# Transition to Parenthood and Bipolar Disorder: What is the Decision-Making Process, Information and Support Needs of Women with Bipolar Disorder and their Partners from Pre-Conception to the Early Postnatal Period?

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## ABSTRACT

The birth of the first child - often referred to as transition to parenthood - is an important and often joyful life event, however, for women with pre-existing severe mental illnesses (such as bipolar disorder) and their partners, it can also be a time of heightened psychosocial distress and complex decision-making. This study aims to gain a better understanding of the decision-making process, information and support needs as experienced by women with bipolar disorder and their partners in each stage of their journey from pre-conception to the early postnatal period. Data will be collected and analysed using a constructivist grounded theory approach. Up to 20 interviews will be conducted in the UK with women diagnosed with bipolar disorder before becoming mothers (up to n=10) and/or their partners (up to n=10) with a first child under 5 years old. Findings of this project, guided by the voices of those with lived experiences, would provide additional information for future service design, perinatal mental health policy, and clinical practice suited to the needs of the individuals who use them.

*Keywords:* perinatal mental health, bipolar disorder, transition to parenthood, partners, lived experiences

## 1. Background

### 1.1 Perinatal mental health

The perinatal mental health of women -usually defined as the period encompassing pregnancy through to the end of the first postpartum year- is increasingly discussed and considered within national policy globally, across both high and low resource settings (e.g. Mental Health Care in the Perinatal Period, 2017 (Australia); Perinatal Mental Health Curricular Framework, 2019 (UK); National Mental Health Policy Framework And Strategic Plan 2013-2020, 2012 (South Africa). Academic and clinical interest in fatherhood has also gathered momentum, however, new fathers have only recently been considered in national policy frameworks, acknowledging that perinatal mental wellbeing strategies should not only focus to mothers but also *"to her infant, partner and other family members"* (Perinatal Mental Health Curricular Framework, 2019). This recommendation, nevertheless, is not

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accompanied by specific guidelines and therefore does not fully challenge the current typical involvement of partners in perinatal mental health services as support sources to mothers without a corresponding focus to their own perinatal mental wellbeing.

Over recent decades, studies have consistently documented the profound effect that perinatal acute onset or relapse of severe mental illness, mostly of postpartum depression, can have on relationships, families, and children. This is usually linked to partner's mental illhealth (Gürber, Baumeler, Grob, Surbek & Stadlmavr, 2017; Paulson, Bazemore, Goodman & Leiferman, 2016; Wee, Skouteris, Pier, Richardson & Milgrom, 2011), higher rates of divorce (Roy, Schumm & Britt, 2014), lower levels of children's emotional and cognitive development (Gentile, 2017; Netsi et al., 2018; Stein et al., 2014) and higher levels of behavioural problems and psychological disorders among children (Gentile & Fusco, 2017; Field, 2011). Additionally, perinatal mental health issues may lead to self-harm, which is one of the leading causes of maternal death around the globe during the first postpartum year (Scottish Intercollegiate Guidelines Network, 2012; Zhong et al., 2016), and infrequently, infanticide (Munk-Olsen et al., 2009; Spinelli, 2004; Wesseloo et al., 2015). Diagnostic and treatment guidelines (e.g. American Psychiatric Association [APA], 2013; Howard, Megnin-Viggars, Symington, & Pilling, 2014) highlight the requirement for a targeted approach to treating mental ill-health during the perinatal period, providing guidance for recognition of risk factors during this period and emphasising the importance of mental health professionals to provide detailed advice about the benefits and harms of treatment in pregnancy and the postnatal period.

#### **1.2** Bipolar disorder and transition to parenthood

Therefore, although the birth of the first child (i.e. transition to parenthood) is an important and often joyful life event, it can also be a time of heightened psychosocial distress and complex decisions, especially for women with pre-existing severe mental illnesses and their partners (Jones, Chandra, Dazzan & Howard, 2014; Roy et al., 2014).

As noted above, much of the research literature in this area has been somewhat diagnostically siloed, focussed on either postnatal depression, or perinatal psychoses. In particular, the effects of a bipolar disorder presentation during transition to parenthood have been relatively neglected. Bipolar disorder (BD) is a chronic mood disorder that affects 1% to 2% of the general population and is characterised by episodes of mania or hypomania alternating with depression (APA, 2013). The majority of individuals with BD retrospectively report experiencing the first BD symptoms prior to adulthood (Perlis et al., 2004), with the mean age of onset estimated to be between late adolescence and early adulthood, placing individuals at high risk to experience BD episodes before becoming parents (Merikangas et al., 2007). In addition, more than half of BD patients report either under-diagnosis or misdiagnosis prior to index diagnosis of BD, with the duration of untreated illness of up to 10 years, suggesting that individuals may not receive adequate support during the perinatal period (Hirschfeld, Lewis & Vornik, 2003; Scott & Leboyer, 2011).

More specifically, research suggests that there is a high rate of recurrence during this period for psychotic, manic, depressive or mixed episodes in women with pre-existing BD (Di Florio et al., 2018; Munk-Olsen, Laursen, Pedersen, Mors & Mortensen, 2006; Wesseloo et al., 2015) and an ongoing challenge about the use of psychotropic medication in pregnancy and lactation period (Khan et al., 2016; Pacchiarotti et al., 2016). Preliminary findings on risk factors and relapse predictors during the perinatal period is still limited and inconsistent with studies pointing to factors such as unplanned pregnancy, rapid discontinuation of medication, sleep deprivation and circadian rhythms interference (Doyle et al. 2012; Lewis et al., 2018). All the above in combination with the strong genetic loading of BD (McGuffin et al., 2003)

underscore the need of health professionals to discuss the issue of pregnancy and its management with every BD patient who has childbearing potential and if applicable their partners, regardless of future reproductive plans.

However, the only, to our knowledge, survey on this topic, indicates that almost half of the women with BD are advised to avoid pregnancy by either a health care professional or a family member (Viguera, Cohen, Bouffard, Whitfield & Baldessarini, 2002). Despite the ongoing policy, research and clinical practice efforts to improve access to high quality perinatal mental health services, findings drawn from a qualitative literature synthesis of motherhood in women with severe mental illness (i.e. schizophrenia, bipolar disorder, postpartum psychosis) from pre-conception to parenting suggests that there is still a lack of adequate information and support provided during this period both from health professionals and the society in general, leading women to feel doubly stigmatised because their capacity to be "a good mother" is automatically doubted due to their mental health status (Dolman, Jones & Howard, 2013).

In addition, there is still very limited research on how women with BD *and* their partners experience transition to parenthood and particularly what is the process of making complex decisions during this period and what are the information and support needs in each stage of their journey (i.e. before, during pregnancy and after childbirth).

#### **1.3 Aims**

The primary aim of the current study is to gain a better understanding of the decisionmaking processes of women with BD and their partners during transition to parenthood and to explore the support and information needs as experienced by women with BD and by their partners from pre-conception to early postnatal years.

#### 2. Method and Analysis

#### 2.1 Paradigm

This study will adopt a constructivist grounded theory approach, which is rooted in pragmatism and relativist epistemology (Charmaz, 2014). This approach assumes that neither data nor theories are discovered but are constructed by the researcher as a result of his or her interactions with the field and its participants. Data are co-constructed by the researcher and its participants and coloured by the researcher's perspectives, values, privileges, positions, interactions, and geographical locations. Within this approach, a literature review is used in a constructive and data-sensitive way without forcing it upon the data (Thornberg, 2012).

#### 2.2 Participants

This study will recruit a sample of up to n=20, of which up to n=10 will be women with a clinical diagnosis of bipolar disorder before becoming mothers, and up to n=10 will be their partners. Eligibility of participants will be identified based on the following inclusion and exclusion criteria:

#### 2.2.1 Inclusion criteria

Female participants will:

- Have a clinical diagnosis of bipolar disorder before becoming mothers
- Have a first child of up to 5-years old
- Be 18 years of age or older
- Be able to give informed consent to participate

Males or females whose partners meet the above inclusion criteria will be eligible for the study. Additional eligibility criteria for the selection of partners will include:

- Having an ongoing relationship with the mother from before pregnancy
- Being the biological, adopted, or stepparent of the child
- Being 18 years of age or older
- Being able to give informed consent to participate

#### 2.2.2 Exclusion criteria

- Anyone self-identified as experiencing acute distress
- Non-fluent English speakers

#### 2.3 Procedure

#### 2.3.1 Recruitment

Recruitment will take place via third sector services that operate in the United Kingdom and provide direct, indirect support and/or advocacy to people affected by mental health issues such as bipolar disorder, their partners and their young children. An invitation poster with information about the study and eligibility criteria will be posted to the services' online social pages and physical spaces. Services may also directly inform eligible individuals about this research project. An animated video will be designed and disseminated online for the purposes of recruitment. Efforts will be made to recruit both partners in the research project; however, if only one of the partners wishes to take part, then they will be included individually.

#### 2.3.2 Informed consent

Interested individuals will be invited to contact the researcher either via email or by phone. A self-completed eligibility screening form (based on the above criteria) and the project information sheet will be sent to all interested individuals by the principal researcher. The information sheet will include the aims of the study, details of who is conducting the research, what participation will involve, confidentiality, data management, the benefits/risks of participating, what will happen with the information gathered and details of who to contact about the project including complaints procedure.

Eligible individuals will be given at least 24 hours between reading the information sheet and being asked to give consent, to allow enough time to consider if they wish to participate in the research project. If eligible individuals decide to take part in the research study, the researcher will contact them to invite individuals to participate in interviews. The interviews will be scheduled separately for each partner and this will take place within 1-2 weeks of the first contact. On attending the interview, participants will be given an additional option to reread the information leaflet and to ask any questions about the study. Individuals that wish to participate will be provided with a consent form, which they will be asked to read and sign if they understand/agree with the points listed.

#### 2.3.3 Data collection

Participants will take part in an audio-recorded 1:1 interview with the researcher that will last approximately 45-60 minutes and will complete a brief demographic questionnaire. Interviews will be conducted in a mutually agreed-upon, confidential setting, either face-to-face at the participants' home or within the third-sector service facilities or via Skype, and will be audio-recorded using an encrypted electronic device. Participant's children will

ideally not be present during the interviews and partners will be interviewed separately to encourage openness and privacy.

An interview guide will be constructed which will be informed by a review of related literature and pilot interviews, however, the interview itself will be co-constructed with participants and it will be mainly guided by the participants and what they wish to share. Interviews will be conducted in five rounds, with two to five interviews in each round. This is consistent with grounded theory where data in previous rounds are tested and refined in subsequent rounds. As a result, the kind of questions and probes the interviewer will ask may change during the data collection process.

After each interview, the researcher will provide participants with a debrief sheet and will give them the opportunity to discuss what it was like for them to participate in the research. All participants will receive a £10 retail voucher as a gesture of appreciation for their contribution. They will also be given the option to receive an overall summary of the research findings and to be contacted by the researcher in the future for a follow-up within the following 5 years.

#### 2.3.4 Confidentiality

The content of participant's interviews and what they disclose will remain confidential unless a participant or another individual is deemed to be at risk of harm to themselves or others. A clear plan is agreed with the project supervisors for informing relevant professionals of situations where follow up from them may be required. All data shared publicly (e.g. in conferences, presentations, publications) will remain anonymous. This will all be detailed on the project information sheet.

#### 2.3.5 Data Management

Ethical approval for the study was granted by the Research Ethics Committee of the School of Health in Social Science, University of Edinburgh.

Data will be managed in line with the Data Protection Act 2018 and The University of Edinburgh (UoE) data management policy. Complying with the minimisation principle, only the absolute minimum of personal data will be collected via a brief demographic questionnaire. Audio files will be downloaded and backed up on to the secure password protected UoE computer system. Audio files will be transcribed verbatim by the principal researcher and then anonymised removing all potentially identifiable data (e.g. names and locations). Only the researcher and supervisors will be able to access these. Following the completion of the interview or the participant withdrawing, the recording will be deleted from the encrypted recorder, leaving the audio file only stored on the secure UoE system. Consent forms will be stored in a locked filing cabinet within the UoE, School of Health in Social Science department, in a limited access space, separate from any printed transcribed interviews - these will be destroyed after 3-6 months of the study ending. In the long term, the anonymised research data will be deposited in a UoE data repository (Edinburgh DataShare) for 10 years. After this time, the storage of this data will be securely disposed of.

#### 2.4 Analysis

In line with grounded theory, data will be analysed parallel with data collection. The latest version of NVivo will be used to facilitate the management and analysis of the data. After transcribing the interviews, data will be coded, and codes will be categorised immediately while the next interview will be prepared and conducted. This cyclical process will continue until the last round of interviews is completed.

Data analysis using constructivist grounded theory follows a certain set of steps and alongside each of these steps, the researcher is required to write memos and constantly compare the data in order to inform analysis (Charmaz, 2014). Briefly, the first step of analysis involves verbatim transcription of the interviews, allowing to visualise verbal and non-verbal expressions of participants and to organise interactions. The second step includes the initial line-by-line coding which involves breaking down the data into small units and labelling these units. The third step of the analysis entails the focused coding, which involves going through the initial codes and either grouping together those with significant meaning and shared similarities, or discharging initial, but of no use codes. The fourth step of analysis is theoretical sampling and theoretical saturation. Theoretical sampling implies collecting more data to extend and refine the categories and their properties while ideally achieving saturation, which implies that additional data collection would not reveal further attributes or new insights that could refine the theory. The final step of the constructivist grounded theory analysis involves the development of a substantive theory or in other words a "theoretical interpretation or explanation of a delimited problem in a particular area" (Charmaz, 2014, p.344). This theoretical explanation is developed through theoretical coding which involves linking categories anew in such a way that they "tell an analytic story that has coherence" (Charmaz, 2014, p. 150).

## 3. Discussion

This project could benefit services that focus on perinatal mental health both at a local and at a national level. Establishing a better understanding of the support and information needs as experienced by women with BD and by their partners when starting a family could enable services to consider these factors during service design and to develop more effective and partner-inclusive services, suited to the needs of the people who use them. This may also confer benefits in terms of better quality, person- and family-centred services; and collateral benefits with regard to economic efficiencies. Findings may also inform further policy development and systems strengthening in this area, especially regarding partner's perinatal mental health.

#### 3.1 Strengths and limitations

To our knowledge, this is the first study to explore the decision-making process, support and information needs of both women with BD and of their partners in a community setting from pre-conception to the early postnatal period. This project intends to bring the voices of people with lived experiences into the current national (and international) conversation around transition to parenthood in the context of severe mental disorders in order to inform prevention and early intervention strategies. The strength of this project lies in its qualitative nature, allowing rich data to be collected on the explored topic. Nevertheless, it is acknowledged that this approach also limits the potential number and diversity of participants, resulting in non-generalisability of findings. Data collected will be subjective and analysis will be based on the researcher's own interpretation, however, through a triangulation approach, it is hoped that credibility and trustworthiness will be achieved.

#### 4. Conclusion

Perinatal mental health is an emerging area of focus worldwide. The findings of this project, guided by the voices of those with lived experiences, could provide additional information for future perinatal mental health policy, clinical practice, service design as well

as highlight areas for further research with a widened lens that includes both women with severe mental illnesses and their partners.

## Declarations

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