Experience of care for mental health problems in the antenatal or postnatal period for women in the UK: A systematic review and meta-synthesis of qualitative research

Abstract

Purpose: Pregnancy and the first postnatal year can be a difficult and distressing period for women with mental health problems, particularly if they are not able to access appropriate and timely assessment and treatment. The aim of this systematic review was to synthesise qualitative evidence on experiences of care for women with (or at risk of developing) antenatal or postnatal mental health problems across a range of disorders (including non-psychotic mental disorders).

Methods: Six electronic databases were searched for papers published from 2000 to April 2014. Thirty-nine studies were identified that met the inclusion criteria. Findings were synthesised using secondary framework and thematic analysis approaches.

Results: Seven key themes were identified across mental disorder groups: an unmet need for collaborative and integrated care; stigma and fears about loss of custody; healthcare professionals unable or unwilling to address psychological needs; focus on babies over mothers; importance of non-judgemental and compassionate support; an unmet need for information; importance of service user involvement in treatment decisions.

Conclusions: Women’s experience of accessing and engaging with care for mental health problems could be improved if given the opportunity to develop trusting relationships with healthcare professionals who acknowledge and reinforce the woman’s role in caring for her baby in a non-judgemental and compassionate manner, and foster hope and optimism about treatment. Information for women, their families and healthcare professionals, and the provision of individualised care and treatment, are also crucial to enable full implementation of a person-centred programme of care.

Key words

Postnatal; pregnancy; mental health problems; systematic review; qualitative research; meta-synthesis

Introduction

Mental disorders are among the most common morbidities of pregnancy and the postnatal period with emerging evidence suggesting that mental disorders across the diagnostic spectrum can occur during this time (Howard et al. 2014; Jones et al. 2014). A large US epidemiological study (Vesga-López et al. 2008) found similar prevalence rates in past-year pregnant or postpartum women as in non-pregnant women with estimates of 25.3-25.7% for any psychiatric disorder, 12-14.6% for any substance misuse disorder, 8.4-9.3% for major depressive disorder, 2.8-2.9% for bipolar disorder, 12.3-13% for any anxiety disorder and 0.4-0.5% for any psychotic disorder. Pregnancy and the first year following childbirth are a time of heightened emotion for all women, but for women with a mental health problem this period can be difficult and distressing, particularly if women are not able to access appropriate and timely assessment and treatment. A recent systematic review and meta-synthesis of qualitative literature examined experiences of motherhood and services for women with severe mental illness (Dolman et al. 2013) and found that women experienced a lack of continuity of care and a number of unmet needs including childcare provision (particularly in a crisis), information and peer support. However, the extent to which the themes identified by Dolman et al. (2013) are specific to severe mental illness remains unclear. In addition to the potential for different needs from, and experiences of, services, women with severe mental illness are likely to use different services, predominantly secondary mental health services (including general adult services, liaison services and specialist perinatal services) compared to the majority of women with common mental disorders who would be treated in primary care.

Meta-synthesis of qualitative papers is increasingly recognised as a parallel technique to meta-analysis of quantitative papers, albeit with important differences such as an interpretative rather than simply aggregative function (Campbell et al. 2003). To our knowledge there have been no meta-syntheses of the qualitative literature on the experience of care for antenatal or postnatal mental health problems that include women with a range of psychotic and non-psychotic disorders (and women with subthreshold symptoms). This thematic analysis and synthesis of the qualitative literature was undertaken for the update of the NICE *Antenatal and Postnatal Mental Health* guideline (NICE 2014). Other relevant NICE guidance sets out the principles for improving the experience of care for people using adult NHS mental health services (*Service User Experience in Adult Mental Health* [NICE 2011; NCCMH 2012]) and general medical services (*Patient Experience in Adult NHS Services* [NICE 2012; NCGC 2012]). However, there are a number of factors, including the impact on the fetus or baby of the mother's mental health and/or treatment, that are unique to pregnancy and the postnatal period and that alter women's experience of mental healthcare, particularly where the needs of the mother and fetus or baby conflict.

We therefore aimed to synthesise the research literature in order to address the following review questions:

- What factors prevent women with a mental health problem who are pregnant or in the postnatal period accessing mental healthcare services?
- What factors improve or diminish the experience of services for women with a mental health problem who are pregnant or in the postnatal period?

Methods

Search strategy

Six databases (CINAHL, Embase, HMIC, Medline, PreMedline, PsycINFO) were searched in February 2014 (updated in April 2014). Keywords for the search included: population terms characterizing the time period (e.g. pregnancy, birth, postpartum period) and mental health problem (mental disorders, anxiety, depression, OCD, phobias, PTSD, eating disorder, schizophrenia, psychosis, personality disorder, substance-related disorders); patient experience terms (e.g. attitude to health, consumer attitude, health care quality, patient attitude, patient centred care); terms for study design (systematic review of qualitative studies, primary qualitative studies, surveys). A summary of the systematic search strategy used is provided in Table 1.

Table 1: Summary of systematic search strategy

Search construction	**Study design searched**	**Databases searched**	**Date range searched**
[((population terms) AND (qualitative systematic review study design filter terms)) OR ((patient experience terms) AND ((primary qualitative study design filter terms OR survey study design filter terms)))]	Systematic reviews of qualitative studies, primary qualitative studies, surveys.	General medical databases: CINAHL, Embase, Medline, PreMedline, PsycINFO	2000 to 07 April 2014
[population terms]		HMIC	2000 to 07 April 2014

Inclusion criteria

Studies were included if they satisfied the following criteria:

- Population: Women with (or at risk of developing) an antenatal or postnatal mental health problem
- Outcomes: Factors (at the service-user or practitioner level) that improve or diminish access to, or experience of, services for mental health problems
- Timing: Pregnancy and the postnatal period (from childbirth up to one year)
- Study design: Published peer-reviewed systematic reviews of qualitative studies, primary qualitative studies, or surveys
- Study setting: UK primary, secondary and tertiary healthcare services and studies published 2000-April 2014.

Synthesis

Qualitative data synthesis was guided by a “best fit” framework synthesis approach (Carroll et al. 2011). The distinguishing characteristic of this type of approach, and the aspect in which it differs from other methods of qualitative synthesis such as meta-ethnography (Campbell et al. 2003) is that it is primarily deductive involving a priori theme identification and framework construction against which data from included studies can be mapped. The current study used the thematic framework identified and developed by the *Service User Experience in Adult Mental Health* guidance (NICE 2011; NCCMH 2012) as a starting point to systematically index and organise all relevant themes and sub-themes within an Excel-based matrix (see Table 2). A secondary thematic analysis was then used to inductively identify additional themes in cyclical stages (Carroll et al. 2011). OMV led the synthesis with independent input from IS who read and re-read all papers, checked coding in the excel-based form and highlighted disagreements or additional findings. 17% of the key themes (represented by rows in Excel) were highlighted for possible discrepancies in coding or additional findings. Disagreements were resolved through discussion and of the 49 (17%) queried codes, an amendment to the final coding was made for 36.

Table 2: Matrix of service user experience (adapted from the NICE *Service User Experience in Adult Mental Health* guidance)

Experience of the disorder		***Key points on the pathway of care***		***Themes that apply to all points on the pathway***
The relationship between individual service users and professionals	Involvement in decisions and respect for preferences			
	Clear, comprehensible information and support for self-care			
	Emotional support, empathy and respect			
The way that services and systems work	Fast access to reliable health advice			
	Effective treatment delivered by trusted professionals			
	Attention to physical and environmental needs			
	Involvement of, and support for, family and carers			
	Continuity of care and smooth transitions			

Study quality assessment

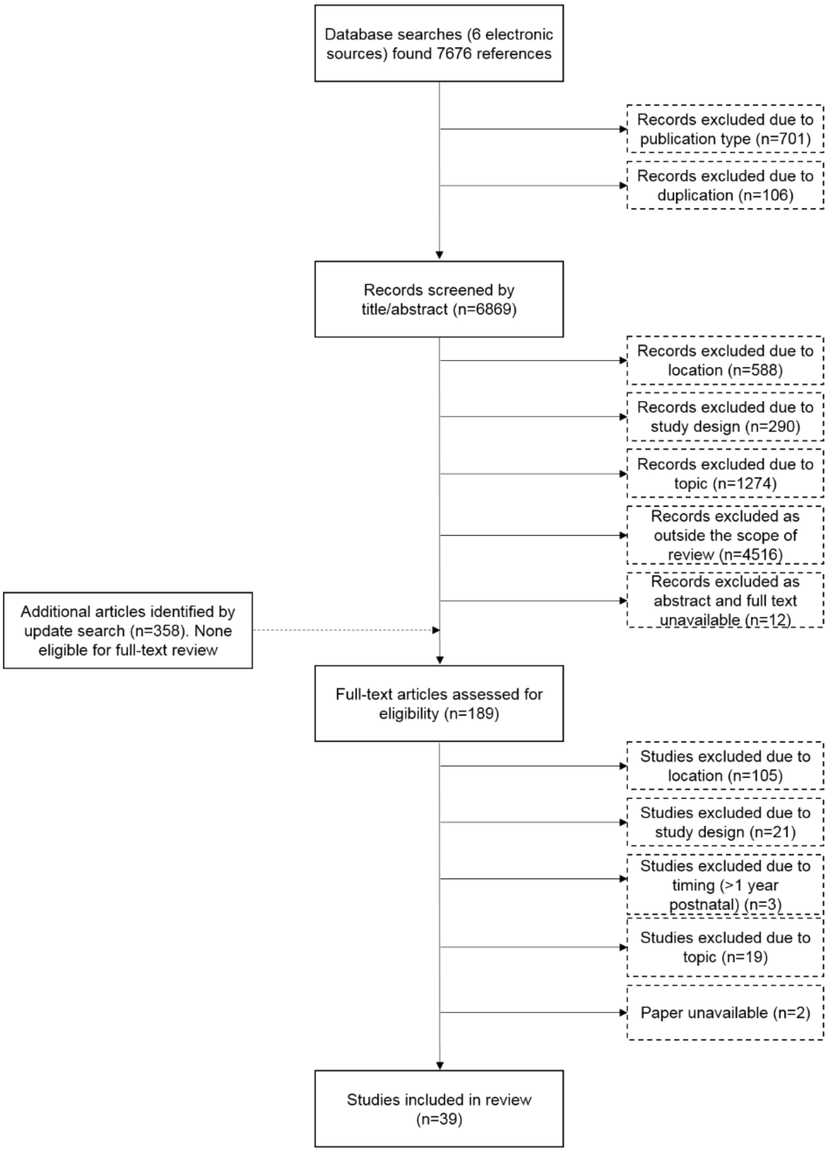
Quality was assessed to allow reliability considerations to be factored in to conclusions but studies were not excluded on the basis of low quality ratings as there is little empirical evidence upon which to base such decisions (Carroll et al. 2011; Dixon-Woods et al. 2006, 2007; Thomas and Harden 2008). Consistent with the methodological appraisal technique adopted in Dolman et al. (2013) a quality checklist was completed for each study which included the previously validated Critical Appraisal Skills Programme CASP (2013) checklist (available from http://www.casp-uk.net/) and elements of the BMJ Qualitative Research Checklist (BMJ 2011). Each study was assessed according to 31 quality criteria, covering 11 main quality issues, and scored out of a total of 62. All studies were independently quality appraised by two reviewers (IS, OMV) and inter-rater agreement was 79.6%. Disagreements were resolved through discussion in order to obtain full agreement.

Results

Description of included studies

The systematic search identified a total of 7676 references, of which 189 met the eligibility criteria for full-text review and 39 studies provided relevant clinical evidence and were included (see Fig. 1). The characteristics of the included studies have been summarised in Table 3. The studies captured the experiences of women with symptoms or diagnosis of a range of mental disorders, including depression (n=13) predominantly in the postnatal period, severe mental illness (n=5) predominantly postpartum psychosis, PTSD (n=2), substance misuse (n=1) and eating disorders (n=1). Studies were also included that focused on women at risk of developing a mental health problem (n=17), for instance, women who had experienced pregnancy loss or a traumatic birth and women who experienced subthreshold symptoms.

Fig. 1 Flow diagram of study search and selection process



Quality of included studies

The papers reviewed were judged to be of generally moderate to high quality (scores for each study can be found in Table 3). Quality appraisal ratings ranged from 22 (35%) to 48 (77%) with an average rating of 39 (63%). It was not possible to factor in reliability considerations to conclusions due to the lack of differentiation between studies in quality ratings. Common weaknesses included: unclear inclusion/exclusion criteria; no discussion of data saturation; no steps taken to identify data contrary to the main findings and hypotheses of the study; no double-coding/level of inter-rater reliability not reported; unclear validation procedures.

Table 3: Characteristics of included studies

Study	N	Research question		Methodology		Quality appraisal score
		Population studied	Outcomes considered	Data collection	Analysis	
Depression						
Boath et al. (2004)	35	Women with diagnosis of depression who reported being prescribed and taking antidepressants	Experience of antidepressants	Four open-ended questions on questionnaire	Content analysis	41
Chew-Graham et al. (2009)	28	Women with diagnosis of depression who were participating in an RCT of antidepressants versus listening visits for the treatment of postnatal depression	Views on the causes of postnatal depression and experiences of treatment	Flexible interview guide	Inductive thematic analysis	45
Edge (2007, 2008)/Edge and Rogers (2005)	12	Black Caribbean women living in the UK (17% with symptoms of antenatal depression; 25% with symptoms of postnatal depression; 17% with symptoms of antenatal and postnatal depression)	Constructions of and responses to postnatal depression	Flexible interview guide	Grounded theory: Constant comparative approach (CCA)	45
Hall (2006)	10	Women with symptoms of depression in the postnatal period	Women's experiences of postnatal depression	Non-directive interview	IPA	40
Hanley and Long (2006)	10	Welsh mothers diagnosed with postnatal depression	Experience of postnatal depression and support preferences	Semi-structured interview	Content analysis	47
Patel et al. (2013)	11	Women with symptoms of postnatal depression	Illness beliefs in women with postnatal depression	Semi-structured interview	CCA	38
Raymond (2009)	9	Women with antenatal depression living in an area of socio-economic deprivation	Women’s feelings of depression during pregnancy and support mechanisms that women report	Semi-structured interview	CCA	45

			(retrospectively) as personally or potentially helpful for depression during pregnancy			
Shakespeare et al. (2006)	16	Postnatal patients from 22 general practices within the area of Oxford City Primary Care Group who had receieved listening visits (63% with symproms of depression)	Experience of listening visits	Semi-structured interview	Framework analysis	42
Slade et al. (2010)	30	Women with probable postnatal depression	Experience of being offered and accepting or declining psychological support	Semi-structured interview	Template analysis	48
Templeton et al. (2003)	20	Women from black and minority ethnic groups with current and past experience of postnatal depression	Experiences of postnatal depression	Semi-structured interview and focus groups	Descriptive thematic analysis	22
Turner et al. (2008)	27	Women diagnosed with postnatal depression	Women’s views and experiences of antidepressants as a treatment for postnatal depression	Semi-structured interview	Framework analysis	41
Turner et al. (2010)	22	Women diagnosed with postnatal depression	Women’s views and experiences of listening visits as a treatment for postnatal depression	Semi-structured interview	Framework analysis	42
Wittkowski et al. (2011)	10	South Asian women living in UK with symptoms of depression in the postnatal period	Women's views on what factors led to and maintained how they were feeling and how they defined and experienced what is meant by the term “postnatal depression”	Semi-structured interview	CCA	42

Severe mental illness						
Antonysamy et al. (2009)	57	Inpatients on a psychiatric mother and baby unit (39% schizophrenia or schizo-affective disorder; 18% bipolar disorder; 25% depresssion with or without psychotic symptoms; 4% OCD; 4% personality disorder; 12% other diagnoses)	Involvement in own care, discussion of problems with psychiatrists and nurses on the unit, organised activities on the ward, most and least helpful aspects of the ward, and any other aspects	Semi-structured interview	Content analysis	36
Edwards and Timmons (2005)	6	Women who had been inpatients on a mother and baby unit (50% postpartum psychosis; 33% severe depression; 17% depressive psychosis)	Mother's experiences, feelings and emotions in relation to stigma and the woman's perception of herself as a mother	Semi-structured interview	Thematic analysis	37
Heron et al. (2012)	5	Women who had recovered from postpartum psychosis	Experiences of the process of recovery from postpartum psychosis and beliefs about the services needed to support recovery	Semi-structured interview	Grounded analytic induction approach	41
McGrath et al. (2013)	12	Women who had experienced postpartum psychosis (92% postpartum psychosis; 8% depression with psychotic features)	Experience of recovery from postpartun psychosis and factors that facilitated recovery	Semi-structured interview	CCA	36
Robertson and Lyons (2003)	10	Women who had been diagnosed with postpartum psychosis	Women's experiences of postpartum psychosis	Semi-structured interview	Grounded theory methodology	42
PTSD						
Ayers et al. (2006)	6	Women who reported having psychological problems as a result of a traumatic birth and met	The effect of a traumatic birth on women, their relationship with their child and their relationship with their partner	Semi-structured interview	Inductive thematic analysis	34

		diagnostic criteria for PTSD				
Nicholls and Ayers (2007)	6	Women (or their partner [though only the women's data extracted for this analysis]) who had experienced a traumatic birth and met DSM-IV criteria for childbirth-related PTSD	Experience of postnatal PTSD in couples and the perceived impact of postnatal PTSD on the couple’s relationship and their relationship with the baby	Semi-structured interview	Inductive thematic analysis	45
Substance misuse						
Smith and Gibb (2007)	9	Women who were being treated for substance misuse (methadone programme) in the postnatal period	Experience of a specialist health visiting service	Semi-structured interview	Content analysis	34
Eating disorders						
Stapleton et al. (2008)	16	Pregnant women, or women who were already mothers to at least one child under the age of 2 years, who self-identified as having an eating disorder	Womens reactions to changes in their weight, shape and body image, and their infant-feeding intentions and actual practices	Semi-structured interview	Inductive thematic analysis based on feminist ethnographic approach	42
‘At-risk’ population						
Breustedt and Puckering (2013)	4	Women who experienced the ‘mellow bumps’ intervention (no mental health problems reported)	Experience of ‘mellow bumps’ intervention	Non-directive interview	Interpretative phenomenological analysis (IPA)	41
Cooke et al. (2012)	7	Parents who had experienced emotional distress during their baby's first year	Access to clinical psychology services	Semi-structured interview	Thematic analysis	31
de Jonge (2001)	12	Teenage mothers (33% depression; 8% drinking problem)	Experience of support women received during pregnancy, birth and their child's preschool years, and suggested improvements	Semi-structured interview	Thematic analysis	38

Edge (2011)	42	Black Caribbean women living in the UK (no mental health problems reported)	Reasons for low levels of consultation for postnatal depression among black caribbean women	Focus group	Framework analysis	39
Hunt et al. (2009)	42	Women who have ended a pregnancy following diagnosis of fetal abnormality (no mental health problems reported)	Experience of decisions that people face in the immediate aftermath of ending a pregnancy following diagnosis of serious fetal abnormality	Semi-structured interview	Framework analysis	39
Mapp (2005); Mapp and Hudson (2005)	10	Women who had experienced an obstetric emergency (no mental health problems reported)	Women's 'lived experiences' of specific obstetric emergencies	Semi-structured interview	Content analysis	39
McCreight (2008)	23	Women who had experienced a miscarriage or stillbirth (no mental health problems reported)	How women emotionally responded to pregnancy loss and the care they received from medical staff	Semi-structured interview	Content analysis	38
Parvin et al. (2004)	25	Bangladeshi women living in Tower Hamlets (no mental health problems reported)	Understanding and experiences of postnatal distress and coping strategies during the postnatal period	Focus groups	Content analysis	32
Ryninks et al. (2014)	21	Women who had experienced stillbirth (no mental health problems reported)	Experience of spending time with their stillborn baby and retrospective feelings about the decision they made to see and hold their baby or not	Semi-structured interview	IPA	42
Shakespeare et al. (2003)	39	Postnatal patients from 22 general practices within the area of Oxford City Primary Care Group (21% with symptoms of depression at 8 weeks)	Experience of routine screening for postnatal women with the EPDS by their health visitor	Semi-structured interview	CCA	48
Simmons et al. (2006)	280	Women who had experienced a miscarriage	Women's personal experience of miscarriage	Open-ended question on questionnaire	Thematic analysis	36

		(no mental health problems reported)				
Snowdon et al. (2012)	9	Women who had experienced severe postpartum haemorrhage (no mental health problems reported)	Experiences of severe postpartum haemorrhage for women and their partners	Semi-structured interview	IPA	43
Stanley et al. (2006)	28	Mothers of young children (<2 years old) (no mental health problems reported)	Experience and awareness of antenatal depression	Focus groups	Framework analysis	32
Thomson and Downe (2008)	14	Women who had experienced a self-defined traumatic birth (no mental health problems reported)	Women's lived experiences of a self-defined traumatic and positive birth	Semi-structured interview	IPA	35
Thomson and Downe (2013)	12	Women who had experienced a self-defined traumatic birth (no mental health problems reported)	Re-interpretation of women's accounts through the conceptual lens of the hero narrative framework	Semi-structured interview	Secondary framework analysis	29
Thurtle (2003)	14	First-time mothers (7% with symptoms of depression)	Views of postnatal depression and the extent to which it is seen as part of the widespread experience of new motherhood	Semi-structured interview	CCA	39
Tsartsara and Johnson (2002)	6	Women who had experienced miscarriage (no mental health problems reported)	Experience of miscarriage from when they first experienced symptoms of miscarriage, through to their experiences of aftercare	Semi-structured interview	IPA	42

Thematic findings

Seven key themes were identified across mental disorder groups: an unmet need for collaborative and integrated care; stigma and fears about loss of custody; healthcare professionals unable or unwilling to address psychological needs; focus on babies over mothers; importance of non-judgemental and compassionate support; an unmet need for information; importance of service user involvement in treatment decisions (see supplementary appendix for full framework meta-synthesis). Informal validation of these key themes was also obtained through discussion with the experts and service users on the NICE clinical guideline development group.

Experiences of women with depression in the antenatal or postnatal period

Collaboration between professionals and continuity of care

Women highlighted the benefits of integrated identification and management for depression in the antenatal or postnatal period, achieved through the provision of care from a single known person (Raymond 2009; Shakespeare et al. 2006). However, positive experiences of integrated care were not common, instead women more frequently described fragmented care contributing to feelings of emotional isolation by making it more difficult to disclose symptoms of depression (Raymond 2009; Slade et al. 2010):

> *Every time I went to see the midwife, or..., I always had somebody different, and I don't want to tell 10 people my story. (Raymond 2009, p. 45)*

As well as acting as a barrier to disclosure, a lack of continuity of care was also experienced later in the care pathway, with women highlighting a need for better post-treatment follow-up (Boath et al. 2004; Turner et al. 2010). For instance, women described how an insufficient number of listening visit sessions made them feel ‘‘left hanging’’ and ‘‘completely exposed’’ (Turner et al. 2010):

> *Just me thinking about it [the idea of no treatment after the visits] now makes me feel quite panicky...what would have been the point of ripping off the plaster and starting to abrade the wound, only to then just say, oh well. (Turner et al. 2010, p. 237)*

Stigma and fears about losing their baby acting as a barrier to disclosure

One of the most salient barriers to access was women's fear that disclosure would lead to the loss of custody (Edge 2007/Edge 2008/ Edge and Rogers 2005; Hall 2006; Hanley and Long 2006; Slade et al. 2010) which in some cases led women to wait until crisis point before disclosing their difficulties and seeking help (Hall 2006; Patel et al. 2013):

> *I didn't respond to the Edinburgh scale honestly… because I was scared what (the health visitor) would say. I was worried. I thought the baby would get taken off me. It wasn't until… I'd just had enough and I phoned up the health visitor. I said I need to see you, I think I need to be admitted into a psychiatric unit.* (Hall 2006, p. 257)

Women talked about the stigma of a diagnosis of depression and how the ‘label’ was a threat to their ‘coping image’, in terms of self-concept and of the image women wanted to portray to healthcare professionals (Chew-Graham et al. 2009; Edge 2007/Edge 2008/Edge and Rogers 2005; Hall 2006; Patel et al. 2013; Raymond 2009; Shakespeare et al. 2006; Slade et al. 2010). South Asian mothers living in the UK described an additional barrier to disclosure, in cultural stereotypes that made the desire to be seen to be coping even more imperative for preserving self-concept, and even more isolating for an already vulnerable group of women (Wittkowski et al. 2011):

> *There is a huge stigma of being mentally ill in the public, but for us Asians there is a double disadvantage. I really fear that work will find out.* (Wittkowski et al. 2011, p. 487)

However, for women who had disclosed and been diagnosed, feelings of relief and reassurance were described (Hanley and Long 2006; Patel et al. 2013). For instance, one woman felt her condition had been *sanctioned* by her diagnostic label and other mothers spoke about the diagnosis giving them *permission to be ill* (Hanley and Long 2006).

Healthcare professionals unable or unwilling to address psychological needs

Women experienced a number of barriers to accessing help from primary care, including system barriers such as difficulty in getting a GP appointment (Chew-Graham et al. 2009) and experiences of GPs or health visitors being too busy or unwilling to listen, or dismissive of attempts to communicate psychological distress (Chew-Graham et al. 2009; Edge 2007/Edge 2008/Edge and Rogers 2005; Raymond 2009; Turner et al. 2010; Wittkowski et al. 2011). Uncertainty around the role of the health visitor further contributed to problems with accessing help, for instance, it was not clear to women that the health visitor role went beyond physical healthcare and the care of the baby (Chew-Graham et al. 2009; Shakespeare et al. 2006; Slade et al. 2010).

Focus on babies over mothers

A related barrier to disclosure, and a common theme, was the perception that healthcare professionals focused on the needs of the baby over the needs of the mother (Edge 2007/Edge 2008/Edge and Rogers 2005; Raymond 2009; Turner et al. 2010). Women felt they had been treated like *a baby carrier* or *a walking womb* (Raymond 2009, p. 45). For some, the opportunity for assessment using the Edinburgh Postnatal Depression Scale (EPDS) was a reassuring process (Hanley and Long, 2006), as it provided an opportunity to switch the focus from their baby to themselves (Slade et al. 2010).

Importance of non-judgemental and compassionate support from healthcare professionals

For women with depression, experiences of treatment and management appeared to be dependent on the quality of the relationship between the woman and the healthcare professional. For instance, positive experiences of listening visits were described where women felt they had a ‘connection’ with the health visitor. Key components identified as being important to the development of professional-service user rapport were health visitors being knowledgeable about mental health issues, having flexible boundaries, being available and willing to listen, being empathetic and non-judgemental, and having the opportunity to build trust and respect (Shakespeare et al. 2006; Slade et al. 2010; Turner et al. 2010). Conversely, a poor rapport was associated with negative experiences of listening visits, in particular, if the health visitor was perceived to be judgemental (Shakespeare et al. 2006; Slade et al. 2010; Turner et al. 2010). The importance of the GP-service user relationship was also considered in the context of the experience of taking antidepressants, with women deciding to take medication on the basis of a reassuring discussion with their GP that addressed their fears (Turner et al. 2008).

Unmet need for information across the care pathway

Women spoke about not knowing what to do when their symptoms of depression did not go away or got worse (Hanley and Long 2006). This lack of awareness made it hard for women to explain their feelings to healthcare professionals and meant that they relied on professionals to help them to understand their feelings as part of a mental disorder (Edge 2007/Edge 2008/Edge and Rogers 2005). However, gaps in professional knowledge could compound feelings of fear and isolation, for example, where women’s attempts to portray a coping image were taken at face value (Edge 2007/Edge 2008/Edge and Rogers 2005).

The unmet need for information and support was also a recurring theme post-diagnosis, where women wanted a discussion with a healthcare professional about their diagnosis of depression and possible treatment options (Hall 2006; Shakespeare et al. 2006; Slade et al. 2010; Templeton et al. 2003).

Finally, women described large gaps in the information provided to them about pharmacological treatment, with concerns having the potential to impact upon adherence. For instance, women expressed concern about taking antidepressants because they perceived these drugs to be addictive and sedative (Chew-Graham et al. 2009; Edge 2007/Edge 2008/Edge and Rogers 2005; Turner et al. 2008), with possible long-term effects for the fetus (Boath et al. 2004; Patel et al. 2013; Turner et al. 2008) and harms for breastfed babies (Edge 2007/Edge 2008/Edge and Rogers 2005; Turner et al. 2008). Women also spoke about stigma associated with taking antidepressants (Boath et al. 2004; Patel et al. 2013; Shakespeare et al. 2006; Templeton et al. 2003). These concerns lead them to self-regulate their dosage or wean themselves off medication (Boath et al. 2004; Turner et al. 2008).

Importance of service user involvement in treatment decisions and individualised treatment

A prominent theme was the importance of avoiding a 'one size fits all' approach for the treatment of depression. Women highlighted the importance of having their voice heard in discussions and decisions about treatment. However, choice was often felt to be lacking. For example, women perceived antidepressants to be the only treatment available (Chew-Graham et al. 2009; Edge 2007/Edge 2008/Edge and Rogers 2005; Turner et al. 2008, 2010).

Mixed experiences of psychological interventions for depression also highlighted the need for women's preferences to be taken into account. For instance, while some women expressed ambivalence about talking therapies (Edge 2007/Edge 2008/Edge and Rogers 2005; Templeton et al. 2003), others valued the opportunity to talk to someone outside of their friends and family about how they were feeling (Shakespeare et al. 2006; Slade et al. 2010; Turner et al. 2010) and others described frustration with the non-directive and unstructured approach of listening visits (Shakespeare et al. 2006; Slade et al. 2010).

The importance of considering and addressing cultural, environmental and practical barriers that may prevent women with depression from being able to access and engage in treatment, particularly psychological or social therapies, was also highlighted, for instance, long waiting lists for counselling (Edge 2007/Edge 2008/Edge and Rogers 2005), lack of culturally-relevant help and support (Edge 2007/Edge 2008/Edge and Rogers 2005; Templeton et al. 2003; Wittkowski et al. 2011), language barriers (Templeton et al. 2003) and a lack of childcare facilities (Edge 2007/Edge 2008/Edge and Rogers 2005; Templeton et al. 2003; Turner et al. 2008). However, as with the other sub-themes in this section, the importance of individual choice in terms of settings for care was emphasised with some women appreciating out-of-home care as an opportunity to escape their immediate surroundings (Raymond 2009), and other women preferring home-based treatment due to privacy, comfort and childcare considerations (Shakespeare et al. 2006; Turner et al. 2010).

Women with depression also suggested aspects of intervention and care that they would have appreciated had they been offered, and a recurrent theme was an opportunity for peer support either in the context of informal social groups or more formalised support networks (Boath et al. 2004; Raymond 2009; Wittkowki et al. 2011). Those who had attended support groups valued the opportunity to meet and talk to women who had shared experiences (Hanley and Long, 2006; Templeton et al. 2003).

Experiences of women with severe mental illness in the antenatal or postnatal period

Collaboration between professionals and continuity of care

Women who had experienced postpartum psychosis and had access to a single known healthcare professional (for example, a community nurse) felt this was beneficial in terms of providing ongoing support and facilitating access to secondary mental healthcare as and when this was necessary, both of which enabled women to focus on their own recovery and on their mothering responsibilities (Heron et al. 2012). Women who had not had this type of support talked about the hospital-to-home transition period as a challenging time when they felt isolated and had low self-esteem and little confidence in their mothering skills. An unmet need for post-discharge home-based, one-to-one support, from a healthcare professional with knowledge and experience of postpartum psychosis who could give practical advice on caring for baby, was expressed (Heron et al. 2012).

Stigma and fears about losing their baby acting as a barrier to disclosure

Women who had experienced serious mental illness in pregnancy or the postnatal period spoke about concealing their illness due to perceptions of stigma, feelings of guilt and shame, and fears about hospitalisation and loss of custody (Edwards and Timmons 2005; McGrath et al. 2013). Women spoke about finding their thoughts and behaviours frightening, horrifying and debilitating, and the reassurance brought about by their diagnosis which had enabled them to recognise their thoughts, feelings and actions as symptoms of a treatable illness (Edwards and Timmons 2005; McGrath et al. 2013). However, the experience of receiving a diagnosis was not universally positive as some women felt that this led healthcare professionals to treat the label rather than being responsive to individual needs (McGrath et al. 2013).

Healthcare professionals unable or unwilling to address psychological needs

Women who had experienced serious mental illness described how the lack of experience of some of the healthcare professionals they encountered led to difficulties in having their illness recognised, delays in receiving treatment and compounded their feelings of fear and isolation (Edwards and Timmons 2005; Robertson and Lyons 2003):

> *...you have no idea what's going on, what's real and what's not, but when the doctors don't appear to know either that's really scary particularly when they're supposed to make you better* (Robertson and Lyons 2003, p. 419)

Importance of non-judgemental and compassionate support from healthcare professionals

Women described a conflict between needing to depend on healthcare professionals when they felt unable to understand, control or predict their symptoms but not trusting the healthcare professionals that they were reaching out to, and how a lack of involvement in treatment decisions provoked fear and feelings of powerlessness (McGrath et al. 2013; Robertson and Lyons 2003). Women valued healthcare professionals who fostered hope and reassurance about recovery, were empathic, and were flexible and responsive in the level of support offered (McGrath et al. 2013).

Unmet need for information across the care pathway

Women who had experienced postpartum psychosis spoke about a strong and unmet need for information tailored to their treatment stage (Heron et al. 2012; McGrath et al. 2013), and would particularly have valued information from other women who had experienced serious mental illness in the antenatal or postnatal period (Heron et al. 2012). The benefits of information for partners on postpartum psychosis were highlighted, however, the information and support for partners and wider family was often insufficient (Heron et al. 2012; Robertson and Lyons 2003):

> *It was hard for him. There wasn't much information out there… My husband I think was unsure whether he would ever get his wife back again. That's very distressing, when it doesn't need to be.* (Heron et al. 2012, p. 162)

Importance of service user involvement in treatment decisions and individualised treatment

Women with postpartum psychosis discussed the need for greater consultation and negotiation in antipsychotic prescription, as they recognised the role of drugs in their clinical recovery but felt that sedative effects interfered with their role as a mother and their social recovery (Heron et al. 2012):

> *… it would have been good I think to have been listened to about the side effects. I was on a very high dose of Olanzepine [sic] and it just knocks you out and makes you into a complete zombie… The psychiatrist was a young guy not understanding that we had needs as a family. My husband really needed me to be awake enough to get my baby dressed and you know, do that kind of stuff. It's just they're managing your risk of going high, maybe that's what they've got to do clinically, but I wanted a bit more of a human face of it really.* (Heron et al. 2012, p. 159-160)

Women who had experienced serious mental illness also discussed the need for specialist treatment and this was linked to attention to physical and environmental needs. For instance, women who had been admitted to a mother-and-baby unit were positive about this environment relative to a general psychiatric ward in that they felt more secure on the unit and felt that having their baby with them contributed to their recovery (Antonysamy et al. 2009). Conversely, women who had been admitted to general psychiatric wards reported distress and anger at being separated from their baby, the lack of specialist treatment available and the impact this had on their confidence in mothering post-discharge (Heron et al. 2012; Robertson and Lyons 2003).

In common with women with depression, women who had experienced serious mental illness also suggested aspects of intervention and care that they would have appreciated had they been offered, and suggested that they would have benefitted from the opportunity for peer support (Heron et al. 2012; Robertson and Lyons 2003). However, amongst those who had experienced support groups feelings were mixed, with some women valuing the opportunity to be open with other new mothers and to educate and inform peers, and other women feeling that group situations were not useful in early recovery due to social vulnerability (Heron et al. 2012).

Experiences of women with other mental health problems (PTSD, substance misuse or eating disorders) in the antenatal or postnatal period

Collaboration between professionals and continuity of care

Women who were being treated for substance misuse in the postnatal period valued the opportunity to develop a relationship with a known healthcare professional who had specialist knowledge (Smith and Gibb 2007). However, in common with women who had experienced depression in the antenatal and postnatal period, women who had experienced other mental health problems generally experienced a lack of continuous care. For instance, women who had developed PTSD in response to traumatic childbirth described a lack of continuity of staff and a lack of professional-to-professional handover necessitating repetition of medical history (Nicholls and Ayers 2007).

Stigma and fears about losing their baby acting as a barrier to disclosure

Women who had experienced PTSD talked about being too terrified to speak to anyone about how they were feeling for fear that their baby would be taken away (Ayers et al. 2006).

Importance of non-judgemental and compassionate support from healthcare professionals

For women with substance misuse problems the opportunity to develop a positive relationship with a specialist health visitor that was characterised by open, honest and non-judgemental communication enabled women to feel valued as a person (Smith and Gibb 2007).

Unmet need for information across the care pathway

Women who had developed PTSD in response to a traumatic birth discussed the need to be given information about what was happening during birth, as inadequate and/or inaccurate information contributed to feelings of loss of control (Nicholls and Ayers 2007).

Importance of service user involvement in treatment decisions and individualised treatment

Women described negative experiences where healthcare professionals had treated the ‘label’ and not the ‘person’. For instance, women who were receiving treatment for substance misuse problems described stigmatising interactions with their GP, where they felt that their individual needs were not listened to or addressed (Smith and Gibb 2007):

> *I just think that if I go and see him about a problem, even if it's just like [describing nature of problem] the first thing he'll ask me is about my drug problem and my methadone and that's not the issue and that's not why I'm going but everything is like linked to that and it's just I think that he looks down a little bit.* (Smith and Gibb 2007, p. 26)

The need for individualised support was also highlighted in the experiences of women with an eating disorder who required support for feeding their baby that was sensitive to their eating disorder. However, experiences were often characterised by a lack of compassionate support for their feeding decision (Stapleton et al. 2008):

> *I couldn’t breastfeed. I just couldn’t. I was desperate to get rid of the weight. I just wanted some reassurance from the midwives that bottle-feeding was all right but all they did was tell me off for not breastfeeding.* (Stapleton et al. 2008, p. 110)

Experiences or perceptions of care for women who may be at risk of mental health problems in the antenatal or postnatal period

Collaboration between professionals and continuity of care

In discussing antenatal depression, women considered that opportunities to disclose negative experiences and emotions were most likely to occur in the context of a relationship with a professional that was continuous through the pregnancy (Stanley et al. 2006). However, the impression across women with and without known mental health problems was that the reality of maternity care was that it was provided by numerous individuals throughout the ante-, intra- and post-partum period (Thomson and Downe 2008).

Stigma and fears about losing their baby acting as a barrier to disclosure

Women described a reluctance to disclose any feelings of emotional distress for fear that their baby would be taken away if they were seen to not be coping (Cooke et al. 2012; de Jonge 2001; Shakespeare et al. 2003). Women who self-identified as having experienced emotional distress within their baby's first year talked about the stigma of diagnosis and how a label has connotations of greater severity (Cooke et al. 2012).

Healthcare professionals unable or unwilling to address psychological needs

Women were frustrated that they could not access services unless they were in crisis (Cooke et al. 2012):

> *You shouldn't have to press that danger button of "I'm gonna self-harm" or "I'm gonna hurt my children" for someone to help you.* (Cooke et al. 2012, p. 35)

In common with women who had experienced depression and described barriers to disclosure including healthcare professionals being too busy to address psychological needs, the perceptions of women without known mental health problems were that midwives and health visitors were preoccupied with checks and procedures and women were not given the time or space to talk about feelings (Edge 2011; Stanley et al. 2006). Women also perceived the health visitor role as being restricted to the physical healthcare of themselves and their baby and felt uncomfortable raising their emotional wellbeing unprompted (Cooke et al. 2012; Parvin et al. 2004).

Focus on babies over mothers

Women expressed resentment that healthcare practitioners focused on the health and wellbeing of their infants to the exclusion of their own needs and spoke about a general unmet need for a woman-centred approach (Edge 2011):

> *... somebody [is] not just checking on the baby but actually sitting down with you asking, 'how are you doing?' 'What can I do to help you?'* (Edge 2011, p. 259)

Importance of non-judgemental and compassionate support from healthcare professionals

A lack of confidence in healthcare professionals was described, with feelings that professional-service user interactions were formulaic and leaflet-driven (Cooke et al. 2012; Edge 2011):

> *My experience has been: leaflet (baby massage); leaflet (postnatal depression); leaflet (baby immunisations). 'Any questions let us know. Any problems, [see your] GP'. It's leaflet, leaflet, leaflet; then 'see you later'.* (Edge 2011, p. 259)

Unmet need for information across the care pathway

Teenage mothers described an unmet need for information about mental health and sources of help, and felt that it was important that midwives and health visitors were aware that teenage women might not be coping as well as they might pretend (de Jonge 2001).

Inadequate provision of information and support was also described in instances where such provision has a potentially preventative function. For instance, women who had experienced miscarriage expressed a need for clear and comprehensible information about the processes of miscarriage so as to alleviate distress (Simmons et al. 2006; Tsartsara and Johnson 2002). Women who had experienced a pregnancy loss through stillbirth or termination of pregnancy due to fetal abnormality also highlighted the importance of being given information in order to prepare them for making a decision about whether to see and/or hold the dead baby (Hunt et al. 2009; Ryninks et al. 2014) and for decisions about a funeral (Hunt et al. 2009). While women who had experienced a traumatic birth described a lack of communication during crises and after childbirth (Mapp 2005/Mapp and Hudson 2005; Snowdon et al. 2012).

Importance of service user involvement in treatment decisions and individualised treatment

The importance of service user involvement and individual choice in management decisions was also considered in the context of protocols following stillbirth. Women who had experienced a stillbirth described mixed feelings upon seeing or holding their baby (Ryninks et al. 2014). Mixed opinions and experiences of photographs or mementoes following termination of a pregnancy because of fetal abnormality were also described (Hunt et al. 2009).

Discussion

Summary of findings

This systematic review identified a number of common and overarching themes, which resonated across the care pathway for women with (or at risk of developing) mental health problems in pregnancy or the postnatal period. This is a finding of note given the considerable heterogeneity of study populations and methodologies included in the meta-synthesis.

Dolman et al. (2013) found stigma about mental disorder to be a particularly prominent theme for women with severe mental illness and this meta-synthesis found that stigma was also a key theme for women with depression, PTSD, and women who might be at risk of developing mental health problems. This stigma was particularly felt in terms of barriers to disclosing problems due to fears around loss of custody. In addition, stigmatizing interactions with healthcare professionals were described by women with depression with the focus on the needs of the baby over the needs of the mother leaving women feeling like they were treated as simply *a walking womb*. Dolman et al. (2013) described the conflict women experience between their "dual identities" of being in need of help as a mentally ill and socially stigmatized woman, but being reluctant or unable to ask for this help due to attempts to meet the idealized concept of competent, nurturing and selfless mother. This conflict also resonates across this review in the paradoxical experiences of needing treatment or support in order for women to care for themselves and their baby, whilst wishing to be seen as coping in order to prevent negative perceptions and repercussions. The unmet need for healthcare professionals to acknowledge and reinforce the woman's role in caring for her baby in a non-judgemental and compassionate manner, and to foster hope and optimism about treatment, were clearly perceived to be vital components of improving women's experiences of accessing and using mental healthcare services. In addition to difficulties with asking for help, another theme that emerged from this review was difficulties that women had in recognising that they were in need of help. This was particularly problematic when women did not have access to trained and competent healthcare professionals. The importance of the provision of information and education to women and their families, and to healthcare professionals, about the signs and symptoms of mental health problems in order to aid recognition was highlighted as a priority in order to improve the experience of care for women with antenatal or postnatal mental health problems.

Another barrier to accessing care highlighted by this review was the lack of trusting relationships with healthcare professionals and this relates in part to a lack of continuity of care (a theme echoed in Dolman et al. 2013). The evidence reviewed here provides a picture of fragmented healthcare with problems with inter-professional communication and organisation, especially between professionals working in different agencies (for example, mental health services and maternity services). A related divide was felt between mental and physical healthcare with primary care professionals being perceived as too busy or unwilling to address psychological need. Moreover, in addition to a lack of inter- and intra-agency collaboration in care planning and pathways, this review found that women were often left out of discussions and decisions about their own care. This is consistent with a key problem, the lack of engagement of service users in decisions about their care, which was identified in *Service User Experience in Adult Mental Health* guidance (NICE 2011; NCCMH 2012). The experiences synthesised in this review suggest that women want, but are not often in receipt of, individualised care and treatment that respects choice and agency.

In order to be properly involved in decisions about their own care, women need to be provided with adequate information to enable them to make informed decisions. The evidence addressing the experience of treatment and management was more limited than the evidence base addressing issues around access. However, a theme that emerged from the studies was the unmet need for information that could potentially address some of the concerns that women have about treatment and its impact on themselves and their fetus or baby and help with weighing up risk-benefit ratios, particularly with regards to making decisions about starting, stopping or continuing with psychotropic medication for pregnant or breastfeeding women. The vast majority of women taking psychotropic drugs abruptly discontinue this medication upon discovering that they are pregnant (Einarson et al. 2001) and this carries a number of significant risks including discontinuation symptoms and risk of relapse. It is also often based on incorrect beliefs about the risks held by the women themselves or by the healthcare professionals responsible for their treatment and management (Einarson et al. 2001). The provision of evidence-based information that balances the benefits of treatment against the risks of the disorder going untreated and of the teratogenic risks, considered in the context of the uncertainty surrounding these risk estimates, is crucial in order to fully implement a person-centred programme of care.

Review limitations

In common with many of the primary qualitative studies included, this meta-synthesis is limited by the lack of formal triangulation, for instance, a qualitative meta-synthesis of healthcare professionals experience of delivering care to women with mental health problems in the antenatal or postnatal period. However, the results of this meta-synthesis were informally validated through the NICE guideline development process and the themes were in line with the experiences of service user, and clinical and academic, members of the guideline development group.

Research gaps

Most of the studies reviewed provide retrospective information from a single time point. This means that in many cases participants have had an opportunity to reflect on experiences and the research study provides only a ‘snap shot’ (with the filter of hindsight) of experiences of treatment and management. However, prospective and/or longitudinal data could shed light on changes in experience over time (Lawton et al. 2009), as they have done in the investigation of other long-term diseases or disorders (Baumgartner 2007; Peel et al. 2007; Whitehead 2006), and this may be particularly interesting in cases where mental health problems are experienced in pregnancy and into the postnatal period.

More generally in respect to timing, there has been a historical focus on mental health problems in the postnatal period, in particular depression, as opposed to in pregnancy. Experience of assessment, treatment and management of mental health problems in pregnancy would be particularly interesting with respect to understanding how women make treatment decisions during the antenatal period. A mother’s concerns about the possible impact of a mental health problem on the fetus and the benefits or possible harms associated with treatment, may outweigh her concerns for her own health. A better understanding of these concerns and about how they may be sensitively addressed would inform the development of decision aids and effective treatment plans.

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