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The City MISS: development of a scale to measure stigma of perinatal mental illness

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Abstract

Objective: This study aimed to develop and validate a scale to measure perceived stigma for perinatal mental illness by 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 Internal 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 62% 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 could provide a useful tool for clinical practice and research regarding 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.

Introduction

The stigma associated with mental illness has been 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 general public, which is labelled external stigma. Internal stigma can also present when a stigmatised individual attaches stigma to their own identity. This could be because they agree with external stigma and then apply it to themselves. They may also experience internal stigma because they feel they are not meeting their own expectations or standards of motherhood. 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 and Watson, 2002).

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 and 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 and Kaplan, 2009). Post-traumatic stress disorder occurs in 3.17% of women after childbirth and 15% of women in high risk groups (Grekin and O'Hara, 2014). In addition, many women suffer from moderate affective symptoms or distress without meeting all the criteria for a diagnosis (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 and post-traumatic stress.

It is possible that the stigma women may experience during pregnancy and/or after birth differs from stigma for mental illnesses at other times of life in a number of ways.

Women may have to cope with the stigma of having a mental illness, and also of being a mother with a mental illness. Women can be worried about being seen by others and/or viewing themselves as a “bad mother” or failure and are consequently less likely to disclose to others (Bilszta et al., 2010; Kingston et al., 2015; McCarthy and McMahon, 2008). They 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 and Timmons, 2005; Hanley and Long, 2006). Therefore, external and internal stigma, as well as the stigma associated with disclosing to others 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, to our knowledge there is no 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.

Method

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 Internal Stigma of Mental Illness Scale (Boyd et al., 2014; ISMI-10). Both scales claim to measure stigma related to mental illness and therefore should correlate. In addition, women were asked if they found it hard to disclose to a healthcare professional or chose to avoid disclosing completely and to give the reason for this. Symptoms of perinatal mental illness using the Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983; HADS) and demographic information were requested.

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 were self-identified as over 18 years old, pregnant or had a child under 4 years old and having experienced or were experiencing perinatal distress. 403 women answered questionnaires via an online survey platform (Qualtrics, LLC, 2015). Women were included in the current analyses if they completed all the City MISS questions and all the ISMI-10 scale questions (total 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.

Ethics

Ethical approval was given by the School of Health Sciences Research Ethics Committee, City University London. 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.

Measures

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 entering the search terms “perinatal depression/anxiety”, “antenatal depression/anxiety”, “postnatal depression/anxiety” AND “stigma” into the databases SCOPUS and Medline. Papers were published between 1999 and 2014 and were included if they contained information about antenatal and/or postnatal mental illness stigma (n=16) (Abrams and Curran, 2011; Battle, 2013; Beck, 2002; Bilszta et al., 2010; Buultjens and Liamputtong, 2007; Byatt et al., 2012; Edge, 2006; Edwards and Timmons, 2005; Gardner et al., 2014; Hanley and Long, 2006; Mauthner, 1999; McCarthy and McMahon, 2008; McLoughlin, 2013; Patel, 2013; Price and Bentley, 2013; Shakespeare et al., 2003). Questions and subscales were developed by the first author in collaboration with two other senior researchers (XX & XX). 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’ and ‘strongly agree’ with 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 what other people think about mothers with psychological problems. It was fundamentally connected to how people thought women fulfilled their role as a mother. Questions were developed from the literature review and captured concerns women had about others seeing them 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", in this case it was specifically related to participant's identity as a mother (Goffman, 1963). The literature review suggested symptoms that exasperate women's feelings of maternal inadequacy were highly associated with internal stigma. Therefore, the scale was developed to capture these symptoms because it is probable that when present there is a high risk of internal stigma. Features of these symptoms were identified from the literature review as 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 review and contained two items that measured how they 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 with six women with infants under two years. Following their feedback no items were excluded, but the two media questions were rescaled to include "neither agree nor disagree".

Concurrent validity

Internalised stigma of mental illness in general was measured using the brief version of the Internal Stigma of Mental Illness scale. The ISMI-10 scale is a shorter form of the 29-item self-report questionnaire (Boyd Ritsher et al., 2003) and has been shown to be a valid and reliable measure and reduces respondent burden.

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 many populations and languages (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 respectively.

Results

Sample

Participant characteristics are shown in Table 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.

The City Mental Illness and Stigma Scale

All 30 items were normally distributed. The initial principle components analysis (PCA) using oblique rotation, oblimin extraction and not specifying the number of factors revealed

nine items failed to correlate well with any other items and were removed. One item had communalities below .40 and was removed.

A second principle components analysis was conducted on the remaining 20 items. All had high communalities, anti-image diagonals were all above .741 and explained 63.76% of the variance. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis (KMO = .84). Five components had Eignevalues over 1, but the forth component only accounted for 5.5% of the variance and the scree plot suggested there were three factors (see Figure 1).

Therefore a principle components analysis was run again with three factors specified. Five items had low communalities and were removed. The final analysis (see Table 1) showed all anti-image diagonals above .767 and KMO = .839. Fifteen questions loaded onto three components and explained 62.47% of the variance. These formed three subscales of: *Perceived external stigma* (variance: 36.68%) which comprised 6 items relating to the variance of the participants view of others attitudes to women with perinatal mental illness. *Internal stigma* (variance: 14.27%) which comprised 5 items relating to the variance of the participants own attitudes towards themselves regarding their perinatal mental illness. *Disclosure stigma* (variance: 11.53%) which comprised 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.

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 2).The City MISS was highly correlated with the ISMI-10 scale suggesting good concurrent validity (r (277) = .56, p < .001). The total score of the City MISS and total score of the ISMI-10 scale were subject to linear regression. There was a significant regression co-efficient of total scores for the City MISS and ISMI-10 scale (R^2 = .31, F(1, 118.95) $p < .001$). The City MISS score could be predicted by the ISMI-10 scale score following the formula 15.669 + (1.095 x ISMI-10 score). Most women said they found it hard to disclose to a healthcare professional or chose to avoid disclose completely (76%, n=212). Of these 212 women, over half of them said that stigma was the main reason for their disclosure difficulties (52.83%, n=112).

Table 1 Sample demographic characteristics

		N	%
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	22	7.9
	A levels	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

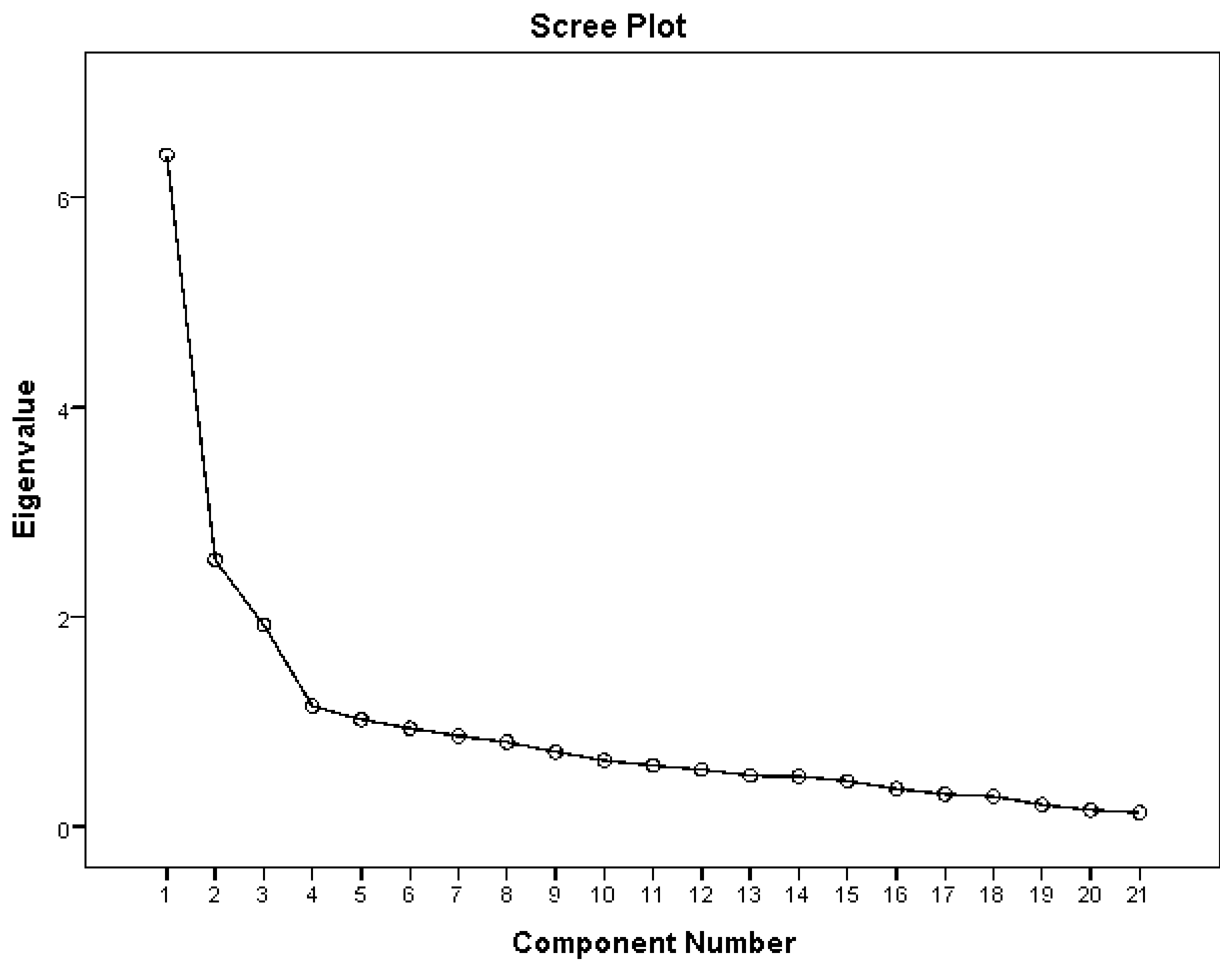
Note: Total number in demographic categories do not add up to 279 as not all participants completed the demographic questions.

Table 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 (36.68%)		0.86
People think mothers with psychological problems will harm their babies	0.87	
People think mothers with psychological problems will harm themselves	0.84	
People think mothers with psychological problems will kill themselves	0.80	
People think mothers with psychological problems don't love their babies	0.79	
People think mothers with psychological problems can't cope with their babies	0.72	
People think mothers with psychological problems are abnormal	0.53	
Internal stigma (14.27%)		0.81
I have thoughts of killing myself	0.80	
I have thoughts of hurting myself	0.80	
I can't cope as well as I'd like with my baby	0.75	
I have thoughts about leaving my baby	0.75	
My psychological problems have meant I have lost time with my baby	0.64	
Disclosure stigma (11.53%)		0.85
I worry that if I told a healthcare provider about my psychological problems the social services would get involved	0.88	

I worry that if I told a healthcare provider about my psychological problems my baby would be taken away	0.84	
I do not want people to know I have psychological problems as they may think I'm a bad mother	0.73	
I worry that if I told a healthcare provider about my thoughts they would think I am an abusive mother	0.66	
Total Scale City MISS (62.47%)		0.84

Figure 1. Scree plot



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 62% 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.

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 inadequacy as a mother. Importantly, it reveals the stigma around disclosing to others which has important implications for help-seeking behaviour and recovery.

However, there are a number of 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 in different socio-

demographic groups and women in pregnancy. Similarly, future research should be sensitive to potential additional complexities regarding stigma for example, race or sexual orientation (Alang and Fomotar, 2015).

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. The scale would benefit from developing perceived external stigma questions to include personally experienced discrimination. 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 sample.

Clinical implications

The scale provides a 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.

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Appendix. The City Mental Illness Stigma Scale

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	1	2	3	4

psychological problems will kill themselves				
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 2involved	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