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# **The first antenatal appointment: an exploratory study of the experiences of women with a diagnosis of mental illness**

## **Introduction**

Perinatal mental illness is a leading cause of maternal death (Lewis, 2007; CMACE, 2011). The perinatal period begins from pregnancy through to the first twelve postpartum months. Research reports that women are at increased risk of depression and anxiety during this period, due to the social, psychological and physical changes associated with pregnancy, childbirth and motherhood (Brown and Lumley, 2000; Ross and McLean, 2006; Lee et al, 2007). For some women, mental illness may occur for the first time during the perinatal period, whereas other women will have a pre-existing diagnosis of mental illness. Research has shown that 50% of women with a pre-existing severe mental illness including enduring depression, bipolar disorder and psychosis, relapse during the perinatal period (Cohen et al, 2006). This risk of relapse is higher for those who discontinue their medication (Viguera et al, 2000). Women with severe and enduring mental illness are also more likely to experience obstetric complications, and their babies are at risk of low birth weight, premature birth, still birth and intrauterine growth restriction which further increases the risk of neurodevelopment, long-term cognitive problems and infant mortality (Howard et al, 2003; Jablensky et al, 2005; Holditch-Davis et al, 2007; Talge et al, 2007). Research on the causes of these risk factors has suggested genetic susceptibility, along with a delayed access to antenatal care, socioeconomic factors, and lifestyle factors including smoking and substance misuse (Howard, 2005; Pacagnella et al, 2014).

In 2007, the National Institute of Clinical Excellence (NICE) introduced a guideline which made recommendations for midwives and other primary health-care clinicians to ask women in pregnancy about any experiences of past or present mental illness (referred to as the Whooley questions). Many studies have focused on the implementation of these recommendations (Elliott et al, 2007; Rothera and Oates, 2011; Rollans et al, 2012) in order to improve the detection and management of maternal perinatal mental health to reduce maternal, fetal and neonatal risks. In a survey conducted by Ross-Davie et al, (2006) on midwives preparedness to undertake their public health role in detecting perinatal mental illness, they found that 90% of practitioners identified psychological care to be a core part of the midwife's role. The majority (68%) of the midwives felt ill-equipped in their ability to fulfil this role due to limited time, skills and knowledge. Additionally, research has found that midwives report feeling unconfident in assessing the needs of women with severe mental illness and referring them to relevant specialist services. Attributable causes have been identified such as lack of pre and post-registration training around perinatal mental illness, poor continuity of care, and lack of available specialist services (Stewart and Henshaw, 2002; McCauley et al, 2011). The reluctance of women to disclose their mental health issues was identified by the Boots Family Trust (2013) who conducted a survey of 1500 women who had experienced perinatal mental illness. They found that around 20% of the respondents disclosed that they had not been completely truthful about their mental illness experiences, with a further 30% reporting that they had never told a health professional that they felt unwell. Fear about services and the potential removal of their child were identified as the main contributable factors for non-disclosure of mental illness during pregnancy and the postnatal period.

Women's perceptions of antenatal care have been the focus of several studies. Using a piloted questionnaire to collect a combination of quantitative and qualitative data, Soltani and Dickinson (2005) explored 700 women's perceptions of the pattern of antenatal care. For 58% of women, their first health professional contact in pregnancy was with a GP, whereas more than half of women would have preferred to see a midwife. Women were found to be satisfied with their antenatal care, although a number of areas were identified where women's preferences differed from that which they routinely receive, including first contact with health professionals. The executive summary, 'Delivered with care: a national survey of women's experience of maternity care' (National Perinatal Epidemiology Unit, 2010) examined the process of antenatal care. For example, 95% of women had contact with a health professional by the twelfth week of pregnancy. The booking appointment had taken place for nearly two-thirds of women by ten weeks.

The Francis Report (2013) emphasised the importance and need for service user's views and involvement in healthcare design and monitoring of clinical effectiveness, recognising that patient safety and quality of care improves when services work in partnership with patients to provide appropriate healthcare delivery. This exploratory research study asks what are the feelings, perceptions, and expectations that influence how women with pre-existing diagnoses of mental illness experience their first antenatal (booking) appointment. The study used semi structured interviews with twelve participants. This study will make recommendations for practice development and collaborative partnership working between healthcare professionals and the pregnant woman in their care.

## **Methods**

The researchers considered the use of qualitative methodology within a framework of the phenomenology, namely the phenomenological approach of Alfred Schutz (1899–1959) as most appropriate in exploring the expectations and experiences of women with pre-existing mental illness of their booking appointment. Influenced in particular by the philosophers Edmund Husserl and Henri Bergson, and the interpretative sociology of Max Weber, Schutz proposed that perceptions of the world result from past experience. The continuous accumulation of experience and knowledge will enable a person to recognise a situation or object, and will determine how they will act. In *The Phenomenology of the Social World* first published in 1932, Schutz distinguishes between "action" and "act." He uses the term "action" to refer to tasks initiated by preconceived constructions of the world and the term "act" as referring to the physical or mental steps taken to enact the task. Tasks undertaken can be considered as repeated but inconclusive ideas that will be tested by the actual acts, which can succeed or fail in achieving a purpose. The desired outcome is to transform an initial perception into a final state, and, in each action, experience and knowledge are increased and developed. What was thought to be clearly understood is, by the process of gaining experience, continuously, as Schutz states, "supplanted by a coming to be and passing away" (1967:47).

The use of qualitative methodology also enables the essence of lived experience to be explored, and according to Cutliffe, can be used to interpret key insights into individual experiences and "lived moments and thus produce a description" (Cutliffe in Sallah and Clark 2005, p.57). The qualitative method of semi structured interviews enables the understanding of the experiences, feelings, values, and perceptions that influence behaviour, and bring about giving voice to those whose views are rarely heard (Sofaer 1999).

The method of using semi-structured interviews was considered by the researchers as having the most potential for achieving the active involvement of the participants. The interview questions (in Appendix 2) for the study were developed on the basis of the literature review conducted, and with the advice of a variety of relevant maternity professions for clarity and applicability. The questions were developed in order to find out the women's history of mental health care; their expectations of their booking appointment; their experiences of this appointment particularly in relation to their disclosure of mental illness and what influenced their decisions to disclose including the response of the midwife, and lastly, their thoughts about the birth of their babies and beyond. In the development of the interview questions, the researchers acknowledged that the questions were influenced by a very specific agenda about the women's decisions to disclose their mental illness diagnoses, which may have influenced the participant's ability to speak from their own perspective. This issue is explored further in the *Reflexivity* section below.

### *Participants*

The inclusion criteria for the research were women who had a pre-existing diagnosis of mental illness and received regular support and care by mental health services. These women had received diagnoses including schizoaffective disorder, bipolar disorder, anxiety and panic disorders, depression, and personality disorders. Some of the women had frequent episodes of mental illness, and required regular support. Many of the women were well for the majority of the time, but could be vulnerable to relapse. The inclusion criteria for this research study included women who wished to take part in the proposed research and were considered well enough to do so by the Lead Practitioner responsible for their care. The study population excluded women considered by their Lead Practitioner to be too unwell to take part in the research.

The researchers aimed to achieve diversity within the sample. The table in Appendix 1 shows the demographic characteristics of the participants. The researchers also ensured that the interview questions were accessible to all the participants. Interpreting services were identified to conduct the interviews but all the participants spoke and understood English.

### *Data Collection*

It was agreed between the researchers that twelve participants for this study would be recruited. Participants were selected from one maternity service and one perinatal mental health service. The researchers distributed leaflets in these services and a poster was also present with information about the study with the researchers' contact details. To avoid the issue of coercion, the recruitment of participants was achieved by asking the midwives in the antenatal clinic and the nurses in the perinatal mental health service, to give patient information sheets to women meeting the criteria for the research. Some women expressed their interest there at the appointment and their names were passed on to the researchers so they could then contact the woman by email or phone to arrange an interview. Other women spent time thinking about their inclusion in the study and then contacted the researchers directly. The researchers were available for queries and questions about the study via telephone or email. The researchers had no previous contact with the participants prior to the interviews. A Research Development Manager was also identified with their contact details on the patient information sheets for the participants to contact if they wanted to ask general questions about participating in a research study.

The researchers worked closely with the participant's Lead Practitioner throughout the study, who was consulted about the process of the study and issues of capability. The participants were clearly informed that they could withdraw from the study at any time. Due to the potentially sensitive subject of the research topic, participants showing any signs of distress during or after the interviews would have been asked if they wanted the interview to stop and offered support if they became distressed from their midwife, GP or a member of the Perinatal Mental Health Team, if they became distressed. During the process of this research, it was not necessary to stop any interviews or to offer the participants any further support. All participants were asked to sign a consent form agreeing to participate in the study. Sixteen women agreed to take part in the study overall, but four were found to be too busy to participate. The participants were informed on the patient information sheets that a small token of thanks would be given to them following the interview. The details of the token (Boots voucher of £20) was not revealed until after the interviews.

The recruitment process took a considerable amount of time due to the diverse workloads of the researchers and practitioners, and possibly, the sensitive nature of the research issue. Overall, there was a higher response rate from the antenatal clinic. The study took place between January and August 2013. By May 2013, only one participant had responded from the perinatal mental health team and nine from antenatal clinic. Consequently, the researchers held a discussion with the manager of this service to ascertain the cause. The high workload among staff in this team causing difficulties in remembering to ask potential participants was identified as contributing to the slower response. The manager consequently reminded the staff about the study, which led to two more participants being recruited. In addition, the researchers asked the service managers to identify some research champions who reminded practitioners in both services to inform potential participants about the research. The agreed number of twelve participants was then achieved and services were subsequently informed. Nine interviews were digitally recorded with the participant's consent, and later transcribed. Three women declined to be recorded. The researchers took notes during all the interviews to ensure credibility.

### *Setting*

The interviews took place either at the women's homes, or within the antenatal service with the consent of the woman and relevant practitioners. The interviews were conducted by the two researchers (authors of this paper) and lasted for no longer than one hour. Only the two researchers and the individual participants were present during the interviews.

### *Reflexivity*

The researchers assumed that the participants may feel uncomfortable, or find difficulty disclosing their mental illness at their booking appointment. The researchers did discuss the impossibility of remaining 'outside' the subject matter being explored. However, within the interviews, the participants were encouraged to speak freely about their experiences and expectations, without being influenced by the assumptions of the researchers.

Prior to conducting the interviews, the researchers (both women) discussed their expectations and assumptions about the research topic, which is referred to as reflexivity (Dowling 2006). It is necessary for researchers to challenge and think through personal and professional beliefs which may potentially influence the research findings. As Etherington (2004) asserts, this vital process can

be used as a central methodological source for inquiry. Reflexivity enables the reciprocal sharing of knowing between the researcher and participants. However, as Mauthner and Doucet (2003) point out, there is often a limit to how reflexive a researcher can be, and to what extent they can make sense of the research at the time of conducting it (2003:415). Expectations, bias and assumptions may only become apparent once the research is completed. In this study, the re-submission process in itself enabled the researchers to consider their attention to the issue of reflexivity and risk of bias during the research, which they did not have space to fully consider in the first submission of the paper.

The process of reflexive exploration and self-awareness is something familiar to both researchers who are mental health specialists. One researcher has several years of midwifery experience, and is a specialist mental health midwife involved in service development and care planning for women with mental health needs going through their transitions to motherhood. This researcher is interested in the influence of psychological changes during pregnancy and following childbirth, and the psychosocial, physical and cultural factors which may impact on the lived experiences of women with pre-existing mental illness. The other researcher is a mental health nursing academic who has experience of conducting qualitative research prior to this study. This researcher is interested in the importance of mental health practitioners' thoughtful attention to their own physical and psychical responses to the people diagnosed with mental illness in their care, which can be used as a tool to understand their experiences (Phillips 2006).

Both researchers wished to prioritise and celebrate the voices of the women interviewed and reflected upon the heartening determination of the women diagnosed with more 'severe' forms of mental illness who readily disclosed their diagnoses at the booking appointment. Schutz would argue that women with mental illness may have encountered a series of assumptions from others, therefore gaining their own understanding of 'acceptable' ways to perform as social actors. Both researchers remained mindful of this and allowed time and space for the women to discuss their experiences of pregnancy and having a diagnosis of mental illness. The researchers recognised the interplay between the woman's early life experiences of being mothered, the societal views on motherhood and the women's own experiences of and expectations about pregnancy and the first contact with maternity services.

The researchers recognised that for the participants, in their experiences of the interview and the booking appointment, professional women were positioned as asking questions about the experience of mental illness. Throughout the research process the researchers were committed to considering participants first and foremost as women, and as collaborators in the research process. The researchers hold the perception that mental illness does not define a person. They were interested in highlighting the participants' experiences as women including aspects that intersected with the researchers own professional and personal experiences including the juggling of relationships, motherhood and work. There was a strong wish to highlight that women frequently experience anxiety as mothers whether they have a mental illness diagnosis or not, and the expression of these anxieties may stand as a reaction against the idealisation of motherhood within our culture. The researchers reflected upon whether they carried these perceptions into the interview process and concluded that this was perhaps inevitable, but hoped that their ability to reflect and be truthful with each other, left space for the women to speak as freely as possible.

### *Ethical considerations*

The researchers followed ethical procedures and all data collected during the process of the research study was handled in confidence. Women's names and any identifying information were not contained in any data collected. The women were informed that the study findings would be written up for a peer reviewed publication and reported at relevant conferences. The data will be stored in anonymised form for 10 years, and no research publication will identify the participants. Approval to conduct the project was sought from the relevant Research Ethics Committee and local Research and Development approval were obtained.

### *Data Analysis*

The analysis of the data involved a process of thematic analysis which has been described as an accessible method for identifying, analysing and reporting patterns or themes within data (Braun and Clarke 2006). These authors outline a series of phases worked through by the researcher to produce a thematic analysis. The researchers listened to all the digital recordings and the transcribed data was then read and re-read several times to verify the precision of transcription. The researchers then identified and noted pertinent and relevant issues within the data relating to the expectations and experiences of women of their booking appointment. Repetitive patterns of data were manually identified and the data was then imported into QSR NVivo 10 software which was used to visually organise the data into codes (or themes). As Bazeley (2007) states, NVivo 10 provides a visual storage area which facilitates the process of analysing. Coding stripes enable researchers to view sections of the text or whole documents.

### **Findings**

Five themes emerged from the interview data which will now be presented one-by-one with illustrative quotations from participants:

The system of R= respondent will be used after each quote, e.g. R1, R2

#### *Thoughts about motherhood*

An interesting and moving theme that arose from this research study was that each woman spoke about her thoughts and feelings about becoming a mother and the challenges of managing work and relationships. Eight of the participants were first time mothers. The first quote could be expressed by any woman independent of her mental health status. However, the second quote appears more specific to a woman's experience of having a mental illness diagnosis:

I'm self-employed and I'm a really hard worker and I was just packing up my studio yesterday. It was really hard to say "I'm going on a break now and there is someone coming I'm to take care of" – it was quite a big thing actually (R2).

I worry about work and having a baby, about my baby's health, about being a parent and a partner. I am worried about my ability to parent. But nobody is more worried about me than I am (R10).

Many of the women expressed their determination to do their very best as mothers and to prevent relapse of their mental illness:

We couldn't love our baby anymore and we want to do the best for her and if that (relapse of mental illness) happens, then we'll deal with it and then I'll come out of it. I'll be the best mother I possibly can and we're doing everything we can to ensure that doesn't happen (R8).

#### *Lack of specific attention from care providers*

Many of the participants stated that they received very little information about their booking appointment. It seemed that most appointments were arranged following the GP referral to maternity services:

No, I wasn't told about what the first appointment involved (R5).

I got very little information (R1).

Several of the women spoke of the apparent lack of knowledge and skills displayed by their GPs when discussing referral to maternity services and the nature of the initial booking appointment:

The GP was quite clumsy. I was feeling emotional and unsure about being pregnant. I think I just got a letter through the post inviting me to the booking appointment with a midwife. I was given a male midwife which I did not expect (R9).

My GP verbally gave me some sort of limited information that it would be a booking appointment because the midwife wasn't actually available to see me for quite a while. That was about it, I wasn't told too much (R5).

I knew that a full medical consultation, if you like, was going to be, was going to have to take place. So I knew that talking about having bipolar was imminent, really. It was going to happen. But it was quite informal (R3).

The length of time between the GP appointment and the maternity booking appointment appeared to increase a level of apprehension about fetal wellbeing in some of the women as expressed clearly in the following quote:

I was nervous about it but at the same time kind of looking forward to it just too sort of see how things were progressing. I feel that when you first go to the doctor and have your pregnancy confirmed, three months is a long time to wait (R4).

I don't know... I kind of... I would never say I forget that I've got bipolar but in this instance, the baby's been a lot more at the forefront than worrying about me kind of thing (R5).

A lack of information given to women prior to the booking appointment may have an impact on their readiness to disclose their history of pre-existing mental illness. This may be further obstructed if the participant is embarrassed to disclose information about her mental health history, as the following participant expressed:

I feel that people are always embarrassed about it; they don't like talking about it, it was a bit embarrassing (R4).



### *Perceptions of too much information at the first antenatal appointment*

Several of the participants stated that there was an excessive amount of information at the booking appointment as stated in the following quotes:

There is so much information – it's too overwhelming (R6).

The apparent overload of information is highlighted in the following response:

They just asked loads and loads and loads and loads questions...I didn't know they were going to ask them questions (R1).

Some of the women wanted additional support for their mental health needs, and thought that the first appointment wasn't the best time for discussions about mental health:

I wanted a more informal meeting with someone, more discussion about mental health. I didn't know what questions to ask about mental health care at the first appointment (R5).

I felt very much like it was a note taking exercise. I felt the mental health question was an add on, although I did want to share information about myself (R9).

It seemed that many of the women were unclear about their mental health needs at the time of the first booking appointment, and needed more opportunities to discuss their mental health needs and the possible impact this would have on their pregnancy, at subsequent follow up appointments:

I didn't know what I wanted at that time – I was so overwhelmed at that time about being pregnant. I knew I wanted someone to talk to but it was hard to say that in the first appointment meeting and there was so much information to take in. I felt shell shocked (R9).

Yeah, there's an awful lot of information to take in and I sort of felt afterwards that it's quite nice to have that sort of month between the 12-week booking in appointment and then coming back at 16 weeks to have all of those results (R4).

### *Wanting to share mental illness diagnosis with care providers to receive specific attention*

All the participants were very positive about disclosing their mental health diagnosis at the first appointment. This was particularly apparent among the women with enduring mental illness, as succinctly expressed in the following quote:

As long as I'm informed and know exactly how I feel, know all my triggers, I'm more empowered to know my own self and nobody can really dictate to me as much (R3).

I do have this illness, but I personally don't feel that I've got anything to be ashamed or embarrassed of. People are diabetic and they have to take an injection. My brain is a little bit broken and I have to take tablets and that's how I deal with it, so I think where other people can get a little bit more upset by the use of the term 'mental illness' or something like that, it's something that I'm happy with (R8).

I would say I've probably suffered some kind of depressive episodes since I was 17. So I'm fairly comfortable talking about it (R2).

Other issues relating to the women's thoughts about disclosure involved the responses they received from the midwives. The participants with a diagnosis of bipolar disorder stated they received a less positive and supportive response from the midwives following disclosure:

She (the midwife) was more cautious. I felt like she was a bit more cautious of my feelings. In fact it came across a little bit patronising but I don't blame her. She was trying to be nice. Over cautious, yeah, a bit over cautious with how I might feel like, "Oh, it's okay. Oh, a bipolar," you know... (R3).

In some ways my perspectives are going to have to change because my priority is now not going to be the children I teach but my own child, so I think, if you need the help then it would have to necessarily...sometimes, it has to come from the patient itself because you kind of, you know how you feel and I think with things like mental health, you've got to be proactive (R4).

One participant mentioned that her bipolar disorder diagnosis has received an increased amount of attention because of her pregnancy:

As soon as you're pregnant these things get a lot more attention than when you're not pregnant (R5).

It was also identified that a lack of awareness around perinatal mental illness amongst partners and family members may act as a potential barrier to disclosure of mental illness at the booking appointment:

Previously my partner had told me not to tell anyone about my mental health (R12).

However, it was found that if a level of sensitivity, receptiveness and interpersonal skills are used by the Midwife, this can be effective in enabling woman to disclosure:

But from my first pregnancy I was open about it. The midwife knew what to ask in terms of my mental health. She was discreet, kind and understanding (R12).

And she was very nice. So it made it very easy for me to talk really about everything (R3).

The midwife was really nice, really personal and that does build up a rapport (R6).

The women also appeared to experience particularly positive responses when they disclosed their mental illness diagnosis:

The midwife saw that I had a history and suggested extra help (R7).

The Midwife asked me about mental health. I thought I feel good, I feel my mind. It is normal to be asked about information (R11).

The midwife that booked me in, she was really friendly, really chatty, kind of made me feel at ease straightaway, so that was good (R4).

The midwife explained why they were asking the questions. Everything was very clear. There was a lot of understanding and sensitivity to my mental health condition (R12).

Another issue that emerged from the discussions about disclosure was that many of the women expressed their disappointment at not having one midwife allocated to them throughout their pregnancies:

It's a bit sad with coming here to the antenatal clinic. I have had a different midwife every time so you can't really build up a personal relationship with one midwife that kind of knows your history (R12).

I had three midwives, so I would like to see just one (R10).

I also saw a different Midwife every time, so there was no personal touch. Seeing a different Midwife really affected me at the beginning (R9).

#### *Perceptions about lack of joined up working*

The women diagnosed with bipolar disorder, schizoaffective disorder and personality disorder needed to be referred to the perinatal mental health service following the booking appointment. The women diagnosed with bipolar disorder stated that the midwives they saw at their booking appointment didn't appear to have much awareness and knowledge of this service:

She didn't tell me extra support would be there. She didn't seem to know anything about the Perinatal Mental Health service, which worried me (R5).

Because she wasn't a mental health professional, she couldn't really give me the answers necessarily that I wanted to know which is, "Is it a unit? How long do they have to see me for? Or how often do they have to see me? Are they going to want to put me on medication?" It was those kinds of questions that she wasn't able to answer (R8).

I wanted to know what it (the perinatal mental health team) involves and how they work. I mean I'm sure she would have played the midwife and would have been able to say because of my diagnosis, how often, or anything like that, and how they work for example like they come to your house or you go to, they have units attached to the hospital? She didn't know any of that which when I found out at a later stage, was a bit scary (R3).

A woman discharged from her Personality Disorder therapist expressed her need for further perinatal mental health team support:

I don't have that therapist no more. So I'm relying on the perinatal team support (R1).

#### **Discussion and implications for practice**

This study did achieve its aim to explore women with pre-existing mental illness diagnoses expectations and experiences of their booking appointment using semi-structured interviews. Previous research on the perceptions of women of antenatal care has used questionnaires and surveys and has therefore effectively gained the views of a large number of women. However, using

semi-structured interviews and asking women directly, the findings in this study contain some interesting insights about the experiences of women with pre-existing mental illness, as mothers for example. Previous research has highlighted that mothers with mental illness frequently experience stigma and judgement both from society and their families, and are frequently perceived as 'incompetent' mothers (Edwards and Timmons 2005; Krumm and Becker 2006; Davies and Allen 2007). As Montgomery (2006) points out, mental illness presents a challenge to the established stereotypical image of the ideal mother. The current study revealed a refreshing insight that the women participants seemed to be generally positive about disclosing their mental illness diagnoses at their booking appointment. This was indeed a surprising finding; the researchers had assumed that the disclosure of a mental illness diagnosis would be a challenge for these women given the potential stigma. The women spoke of their determination to take care of themselves during their pregnancies and beyond. As well as these positive expressions, the women's narratives seemed to reflect those of all mothers and their frequent challenges in managing the demands of everyday life particularly in relation to working. Therefore, this research can be applied to contexts outside that in which the research took place.

Overall, the participants in this study were very positive about the skills of midwives. However, women with mental health diagnosis of bipolar disorder in particular, found that midwives did not appear to have sensitivity and knowledge about their diagnosis, and appeared to express uncertainty. This is in line with previous research which has clearly indicated that midwives often have poor understanding and knowledge of mental health diagnoses (Ross-Davie et al, 2006) and often feel unconfident in their role in responding to women with mental illness. In addition, research has found that midwives and other health-care professionals frequently feel unconfident in their role in appropriately assessing and referring women who experience perinatal mental illness to relevant specialist services (Stewart and Henshaw 2002; McCauley et al, 2011). Other research has highlighted the poor levels of training, but revealed good knowledge of antenatal depression and appropriate illness perceptions of this condition (Jomeen et al, 2009).

Midwives need to be supported by both their line managers and supervisors of midwives in providing safe and evidence-based maternity services for women. There is a necessity for midwives to have access to relevant and up-to-date knowledge and receive training on antenatal and postnatal mental illness issues and treatments in order to help women to achieve a satisfactory outcome for themselves, their babies and their families. Midwives should also be encouraged to use the statutory supervision platform to identify their training needs within a supervisory context.

This study, although recruiting a small number of participants, appears to be unique in identifying the lack of information some women receive prior to their booking appointment. The majority of the participants were first time expectant mothers (96%). Therefore, they would have had no prior knowledge of what information would be required and the implications of perinatal mental illness during pregnancy. Perhaps there needs to be a stipulation in primary care that women with mental health needs are given information from their GPs about what the booking appointment will involve.

Many of the women commented that their GP did not appear to have the necessary knowledge or skills to inform or provide them with the required information about the booking appointment. It was also identified that that a lack of information given prior to this appointment may affect the women's readiness to disclose a pre-existing history or current symptoms of mental illness to the

midwife. This is further obstructed if the woman is unable to recognise her mental health needs or unprepared to disclose her mental health history. As stated in the literature review above, women with severe mental illness have an increased risk of relapse or exacerbation of their symptoms during the third trimester and following childbirth. Additionally, untreated perinatal mental illness can lead to an increase of obstetric complications and have a negative impact on mother-child interactions. It is therefore recommended that GPs receive adequate training in order to equip them with the skills needed to discuss sensitive issues around perinatal mental illness and the impact on pregnancy and childbirth, along with discussing treatment options and the effects on the woman, fetus or new born. Ideally these discussions would be held preconceptionally and all women with severe pre-existing mental illness would be referred to a perinatal mental health service by their GP in order to receive tailored preconception family planning advice (Joint Commissioning Panel for Mental Health, 2012). This method of support and information sharing with women would enhance their level of understanding about their treatment options and would provide the GP with a platform on which to discuss the process of referral to maternity care and the nature of the booking appointment. However, significant gaps have been identified in maternal access to specialist perinatal mental health support, with less than 60% of community based perinatal mental health services across the UK (Maternal Mental Health – Everybody’s Business Campaign, 2014). Evidently, access to specialist perinatal mental health care is currently dependent on the woman’s geographical area, identifying a need for an increase in availability of perinatal mental health services to enable maternal access to care.

The theme of too much information at the first appointment also appears unique to this study, with many of the women reporting that they felt overwhelmed and needed more opportunities to discuss their mental health needs. It would appear that the time between GP discussion and the initial booking appointment may provide an ideal window of opportunity for additional consultation to be given to women with pre-existing mental illness. NICE (2007) recommends that pregnant women with existing mental illness should be given sensitive information about the impact of perinatal mental illness, treatment options and the potential maternal and fetal side effects of medication during pregnancy and the postpartum period. It is also recommended that women with severe pre-existing mental illness should be asked about their mental illness at each subsequent appointment so they receive continuity of care. To address this, it would be beneficial for all women to have their emotional and physical health needs assessed at each follow-up antenatal appointment. This way assessment of mental health needs would form a standardised requirement within maternity care, therefore normalising the process for routine enquiry and fostering openness and transparency which recognises that emotional wellbeing is an essential component within a woman’s overall health, wellbeing and transition to motherhood.

The need for collaboration and coordinated care provided by perinatal mental health professionals and other agencies has been highlighted in several studies (Rothera and Oates, 2008; Rowan and Bick, 2008; Lees et al, 2009). The NICE guidelines (2007) and the NSPCC report on perinatal mental illness (Hogg, 2013) in particular, state the need for effective collaborative working to be established between health professionals involved in a pregnant woman’s care, and for this to be maintained throughout her pregnancy. Effective management of pregnant and postnatal women with mental health problems depends on good coordination between the different services and specialists. One of the key issues raised in the CEMACH report (Lewis, 2007) and identified in a survey conducted by Rowan and Bick (2008) were the challenges professionals experienced liaising with colleagues in

other professional groups. The differing health professionals interviewed were not always aware of the services available in other areas of the health service and recommended that named links were circulated to ensure better joined up working.

Likewise, in the current study, several participants considered to be at risk of relapse and recurrence of their mental illness postnatally, expressed that the midwives at their first appointments did not appear to be able to provide them with the necessary information about perinatal mental health services. It is essential that all professionals receive training on effective multi-disciplinary working and the referral process. The presence of a co-ordinator who links between differing perinatal mental health services would be particularly useful. This has been highlighted as the crucial role of the Specialist Mental Health Midwife (Maternal Mental Health Alliance, 2013) who can accomplish a greater awareness among professionals of referral systems and processes, and be the individual to liaise with when concerns are identified.

The under-representation of ethnic minority groups in empirical research has been explored in several studies (Sheldon et al, 2007), and is apparent in the current study resulting in the potential for reduced generalizability. One recommendation to promote the inclusion of ethnic groups within research is proposed in a study by Twamley et al, (2009). They suggest using a research site accessible to minority groups and to adopt a collaborative approach by requesting that health professional recruit on the site. This was achieved in the current study, but it seemed that a majority of white Caucasian women offered to participate. It was also evident that these women were from higher socio-economic groups. It is vital that access to maternity services is given priority, which has been illuminated in several studies (Ali et al, 2004; Cross-Sudworth et al, 2011). This study did involve women from other ethnic groups on a small scale and if a higher number of participants were recruited, a considerably higher representation of ethnic minority groups might have been achieved.

This study was conducted with a small number of women in one locality. Therefore, there is a limitation of the generalizability of the findings. A longitudinal quantitative research study may provide more detailed information about the needs of women in relation to their booking appointment. Despite these limitations, by asking women directly, this research study offers a valuable insight into the thoughts and experiences of women with a variety of pre-existing mental illness diagnoses of their booking appointment. It is not clear how much the participants were led the researcher's agenda. However, the researchers were careful to reflect upon the ways in which their own preconceptions and assumptions may have influenced the research findings and might have led the participants to answer questions in a way that was 'expected' of them as women with a diagnosis of mental illness. There are some suggested methods for data analysis to enable researchers to fully engage in the reflexivity process and to address the risk of bias in woman-centred research. Mauthner and Doucet (1998) describe their use of the voice-centred relational method of data analysis developed by Brown and Gilligan (1992) in order to demonstrate a meaningful use of reflexivity. They state that few researchers fully offer reflexive accounts of data analysis. The process of using the voice centred method means the researcher passes through three or more readings of the interview text. The researcher as reader, places herself and her individual experiences in relation to the participant. Reading on her own terms, she listens to her own unique intellectual and emotion responses. A 'worksheet' technique is used whereby the participant's words are presented in one column and the researcher's responses, reactions and interpretations

are recorded in an adjacent column. This process enables a relational aspect in the data analysis and potential for a full immersion in the data.

Applying the work of Schutz to the findings in this study, a woman is positioned linguistically, culturally and socially within the world. Through her experiences, she has encountered the perceptions of others which have contributed to her construction of herself. The researchers reflected upon how a woman may perceive herself and speak as a woman diagnosed with a 'mental illness' at the booking appointment. What is she to say in her anticipation of and response to others social constructions of a mentally ill woman? The researcher explored whether the women in the interviews answered our questions in a specific way in response to what they perceived was expected of them. There are no definitive answers to these questions. However, Schutz's phenomenological framework has provided the researchers with a useful conceptual tool to facilitate discussion and reflection about the nature of the lived experiences of women diagnosed with mental illness.

## **Conclusion**

A significant finding in this study is that the women interviewed perceived a general lack of joined up working between antenatal and perinatal mental health services. The necessity for joined up working relates to each theme from the first referral by a GP through to the collaboration between antenatal services and the woman's referral and subsequent care by perinatal mental health services following birth. Early interventions for mental illness are essential to reduce risks to the mother and her baby. If the disclosure of mental illness at the booking appointment is managed in a sensitive and timely way, a pregnant woman with mental illness can be referred to specialist services and given appropriate care and treatment. If early intervention does not take place, problems may escalate at a later stage which may also be costly in terms of service provision. An increased number of health professionals would need to be involved in the woman's care, and she may need to be referred to inpatient services, which would have consequences on her well-being and relationship with her baby. Therefore, it is vital that health professionals work collaboratively and educate and make decisions jointly with the pregnant woman, so her treatment can be sensitively and carefully managed. The NICE guidelines recommend that future research should cover the degree of integration of services and there should be common protocols. The results of this study could therefore be a foundation upon which to conduct a further study measuring the barriers and facilitators of joined up working between antenatal and perinatal mental health services.

The first antenatal appointment with a midwife, and the first and only interview initiated by the researchers share similarities. In both situations, professional women in caring roles are positioned as 'experts' in asking questions about the women's experience of mental illness. The passing of time between the first antenatal appointment and the interview has enabled the women to gain new experiences of who they are as women and as mothers with a diagnosis of mental illness. The women's experiences will continue to accumulate, as Schutz describes as the new growing out of something old, 'at one moment an experience waxes, then it wanes' (1967:61). Through a process of reflection, the researchers have managed to capture the women's significant experiences briefly in this paper. The researchers hope that for future qualitative research and antenatal clinical practice, such encounters if managed with thoughtfulness and respect, can be methodologically

valid and meaningful in enabling an improved understanding of the experiences of women diagnosed with mental illness.

*I want to be understood and listened to.... People with mental health problems often know what they need, but they need the help and the tools to help them do it (R12).*



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**Appendix 1: Demographics of research participants**

<b>Age</b>	<b>Total</b>
19 - 23 yrs. old	1
24 - 31 yrs. old	2
32 - 42 yrs. old	8
43 - 53 yrs. old	1
<b>Ethnicity</b>	
African (Black)	1
Mixed Caribbean & British	1
Eastern & Other European (White)	3
United Kingdom (White)	7
<b>Parity</b>	
0	8
1 - 3	3
4 - 5	1
<b>Employed</b>	
Yes	9
No	3 (2 were Students) (1 Housewife)
<b>Marital Status</b>	
Single (Supported)	1
Single (Unsupported)	1
Married	6
Cohabiting	4
<b>Mental Health Diagnosis</b>	
Depression	4
Anxiety	1
Anxiety & Depression	3
Bipolar Affective Disorder	2
Schizoaffective Disorder	1
Borderline Personality Disorder & Depression	1

## **Appendix 2** Semi structured interview questions

1. How long have you had support from mental health services?
2. From your contact with support services, have your particular needs or requirements been given a name or diagnosis?
3. Have you previously been admitted to inpatient or day care services on account of how you have been feeling?
4. How was your first antenatal appointment arranged?
5. What information did you receive about this appointment?
6. What were your expectations of this appointment?
7. How many weeks pregnant were you?
8. Did you attend the appointment alone or accompanied?
9. What were your feelings/thoughts about disclosing your mental illness before the appointment?
10. How did it feel to disclose your mental health diagnosis to the midwife at this appointment?
11. What helped you disclose?
12. Did anything or anyone influence your decision to disclose your diagnosis of mental illness?
13. Can you describe how this information was received by the Midwife? What did they say? How did they appear to you?
14. What were the positive things about your first appointment?
15. What were the negative things about your first appointment?
16. Could anything have been done differently?
17. What happened next in terms of your pregnancy care?
18. Can you describe the care you expect to receive through your pregnancy?
19. What are your thoughts about your baby's birth and after that?