

Mothers' Experiences of First Onset Postpartum Psychosis

Siobhan Kelly

September 2018

*Research submitted in partial fulfilment of the requirements for the degree of Doctor
in Clinical Psychology (DClinPsy), Royal Holloway, University of London.*

Acknowledgements

I would like to thank South London and Maudsley NHS Foundation Trust for supporting this project and assisting with recruitment across their perinatal teams. I would also like to thank Action on Postpartum Psychosis for their essential role of providing service user consultants and repeatedly advertising the project to aid recruitment. This project would not have been possible without these services. Additionally, I would like to thank my internal supervisor, Dr Olga Luzon, for her patience and guidance throughout this research project and my field supervisor, Dr Crispin Day, for his knowledge and direction. Lastly, a special thanks to my fellow trainees and friends for their continued support and encouragement, and most importantly, my mum and dad, throughout all of training.

TABLE OF CONTENTS

| | |
|---|-----------|
| Executive Summary | 8 |
| OVERVIEW | 8 |
| THE MOTHER-INFANT RELATIONSHIP AND PERINATAL MENTAL HEALTH | 8 |
| POSTPARTUM PSYCHOSIS | 9 |
| SYSTEMATIC REVIEW | 10 |
| EMPIRICAL PAPER | 11 |
| INTEGRATION, IMPACT & DISSEMINATION..... | 14 |
| How Does Postpartum Psychosis Affect The Mother-Infant Relationship: A | |
| Systematic Review | 17 |
| ABSTRACT | 17 |
| INTRODUCTION..... | 18 |
| BECOMING A MOTHER | 19 |
| POSTPARTUM PSYCHOSIS | 21 |
| SUPPORT FOR POSTPARTUM PSYCHOSIS | 22 |
| AIMS | 24 |
| METHOD | 25 |
| SEARCH STRATEGY AND SELECTION OF STUDIES | 25 |
| QUALITY APPRAISAL..... | 26 |
| RESULTS..... | 27 |
| DATA EXTRACTION | 27 |
| DATA SYNTHESIS | 28 |

| | |
|---|-----------|
| CHARACTERISTICS OF PARTICIPANTS | 29 |
| TABLE 1: SUMMARY OF PAPERS INCLUDED AND DEMOGRAPHIC CHARACTERISTICS OF SAMPLES | 30 |
| RECRUITMENT SETTINGS | 33 |
| QUALITY RATINGS | 33 |
| DESIGNS | 35 |
| PSYCHOMETRIC MEASURES | 36 |
| QUANTITATIVE FINDINGS | 38 |
| TABLE 3 METHODS AND RESULTS OF QUANTITATIVE ARTICLES..... | 41 |
| QUALITATIVE FINDINGS | 44 |
| TABLE 4 METHODS AND RESULTS OF QUALITATIVE ARTICLES | 46 |
| QUALITATIVE THEMES | 49 |
| DISCUSSION..... | 51 |
| STRENGTHS AND LIMITATIONS OF INCLUDED ARTICLES..... | 55 |
| FUTURE RESEARCH | 59 |
| CONCLUSIONS..... | 62 |
| Empirical Paper | 63 |
| ABSTRACT..... | 63 |
| INTRODUCTION..... | 64 |
| MOTHERHOOD | 64 |
| EFFECTS OF PERINATAL MENTAL HEALTH ON THE MOTHER-INFANT RELATIONSHIP . | 64 |
| POSTPARTUM PSYCHOSIS | 67 |
| THE PRESENT STUDY | 72 |

| | |
|---|-----------|
| AIMS | 74 |
| METHOD | 75 |
| DESIGN..... | 75 |
| RATIONALE FOR USING THEMATIC ANALYSIS | 75 |
| ETHICS | 76 |
| INCLUSION/EXCLUSION CRITERIA | 77 |
| PROCEDURE | 78 |
| TABLE 1: PARTICIPANTS' DEMOGRAPHIC INFORMATION | 80 |
| INTERVIEW SCHEDULE | 82 |
| DATA ANALYSIS..... | 83 |
| REFLEXIVITY | 84 |
| RESULTS..... | 86 |
| EXPECTATIONS VS. REALITY OF MOTHERHOOD | 89 |
| <i>WHAT'S GOING ON?</i> | 89 |
| THE BARRIERS TO CARING FOR MY BABY | 90 |
| <i>WANTING TO BREASTFEED VS. NEEDING MEDICATION</i> | 90 |
| <i>WHY ARE YOU TAKING ME FROM MY BABY?</i> | 91 |
| <i>YOU CANNOT BREAK OUR BOND</i> | 92 |
| WHAT COMES WITH POSTPARTUM PSYCHOSIS | 94 |
| <i>THE TERROR OF THE WORLD</i> | 95 |
| <i>THE CONFUSION OF REALITY</i> | 96 |
| <i>THE DEPRESSION THAT FOLLOWS</i> | 97 |
| WHERE THE SYSTEM FAILS AND THRIVES | 98 |
| <i>THE NEGATIVES OF GENERIC CARE</i> | 98 |
| <i>THE POSITIVES OF SPECIALIST PROVISIONS</i> | 99 |

| | |
|--|------------|
| LET’S TALK ABOUT POSTPARTUM PSYCHOSIS | 101 |
| SUPPORT | 102 |
| <i>WHERE SUPPORT SHOULD COME FROM: THE HEALTHCARE SYSTEM</i> | 103 |
| <i>WHERE SUPPORT DOES COME FROM: PARTNERS AND FAMILY</i> | 104 |
| MAKING SENSE OF IT ALL | 105 |
| DISCUSSION. | 109 |
| EXPECTATIONS VS. REALITY | 109 |
| POSTPARTUM PSYCHOSIS VS. DEPRESSION..... | 110 |
| STRENGTHS AND LIMITATIONS..... | 112 |
| CLINICAL IMPLICATIONS..... | 117 |
| IMPLICATIONS FOR FUTURE RESEARCH | 121 |
| CONCLUSIONS..... | 124 |
| Integration | 125 |
| Impact & Dissemination | 131 |
| References | 138 |
| Appendix | 155 |
| APPENDIX 1: PARTICIPANT INFORMATION SHEET | 155 |
| APPENDIX 2: PARTICIPANT CONSENT FORM | 158 |
| APPENDIX 3: PARTICIPANT DEBRIEF INFORMATION | 159 |
| APPENDIX 4: RISK MANAGEMENT PROTOCOL | 161 |
| APPENDIX 5: HRA ETHICAL APPROVAL | 162 |

| | |
|---|------------|
| APPENDIX 6: ROYAL HOLLOWAY UNIVERSITY OF LONDON ETHICAL APPROVAL | 166 |
| APPENDIX 7: SLAM R&D APPROVAL | 169 |
| APPENDIX 8: SEMI-STRUCTURED INTERVIEW SCHEDULE..... | 171 |
| APPENDIX 9: INTERVIEW TRANSCRIPT WITH CODES..... | 175 |
| APPENDIX 10: CODE BOOK..... | 177 |
| APPENDIX 11: REFLECTIVE DIARY EXTRACT..... | 179 |

EXECUTIVE SUMMARY

Overview

The mother-infant relationship and perinatal mental health

- The postpartum period covers the first year after birth and is when a mother learns to react to her baby's needs appropriately and develop a close and warm relationship with her infant (Perun, 2013).
- There are a range of parental psychological features that influence the nature and shape of an infant's internal working model and attachment, such as maternal sensitivity and mind-mindedness (Meins, Fernyhough, Fradley, & Tuckey, 2001), where a mother makes accurate inferences about her child's mental state.
- Perinatal mental disorders have been found to disrupt this process by mothers responding inappropriately to infant's needs (Bakermans-Kranenburg, van Ijzendoorn, & Juffer, 2003), not showing sufficient warmth and being unable to regulate infant distress (Murray, Halligan, Goodyer, & Herbert, 2010).
- Perinatal mental disorders can compromise the quality of parenting which has been found to increase the risk of psychological and developmental disturbances in children (Stein et al., 2014). This supports the need for psychotherapeutic interventions in perinatal mental disorders that focus both on the mother's mental health and the mother-infant interaction (Murray et al., 2010).
- NICE (2014) guidelines recommend specialist perinatal inpatient services for antenatal and postnatal mental health, where mothers and babies have access to

specialist perinatal mental health staff and a full range of therapeutic services focused on the mother-infant relationship.

Postpartum psychosis

- Postpartum psychosis is considered the most serious type of perinatal mental disorder that typically occurs in the days following childbirth and should be considered a psychiatric emergency (Heron et al., 2012).
- Postpartum psychosis occurs in one to two in every thousand births (Munk-Olsen, Laursen, Pedersen, Mors, & Mortensen, 2006) and more than 50% of women who develop postpartum psychosis have no mental health history (first onset postpartum psychosis; Blackmore et al., 2013). Women with bipolar disorder however have a 25% risk of developing postpartum psychosis (Jones & Craddock, 2005).
- First onset postpartum psychosis has been associated with treatment delay due to misdiagnosis (Edwards & Timmons, 2005) and higher levels of confusion and disorientation (Kirpinar, CosLkun, Çayköylü, & Özer, 1999). This population however tend to have shorter hospital stays (Kirpinar et al., 1999), better treatment outcomes (Jones, Chandra, Dazzan, & Howard, 2014) and substantial improvement in mother-infant interaction at recovery (Thiels & Kumar, 1987). Current research does not differentiate outcomes between women at risk of postpartum psychosis and first onset (e.g. Hornstein et al., 2006; Noorlander, Bergink, & van den Berg, 2008).
- Mothers with postpartum psychosis have been observed to show dysfunctional cognitions, poor insight and difficulties understanding their child's needs

(Murray, Cooper, & Hipwell, 2003), as psychotic symptoms contribute to poor concentration, fatigue and agitation (Hornstein et al., 2006). These symptoms are likely to affect bonding between mother and baby, which the present study aims to explore.

- Maternal responsiveness is also affected by how women experience motherhood, which has been described by women who have experienced postpartum psychosis as traumatic due to the disruption and confusion experienced by mothers (Heron et al., 2012).

Systematic review

- A systematic review was conducted to explore the impact of postpartum psychosis in the postpartum period on the mother-infant relationship, looking at both quantitative and qualitative articles.
- Empirical studies investigating the mother-infant relationship in postpartum psychosis were included. Five online databases (PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycEXTRA, Medline) and references of included studies were searched. Study characteristics, participant demographics, methods and results were extracted for both quantitative and qualitative papers. Five studies were assessed for quality and narrative synthesis was conducted.
- Findings showed that mother-infant bonding and interactions were not significantly impaired in mothers with postpartum psychosis compared to women with postnatal depression.

- Qualitative findings on the other hand highlighted the difficulties women experience caring for and interacting with their baby due to their psychotic symptoms when experiencing postpartum psychosis.
- Data gathered within this review is representative of mothers when they are acutely unwell and does not explore longer term relationships, which would provide further valuable information.
- Women with longstanding mental health difficulties, such as bipolar disorder, are also grouped with women with no previous mental health difficulties. Separating these groups of women would be beneficial in future research to understand what these experiences are like for different populations of mothers.

Empirical paper

- The empirical study used a retrospective qualitative design to explore mothers' experience of first onset postpartum psychosis and the mother-infant relationship using semi-structured interviews.
- Seven women were recruited from NHS perinatal mental health teams and Action on Postpartum Psychosis (APP); a network of women throughout the UK who have experienced postpartum psychosis which is involved in research, information sharing and peer support for women and families.
- The semi-structured interview schedule aimed to capture information about the mother's feelings towards her infant and her role as a mother sequentially from pregnancy, birth, the postpartum period, to onset of postpartum psychosis and through to recovery and present time. Service user consultation was used in developing the interview schedule.

- Thematic analysis was the chosen methodology due to the limited focus of previous research on first onset postpartum psychosis and the mother-infant relationship and the aim to develop an initial understanding of this relationship.
- Women in this sample had a mean age of onset of postpartum psychosis of 32 years, with an age range of 28-38 years. All participants were with the same partner since diagnosis, despite one who was going through a separation at the time of interview. Four participants were white British, one was white Other, one was black British, and one was black African. One woman had a child prior to postpartum psychosis, one woman had a child before and after postpartum psychosis, and one woman had another child after postpartum psychosis.
- Three women were admitted to mother and baby units, two women were admitted to general psychiatric wards and two women were first admitted to general psychiatric wards followed by a mother and baby unit.

Results

- Seven core themes and 11 subthemes emerged from the interview data:
 - *Expectations vs. reality of motherhood* refers to women expecting having a baby to be a joyful time and this being disrupted by postpartum psychosis; *what's going on* illustrates how women had no knowledge of postpartum psychosis and not understanding their symptoms and experiences.
 - *The barriers to caring for my baby* is how women felt towards their baby during their experience of postpartum psychosis: *wanting to breastfeed vs. needing medication* was deemed important to all women and was disrupted by medication and separation from the baby. *Why are you taking me from my baby?* is when women were admitted to general psychiatric wards

without their baby and specialist perinatal mental health provisions were not available to facilitate joint admission. *You cannot break our bond* is how women felt about their child during their experience of postpartum psychosis.

- *What's comes with postpartum psychosis* refers to what mothers wanted others to understand about postpartum psychosis; describing their experiences of *the terror of the world, the confusion of reality* and *the depression that follows* that commonly follows an episode of postpartum psychosis.
- *Where the system fails and thrives* refers to the perceived poor care received by mothers admitted to general psychiatric wards or having their symptoms and concerns dismissed by professionals (*the negatives of generic care*) and how women valued the mother and baby unit and being listened to and supported by specialist perinatal mental health staff (*the positives of specialist provisions*).
- *Let's talk about postpartum psychosis* emphasises women's concerns for the lack of knowledge and understanding about the illness within antenatal and perinatal care, and the stigma associated with a perinatal mental disorder.
- *Support* highlights circumstances where some women did not feel supported by healthcare professionals at the time of postpartum psychosis and the postpartum period (*where support should come from: the healthcare system*) and the values women place on their partners and families helping them during this time (*where support does come from: partners and family*).
- *Making sense of it* lastly refers to how women reflect on their experience and what they would want others to know about postpartum psychosis.

Conclusions

- Women with first onset postpartum psychosis did not feel this experience has long-term effects on the mother-infant relationship. Although they note disruptions when they were acutely unwell, they did not report difficulties with bonding or caring for their baby. Women maintained their role as a mother and continued to care for their baby with support from specialist perinatal mental health staff, partners and families.
- Depression following postpartum psychosis was reported to be detrimental to the mother-infant relationship, with women feeling that this affected how they bonded with and cared for their infant.
- All women felt that understanding of and care for postpartum psychosis needs to be improved. The Maternal Mental Health Alliance (MMHA) launched the ‘Everyone’s Business’ campaign in 2011 for all women in the UK to get “consistent, accessible and quality care and support” for their antenatal and perinatal mental health. Study findings highlight the need for further research to inform improvements in perinatal mental health care and the strengths of specialist perinatal mental health provisions.

Integration, impact and dissemination

- Systematic review findings support the need to separate groups of mothers by diagnosis and the focus of the empirical paper on first onset postpartum psychosis. Mixed evidence about how the mother-infant relationship is affected by postpartum psychosis required further exploration of the meaning of this to mothers’ themselves.

- Women report that awareness of postpartum psychosis and the possibility of developing depression following this should be raised in the healthcare field, particularly in antenatal and perinatal care. All women felt that systems around the mother and baby needed to be aware of what postpartum psychosis feels like to provide appropriate support. It would be useful to find out more about what staff training consists of in perinatal mental health and inform teaching through service user involvement.
- The positive experiences of the mother and baby units and negative experiences of being cared for in general psychiatric wards highlights the value of specialist services and the need to fund and preserve perinatal mental health provisions. It may be useful for specialist staff to offer consultations to general mental health practitioners supporting mothers with postpartum psychosis.
- The need to support partners during postpartum psychosis was also reiterated. This supports recommendations for perinatal mental healthcare providers to establish care plans with a therapeutic and pharmacological component, considering the partner, supporting the mother, and their relationship (Holford, 2016).
- Accessibility of information on discharge from the labour ward and mother and baby units about developing any perinatal mental health problems needs to be implemented. Normalising symptoms and concerns and providing mothers with support groups, numbers and forums is an effective way of doing this. Providing leaflets through antenatal and perinatal checks would be useful.
- Publication of research findings will focus on journals read by midwives, nurses and mental health professionals. Commissioners of relevant reports and

perinatal mental health conferences will also be targeted. NHS teams involved in recruitment for the empirical study and APP will too be platforms for dissemination of findings.

How does postpartum psychosis affect the mother-infant relationship: A systematic review

ABSTRACT

Objective: Postpartum psychosis is considered the most serious mental health disorder a mother can develop after childbirth; affecting 1-2 in every 1000 births. Research shows that children exposed to early adverse experiences, which affect bonding and attachment, are at increased risk for the development of depression, anxiety and other stress-related disorders during adolescence and in adulthood. The aim of this systematic review was to assess evidence exploring the mother-infant relationship in the context of postpartum psychosis.

Methods: Empirical studies investigating the mother-infant relationship in postpartum psychosis were included. Five online databases (PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycEXTRA, Medline) and references of included studies were searched. Study characteristics, participant demographics, methods and results were extracted for both quantitative and qualitative papers. Five studies were assessed for quality and narrative synthesis was conducted.

Results: Findings produced mixed results about the mother-infant relationship in postpartum psychosis. Quantitative studies showed that bonding and interactions were not significantly impaired in this group of mothers compared to women with postnatal depression, yet qualitative findings highlight the difficulties women experience caring for and interacting with their baby due to their psychotic experiences and symptoms. There were exceptions within qualitative samples however where bonding was not

deemed to be affected. Data gathered within this review are representative of mothers when they were acutely unwell and does not explore longer term relationships. Women with longstanding mental health difficulties, such as bipolar disorder, are also grouped with women with no previous mental health difficulties. Separating these groups of women would be beneficial in future research.

Conclusions: There are mixed findings about the impact of postpartum psychosis on the mother-infant relationship. Impairments to interaction and bonding are not significant when compared to women with postnatal depression, yet subjective reports highlight the difficulties mothers experience themselves of caring for their baby when experiencing postpartum psychosis. Future research is required to explore longer term effects of postpartum psychosis on the mother-infant relationship. It is important to differentiate mothers experiencing postpartum psychosis as a first presentation of mental illness compared to women with longstanding diagnoses. Overall, postpartum psychosis is subjectively reported to negatively impact on the mother-infant relationship, but impairments in mother-infant interaction are not significant.

INTRODUCTION

The following review aims to assess the research into the mother-infant relationship during postpartum psychosis. Focus will first be drawn to the transition to motherhood and the experiences of early parenting, followed by what is known about disruptions to perinatal mental health. Information about postpartum psychosis and evidence about the impact of this diagnosis will then be outlined to guide the reader to the aims and methodology of this review.

Becoming a mother

Pregnancy, birth and parenting are considered a positive time for many women. However, the transition to motherhood can be challenging (Smyth, 2012) and between 10 and 20% of women suffer from mental health problems during this period (Ayers & Shakespeare, 2015). The sudden and unexpected changes to a woman's role, responsibilities and lifestyle lead many women to feel out of control in the early months of parenting, causing mood disturbances, such as stress and anxiety (Friedman & Resnick, 2009). The first three months in particular are often considered the most challenging, although this can extend beyond this period (Harries & Brown, 2017). There are often societal pressure for mothers to "get it right" and be a "good mother" (Rallis, Skouteris, McCabe, & Milgrom, 2014) and this extends to mothers being held accountable for the health and development of their child based on their early interactions (Smyth, 2012).

The perinatal period includes pregnancy and the first year after birth (Rallis et al., 2014). There are many important aspects of mothering in the child's early life which may be affected by a woman's adjustment to motherhood (Barrett & Fleming, 2011). These include the frequency and quality of the interaction, the warmth expressed by the mother, the level of physical contact and play, vocalisation with the baby, and visual reciprocity (Bornstein, Tamis-LeMonda, Hahn, & Haynes, 2008). Mother's responses demonstrate a shared relationship and enables the infant to understand their ability to communicate through expression of acceptance, affection, liking and caring (Barratt & Fleming, 2011).

Important elements of effective parenting include meeting the child's basic physical

needs, developing their social and cognitive skills and providing a secure and positive attachment (Gutman, Brown, & Akerman, 2009). The quality of parenting is enhanced by a mother's interpersonal sensitivity (Gutman et al., 2009), which is fundamental to the attachment relationship in the first year (Demo & Cox, 2000). Maternal sensitivity is a mother's responsiveness and attunement to her baby's needs, such as soothing distress and reading cues accurately and appropriately (Bornstein et al., 2006). These factors are particularly important during the first year of life when a sense of security is being developed (Gutman et al., 2009). The quality of the attachment of the mother-infant relationship is key in defining future relationships and the development of a child's personality (Gutman et al., 2009). Disturbances to a mother's psychological functioning negatively influence the quality of parenting (Gutman et al., 2009). Gutman et al. (2009) produced this report on parenting in the early years using an ongoing longitudinal study of 12500 families. Despite the large sample size, Gutman et al. (2009) state that families with lower socio-economic status are under-represented in their sample and that their findings generally represent families with higher-incomes and more highly educated mothers. Gutman et al. (2009) aimed to capture parenting using observational techniques to assess one-off mother-child interactions, which may not be illustrative of the fluid nature of parenting.

Mental health problems in the postpartum period commonly consist of anxiety, postnatal depression (PND), post-traumatic stress disorder following a difficult birth and stress-related conditions such as adjustment disorder (Ayers & Shakespeare, 2015). Severe postnatal mental illness such as postpartum psychosis (PPP) is less common; occurring in one to two in every thousand births (Munk-Olsen et al., 2006). Perinatal mental health awareness has increased in the UK in recent years following the

formation of the Maternal Mental Health Alliance (MMHA), which launched a campaign named ‘Everyone’s Business’ in 2011 (Ayers & Shakespeare, 2015). This highlighted the variation of perinatal mental health provisions across the UK and provided evidence that maternal mental health problems are associated with a variety of adverse outcomes for women and children. The evidence however focuses on postnatal depression, PTSD and anxiety (Ding et al., 2014; Yonkers et al., 2014). Ayers and Shakespeare (2015) in their editorial ‘*Should perinatal mental health be everyone’s business?*’ highlight that there are still gaps in our knowledge of perinatal mental health. The type of mental illness and whether it occurs pre or postnatally also influences the impact on the mother and child (Ayers & Shakespeare, 2015).

Postpartum psychosis

Postpartum psychosis is considered the most serious type of maternal mental health condition that typically occurs in the days following childbirth and should be considered a psychiatric emergency (Heron et al., 2012). Symptoms include the rapid onset of hallucinations, delusions, mania, bizarre behaviour, severe confusion, elated mood, and depression (Heron, McGuinness, Blackmore, Craddock, & Jones, 2008), which are accompanied by a lack of insight (Engqvist & Nilsson, 2013). Postpartum psychosis can take a year or longer to recover from (Sit, Rothschild & Wisner, 2006) and it is frequently followed by an acute episode of depression, symptoms of anxiety and mood swings (Heron et al., 2012). Changes to classification systems meant that a postpartum onset was required for diagnosis of postpartum psychosis; within 4 weeks by DSM-IV (1994) and within 6 weeks by ICD-10 (1992). Postpartum psychosis was previously classified as “atypical psychosis” under “psychotic disorders not elsewhere

classified” and is now attached to mood disorders (Major Depression, Bipolar I or Bipolar II disorder) and brief psychotic disorder (Austin, 2010).

Postpartum psychosis can occur in women from all social classes, education levels, and occupational backgrounds (Heron et al., 2012). The illness is seen across different ethnicities, countries and cultures with constant rates reported transculturally (Robertson & Lyons, 2003). Women with a history of bipolar disorder have approximately a 25% risk of postpartum psychosis (Heron et al., 2012), and there is an estimated 50% risk of relapse in subsequent births in women with a previous episode of postpartum psychosis (Blackmore et al., 2013). The differential diagnosis for postpartum psychosis can include major depression with psychotic features, bipolar I, bipolar II, schizoaffective, unspecified functional psychosis, and brief psychotic disorder (Doucet, Dennis, Letourneau, & Blackmore, 2009). However, many women may experience mental health difficulties for the first time through the onset of postpartum psychosis. First time mothers are reported to be at greater risk of postpartum psychosis (Blackmore et al., 2006), although there are no confirmed explanations for this (Munk-Olsen, Jones, & Laursen, 2014). Research has suggested that avoidance of subsequent pregnancies could explain the proportions observed in primiparity (Munk-Olsen et al., 2014).). however, it is not uncommon for women to have other children prior to onset of postpartum psychosis (Munk-Olsen et al., 2014).

Support for postpartum psychosis

Postpartum psychosis often requires inpatient admission but has a good prognosis with a typically short-lived acute episode (Sit et al., 2006). There is a wide variation in

perinatal psychiatric care available which influences the impact of postpartum psychosis on the mother-infant relationship (Heron et al., 2012). Some women may be admitted to a specialist mother and baby unit (MBU) whilst others are cared for in general psychiatric wards without their baby or in regions away from their home and family (Heron et al., 2012). National Institute for Health and Care Excellence (NICE) guidelines (2014) state that women who require inpatient care for a mental health problem within the first year of childbirth should be admitted to a specialist mother and baby unit unless there are specific reasons for not doing so.

Mother and baby units provide inpatient psychiatric care for mothers and their infants up to a year after childbirth (Gillham & Wittkowski, 2015). Evidence shows that separating mother and baby within the first year can have a negative impact on the attachment relationship (Main, 1958). Joint admission enables observation of mother and baby and ongoing risk assessment. Mother and baby units are commissioned not only to stabilise the mother's mental health but to also support the mother-infant relationship (Gillham & Wittowski, 2015). Postpartum psychosis can be perceived as having significant consequences due to its timing and separation of mother and baby from the family (Wyatt, Murray, Davies, & Jomeen, 2015). Women suffering from postpartum psychosis have reported to feel guilty about the effect of their illness on their families. Mothers have expressed guilt that their babies were in a psychiatric hospital being cared for by staff rather than themselves or their family and were concerned about the impact of hospitalisation on the child's development (Robertson & Lyons, 2003). Women felt that they had lost out on the experience of motherhood through not caring for their baby, or in some cases being unaware that they had a baby due to their psychotic symptoms (Robertson & Lyons, 2003). Although mothers often

return to high levels of social and occupational functioning (Pfuhmann, Stoeber, & Beckmann, 2002) further distress is commonly experienced outside of the postnatal period (Nager, Szulkin, Johansson, Johansson, & Sundquist, 2013) which has been found to lead to potential marriage breakdown following postpartum psychosis (Blackmore et al., 2013). This negative impact on relationships may be linked to a lack of mental health awareness (Glover, Jomeen, Urquhart, & Martin, 2014) as partner support has been found to be a moderating factor to length of maternal hospitalisation (Grube, 2005). Support provided by friends and family can also promote positive reappraisal of relationships during this period (Robertson & Lyons, 2003).

Aims

The present review aims to explore the mother-infant relationship in postpartum psychosis as the postpartum period is a vital time for the development of the mother-infant relationship. The mother-infant relationship consists of the mother caring for and interacting with her baby, which facilitates mother and baby bonding. How a mother parents has been found to influence a child's development from babyhood to late adolescence (Gutman et al., 2009). Research shows that children exposed to early adverse experiences, including those related to bonding and attachment, are at increased risk for the development of depression, anxiety and other stress-related disorders in adolescence (Herrenkohl et al., 2010) and adulthood (Putnam, 2003). Evidence has also shown that postpartum psychosis can affect the psychological and intellectual development of the infant as well as other children in the family (Brockington, 2004; Hornstein et al., 2006; Philipp, Fivaz-Depeursinge, Corboz-Warnery, & Favez, 2009). This paper aims to identify and systematically review the existing evidence around

postpartum psychosis and the mother-infant relationship. It is hoped that this will guide future research and inform psychological understanding of the impact of postpartum psychosis on this relationship by answering the following question: *What effects does postpartum psychosis have on the mother-infant relationship in the postpartum period?*

METHOD

Search strategy and selection of studies

A systematic search was conducted on 27th October 2017 using five databases: PsycINFO, PsycARTICLES, Psychology and Behavioral Sciences Collection, PsycEXTRA and Medline. Eligibility criteria included (1) published journal articles and unpublished dissertations, (2) research written in English language, (3) sample of mothers with a self-reported diagnosis of postpartum psychosis or based on DSM-IV or ICD-10 classification systems, (4) study outcomes that refer to the mother-infant relationship when mother was acutely unwell (e.g. bonding, interactions, caring for baby), (5) research published from 1992 to include DSM-IV (1994) and ICD-10 (1992) diagnostic changes, (6) both quantitative and qualitative designs were included in this review to gain a rich understanding of the literature.

Databases were searched using the following search terms:

1. Terms relating to diagnosis (*postpartum psychosis* OR *puerperal psychosis* OR *postnatal psychosis* OR *psychosis*). This was applied to the Title field.
2. Terms relating to the target population of mothers (AND *mother** OR *parent**)
3. Terms relating to infants (AND *child** OR *bab** OR *infan**)

4. Terms relating to the relationship being explored (AND *relation** OR *interact** OR *bond**).

Search terms for mothers, infants and relationship were applied to the Abstract field.

Exclusion criteria for these articles included:

- 1) Diagnoses not including psychotic experience, e.g. postnatal depression, postpartum obsessive-compulsive disorder
- 2) Risk factors for developing psychosis rather than outcomes of psychosis, e.g. genetics, pregnancy and birth complications
- 3) Child(ren) with psychosis
- 4) Fathers with psychosis
- 5) Treatment and theories of psychosis, e.g. medication and biology of psychosis
- 6) Non-empirical papers

Quality appraisal

An important element of reviewing literature to answer a specific question is to consider the quality of the research contributing to the findings. The Quality Assessment Tool for Studies with Diverse Designs (QATSDD; Sirriyeh, Lawton, Gardner, & Armitage, 2011) was used to quality appraise the selected articles as these included both quantitative and qualitative methodologies. The QATSDD was developed to assess both qualitative and quantitative designs exploring similar areas of research. The QATSDD has been reviewed through the development of the tool and has shown good face validity, substantial inter-rater reliability ($k=71.5\%$) and good to substantial test-retest reliability (Sirriyeh et al., 2011).

RESULTS

One hundred and seventy-seven articles were initially found, and 116 articles remained when duplicates were removed. Initial screening of titles and abstracts removed 95 citations based on articles not meeting inclusion criteria. Twenty-one articles were then read in full and a further 19 citations were excluded based on not meeting inclusion criteria; specifically, for not exploring the mother-infant relationship within an empirical framework (see Figure 1). Three additional articles were then included in the study selection (Engqvist et al., 2011; Engqvist & Nilsson, 2013; Hornstein et al., 2006). These articles were included based on checking references of included articles and the relevance of papers to the review question.

Data extraction

A total of five papers were identified for inclusion in this review (Figure 1). These papers all explored the mother-infant relationship in postpartum psychosis; looking at caring for the baby, bonding and interaction. The following items were selected for the process of data extraction: country of research, sample size, diagnosis of participants, method of diagnosis, recruitment setting, age of mother, relationship status and number of children; with quantitative papers presented first followed by qualitative papers (Table 2). Separate tables present information about the method and results of the final papers, separated by quantitative (Table 3) and qualitative design (Table 4).

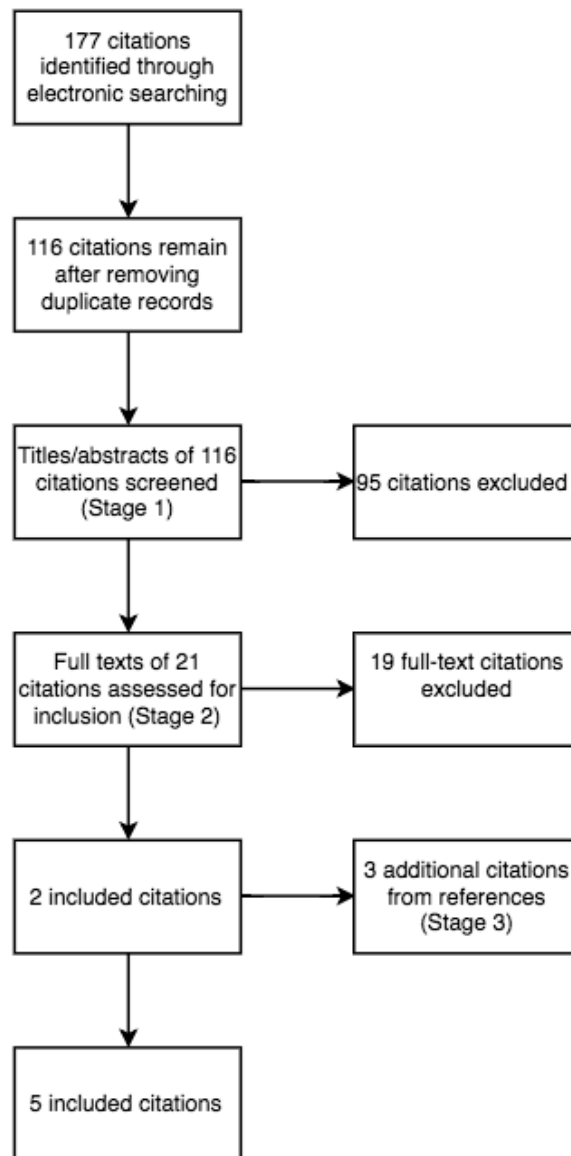


Figure 1: PRISMA diagram detailing study selection

Data synthesis

As this review incorporated both quantitative and qualitative papers, a narrative synthesis was used to develop a collaboration of findings and explore relationships in the data, whilst assessing robustness of the synthesis. This involves exploring relationships within and across included studies, and how relationships have been identified and analysed which is critical to the quality of the process of narrative

synthesis. The benefits of using narrative synthesis involve developing an understanding of which aspects of an intervention may link to its success and investigating theoretical variables. This enables conclusions to be drawn with an overall assessment of the strength of the evidence provided (Popay et al., 2006). Narrative synthesis requires studies to be organised meaningfully; in this case, by study design due to the use of different reports of methods and outcomes.

Characteristics of participants

This review is based on a sample of 95 participants. Primary diagnoses included postpartum psychosis (63%) and postpartum depression (37%; 4% depression with psychotic symptoms). Where papers have reported on samples other than postpartum psychosis (e.g. comparing outcomes of the mother-infant relationship in postnatal depression and postpartum psychosis; Hornstein et al., 2006; Noorlander et al., 2008), characteristics and outcomes related to the postpartum psychosis sample only are recorded within this review. Within the postpartum psychosis category, 43% had specified that there was no previous psychiatric history prior to onset of postpartum psychosis (Table 1). The relationship status of participants and number of children was not consistently recorded, but papers that have included these demographics represent mothers who are single, with a partner and separated, and mothers with one or more children. One of the studies spoke to partners and next of kin of women with postpartum psychosis as well as mothers themselves (Engqvist & Nilsson, 2013) and two papers compared mothers with postpartum depression and mothers with postpartum psychosis (Hornstein et al., 2006; Noorlander et al., 2008).

Table 1: Summary of papers included and demographic characteristics of samples

| AUTHORS | COUNTRY, SETTING | SAMPLE SIZE (n), MEAN, AGE (range) | DIAGNOSIS, DIAGNOSIS CRITERIA | RELATIONSHIP STATUS | NO. OF CHILDREN |
|-----------------------------|---------------------|--|---|--|---|
| <i>QUANTITATIVE:</i> | | | | | |
| Hornstein et al. (2006) | Germany, MBU | 35 32.5 years (22-43 years) | 18 Postpartum depression 17 Postpartum psychosis DSM-IV & ICD-10 | 4 single 12 with partner 1 other | 6 first child (17%) |
| Noorlander et al. (2008) | Netherlands, MBU | 25 31.7 years * | 13 Postpartum depression 12 Postpartum psychosis 7 bipolar disorder relapse 6 first presentation bipolar (8 no psychiatric history) | 12 cohabiting | 11 first child (44%) 1 >one child |

| | | | |
|-------------------------------|-----------------|----|------------------------|
| <hr/> | | | |
| <i>4 psychiatric history)</i> | | | |
| DSM-IV | | | |
| <hr/> | | | |
| <i>QUALITATIVE:</i> | | | |
| Engqvist et al. | USA, | 10 | Postpartum psychosis |
| (2011) | Internet sites | * | <i>All first onset</i> |
| | concerning | * | DSM-III and DSM-IV |
| | information, | | |
| | support, and | | |
| | assistance to | | |
| | women who | | |
| | have postpartum | | |
| | mood disorders. | | |
| <hr/> | | | |

Recruitment settings

All papers recruited women with postpartum psychosis; three of which recruited mothers who had been admitted to a mother and baby unit (Hornstein et al., 2006; Noorlander et al., 2008), two papers recruited mothers by other means of opportunity sampling from advertising on the internet and radio (Engqvist et al., 2011; Engqvist & Nilsson, 2013), and Plunkett, Peters, Wieck, & Wittkowski (2017) used both recruitment methods. All papers recruited from different countries, although ethnicity was not consistently reported across articles.

Quality ratings

Following instructions for using the QATSDD, percentage scores were calculated using the actual score and the maximum total score of 42 and reported in Table 2. Each of these items was scored 0 (not at all), 1 (very slightly), 2 (moderately) or 3 (complete)* with verbatim specific to each criterion as to how each score would be met. Papers scoring over 75% were considered “high” quality, those between 50% and 75% “good”, 25%–50% “moderate”, and below 25% “poor” (Sirriyeh et al., 2011)

Scores on the selected articles ranged from 62% to 86%, with a mean of 75% (Table 2), which suggests a selection of high-quality papers were included in this review. This indicates that the research within this review was conducted rigorously, which adds value to the findings of the included papers.

Table 2 *QATSDD scoring*

| | Hornstein et al. (2006) | Noorlander et al. (2008) | Engqvist et al. (2011) | Engqvist & Nilsson (2013) | Plunkett et al. (2017) |
|--|-------------------------------|--------------------------------|------------------------------|------------------------------------|------------------------------|
| Criteria (Rated 0-3*) | | | | | |
| Explicit theoretical framework | 3 | 2 | 3 | 2 | 3 |
| Statement of aims/objectives in main body of report | 2 | 3 | 3 | 3 | 3 |
| Clear description of research setting | 3 | 3 | 3 | 3 | 3 |
| Evidence of sample size considered in terms of analysis | 0 | 0 | 1 | 0 | 2 |
| Representative sample of target group of a reasonable size | 2 | 2 | 0 | 2 | 1 |
| Description of procedure for data collection | 2 | 3 | 3 | 3 | 3 |
| Rationale for choice of data collection tool(s) | 3 | 3 | 3 | 3 | 3 |
| Detailed recruitment data | 2 | 3 | 3 | 3 | 2 |
| Statistical assessment of reliability and validity of measurement tool(s) (<i>Quantitative</i>) | 0 | 3 | / | / | / |
| Fit between stated research questions and method of data collection (<i>Quantitative</i>) | 3 | 3 | / | / | / |

| | | | | | |
|--|------|------|------|------|------|
| Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative) | / | / | 2 | 3 | 3 |
| Fit between research questions and method of analysis | 3 | 3 | 3 | 3 | 3 |
| Good justification for analytical process | 3 | 3 | 3 | 3 | 3 |
| Assessment of reliability of analytic process (Qualitative) | / | / | 3 | 0 | 3 |
| Evidence of service user involvement in design | 0 | 0 | 0 | 0 | 1 |
| Strengths and limitations critically discussed | 0 | 3 | 1 | 3 | 3 |
| TOTAL | 26 | 34 | 31 | 31 | 36 |
| PERCENTAGE SCORE | 62% | 81% | 74% | 74% | 86% |
| QUALITY RATING | Good | High | Good | Good | High |

Designs

Of the five studies, two used quantitative designs to explore the mother-infant relationship using psychometric measures (Hornstein et al., 2006; Noorlander et al., 2008; Table 3). Hornstein et al. (2006) and Noorlander et al. (2008) both used cross-sectional designs comparing postnatal depression and postpartum psychosis. Hornstein et al. (2006) developed a longitudinal therapy study and Noorlander et al. (2008) used repeated measures; testing participants at admission and discharge from a mother and baby unit. The remaining three studies used qualitative methods of semi-structured

interviews (Engqvist & Nilsson, 2013; Plunkett et al., 2017) and an exploratory qualitative design (Engqvist et al., 2011; Engqvist & Nilsson, 2013).

As studies have been separated by design when summarising results, the following sections will first cover the psychometric measures used within quantitative papers, followed by quantitative findings. Qualitative findings will then be summarised before moving onto the discussion of the review.

Psychometric measures

The following psychometric measures were used to assess the mother-infant relationship within the sample of quantitative papers selected in this review:

Objective measurement of mother-child interaction

The objective measurement of mother-child interaction (MCI) used by Hornstein et al. (2006) involved observing mothers and infants in a video laboratory engaging in a standardised nursing and play situation. This was used to assess different aspects of the mother and child relationship. Based on these observations, maternal responsiveness and interactive behaviours were coded by a trained rater who was blind to participants' diagnosis (postnatal depression or postpartum psychosis). Maternal responsiveness was rated at 5-second intervals and included all behaviour conducted in response to the infant behaviour (vocal, facial or motor responsiveness) and no response when action was expected. Interactive behaviour was assessed at 30-second intervals and focused on the mother's style of interaction and how she provided appropriate stimulation, guidance and control to the child in the interaction. At every interval, a behaviour was

rated as either present or absent. More than one behaviour could be coded at the same interval, but no behaviour category was scored more than once for a given interval.

Bethlem Mother–Infant Interaction Scale

The Bethlem Mother-Infant Interaction Scale (BMIS: Hipwell & Kumer, 1996) was used by Noorlander et al. (2008). Noorlander et al. (2008) had nursing staff complete the BMIS to assess mothers with postnatal depression and postpartum psychosis interacting with their babies. The BMIS is used to assess the quality of interactions between mothers and infants who are admitted together to a psychiatric unit. The BMIS consists of seven subscales, the first four of which are observed from the mother to the baby: eye contact, physical contact, vocal contact, and mood; followed by general routine, physical risk to the baby, and the baby's contribution to the interaction.

Postpartum Bonding Questionnaire

The Postpartum Bonding Questionnaire (PBQ: Brockington et al., 2001) was the only outcome measure to be used in both quantitative studies (Hornstein et al., 2006; Noorlander et al., 2008). The PBQ was used to measure a mother's perception of bonding with her child. The PBQ is a well validated self-report measure designed to screen for disorders of the early mother-infant relationship. The questionnaire is particularly well validated for screening in postnatal depression (Noorlander et al., 2008) but there are no reports on its use for screening in postpartum psychosis.

The PBQ was used by both Hornstein et al.'s (2006) and Noorlander et al.'s (2008) to explore the mothers' experience of bonding. However, cut-off scores of the measure vary between Hornstein et al. (2006) and Noorlander et al. (2008), with exception for

the 'risk of abuse' scale, which was excluded from Hornstein et al.'s (2006) study as no association was found with any form of bonding disorders (Brockington et al., 2001). The change of cut off scores is based on a validation study by Brockington, Fraser, & Wilson (2006) where a revision of the thresholds aimed to improve sensitivity of the PBQ (Brockington et al., 2006). Results from Hornstein et al.'s (2006) may therefore be less sensitive than Noorlander et al.'s (2008) interpretations of the PBQ. However, there is no mention of the validity of measuring the mother-infant relationship in postpartum psychosis using the PBQ as there is for postnatal depression (Noorlander et al., 2008).

Hornstein et al. (2006) look specifically at bonding and interactions between mother and infant. They use the PBQ and objective measure of MCI, although do not state when video observations took place and whether mothers were aware of this. There is no mention of interrater reliability or internal consistency (Hornstein et al., 2006), although the rater was blind to the participants' diagnosis which adds validity to the results by controlling for this bias. The BMIS on the other hand, which was used by Noorlander et al. (2008), has demonstrated a very high internal consistency (0.93) and interrater reliability for the different scales ranging from 0.44 to 0.97 (Hipwell & Kumar, 1996). This may be viewed as a more naturalistic assessment as it is based on nurses' observations of mothers and infants admitted to hospital together.

Quantitative findings

Hornstein et al. (2006) explored differences in mother's subjective experiences of bonding and observed mother-child interactions of women with postpartum psychosis

and postnatal depression. Hornstein et al. (2006) discovered that psychotic mothers felt a good bond towards their children and did not hold feelings of inadequacy and self-doubt in comparison to depressed mothers. This may be mediated by fears around loss of custody and a lack of insight in postpartum psychosis, as responsiveness and other aspects of interactive behaviour, such as stimulation and intrusiveness, were observed to be impaired (Hornstein et al., 2006). Hornstein et al. (2006) found that nurses observed children of mothers with postpartum psychosis to avoid eye contact significantly more than children of mothers with postnatal depression. They also found that mothers with postpartum psychosis who felt well bonded with their child showed more overstimulation and motor responsiveness when interacting with their baby, which indicated greater efforts in interaction (Hornstein et al., 2006). This study suggests that it is the symptoms of the negative syndrome of psychosis, such as affect, drive and psychomotor activity that seemed to influence interactive behaviour, more so than positive psychotic symptoms which most of the participants were displaying at admission.

Nurses in Noorlander et al.'s (2008) study observed a trend in which mothers with postpartum psychosis may have more difficulties interacting with their child when acutely unwell. Women with postpartum psychosis were observed at admission to the mother and baby unit by nursing staff and tended to produce higher scores for all subscales of the BMIS. However, these scores were not significant and mothers with postpartum psychosis had lower scores on the BMIS at discharge compared to depressed mothers. No significant correlations were found between the PBQ and BMIS in the postpartum psychosis group, which highlights the difference in mother's

perceived bond with their infant and nurses' observations of the mother-infant interaction.

Table 3 *Methods and results of quantitative articles*

| AUTHOR | DESIGN | INTERVENTION: | RESULTS |
|-------------------------|--|---|---|
| | ANALYSIS | MEASURES | |
| Hornstein et al. (2006) | Cross-sectional. Bivariate analyses (chi-square for categorical variables and t-tests for continuous variables) to examine differences between diagnostic groups. | - 10-minute standardised nursing and playing situation of mothers and infants at video laboratory. - Standardised interview. - Clinical Global Impression (CGI: National Institute of Mental Health, 1970). - Social and Occupational Functioning Assessment Scale (SOFAS: Startup, Jackson and Bendix, 2002). | Psychopathology: Psychotic mothers had more previous admissions and lower SOFAS scores. <i>Subjective experience of bonding (PBQ):</i> Psychotic mothers scored lower on ratings of impaired bonding, rejection and anger, and anxiety about care than depressed mothers. |

| | | |
|--|--|--|
| <p>Spearman-rho correlations to determine the association between the subjective experience of bonding to the child and the objective assessed mother–child interaction.</p> | <ul style="list-style-type: none"> - Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I: Wittchen, Zaudig and Fydrich, 1997). - Positive and Negative Syndrome Scale (PANSS: Kay, Fiszbein and Opler, 1987). - Hamilton Depression Scale (HAMD-21: Hamilton, 1967). - Postpartum Bonding Questionnaire (PBQ: Brockington et al., 2001). | <p><i>Objective measurement of mother-child interaction (MCI):</i> Children of psychotic mothers showed significantly more avoidance of eye contact than children of depressive mothers.</p> <p>Psychotic mothers who scored low in the scales of the PBQ, indicating a non-impaired bonding to the child, showed more over-stimulation and more motor responsiveness.</p> |
|--|--|--|

| | | | |
|-----------------------------|---|--|---|
| Noorlander et al. (2008) | Cohort study | <ul style="list-style-type: none"> - Video intervention. - Feedback from nursing staff. - Therapy group for mothers. | <p>Women with PPP scored significantly lower scores on the PBQ in the first week of admission compared with women with PND.</p> <p>No significant differences in mother-infant interaction for PND and PPP at T1 or T2.</p> <p>Higher scores at T1 for PPP, higher at T2 for PND, as rated by nurses.</p> <p>No risk of abuse in PPP group.</p> <p>No correlations in PPP between PBQ and BMIS.</p> |
| | <p>Bivariate analyses, chi-square, independent t-tests, Spearman rho correlations</p> | <ul style="list-style-type: none"> - Bethlem Mother–Infant Interaction Scale (BMIS: Hipwell and Kumar, 1996). - PBQ. - CGI. | |

Qualitative findings

Having outlined quantitative findings, we will now review results from qualitative studies and how themes emerged. Engqvist et al. (2011) provide clear justification for all elements of their research and clearly consider issues of sincerity and credibility through employing four authors with different (albeit similar) backgrounds. Engqvist et al. (2011) explained the reasons for using cross-case analysis to identify similarities and differences across participants (Krippendorff, 2004) and content analysis for the substance of the narratives. The stages and purpose of each were outlined in detail. The internet narratives were described as rich and providing a deep understanding of postpartum psychosis (Engqvist et al., 2011). Credibility of this analysis was enhanced by providing background information about the research team and cross-checking results, this was further enhanced by a researcher external to the study also reviewing results. Direct quotations from the narratives were used to illustrate credibility and conformability.

Engqvist and Nilsson (2013) also used content analysis with a description of this process (Graneheim & Lundman, 2004) and justified their data collection and sample. Analysis was conducted by one psychiatric nurse with clinical experience of working with postpartum psychosis, which was described as a strength of the study (Engqvist & Nilsson, 2013). However, means to account for sincerity and credibility were not considered; there was no mention of member-checking or self-reflexivity in the process of collecting, analysing and interpreting data. Nonetheless, data were described as rich, credible and to meet conformability criteria, i.e. describing the set context (Engqvist & Nilsson, 2013).

Plunkett et al. (2017) on the other hand described clearly the steps taken to improve validity of their research; including member-checking, an audit trail of discussions and decisions, use of a reflective diary and personal biases of the research team. Plunkett et al. (2017) used inductive thematic analysis with a clear explanation and justification for this choice of analysis being owed to applying meaning to reality when there is limited pre-existing research in an area of interest (Braun & Clarke, 2013). Again, stages of analysis were outlined and details of who conducted this were provided. Issues of agreement were named, and 100% agreement was met on themes which enhanced transparency and trustworthiness of the analysis (Peters, 2010). Clinical implications were explicitly outlined, clarifying the significant contribution of this research and suggestions for future research in this area. Plunkett et al. (2017) have ensured that all items of the quality framework for qualitative research have been covered by their study which provides meaningful and useful research

Table 4 *Methods and results of qualitative articles*

| AUTHOR | DESIGN | THEMES | SUBTHEMES |
|------------------------|---|--|---|
| | ANALYSIS | | |
| Engqvist et al. (2011) | Inductive explorative qualitative design using cross-case analysis and content analyses of narratives online regarding PPP. | 1) Unfulfilled dreams 2) Enveloped by darkness 3) Disabling symptoms 4) Feeling abandoned | 1. Disappointment with the delivery 2. Inability to take care of the baby 3. Pervasive paranoia and guilt 4. Overwhelming fear 5. Being in an unreal world 6. Being controlled 7. Disorganized thinking 8. Feeling ill at ease 9. Loss of sleep 10. Self-destructive behaviour |

11. Lack of concentration
12. Distrust of everyone
13. Detachment from the baby and the world
14. Dissatisfaction with staff and care

| | | | |
|-----------------------------------|--|---|--|
| Engqvist and Nilsson (2013) | An exploratory qualitative design using content analysis of open-ended interviews. | 1) Shades of black with a ray of light | <ol style="list-style-type: none"> 1. Loss of sleep 2. Being in an unreal world 3. From a wanted baby to an unwanted baby 4. Infanticidal ideation 5. Suicidal ideation—a complete darkness |
|-----------------------------------|--|---|--|

| | | | |
|------------------------|--|--|--|
| Plunkett et al. (2017) | Qualitative: Semi-structured interview | <ul style="list-style-type: none"> 1) The baby has a role in recovery 2) The baby is a barrier to recovery 3) The baby facilitates recovery | <ul style="list-style-type: none"> 1. The baby increases emotional distress 2. The baby hinders getting help and self-care 3. The baby reduces emotional distress 4. The baby interacts with the mother 5. The baby increases self-efficacy |
|------------------------|--|--|--|

Qualitative themes

Of the three qualitative papers in this review, two used open-ended semi-structured interviews analysed by content analysis (Engqvist & Nilsson, 2013) and thematic analysis (Plunkett et al., 2017) and the other analysed narratives using cross-case analysis and content analysis (Engqvist et al., 2011). Of the eight core themes identified by these papers, mothers highlighted experiences of postpartum psychosis in the themes of *unfulfilled dreams, enveloped by darkness, disabling symptoms, feeling abandoned* (Engqvist et al., 2011) and *shades of black with a ray of light* (Engqvist & Nilsson, 2013). The influence of the baby during this period was illustrated in *the baby has a role in recovery, the baby is a barrier to recovery and the baby facilitates recovery* (Plunkett et al., 2017).

Qualitative findings illustrated a predominantly negative experience of postpartum psychosis and the effects this has on the mother and baby. What is evident from themes produced across studies is the focus on the mother and less attention drawn to the baby. Engqvist et al. (2011) and Engqvist and Nilsson (2013) depicted difficult experiences of the mother-infant relationship: *inability to take care of the baby, detachment from the baby and the world* (Engqvist et al., 2011), *from a wanted baby to an unwanted baby and infanticidal ideation* (Engqvist & Nilsson, 2013).

Engqvist et al. (2011) suggested that women with postpartum psychosis felt unable to care for their baby. Women felt unable to feed the baby, pick the baby up or bathe them, and required help from family and nursing staff. They also reported fear of harming the baby and acting impulsively on infanticidal thoughts, as well as fear of the baby being

taken from them. This led some women to never leave their baby and be reluctant to accept help from staff. Several of the women in Engqvist et al.'s (2011) study reported severe depression which prevented sleeping and eating, and all women reported anxiety and restlessness. Other reports included confusion of understanding the past and present, lack of concentration and forgetfulness, which are all likely to impact on availability and responsiveness to the baby. Women felt disconnected from their baby and detached from the world.

The women in Engqvist and Nilsson's (2013) paper described a range of thoughts and interactions with their baby. Some women reported being uncertain about whether the baby was theirs and having no desire to touch or kiss their child. One woman remembers not wanting her baby and not wanting to care for or embrace her baby. Another woman however explicitly states that she did not experience difficulties bonding with her baby. Next of kin noticed lack of baby talk and reported to observe hard callous treatment of the infant; one woman would not even look at her baby. Lack of joy from the newborn was noted by next of kin who felt that mothers had a changed personality which they did not know how to relate to. Several women had thoughts of harming their baby and their other children, and in the case when the partner knew, the mother was not left alone with her child. Women reported feeling guilt and shame, and this confusion and fear of personality change resulted in some women self-harming and trying to take their own life. Women described not thinking of their baby when dealing with their own suicidal thoughts.

Plunkett et al. (2017) focused their study on the role of the baby in the recovery of postpartum psychosis and discovered that interactions with the baby were viewed as

positive incentives towards recovery, although they could also be linked to emotional distress and anxiety due to the responsibility of caring for a newborn. This hindered recovery and impacted on the mother's capacity for self-care. Fear that they could not provide good enough care resulted in mothers distancing themselves from their baby. Societal expectations around mothering delayed some mothers from seeking help and mothers reported that the pressure to appear to be coping caused anxiety. Mothers also stated that the demands of getting better reduced their responsiveness to their baby's cues, which negatively impacted on their emotional wellbeing. However, as mother-infant interactions increased, bonding was enhanced. The realisation that they had bonded with their baby was crucial to many mothers' recovery. Mothers reported that professionals, particularly mother and baby unit staff, assisted with efficacy within the mother-infant relationship of both practical and emotional care.

DISCUSSION

This review is based on a small selection of articles, which limits findings and weakens conclusions. We will first discuss the quantitative methodologies and results, followed by qualitative methods and findings.

When compared with postnatal depression, mothers with postpartum psychosis were shown to display impaired interaction with their child through overstimulation and intrusiveness (Hornstein et al., 2006). However, mothers with postpartum psychosis still felt a good bond with their baby (Hornstein et al., 2006; Noorlander et al., 2008). Hornstein et al. (2006) suggested that the negative syndrome of psychosis has more of an impact on mother-infant reactions than the positive syndrome. The negative

symptoms of psychosis typically resemble similar symptoms of depression, which may further support arguments that depression is more detrimental to mother-infant relationships than psychosis (Noorlander et al., 2008). Further research is required in this area to draw conclusions however as Hornstein et al. (2006) only report administering the PBQ on admission, which represents mothers when they are acutely unwell only. Noorlander et al. (2008) overcome this issue by measuring mother-infant interactions at admission and discharge from the mother and baby unit and provide additional evidence that there is a favourable prognosis for postpartum psychosis compared to postnatal depression.

Postnatal depression can be harder to detect as symptoms are common of most postpartum women and considered to be normal (Doucet et al., 2009). Postnatal depression is often treated and monitored in primary health settings (only with a psychiatrist if resources permit) as opposed to postpartum psychosis which is typically treated in hospital (Doucet et al., 2009). Treatment of postnatal depression often involves psychosocial and psychological interventions, compared to mainly biological treatment of postpartum psychosis (Doucet et al., 2009). These are important factors to consider in understanding outcomes of postnatal depression and postpartum psychosis when comparing these disorders.

Research exploring experiences of postpartum psychosis without making comparisons to postnatal depression indicated that mothers did not regard their baby as important when they were psychotic (Engqvist et al., 2011). Themes and subthemes illustrated that postpartum psychosis can negatively influence the experience of the mother-infant relationship. It is important to understand how parenting and bonding are affected in

this population to provide effective support for mothers and to guide professionals working with postpartum psychosis (Dolman, Jones, & Howard, 2013). Research shows that early adverse experiences related to bonding and attachment puts children at increased risk for psychiatric difficulties later in life (Herrenkohl et al., 2010; Putnam, 2003). It is possible that negative feelings about the baby could be normalised for mothers, which can then be used to facilitate recovery in postpartum psychosis (Plunkett et al., 2017).

Engqvist et al.'s (2011) illustrated that mothers with postpartum psychosis felt unable to take care of their baby and required help from nursing staff or relatives. Women feared accidentally hurting the baby or acting on impulses of harming the baby, which left mothers being reluctant to handle the baby. Mothers avoided sharing these thoughts however through fear of their baby being taken away, which caused further anxiety. All women had delusions that something was wrong with their baby, that something could happen to their baby, and doubting whether their baby would live. Such feelings left mothers feeling remote from their baby. Based on analysing narratives from the internet, it is not clear what treatment this sample of women received. Research has shown that mothers are grateful for admission to a mother and baby unit. The mother and baby unit normalises women's experience of motherhood in the context of mental illness and the supportive staff relieves the overwhelming responsibility of becoming a mother experiencing high levels of fear and confusion (Chotai, 2016).

Despite overarching themes that perinatal mental health has a negative impact on the mother-infant relationship, there were exceptions within samples where women said they had strong bonds with their baby (Engqvist et al., 2011; Engqvist & Nilsson, 2013)

and had no negative feelings related to the baby (Engqvist et al., 2011). The detachment, disconnection and loss of interest in the baby in women with postpartum psychosis was related to mothers being lost in their psychotic world. This meant that women forgot about the baby, lacked concentration and were unable to respond to the baby (Engqvist et al., 2011) when they were acutely unwell. The reference to suicide attempts in this population was identified as mothers feeling that their family was better off without them (Engqvist et al., 2011), and the newborn baby was not given as a protective factor (Engqvist & Nilsson, 2013). Infanticidal ideation was also associated with fear of these thoughts and anxiety (Engqvist et al., 2011; Engqvist & Nilsson, 2013). The assessment of safety of the mother and child(ren) is therefore of highest priority (Doucet et al., 2009). Asking about suicidal and infanticidal thoughts should occur repeatedly as hallucinations and delusions can lead to thoughts of harming the self and the infant (Doucet et al., 2009). Rates of suicide and infanticide in this population are 0.2% completing suicide (Sit et al., 2006) and 4% of women completing infanticide (Spinelli, 2009).

Although all included studies explore the mother-infant relationship in the context of postpartum psychosis, many of the findings in this review draw focus on the mother's experiences of the mother-infant relationship without capturing the impact on the infant. When focusing on mother's experience of the baby in recovery, the baby was viewed as both a facilitator and a barrier to getting well. This highlights the focus of the mother's needs in postpartum psychosis rather than the developmental needs of the infant, which is ethically and clinically questionable.

Strengths and limitations of included articles

As this review aimed to understand more about the mother-infant relationship in postpartum psychosis, the following points identify areas of caution when interpreting findings from included articles.

Diagnosis

Not all articles specify whether women in their sample experienced first onset postpartum psychosis or if this presentation was linked to a previous diagnosis (Hornstein et al., 2006; Engqvist & Nilsson, 2013). This information is deemed important as women with first onset postpartum psychosis are reported to experience higher levels of confusion but have shorter stays in hospital (Kirpinar et al., 1999). Women with first onset postpartum psychosis have also been found to have better family and social support compared to women with a previous mental health diagnosis (Dolman et al., 2013). A diagnosis of bipolar disorder however is a risk factor for postpartum psychosis, with rates of approximately 25% in this population (Brockington, 1996). Women with bipolar disorder are therefore expected to be monitored more closely during pregnancy and in the postpartum period to detect symptoms early and act quickly (McElroy, 2004).

Nonetheless, women with a chronic psychotic illness, such as schizophrenia or bipolar disorder, are often living in socioeconomic disadvantage, are single parents and experience a lifelong struggle to cope with parenting (Chernomas, Clarke, & Chisholm, 2000; Diaz-Caneja & Johnson 2004). These different presentations have a different diagnostic, treatment and recovery process (Plunkett et al., 2017). For example, mothers with schizophrenia have previously been thought to have greater interaction deficits

with their infants (Riordan, Appleby, & Faragher, 1999). Kenny, Conroy, Pariente, Seneviratne, & Pawlby (2013) however have shown that appropriate support through video feedback intervention improves outcomes for mothers with schizophrenia and their infants. It is therefore important to capture information about how postpartum psychosis presents to ensure suitable interventions can be applied reliably to appropriate populations.

Recruitment

When trying to capture the mother-infant relationship, the majority of the selected studies recruited mothers from mother and baby units. These studies are expected to capture the very early stages of the mother-infant relationship as postpartum psychosis usually has an acute onset and typically occurs within 2-4 weeks of childbirth (Sit et al., 2006). This enables researchers to capture this vital early period of attachment (Stein et al., 2014) and the immediate effects of postpartum psychosis on the mother-infant relationship. It also provides information to inform NICE (2014) recommendations that mothers and their babies should be admitted to a specialist unit when acutely unwell and the value of mother and baby not being separated. However, only Noorlander et al. (2008) included a follow-up period assessing the mother-infant relationship in postpartum psychosis over two time-points. Hornstein et al. (2006) report to develop a longitudinal study but only mention the administration of a standardised interview and measurement of subjective experience of bonding to the child in the first week of admission to the mother and baby unit.

The remaining samples were recruited through opportunity sampling without a timeframe since postpartum psychosis, which raises issues of recall accuracy. The time

since postpartum psychosis ranged from 7-32 years in Engqvist and Nilsson's (2013) study. Evidence does however state that women remember high levels of detail about their experiences of postpartum psychosis regardless of time lapsed and women have expressed a need for this distance from diagnosis and treatment to be able to talk about their experiences (Engqvist & Nilsson, 2013).

Engqvist et al. (2011) used internet narratives as part of their exploratory design. These tend to be more detailed than verbal narratives, perhaps due to the sense of anonymity in sharing experiences through this medium, particularly with the stigma associated with mental health (Engqvist et al., 2011). This method removes issues around recruitment and attrition; providing a more reliable sample. Narratives meeting criteria for experiences of postpartum psychosis were also reviewed by three professionals; adding credibility to the selected sample (Engqvist et al., 2011).

Plunkett et al. (2017) invited women to take part in a semi-structured interview through online advertisement and recruitment from a mother and baby unit with the hope of recruiting mothers with a range of experiences at different stages of recovery. Plunkett et al. (2017) adapted their semi-structured interview based on mothers' feedback and comments, which is a strength of qualitative research methods being flexible and adaptable. It was also hoped that recruiting from the selected mother and baby unit would provide an ethnically diverse sample based on the characteristics of women admitted to the unit. However, inclusion criteria to participate in the study included being fluent in English, which limited accessing the ethnically diverse sample intended.

Quality appraisal

Although limitations exist within this review, a strength is the inclusion of published articles only, all falling within ‘good’ to ‘high’ quality appraisal based on the QATSDD. The detailed descriptive element of scoring articles using the QATSDD minimised researcher bias by clarifying how each criterion should be scored, which has substantial inter-rater reliability and test-retest reliability (Sirriyeh et al., 2011). However, scores were still selected by one researcher and reliability would have been improved by cross-checking to eliminate bias.

Demographic information

The breadth of information collected about participants’ demographics (Table 1) is another strength of this review. Demographic factors have previously been explored in the context of postpartum psychosis. Stein et al. (2014) for example have highlighted that the effects of perinatal mental disorders on child outcomes are mediated by recurrent or persistent exposure to the disorder, which is why it is important to capture information around diagnosis of postpartum psychosis. Obstetric factors have also been explored in risk of postpartum psychosis and consistently show a strong association with primiparity (Blackmore et al., 2006; Bergink, Lambregtse-van den Berg, Koorengevel, Kupka, & Kushner, 2011); underlining the need to capture number of children women have. Doucet et al. (2009) highlight that research regarding marital status of women with postpartum psychosis remains inconclusive; with some studies demonstrating married women are at higher risk (Kirpinar et al., 1999) and others suggesting unmarried women are more at risk (Nager, Johansson, & Sundquist, 2005). In addition, age of mothers at time of diagnosis is important as studies suggest that older first-time mothers are at greater risk of developing postpartum psychosis, with the

highest risk presenting between 40 and 44 years of age (Nager et al., 2005). Older age at pregnancy has implications in women waiting longer to have children (Doucet et al., 2009).

Future research

Based on this review and the conflicting conclusions drawn from a mix of quantitative and qualitative papers, it appears that more stringent search and eligibility criteria may be able to overcome such dilemmas. A key downfall of the search terms selected was that three of the five articles were sought from references from included papers. Systematic review guidelines suggest that key papers should be generated through initial searches, and not weighted from references of included articles (Boland, Cherry, & Dickson, 2017). This suggests that improvements could have been made to search terms used to prevent the selection of final articles being critiqued. However, several searches were run and due to the limited research in the field of postpartum psychosis, the final search terms were deemed most suited to answering the systematic review question, despite not initially generating key papers. On reflection, despite several alterations to search terms, more relevant articles may have been produced with the addition of *attach** within the search terms. It may also have been useful to include other terms related to the postpartum period, such as *post-birth* and *after-birth* to capture wider literature. These suggestions may be useful to consider for future systematic reviews in this area; search terms may need to continue to be adapted until key papers arise within initial search results. This can be seen as a limitation of the systematic review process and requires further attention for future research.

Future research may wish to focus on postpartum psychosis in the context of first onset or as a manifestation of bipolar disorder for example. Looking at specific populations may produce more reliable and generalisable information. There were also conflicting inclusion and exclusion criteria within studies, with some excluding schizophrenia for example and others including this diagnosis. This demonstrates the perceived differences across samples which needs to be considered when interpreting results and considering clinical implications and future research.

It may also be of value to look at either mothers' subjective experiences or the observed impact on the mother-infant relationship rather than grouping information together. Nurses and next of kin for example appeared to have different views of how mothers interacted and bonded with their children. This review provided important information about how mothers present and feel in the acute stages of being unwell, which is essential for providing appropriate clinical care and normalising experiences for mothers. By understanding how the healthcare system and family for example perceive postpartum psychosis, appropriate training and education can be provided so that this develops to fit more with women's subjective experiences and needs. Qualitative research lends itself to this type of investigation as it provides rich detailed data and can contribute to understanding how services can be improved (Dolman et al., 2013). NICE (2007) guidelines have specified that more research is required on "staff's views on the delivery of care" (Dolman et al., 2013).

Future studies would benefit from exploring longer term outcomes of the mother-infant relationship in postpartum psychosis and looking specifically at the impact of postpartum psychosis on the infant. Previous literature appears to have focused on this

in populations of postnatal depression but overlooked this in postpartum psychosis. Understanding the longer-term impacts of this diagnosis can again be used to educate others; mothers in particular may wish to know about the possible effects on their child and their relationship. Readministering outcome measures throughout stages of recovery is a possible way of exploring longer term effects.

Another limitation of this review is that conclusions reached by Hornstein et al. (2006) and Noorlander et al. (2008) are based on comparisons between mothers with postpartum psychosis and postnatal depression and do not include a non-clinical control group. A control group would have improved the reliability of the findings and specified how the mother-infant relationship may be affected compared to a non-clinical group. Sands (1995) for example found that mothers with serious mental illness regarded being a mother as the most important thing in their lives. This was compared to a group of well mothers who expressed ambivalence about their parenting role (Dolman et al., 2013).

As outlined, there are several suggestions for future research stemmed from this review. Further suggestions include research focused on the PBQ. As the PBQ was used in two of the papers exploring bonding in postpartum psychosis (Hornstein et al., 2006; Noorlander et al., 2008), it may be worthwhile validating this measure for this population. The PBQ is currently only validated for measuring bonding in postnatal depression (Brockington et al., 2001) but the value added from implementing this measure suggests that it can provide useful information about postpartum psychosis also.

Conclusions

Postpartum psychosis has been shown to have a negative influence on mothers' subjective experiences of their relationship with their child. Qualitative data suggest that mothers experience a great deal of distress in their experience of postpartum psychosis, which negatively impacts on their relationship with their baby and their role as a mother, although not universally. Mothers with postpartum psychosis experience anxiety around caring for and interacting with their baby and refer to postpartum psychosis as a dark and disruptive experience. However, it appears that using psychometric measures to compare postpartum psychosis to postnatal depression, postpartum psychosis does not have a significant impact on mother-infant interactions and bonding. This highlights the value of understanding individual experiences of postpartum psychosis and the mother-infant relationship from different samples of women and those involved in their care.

EMPIRICAL PAPER:

Mothers' Experiences of First Onset Postpartum Psychosis

ABSTRACT

Women are more likely to experience a mental health difficulty during the postpartum period than at any other time in their life. The most serious type of perinatal mental health disorder is postpartum psychosis. Bipolar disorder and a family history of postpartum psychosis are identified risk factors for development of postpartum psychosis, however 50% of women who receive this diagnosis have no prior mental health issues. The postpartum period covers the first year after birth, which is the time where a mother and baby start to develop a relationship. It is important to understand how disruptions caused by postpartum psychosis affects the mother-infant relationship, particularly in mothers with no expectations of becoming unwell. Women with first onset postpartum psychosis were interviewed about their experiences of becoming a mother. Using thematic analysis, themes which emerged drew on the wider context of postpartum psychosis in addition to the mother-infant relationship, although illustrated how being a mother with postpartum psychosis affected caring for the baby, what this experience was like for these women and how they received care and support. Mothers did not feel that postpartum psychosis affected their relationship with their child but did cause disruptions when they were acutely unwell due to fear of their baby being harmed, medication affecting breastfeeding and mother and baby being separated. Women tended to focus on their experiences of care during postpartum psychosis and the need for raising awareness of postpartum psychosis to assist understanding as a key area for supporting women and their families with postpartum psychosis.

INTRODUCTION

Motherhood

Motherhood is described as both a desirable and joyful experience (Johnston & Swanson, 2003) and a challenging and demanding life-role (Barbot, Crossman, Hunter, Grigorenko, & Luthar, 2014). As a mother learns to react to her baby, her individual style of mothering is forming. Establishing successful mother-infant interactions supports the development of the baby and the maternal identity of the mother (Perun, 2013). Attachment is developed from a caregiver's responsiveness to the child during their early experiences (Stein et al., 2014) and involves maternal sensitivity, where a mother is able to respond to her child's outward behaviour by making accurate inferences about the mental state behind that behaviour, referred to as mind-mindedness (Meins et al., 2001). A child's need for safety, security and protection are vital in infancy and childhood. Ainsworth (1969) showed that mother-infant relationships and attachment are formed during the baby's first year. However, perinatal mental disorders occur during this timeframe and the impact of these on the mother-infant relationship are an important area to be considered.

Effects of perinatal mental health on the mother-infant relationship

Inappropriate responses to attachment cues, disruptions to parental availability (Bakermans-Kranenburg et al., 2003) and capacity for mind-mindedness (Meins et al., 2001) are associated with attachment security. A child's emotional regulation and behaviour are negatively affected when a parent displays insufficient parental warmth, intrusiveness in stressful situations, and when there are difficulties with emotional scaffolding, which involves a parent regulating an infant's distress (Murray et al.,

2010). These factors have been observed in perinatal mental disorders to negatively impact on the mother-infant interaction; specifically, in schizophrenia and depression in the postpartum period (Steadman et al., 2007). Stein et al. (2012) found that parenting capabilities in postnatal depression and generalised anxiety disorder in the perinatal period may be affected due to disruptions to responding to the environment and therefore not responding contingently and appropriately to infant cues. Women in Stein et al.'s (2012) study however were primed to worry in an experimental design for a short period of time and observed briefly (infants were also looked after by an experimenter which may have increased infant distress), which reduces generalisability of these findings to more naturalistic settings (Stein et al., 2012).

Stein et al. (2014) found an increased risk of psychological and developmental disturbances in children when reviewing the literature of the effects of perinatal mental disorders on the foetus and the child. However, effect sizes for these associations were moderate or small and these outcomes therefore do not always develop in children of mothers with perinatal mental disorders. Stein et al. (2014) outlined that moderating factors such as low socioeconomic status, absence of support and persistent parental disorder increased adverse child outcomes in the context of perinatal mental disorders. Stein et al. (2014) suggest that understanding the quality of parenting and the relationship between specific parenting behaviours and different child outcomes is crucial. However, Stein et al.'s (2014) review was mainly focused on depression and anxiety disorders during the perinatal period, although did assess the evidence for bipolar disorder, other psychoses, personality disorders, and eating disorders. Stein et al. (2014) note that there is little research on these disorders in relation to child outcomes.

Wan and Green (2009) conducted a review to consider the evidence of the impact of maternal psychopathology on the mother and child attachment. Wan and Green (2009) aimed to explore attachment in mothers with depression and psychosis, although the review was weighted by mothers with depression. The review illustrated that untreated maternal mental illness has profound effects on the mother, infant and family, in relation to the child's attachment relationships. Wan and Green (2009) emphasise the need for further research to understand the role and consequences of the attachment relationship in maternal psychopathology and child development.

Considering the effects of perinatal mental disorders on the child, psychotherapeutic interventions addressing the mother's mental health needs alone have not been found to be effective in improving the outcome for the baby (Forman et al., 2007) or the mother-infant interaction when exploring early parenting in depressed mothers (Murray et al., 2010). The NICE (2014) guidelines for antenatal and postnatal mental health recognise the importance of specialist perinatal inpatient services for mothers and infants. Mother and baby units are expected to consist of specialist perinatal mental health staff and provide a full range of therapeutic services to address the mother-infant interaction and relationship, as supported by research by Kenny et al. (2013). Kenny et al. (2013) recruited a sample of mothers from a mother and baby unit with schizophrenia, depressive mood disorders with or without psychosis, and mood disorder where manic symptoms were present. Kenny et al. (2013) found improvements in the mother-infant interactions from targeted interventions on mother and baby units, suggesting successful treatment for a variety of disorders. However, their conclusions could not solely be attributed to the mother-infant intervention without considering the context of the therapeutic environment of the mother and baby unit as a whole (Kenny

et al., 2013).

Postpartum psychosis

Postpartum psychosis is considered the most serious type of perinatal mental disorder that typically occurs in the days following childbirth and should be considered a psychiatric emergency (Heron et al., 2012). Postpartum psychosis occurs in one to two in every thousand births (Munk-Olsen et al., 2006) and more than 50% of women who develop postpartum psychosis have no history that suggests they should be considered at risk of this perinatal mental disorder (Blackmore et al., 2013); it occurs “out of the blue” (Heron et al., 2012). Women with bipolar disorder however have a 25% risk of developing postpartum psychosis (Jones & Craddock, 2005). Please see Systematic Review Chapter (Page 21) for more details about the symptoms and experiences of postpartum psychosis.

Postpartum psychosis appears to arise independently of general environmental adversity (Murray et al., 2003) and can affect women from all social classes, education levels and occupational backgrounds (Heron et al., 2012). Postpartum psychosis often requires inpatient admission (Sit et al., 2006), and Jones et al. (2014) propose that the incidence of postpartum psychosis may be higher than reported due to some mothers being admitted with different diagnoses or being treated at home. In a review on postpartum psychosis, Sit et al. (2006) illustrated favourable outcomes for women receiving help within one month of delivery compared to those receiving help after a month postpartum. Sit et al. (2006) noted that the development of the mother-infant relationship in the context of perinatal mental disorders remains an under-researched

area. The present study aims to contribute to this; specifically focusing on women who develop first onset postpartum psychosis.

Research has shown that women with a first onset of mental illness in the postpartum period often experience higher levels of confusion and disorientation (Kirpinar et al., 1999) but show substantial improvement in their interaction with their infant at recovery (Thiels and Kumar, 1987). This group of women have been found to require half the time in hospital to achieve a treatment response compared to those with longstanding psychosis (Kirpinar et al., 1999), which is why it is important to differentiate women with longstanding psychotic illness from those women with the acute onset of psychosis in the postpartum period (Jones et al., 2014). Kirpinar et al., (1999) specifically looked at first onset postpartum psychosis in a rural region of Eastern Turkey. The aim of Kirpinar et al.'s (1999) study was to explore the clinical and demographic features of postpartum psychosis and the long-term course of the diagnosis. This study involved extracting information from case histories and then contacting patients for interview through their GP. This study employed a control group and researchers were blind to participant diagnosis, which adds validity to findings. However, researchers were aware that participants had received a mental health diagnosis which may have biased their interpretation. Findings from this study also lack generalisability as participants were mainly housewives living in rural Turkey. Nonetheless, this research provides preliminary information about first onset postpartum psychosis and contributes to an initial level of understanding about this phenomenon. Jones et al. (2014) in their review of the literature on severe mental illness in the postpartum period indicate that further research is vital to develop understanding

about disorders triggered by childbirth to provide appropriate treatment and identify women at risk. The present study aims to inform this gap in understanding.

Current research does not differentiate outcomes between women susceptible to postpartum psychosis, i.e. those with bipolar disorder, and those with first onset when exploring the mother-infant relationship in postpartum psychosis (e.g. Hornstein et al., 2006; Noorlander et al., 2008). Further details about this research can be found in the Systematic Review Chapter. The need to separate these populations is emphasised by Jones et al. (2014) who highlight that risk to children and involvement of social services is increased by a mother's psychiatric and personal history, particularly a diagnosis of schizophrenia. Hipwell and Kumer (1996) in developing the Bethlam Mother-Infant Interaction Scale (BMIS) to aid assessment and clinical decisions of parenting in perinatal mental disorders claimed that diagnosis is considered the most important single predictor of parenting outcome. Women who experience first onset postpartum psychosis are more likely to experience treatment delay due to misdiagnosis (Edwards & Timmons, 2005), shorter hospital admissions and improved treatment outcomes (Jones et al., 2014), compared to women with longstanding mental health problems. It is therefore necessary to separate these groups of mothers by diagnosis when exploring postpartum psychosis in consideration of treatment and outcomes.

The need to focus research specifically on first onset postpartum psychosis has been supported by the Royal College of Obstetricians and Gynaecologists, who produced a report *Maternal Mental Health – Women's Voices* (2011), which showed that women who had a history of mental health problems were more likely to be referred to perinatal mental health services; with figures showing 32% compared to 13% of women with no

mental health history. Women with a mental health history were also more likely to be referred to mother and baby units (17%) and specialist perinatal mental health services (45%) compared to 4% and 25% respectively of women with no previous diagnoses. Although women with psychosis had the highest referral rates (46%), 40% of women reporting psychosis were not given further support. These figures require further research to understand these treatment differences and make positive changes in perinatal mental health care. Qualitative research in particular lends itself to understanding experiences.

Research combining mothers with first onset postpartum psychosis and previous diagnoses has found that postpartum psychosis has been shown to involve dysfunctional maternal cognitions, poor insight and reduced awareness or understanding of the child's emotional and physical needs (Murray et al., 2003). Hornstein et al. (2006) suggest that the mother-infant interaction is affected as psychotic symptoms, poor concentration, fatigue, or agitation may be linked to mothers displaying more disorganised and poorer quality child care, and difficulties with sensitive and consistent responses to their child. As the postpartum period is the time for developing an emotional relationship between mother and baby, the bonding and interaction may be disturbed in mothers with postpartum psychosis as accessing the emotions of the self and others has been observed to be disrupted (Hornstein et al., 2006). The present study aims to provide details regarding this in first onset postpartum psychosis.

Hornstein et al. (2006) discovered that mothers with postpartum psychosis did not report impaired bonding with their child when compared to women with postnatal

depression; although this may be understood by lack of insight associated with postpartum psychosis. Significance of Hornstein et al.'s (2006) results can only be inferred when comparing postpartum psychosis to postnatal depression and would be more valid with the addition of a control group of mothers with no perinatal mental health difficulties. Abel, Webb, Salmon, Wan, and Appleby (2005) suggest that psychotic disorders in general have been found to have a higher negative impact on mother-infant bonding compared to depression or bipolar disorders in the postpartum period. The present study will explore bonding in first onset postpartum psychosis.

How women experience motherhood has an impact on the quality and intensity of maternal responsiveness. Women who have experienced postpartum psychosis have described their transition to motherhood as traumatic; experiencing a sense of loss, guilt, isolation and failure (Heron et al., 2012). Heron et al.'s (2012) research showed that the experience of postpartum psychosis was generally one of disruption, incoherence, and dissonance to one's sense of reality, identity, and expectations about the way the world works and the future of their recovery. This was based on qualitative evidence from mothers themselves with a sample representative of an active integrative recovery style, which suggests higher social functioning and improved outcomes (McGlashan, 1987) compared to women who avoid or minimise their experience (Heron et al., 2012). This study produced detailed descriptions of women's needs during recovery from postpartum psychosis, which can be implemented by healthcare professionals for the development of services and interventions (Heron et al., 2012). Again, this study drew conclusions from women's experiences in both the context of bipolar disorder and first onset postpartum psychosis, which the present study aims to

overcome to provide a clearer understanding specifically of first onset postpartum psychosis.

As outlined, postpartum psychosis is the most serious type of perinatal mental disorder. Fifty percent of women who experience postpartum psychosis experience this as first onset of mental illness. This population of women have been shown to display higher levels of confusion, to experience delays in treatment due to misdiagnosis and receive less support compared to women at risk of postpartum psychosis. Understanding what these experiences are like for women with first onset postpartum psychosis is essential to improving care and outcomes for these women and their families. There has been mixed evidence around how psychotic symptoms may impact on a mother meeting her baby's needs, which professionals need to know more about to provide appropriate support for mothers and babies. Research has also suggested that postpartum psychosis can change women's views of the world. This is likely to be more relevant to women experiencing this as first onset and also needs further exploration.

The present study

Much of the literature around maternal mental health does not refer to postpartum psychosis when investigating perinatal mental disorders, and a major focus has been on postnatal depression. Further research is required to help understand and improve treatments for women who experience postpartum psychosis (Jones et al., 2014) and this study aims to recruit mothers who have no previous mental health diagnoses prior to this.

In order to gain a detailed understanding of becoming a mother with first onset postpartum psychosis, a qualitative approach is the preferred methodology. A qualitative approach allows meaning to be gathered through data to gain a detailed understanding of experience and perspectives (Braun & Clarke, 2006). Qualitative research is increasingly recognised as valuable within health, social and public policy (Campbell et al., 2007). Understanding through exploration of deeper aspects of experiences are particularly useful when there is little previous research in an area as this can provide advanced knowledge (Campbell et al., 2007). Qualitative interviews are more sensitive to detecting aspects of experience or difficulties that cannot be measured by questionnaires or through observation of specific variables (Yardley, 2000) and they provide descriptive data from individuals (Ritchie, Spencer, Bryman, & Burgess, 1994). Specifically, thematic analysis is a flexible and useful research tool which aims to produce a detailed and complex account of data (Braun & Clarke, 2006). Thematic analysis involves identifying, analysing and reporting patterns within data.

As outlined, research exploring postpartum psychosis has not previously differentiated between women with previous mental health problems and a first onset diagnosis. Mixed evidence has been produced about the impact of postpartum psychosis and how this may affect the mother-infant relationship. Focus on this population is important as experiencing a perinatal mental health disorder “out of the blue” is likely to have different implications compared to a woman at risk of a perinatal disorder. In terms of the mother-infant relationship, women with first onset postpartum psychosis may experience prenatal bonding, which may lessen the impact of the disruptions to the mother-infant relationship when the mother is acutely unwell. This prenatal bonding may also make it easier for women to return to their role as a mother after experiencing

a psychotic episode. On the other hand, the unexpected occurrence of this experience may change women's beliefs about motherhood and the relationship with their baby.

Aims

Using semi-structured interviews, mothers who had recovered from first onset postpartum psychosis were asked about their experience of becoming a mother. The aims were to increase understanding of the mother-infant relationship in this population of women by asking women about their feelings towards their baby during the experience of postpartum psychosis and how they feel that their psychotic symptoms influenced their ability to care for and develop a relationship with their baby. This research aimed to answer the following question:

How do mothers with first onset postpartum psychosis experience their relationship with their baby?

METHOD

Design

This study used a retrospective qualitative design. Semi-structured interviews were designed, conducted and analysed using thematic analysis. Seven women who had experienced first onset postpartum psychosis were interviewed about their experiences of motherhood and relationship with their child.

Rationale for using thematic analysis

Thematic analysis is particularly suited to less researched areas and where views or experiences of a group are unknown (Braun & Clarke, 2006). Due to the limited focus of previous research on first onset postpartum psychosis specifically on the mother-infant relationship, thematic analysis was chosen as it involves searching across a data set to find repeated patterns of meaning (Braun & Clarke, 2006). In the case of this study, to inform an initial understanding of mother's experiences of the mother-infant relationship in first onset postpartum psychosis. Thematic analysis is a transparent method, which is often criticised as lacking in qualitative research, as it shows how conclusions and interpretations are drawn (Braun & Clarke, 2006). Thematic analysis enables research to generate data from which an understanding might be developed, rather than proving a hypothesis (Taylor & Ussher, 2001), and provides flexibility and accessibility to readers (Braun & Clarke, 2006).

Other qualitative methods were considered, but it was felt that thematic analysis was most suited to the aims of this research:

- Grounded theory aims to produce a situation-specific theory. Based on the lack of detailed research in first onset postpartum psychosis, initial steps should focus on generating themes that encapsulate the experience.
- Interpretative phenomenology analysis was considered, but again, the aim was to observe patterns and themes across women's experiences rather than focus specifically on how individuals interpret their experiences.
- The research also did not aim to explore language of participants and used an interview schedule to guide discussion, which ruled out appropriateness of discourse and narrative analysis.

This study came from a critical realist position which acknowledges individuals' meanings of experience within the broader social context, while retaining focus on the material and concept of 'reality' (Braun & Clarke, 2006). This study used both an inductive and deductive approach as coding was inductively data-driven whilst also attempting to extract data to answer the research question.

Ethics

Ethical approval was granted by an NHS Research Ethics Committee and Royal Holloway University of London. Research approval was received from the local NHS recruitment site's Research and Development Office. Professional guidelines regarding conduct and ethics were adhered to throughout the study (British Psychological Society, 2009; Health & Care Professions Council, 2012). Informed consent was gained at the beginning and end of all interviews and participants were informed of their right to

withdraw at any stage. Time to reflect was provided at the end of each interview and no concerns were raised.

Inclusion/exclusion criteria

Inclusion criteria required participants to be English speaking mothers who had recovered from a diagnosis of first onset postpartum psychosis. **Women were required to be recovered from postpartum psychosis to minimise risk management and be able to offer insight into their experiences without psychotic symptoms interfering.** Women were excluded if they had received a diagnosis of a serious mental health condition, such as bipolar disorder, prior to postpartum psychosis, **as this would not be considered first onset postpartum psychosis.**

Women recruited from NHS perinatal mental health teams had received a diagnosis of postpartum psychosis within the last 6-18 months. **This timeframe was set to improve recall of events whilst allowing time for recovery to improve validity of findings. This timeframe was later lifted through APP recruitment due to slow recruitment rates. In hindsight, it would have been more practical to have a timeframe of 6 months since diagnosis with no outer limit; as this prevented women identified by NHS sites to be contacted as they fell out of the 18-month window. NHS ethical approval however specified this inclusion criteria and could not be lifted through NHS recruitment sites; this therefore limited findings. As previous research has suggested that recall accuracy is not affected by time passed in women who experience postpartum psychosis (Engqvist & Nilsson, 2013), this should be considered for recruitment in future studies.**

A practical limitation excluded women who did not live within the London area due to conducting face to face interviews and not having ethical approval to offer phone or Skype interviews. The aim of the project was to recruit 6-10 participants, which is recommended for thematic analysis of small interview projects (Braun & Clarke, 2013), as this range is expected to produce enough data to illustrate patterns without being too much data to manage (Fugard & Potts, 2015). As the project did not have funding for the use of interpreters, English speaking women were only eligible for interview.

Procedure

Four women were recruited from NHS perinatal mental health teams. Potential participants were approached by staff members who provided Participant Information Sheets and requested consent to pass on contact details to the researcher, SK. Participants were introduced to the study and given opportunity to ask questions before agreeing to take part. A time and place for interview was then arranged. One woman despite agreeing to participate was not available to interview on three occasions arranged and contact was lost.

Three women were recruited from Action on Postpartum Psychosis (APP) Network via social media forums of Facebook and Twitter. APP is a network of women throughout the UK who have experienced postpartum psychosis. The network is involved in research, information sharing and peer support for women and families. An advert for the project was posted with contact details for researcher, SK, and potential participants could make direct contact to express interest in participation. Seventeen women expressed interest but did not meet eligibility criteria due to living outside of London;

ethical approval was not sought for phone interviews or to refund travel outside of London travel zones. However, three women did meet inclusion criteria.

Three women were interviewed at their homes, one woman was interviewed at the perinatal mental health team base, one woman was met at a local library and two women at a university site for interview. Participant demographic information was collected at the beginning of each interview (Table 1). Table 1 illustrates time since diagnosis, with all but one participant falling within a 5-year time frame, which suggests a strength of recall accuracy.

Table 1: Participants' Demographic Information

| Participant code | Ethnicity | Mother's age at onset of PPP | Age of infant when PPP diagnosed | Time since diagnosis (months) | Admission (Status) | Length of admission | Medication | Job status (before maternity leave) |
|-----------------------------|----------------------|---|---|--|--|--------------------------------|------------------------------|--|
| 01 | White British | 31 | Newborn | 16 | General psychiatric ward, MBU (Informal) | 2 weeks | Olanzapine | Teacher |
| 02 | White Other | 38 | 5 months | 11 | MBU (Section) | 2 weeks | Olanzapine | Secretary |
| 03 | White British | 28 | Newborn | 54 | 2 general psychiatric wards, MBU (Section) | 3 months | Olanzapine | Curator |
| 04 | White British | 31 | Newborn | 30 | Labour ward, | 8 days | Olanzapine Sertraline | Scientist |

| | | | | | | | | |
|----|----------------------|----|----------|----|---|----------|---|-------------------------------------|
| | | | | | general psychiatric ward (Informal) | | Haloperidol | |
| 05 | Black British | 28 | 7 months | 14 | 2 general psychiatric wards (Section) | 3 weeks | Olanzapine | Retail manager |
| 06 | Black African | 32 | 5 months | 17 | 2 MBUs (Section) | 2 months | Olanzapine | Maternity leave |
| 07 | White British | 33 | Newborn | 96 | MBU (Informal) | 3 days | Olanzapine Venlafaxine Citalopram Aripiprazole | Tele- communications engineer |

Interviews were audio recorded and lasted on average 59 minutes, ranging from 27-98 minutes. At the end of the interviews, women were provided with a Participant Debrief Sheet (Appendix 3), which outlined the study and provided contact details for support networks. No women withdrew from the study and no risk issues were raised throughout the duration of the study. A Risk Management Protocol (Appendix 4) was developed to manage risk if it arose during interviews.

Interview schedule

A semi-structured interview schedule was developed by the researcher, SK, which aimed to capture information about the mothers' feelings towards their infant and their role as a mother sequentially from pregnancy, birth, the postpartum period, to onset of postpartum psychosis and through to recovery and present time (Appendix 8). This timeframe was chosen as research has shown that the relationship between mother and infant starts before birth and highlights the importance of studying the very early mother-infant relationship and a mother's attitude towards her baby when assessing bonding (Taylor, Atkins, Kumar, Adams, & Glover, 2000). Darvill, Skirton, and Farrand (2010) explored psychological factors that impact on women's experiences of motherhood, and proposed that these adapted from pregnancy, labour, birth and the postpartum period. The semi-structured interview aimed to capture mothers' experiences across these stages of motherhood to get a sense of how the mother-infant relationship developed and how mothers reflect on this after recovery from postpartum psychosis.

The APP Network was contacted for service user consultation. A Trustee of APP volunteered to act as a service user consultant and identified another service user researcher to provide feedback on the interview schedule. Feedback focused on the wording of the interview schedule in asking sensitive questions about postpartum psychosis and highlighted the need to normalise the experience and the potential difficulties in eliciting clear memories of the event.

Recorded interviews were transcribed by SK. Each interview was listened to several times for transcription accuracy and familiarisation with the data. The first interview was also listened to by another researcher for feedback on interview style. Feedback and SK's observations highlighted the need to draw focus to the mother-infant relationship rather than description of postpartum psychosis. SK adapted this by making a disclaimer to participants about the need to bring attention to this without undermining or minimising the value of other information. This involved drawing mothers' focus to how experiences influenced their interactions with their baby and their role as a mother. It was important to expand on emotions and thoughts identified to get a sense of how these affected the mother-infant relationship.

Data Analysis

Based on Braun & Clarke's (2006) guide to using thematic analysis in psychological research, transcribed interviews were read several times and codes were generated throughout this process using NVivo database for qualitative research. Once all codes had been identified, themes were drawn and cross-checked by a researcher external to the study.

Reflexivity

It is understood that researchers enter research with their own assumptions and expectations, and interpretations of how participants present. This can lead to biases and preconceptions within the research (Holloway & Todres, 2003) which are important to be aware of. A reflective diary (Appendix 11) was used to record these opinions and feelings to improve rigour of thematic analysis (Vaismoradi et al., 2013). Researcher, SK, is a white British female Trainee Clinical Psychologist with no children of her own, although has a lot of experience of caring for young children and working in child and adolescent mental health services. This dynamic was important to consider when interpreting data and assisted with building rapport with participants due to shared personal and clinical experiences.

Personal expectations were that women would report difficulties in their relationship with their baby due to the struggle of being a new mother without the addition of a mental health problem. However, stigma around women speaking about the challenges of being a mother, particularly to someone without children of their own, may have biased women's reports for fear of being judged. A social desirability bias may have led the researcher to have a more positive view of what motherhood is like in the context of postpartum psychosis; with negative experiences being minimised. Alternatively, empathy from the researcher based on life experiences with the difficulties of motherhood appeared to enable more honest conversations about mother's struggles and difficult feelings. Knowledge based on previous research however, focusing on mothers' strong negative emotive responses to their babies in the context of postpartum psychosis, did not correspond with the experiences that were being shared within interviews of the current study. This again may have led to bias

interpretation of data due to wanting to highlight the opposing experiences compared to previous literature.

RESULTS

The following section illustrates the results of this study as themes and subthemes emerged from the interview data using thematic analysis. Women in this sample had a mean age of onset of postpartum psychosis of 32 years, with an age range of 28-38 years. Participant demographic information is presented in Table 1. All participants were with the same partner since diagnosis, except one who was going through a separation at the time of interview. At time of interview, one woman had a child before her experience of postpartum psychosis, one woman had a child before and after her experience of postpartum psychosis, and one woman went on to have another child after postpartum psychosis. Three women were admitted to mother and baby units, two women were admitted to general psychiatric wards and two women were first admitted to general psychiatric wards followed by a mother and baby unit. This sample represents a variety of ethnicities, a range of family set ups and a diversity of treatment received for postpartum psychosis, which widens generalisability of findings. All women in this sample however were supported by a partner at the time of postpartum psychosis and the age range is representative of average to older mothers (Office of National Statistic, 2016); results are therefore less representative of younger mothers and single parents.

Participants will be represented by codes and identifiable information has been removed to ensure anonymity of data; ‘...’ indicates where verbatim has been deleted. The seven interviews produced rich data which emerged as seven core themes and 11 subthemes. These are outlined in Table 2 and will be discussed in more detail below. Appendix 10 illustrates how themes and subthemes emerged from the codes from the data.

It was clear from conducting the interviews that women wanted their experience of care and support to be highlighted in understanding their experiences of being a mother with first onset postpartum psychosis. The majority of mothers interviewed spoke about their desire to protect and be with their baby when they were acutely unwell. All mothers spoke about their ability to continue to care for their baby during their psychotic experience and the appreciation of support from partners and family during this time. None of the women in this sample felt that they had difficulties bonding with their baby in relation to postpartum psychosis, although experiences of depression left women questioning the impact of this on their ability to care for and bond with their baby. These themes emerged in the process of interviewing and were consistent within the data.

Based on pre-conceptions of wanting to answer the research question about the mother-infant relationship in postpartum psychosis, it was valuable to have an external researcher to cross-check and discuss codes and themes. This highlighted potential bias of emerging themes linking to bonding and improved reliability of the data. As will be illustrated, the interview data have not solely provided detailed information specifically about the mother-infant relationship as mothers tended to report no concerns about this aspect of their experience of postpartum psychosis. It is possible that mothers felt unable to talk about difficulties in their relationship with their baby due to fear of stigma and social-desirability biases. Mothers instead drew on other elements of their experience and spoke about what they would like other women with postpartum psychosis to be aware of from a reflective and retrospective standpoint.

Table 2: Themes and subthemes of interview data

| Theme | Subthemes | | |
|--|--|--|------------------------------------|
| Expectations vs. reality of motherhood | <i>What's going on?</i> | | |
| The barriers to caring for my baby | <i>Wanting to breastfeed vs. needing medication</i> | <i>Why are you taking me from my baby?</i> | <i>You cannot break our bond</i> |
| What comes with postpartum psychosis | <i>The terror of the world</i> | <i>The confusion of reality</i> | <i>The depression that follows</i> |
| Where the system fails and thrives | <i>The negatives of generic care</i> | <i>The positives of specialist provisions</i> | |
| Let's talk about postpartum psychosis | | | |
| Support | <i>Where support should come from: the healthcare system</i> | <i>Where support does come from: partners and family</i> | |
| Making sense of it | | | |

Expectations vs. reality of motherhood

When interviewing mothers about their experiences from finding out they were pregnant through to present time, comparisons were frequently made to what they had expected motherhood to be like and how this was disrupted by postpartum psychosis. This was pronounced as none of these women had previously experienced mental health difficulties. Expectations of motherhood were typically painted in a positive light, with postpartum psychosis taking this away. This disruption was reported by both first-time mothers and those who already had children, who were able to make comparisons based on real experiences with their previous children.

“You know, you have this sort of idea of what motherhood is going to be like, and then this, you have this horrible event that replaces what should be a really happy time.”

(Participant 04)

Data emerging within this theme felt unsurprising from a personal and clinical point of view, as this would be how many may expect women to experience such a disruption in the postpartum period. This also highlights the societal view of motherhood being a happy and joyful time and how mothers expected to be able to cope with a new baby.

What’s going on?

The disruption of women’s expectations of motherhood led to the subtheme ‘*what’s going on?*’ as all women spoke about having never heard of postpartum psychosis before their diagnosis, which meant that they could not understand their symptoms and recognise warning signs that they were becoming unwell. This was observed through

the duration of this study when speaking to others clinically and personally, including many mothers who had not heard of postpartum psychosis. Many people often thought this related to postnatal depression. Two women said that postnatal depression had been mentioned in antenatal classes, but none had been told about postpartum psychosis during their antenatal care. Women felt a sense of being let down by the system based on this lack of awareness for them and their families.

“...I get angry that the NCT don’t cover it, cos they talk about mental health, they talk about postpartum depression, but they don’t talk about psychosis and yeah, I think at that point, where I was like well I’ve either been raped or I’m going mad [psychotic symptoms] and I’m obviously going mad because why would I suddenly go mad? At least if I had known actually ‘yeah this is... you can, having a baby can make you lose your marbles’.” (Participant 01)

The barriers to caring for my baby

During the interviews, women were able to reflect on their relationships with their infants, and commonly spoke about breastfeeding, separation and connecting with their baby, which constitute the following subthemes. This theme draws on the mother-infant relationship more so than other themes, and covers the practical barriers posed by postpartum psychosis to this relationship.

Wanting to breastfeed vs. needing medication

Despite mothers talking about not understanding what was going on for them when they developed postpartum psychosis, breastfeeding was a focus for all women and signified them functioning in their role as a mother.

“..I just felt, I just remember being in bed ... and she was breastfeeding, and I was just in bed, and this is just like the most natural thing in the world that just felt like, just perfect.” (Participant 01)

Many women faced either making a decision about continuing to breastfeed whilst taking medication or had that decision taken away from them by their care team. All were able to breastfeed before the impact of medication took precedence and this was consistently reported as a positive experience that assisted bonding and closeness to their babies. The apparent stigma around bottle feeding over breastfeeding appeared to underlie many of these concerns, which was surprising within modern society that has an array of options for bottle feeding.

“I felt because I'd always wanted to breastfeed, and I knew all the benefits of it and I was really, I wouldn't say anti bottle feeding, but I was like ‘that's not for me, I'm going to persevere with breastfeeding’.” (Participant 04)

Why are you taking me from my baby?

Difficulties women faced when being diagnosed with postpartum psychosis and wanting to continue in their role as a mother was further affected by mother and baby being separated due to services not being able to facilitate joint admissions. Of the seven women interviewed, two were temporarily separated from their babies on admission to hospital, one fought not to be separated and one was separated due to her baby being in neonatal intensive care. This separation was the result of bed availability on mother and baby units. One woman was sent to a mother and baby unit in a different

part of the country because of this and was subsequently separated from her family in the process.

“I don’t know what’s happening that day, I went from feeling not very [well] because I [was] not sleeping or eating for two days and they take me with the girl. And you know what, the girl was the most important for me, even if I’m not feeling well, even when I’m not sleeping, changing her and stuff, breastfeeding was easy, and I didn’t want to let anyone near her...” (Participant 06)

You cannot break our bond

Women faced disruptions to their mothering roles due to psychotic symptoms such as delusions and hallucinations yet reported a good relationship with their child at time of interview. There were mixed views about their baby at the time of their illness for this sample of mothers, with postpartum psychosis leaving two mothers unsure as to whether they had actually given birth:

“...they were telling me that I had [baby], but I was very confused about this because I was like, and they were showing me a picture and I was like ‘I don’t recognise this person’ and that was a picture of [baby]. I think because I couldn’t remember her, I just was really, my mind just wouldn’t, couldn’t really process very well.” (Participant 04)

Four mothers questioned their relationship with their baby and ability to meet their baby's needs when processing their experience of postpartum psychosis and returning home to their role as a mother.

"I think a lot of it was because I felt I didn't love [baby] the way I should and that made me the worst, a horrible mum... It was, I just thought, I just felt because I felt I should love her more. I was like she's this perfect little baby, she's brilliant, she's such a good baby. Why don't I love her more?" (Participant 04)

Although three mothers reported initial concerns about bonding with their baby, all found focusing on their baby to be a motivation for recovery, particularly when there had been separation and reunion with their infants. A common experience appeared to be mothers having delusions about harm coming to their baby and wanting to protect them.

"Because I think that him being there made me so much more aware of needing to be just more with it... I did very quickly get a lot better." (Participant 03)

"And then as soon as I had those thoughts, I started to pick up myself. Like, just wanted to get back to my children. I'll do anything for them and if that means recovering, then stay focused on getting out of this place that I was in, then that was it." (Participant 05)

As illustrated by the above quotes, mothers appeared to be attributing recovery to will power rather than treatment. It would have been valuable to explore this further during

interviews when reflecting on the data. Although mothers were focused on getting better for their children, they also worried about the potential impact of postpartum psychosis on their children when they were acutely unwell. Several mothers spoke about their children being too young to remember this period of disruption.

“I went through a stint of feeling really guilty around how I might have behaved around my son, and then sort of keep having to remind myself he would never know, he would never have remembered.” (Participant 07)

This was not consistent for all mothers however, who believed that their relationship with their baby was not affected by postpartum psychosis and have been able to reflect positively on this.

“In terms of relationship with [baby], I don't think it's affected anything. So, even though I had two weeks... apart from him, which is, is really hard to look back on. And I've had it when, when some friends of mine has had their second babies and things and I've seen their really tiny babies and held them. You know it's really sad that I didn't get to experience that two weeks, but like he was with [dad] and with my mum and stuff, so it's like it's fine, he doesn't have to be with me the whole time.” (Participant 03)

What comes with postpartum psychosis

The initial themes discussed draw on women's thoughts and feelings around being a mother. The following theme of '*what comes with postpartum psychosis*' is illustrated

by subthemes of ‘*the terror*’, ‘*the confusion*’ and ‘*the depression*’. Women wanted others to be aware of this to aid understanding and support for postpartum psychosis. In particular, these women wanted healthcare professionals to hear about the fear and confusion felt during this time, and to speak about the possibility of becoming depressed after postpartum psychosis. Women who did experience depression following postpartum psychosis felt that this had more of a negative impact on their role as a mother and their relationship with their child than the postpartum psychosis itself.

The terror of the world

The need for those around the mother and baby to understand ‘*the terror*’ was deemed as something often incomprehensible for people without direct experience of postpartum psychosis.

“I would say people who understood your fear, like because I cannot tell you how utterly terrifying it is. You cannot understand it unless you've experienced it. Like, it's like being in a nightmare, in a scary horror film and you can't get out of it.”
(Participant 04)

This fear was often centred around the baby and fears of the baby being harmed, which women felt that healthcare professionals need to understand when working with women with postpartum psychosis.

“And I remember being really fearful for her, so I was just clinging onto her for dear life. Not letting anyone else touch her.” (Participant 01)

Quotes illustrating this fear are powerful indicators of what a psychotic episode feels like. This phenomenon of wanting to protect the baby appears to contradict previous literature around postpartum psychosis, which often speaks about women wanting to harm their babies and infanticide (Chandra, Bhargavaraman, Raghunandan, & Shaligram, 2006; Engqvist et al., 2011; Engqvist and Nilsson, 2013; Jones et al., 2014). More information about whether mothers were able to communicate this fear at the time would shed light on how professionals responded to this if they had understood the mother’s internal world.

“I was scared to go to sleep, I was scared for my baby and for my whole family. I thought one of the nurses... was meant to do my baby harm.” (Participant 02)

Mothers wanting to protect their baby from harm may explain why this study appears to illustrate less adverse impacts of first onset postpartum psychosis on the mother-infant relationship; as the mothers are involved in parental protection in response to a psychotically driven perceived threat.

The confusion of reality

Again, mothers felt that those supporting women with postpartum psychosis need to bear in mind ‘*the confusion*’ when communicating with these mothers. Women report experiencing fluctuating thoughts and feelings which left them feeling unsure of reality.

This may be particularly prominent in first onset postpartum psychosis due to the unexpected nature of this experience and mothers being unaware of how psychosis may present.

“A bit of a nightmare because I still couldn’t make sense of the world around me. I was kind of writing lists of things, just not making much sense. And also, with these emotions that were all over the place.” (Participant 07 describing returning home from the labour ward)

The depression that follows

Four of the seven women experienced depression in the postpartum period, which they reported made being a mother and caring for their infant a struggle. This lasted months (and years for one woman) and was the harder diagnosis to overcome for these women. Mothers found this a particularly emotive and difficult period to talk about. One woman had Cognitive Behaviour Therapy for postnatal depression, which she found was a key turning point for her getting back to her role as a mother. More information about therapy for postpartum psychosis would be valuable for future research.

“I felt like I’d worked so hard to get to that point, it was such a setback. And my, everything then just I think plummeted. I was like, I just kind of, I’d be crying every day and everyday was a struggle. And literally just getting up in the morning and going, doing sterilisers seemed like the most hardest thing in the world and everything was an effort.” (Participant 04)

“Because when I became depressed it was almost someone had turned the love off. I’d just gone from this lovely bond to back, right back to square one of really not caring, not wanting anything to do with him, wanting to cut him off. At one point I suggested having him adopted; just couldn’t have cared less.” (Participant 07)

Where the system fails and thrives

Despite these women now being aware of their symptoms related to postpartum psychosis and depression, different experiences of treatment and support were received across this sample and suggest a lack of consistency in care for women with postpartum psychosis; illustrated by the following subthemes.

The negatives of generic care

Mothers admitted to general psychiatric wards reported to have a particularly difficult experience of being cared for and felt that staff lacked understanding, empathy and consideration for these mentally unwell women who had just given birth.

“...they were really not happy for me to express milk, and we had to have, it was almost like a battle, and in the end, they sat and watched while my mum helped me express. And that, it really didn't feel like that was necessary. OK, they didn't know that I wasn't a danger to myself I suppose, and they didn't know, but they'd happily let me walk around that ward and out in the garden and not supervise me at all, but when it came to expressing, I had to be supervised with my mum. Even though my mum was there and every single time I expressed they would like, sit and watch me, and it's, you know,

it's not your, especially when you first start, you need to get completely topless.”
(Participant 04)

One mother repeatedly asked for help from professionals after returning home from the maternity ward and felt that her concerns were dismissed over several weeks of trying to seek support from a range of services. Both quotes used to illustrate how women negatively experienced the healthcare system contributed to these women making formal complaints about their care. The quote below highlights treatment delay due to misdiagnosis 8 years ago. Other women in this sample did not experience such a delay, which may suggest there have been improvements in systems recognising the need to act on mothers' concerns in more recent years. Although this is a highly speculative conclusion based on a small sample of women.

“I hadn't come across the postpartum psychosis just then and I kept saying to the people that was visiting ‘well, I've developed bipolar disorder’ and everyone just sort of looked at me like I was barmy, even though I had an assessment by... a mental health hospital near me, and they came and assessed me and in the end they said ‘well, what are you so worried about?’ and I said ‘well, I think I've got bipolar disorder’ and they went ‘no, no, no. You're just a bit of a control freak’.” (Participant 07)

The positives of specialist provisions

Despite the evidence of negative experiences, not all mothers received this response from the healthcare system and mothers who were admitted to a mother and baby unit experienced this as a positive and supportive environment. Findings from this study

illustrate the issue of mothers trying to parent their babies when they are affected by extremely unusual experiences. Women in this sample report trying to be the best mother despite their psychosis, which is a key finding about the mother-infant relationship in first onset postpartum psychosis. The level of care and support reported by these women was an encouraging comparison to the negative experiences of the healthcare system as a reminder of the valuable work provided by NHS staff.

“I think also, just the nurses, so the mental health nurses and the nursery nurses were really, I found them really supportive because I think at the beginning they had to do lots of supervision and stuff. But actually, it didn't feel really intrusive or like, I don't remember it being that... They were just so nice that I think I felt it was such a nice atmosphere...” (Participant 03)

“Because I'd obviously been seeing experts in their field, do you know what I mean? So, it was weird, but I felt like very confident and very like all these milestones I'd been forced to do early, like leaving her with other people and bottle feeding, letting other people feed her or like tips on how to get them to sleep. Like, I'd had a whole nursing team to help, I'd been around nursery nurses to teach me how the best way to do a bottle and do you know what I mean? ..I remember trying to make a bottle being the hardest thing in the world, but they make you confident in doing it so...” (Participant 01)

Likewise, other professionals were noted as responding appropriately to women's concerns; one woman had a particularly positive response when making a complaint

about her care during her admission to a general psychiatric unit when she was psychotic.

“...and then they were great, they met with me; I think it was like the chief nurse and one of the board members and went through everything. I think they were really, you could tell they were really upset by what had happened... I think you know, when you actually talk to someone and they can see the impact of that. They were really good and they kind of went through, they'd already recognised that there was a problem with the culture in the hospital and the staff culture of just not really being caring and compassionate, and they put measures in place to address that...” (Participant 04)

This response created a sense of closure on a difficult period and was viewed as a positive outcome of the experience of postpartum psychosis. It was encouraging that a difference could be made for future care of women going through similar situations.

Let's talk about postpartum psychosis

Following on from both the negative and positive care received by this sample of women, all women highlighted the need to talk about postpartum psychosis and for healthcare professionals to portray a better understanding of this. The lack of communication around postpartum psychosis was often felt to be a downfall of the service provided and contributing to the stigma around mental health; both of which appear to be valid interpretations. The quote below highlights mothers wanting to stay close to their infants and the fear caused by separating mother and baby.

“I didn't understand why I was going to this hospital and I thought I would never see [baby] again, and I thought I'd never see [husband] or my mum again. And so that I remember having to say goodbye, like saying goodbye to [husband] in the ambulance and I was distraught, and I just couldn't, I didn't know what was happening, why.”
(Participant 04)

The issue of stigma resonates across all mental health issues in general. Women expressing their role in advocating for postpartum psychosis after their recovery felt this to be a powerful tool for coming to terms with their experience and making a difference for others affected by postpartum psychosis.

“And I think talking to people, I think it took me a long time but then I think that's a process in yourself, because you know you have to get to a point where you can talk about it. But when I started talking about it was when things started to get better. And all, most of my friends now know, my work know because I was off... And I think that's another thing that's really hard about such a serious mental illness, is that right you could say ‘ok, I had my appendix out’ or something. It's very hard to say to someone ‘I've been psychotic,’ because they don't know what that means. Because it's not, we don't talk about it in society and but, I remember once reading the statistics and it seems like probably quite a lot of people suffer psychosis in the population, so maybe we should talk about it more.” (Participant 04)

Support

A key theme that arose was women's thoughts about the support received and where it was lacking. It appears that women in this sample admitted to mother and baby units had positive views of support from the healthcare system, whereas women admitted to general psychiatric wards felt less supported and understood by professionals. The support provided by partners, families and peers appeared to be invaluable for the majority of the women interviewed.

Where support should come from: the healthcare system

Women felt that there was a lack of understanding and communication around postpartum psychosis which contributed to delayed diagnosis, poor treatment and a lack of psychoeducation around their symptoms and outcomes.

“No, we knew things weren't right, we kept saying, because at that point we were still having daily visits from the maternity unit. Kept saying ‘things aren't right, you know I keep crying’, I said to them ‘I've realised that people I thought were visiting me in hospital hadn't’ I said, ‘I'd been seeing people, seeing things’. They didn't really seem that bothered until one day they turned up and told me that they'd contacted social services, and we really couldn't understand what was going on at that point.”
(Participant 07)

Although these obstacles appeared to be tackled by the mother and baby unit staff who displayed a better understanding of mothers and their families' needs, none of the women spoke about their partners being supported during their illness. This was

thought of as an essential change required, not only for supporting the partner but for the partner supporting the baby.

“I think support for partners is something that's still really lacking and Dr [name] was really good once we'd got to that stage of being in the mother and baby unit. But I think that, but I think that that two weeks of, I just think were just really hard for [partner] because obviously I was really ill, he didn't know what was happening, he had a new baby... So even though it was, it wasn't that bad for me because I don't remember it, that for him, obviously that's really hard.” (Participant 03)

Where support does come from: partners and family

Many women relied on their partners and families to help them through the process of recovery from postpartum psychosis, rather than healthcare professionals, which they felt was crucial to their recovery.

“Ah so [partner] did a lot of the night stuff. So, when I first came out [partner] would look after all the night feeds and stuff. And at that stage I was doing a mixture of breastfeeding and bottle feeding, so through the night he looked after that, which was just amazing.” (Participant 03)

Healthcare systems also recognised the importance of the mother and baby receiving support outside of the ward and mothers aware of APP valued peer support; with the ability to share stories and have their experiences normalised. This may be of particular

relevance in first onset postpartum psychosis due to the whole mental health system being a new environment to navigate.

“Yeah, I think that was one of the reasons why they let me go home when we were discharged from hospital because they could see I had a massive support network around me and it's also why I recovered so quickly, I think.” (Participant 04)

“And the other thing is the peer to peer support is when you post on that and the people come back and they're like, you know they've experienced it, it was the first time of kind of connecting with other people who had gone through this experience.” (Participant 04)

Making sense of it all

The final theme to arise from the interviews was how all women had tried to reflect and make sense of their experiences. Women in this sample reported being more in touch with their emotions and reiterated the importance of being open with others about this.

“I think from now at this point in time it's the, it's a weird thing to say but I feel glad that it happened because I think it has made me realise like how important your mental health is. And it's made me much more sympathetic to people. So, I think it's... definitely made me a better person in terms of being understanding of other people and thinking, kind of campaigning for mental health awareness, and also it means that people talk to me about stuff.” (Participant 03)

Women also thought about what they would like to share with other women experiencing postpartum psychosis.

“I think everybody is different. I think every child is different and I think every moment in your life is of an experience is different. So, you have to take it. You can't think that everything's going to be the same way, it won't run even. Though it was something that I would never think of happening to me. But now I'm more open minded about the possibilities and I'm more open minded about how I'm feeling and yeah anything is possible, that's just what I think. Because I'm happy and I'm just so content, honestly. And I'm so grateful that I had the people around me and having the support of my friends, like all the healthcare professionals that were around, honestly I don't know where I would be.” (Participant 05)

As this research aimed to contribute to understanding the mother-infant relationship in the context of first onset postpartum psychosis, results highlighted that although women did feel worried about their relationship with their baby when they feared being separated or not being able to breastfeed, this was typically short-lived, and the baby was often a focus for recovery. One woman described her relationship with her baby using a wonderful juxtaposition, which summarised how many mothers in this sample felt about their experience of postpartum psychosis.

“...it's kind of like having the poison and the antidote at the same time; like her coming into the world sent me completely haywire, but the point where I was completely at sea, she was kind of a rock to focus on.” (Participant 01)

As can be seen, women with postpartum psychosis do not raise long-lasting concerns about their relationship with their child in the context of postpartum psychosis. The reported little residual impact may be explained by mothers with postpartum psychosis always trying to be a good parent. Mothers emphasise the meaning of their baby during these experiences and highlight their protectiveness and desire for their baby to be safe and nurtured. This provides a different lens to the experience of being a mother in highly unusual circumstances.

Women reiterate the importance of not being separated from their baby, the importance of education around breastfeeding and the need for professional, partner and peer support during this period of disruption at what is expected to be a joyful time. It appears that the experience of depression during the postpartum period causes distress and the impact of this on the baby and mother-infant relationship is highlighted by mothers. Psychoeducation around postpartum psychosis leading to depression needs to be reiterated.

Interestingly, all women drew attention to their experiences of care during their treatment of postpartum psychosis and highlighted the need for further focus on this area. The need for wider support was emphasised and recommendations made for how to improve women's experiences and outcomes during postpartum psychosis. Women wanted others to understand the inner experiences of postpartum psychosis and how these might present outwardly; to normalise these experiences for other women also. Reflectively, a wealth of information specifically about the mother-infant relationship has not emerged from this sample of women as they focused on other aspects of their

postpartum psychosis experience too. The implications of this will be discussed in the next chapter.

DISCUSSION

Using thematic analysis to explore the mother-infant relationship in women with first onset postpartum psychosis, this study aimed to develop an understanding of this less researched area of postpartum psychosis. As described, these data produced seven core themes: *expectations vs. reality of motherhood, me and my baby, what comes with postpartum psychosis, where the system fails and thrives, let's talk about postpartum psychosis, support, and making sense of it*. This chapter will review these in the context of existing literature and the research question, and then consider methodological, clinical and future implications of the research.

Expectations vs. reality

Expectations versus reality can be seen as an overarching premise of all themes as women's expectations of motherhood, becoming unwell, the healthcare systems and perinatal support were experienced differently in reality to how women had expected (i.e. motherhood being a joyful experience, healthcare systems being accessible in time of need and support being empathetic and tailored to perinatal needs). Previous research by Darvill et al. (2010) found that mothers reported the reality of motherhood to be very different from their expectations, although the overwhelming love felt for their infant outweighed the negative features of being a mother. This conflict between expectations and reality of motherhood can be difficult for mothers to process due to motherhood being culturally shaped as a time of enjoyment (Darvill et al., 2010). This was echoed by women in this study. Even without the addition of postpartum psychosis, the postpartum months are described as a time of uncertainty and emotional lability for

the mother (Nelson, 2003), with mothers feeling unprepared both emotionally and physically (Darvill et al., 2010).

The value of partner and peer support during this time, as illustrated in this research, has been documented as contributing to mothers' confidence and protection from vulnerability across a variety of studies (Darvill et al., 2010; Logsdon, Birkimer, & Usui, 2000; Leahy Warren, 2005). Evidence suggests that the physical changes of pregnancy and motherhood are perhaps given more attention by midwives, for example, than the psychological components of this transition (Emmanuel, Creedy, St John, & Brown, 2011; Wilkins, 2006). However, the women composing Darvill et al.'s (2010) research were all white married women, many with higher qualifications, which limits generalisability of findings to different ethnicities, marital status and education levels. Although all women were married in the present study, they did include a wider variation of ethnicities, which makes findings somewhat generalisable beyond white women only (although based on a small sample size).

Postpartum psychosis vs. depression

Previous research has shown that psychotic symptoms may affect the mother-infant relationship when the child is involved in delusions and hallucinations, and through the mothers' potential unavailability (Howard, Gross, Leese, Appleby, & Thornicroft, 2004). This was evident in the present study where mothers were unsure if they had given birth and/or when mothers and babies were separated due to the mother's illness. Supporting Plunkett et al.'s (2017) findings, this study provided data that the baby played a key role in women's recovery. Focusing on the baby was a motivating factor

for mothers but caring for the baby was a struggle for those mothers who went on to develop depression.

Themes from the present study suggest that mothers do not subjectively experience long-lasting difficulties in their relationship with their baby during postpartum psychosis; with disruptions being linked to physical factors of separation and breastfeeding. Mothers in this sample did not support previous literature linking postpartum psychosis with harm to infant care and development. Instead, mothers highlighted protection of their infants and continuing to focus on their role as a parent in the midst of their psychotic symptoms. This is of particular interest for future research to understand more about whether this is linked specifically to first onset postpartum psychosis and mothers' perceptions of a good relationship with their infant. Mothers who developed depression were able to name that this is where difficulties arose in caring for and bonding with their baby.

Perinatal mental health care

Previous research highlights that the ability to parent can be influenced by the mother's support system (Gopfert, Webster, Pollard, & Nelki, 1996). All mothers in the sample of the present study were able to rely on their families to support their babies in their absence. Lagan, Knights, Barton, and Boyce (2009) highlight the gap between what is required and what is available for supporting the needs of mother and baby in perinatal mental illness, as found in the present study. In 2011, the Maternal Mental Health Alliance (MMHA) launched the 'Everyone's Business' campaign to push for all women in the UK to get "consistent, accessible and quality care and support" for their antenatal and perinatal mental health. The MMHA brings together national

membership organisations across sectors to campaign for and support change in perinatal mental health care. The present study supports this campaign and can be used to highlight the continued need for improvements in perinatal mental health care, whilst highlighting the strengths of specialist perinatal mental health provisions. Reviewing the 'Next Steps on the NHS Five Year Forward View', positive changes to perinatal mental health provisions include additional mother and baby units across the UK, increased bed numbers in existing units and new or expanded specialist perinatal mental health teams. Goals from these changes are expected to treat 2000 more women with severe perinatal mental health problems in 2017/18, increasing to 9000 more women by 2018/19. The present study again supports these government improvements in perinatal mental health care.

Strengths and limitations

A key strength of this research is that it has provided information to address a gap in the literature focusing on the mother-infant relationship in first onset postpartum psychosis. Despite their symptoms, women maintained their role as a mother and continued to care for their baby in the majority of cases when acutely unwell. Separation from their baby was viewed as a mainly negative experience and women saw their babies as helping their recovery. No women in this sample reported that they had concerns about the impact of their experience on their relationship with their child. However, it is important to remain aware of recall bias in women's reports of past experiences and social desirability biases through the nature of the research.

As highlighted, none of these women were aware of postpartum psychosis prior to diagnosis, which added to their and their families' distress of not knowing what was wrong with them. Based on their experiences, women felt that a range of healthcare professionals shared their lack of knowledge about postpartum psychosis which mothers believed to have affected the care provided.

Methodological strengths of this research included service user involvement in the development of the interview schedule. Validity of interviews and results were supported by piloting the interview and making adaptations based on feedback and observations, and through cross-checking codes and themes with an external researcher. Thematic analysis itself can be used flexibly and the results produced are accessible; highlighting both similarities and differences across a data set.

Something that can be viewed as both a limitation and strength of this study is that all interviews were conducted face to face. There is added value in conducting face to face interviews through observing non-verbal communication and building rapport. This was a limitation in that ethical approval was not sought for phone interviews, which meant that women willing to participate through APP who did not live in the London area were not eligible for the study. This limited the sample size to approximately a third of what it could have been (i.e. 23 women expressed interest in participating, only seven met eligibility criteria). *Although the small sample size can be critiqued within this study, the nature of this research set out to recruit 6-10 participants, and therefore met this criterion. Braun and Clarke (2013) propose that sample size for thematic analysis is determined by the type of data collection and the size of the project; this would be 6-10 participants for interview studies. Fugard and Potts (2015) suggest that*

this sample size is expected to produce enough data to illustrate patterns without being too much data to manage. Guidelines for qualitative research however vary greatly, with suggestions for sample sizes ranging from 12 to 101 participants for qualitative interviews (Fugard & Potts, 2015). The information gathered within this research however was rich and informative, and thematic saturation was met regarding expectations of motherhood and the reality of postpartum psychosis. Data saturation is considered the gold standard of determining sample size (Mason, 2010) and the saturation point for any given study may vary, which means planning a sample size may be difficult (Wray, Markovic, & Manderson, 2007) and can be left open to criticism.

However, the final sample can be critiqued for additional biases. As there are only 17 mother and baby units across the UK (MMHA Everyone's Business Campaign), three of which are in London, women in this sample are more likely to have access to mother and baby units compared to women outside of London, which may be an area for future research. The provision of mental health services being higher in London compared to other areas of the UK may also suggest that mothers within the recruited sample and had a better understanding of mental health due to the availability of support services. Another consideration is that the women interviewed all reported to have recovered from postpartum psychosis. Although acutely unwell women were excluded from the inclusion criteria as ethical approval had not been sought to interview women when they were acutely unwell, the information gathered is therefore only representative of women who have recovered from postpartum psychosis and does not capture women's experiences from a range of phases, which may offer different perspectives on motherhood. Lastly, an important bias to note is that this study relied on voluntary

participation, which may not be representative of all women who experience postpartum psychosis (Heron et al., 2012). Women who feel unable or reluctant to talk about becoming a mother with postpartum psychosis may have processed their experiences differently to mothers who wish to share their stories and would therefore provide an alternative perspective to motherhood in the context of postpartum psychosis.

When developing this study, NHS perinatal mental health teams had suggested that they would have several women to recruit from their caseloads for participation in the study. However, at time of recruitment, despite all efforts, fewer women than expected met eligibility criteria based on time since diagnosis (falling out of the 18-month timeframe), not being able to provide an interpreter for interviews and postpartum psychosis not being first onset. Nonetheless, only one identified potential participant refused to be contacted by SK, with reasons unknown, and only one potential participant failed to attend arranged interview times. Response rates were therefore high. All NHS perinatal mental health teams raised lack of funding for an interpreter as a weakness of the study and an obstacle to recruitment, which should be considered for future research. These factors and time constraints led to the small sample size for this study. Despite the small sample size however, it appeared that thematic saturation had been met based on the emerging codes and themes.

Thematic saturation is achieved when no new data are produced from additional interviews (Francis, Johnston, Robertson, Glidewell, Entwistle, Eccles, et al. 2010). A codebook was developed as codes emerged from interviews. The codebook was then applied to all transcripts for modifications of codes and their definitions. This was done

to reduce the chance of losing any relevant data. An independent rater was then asked to check a subset of interviews that had already been analysed using the code book. No new codes were developed as the interviews progressed and therefore thematic saturation was deemed to have been met. The development of themes and subthemes after thematic saturation had been met were again cross-checked with the same external researcher to improve reliability of data. Findings would have been further improved by external validation of experiences from healthcare professionals and partners/families, although this was not within the scope of this study.

A point for consideration in the present study is that DSM-IV and ICD-10 criteria state that a diagnosis of postpartum psychosis is typically given within 4-6 weeks postpartum, and three of the women in this sample received a diagnosis by mental health professionals outside of this timeframe but within the postpartum period of one year. These women all identified as having postpartum psychosis and were all recruited from NHS perinatal mental health teams. Each referrer confirmed that these women had been treated for postpartum psychosis despite the later than typical onset, which is why they were included in the study. This should be considered in recruitment for future research which may inform diagnostic policies.

Expressed interest from women associated with APP highlights the valuable contribution of this charity to research in postpartum psychosis. APP was spoken positively about by this sample of women, and the network was continuously supportive of advertising this study. Participants recruited through APP were not restricted to the initial timeframe of 6-18 months since diagnosis, which was lifted specifically for this recruitment method to increase sample size within a limited

timeframe. The decision to extend the timeframe since diagnosis was based on previous research not limiting samples by time passed since diagnosis. Research has shown that mothers have a good recall of their experiences of postpartum psychosis regardless of time lapsed and that some women need distance from their psychotic episode to be able to talk about their experiences (Engqvist & Nilsson, 2013). This decision was deemed not to affect validity of the sample.

Relying on recall of events after months or years remains a limitation of this study, which the initial time restriction of 6-18 months since diagnosis aimed to reduce. As this was not a feasible inclusion criterion due to slow recruitment rates, it would have been worthwhile to make this informed decision at an earlier stage of the study to assist with recruitment through NHS perinatal teams also. Time pressures prevented this change from going through NHS ethical procedures. Women in this sample ranged from 11 months to 8 years since diagnosis, with a mean of 20 months. **Table 1** highlights that all but one participant fell within a 5-year timeframe since diagnosis, suggesting a strength of recall accuracy compared to studies with a wider range of time since diagnosis. Women in this sample did however name that some of their memories were unclear regarding specific details of their experiences.

Clinical implications

Regarding the mother-infant relationship in postpartum psychosis, findings suggest that mothers fear for their baby's safety rather than previous research which indicates that mothers have thoughts of harming their babies or that their babies may do them harm (Engqvist et al., 2011). Awareness of this needs to be raised in assessing mothers and to reduce stigma around this diagnosis. Offering mothers reassurance is part of

providing optimal care for the baby and for mothers to accept help in getting sleep and letting staff care for their baby when they are acutely unwell.

Professionals need to understand the positive role that the baby plays in women's recovery and to encourage interaction and bonding when possible, after full risk assessment of mother's mental state. Separating mother and baby stops any chance of this facilitation to recovery. Giving mothers choices around breastfeeding when possible should also be thought about and consideration of ongoing support after discharge, not only from the labour ward but also from the mother and baby unit or general psychiatric ward. No mothers in this sample received discharge information about developing any mental health problems following birth and felt that this would have been beneficial to them and their families. Normalising their symptoms and concerns for their relationship with their baby is required to ease mothers' anxiety during this unexpected experience and providing mothers with support groups, numbers and forums is an effective way of doing this. It would also be useful to facilitate discussion around mothers concerns and planning in partnership with their partner, the staff caring for them and the mother herself. Facilitating peer support is likely to assist with this process also.

As highlighted by this study, there is a continued need for raising awareness of postpartum psychosis, particularly in antenatal and perinatal care. All women felt that antenatal classes had failed in not addressing the issue of postpartum psychosis, although this requires validation from the direct sources to confirm that this was the case. In the context of first onset postpartum psychosis, women may not have recalled information that may have seemed irrelevant to them at the time. The themes generated

in this study similarly mapped previous findings by Engqvist et al. (2011) who illustrated that mothers felt “misunderstood, neglected, and not well taken care of” and suggested further education of healthcare professionals to improve care in postpartum psychosis.

The positive reactions to mother and baby units and negative experiences of being cared for in general psychiatric wards emphasises the value of specialist services and the need to fund and preserve these facilities. Research across different countries has shown that 75-80% of mothers admitted to mother and baby units have a good outcome (Glangeaud-Freudenthal et al., 2001), with an average admission of 8-11 weeks (Jones et al., 2014). However, lack of availability of mother and baby units across many parts of the UK (Heron et al., 2012) can result in mothers refusing admission due to fear of separation from their baby. Admission to specialist perinatal mental health services is expected to reduce disruptions to breastfeeding and the mother-infant relationship, shorten stays in hospital and ease responsibility of childcare placed on the partner and family (Wisner, Jennings, & Conley, 1996). Mothers themselves have reported that mother and baby units are necessary, where specialist knowledge about parenting can be accessed, and are more appropriate than general psychiatric care in the face of postpartum psychosis (Robertson & Lyons, 2003). Two of the women in this sample went on to make formal complaints about the care they received. Women’s perceptions of their experiences suggested that there was a need for improved staff training in understanding and treating postpartum psychosis, and how to adapt services when specialist provisions are not available.

Support for partners was consistently identified as lacking in this field. Holford et al., (2016) have made recommendations for perinatal mental healthcare providers to establish care plans with a therapeutic and pharmacological component, considering the partner, supporting the mother, and their relationship. The Royal College of Obstetricians and Gynaecologists Women's Voices Report (2011) also made recommendations for healthcare professionals to acknowledge and understand the impact that pregnancy and birth can have on a woman's partner, particularly if the mother is experiencing mental health problems. This report suggests that the whole family's mental health needs during the perinatal period are currently overlooked and recommend that the government should develop a strategy to support the mental health of partners.

Another clinical implication is the need for healthcare professionals to be aware of the fear and confusion experienced by these mothers when experiencing postpartum psychosis. This should be taken into account when communicating with mothers and their families and when considering separation of mother and baby. Staff's ability to communicate what is happening in the care of mother and baby may serve to alleviate these symptoms. In exploring the process of recovery in women with postpartum psychosis, McGrath, Peters, Wieck, and Wittkowski (2013) noted the value mother's place on staff treating them with optimism and hopefulness. The need to be open about the possibility of developing depression following an episode of postpartum psychosis should be discussed with women and their support system to facilitate noticing early warning signs and seeking appropriate help.

Implications for future research

As mentioned, data from the present study has not produced vast information about the mother-infant relationship in the context of postpartum psychosis due to the small sample size and women's perceptions of their experiences. Although this can be considered a limitation of the present study, the fluid nature of qualitative research is to work with the data as it emerges. Going with what the participant is focusing on is a key aspect of qualitative research, particularly from a critical realist standpoint. In the case of this research, mothers tended to focus less on the potential impact of their experience on the mother-infant relationship. This may be understood by interpreting mothers' views of postpartum psychosis as a transient experience that they have been able to recover from and make sense of.

Mothers elicited themes around support needs in the context of no previous mental health difficulties, and therefore focused more on these areas of relevance to their experience. It would be valuable to explore further whether this is applicable to first onset postpartum psychosis through larger sample sizes. It would also be beneficial for future research to develop specific ways of extracting information specifically about the mother-infant relationship. As mentioned in recommendations of the Systematic Review chapter, it may have been valuable to validate the Postpartum Bonding Questionnaire (PBQ: Brockington et al., 2001) in a postpartum psychosis population. As this questionnaire has provided useful information about bonding disorders in postnatal depression, it may be able to provide quantitative information about bonding in postpartum psychosis.

Thinking about social desirability biases, external validity could be achieved by obtaining information from family members and staff when working with mothers with first onset postpartum psychosis. This may provide a sense of how they are observed to be coping with their baby and postpartum psychosis. As the present study relied on women's subjective reports of their experiences, viewing clinical notes for example would provide further information about what was being observed of the mother and baby at the time of the mother being acutely unwell. Asking partners and families about how they experienced the mother and infant's relationship would provide informative collateral information.

Looking at other areas of research that have explored the mother-infant relationship, observational tools may be useful in understanding the mother-infant relationship in first onset postpartum psychosis. As the present study aimed to provide information specifically about the first onset population, comparing mothers who were aware of their risk of postpartum psychosis to those who receive their diagnosis "out of the blue" may provide further information about the appropriate treatment and outcomes for this population of mothers. Using video-interactive technology for example may provide direct information about the mother-infant relationship and could be explored in a controlled setting with baseline and outcome measures.

Another way of enhancing sample size to assist understanding postpartum psychosis would be to use the technique employed by Engqvist et al. (2011), which analysed narratives from the internet. APP for example has a whole section of their website dedicated to mothers' stories about their experience of postpartum psychosis and would be able to provide rich data from mothers themselves. The benefits of using this

technique include anonymity, default consent and no attrition rates, and removes issues of social desirability biases. Considering the time constraints of the empirical study, this may have been a more practical approach.

Methodologically, future research may wish to develop understanding of the mother-infant relationship over a longer time period; using outcome measures to assess the relationship over various points in time. This research did not use outcome measures as the aim was to gain rich and detailed understanding about the experience of postpartum psychosis from women themselves. This can be used to inform future research which may wish to explore more about the support available for partners and families, and the role of peer support as suggestions. A key factor highlighted as affecting the mother-infant relationship was the onset of depression following postpartum psychosis, which requires further exploration.

Several women reported a lack of awareness of postpartum psychosis amongst healthcare professionals who were unable to provide appropriate support. No women mentioned talking therapy in their journey through postpartum psychosis, and future research would be useful in evaluating types of therapy available to women with postpartum psychosis. This may inform recommendations for future interventions. Wyatt et al., (2015) have previously suggested that therapy facilitating women's meaningful understanding of their unusual experiences will allow women to relate differently to their experience and reduce distress; often associated with 'psychotic' symptoms being treated as inexplicable by others. Future research may wish to evaluate the effectiveness of such recommendations.

Conclusions

This study highlights the importance of understanding women's experiences of postpartum psychosis to guide future research and inform clinical care. Although all women reported a good relationship with their child at time of interview, the confusion, fear and separation issues that arose within postpartum psychosis were said to impact on how the women experienced being a mother. All women felt that systems around the mother and baby needed to be aware of what postpartum psychosis feels like to provide appropriate support. Downfalls of the healthcare system were highlighted by several of the women, with previous research illustrating the importance of accessing appropriate support and receiving useful and reassuring information about the course of postpartum psychosis (McGrath et al., 2013), and the possibility of developing depression following an episode of postpartum psychosis. NICE (2014) guidelines have made similar recommendations. Overall, the experience of postpartum psychosis has been described as one of fear and confusion, with the baby often being the centre of women's thoughts and focus for recovery. Mothers with first onset postpartum psychosis describe being protective and fearful for the safety of their baby and remain aware of their role as a mother during their experiences. The value of mother and baby units has been evidenced and the need for continued research to raise awareness and improve treatment of this perinatal disorder has been reiterated.

INTEGRATION, IMPACT AND DISSEMINATION

INTEGRATION

This research has focused on mothers' experiences of postpartum psychosis and the impact of this on the mother-infant relationship. In regard to the mother-infant relationship, information has been provided about how postpartum psychosis may affect mothers' responses to their infants (e.g. due to psychotic symptoms), practicalities of meeting their baby's needs when acutely unwell (e.g. if admitted to hospital) and how mothers experienced bonding with their baby. Findings of the systematic review produced mixed results about how postpartum psychosis affects the mother-infant relationship and highlighted the need to separate first onset postpartum psychosis from mothers at risk of postpartum psychosis. Systematic review findings illustrated differences in mothers' reports of their experiences compared to observations of nursing staff and perceptions of family members. This emphasised the need to focus on mothers' reports of their experiences to gain a true understanding of how they experience becoming a mother with postpartum psychosis.

Thinking about how the systematic review and empirical paper form a unified whole, the systematic review and previous research showed the importance of separating groups by diagnosis. Differentiating groups helps to make accurate inferences about the mother-infant relationship in postpartum psychosis when exploring the impact on mothers' feelings towards their child and interactions with their child. Although the systematic review included articles comparing postpartum psychosis with postnatal depression, these different diagnoses influenced length of hospital admission, focus of

intervention and the support networks available to mothers and their families. This supports the focus of the empirical paper on first onset postpartum psychosis only to deepen understanding about what this population of mothers may experience regarding symptoms, intervention and outcomes.

Both the systematic review and empirical paper focus on mothers' experiences when they are acutely unwell and how they felt about being a mother during this time. This provides information about a specific period of the mother-infant relationship and it may be useful to explore further how mothers view their relationship with their child since their diagnosis and recovery. Only one question was asked about this at the end of the interview schedule in the empirical paper "*How do you think your relationship with [baby's name] is now?*". The systematic review included articles exploring outcomes of interventions on mother and baby units, as well as nurses' observations of mothers with their babies. The experience of care was highlighted by mothers in the empirical paper when questions were not directly asked about this. This emphasises the significance of exploring women's experiences of care of postpartum psychosis as an area of focus for future research.

When critically appraising the empirical paper, the recruitment issues of not seeking approval for non-face-to-face interviews over the phone, Skype or FaceTime for example, was a limitation of the empirical study and a technique used by one of the papers included in the systematic review article (Plunkett et al., 2017). The information gained from phone interviews by Plunkett et al. (2017) was regarded as informative as face-to-face interview data and would have been valuable to consider when proposing the empirical study. This justification would have saved time and aided recruitment at

the early stages of developing the study. Nonetheless, NHS perinatal mental health teams had been supportive and encouraging of recruiting participants. It was unexpected at time of recruitment that fewer participants would materialise despite teams trying to identify women on their caseloads. Women who had not signed ‘consent for contact’ during treatment, which is designed to assist with facilitating research, were unable to be contacted once discharged from the perinatal mental health team. This was an unforeseen barrier when proposing the empirical study.

A strength of the empirical paper was having service user involvement in the design of the study, which was absent in the quality of all systematic review articles. The service user consultant for the empirical study had felt that she would have struggled to speak about her experiences so close to recovery, which was echoed in Engqvist and Nilsson’s (2013) study. Nonetheless, mothers within the sample of the empirical study had wished to be interviewed and some women spoke about never having had the opportunity to speak in such detail about their experiences, which they found cathartic. One women highlighted how it had been distressing when she had previously been interviewed about her experiences of postpartum psychosis. She felt that the approach of the previous research project had lacked sensitivity in asking questions and debriefing, although reported that the interview process of the empirical study overcame this. It may be worth capturing more information about the women who find talking about postpartum psychosis therapeutic compared to women who need distance from their experience. This may provide further understanding about how women with different recovery styles experience postpartum psychosis.

Despite barriers limiting the final sample size of the empirical paper, I had felt from conducting the interviews that thematic saturation had been reached. I was surprised how none of the mothers in the sample felt that there had been an impact of their experience on their relationship with their baby. Mothers portrayed a more positive mother-infant relationship compared to mothers in qualitative papers of the systematic review. This expectation came from knowledge of previous literature and a personal bias. As a psychologist, I would have had concerns about my absence, both physically and mentally, from my baby's early experiences. This has been reiterated by other people I have spoken to personally and professionally about this research, who too felt that they would have had similar concerns. It is enlightening to hear that mothers were able to reflect on their experiences as not having this presumed negative impact on the mother-infant relationship. This is echoed by quantitative systematic review articles where a negative mother-infant relationship was not observed by nursing staff. Alternatively, there is an underlying speculation that mothers may be in denial and using this as a protective mechanism when reflecting on their experiences.

An unforeseen element of the interview process involved some mothers referring to me, the researcher, as an expert in the field, and asking questions about their symptoms, diagnosis and outcomes of their experience. I could only provide information based on research I had read and discussions I had had with other mothers and professionals. I was able to direct participants to the support networks on the Participant Debrief Sheet for further information, which I was surprised to learn that many of the women had not been aware of. This highlighted women's wishes for more knowledge and information about postpartum psychosis. It made me wonder how a simple sheet of relevant support

networks could not be put together for women to access at various stages of their journey through postpartum psychosis.

As discussed, a limitation highlighted in the empirical study was the time that women received a diagnosis of postpartum psychosis following childbirth. Several women did not fall within the ICD-10 and DSM-IV timeframes of 4-6 weeks postpartum. When staff who identified these participants were questioned about this, they had felt that based on their clinical experience of working with postpartum psychosis that these women met diagnostic criteria and received the same treatment despite falling out of this time period, which is why these women were included in the empirical study. This may be important to consider when developing guidelines around diagnoses as all women described their experience as postpartum psychosis. Consideration of this may also have added more articles within the systematic review inclusion criteria which was limited to DSM-IV and ICD-10 diagnostic criteria. I think gaining understanding from women who identified with postpartum psychosis and were treated as having postpartum psychosis provides valuable information about an under-researched field rather than limiting findings based on diagnostic criteria.

Considering the time passed since diagnosis in qualitative papers in the systematic review (Engqvist et al., 2011; Engqvist & Nilsson, 2013), an initial hope of this study was to capture women in the early period of recovery; recruiting mothers who had received a diagnosis of postpartum psychosis within the last 6-18 months. Unfortunately, this limited the sample dramatically within the recruitment timeframe and meant that this had to be expanded for recruitment through APP. The hope was for improved recall accuracy, which has been named as a possible limitation of previous

research. However, women still spoke about difficulties with their memory which may be a result of psychotic symptoms more so than the time passed since their diagnosis. It may be of importance to assess women's bonding and interactions at time of admission, discharge and follow-up to gain rich understanding about how postpartum psychosis influences the mother-infant relationship over time. Although this was captured by Noorlander et al. (2008) in the systematic review, qualitative research would lend itself to understanding more about these conclusions. Looking back to the interview schedule of the empirical paper, it would have been helpful to ask women whether they noticed differences in how they reflected on their experiences during recovery compared to how they processed these when they were acutely unwell.

The added value of qualitative data providing rich and meaningful information is often criticised as being subjective and lacking rigour. The empirical study aimed to overcome this by having an external researcher cross-check codes and themes generated from the interviews and therefore interpretation of results. My clinical experience had been attachment focused for some time before and during interviewing mothers and continued when analysing results. This meant that inferences were made about how verbatim related to attachment and bonding which would not have been interpreted necessarily by someone not focused on attachment and answering the question about the mother-infant relationship. Cross-checking enabled codes to be debated and themes to be broadened out to capture a wider breadth of information. This was of particular importance when it became apparent that the themes emerging were not drawing directly on information to answer the research question. There was a risk of bias at this stage without cross-checking to fulfil the aims of the study and taking away the value of qualitative research. This issue has continuously been reflected on

and I have felt that the data has produced valuable and novel information about women's experiences of becoming a mother with first onset postpartum psychosis, despite potential for criticism.

IMPACT & DISSEMINATION

This next section will make suggestions based on the findings of this research. It will consider how findings will impact on individuals affected by postpartum psychosis and the wider systems regarding perinatal mental health. Thinking initially about the healthcare systems, the empirical study and previous research suggests that there is a need to understand the training that staff receive regarding perinatal mental health, particularly postpartum psychosis. This includes GPs, midwives, health visitors, NCT class facilitators and nurses. It would be helpful to compare this training and teaching to specialist perinatal mental health staff to identify key gaps to enhance understanding, recognition and treatment for postpartum psychosis.

As an aim of all research should be to advance understanding in a specified field, and the highlighted issues related to experience of care, it would be worthwhile to gain more information about how mothers and professionals experience receiving and providing care to explore where this may be going wrong. This may provide knowledge of what nurses are not aware of and what mothers would like more support with. Understanding what in particular is working well on mother and baby units and with specialist perinatal staff can be used to inform training and consultations with staff.

Thinking about those involved in the study, participants and NHS perinatal mental health teams will receive a summary of the study prior to publication to highlight their

invaluable role in the research. Feeding back to recruitment sites is a requirement of the NHS Trust's Research and Development process also. The hope will be that other perinatal mental health teams will be contacted to hear about these findings and this will involve talking to policy makers about raising awareness, improving care and reducing stigma of postpartum psychosis through continued research bridging gaps in knowledge.

Due to lack of funding and bed availability, it would be valuable for mother and baby unit staff to offer consultations to general mental health practitioners when working with a mother with postpartum psychosis. Specialist perinatal teams could provide relevant information and suggestions for support for non-perinatal staff to have ready access to with new admissions on general psychiatric wards and to A&E for example. Staff training and accessible information about postpartum psychosis will benefit mothers with postpartum psychosis and their families. It will also benefit healthcare systems by reducing professional contact through misdiagnosis, i.e. mothers will not repeatedly present to the GP or A&E for example as symptoms will be recognised and treated from first presentation to services.

Meeting the needs of women highlighted in this study and raising awareness of postpartum psychosis in general would involve sharing information at mother and baby mornings at local libraries, leisure centres and cafes for example. Walk-in centres, family planning clinics and GP surgeries also need to have information accessible and on display to raise public awareness. Leaflets, posters and accessible information should be provided by NCT classes and at antenatal and perinatal checks. Recent story lines in soap operas have raised awareness of postpartum psychosis to some degree,

but this could be furthered by public advertising campaigns, which fit with the movement of increasing mental health awareness in general.

Information about postpartum psychosis should provide education and advice about breastfeeding when taking antipsychotic medication, which healthcare professionals need to be aware of to avoid giving mixed messages to mothers. Mothers can then make informed decisions about whether to continue breastfeeding or not. Looking at The Breastfeeding Network: Drugs in Breastmilk Information, there is not information titled 'breastfeeding and postpartum psychosis'. Information about antipsychotic medication when breastfeeding is provided under 'bipolar disorder and breastfeeding'. Adding postpartum psychosis to this title may be something simple yet effective for women experiencing postpartum psychosis feeling heard and recognised in perinatal mental health advice.

The need to highlight that there is a potential to develop depression following this episode is essential. Mothers and their families need to be aware of warning signs to assist with early diagnosis and accessing support. Participants did not speak about follow-up appointments after discharge from mother and baby units. Finding out more information about when this is offered and what this entails may enhance mothers' understanding of subsequent depression and relapse prevention plans. As the empirical study did not seek to understand this phenomenon it would be useful for future research to expand upon this. This is of particular importance as mothers within both the systematic review and empirical study appear to struggle more with their baby due to the symptoms of depression than psychosis. This needs to be treated quickly and appropriate support provided for mother, baby and family. Some mothers also spoke

about thinking about having more children and feeling that this needed to be thought about in the context of their illness. This too requires accessible information for mothers and families to be able to make an informed decision about subsequent pregnancies and how to manage relapse.

Not only does awareness of postpartum psychosis itself need to be raised but support available for partners and families affected by postpartum psychosis. Platforms of dissemination therefore need to draw attention to support groups and networks for fathers and families at this time of need. The Maternal Mental Health Alliance's Everyone's Business campaign is key to supporting impact and dissemination of this research, as aims of this campaign are for women and families affected by perinatal mental health "to receive the care they need, wherever and whenever they need it".

Considering economic implications of healthcare, the availability of mother and baby units needs to be equal nationally; it should not be a postcode lottery determining quality of care. The positive experiences spoken about regarding the mother and baby units in the empirical study should be used to support bids for funding. The complaints made about treatment of women with postpartum psychosis in general psychiatric wards should also be used to emphasise the need for specialist services. The complaints process can be labour intensive and creates problems for NHS Trust's applying for funding. It is therefore in the Trust's benefits to reduce postpartum admissions to general psychiatric wards. Although the empirical paper was conducted in the UK, the systematic review included studies across the world. The provision of perinatal services worldwide should consistently offer specialist care for the best outcomes for mother

and baby. It may be worth comparing care systems across countries to establish which services have the best outcomes.

Thinking about individual needs and wider society, the continued issue of stigma in mental health covers all aspects of mental illness, yet there appears to be additional stigma tied with postpartum psychosis and societal expectations of motherhood. Women place hardships on themselves for not coping and not enjoying their role as a mother, and society deems difficulties with newborns as the norm. Warning signs of postpartum psychosis, such as sleep deprivation and emotional lability, may be dismissed as part of being a new mother. By increasing public awareness and understanding of postpartum psychosis, the hope is that stigma will be reduced, and others will be aware of how to support women struggling. The need to raise awareness of cultural differences in understanding postpartum psychosis is also essential for supporting mothers and families. Religion was referred to as a protective factor for some mothers in the empirical study so perhaps religious leaders need to be educated about postpartum psychosis to ensure that appropriate support and advice is given.

Looking at recent perinatal mental health publications on the Maternal Health Task Force website, the following journals would be suited for publishing this present study: *Journal of Midwifery & Women's Health*, *Archives of Women's Mental Health*, *Women and Birth*, *BMC Pregnancy and Childbirth*. Targeting journals that will be read by midwives, nurses and mental health professionals will have the widest impact on disseminating information from this study.

Some key relevant reports identified through maternal mental health alliance include:

- *Royal College of Obstetricians and Gynaecologists Maternal Mental Health – Women’s Voices Feb 2017*
- *Next Steps on the NHS Five Year Forward View – March 2017*
- *Antenatal and postnatal NICE Guidance 2014*
- *Everyone’s Business Campaign*
- *MBRRACE-UK – Maternal Report 2015*

It would be valuable to contact the commissioners of these reports to provide further evidence illustrating the value of specialist perinatal mental health care and highlight how women continue to experience postpartum psychosis. It is important to highlight that the empirical study provides valuable information specifically about first onset postpartum psychosis, which is an area given little direct attention by previous research and recommendations.

There are also a variety of perinatal mental health conferences that would be important platforms to use to disseminate this research. These include:

- *Improving the quality of perinatal mental health services, National Child and Maternal*
- *NW London Perinatal Mental Health Conference, Perinatal Mental Health Community Education Provider Network*
- *Perinatal Mental Health for Healthcare Professionals, London South Bank University*
- *Maternal Mental Health Network*
- *Royal College of Midwifery*

- *Faculty of Perinatal Psychiatry Annual Conference, Royal College of Psychiatrists*

A key platform for dissemination will be through APP. The APP network is actively involved in raising public awareness of postpartum psychosis and having facilitated this research project will want to share the findings. Speaking to staff and service users from APP will maximise dissemination. Plans will be for APP to share the study on their website, through social media forums and through any relevant campaigns and conferences. APP have been involved in raising awareness through radio programmes, the news and Sports Relief as examples, and is a key player in sharing information and raising awareness of postpartum psychosis. Additional service user forums and support networks for perinatal mental health will also be contacted to present research findings at and again to be used as platforms to assist with dissemination.

REFERENCES

- Abel, K. M., Webb, R. T., Salmon, M. P., Wan, M. W., & Appleby, L. (2005). Prevalence and predictors of parenting outcomes in a cohort of mothers with schizophrenia admitted for joint mother and baby psychiatric care in England. *J Clin Psychiatry*, 66(6), 781-789.
- Ainsworth, M. D. S. (1969). Object relations, dependency, and attachment: A theoretical review of the infant-mother relationship. *Child development*, 969-1025.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders (4th ed.)*. Washington, DC: Author.
- Austin, M. P. (2010). Classification of mental health disorders in the perinatal period: future directions for DSM-V and ICD-11. *Archives of women's mental health*, 13(1), 41-44.
- Ayers, S., & Shakespeare, J. (2015). Should perinatal mental health be everyone's business? *Primary Health Care Research & Development*, 16, 323-325.
- Bakermans-Kranenburg, M. J., Van Ijzendoorn, M. H., & Juffer, F. (2003). Less is more: meta-analyses of sensitivity and attachment interventions in early childhood. *Psychological bulletin*, 129(2), 195.

- Barbot, B., Crossman, E., Hunter, S. R., Grigorenko, E. L., & Luthar, S. S. (2014). Reciprocal influences between maternal parenting and child adjustment in a high-risk population: A 5-year cross-lagged analysis of bidirectional effects. *American Journal of Orthopsychiatry*, 84(5), 567–580.
- Barrett, J., & Fleming, A. S. (2011). Annual research review: All mothers are not created equal: Neural and psychobiological perspectives on mothering and the importance of individual differences. *Journal of Child Psychology and Psychiatry*, 52(4), 368-397.
- Bergink, V., den Berg Lambregtse-van, M. P., Koorengevel, K. M., Kupka, R., & Kushner, S. A. (2011). First-onset psychosis occurring in the postpartum period: a prospective cohort study. *The Journal of clinical psychiatry*, 72(11), 1531-1537.
- Blackmore, E., Rubinow, D. R., O 'connor, T. G., Liu, X., Tang, W., Craddock, N., & Jones, I. (2013). Reproductive outcomes and risk of subsequent illness in women diagnosed with postpartum psychosis.
- Boland, A., Cherry, G., & Dickson, R. (Eds.). (2017). *Doing a systematic review: A student's guide*. Sage.
- Bornstein, M. H., Tamis-LeMonda, C. S., Hahn, C. S., & Haynes, O. M. (2008). Maternal responsiveness to young children at three ages: Longitudinal analysis of a multidimensional, modular, and specific parenting construct. *Developmental Psychology*, 44(3), 867.

BPS (2009). *Code of Ethics and Conduct*. Leicester: The British Psychological Society
2009.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. sage.

Brockington, I. F., (2004). Postpartum psychiatric disorders. *The Lancet*, 363(9405), 303-310.

Brockington, I. F., Fraser, C., & Wilson, D. (2006). The Postpartum Bonding Questionnaire: a validation. *Arch Womens Ment Health*, 9, 233-242.

Brockington, I. F., Oates, J., George, S., Turner, D., Vostanis, P., Sullivan, M., ... & Murdoch, C. (2001). A Screening Questionnaire for mother-infant bonding disorders. *Arch Womens Ment Health*, 3, 133-140.

Campbell, N. C., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., ... & Kinmonth, A. L. (2007). Designing and evaluating complex interventions to improve health care. *BMJ: British Medical Journal*, 334(7591), 455.

Chandra, P. S., Bhargavaraman, R. P., Raghunandan, V. N. G. P., & Shaligram, D. (2006). Delusions related to infant and their association with mother-infant

- interactions in postpartum psychotic disorders. *Archives of Women's Mental Health*, 9(5), 285–8.
- Chernomas, W. M., Clarke, D. E., & Chisholm, F. A. (2000). Perspectives of women living with schizophrenia. *Psychiatric Services*, 51(12), 1517-1521.
- Chotai. (2016). Postpartum Psychosis and Beyond: Exploring Mothers' Experiences of Postpartum Psychosis and Recovery. *Thesis*, (August).
- Darvill, R., Skirton, H., & Farrand, P. (2010). Psychological factors that impact on women's experiences of first-time motherhood: A qualitative study of the transition. *Midwifery*, 26(3), 357–366.
- Demo, D. H., & Cox, M. J. (2000). Families with young children: A review of research in the 1990s. *Journal of Marriage and Family*, 62(4), 876-895.
- Diaz-Caneja, A., & Johnson, S. (2004). The views and experiences of severely mentally ill mothers. *Social Psychiatry and Psychiatric Epidemiology*, 39(6), 472-482.
- Ding, X. X., Wu, Y. L., Xu, S. J., Zhu, R. P., Jia, X. M., Zhang, S. F., ... & Tao, F. B. (2014). Maternal anxiety during pregnancy and adverse birth outcomes: a systematic review and meta-analysis of prospective cohort studies. *Journal of affective disorders*, 159, 103-110.
- Dolman, C., Jones, I., & Howard, L. M. (2013). Pre-conception to parenting: A

systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness. *Archives of Women's Mental Health*, 16(3), 173–196.

Doucet, S., Dennis, C. L., Letourneau, N., & Blackmore, E. R. (2009). Differentiation and clinical implications of postpartum depression and postpartum psychosis. *JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 38(3), 269–279.

Edwards, E., & Timmons, S. (2005). A qualitative study of stigma among women suffering postnatal illness.

Emmanuel, E. N., Creedy, D. K., St John, W., & Brown, C. (2011). Maternal role development: The impact of maternal distress and social support following childbirth. *Midwifery*, 27(2), 265–272.

Engqvist, I., & Nilsson, K. (2013). Involving the family in the care and treatment of women with postpartum psychosis: Swedish psychiatrists' experiences. *Psychiatry J.*

Forman, D. R., O'hara, M. W., Stuart, S., Gorman, L. L., Larsen, K. E., & Coy, K. C. (2007). Effective treatment for postpartum depression is not sufficient to improve the developing mother–child relationship. *Development and psychopathology*, 19(2), 585-602.

- Francis, J. J., Johnston, M., Robertson, C., Glidewell, L., Entwistle, V., Eccles, M. P., & Grimshaw, J. M. (2010). What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology and Health*, 25(10), 1229-1245.
- Friedman, S. H., & Resnick, P. J. (2009). Neonaticide: Phenomenology and considerations for prevention. *International journal of law and psychiatry*, 32(1), 43-47.
- Fugard, A. J., & Potts, H. W. (2015). Supporting thinking on sample sizes for thematic analyses: a quantitative tool. *International Journal of Social Research Methodology*, 18(6), 669-684.
- Gillham, R., & Wittkowski, A. (2015). Outcomes for women admitted to a mother and baby unit: A systematic review. *International Journal of Women's Health*, 7, 459–476.
- Glangeaud-Freudenthal, N. C., Sutter, A. L., Thieulin, A. C., Dagens-Lafont, V., Zimmermann, M. A., Debourg, A., ... & Poinso, F. (2011). Inpatient mother-and-child postpartum psychiatric care: factors associated with improvement in maternal mental health. *European Psychiatry*, 26(4), 215-223.
- Glover, L., Jomeen, J., Urquhart, T., & Martin, R. (2014). Puerperal psychosis – a qualitative study of women's experiences. *Journal of Reproductive & Infant Psychology*, 32(3), 254–270.

- Göpfert, M., Webster, J., Pollard, J., & Nelki, J. S. (1996). The assessment and prediction of parenting capacity: A community-oriented approach.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*, 24(2), 105-112.
- Grube, M. (2005). Inpatient treatment of women with postpartum psychiatric disorders- The role of the male partners. *Archives of Women's Mental Health*, 8(3), 163–170.
- Gutman, L. M., Brown, J., & Akerman, R. (2009). Nurturing parenting capability: The early years. *Wider Benefits of Learning Research Report*, (30).
- Harries, V., & Brown, A. (2017). Early Child Development and Care The association between use of infant parenting books that promote strict routines, and maternal depression, self-efficacy, and parenting confidence.
- Harvard T.H. Chan, School of Public Health. *The Maternal Health Task Force (MHTF)*. The Women and Health Initiative. Boston.
- HCPC (2012). *Health and Care Professions Council - Standards of conduct, performance and ethics*.
- Heron, J., Gilbert, N., Dolman, C., Shah, S., Beare, I., Dearden, S., ... Ives, J. (2012). Information and support needs during recovery from postpartum psychosis.

Archives of Women's Mental Health, 15(3), 155–165.

Heron, J., McGuinness, M., Blackmore, E. R., Craddock, N., & Jones, I. (2008). Early postpartum symptoms in puerperal psychosis. *BJOG: An International Journal of Obstetrics and Gynaecology*, 115(3), 348–353.

Herrenkohl, T. I., Kosterman, R., Mason, W. A., Hawkins, J. D., McCarty, C. A., & McCauley, E. (2010). Effects of childhood conduct problems and family adversity on health, health behaviors, and service use in early adulthood: Tests of developmental pathways involving adolescent risk taking and depression. *Development and Psychopathology*, 22(3), 655-665.

Hipwell, A. E., & Kumar, R. (1996). Maternal psychopathology and prediction of outcome based on mother-infant interaction ratings (BMIS). *The British Journal of Psychiatry*, 169(5), 655-661.

Holford, C., Psychology, C., & Wales, S. (2016). The Impact of Postpartum Psychosis on Partners Supervised by : Dr Sue Channon Professor Ian Jones, (May).

Holloway, I., & Todres, L. (2003). The status of method: flexibility, consistency and coherence. *Qualitative research*, 3(3), 345-357.

Hornstein, C., Trautmann-Villalba, P., Hohm, E., Rave, E., Wortmann-Fleischer, S., & Schwarz, M. (2006). Maternal bond and mother-child interaction in severe postpartum psychiatric disorders: Is there a link? *Archives of Women's Mental*

Health, 9(5), 279–284.

Howard, L. M., Goss, C., Leese, M., Appleby, L., & Thornicroft, G. (2004). The psychosocial outcome of pregnancy in women with psychotic disorders. *Schizophrenia research*, 71(1), 49-60.

Jones, I., Chandra, P. S., Dazzan, P., & Howard, L. M. (2014). Bipolar disorder, affective psychosis, and schizophrenia in pregnancy and the post-partum period. *The Lancet*, 384(9956), 1789–1799.

Jones, I., & Craddock, N. (2005) cited in Heron, J., Gilbert, N., Dolman, C., Shah, S., Beare, I., Dearden, S., ... Ives, J. (2012). Information and support needs during recovery from postpartum psychosis. *Archives of Women's Mental Health*, 15(3), 155–165.

Kenny, M., Conroy, S., Pariante, C. M., Seneviratne, G., & Pawlby, S. (2013). Mother-infant interaction in mother and baby unit patients: Before and after treatment. *Journal of Psychiatric Research*, 47(9), 1192–1198.

Kirpinar, I., CosLkun, I., Çayköylü, A., & Özer, S. A. H. (1999). First-case postpartum psychoses in Eastern Turkey: a clinical case and follow-up study. *Acta Psychiatrica Scandinavica*, 100(3), 199–204.

Krippendorff, K. (2004). Reliability in content analysis. *Human communication research*, 30(3), 411-433.

Lagan, M., Knights, K., Barton, J., & Boyce, P. M. (2009). Advocacy for mothers with psychiatric illness: A clinical perspective. *International Journal of Mental Health Nursing*, 18(1), 53–61.

Leahy Warren, P. (2005). First-time mothers: Social support and confidence in infant care. *Journal of advanced nursing*, 50(5), 479-488.

Logsdon, M. C., Birkimer, J. C., & Usui, W. M. (2000). The link of social support and postpartum depressive symptoms in African-American women with low incomes. *MCN: The American Journal of Maternal/Child Nursing*, 25(5), 262-266.

Main, T. F. (1958). Mothers with children in a psychiatric hospital. *The Lancet*, 272(7051), 845-847.

Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3).

Maternal Mental Health Alliance (2011). *Everyone's Business*. England and Wales.

McGlashan, T. H. (1987). Recovery style from mental illness and long-term outcome. *Journal of nervous and Mental Disease*, 175(11), 681-685.

McGrath, L., Peters, S., Wieck, A., & Wittkowski, A. (2013). The process of recovery in women who experienced psychosis following childbirth. *BMC Psychiatry*,

13(January 2016), 341–351.

Meins, E., Fernyhough, C., Fradley, E., & Tuckey, M. (2001). Rethinking Maternal Sensitivity : Mothers' Comments on Infants' Mental Processes Predict Security of Attachment at 12 Months. *J. Child Psychol. Psychiat. Association for Child Psychology and Psychiatry*, 42(5), 637–648.

Munk-Olsen, T., Laursen, T. M., Pedersen, C. B., Mors, O., & Mortensen, P. B. (2006). New parents and mental disorders: a population-based register study. *Jama*, 296(21), 2582-2589.

Munk-Olsen, T., Jones, I., & Laursen, T. M. (2014). Birth order and postpartum psychiatric disorders. *Bipolar Disorders*, 16(3), 300–307.

Murray, L., Cooper, P., & Hipwell, A. (2003). Mental health of parents caring for infants. *Archives of Women's Mental Health*, 6(0), s71–s77.

Murray, L., Halligan, S. L., Goodyer, I., & Herbert, J. (2010). Disturbances in early parenting of depressed mothers and cortisol secretion in offspring: A preliminary study. *Journal of Affective Disorders*, 122, 218–223.

Nager, A., Johansson, L. M., & Sundquist, K. (2005). Are sociodemographic factors and year of delivery associated with hospital admission for postpartum psychosis?

A study of 500 000 first-time mothers. *Acta Psychiatrica Scandinavica*, 112(1), 47-53.

Nager, A., Szulkin, R., Johansson, S.-E., Johansson, L.-M., & Sundquist, K. (2013). High lifelong relapse rate of psychiatric disorders among women with postpartum psychosis. *Nordic Journal of Psychiatry*, 67(1), 53–58.

Nelson, A. M. (2003). Transition to motherhood. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 32(4), 465-477.

National Institute for Health and Care Excellence (2007). *Antenatal and postnatal mental health: clinical management and service guidance*.

National Institute for Health and Care Excellence (2014). *Antenatal and postnatal mental health: clinical management and service guidance*.

NHS (2017). Next Steps on the NHS Five Year Forward View.

Noorlander, Y., Bergink, V., & van den Berg, M. P. (2008). Perceived and observed mother-child interaction at time of hospitalization and release in postpartum depression and psychosis. *Archives of Women's Mental Health*, 11(1), 49–56.

Office of National Statistic (2016). *Births by parents' characteristics in England and Wales: 2016*.

- Perun, M. (2013). Maternal identity of women in the postpartum period. *The Journal of Education Culture and Society*, (1), 95–105.
- Peters, S. (2010). Qualitative research methods in mental health. *Evid Based Ment Health*, 13(2), 35-40.
- Pfuhmann, B., Stoeber, G., & Beckmann, H. (2002). Postpartum psychoses: prognosis, risk factors, and treatment. *Current Psychiatry Reports*, 4(3), 185-190.
- Philipp, D., Fivaz-Depeursinge, E., Corboz-Warnery, A., & Favez, N. (2009). Young infants' triangular communication with their parents in the context of maternal postpartum psychosis: Four case studies. *Infant Mental Health Journal*, 30(4), 341–365.
- Plunkett, C., Peters, S., Wieck, A., & Wittkowski, A. (2017). A qualitative investigation in the role of the baby in recovery from postpartum psychosis. *Clinical Psychology and Psychotherapy*, (July 2015), 1099–1108.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Version, 1.
- Putnam, F. W. (2003). Ten-year research update review: Child sexual abuse. *Journal of the American Academy of Child & Adolescent Psychiatry*, 42(3), 269-278.

- Rallis, S., Skouteris, H., McCabe, M., & Milgrom, J. (2014). The transition to motherhood: Towards a broader understanding of perinatal distress. *Women and Birth*, 27(1), 68–71.
- Riordan, D., Appleby, L., & Faragher, B. (1999). Mother–infant interaction in postpartum women with schizophrenia and affective disorders. *Psychological medicine*, 29(4), 991-995.
- Ritchie, J., Spencer, L., Bryman, A., & Burgess, R. G. (1994). Analysing qualitative data.
- Robertson, E., & Lyons, A. (2003). Living with puerperal psychosis: a qualitative analysis. TL - 76. *Psychology and Psychotherapy*, 76 (4), 411–431.
- Royal College of Obsestricians & Gynaecologists (2011). *Maternal Mental Health - Women's Voices Report*.
- Sands, R. G. (1995). The parenting experience of low-income single women with serious mental disorders. *Families in Society*, 76(2), 86.
- Sirriyeh, R., Lawton, R., Gardner, P., & Armitage, G. (2012). Reviewing studies with diverse designs: the development and evaluation of a new tool. *Journal of evaluation in clinical practice*, 18(4), 746-752.

- Sit, D., Rothschild, A. J., & Wisner, K. L. (2006). A review of postpartum psychosis. *Journal of women's health, 15*(4), 352-368.
- Smyth, L. (2012). *The demands of motherhood: Agents, roles and recognition*. Springer.
- Spinelli, M. G. (2009). Postpartum psychosis: detection of risk and management. *American Journal of Psychiatry, 166*(4), 405-408.
- Steadman, J., Pawlby, S., Mayers, A., Bucks, R. S., Gregoire, A., Miele-Norton, M., & Hogan, A. M. (2007). An exploratory study of the relationship between mother–infant interaction and maternal cognitive function in mothers with mental illness.
- Stein, A., Craske, M. G., Lehtonen, A., Harvey, A., Savage-McGlynn, E., Davies, B., ... & Counsell, N. (2012). Maternal cognitions and mother–infant interaction in postnatal depression and generalized anxiety disorder. *Journal of Abnormal Psychology, 121*(4), 795.
- Stein, A., Pearson, R. M., Goodman, S. H., Rapa, E., Rahman, A., Mccallum, M., ... Pariente, C. M. (2014). Perinatal mental health: Effects of perinatal mental disorders on the fetus and child. *The Lancet, 384*, 1800–1819.
- Taylor, A., Atkins, R., Kumar, R., Adams, D., & Glover, V. (2005). A new Mother-to-Infant Bonding Scale: links with early maternal mood. *Archives of Women's Mental Health, 8*(1), 45-51.

- Taylor, G. W., & Ussher, J. M. (2001). Making sense of S&M: A discourse analytic account. *Sexualities*, 4(3), 293-314.
- The Breastfeeding Network (2014). *Breastfeeding and Perinatal Mental Health: Bipolar Disorder and Breastfeeding*.
- Thiels, C., & Kumar, R. (1987). Severe puerperal mental illness and disturbances of maternal behaviour. *Journal of Psychosomatic Obstetrics & Gynecology*, 7(1), 27-38.
- Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & health sciences*, 15(3), 398-405.
- Wan, M., & Green, J. (2009). The impact of maternal psychopathology on child-mother attachment.
- Wilkins, C. (2006). A qualitative study exploring the support needs of first-time mothers on their journey towards intuitive parenting. *Midwifery*, 22(2), 169-180.
- Wisner, K. L., Jennings, K. D., & Conley, B. (1996). Clinical dilemmas due to the lack of inpatient mother-baby units. *The International Journal of Psychiatry in Medicine*, 26(4), 479-493.

World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Wray, N., Markovic, M., & Manderson, L. (2007). Researcher saturation: The impact of data triangulation and intensive-research practices on the researcher and qualitative research process. *Qualitative Health Research*, 17, 1392–1402.

Wyatt, C., Murray, C., Davies, J., & Jomeen, J. (2015). Postpartum psychosis and relationships: their mutual influence from the perspective of women and significant others. *Journal of Reproductive and Infant Psychology*, 33(4), 426–442.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, 15(2), 215-228.

Yonkers, K. A., Smith, M. V., Forray, A., Epperson, C. N., Costello, D., Lin, H., & Belanger, K. (2014). Pregnant women with posttraumatic stress disorder and risk of preterm birth. *Jama Psychiatry*, 71(8), 897-904.

APPENDIX

APPENDIX 1: Participant Information Sheet

Understanding Psychological Processes of Mothering in Women with Postpartum Psychosis

Information Sheet for Participants

You are being invited to take part in a research project being carried out as part of a Clinical Psychology Doctorate at Royal Holloway, University of London. This project has been reviewed and approved by RES Committee London – Camden and Kings Cross, which means it has received NHS ethical approval.

Joining the study is entirely up to you and it is important that you understand why the research is being done and what participation would involve for you before you decide to take part. Please take the time to read the following information carefully and feel free to ask if there is anything that is not clear or if you would like more information. You may also wish to talk to others about the study before deciding whether you wish to take part. Thank you for taking the time to read this.

Why the research is important

Postpartum Psychosis affects 1-2 women in every 1000 births and can develop in women with no previous psychiatric difficulties. While there is considerable evidence that the mental health function of women and aspects of infant care are affected by postpartum psychosis, little is known about the impact of this diagnosis on mother's own experience of early mothering and the mother-infant relationship. This research aims to explore this with mothers who have recently experienced postpartum psychosis.

What the study involves

The research hopes to recruit mothers who have received a diagnosis of postpartum psychosis in the last 6-18 months with no previous psychiatric history. If you agree to take part, a suitable time and place for an interview will be arranged. This will be a one-off interview either at your home, at Royal Holloway University of London, 11 Bedford Square London WC1B 3RF, or in your clinical setting (either Mother and Baby Unit or perinatal mental health team base) with researcher, Siobhan Kelly (Trainee Clinical Psychologist). In the interview, you will be asked about your experience of becoming a mother with postpartum psychosis. This interview should last no longer than 90 minutes. Unfortunately, it is not possible to provide childcare arrangements for this time, but maximum flexibility will be provided on time and location of interview.

Data storage

Interviews will be recorded and stored securely to be typed out. Audiotapes/audio files will be destroyed once transcribed. Transcriptions will be stored anonymously and securely at Royal Holloway University of London for research and audit purposes.

Once the study has ended, the data will be retained by the lead supervisor, Dr Olga Luzon, Royal Holloway University of London. Hard copies of data may need to be stored securely for up to five years following publication in a scientific journal for audit purposes. However, to minimise the need for physical storage, hard copies will be scanned and stored in electronic form whenever possible.

Signed consent forms will be kept separately (by Dr Olga Luzon) as these are frequently audited for research governance monitoring. These will be kept for at least two years and then destroyed. If possible, these will be kept apart from the corresponding anonymised data to guard against potentially identifying participants.

Extracts from your interview will be used to inform the results of the project and all identifiable information will be removed. A summary of the results of this study will be made available to all research participants.

What are the benefits of taking part?

There are no explicit direct benefits, but by helping researchers understand the experience of postpartum psychosis from the mother's perspective, information from this project may be able to help others going through similar experiences.

Participation is voluntary, and you will not be paid for your involvement. However, travel costs will be reimbursed if you decide to travel to be interviewed.

What are the risks of taking part?

Talking about this difficult time in your life can be distressing. Interviews will be conducted by a Trainee Clinical Psychologist with clinical experience who will be able to help you through this process and provide you with contact numbers for further support. Your clinical care team will also be informed of your participation in the study. It is advised that you arrange childcare for the interview process and afterwards should you become upset when talking about your experience of postpartum psychosis. Yours and your child's wellbeing are of upmost important to participation in the project.

Participants' rights

It is completely up to you to decide whether to take part in this study. If you do decide to take part, then please be assured of the following:

- You can decide to stop the interview at any point and you do not have to answer any questions if you do not want to
- You can decide to stop being part of the research at any time
- You do not need to explain your reasons for any of the above and this does not affect your clinical care
- If you decide to stop the interview or stop being part of the research, then your interview data will be destroyed and will not be used in the project

If you have questions or concerns about this research then please contact the researcher, Siobhan Kelly (details below), or her supervisor, *Dr Olga Luzon* (olga.luzon@rhul.ac.uk). If you remain unhappy then please contact the Trust's Chief Executive or Complaints Department at *Complaints Department, Maudsley Hospital, 111 Denmark Hill, London, SE5 8AZ, telephone: 020 3228 2444/2499 or email: complaints@slam.nhs.uk*.

Confidentiality

With permission, your contact details will be passed on to the researcher by your clinical care team and you will be contacted to discuss the project. All information will remain confidential and has been approved by NHS and University ethics. Your name will be removed from all information and the interview data will be made anonymous. You will have the right to withdraw at any stage of the research. Confidentiality will only be breached when a risk to yourself, your child or others becomes known to the researcher. Unless otherwise indicated, the researcher will share her concerns with you and the actions she recommends being taken.

FURTHER INFORMATION

If you are interested in finding out more about taking part in this study, please let your clinical team know and your contact details will be passed on to the researcher. Alternatively, please contact Siobhan Kelly at **siobhan.kelly.2015@live.rhul.ac.uk**. Arrangements will then be made directly with you to discuss the project and to conduct the interview should you wish to participate.

This project is supervised by:

Dr Olga Luzon

Clinical Psychologist

Royal Holloway, University of London

Dr Crispin Day

Clinical Psychologist

Kings College London

APPENDIX 2: Participant Consent Form

Understanding Psychological Processes of Mothering in Women with Postpartum Psychosis

Participant Identification Number: _____

Please
initial
box

1. I confirm that I have read the information sheet dated 10th August 2017 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my treatment being affected. ☐
3. I agree to take part in a research interview and for this interview to be recorded. Extracts from this interview can be used for research purposes and will be anonymised. ☐
4. I understand that the information collected about me will be kept securely and anonymously ☐
5. I agree to my clinical care team [INSERT NAME OF SERVICE] being informed of my participation in the study. ☐
6. I understand that confidentiality may be breached if there are concerns for the safety of myself, my child(ren) or others, and that this will be discussed with me and my clinical care team unless otherwise indicated. ☐
7. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix 3: Participant Debrief Information

Understanding Psychological Processes of Mothering in Women with Postpartum Psychosis

Thank you for your participation in this research study.

The purpose of this research is to understand the mother-infant relationship in mothers who have recently experienced postpartum psychosis. We hope to learn more about what this experience is like from the mothers' perspective in the early stages of mothering to improve understanding for professionals and families who go through these experiences.

Your participation in this study is greatly appreciated, and any contribution you have made will be treated in the strictest confidence. However, if you wish to withdraw any data you may do so now and will not be asked to give a reason.

Who can I contact if I have any questions or need some support?

If you have any additional questions regarding this research, please feel free to ask them now.

If you have additional questions at a later date please contact the researcher (Siobhan Kelly) at Siobhan.kelly.2015@live.rhul.ac.uk , or the study supervisor (Dr. Olga Luzon) at: olga.luzon@rhul.ac.uk.

If you require additional support as a result of taking part in this study, please speak to your care co-ordinator or another member of your perinatal mental health team.

Other contacts you mind find helpful are listed on the next page.

Useful contacts:

You can contact your care co-ordinator or GP for additional help and support.

Action on Postpartum Psychosis

app-network.org

APP is a network of women across the UK and further afield who have experienced PP. It is a collaborative project run by women who have experienced PP and academic experts from Birmingham and Cardiff Universities.

Pandas Foundation

Helpline: 0843 2898 401
pandasfoundation.org.uk

Pandas Foundation is the leading UK charity in supporting families suffering from pre (antenatal) and postnatal depression and psychosis. Offering sufferers and their families support and advice to help aid their recovery.

Postpartum Progress

postpartumprogress.com

Postpartum Progress® is the world's most widely-read blog on postpartum depression and all other mental illnesses related to pregnancy and childbirth, including: postpartum anxiety, postpartum OCD, depression during pregnancy (antenatal depression), post-adoption depression, postpartum PTSD, depression after miscarriage or perinatal loss and postpartum psychosis. We focus on positive messages of empowerment and recovery, because PPD is temporary and treatable with professional help.

Perinatal Illness UK

pni-uk.com

For women and their families who have or think they have any kind of perinatal illness, including antenatal depression, postnatal depression, puerperal psychosis and birth trauma. Online message boards and chatrooms are available.

Puerperal Psychosis and Postnatal Depression Support

puerperalpsychosis.org.uk

This site is here to support new mothers who are having trouble being mothers, and their partners. Its main focus is a condition called puerperal psychosis, but we also cover postnatal depression and the baby blues, treatments, help and a forum if you want to talk to like-minded people.

What shall I do if I am in crisis and I am worried that I might harm myself or another person?
Call 999 and ask for help. Alternatively, you can go to your nearest Accident & Emergency department (A&E).

Appendix 4: Risk Management Protocol

Risk management has been an important consideration for the research, and the following guidelines will be adhered to during the course of the study:

- Each referral to the study is likely to have had a full risk assessment as they will be known to mental health services and have a care co-ordinator and community perinatal mental health team. All participants will have had a brief assessment of risk completed to be deemed appropriate to participate in the study.
- Details of any risks presented will be requested by Siobhan Kelly (SK) at the time of referral to the study.
- If prior to the initial contact there is any indication that risk is present from the assessment, the referral will be deemed to be unsuitable and therefore the researcher will not contact them.
- Any observations made by SK in the course of the interview which would have implications for the safety of the participant, for children, or any others will be reported to the care coordinator or any person with immediate responsibility for the care immediately.
- SK will inform staff of the location and length of interview if interviews are conducted on NHS sites, and there will always be within working hours, at clinical sites with senior cover.
- SK will inform supervisor, Dr Olga Luzon, of location and time of interviews conducted in participant homes or university campus and make contact when interviews have been completed. This is in line with Camden and Islington's NHS Foundation Trust's Lone Working Policy.
- If risk arises immediately during the interview, SK will need to monitor safety and contact the care coordinator or duty supervisor for further instructions to manage the situation. Any concerns for risk will always be reported back to the participant's perinatal mental health team or care coordinator.
- SK will follow Camden and Islington's NHS Foundation Trust's Lone Working Policy at all times and risk assess locations of interviews, suitability of interview rooms, be aware of exits and have a specific plan in place for each interview arranged with supervisor, Dr Olga Luzon, and the participant's perinatal mental health team.

Appendix 5: HRA Ethical Approval



Health Research
Authority

London - Camden & Kings Cross Research Ethics Committee

Jarow Business Centre
Rolling Mill Road
Jarow
NE32 3DT

Telephone: 0207 104 8086

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

08 August 2017

Ms Siobhan Kelly
Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Doctorate in Clinical Psychology Programme, Bowyer Building
Royal Holloway University of London
Egham, Surrey
TW20 0EX

Dear Ms Kelly

Study title: Understanding Psychological Processes of Mothering in Women with Postpartum Psychosis (PPP)
REC reference: 17/LO/0993
IRAS project ID: 225325

Thank you for your letter of 2nd August, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation

as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|--|---------|------------------|
| Copies of advertisement materials for research participants [Participant Advert] | v2 | 24 May 2017 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance] | v1 | 10 November 2016 |
| GP/consultant information sheets or letters [HCP Information Sheet] | v1 | 27 March 2017 |
| Interview schedules or topic guides for participants [Draft Interview Schedule] | v4 | 23 June 2017 |
| IRAS Application Form [IRAS_Form_09062017] | | 09 June 2017 |
| Other [External supervisor CV] | v1 | |
| Other [Demographic questions v1] | v1 | 06 June 2017 |
| Other [APP Recruitment Advert] | v2 | 20 July 2017 |
| Other [Responses to the REC] | v1 | 20 July 2017 |
| Participant consent form [Participant Consent Form] | v2 | 20 July 2017 |
| Participant information sheet (PIS) [Participant Information Sheet] | v2 | 20 July 2017 |
| Research protocol or project proposal [Main Research Proposal] | v2 | 27 January 2017 |
| Summary CV for Chief Investigator (CI) [Siobhan Kelly CV] | v1 | 11 May 2017 |
| Summary CV for student [Siobhan Kelly CV] | v1 | 11 May 2017 |
| Summary CV for supervisor (student research) [Internal supervisor CV] | v1 | 20 February 2017 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

17/LQ/0993

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Mrs Rosie Glazebrook
Chair

Email: nrescommittee.london-camdenandkingscross@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Annette Lock
Ms Farzana Khanom, Joint R & D Office of SLaM NHS Foundation Trust
and Institute of Psychiatry, Psychology & Neuroscience (IoPPN)

Appendix 6: Royal Holloway University of London Ethical Approval



Ethics Review Details

| | |
|---|---|
| You have chosen to self certify your project. | |
| Name: | Kelly, Siobhan (2015) |
| Email: | Siobhan.kelly.2015@live.rhul.ac.uk |
| Title of research project or grant: | Understanding Psychological Processes of Mothering in Women with Postpartum Psychosis |
| Project type: | Royal Holloway postgraduate research project/grant |
| Department: | Psychology |
| Academic supervisor: | Olga Luzon |
| Email address of Academic Supervisor: | olga.luzon@rhul.ac.uk |
| Funding Body Category: | No external funder |
| Funding Body: | |
| Start date: | 04/09/2017 |
| End date: | 01/06/2018 |

Research question summary:

What is the experience of the mother-infant relationship in the context of postpartum psychosis?

Research method summary:

6-10 mothers with a diagnosis of postpartum psychosis will be recruited from South London and Maudsley NHS Foundation Trust perinatal mental health teams and online postpartum psychosis support forums. Participants will be interviewed using a semi-structured interview schedule devised with service user involvement. Interviews will be exploring the mother-infant relationship in the context of postpartum psychosis and will be analysed using thematic analysis.

Risks to participants

Does your research involve any of the below? Children (under the age of 16),
No

Participants with cognitive or physical impairment that may render them unable to give informed consent, No

Participants who may be vulnerable for personal, emotional, psychological or other reasons, Yes

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),
Yes

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),
No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),
No

Details,

Capacity to consent to take part in this research is vital to determine prior to participation. This will be informed by clinicians of recruitment sites, which will be established at selection stage. Exclusion criteria for the sample also clarifies that participants must not be seeking

psychological intervention at the time of the research, except for treatment targeting postpartum psychosis and post-natal support to ensure safety of all participants' needs. Details of any specific postpartum psychosis interventions will be gathered from participants.

All participants will need to provide informed consent and be debriefed. Participants will be identified by unique codes to ensure anonymity and will be reminded of their right to withdraw at any stage of the research. A risk assessment/management protocol will also be put in place.

Due to the nature of this research involving interviewing mothers about a distressing and emotive experience for them, it will be vital for researcher, SK, to monitor psychological status throughout interviews, which will be delivered with upmost sensitivity. It will be important to outline the potential for interviews to generate distress and evoke unpleasant memories; giving participants the option to stop or take breaks at any time. Participants will be informed about the clinical experience of SK to aid comfort and understanding regarding the emotive subject of postpartum psychosis.

Confidentiality and risk protocol will also be made explicit at the beginning of the interview and reviewed at the end of the session. Participants will be offered support and crisis numbers, and consent will be reconfirmed at the end of the interview to ensure genuine consent from all participants. As a trainee clinical psychologist, SK will also check-in regarding self-care and support following the nature of the interview to ensure participant safety. All participants will also have contact details for SK should they wish to withdraw at any later stage of the research.

Risk to the child(ren) will be of significant importance within the risk assessment/management protocol and be made clear to all participants.

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time? No

Is there a risk that participants may be or become identifiable? No

Is pain or discomfort likely to result from the study? No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?
No

Does this research require approval from the NHS? Yes

If so what is the NHS Approval number, 17/LO/0993

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?
No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project? No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use? No

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?
No

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures? No

Details,

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artefacts? No

Will the research be undertaken on private or government property without permission? No

Will geological or sedimentological samples be removed without permission? No

Will cultural or archaeological artefacts be removed without permission? No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)? No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?
Yes

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?
No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?

No

Is there any reputational risk concerning the source of your funding? No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute? No

Details,

In the event that participants disclose any information that will be deemed as concerning in terms of risk to self or others (and in particular children), the researcher will pass this information to the relevant clinician or duty person in the clinical team. Should this occur with women recruited online, SK will call her supervisor to discuss actions. This will be made very clear to all participants at the beginning of the interview before informed consent is obtained. This is also outlined in the informed consent form.

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, PCVA047

| | |
|--------------------|---|
| Date: | 16/01/2018 11:01 |
| Signed by: | Kelly, Siobhan (2015) |
| Digital Signature: | Siobhan Kelly |
| Certificate dated: | 1/16/2018 11:22:13 AM |
| Files uploaded: | NHS Ethical Approval 225325%2c 17.LO.0993 Further Info Fav Opinion 08.08.17.pdf Full-Review-596-2017-08-10-16-23-PCVA047.pdf Full-Review-596-2017-08-10-16-57-PCVA047.pdf Full-Review-596-2017-08-10-17-00-PCVA047.pdf Full-Review-596-2018-01-12-10-41-PCVA047.pdf |

Appendix 7: SLAM R&D Approval

Dear Ms Kelly,

IRAS ID: 225325

Study Title: Understanding Early Mothering in Women with Postpartum Psychosis

Sponsor: Royal Holloway University of London

Trust R&D Ref: R&D2017/092

Please take this e-mail as confirmation that South London and Maudsley NHS Foundation Trust (SLaM) has the capacity and capability to host this research study. This study can therefore now commence at SLaM. Your Trust reference number has been quoted above and should be used at all times when contacting this office about this study. Please read the conditions outlined below and keep a copy of this email for future reference.

The confirmation of capacity and capability to host this research study relates to work in the **Psychological Medicine and Integrated Care CAG** and to the specific protocol and informed consent procedures described in approved by the REC and the HRA. Any deviation from this will be deemed to invalidate this confirmation.

You have committed to recruit **10 participants** between **16th November 2017** and **29th June 2018**.

There is a mandatory requirement that your study team provides monthly accrual / recruitment data as requested – completion of this is a condition of your continuation of SLaM approval of this study. All research studies taking place in SLaM are required to report recruitment weekly onto EDGE, our Local Patient Management System. Please find additional guidance attached, we will be in contact with you shortly to set this up.

Honorary contracts: Members of the research team must have appropriate substantive or honorary contracts or letters of access (as appropriate) with the Trust prior to conducting any research on Trust premises. Any additional researchers who join the study at a later stage must also hold a suitable contract or must contact the R&D department to arrange an honorary contract/letter of access. For any researchers requiring an honorary contract or letter of access via their research passport, please contact the R&D office to organise this for you.

Protocol Amendments: Please alert the R&D Department if there is an amendment to the study. An amendment may include changes to study documentation, a decision to use advertising, changes to staff or revisions to study timelines. Trust confirmation of capacity and capability must be issued prior to the implementation of any amendment. As SLaM is the co-sponsor for this study, any changes to the study including changes to the protocol and/or other study documents, addition of new sites, addition of new funding, change in the end date of the study must be notified to the SLaM/IoPPN R&D Department for review prior to submission to the HRA or implementation of the changes.

Study status, annual progress reports and end of study declaration reports: Under the Research Governance Framework, SLaM maintains responsibility for keeping an accurate record of study status for all research on Trust premises. Please notify the R&D department if your study ends before the end date declared on your original application.

Annual Progress Reports: <http://www.hra.nhs.uk/resources/during-and-after-your-study/nhs-rec-annual-progress-report-forms/> The Chief Investigator must submit an annual progress report to the Health Research Authority, sending a copy to the R&D department at each participating site. These reports must be sent each year on or before the anniversary of the Health Research Authority Ethics approval.

End of study declaration forms: <http://www.hra.nhs.uk/research-community/end-of-study-and-beyond/notifying-the-end-of-study/> The Chief Investigator of a study must notify the Health Research Authority, within 90 days of the end of a study, sending a copy to the R&D department at each participating site.

Within SLaM, please also send a copy of any reports or publications which result from this study to the Trust Departments involved in the study if requested.

Compliance with Trust policies and procedures: All policies and procedures of the Trust which relate to research must be complied with: <http://www.slam.nhs.uk/about-us/policy-and-publications/policies-and-procedures>

SLaM Consent for Contact (C4C): If your study is planning to recruit Trust patients via the SLaM C4C initiative, please now complete and submit the online application here: <http://www.slam.nhs.uk/research/cris/cris-project-application> which includes sections for C4C. The application will be reviewed by the CRIS oversight committee and once approved you will be provided with instructions on how to access CRIS to identify Trust patients who have consented to be contacted for research. Please be aware this is the correct Trust route for identifying patients who have consented to be contacted for research and searches on epjs should not be conducted outside of this process.

Adverse events / complaints: Please inform the Trust's Health and Safety Coordinators and/or the Complaints Department or of any adverse events or complaints, from participants recruited from within this Trust, which occurs in relation to this study in line with Trust policies. Contact details are available from the R&D Office if required.

Audit and Inspection: The Chief Investigator must notify the R&D department as soon as they receive notification of an inspection by an external body. Your study may be inspected by the Trust internally at any point.

Best wishes,

Carol

Carol Cooley

Research Governance Facilitator
Joint R&D Office of South London and Maudsley NHS Foundation Trust
and Institute of Psychiatry, Psychology & Neuroscience (IoPPN)

R&D Office (POO5)
Room W1.08, IoPPN Main Building
King's College London, De Crespigny Park, London SE5 8AF

Tel: 020 7848 0339
Email: carol.cooley@kcl.ac.uk / slam-ioppn.research@kcl.ac.uk

Visit the R&D Office web pages at
<http://www.kcl.ac.uk/ioppn/research/office/index.aspx>

Appendix 8: Semi-Structured Interview Schedule

Interview set-up (5mins):

- Introduce self – experience as a clinician and wanting to understand personal experiences*
**use interviewee's words for PPP*
- Explain confidentiality (including recording) and safeguarding
- Inform about support available (check childcare arrangements)
- **Review participant information sheet and go through consent form**
 - *Have risk-management protocol to hand*
- Remind that interview has been drawn with mum whose gone through similar experiences
- Explain process of interview, e.g. some general questions first followed by more open discussion. May feel repetitive at times but important to establish how your experience has evolved over time
- State can pause at any time, if process is too difficult, stop interview at any time
- Clarify that it is common for some details of this period to be difficult to remember – normalise, validate (short-lived), opportunity to discuss
- Any questions before we start?

This interview will focus on your experiences as a mother, from finding out you were pregnant to how things are now. I understand that this can be a difficult and upsetting topic, so please let me know if you wish to pause or find this too challenging at present, but it would be helpful to help us understand these experiences from mum's point of view

Pregnancy (10mins)

Q: Looking back now, during your pregnancy, what was your sense of becoming a mother?

P: What thoughts and feelings did you have about being a mother?

Q: How did these develop, change or evolve over the course of your pregnancy?

P: From, perhaps even before you found out you were pregnant, to the weeks and days leading up to giving birth?

P: What about your thoughts and feelings towards your little one during pregnancy?

P: How did these evolve and develop over the course of your pregnancy?

Birth (10mins)

Q: What was it like in the period leading up to going into labour and XXX being born?

P: How did you feel as a mother and in becoming a mother?

P: What was the meaning of labour and birth for you as a mother?

P: How did it affect your sense of being a mother, your feelings about being a mum, and your feelings about your little one?

Q: What do you remember about how you felt/any thoughts you had when you first saw your baby?

P: Emotions, feelings, beliefs, comments from others

P: Were you able to hold your baby straight away, care for them, stay in hospital, breastfeed?
What would have been helpful?

First few days (20mins)

Q: What were the first few days like after your child was born?

P: Where were you?

P: Were there any complications/medical interventions?

P: Support around you?

Q: How did you feel about this new role?

P: What thoughts and feelings did you experience about your baby/you?

P: How did this make you feel?

Q: How did you find caring for (use baby's name)?

P: Responding to needs/giving attention?

P: How many days were you in hospital after the birth?

P: What support did you have around you during this time?

Q: How did you find being a new mum/mum again?

P: What are your memories of how you felt towards (baby's name) in the first few days after birth? E.g. when you were feeding him/her, when they were sleeping?

P: What feelings did you have about your baby?

P: Did you feel differently towards (baby's name) when you were able to get back to familiar surroundings after being in hospital?

P: Was there anything that helped/particularly difficult in those first few days?

P: Sometimes mothers experience contradicting feelings in the early days, do you remember experiencing any of these or any difficult feelings towards your baby, their needs, or your role as a mother? (Elation, negative, confusing)

P: Who else was around at that time?

P: Were they involved more with the care of your baby than expected or did you find it helpful to rely on another member of the family?

Postpartum Psychosis (20mins)

The next few questions are about your experience of PPP when you were most unwell, and how that may have impacted on you as a mother and your relationship with your child.

Reminder: some of the questions might be difficult to answer so please feel free to tell me as much or as little as you feel you can. Our aim is to better understand the experiences of mothers to support women in a similar situation to yours.

Q: When did you begin to experience unusual things/feelings (or others noticed) that you may have later understood to be signs of PPP?

P: Where were you?

P: What were the early signs?

P: How did it evolve?

P: What was that like?

Very personal and grateful for sharing difficult info – very impressed with what you've told me so far.

Q: Can you tell me about the thoughts/feelings you had when signs of (what you now know as) PPP began?

P: Did beliefs relate to you, baby, anyone else, voices?

P: How did you feel towards your baby when he/she cried, dealing with their sleeping and feeding routines?

Behavioural impact? What did she do/not?

P: What helped you during that time?

Q: Could you describe how was it for you to be a mother during those days/weeks?

What has your journey of recovery been like so far for you and your baby?

Q: How do you feel your illness affected the way you see yourself as a mum or how you relate to your baby (positive/negative)?

P: How do you feel things would be different if you had not experienced PPP?

P: Can you think of anything that was helpful during this experience?

P: Do you feel there have been positive experiences derived from PPP that have influenced being a mum?

P: What do you feel could have helped with this experience in retrospect from both a clinical and practical point of view? (e.g. could clinicians do anything different/services offer anything more?)

To present time (20mins)

Thinking about the journey of your experiences, it would be helpful to hear a bit more about how

things are for you and (baby's name) now.

Q: How do you feel about your relationship with (baby's name) now?

P: How are you getting on?

P: How are you experiencing being a mum?

Q: How do you see yourself as a mum now?

P: How do you feel on the inside being a mum compared to how others might see you?

P: Can you tell me what has helped or got in the way of you enjoying time with your baby over the last x months?

P: Explore nurturing behaviours, physical and social interaction, and practicalities (smiles, cuddles)

Q: How do you make sense of your experiences now?

Q: Is there anything else which you think might be important for me to know about your relationship with your child following their birth?

Interview debrief (15mins)

- Thank for taking part
- Acknowledge difficulty of topic and certain questions
 - Some of the things we have discussed today might have been rather difficult to remember or talk about, we hope we will get a better understanding of how it is for mums with similar experiences.
 - It's important to highlight that difficulties mothers experience in the early stages of their baby's life are short-lived, which is why we are trying to capture this specific period of motherhood
- How did they find the experience?
- What support available after interview?
- Re-ask for consent
- Remind of contact details for support services and SK if wish to withdraw
- Address need for self-care after emotive period

Appendix 9: Interview transcript with codes

| Participant 01 transcript | Initial codes | Theme/subtheme |
|--|-----------------------|--|
| <p>P: Umm so it's hard to distinguish, what's been really helpful is having a friend, like my best friend gave birth 10 weeks after me</p> <p>R: Ok so you had someone going through motherhood</p> | Support | Where support comes from |
| <p>P: Umm I think I definitely was, yeah, it's just hard isn't it because any new mum will say it's difficult</p> <p>R: Yeah, exactly</p> <p>P: It's just hard to</p> <p>R: Yeah</p> <p>P: Say what</p> <p>R: What's been difficult for you</p> <p>P: What is PPP and what is normal motherhood</p> | Understanding PPP | Expectations vs. reality of motherhood |
| <p>P: I went on umm a thing called mindful mums</p> <p>R: Oh yeah, I think I've heard of that</p> <p>P: Umm and it was quite good because that was just all talking about umm like challenges that mums face and things like that. So, it was quite good just to talk to other women and I was like oh these are like mum problems</p> <p>R: Yeah, yeah</p> <p>P: Not psychosis problems</p> <p>R: Yeah</p> <p>P: So, I just like that made me feel 10 times better umm I think it gave me a bit more confidence as well</p> | Peer support | Where support comes from |
| <p>P: Just speaking to other mums and saying yeah "sometimes this sucks"</p> <p>R: Yeah</p> <p>P: Rather than that glossy motherhood image do you know what I mean</p> | Reality of motherhood | Expectations vs. reality of motherhood |

| | | |
|---|--|----------------------|
| <p>P: But I think they're letting me people down cos</p> <p>R: Yeah, yeah</p> <p>P: I think it creates more stigma cos</p> <p>R: Yeah</p> <p>P: And then you hear about it on the news and it's about like</p> <p>R: Oh, it's always</p> <p>P: Women killing their babies</p> <p>R: Exactly. The worst side of it</p> <p>P: And it's like I never wanted to harm my baby</p> <p>R: Yeah</p> <p>P: I thought everyone was harming her or me</p> <p>R: Yeah</p> <p>P: And I got scared for both of us</p> <p>R: Yeah</p> <p>P: But I never felt like harming her like</p> | <p>Understanding PPP</p> <p>Feeling scared</p> | <p>Bonding</p> |
| <p>P: Which I guess is a bonus and also in the first few weeks after the first few weeks I felt a lot better than my NCT friends because I'd had effectively night nannies for 6 weeks and they'd been up all night so</p> <p>R: Yeah, yeah</p> <p>P: I felt I ended up feeling better than them</p> | <p>Positive care</p> <p>MBU</p> | <p>The positives</p> |

Appendix 10: Code book

| Expectations vs. reality of motherhood | What's going on? | | | | |
|---|---------------------------------|------------------------------------|-----------------------------------|-----------------------------------|------------------------------|
| | expectations of motherhood | birth plans | onset/description of ppp | not aware of ppp beforehand | not knowing what to do |
| | expectations from others on mum | birth difficulties | sleep deprivation | not spoken about during pregnancy | not coping |
| | normal vs. ppp | physical pain | impact of medication | difficult baby | adjustment |
| Me and my baby | <i>breastfeeding</i> | <i>separation</i> | <i>bonding</i> | | |
| | importance of breastfeeding | of mum and baby | no perceived bond initially | guilt | perceived good bond |
| | | of mum and partner/family | no connection or bond | loss | no perceived negative impact |
| | | impact of separation on bonding | fear of impact of ppp | focus on baby | |
| What comes with postpartum psychosis | <i>The terror</i> | <i>The confusion</i> | | <i>The depression</i> | |
| | fear | confused feelings | not feeling present | depression | |
| | worrying | unclear memory | loss of control | suicidal thoughts | |
| | anxiety over baby | documenting experience | couldn't make sense of experience | self-harm | |
| | thoughts of baby being harmed | trying to make sense of experience | not processing experience | | |
| | harming others | | | | |
| | paranoia | | | | |

| Where the system fails and thrives | <i>Poor care</i> | | | <i>The positives</i> | |
|--|---|---------------------------------------|------------------------------------|---|---------------------|
| | dismissed or minimised by others | panicked response from professionals | input as intrusive | mother and baby unit | |
| | missed opportunities from professionals | unhelpful response from system | negative experience | close monitoring | |
| | lost faith in professionals | problematic support of service | Traumatic/PTSD | positive response from others | |
| Let's talk about postpartum psychosis | trying to communicate distress | trying to seek support | trying to hide internal experience | internal world not communicated to others | |
| | communication | openness | lack of communication | stigma | |
| Support | <i>Where it should come from</i> | | <i>Where it does come from</i> | | |
| | further support for partners | further support for professionals | partner support | peer support | |
| | independent research | advice for professionals | seeking support | supporting others in similar situations | |
| | | | family support | | |
| Making sense of it | reflection | positive outcomes | reflecting on lack of insight | relapse | recovery takes time |
| | thinking back to ppp | impact on decision re future children | subsequent pregnancy | recovery | determination |
| | | | | religion | |

Appendix 11: Reflective Diary Extract

Interview 04

- as she had also been mentioned to me by CD, I had expectations that she has previously been involved in research, which was the case as APP SU Researcher
- felt quite difficult to pull apart info about relationship
- surprised by seemingly no concerns about the impact of separation & lengthy admission
- interesting & valuable to hear the positive experience of the MBU & staff
- important to hear about wanting more focus on partner, family & support
- maybe should be asking the question about impact of PPP on wanting more children - if not, why not?
- shed further light on experience & concerns