illness.

Unlike previous research on perinatal mental health forums, there were 3 posts that shared negative experiences of disclosing to health care providers [32-34]. Despite the vast majority of posts presenting positive experiences, the potential effect of negative posts should be considered. Some women who experience stigma can suffer with intense feelings of inadequacy and worry that health care providers will not understand or social services will become involved [20]. Future work should investigate if negative posts reinforce these anxieties and if in turn this inhibits disclosure and help-seeking behavior. The culture of discussions and attitudes to disclosure may be very different in other online communities, for example, a birth trauma support group may include many posts describing negative experiences with health care providers. This group gives women an opportunity to voice their concerns that they may not be able to do offline, however, there is potential for conversations to negatively impact healthcare decisions. Concerns are warranted, especially if the forum is unmoderated and lacks encouragement to engage with health care providers.

Limitations

This is the first study of messages on a perinatal mental illness forum that explores stigma and disclosure and suggests potential concerns for users. Unfortunately, this study only considered one online forum as all other moderators either did not give consent or failed to reply to requests for consent. Future research should observe other forums to ensure the validity and generalizability of findings. Messages reported that half of women sought help as a direct consequence of using the forums. We do not know if there was an effect on the women who did not reply or those who read forums without posting. Users who read without posting are also known as lurkers and account for the majority of forum users [45,46]. Therefore, future research should aim to explore both posters’ and lurkers’ experiences and survey women with various levels of participation in different forums.

Clinical Implications

This study provides further insights into the stigma women with perinatal mental illness may experience and how they communicate online. This could be used to develop targeted interventions to help women disclose to health care providers and get treatment, for example, forums could be developed to offer this support to at risk women and their subsequent disclosure could be measured against a control group. Future theoretical models could draw on this evidence and investigate if online forum use for perinatal mental illness impacts the stigma experienced by some women and if this affects disclosure to health care providers.

Conclusions

Forum posts often expressed internal and external stigma from health care providers and treatment stigma as major barriers to disclosure and help-seeking behavior. Forum replies challenged this stigma and provided a place to discuss stigma. Forum discourse reconstructed the idea of a good mother as compatible with perinatal mental illness, especially if the woman sought help and adhered to treatment.

The vast majority of posts encouraged women to engage with and trust in health care providers, and consequently some women sought help and engaged in treatment. This study showed that this forum has the potential to increase women’s disclosure to health care providers and strengthen professional treatment uptake and adherence. However, there are possible concerns when using forums. Health care providers should exercise discernment when directing their clients to online forums.

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Conflicts of Interest

None declared.

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<http://mental.jmir.org/2016/2/e18/>

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Original Paper

Use of Online Forums for Perinatal Mental Illness, Stigma, and Disclosure: An Exploratory Model

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Abstract

Background: Perinatal mental illness is a global health concern; however, many women with the illness do not get the treatment they need to recover. Interventions that reduce the stigma around perinatal mental illness have the potential to enable women to disclose their symptoms to health care providers and consequently access treatment. There are many online forums for perinatal mental illness and thousands of women use them. Preliminary research suggests that online forums may promote help-seeking behavior, potentially because they have a role in challenging stigma. This study draws from these findings and theoretical concepts to present a model of forum use, stigma, and disclosure.

Objective: This study tested a model that measured the mediating role of stigma between online forum use and disclosure of affective symptoms to health care providers.

Methods: A Web-based survey of 200 women who were pregnant or had a child younger than 5 years and considered themselves to be experiencing psychological distress was conducted. Women were recruited through social media and questions measured forum usage, perinatal mental illness stigma, disclosure to health care providers, depression and anxiety symptoms, barriers to disclosure, and demographic information.

Results: There was a significant positive indirect effect of length of forum use on disclosure of symptoms through internal stigma, $b=0.40$, bias-corrected and accelerated (BCa) 95% CI 0.13-0.85. Long-term forum users reported higher levels of internal stigma, and higher internal stigma was associated with disclosure of symptoms to health care providers when controlling for symptoms of depression and anxiety.

Conclusions: Internal stigma mediates the relationship between length of forum use and disclosure to health care providers. Findings suggest that forums have the potential to enable women to recognize and reveal their internal stigma, which may in turn lead to greater disclosure of symptoms to health care providers. Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to health care providers.

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KEYWORDS

Internet; social stigma; depression; postpartum; mood disorder; female

Introduction

Perinatal Mental Illness and Stigma

The term *perinatal mental illnesses* is used throughout this paper to refer to conditions that include depression, anxiety, obsessive compulsive disorder, post-traumatic stress disorder, and puerperal psychosis. Perinatal mental illness is a global health concern [1]. However, prevalence varies depending on a variety of factors such as the instrument used to measure symptoms, developed versus less developed countries, time of evaluation in the gestational or postnatal period, and whether the sample is high risk. Antenatal depression and anxiety occur in approximately 7% to 25% of pregnant women [2-4]. Postnatal depression has a prevalence of 12% to 20% and postnatal anxiety affects 3% to 43% of women [5,6]. Post-traumatic stress disorder occurs in 3.17% of new mothers and can affect up to 15% of women in high-risk groups [7]. Puerperal psychosis occurs in approximately 1-2 per 1000 women [8,9]. Moreover, many women suffer from symptoms associated with mental illness without detection because they do not conform to all the diagnostic criteria [10].

Approximately half the women with perinatal mental illness fail to get professional treatment despite regular contact with health care providers [11]. One reason for this is that the stigma associated with perinatal mental illness can be a barrier to women disclosing and seeking help [12]. External stigma is a negative attitude held by the general public toward an individual or group based on an undesirable quality, for example, mental illness [13]. These negative social stereotypes can lead to labeling the individual as deviant or inferior. Consequently, discriminatory behavior can occur toward the stigmatized group, for example, through social exclusion and marginalization [14]. A UK survey showed that 85% of respondents believed people with mental illness experience stigma and discrimination [15]. There has been noteworthy research and interventions to combat this pervasive social problem; for example, Mind and Rethink Mental Illness developed the “Time to Change” campaign [16].

Internal stigma can occur when stigmatized individuals agree with external stigma and apply it to themselves or they may feel external stigma is unreasonable yet still appraise themselves negatively. There are many detrimental outcomes of internal stigma including lowered self-esteem, lowered life satisfaction, and avoidance of both disclosure and help-seeking behavior [17,18]. High levels of internal stigma have been identified in approximately a third of people with severe mental illnesses [19]. Furthermore, it is important to distinguish between discrimination an individual experiences and external stigma the individual believes others hold without actually experiencing it (known as perceived external stigma). Perceived external stigma correlates with adverse health and mental health outcomes [20,21]. One consequence of perceived external stigma and internal stigma is that they can contribute to stigma associated with disclosure [22]. This paper defines this as “disclosure stigma”: the anticipated negative appraisal and anticipated negative behavior toward the stigmatized individual if he or she chose to disclose to others. This means that stigma could be a key component in an individual’s decision-making

process when choosing whether or not to disclose his or her symptoms of mental illness.

Internet Forums for Stigmatized Mental Illnesses

Internet forums are online discussions where users can have conversations with others by posting messages. They have potential to be an acceptable aid to people with stigmatized conditions as they can use them anonymously, thus circumventing possible negative outcomes associated with stigma [23,24]. Anonymity may also assist online disclosure, which may otherwise be difficult offline [25,26]. Forums for mental health have shown potential for helping people manage or recover from a variety of mental illnesses, in particular, depression [27-29]. They provide an opportunity to connect with similar others and share informational and emotional support [30]. Benefits include social support, communicating experiences with others who share their illness, expressing emotions, group identity, and empowerment and can reduce isolation [29,31-35]. There is some evidence from randomized controlled trials that forum use reduces depressive symptoms [36]. These and other benefits have been reported by both active users (visitors who post on forums) and lurkers (visitors who only read forum messages and do not post), although some evidence suggests lurkers benefit less than active users [37,38]. It is estimated that lurkers make up the majority of forum visitors, with reports of between 45% and 90% of users lurking [39,40].

There is some evidence that engagement with online forums has the potential to reduce stigma [41,42]. Online forums may challenge stigma, help cope with stigma, provide useful tools in testing out disclosing of symptoms and conversing about stigma surrounding mental health. Some research suggests that online forums could challenge stigma through empowerment, giving hope of recovery, and increasing knowledge of health care decisions [29]. Theoretically, all these factors could positively influence disclosure to health care providers and subsequently increase treatment uptake and recovery rates. Disclosure may also be encouraged through social support and posts that direct posters to consult health care providers [30]. Nonetheless, it should be noted that recent research highlights concerns regarding forum use and detrimental outcomes such as social avoidance, Internet addiction, and enabling negative behaviors, such as pro-anorexic forums [43-45].

Online Forums for Perinatal Mental Illness and Stigma

It is arguable that stigma associated with perinatal mental illness is distinct from mental illness stigma experienced at other times. There are specific concerns related to maternal identity and mental illness such as worries about social services’ involvement, custodial rights, and being judged by others and judging themselves as a “bad mother” [46]. This is complex as some symptoms are highly stigmatized and propagate guilt, shame, and consequent concealment of their illness, for example, suicidal ideation and thoughts of child abuse. Goffman’s (1963) theory of spoiled identity could be applied to understand how women may experience stigma affecting their maternal identity [13]. Many symptoms of perinatal mental illness are seen as incompatible with being a good mother and can exacerbate women’s illness. For example, a woman with postnatal obsessive

compulsive disorder might have persistent intrusive thoughts about harming her baby even though she does not act on them. This is a symptom of the illness, but it generates substantial distress and can damage her identity as a mother as these thoughts are not what she thinks a good mother should have.

Indeed, perinatal mental illness stigma could be conceptualized as multifaceted: comprising stigma associated with mental illness and stigma associated with being a mother with a mental illness. This stigma could comprise perceived external stigma, internal stigma, and disclosure stigma. All facets of this stigma could contribute to a woman's reluctance to disclose symptoms to health care providers [47,48]. It is vital that research and interventions target perinatal mental illness stigma to enable women to disclose, which is the first step to recovery.

One possible avenue for reducing stigma are online forums for perinatal mental illness. There are thousands of online forums for perinatal mental illness with a large flow of traffic indicating that they are highly used [49]. Some evidence highlights that perinatal mental illness forums might provide women with valuable peer support outside the hours of health care provider appointments [50]. Moreover, some research suggests that these forums provide social support that may challenge stigma. One study found an online forum for postnatal depression to be nonjudgmental and posts encouraged users to disclose and seek professional help [51]. Another study documented how online support forums for lesbians with postnatal depression provided social support and a space to communicate stigma [52]. Many women were reluctant to disclose and seek help because of stigma; they were worried about being seen as an unfit mother and concerned their child would be taken away. The dichotomy of "good mother, bad mother" deterred help-seeking behavior; this may be because it contributed to stigma. However, little is known about the relationships between perinatal mental illness forum use, stigma associated with perinatal mental illness, and help-seeking behavior of forum visitors.

A qualitative interview study (N=15) with women who had used forums to assist their recovery from perinatal mental illness explored how women visited forums to reduce their feelings of

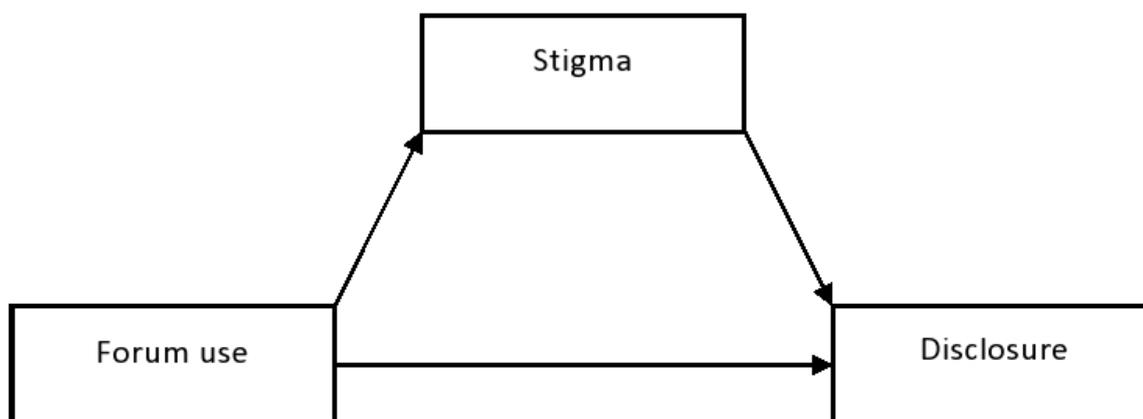
inadequacy as a mother and perceived stigma from others [53]. Benefits were reported by both active users and lurkers and women valued the anonymity provided by these forums as they could access social support without fear of judgment. Interestingly, most women suggested that forum culture normalized and validated their stigmatized symptoms and unraveled their identity as a "bad mother" with a mental illness from their identity as a "good mother." Many women felt they were helped by visiting these forums by developing a collective understanding and discourse about their illness. They suggested that this discourse challenged their internal stigma and empowered them to disclose to others offline.

A thematic analysis of posts on an antenatal and postnatal depression forum suggested that use may increase women's disclosure to health care providers, possibly by reducing stigma [22]. Posts provided positive experiences of disclosure to health care providers that challenged women's concerns about external stigma. Discourse addressed internal stigma by promoting that a "good mother" can have perinatal mental illness and if a woman discloses and gets treatment she is a "good mother." Forums for postnatal mental illness may therefore provide a place where women can express internal stigma and concerns about external stigma and disclosure stigma. They offer a unique opportunity to anonymously explore sensitive and highly stigmatized issues around their illness with others who may be experiencing the same problems. Potentially, these types of stigma could be challenged by women sharing positive experiences of disclosure. Forum rhetoric could reconstruct the idea of a good mother as compatible with perinatal mental illness, especially if women seek help. Thus, forum use has the potential to increase women's disclosure to health care providers by influencing stigma.

Aims

This study aimed to test a model that examined the role perinatal mental illness stigma has in mediating between forum use and disclosure to health care providers. It was hypothesized that perinatal mental illness stigma would mediate between online forum usage and disclosure to health care providers (Figure 1).

Figure 1. Hypothesis model.



Methods

Design

A cross-sectional Web-based survey of forum use, stigma, and disclosure in women during pregnancy and up to 5 years after birth who identified themselves as having some level of distress or psychological problems was conducted. Because of the sensitive nature of stigma, the information about the study did not use the term perinatal mental illness as some women might not have wanted to associate with the label; instead, the terms “psychological problems, stress or isolation” were used. Demographic information was collected and symptoms were also measured.

Participants

Respondents were recruited by advertising on perinatal mental illness websites, motherhood-related websites, Facebook groups, and Twitter. A total of 422 women started the questionnaires via a Web-based survey and 200 had complete answers for the measures used in the model [54]. The survey questions can be found in [Multimedia Appendix 1](#). Inclusion criteria stipulated that women were older than 18 years, were pregnant or had a child younger than 5 years, were a UK resident, considered themselves to be experiencing psychological distress, and had used perinatal mental illness forums.

Measures

City Mental Illness Stigma Scale

Stigma was measured using the City Mental Illness Stigma Scale (City MISS), a 15-item scale that measures the unique stigma women with perinatal mental illness experience (see [Multimedia Appendix 1](#)). It was developed from a literature review of perinatal mental illness stigma and tested via a Web-based survey with women with perinatal mental illness ($n=279$). Factor analysis was used to create the final 15-item scale. The scale accounted for 54.0% of the variance in the sample and had good reliability with Cronbach alphas between .81 and .86 for subscales and an overall alpha of .84 for the total scale indicating high reliability. The City MISS was highly correlated with a reliable measure for mental illness stigma (brief version of the Internalized Stigma of Mental Illness; ISMI-10 scale), which suggested good concurrent validity ($r_{277}=.56, P<.001$).

Respondents were asked to score the extent to which they agreed with a series of statements measured on Likert scales (1-4): “strongly disagree,” “disagree,” “agree,” and “strongly agree,” with higher scores signifying greater stigma. The scale has a 3-factor structure: the first concerns perceived external stigma, the second internal stigma, and the third disclosure stigma.

The perceived external stigma subscale comprised 6 statements that measured the respondent’s beliefs about what other people think about mothers with psychological problems, for example, “people think mothers with psychological problems will harm themselves.” The internal stigma subscale contained 5 questions that extend the concept of a “spoiled identity”; in this case it was specifically related to the respondent’s identity as a mother, for example, “I have thoughts about leaving my baby” [13].

The disclosure stigma subscale contained 4 questions that measured respondents’ anticipated discrimination if they disclosed their symptoms or diagnosis to health care providers. It contained 2 items that measured how they believed others would perceive them if they disclosed their psychological problems, for example, “I worry that if I told a health care provider about my thoughts they would think I am an abusive mother.” It contained 2 items that rated the potential negative consequences of disclosure, for example, “I worry that if I told a health care provider about my psychological problems the social services would get involved.”

Hospital Anxiety and Depression Scale

Current affective symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS) [55]. The HADS questionnaire has 14 items, 7 questions to measure depression and 7 questions to measure anxiety; it is widely used to score symptoms for many mental health conditions and is available in many languages [56]. It has good validity and reliability. Many studies from various countries including samples with different health conditions have reported factor analysis results supporting the 2-factor structure: depression and anxiety and significant correlations between the 2 factors [57]. The scale has also shown correlations with other scales that measure depression and anxiety [58].

Assessment of Forum Usage, Disclosure, and Demographic Information

Forum usage was measured with questions specifically developed for the study that measured frequency and duration of forum use, frequency of writing posts, and frequency of reading posts. Participation level was classified in accordance with previous literature that defined active and lurker status [59,60]. Women were categorized as active if they started threads or replied to posts and lurker if they did not contribute to forum conversations. Frequency of forum visits and duration of forum use categories were developed by all authors and subject to data analysis several times using different classifications and cutoffs to see if the results were altered. All authors agreed on the final categories based on face validity and categories with approximately equal numbers. Frequency of forum visits was measured as occasional when women reported visiting 3 times or less a month and frequent when reported as once or more a week. Duration of forum use was measured as long-term for members who had been visiting a year or more and short-term if under a year.

Disclosure was ascertained by participants indicating the people they had disclosed symptoms or diagnosis to, for example, a health visitor, family member, midwife. Results were coded as disclosed to a health care provider or not disclosed to a health care provider.

Demographic information was collected about marital status, ethnicity, occupation, education, number of children, and diagnosis.

Procedure

The survey was pilot-tested with 6 women with children younger than 2 years who had perinatal mental illness; the participants

completed the questionnaire online using a mobile phone and all found it acceptable and easy to understand and answer. Ethical approval was given by City, University of London, United Kingdom. Website and forum administrators were contacted to ask for consent to post information about the study and a hyperlink to the survey. The participant information sheet and the first and last pages of the survey urged women to contact their health care provider should they feel upset and provided details of external organizations that offered support. The first page of the survey was the participant information sheet and participants had to click a box to confirm that they consented to the study before they could progress to the survey.

Data Analysis

Results were included if the respondent had completed all the forum questions and the City MISS questions ($n=200$). Internet protocol addresses were checked for duplication, but none were identified. The models were analyzed using the statistical software package IBM SPSS 20.0 (IBM Corporation) and the moderation and mediation plug-in PROCESS [61]. Mediation analysis was conducted using the method suggested by Hayes [62]. This method was used because it tests whether there is an indirect effect and has good power because it uses bootstrapping [62,63]. Frequency of forum visits, duration of forum use, and frequency of writing posts were entered as predictor variables. City MISS scores for subscales internal stigma, external stigma, and disclosure stigma were entered as mediators. The outcome variable was disclosure of symptoms to a health care provider. HADS scores were entered as a covariate to account for potential confounding effects on the relationships between variables. The bootstrapping method was used to test the potential mediation effect using 1000 iterations. This method was chosen as it allows for multiple mediators, controls for the effects of covariates, has a higher power than the traditional Sobel test, and reduces the possibility of a type I error. The bootstrapping procedure computes the confidence intervals (CIs) for the indirect path. The null hypothesis is that the indirect path does not significantly differ from zero, so if the CIs do not include zero then the null hypothesis can be rejected and the indirect effect is significant when $P < .05$. Qualitative answers regarding disclosure barriers were transferred to the NVivo 10 (QSR International) software package and coded for external stigma, internal stigma, and disclosure stigma [64].

Results

Sample Characteristics

Participant characteristics are provided in Table 1. Most participants classed themselves as white ($n=191$) and married or living with a partner ($n=133$, $n=48$). More than 60.0% ($125/200$) were educated to degree level or above and most had 1 child ($n=139$). The majority of women had a diagnosis of one or more postnatal mental illnesses ($142/200$, 71.0%), and 23.0% ($46/200$) of women reported postnatal mental illness but had not sought a professional diagnosis. The remaining women had a diagnosis of antenatal mental illness ($3/200$, 1.5%) or both antenatal and postnatal mental illness ($9/200$, 4.5%). On the basis of the HADS measure completed during this study ($n=200$), 66.5% ($133/200$) of the women had moderate or severe anxiety and 34.5% ($69/200$) had moderate or severe depression. Forum use characteristics are presented in Table 2. Women were almost evenly categorized as frequent or occasional users and long-term or short-term users ($n=108$, $n=92$). There were nearly 3 times as many active users than lurkers ($n=156$, $n=44$).

Correlational Analysis

Relationships between variables are presented in Table 3. The length of forum use was significantly correlated to internal stigma score (subscale of City MISS). Frequency of forum visits was significantly correlated to participation level. Total stigma score was significantly correlated to internal stigma, external stigma, and disclosure stigma (stigma subscales of City MISS). Internal stigma score was significantly correlated to disclosure to a health care provider. Total affective symptoms score was significantly correlated to total stigma score, internal stigma, external stigma, and disclosure stigma. Total affective symptoms score was the only variable that had significant correlations with the model variables, that is, all mediator variables. Therefore, total affective symptoms score was entered as a covariate in the following analyses.

Stigma Mediating the Relationship Between Forum Use and Disclosure

There was a significant indirect effect of length of forum use on disclosure of symptoms to a health care provider through internal stigma, $b=0.399$, bias-corrected and accelerated (BCa) CI 0.133-0.846. There were no other indirect effects between variables and there was no direct effect between forum variables and disclosure, $b=0.133$, $P=.79$ (Figure 2).

Table 1. Sample demographic characteristics.

Characteristics	Subcategories	n (%) (N=200 ^a)
Marital status	Single	12 (6.0)
	Married	133 (66.5)
	Living with partner	48 (24.0)
	Separated	3 (1.5)
	Other	2 (1.0)
Ethnicity	White	191 (95.5)
	Mixed or multiple ethnic groups	5 (2.5)
	Other	2 (1.0)
Occupation	Employed	104 (52.0)
	Self-employed	17 (8.5)
	Out of work	9 (4.5)
	Homemaker	47 (23.5)
	Student	11 (5.5)
	Unable to work	10 (5.0)
Education	GCSE ^b	17 (8.5)
	A Levels	30 (15.0)
	Trade or vocational training	26 (13.0)
	Bachelor's degree	89 (44.5)
	Master's degree	34 (17.0)
	Doctoral degree	1 (0.5)
Number of children	1	139 (69.5)
	2	45 (22.5)
	3	6 (3.0)
Diagnosis	Antenatal depression	2 (1.0)
	Antenatal depression and anxiety	1 (0.5)
	Antenatal depression and postnatal depression	9 (4.5)
	Postnatal depression	53 (26.5)
	Postnatal anxiety	9 (4.5)
	Post-traumatic stress disorder (PTSD)	23 (11.5)
	Postnatal depression and anxiety	23 (11.5)
	Postnatal depression and PTSD	19 (9.5)
	Three or more postnatal mental illnesses	7 (3.5)
	Puerperal psychosis	3 (1.5)
Other postnatal mental illness	5 (2.5)	
	No diagnosis sought	46 (23.0)

^aThe total number of participants in demographic categories does not add up to 200 as not all participants completed the demographic questions.

^bGCSE: General Certificate of Secondary Education.

Table 2. Sample forum use characteristics.

Variable	Category	n (%) (N=200)
Frequency of visits	Frequent	108 (54.0)
	Occasional	92 (46.0)
Participation level	Active	156 (78.0)
	Lurker	44 (22.0)
Duration of use	Long-term	108 (54.0)
	Short-term	92 (46.0)

Table 3. Bivariate correlations of dependent variables, independent variables, mediators, and control variable.

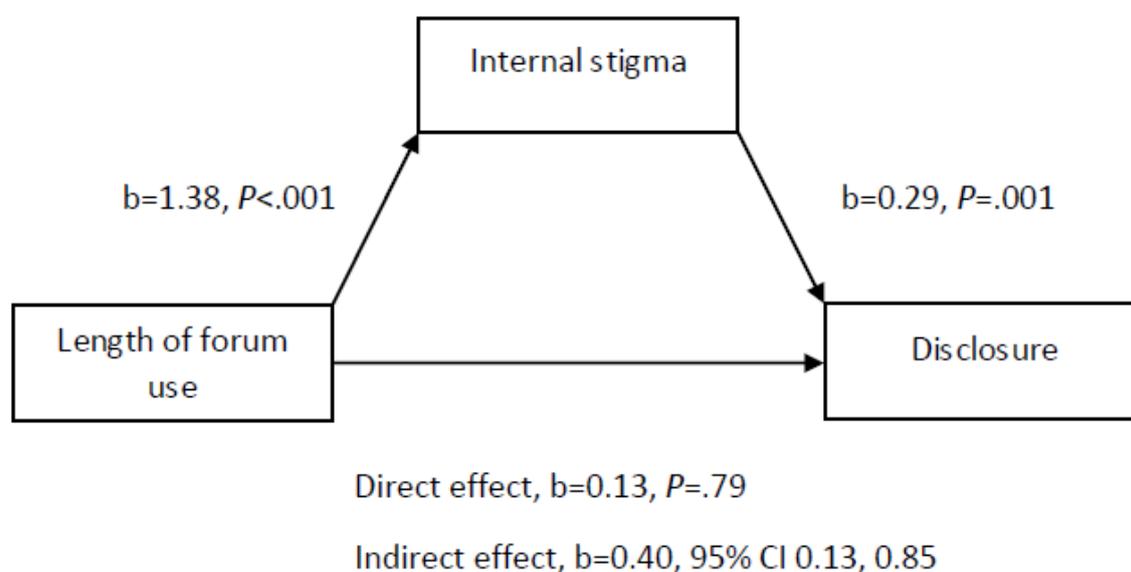
Variable	1	2	3	4	5	6	7	8	9
1. Disclosure	1	.060	-.004	.045	.138	.230 ^c	.074	-.019	.019
2. Length of use		1	-.087	.043	.150 ^d	.180 ^d	.064	.087	-.020
3. Frequency of visits			1	.285 ^c	.088	.065	.031	.111	.066
4. Participation				1	.058	.095	.061	-.041	.032
5. Total City MISS ^a					1	.751 ^c	.766 ^c	.744 ^c	.423 ^c
6. Internal stigma						1	.299 ^c	.331 ^c	.393 ^c
7. External stigma							1	.434 ^c	.222 ^c
8. Disclosure stigma								1	.339 ^c
9. HADS ^b									1

^aCity MISS: Mental Illness Stigma Scale.

^bHADS: Hospital Anxiety and Depression Scale.

^cCorrelation is significant at the .01 level (two-tailed).

^dCorrelation is significant at the .05 level (two-tailed).

Figure 2. Model with statistics.

Discussion

Principal Findings

This study tested a model based on previous research that proposed perinatal mental illness stigma mediates between forum use and disclosure. There was a significant indirect effect of length of forum use on disclosure of symptoms to health care providers through internal stigma. Long-term forum users reported higher internal stigma scores and higher internal stigma was associated with disclosure to a health care provider. There was no indirect effect of perceived external or disclosure stigma, nor was there a direct effect between length of forum use and disclosure. Qualitative findings support this as many women reported that external stigma, internal stigma, and disclosure stigma specific to perinatal mental illness were barriers to their disclosing to health care providers.

There was theoretical reason to believe that increased forum use would decrease stigma and subsequently increase disclosure to health care providers. Also, social support offered by forum members might be empowering and play a role in disclosure. Results unexpectedly indicated that forum use was associated with increased reported internal stigma. There are a number of possible explanations for this. It is plausible that visiting forums might have adversely affected internal stigma or it may be that women with higher internal stigma use forums for longer. However, this study advocates an alternative explanation of the findings and proposes that forum messages encouraged these women to recognize their feelings of internal stigma, and this increased their self-awareness, enabling them to make a fuller disclosure when completing the stigma questionnaire. Previous research suggests that forums may provide a place where women can explore their feelings, and this may have meant that implicit feelings of internal stigma could have become explicit [22]. Also, women may have overcome barriers to revealing this internal stigma through forum benefits such as social support, identification with the forum group, and an alternative perspective of perinatal mental illness that shifted their “spoiled identity” to an empowered identity as a good mother despite having a mental illness.

Interestingly, there was no direct effect between forum use variables and disclosure. Current research suggests that mediation can occur without results showing a direct effect [65,66]. It is possible that other factors omitted from the analyses may have weakened the direct effect, also known as suppressor variables. Possible suppressor variables are individual differences such as personality traits, experience of discrimination, and social support. Furthermore, there may have been an overrepresentation of a subset of women who do not have a significant relationship between the predictor and outcome variables, and thus a direct effect would have been neutralized. Future research could measure potential suppressor variables to explore this intricate relationship.

Limitations

Caution should be exercised when considering generalization from this sample as there are a number of characteristics that might not be true of the general population of forum users. First, the women were mostly white and educated to A Level or above.

There was also an overrepresentation of active users, possibly because active users have a more vested interest in forum research or they have different traits that might make them more likely to post on forums and participate in Web-based surveys [45]. The majority of women had experienced symptoms in the postnatal period, and thus findings might not extend to antenatal populations. The model could benefit from future modifications such as including a measure of whether women had experienced discrimination when disclosing, such as “health professional stigma” [67]. Similarly, there was no measure of other social media use that may affect stigma levels and have further implications for disclosure behavior. The type of forum or combination of forums women used may have had an impact on the results, for example, if the forum was moderated or unmoderated. The study cannot determine the direction of causality because it was cross-sectional. It may therefore be that women who disclosed may be more likely to visit forums rather than forum use in itself increasing disclosure behavior. Future research should use experimental and longitudinal designs to be able to ascertain the direction of this potential effect and include a measure of forum type. Future research could test the theories suggested as part of prevention and intervention studies. It might also be beneficial to include other means of social support into the model.

Comparison With Prior Work

This study supports and extends previous research that suggests forum use may affect internal stigma and in turn lead to disclosure; however, this relationship may be more complex than our initial model proposed [41,42]. Interpretation of the findings suggests that perceived external stigma and disclosure stigma do not mediate between forum use and disclosure. This is surprising because prior studies showed that perinatal mental illness forum messages are pro-disclosure and supply positive experiences with health care providers [22,51,52].

Another consideration is that forums differ in their posts concerning health care providers. Recent research has highlighted that some forums include many negative experiences with illness symptoms and experiences with health care providers [68]. Thus, some forums may contain conversations that reduce disclosure stigma and external stigma, and others, albeit inadvertently, may increase external stigma and disclosure stigma. Women in this sample may have been visiting a mixture of these types of forums and they may have had different effects on perceived external stigma and disclosure stigma. Therefore, future research should not dismiss exploration of external stigma and disclosure stigma in forum use.

Qualitative findings confirm that stigma is a major barrier to disclosure and details the complex relationship between maternal identity and internal stigma, external stigma, and disclosure stigma [22]. Other studies advocated a negative effect on disclosure from an overreliance on forums, but this was not suggested in our findings [44,45]. However, it may be worth investigating whether there are forums that maintain or generate stigma, for example, through providing negative experiences with health care providers, such as a forum for birth trauma.

Conclusions

Findings suggest internal stigma of perinatal mental illness mediates between forum use and disclosure. Using forums may provide valuable social support and improve women's disclosure to health care providers through enabling expression of their internal stigma. Theoretical reasons for this have been discussed; in particular, it is suggested that women can explore their feelings, so they become more aware of their internal stigma and are empowered to express these feelings. Furthermore,

women may be enabled to disclose by reconciling the negative impact of internal stigma on their maternal identity by agreeing with forum discourse that promoted the idea that one can be a good mother despite having perinatal mental illness. Future work could test these theories and continue to strengthen knowledge of perinatal mental illness, forum use, stigma, and disclosure behavior. Clinicians could refer clients to trustworthy and moderated online forums that facilitate expression of perinatal mental illness stigma and promote disclosure to health care providers.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Web-based survey questions.

[[PDF File \(Adobe PDF File\), 47KB - mental_v4i1e6_app1.pdf](#)]

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Abbreviations

BCa: bias-corrected and accelerated

City MISS: City Mental Illness Stigma Scale

HADS: Hospital Anxiety and Depression Scale

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