Experiences of informal caregivers supporting individuals with bipolar disorder and postpartum psychosis: a thematic synthesis and empirical qualitative study

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Thesis Portfolio Abstract

Informal caregivers supporting individuals with severe mental illnesses (SMI), such as bipolar disorder (BD) or postpartum psychosis (PP), play a crucial role in providing day-to-day care and symptom management. However, it is not uncommon for caregivers to experience high levels of burden, a lower quality of life, and emotional distress. It is therefore of utmost importance that caregivers' needs are recognised and addressed, especially as the transition to community-based mental health care becomes more established. The thesis portfolio aimed to build upon existing research whilst providing novel insights into caregivers' experiences within the context of two overlapping SMIs. A systematic review and thematic synthesis was undertaken to synthesise qualitative studies exploring the experiences of caregivers supporting individuals with BD. The empirical qualitative study was conducted to explore care experiences from mental health services among partners of women accessing support for PP. Semi-structured interviews were completed, and data were analysed thematically. The review identified three analytical themes: 'burden of caregiving', 'healthcare system challenges', and 'coping with the shifting landscape', with supporting descriptive themes and subthemes. The empirical study produced three themes: 'understanding and responding to PP', 'partners' involvement in PP care', and 'the responsibilities undertaken and partner wellbeing', with supporting subthemes. The thesis portfolio highlighted commonalities and variations across caregiver experiences across differing diagnoses, caregiver relations and backgrounds, and time periods. Most caregivers felt a great sense of responsibility and advocacy, wellbeing challenges, and reported various difficulties with mental health services and support offered. Implications and future directions are outlined.[1]

[1] Where appropriate, material from my ClinPsyD Thesis Proposal has been used throughout the Thesis Portfolio.

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Chapter 1: Introduction

This chapter provides an overview of the key concepts included throughout the thesis portfolio. It will begin by providing a description of bipolar disorder (BD) and postpartum psychosis (PP), with a focus on their relationship. An introduction to informal caregiving and its role in severe mental illness (SMI) will follow. Then, the NHS Long Term Plan (NHS England, 2019a) and the shift toward community-based mental health care, noting their implications for caregivers. The chapter will conclude with the aims and structure of the thesis portfolio.

The Relationship Between Bipolar Disorder and Postpartum Psychosis

Bipolar disorder (BD) is a chronic mood disorder that involves periods of mania, hypomania, and depression (McIntyre et al., 2020). It is often referred to as a SMI due to its significant impact on an individual's ability to function and engage in activities (NHS England, 2019a). The condition is characterised by Bipolar I and Bipolar II. Bipolar I is defined by the occurrence of at least one manic or mixed episode, often followed by recurrent depressive, manic (and or hypomanic), or mixed episodes. Whereas Bipolar II is defined by at least one hypomanic and depressive episode, with no history of manic or mixed episodes (World Health Organization, 2019). Below are the definitions for manic, hypomanic, depressive, and mixed episodes, as outlined in the ICD-11 (World Health Organization, 2019):

1. 'A manic episode is an extreme mood state lasting at least one week unless shortened by a treatment intervention characterised by euphoria, irritability, or expansiveness, and by increased activity or a subjective experience of increased energy, accompanied by other characteristic symptoms such as rapid or pressured speech, flight of ideas, increased self-esteem or grandiosity, decreased need for sleep, distractibility, impulsive or reckless behaviour, and rapid changes among different mood states (i.e., mood lability)'.
2. 'A hypomanic episode is a persistent mood state lasting for at least several days characterised by persistent elevation of mood or increased irritability as well as

increased activity or a subjective experience of increased energy, accompanied by other characteristic symptoms such as increased talkativeness, rapid or racing thoughts, increased self-esteem, decreased need for sleep, distractibility, and impulsive or reckless behaviour. The symptoms represent a change from the individual's typical mood, energy level, and behaviour but are not severe enough to cause marked impairment in functioning'.

3. 'A depressive episode is characterised by a period of depressed mood or diminished interest in activities occurring most of the day, nearly every day during a period lasting at least two weeks accompanied by other symptoms such as changes in appetite or sleep, psychomotor agitation or retardation, fatigue, feelings of worthless or excessive or inappropriate guilt, feelings or hopelessness, difficulty concentrating, and suicidality'.
4. 'A mixed episode is characterised by the presence of several prominent manic and several prominent depressive symptoms consistent with those observed in manic episodes and depressive episodes, which either occur simultaneously or alternate very rapidly (from day to day or within the same day). Symptoms must include an altered mood state consistent with a manic and or depressive episode (i.e., depressed, dysphoric, euphoric or expansive mood), and be present most of the day, nearly every day, during a period of at least two weeks, unless shortened by a treatment intervention'.

Furthermore, PP is a rare but SMI often occurring within the first two weeks after childbirth (Jones et al., 2014; Perry et al., 2021). Although, women can remain at an increased risk months after birth (Sharma et al., 2022). PP is not formally recognised as a distinct diagnostic entity. The ICD-11 (World Health Organization, 2019) classifies PP as one of the syndromes associated with pregnancy or the puerperium, that starts within approximately six weeks after childbirth. The syndrome includes psychotic symptoms (i.e., delusions, hallucinations or other psychotic symptoms), often accompanied by mood symptoms such as depression and or mania. The term PP, however, remains widely used by

clinicians, women themselves, and in research (Action on Postpartum Psychosis, n.d.; Perry et al., 2021). Likewise, it is a term typically used for both women with a diagnosis of BD who experience a postpartum episode and those with a first-time onset (Bergink et al., 2011).

The relationship between PP and BD has been a subject of ongoing discussion. There is strong evidence to suggest a clear link between the two conditions (Munk-Olsen et al., 2009; Robertson et al., 2005; Wesseloo et al., 2015), although a particular debate revolves around whether PP should be classified as a distinct disorder. Research has demonstrated that first episode PP has differing nosological and phenomenological characteristics compared to non-postpartum episodes, whilst still sharing significant overlap with the bipolar spectrum (Bergink et al., 2011; Di Florio et al., 2021; Gordon-Smith et al., 2020; Rommel et al., 2021). Likewise, Gilden and colleagues (2020) showed that whilst some women had a time-limited first episode of PP, or a subsequent episode linked to the postpartum period, a large proportion of women went onto experiencing a severe mood episode outside the perinatal period (i.e., from conception to a year postpartum). This supports arguments that childbirth may trigger an underlying BD vulnerability, alongside the beginning of living with and managing a formal BD diagnosis (Perry et al., 2021; Sit et al., 2006). Nonetheless, the relationship between PP and BD remains unclear, posing barriers to treatment and added confusion for healthcare professionals, women themselves, and informal caregivers.

Informal Caregivers and Their Role in Severe Mental Illness

An informal (typically unpaid, although may receive related benefits) caregiver is an individual who provides vital care and support for a family member, partner, friend, or neighbour due to physical and or mental health difficulties (House of Commons Library, 2024a). The care provided can be either short or long-term (House of Commons Library, 2024b). Individuals can sometimes struggle to self-identify as a caregiver, with many taking over a year to acknowledge their role (Carers UK, 2022b). Caregivers can be children or adults and are more likely to identify as female than male, with many remaining in

employment alongside their caring responsibilities (Department for Work & Pensions, 2024). A Family Resources Survey found that there were approximately 5.2 million informal caregivers in the UK between 2022 to 2023 (Department for Work & Pensions, 2024). However, other reports have noted that this number may be as high as 10.6 million, with figures rising as the years progress (Carers UK, 2022a).

Caregivers of individuals with SMI (such as BD and PP) can provide an array of support, such as assistance with daily tasks, medication management, attending appointments, advocating on behalf of the individual, monitoring of mental and physical health, managing finances, crisis management, and access to and navigation of mental health services (Carswell et al., 2024; Rowe, 2012). Their responsibilities can be shaped by the nature of the condition, symptom severity, and the individual's self-management of their condition. For example, some caregivers may provide ongoing support for daily functioning, whilst others may provide more intensive but short-term intervention during acute episodes. It is well recognised that caregivers supporting those with SMI can experience great levels of burden, alongside physical and mental health difficulties (Alqhtani et al., 2021; Cheng et al., 2022; Karambelas et al., 2022).

The NHS Long Term Plan and the Shift Toward Community-Based Mental Health Care

In June 2018, the UK government announced a £20.5 billion funding settlement over the course of five years for the National Health Service (NHS). In response to this, the Long Term Plan was introduced as a way to ensure that this funding was best placed (NHS England, 2019a). This resulted in an ambitious direction for the NHS in England over the subsequent 10 years, with key targets set for 2023/24. Although there are various commitments outlined in the plan, particular attention will be paid to the shift towards new models, systems, and pathways to improve community-based mental health care (and perinatal support) for those with SMI, with special consideration to those supporting them.

The Lord Darzi (2024) independent investigation of the NHS in England highlighted significant barriers to the Long Term Plan implementation. The investigation found that

progress towards targets had been inconsistent, with waiting lists for community mental health services, accident and emergency (A&E), and general practitioners (GPs) on the rise, and investment still favouring hospitals over community care. As a result, many caregivers may continue to fill gaps in service provision, often without the recognition and support previously noted as being required in the Long Term Plan (NHS England, 2019a). This not only underscores the disconnect between policy ambition and real-life implementation, but also the increased state of uncertainty that caregivers supporting those with SMI are having to contend with. They continue to navigate an ever-changing NHS system, whilst carrying the burden of care with potentially limited support. As the NHS prepares to release an updated 10 year plan, it is crucial to ensure that the needs of caregivers of individuals with SMI are accurately captured.

The Thesis Portfolio

The overarching aim of the thesis portfolio was to develop a deeper understanding of caregiver experiences within the context of SMI, specifically focusing on PP and BD. Chapter Two presents a systematic review and thematic synthesis which focuses more broadly on caregiver experiences when supporting an individual with BD, whilst also highlighting any specific caregiver needs. Chapter Three is a bridging chapter, linking the systematic review and thematic synthesis in Chapter Two and the empirical research project in Chapter Four. Chapter Four presents the empirical research project, which homes in on a particular aspect of caregiving, the interaction with and support from mental health services. This specifically focuses on partners experiences and needs, within the context of PP. Chapter Five introduces additional methodology for the empirical research project, providing further explanation on the ontological and epistemological stance, reflexivity, recruitment, interviews, and ethical considerations. Finally, chapter six focuses on outlining, discussing, and critically evaluating findings from both papers. Consideration is paid to strengths and weaknesses, as well as implications for research and clinical practice. There are three reference lists provided within the thesis portfolio, with the first being at the end of Chapter

Two, the second after Chapter Four, and the third following Chapter Six. The final reference list contains references from all chapters.

Chapter 2: Systematic Review and Thematic Synthesis

Experiences of informal caregivers supporting individuals diagnosed with bipolar disorder: A systematic review and thematic synthesis

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Author guidelines can be found in Appendix A.

Abstract

Objectives: To identify, appraise, and synthesise qualitative studies exploring the experiences of informal caregivers (unpaid individuals providing emotional and or practical care) supporting individuals diagnosed with bipolar disorder (BD), and to identify any emotional, practical, or informational needs.

Data sources: Ovid, MEDLINE, Scopus, PsychINFO and CINAHL were searched from 1980 to January 2025.

Review methods: Studies were eligible for inclusion if they were peer viewed, published in English, used qualitative data collection and analysis, had data on the experiences of caregivers (aged 18 or above) supporting individuals with BD (aged 14 or above), and were conducted in western countries with individualistic cultures. Studies were appraised using the Critical Appraisal Skills Programme checklist. Data were analysed using thematic synthesis.

Findings: Fourteen papers were included in the review. Three analytical themes: 'burden of caregiving', 'healthcare system challenges', and 'coping with the shifting landscape' were identified, encompassing six descriptive themes and three supporting subthemes.

Limitations: The included studies lacked diversity in participant demographics, which may limit the transferability of findings to wider caregiver populations.

Conclusions: Caregivers supporting individuals with BD face complex emotional and physical challenges, coupled with significant sacrifices and responsibilities. The relapsing and unpredictable nature of BD can exacerbate caregiver demands. There is a need for increased societal awareness of BD, improved communication and collaboration between mental health services and caregivers, and improved support for caregiver wellbeing. Further research exploring cultural, gender, and role specific needs of caregivers is warranted.

Keywords: Bipolar disorder, Meta-synthesis, Thematic synthesis, Caregivers, Qualitative research

1. Introduction

Bipolar disorders (BD), characterised by extreme changes in mood, affects over 1% of the world's population (Grande et al., 2016; McIntyre et al., 2020). Whilst 'stable' periods can last weeks, months, or even years (Bipolar UK, 2021), subsyndromal symptoms between episodes are common (Grunze & Born, 2020). BD follows a lifelong relapsing and remitting course, with unpredictable episodes making it difficult to manage for everyone involved (Hajda et al., 2016; Mignogna & Goes, 2024). The aetiology of BD is complex, likely involving genetic, biological, psychological, and environmental factors (Goes, 2023; McIntyre et al., 2020), with onset often in adolescence or early adulthood (McGrath et al., 2023; Nowrouzi et al., 2016; Vieta et al., 2018). Early recognition and intervention are key for improving prognosis (Vieta et al., 2018). However, there is an average delay of approximately nine and a half years from the onset of symptoms to diagnosis (Bipolar UK, 2021; Fritz et al., 2017).

BD significantly impacts psychosocial functioning (Bonnín et al., 2019; MacQueen et al., 2001), with multiple episodes suggestive of poorer outcomes (Rosa et al., 2012). Compared to the general population, individuals with BD are at increased risk of physical health conditions, including diabetes, obesity, respiratory issues, and cardiovascular and kidney disease (Hayes et al., 2015; Kang et al., 2024; Nierenberg et al., 2023). They are also more likely to have comorbid psychiatric diagnoses, such as anxiety disorders, substance use, personality disorders, eating disorders, obsessive-compulsive disorder, and attention-deficit hyperactivity disorder (Altinbaş, 2021; Carvalho et al., 2020; Krishnan et al., 2005). Additionally, the suicide rate among individuals with BD is approximately 20 times higher than that of the general population (Plans et al., 2019). A recent commission report highlights the need for improved monitoring, integrated care models, and tailored interventions to address these disparities and improve overall health outcomes (Firth et al., 2019).

Most guidelines recommend pharmacological treatment, including mood stabilisers (such as lithium) and or antipsychotic medication, for acute and long-term symptom

management to prevent relapse and to stabilise mood (Connolly & Thase, 2011; Goes, 2023; NICE, 2023). These are often combined with psychosocial treatments, such as psychological therapies like Cognitive Behavioural Therapy and family-focused interventions, and or lifestyle approaches (Goes, 2023; NICE, 2023; Vieta; 2018). Beyond these treatments, informal caregivers (referred to as caregivers throughout this paper), usually unpaid family members, partners, or close friends, can provide emotional and or practical support to individuals with BD (Hannan, 2013; House of Commons Library, 2024; Lynch et al., 2018; NHS England, 2025). Caregivers often assist with daily tasks, symptom monitoring, and treatment adherence, which can further reduce the risk of relapse and improve the quality of life for the individual with BD (Pompili et al., 2014; Van Den Heuvel et al., 2018). However, caregiving relationships can be complex and may contribute to challenges for those with BD (Sharma et al., 2021; Ogilvie et al., 2005).

Despite the significant role that caregivers play in promoting the wellbeing of individuals with BD, they often experience high levels of burden (Bauer et al., 2011; Karambelas et al., 2022; Van Der Voort et al., 2007). This can lead to mental health difficulties such as depression and anxiety (Steele et al., 2010). Higher caregiver burden has been associated with the severity of the individual's symptoms and the hours spent providing care (Mirhosseini et al., 2024; Saleh et al., 2013). Some caregivers feel they have no choice in taking on this role, with research suggesting that this alone could increase levels of emotional distress and poorer physical health outcomes (Schulz et al., 2012). Although caregiving can have positive aspects (Maskill et al., 2010; Veltman et al., 2002), it also involves many sacrifices and challenges, including financial, social, relational, and health impacts (Bauer et al., 2011; Guan et al., 2023; Hailegabriel & Berhanu, 2023; Maskill et al., 2010; Seddigh et al., 2018; Speirs et al., 2023; Tranvåg & Kristoffersen, 2008).

It is crucial to ensure that caregivers have access to appropriate resources, support, and are actively involved by services. Guidelines recommend that caregivers should receive psychoeducation about BD, be involved in treatment and crisis planning, be provided with or signposted to psychological therapies and peer support, and if possible, respite care (APA,

2002; Malhi et al., 2015; National Collaborating Centre for Mental Health, 2006; NICE, 2023; Yatham et al., 2018). This is particularly important as community-based and psychosocial care becomes more embedded in the UK and other parts of the world (NHS England, 2019a; NHS England, 2019b; WHO, 2022). Therefore, there is a need to acknowledge the potential additional strains that caregivers may experience and better understand their needs.

Qualitative research offers a rich understanding of caregivers' experiences of involvement and support from healthcare services. Many expressed feeling excluded from care processes, which sometimes led to distrust in healthcare professionals, and not being provided with psychoeducation on BD or support for their own wellbeing (Baruch et al., 2018a; Bauer et al., 2011; Chatzidamianos et al., 2015; Richard-Lepouriel et al., 2022; Rusner et al., 2012; Shamsaei et al., 2010; Speirs et al., 2023). Despite the general dissatisfaction, some reported positive experiences where they were provided with information about BD and were involved in the individual's care (Clements et al., 2019; Granek et al., 2018; Maskill et al., 2010; Tranvåg et al., 2008).

Although existing research has provided valuable insights into caregivers' experiences, synthesising evidence allows for a more systematic and comprehensive understanding of their needs. Previous systematic reviews have focused on psychological interventions for caregivers (Baruch et al., 2018b), caregiver burden, coping, and support needs (Van Der Voort et al., 2007), or on understanding stigma (Latifian et al., 2023). However, none have explored the broader experiences of caregivers whilst capturing any nuances offered by employing a thematic synthesis approach. Therefore, this systematic review and thematic synthesis aims to systematically identify, appraise, and synthesise qualitative studies that explore the experiences among caregivers supporting individuals with BD, and to identify any emotional, practical, and or informational support needs.

2. Methods

The current review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Page et al., 2021)

(Appendix B) and the Enhancing Transparency in Reporting the Synthesis of Qualitative research (ENTREQ) statement (Tong et al., 2012). The review protocol was developed collaboratively with the research team and registered on the Prospective Register of Systematic Reviews (PROPSERO) (reference number CRD42023487273) (Appendix C).

2.1. Search strategy

The SPIDER tool (Cooke et al., 2012) informed the free-text terms used in the search strategy, and the research questions. Compared to the PICO framework, the SPIDER tool is better suited for identifying qualitative papers due to its inclusion of 'design' and 'research type' (Methley et al., 2014). Incorporating these terms within 'evaluation' improved the retrieval of relevant qualitative papers. Boolean operators 'AND' and 'OR' were used to adjust the search scope, along with truncations for word variations. A librarian at the University of East Anglia reviewed the final search strategy for robustness, as found in Table 1. Searches were conducted by the first author on the 11th of December 2023 (and rerun on the 26th of January 2025 to account for any recent publications) across four electronic databases: Ovid MEDLINE, Scopus, PsychINFO and CINAHL. Searches were from 1980 to present (2025), reflecting the updated classification of BD in the DSM-III (Mason et al., 2016). Searches were limited to title and abstract, and peer reviewed journal articles in English. Phenomenon of interest was limited to title only.

Table 1

Final search strategy informed by the SPIDER tool (Cooke et al., 2012)

S-sample	Famil* OR caregiv* OR relative* OR partner* OR spouse AND
PI-phenomenon of interest	"Bipolar disorder" OR "mood disorder" OR "Bipolar" AND
D-design	(terms included in evaluation)
E-evaluation	Experience* OR perception* OR qualitative OR interview OR "mixed methods" OR

	"grounded theory" OR "thematic analysis" OR "interpretative phenomenological analysis" OR IPA OR "discourse analysis" OR "realist" OR "content analysis" OR "focus group"
R-research type	(terms included in evaluation)

2.2. Inclusion and exclusion criteria

Studies were eligible if they had a qualitative or mixed-methods design and reported on the experiences of caregivers supporting an individual diagnosed with BD. For mixed-methods studies, only qualitative data were extracted. Studies including perspectives from other stakeholders or caregivers of individuals with different diagnoses (e.g., schizophrenia) were eligible, but only data clearly pertaining to caregivers of those with BD were extracted. If BD caregiver specific data were unclear, it was omitted.

Caregivers needed to be 18 years or older and either be a parent (where the individual with BD is aged 14 years or older, in line with the Early Intervention in Psychosis Services in England, NHS England, 2023), adult child, sibling, spouse (or partner), other relative, close friend or neighbour. They also had to have a close relationship with the individual diagnosed with BD and or provide support (e.g., emotional, practical). If it was unclear who the caregivers were or whether they met the inclusion criteria, studies were either excluded or efforts were made to ensure that only relevant data were extracted.

Only studies conducted in western countries with individualistic cultures were included (Hofstede, 1984). Following a discussion among reviewers (ER, JH & BLT), this was agreed to provide the most relevant and comparable insights, given notable cultural differences in caregiving perceptions, healthcare systems, and mental health approaches. A systematic approach was undertaken, with the first author and JH discussing each paper retrieved for full text screening (n = 50) until reaching consensus on its eligibility. It is recognised that some caregivers from collectivist cultures and or non-western origins may

reside in western countries; any relevant cultural nuances were noted and synthesised where applicable.

Amendments to the protocol were made in March 2024, further information is available on PROSPERO (reference number CRD42023487273). These did not affect the search. See Table 2 for inclusion and exclusion criteria.

Table 2

Inclusion and exclusion criteria

Inclusion	Exclusion
Qualitative research studies exploring the views of informal caregivers over the age of 18 who identify as either a parent (to an individual aged 14 years or older), adult child, sibling, spouse (or partner), other relative, close friend or neighbour who have a close relationship and or provide substantial support to an individual diagnosed with bipolar disorder.	Informal caregivers under the age of 18 years old.
Individuals from western countries with individualistic cultures.	Studies exploring the evaluation of interventions (e.g., support groups, programmes).
Qualitative component of mixed-method studies.	Studies using only a quantitative research design.
English language.	Studies not available in the English language.
Studies exploring the experiences of informal caregivers which encompass other stakeholders' views.	Studies reported in book chapters, conference papers, editorials, or letters.
Studies exploring the experiences of informal caregivers which encompass bipolar disorder among other mental health conditions.	Studies that do not include the views of informal caregivers of those who support an individual diagnosed with bipolar disorder.

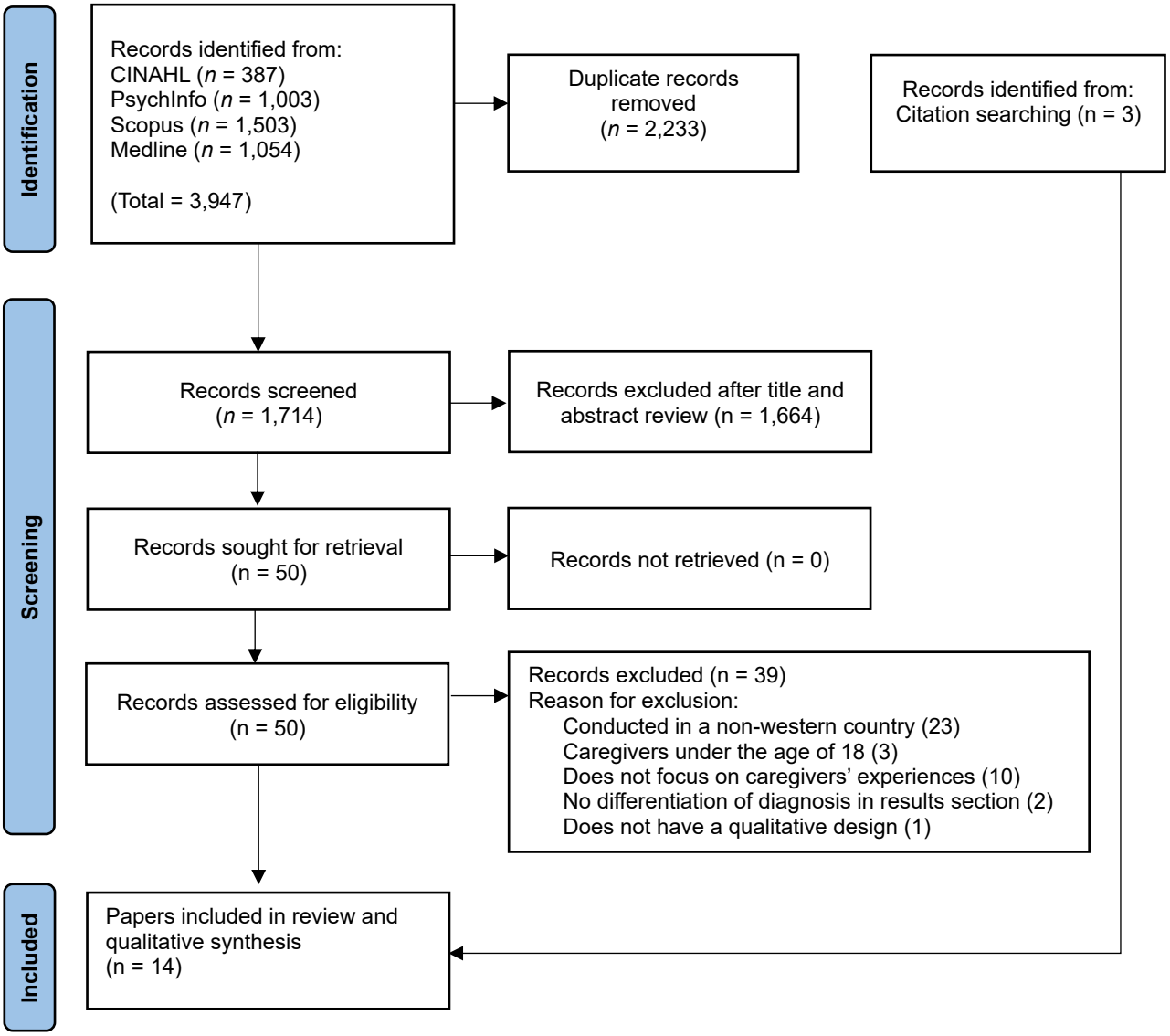
Studies published in peer-reviewed journals.	Systematic reviews or thematic or meta-synthesis.

2.3. Screening

All records returned by the electronic database searches were imported into Zotero (version 6.0.37) and subsequently exported into Rayyan (Ouzzani et al., 2016) for deduplication and screening. The electronic searches identified 1,714 records after deduplication, 1,664 records were excluded following title and abstract screening and 39 records were excluded after full text screening, resulting in a total of 14 records, inclusive of three records (Rusner et al., 2013; Tranvåg & Kristoffersen, 2008; Veltman et al., 2002) identified from backward citation searching of included papers. Forward citation searching was also performed in Google Scholar, revealing no relevant studies. See Figure 1 for the PRISMA flow diagram. A second reviewer (AR) conducted full-text screening on 30% of the included papers, with any discrepancies discussed until a consensus was reached.

Figure 1

PRISMA flow diagram of study selection process



2.4. Quality appraisal

The Critical Appraisal Skills Programme (CASP) checklist (2024) was used to assess the methodological quality of each paper (Appendix D). Recognised as a widely used tool in qualitative research (Long et al., 2020), the CASP checklist is also endorsed by the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2018). The first author rated each CASP criterion as "Yes", "No", or "Can't tell", with a second reviewer (AR) independently rating 30% of the papers; any discrepancies were discussed until consensus was reached. The "Can't tell" rating was assigned to criteria lacking clear or sufficient

information. The purpose of quality appraisal in this review was to assess the quality of available evidence on this topic. Studies were not excluded based on quality rating (Garside, 2014), but quality and reliability of findings were considered in the synthesis.

2.5. Data extraction

Data were extracted by the first author using a data extraction form created in Microsoft Excel, which was cross-checked by a second reviewer (JH), and piloted with two studies to ensure it effectively captured all relevant information (Long & Abraham, 2016). This included contextual information of the studies, such as the author(s), year and country, aim(s), sampling method, population characteristics, method of data collection and analysis, and an overview of key findings (Table 3). All text under the results or findings section of the studies were extracted and organised into separate files, which were then imported into NVivo 14 Software to aid the synthesis.

Table 3

Characteristics of included studies

Author(s), year, and country	Aim(s)	Sampling method	Population characteristics	Data collection and analysis	Key themes
Baruch et al., (2018a), United Kingdom	To explore what challenges family members face in supporting a relative with bipolar disorder, and how they attempt to manage them.	Sample recruited from voluntary sector organisations, university website, and through word of mouth.	*N* = 18 Age: Mean = 48 (range 31 to 67) Gender: 14 females Ethnicity: 8 White British, 4 Other White, 4 Asian/Asian British, 2 Mixed Employment: not reported Relation: 6 parents, 5 spouses/partners, 3 siblings, 1 spouse and parent Time caring for: not reported Caregiver definition: close family member perceived themselves as providing substantial support	Semi-structured interviews Phenomenological Analysis	1) Not knowing: "like being in a minefield" 2) It's out of my control: "Sitting waiting for the next thing to happen" 3) "Treading on eggshells" 4) "Picking up on signs" 5) Times of crisis: "between a rock and a hard place" 6)"I have to make my voice heard"
Bauer et al., (2011), Germany	To qualitatively assess the burden on caregivers of patients with bipolar disorder.	Sample recruited via person with bipolar disorder (inpatient) at a tertiary referral centre.	*N* = 32 Age: Mean = 46.8 Gender: 22 females Ethnicity: not reported Employment: 26 full time/part time/apprenticeship, and 6 unemployed/retired Relation: 18 spouses, 7 parents, 3 children, 3 siblings, 1 friend Time caring for: not reported Caregiver definition: caregiver with whom they had the closest contact to	Semi structured interviews Content Analysis	1) Lack of understanding patient's behaviour, helplessness and hopelessness of the caregiver 2) Caregiver's consternation resulting from the extent of patient's suffering 3) Patient's uncooperative behaviour and refusal of caregiver 4) Worries about the future 5) Burdened by specific symptoms of bipolar disorder 6) Switches between depression and mania burdensome
Chatzidamianos et al., (2015), United Kingdom	To explore the barriers and facilitators to relatives' involvement in bipolar disorder.	Self-referred volunteers. No further details available.	*N = 12* Age: Mean = 60 Gender: 7 females Ethnicity: 11 White British, 1 White Other Employment: 2 full time, 4 part time Relation: not reported Time caring for: not reported Caregiver definition: Had to be in regular contact and have emotional/practical supporting role in person's life	Semi-structured interviews Framework Analysis	1) Pre-existing world views 2) The quality of relationships and communication 3) Other structural impediments

Table 3 continued

Author(s), year, and country	Aim(s)	Sampling method	Population characteristics	Data collection and analysis	Key themes
Clements et al., (2019), United Kingdom	To explore relatives' and service users' experience of mental health services in relation to suicidal behaviour in bipolar disorder.	Sample recruited via people who had presented at hospital with self-harm, via clinical studies officers in NHS, advertising via mental health charities and local newspapers, in-person visits to charities, and personal referrals from other participants/research colleagues.	-	Semi-structured interviews Thematic Analysis	1) Access to care 2) Problems with communication
Jönsson et al., (2011), Sweden	To elucidate what it means for family members to live with an adult person with bipolar disorder, with reference to their views concerning the condition of the person affected and the future.	Sample recruited via person with bipolar disorder within outpatient services.	*N* = 17 Age: Mean = 47 (range 28 to 82) Gender: 12 females Ethnicity: not reported Employment: 15 full time, 1 part time, 1 unemployed, 1 retired Relation: 10 parents, 5 married/cohabitating partner, 2 adult child Time caring for: not reported Caregiver definition: be regarded by person with bipolar disorder as significant influential person	Semi-structured interviews Content Analysis	1) The family member's view of the condition of the person with the illness 2) The family member's view of their future
Maskill et al., (2010), New Zealand	To identify and gain a greater understanding of the way the lives of individuals have been both positively and negatively affected by supporting someone diagnosed with bipolar disorder.	Sample recruited via advertisements being placed in local community, including government and non-government-based consumer services.	*N* = 12 Age: range 30 to 65+ Gender: 11 females Ethnicity: not reported Employment: not reported Relation: 10 parents, 1 spouse, 1 sibling Time caring for: not reported Caregiver definition: spouse or equivalent, most frequent contact and involvement in treatment, be supporting financially, be emergency contact	Semi-structured interviews Thematic Analysis	1) I am a much more compassionate person 2) It's tough and It's a sacrifice

Table 3 continued

Author(s), year, and country	Aim(s)	Sampling method	Population characteristics	Data collection and analysis	Key themes
Richard-Lepouriel et al., (2022), Switzerland	To explore the stigma-related experiences of family members, to explore how relatives perceive, experience and cope with stigma by association, and to assess whether coping differs in accordance with their roles in the family.	Sample recruited from a mood disorder unit, either directly (via psycho-educational group for relatives) or indirectly (via person with bipolar disorder).	*N* = 12 Age: Mean = 53 (range 28 to 62) Gender: 8 females Ethnicity: not reported Employment: 28% professionals, 19% managers, 14% technicians, 24% retired, 10% unemployed, and one (5%) on disability insurance. Time caring for: not reported Caregiver definition: not reported	Semi-structured interviews Thematic Analysis	1) Language 2) Identity 3) Emotions 4) Others' reactions 5) Coping with BD 6) Relative's Needs
Rusner et al., (2012), Sweden	To elucidate the existential meaning of being closely related to a person with bipolar disorder.	Not clearly defined.	*N* = 12 Age: range 21 to 71 Gender: 6 females Ethnicity: not reported Employment: not reported Relation: 5 married/cohabitating, 4 parents, 2 siblings, and 1 adult child Time caring for: not reported Caregiver definition: adults closely related	Semi-structured interviews Phenomenological Analysis	1) Struggling for survival 2) Having to compensate 3) Being both one step ahead and one step behind
Rusner et al., (2013), Sweden	To explore and describe what makes life as a close relative of a person with bipolar disorder more liveable.	Not clearly defined.	*N* = 12 Age: range 21 to 71 Gender: 6 females Ethnicity: not reported Employment: not reported Relation: 5 married/cohabitating, 4 parents, 2 siblings, and 1 adult child Time caring for: not reported Caregiver definition: adults closely related	Semi-structured interviews Phenomenological Analysis	1) Essential meaning – influencing the unpredictable 2) Keeping a distance 3) Having stability 4) Strengthening equality through transparent communication

Table 3 continued

Author(s), year, and country	Aim(s)	Sampling method	Population characteristics	Data collection and analysis	Key themes
Speirs et al., (2023), Australia	To gain insight into the experiences of carers, and to better understand what help and information carers need.	Sample recruited via social media advertising.	*N* = 15 Age: Mean = 41 (range 20 to 60) Gender: 13 females Ethnicity: not reported Employment: not reported Relation: 7 spouses/partner, 5 parents, 2 adult children, 1 friend/housemate. Time caring for: not reported Caregiver definition: main support person for individual with bipolar disorder	Semi-structured interviews Thematic Analysis	1) Separation of the person and the disorder 2) Carer health and coping strategies 3) Unpredictability and variability of symptoms 4) Carer disillusionment and silencing 5) Story sharing and support needs
Tranvåg & Kristoffersen (2008), Norway	To explore the experiences of spouses/cohabitants who over time have lived with a partner who has bipolar disorder.	Sample recruited from two psychiatric hospitals.	*N* = 8 Age: Mean = 62 (range 31 to 85) Gender: 4 females Ethnicity: not reported Employment: not reported Relation: 8 spouses/cohabitants Time caring for: range from 6 to 51 years after onset of illness Caregiver definition: lives with partner and has experienced two episodes which led to psychiatric institution	Semi-structured interviews Phenomenological Analysis	1) Experience formed part of a cumulative process (14 experiences) 2) Each experience creates a preunderstanding that affected how subsequent experiences were perceived 3) Preunderstanding also affected how they managed to master new illness-related challenges.
Veltman et al., (2002), Canada	To gain a greater knowledge of the meaning that caregivers derive from their situation, including positive aspects.	Sample recruited via advertisements in teaching hospital, through local mental health organisations, and family support groups.	-	Semi-structured interviews Analysis not reported	1) Stigma 2) Systems issues 3) Life lessons learned 4) Love and caring for the ill relative

Table 3 continued

Author(s), year, and country	Aim(s)	Sampling method	Population characteristics	Data collection and analysis	Key themes
Van Den Heuvel et al., (2018), The Netherlands	To describe how caregivers have learned to overcome the impact of emotional burden and experienced distress, and how they have developed a personal definition of efficient self-management support for individuals living with bipolar disorder.	Sample recruited by asking individuals with bipolar disorder who were part of a parallel study to identify caregiver.	*N* = 10 Age: Mean = 52 Gender: 7 females Ethnicity: not reported Employment: not reported Relation: 5 spouses, 2 parents, 1 sibling, 1 friend, 1 adult child. Time caring for: Mean = 11.5 years Caregiver definition: significant person who support them in self-management activities	Semi-structured interviews Phenomenological Analysis	1) Understanding bipolar disorder 2) Overcoming the dilemmas in self-management support for individuals living with bipolar disorder 3) Dividing tasks and responsibilities 4) Acquiring a personal definition of self-management support for individuals living with bipolar disorder
Van Der Voort et al., (2009), The Netherlands	To gain a greater insight into experienced burden, coping mechanisms, and the support needs of spouses.	Sample recruited during an annual meeting for spouses of those with bipolar disorder, via an online advertisement posted on a website for single parents, and via newspaper advertisements.	*N* = 15 Age: Mean = not reported (range 30 to 60) Gender: 9 females Ethnicity: not reported Employment: not reported Relation: 11 spouses, 4 ex-spouses Time caring for: not reported Caregiver definition: Spouse of at least 5 years who lives with the person with bipolar disorder	Semi-structured interviews Grounded Theory	1) Burden 2) Appraisal 3) Self-effacement versus self-fulfilment 4) Mediating factors 5) Resignation

2.6. Data synthesis

Findings were analysed using Thomas and Harden's (2008) thematic synthesis approach, which involves three steps: First, line-by-line coding, where codes were applied to each line of data across all papers. Data were applied to existing codes, or new codes were created as needed. Second, descriptive themes were developed by grouping related codes across papers, they remained close to the original meaning of the primary data. Third, analytical themes were generated to interpret deeper meanings, taking the synthesis beyond the primary data to address the research questions proposed in this review using an inductive approach (Thomas & Harden, 2008). Data synthesis was undertaken by the first author, with ongoing discussions with reviewers (JH & BLT) to ensure a triangulation approach throughout the synthesis, which led to framework adaptations.

3. Findings

3.1. Study characteristics

The 14 studies included in the review represented the views of over 163 caregivers, most of whom were female (N ≅ 119). Clements et al., (2019) and Veltman et al., (2002) included additional stakeholders and caregivers of individuals with other diagnoses, making it difficult to isolate the number of caregivers specific to individuals with BD. Rusner et al.'s (2012, 2013) studies shared the same dataset but explored different aims.

Participants were recruited through various methods, and the studies were conducted across the United Kingdom, (n = 3), Australia, Germany, Switzerland, The Netherlands (n = 2), Sweden (n = 3), New Zealand, Norway and Canada. Participants' ages ranged from 20 to 85 years, with several studies reporting average ages only (Bauer et al., 2011; Chatzidamianos et al., 2015; Clements et al., 2019; Van den Heuvel et al., 2018). Ethnicity was reported in only two studies, time spent caring for the individual in two, and employment status in four. Rusner et al., (2012, 2013) noted that one participant had

immigrated to Sweden from an Asian country, whilst another was raised by immigrant parents from South America.

All studies, except Clements et al., (2019), reported the caregiver's relationship to the individual with BD. Spouses/partners (n = 74) were the most frequently reported, followed by parents (n = 49), siblings (n = 14), adult children (n = 12) and friends (n = 3). Different methods of reporting caregiver relationship in some studies (Chatzidamianos et al., 2015; Clements et al., 2019; Rusner et al., 2013; Veltman et al., 2002) made it challenging to summarise the overall number of caregivers by relationship. Although all studies met the inclusion criteria, definitions of informal caregiver varied across studies, thus reflecting differences in how caregiving is conceptualised.

Data were collected through semi-structured interviews and analysed using thematic analysis (Clements et al., 2019; Maskill et al., 2010; Richard-Lepouriel et al., 2021; Speirs et al., 2023), content analysis (Bauer et al., 2011; Jönsson et al., 2011), phenomenological analysis (Baruch et al., 2018a; Rusner et al., 2012, 2013; Tranvåg & Kristoffersen, 2008; Van Den Heuvel et al., 2018), framework analysis (Chatzidamianos et al., 2015), and grounded theory (Van Der Voort et al., 2009).

3.2. Quality Assessment

See Table 4 for CASP ratings. All 14 studies employed appropriate qualitative methodologies, clearly stated their aims, and aligned their research designs with these aims. Recruitment strategies were appropriate to the aims of the research in all studies except for Jönsson et al., (2011), where it was unclear how participants were invited to take part. Data collection methods in all studies effectively addressed the research aim. However, seven studies provided limited and or unclear information on considerations regarding the potential influence of the researcher's background and how this might introduce bias into the research processes. Ethical issues were taken into consideration in 13 studies; however, Richard-Lepouriel et al., (2022) would have benefitted from specifying how the research was explained to participants to assess whether ethical standards were maintained. All studies

provided clear statement of findings, although Veltman et al., (2002) did not outline the type of data analysis undertaken. Nonetheless, 13 studies demonstrated sufficiently rigorous data analysis, and all studies were considered valuable contributions to research.

Table 4

Quality assessment of included papers

First author	Aims	Qualitative Methodology Appropriateness	Design	Recruitment	Data Collection	Researcher relationships	Ethics	Analysis	Findings	Value
Baruch (2018a)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bauer (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes
Chatzidamianos (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Clements (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jönsson (2011)	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Yes
Maskill (2010)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Richard-Lepouriel (2022)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Rusner (2012)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Rusner (2013)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Speirs (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tranvåg (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Veltman (2002)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes
Van Den Heuvel (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Van Der Voort (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

3.3. Thematic Synthesis

Three analytical themes were identified, encompassing a total of six descriptive themes, with three supporting subthemes (Table 5). The analytical themes were ‘burden of caregiving’, ‘healthcare system challenges’, and ‘coping with the shifting landscape’

Table 5

Analytical Themes with supporting descriptive themes and subthemes of included papers

	Baruch (2018a)	Bauer (2011)	Chatzidamianos (2015)	Clements (2019)	Jönsson (2011)	Maskill (2010)	Richard-Lepouriel (2022)
Analytical Theme 1: Burden of Caregiving	√	√			√	√	√
The weight of care		√				√	√
Coming to terms	√	√				√	√
The hidden costs		√			√	√	√
Alone in the struggle		√			√		√
Analytical Theme 2: Healthcare System Challenges	√	√	√	√		√	√
Left out of the loop	√	√	√	√		√	√
Barriers at every turn		√	√	√		√	
What we need	√			√			√
Analytical Theme 3: Coping with the Shifting Landscape	√	√	√	√	√	√	√
Riding the rollercoaster	√	√	√	√	√	√	√
Living on high alert	√	√					√

Table 5 continued

Rusner (2012)	Rusner (2013)	Speirs (2023)	Tranvåg (2008)	Veltman (2002)	Van Den Heuvel (2018)	Van Der Voort (2009)
√	√	√	√	√	√	√
√	√	√		√	√	√
√	√	√	√	√		√
√	√	√	√	√		√
√			√	√		√
√	√	√	√	√	√	√
√	√	√	√		√	
√		√		√		√
	√	√				√
√	√	√	√		√	√
√	√	√	√		√	√
√		√	√		√	

3.3.1. Burden of Caregiving

The first analytical theme, comprising one descriptive theme, and three subthemes, captures the multifaceted burden caregivers face when supporting individuals with BD. Caregiving demands reshape their daily lives and can affect their mental and physical wellbeing. This is often accompanied by isolation from friends and family, sometimes worsened by stigma and others' judgements. Despite these challenges, caregivers strive to find coping strategies and sustain hope for the future.

3.3.1.1. Descriptive Theme: The weight of care

Being responsible meant ensuring the wellbeing of the person with BD, including monitoring their symptoms, managing medication, overseeing the household, and or childcare duties (Bauer et al., 2011; Maskill et al., 2010; Rusner et al., 2012; Van Der Voort et al., 2009).

If I happen to make a mistake…everything is going to collapse…this responsibility is very heavy (Van Der Voort et al., 2009, p. 437).

Caregivers commonly sacrificed time for self-care, leisure, and family connections (Bauer et al., 2011; Maskill et al., 2010; Rusner et al., 2012; Veltman et al., 2002). The chronic nature of BD enforced a 'forever strain' of responsibility, often causing hopelessness, frustration, and a need for respite to continue (Maskill et al., 2010; Rusner et al., 2012; Veltman et al., 2002). One parent noted that the diagnosis made them realise they would be responsible for their child 'until the day they die' (Maskill et al., 2010, p. 539).

So what we're talking about is the duration…say a manic spell or whatever… you get over it…but when it comes back and it's again, and it's again…it just gets pretty oppressive. This is not year one, this is year twenty one and I am exhausted (Maskill et al., 2010, p. 539).

This sense of responsibility often disrupted caregivers' work lives, with some quitting their jobs or reducing their hours, leading to financial strain (Bauer et al., 2011; Rusner et al., 2012; Van Der Voort et al., 2009). This was further exacerbated when individuals engaged in manic overspending (Bauer et al., 2011). Caregiving responsibilities often shifted family dynamics, with children adopting parental roles (Rusner et al., 2012; Speirs et al., 2023), spouses taking on additional roles (Bauer et al., 2011; Van Der Voort et al., 2009), and siblings taking on mediating roles (Richard-Lepouriel et al., 2022; Van Den Heuvel et al., 2018). Some caregivers managed their responsibilities by encouraging self-management

and negotiating tasks, whilst others felt that distance was necessary (Rusner et al., 2013; Van Den Heuvel et al., 2018).

I told him 'I am so tired and sad and have no energy left due to taking care of you. I need peace and quiet and have to get some more energy for myself'…I told him that I am still his girlfriend but I need to move out from the apartment (Rusner et al., 2013, p. 165).

Many also highlighted positives, such as increased empathy, patience, and or deeper sense of love for the person with BD (Maskill et al., 2010; Rusner et al., 2012; Speirs et al., 2023), which made their role feel less burdensome.

3.3.1.2. Subtheme: The hidden cost

Caregivers experienced a complex range of emotions, such as worry, stress, guilt, hopelessness, and grief over what BD had taken from both the individual and themselves (Bauer et al., 2011; Maskill et al., 2010; Speirs et al., 2023; Tranvåg et al., 2008; Veltman et al., 2002).

It's just totally depressing, it's awful. Hopelessness for him and hopelessness for me. Thinking of him living a life that's so dysfunctional and so often unhappy and lonely (Maskill et al., 2010, p. 538).

They also struggled with feelings of anger, shame, and despair because of the 'BD label' and burdens they faced (Richard-Lepouriel et al., 2022; Tranvåg et al., 2008). Many caregivers experienced profound loneliness, even during 'stable' periods (Rusner et al., 2012; Tranvåg et al., 2008; Van Der Voort et al., 2009).

It is not possible to be in contact with him…no matter how hard you want to…that causes so much grief and pain… the being alone (Van Der Voort et al., 2009, p. 437).

This emotional strain often resulted in new or worsening mental health difficulties, such as anxiety and depression (Speirs et al., 2023). Some caregivers also experienced physical health difficulties, including weight gain, muscular pain, tension, and fatigue (Bauer et al., 2011; Speirs et al., 2023; Tranvåg et al., 2008; Van Der Voort et al., 2009). Uncertainty about their capacity to provide adequate care added further stress (Tranvåg et al., 2008). Some spouse (or partner) caregivers ended or considered ending their relationship, although this was not an option for parents (Richard-Lepouriel et al., 2022; Rusner et al., 2012; Van Der Voort et al., 2009).

'I'm fed up of living like this, but I love him, I'm staying anyway,' the fact of staying leads us to start asking ourselves 'But do I respect myself?.' Somebody else would leave in two seconds (Richard- Lepouriel et al., 2022, p. 181).

A father can't cut his ties with his son, it's unthinkable. You can't let your children down (Rusner et al., 2012, p. 203).

For many, the inability to express their needs exacerbated loneliness and stress, although some found helpful ways to navigate this (Baruch et al., 2018a; Rusner et al., 2012, 2013; Van Der Voort et al., 2009)

Many times I couldn't stop crying. I didn't protect him in showing my feelings…And then because I was really low we somehow will reverse position…he was looking after me…which made him feel good. (Baruch et al., 2018a, p. 1127).

Some caregivers found relief through psychological or pharmacological support, or substances, whilst others managed by setting boundaries, creating personal space, or implementing self-care practices (e.g., exercise, meditation, hobbies) (Richard-Lepouriel et

al., 2022; Rusner et al., 2013; Speirs et al., 2023; Tranvåg et al., 2008; Van Der Voort et al., 2009). Reflecting alone or with others also helped reduce their emotional burden and provided moments of relief (Rusner et al., 2013; Van Der Voort et al., 2009).

3.3.1.3. Subtheme: Alone in the struggle

Caregivers often experienced significant social isolation, with many withdrawing or cancelling plans due to the demands of their role and the unpredictable nature of BD (Bauer et al., 2011; Maskill et al., 2010; Richard-Lepouriel et al., 2022; Rusner et al., 2012; Tranvåg et al., 2008). Many felt misunderstood and unsupported by friends and family, particularly during crisis or hospital admissions (Richard-Lepouriel et al., 2022; Rusner et al., 2012; Speirs et al., 2023; Tranvåg et al., 2008).

Our existence is very lonely. We can't visit anyone, and it's very seldom that anyone drops in on us. It isn't so easy to leave her to visit mates…sometimes I drive down to the harbour and look for familiar faces when she has gone to sleep at night (Tranvåg et al., 2008, p. 9).

This lack of support was worsened by friends' and families' limited understanding of BD, with caregivers frequently at the receiving end of unhelpful responses (Jönsson et al., 2011; Maskill et al., 2010; Speirs et al., 2023; Tranvåg et al., 2008). The stigma surrounding BD heightened feelings of social isolation, especially when the individual displayed visible symptoms (Jönsson et al., 2011; Richard-Lepouriel et al., 2022; Van Der Voort et al., 2009). Some caregivers reframed reasons for hospitalisations to avoid stigma (Richard-Lepouriel et al., 2022). They also felt their caregiving role was misunderstood, with others failing to appreciate its complexities (Richard-Lepouriel et al., 2022; Veltman et al., 2002).

I have friends who don't respect what I do, they don't understand it, they feel sorry for me, they're so prepared to be sympathetic. There's an assumption that is made that there's no

quality of life for a caregiver, that it can't possibly be rewarding or interesting (Veltman et al., 2002, p. 110).

The lack of social connection increased caregivers' feelings of burden, leading some to dedicate more attention to the individual with BD (Rusner et al., 2012). Hypervigilance to protect the individual from stigma further added to their responsibilities (Rusner et al., 2012). Caregivers called for greater societal awareness of BD to reduce stigma and discrimination, making the diagnosis easier to manage (Richard-Lepouriel et al., 2022; Veltman et al., 2002). Whilst most found it difficult, some were able to talk to friends and family about their difficulties, providing relief and strength to continue (Jönsson et al., 2011; Richard-Lepouriel et al., 2022). Some friends and family offered visits or practical support, which caregivers welcomed (Maskill et al., 2010; Rusner et al., 2013; Van Der Voort et al., 2009).

3.3.1.4. Subtheme: Coming to terms

Caregivers found that adjusting their perspective was essential for acceptance (Jönsson et al., 2011; Van Der Voort et al., 2009; Veltman et al., 2002). Many recognised a 'new normal', shifting from an idealised expectation to acceptance of how things were, which provided inner peace (Jönsson et al., 2011; Rusner et al., 2012; Tranvåg et al., 2008).

Different things happen with my father…you automatically get used to…how he answers the phone, what he's like when he comes over…these things become part of your everyday life…I do not find anything complicated…you just live with it; it's that simple because it's my dad (Jönsson et al., 2011, p. 32).

Caregivers often made an active choice to accept the individual's diagnosis (Tranvåg et al., 2008; Van Der Voort et al., 2009). Others maintained a positive attitude, appreciated small moments, and focused on being present (Tranvåg et al., 2008; Veltman et al., 2002).

These approaches fostered acceptance and a more balanced view of life with an individual with BD.

Living successfully with a family member with a mental illness means living unconventionally. You can't worry about tomorrow too much…I've learned to cherish every day…every relationship, and I look at life very differently now (Veltman et al., 2002, p. 112).

Hope was essential for caregivers (Tranvåg et al., 2008; Richard-Lepouriel et al., 2022). They believed in the potential for improvement and stability in the individual's condition (Jönsson et al., 2011). Many recognised the need to step back and allow the individual autonomy, aiming for a balance in responsibilities (Richard-Lepouriel et al., 2022; Van Der Voort et al., 2009). However, some struggled with the urge to always be present (Jönsson et al., 2011), alongside concerns about who would care for them in the future (Bauer et al., 2011; Jönsson et al., 2011; Rusner et al., 2012; Veltman et al., 2002).

3.3.2. Healthcare System Challenges

The second analytical theme, consisting of three descriptive themes, highlights the barriers caregivers encountered within the healthcare system. Challenges included collaborating with healthcare professionals and navigating certain service structures. Caregivers noted gaps in services failing to meet their needs and emphasised the need for improvements.

3.3.2.1. Descriptive Theme: Left out of the loop

Caregivers often feel excluded from care processes, especially during inpatient stays (Baruch et al., 2018a; Bauer et al., 2011; Chatzidamianos et al., 2015; Rusner et al., 2012, 2013). Caregivers were often privy to key information about the individual. They felt frustrated when healthcare professionals overlooked their input, especially when lacking

understanding of the individual's background (Chatzidamianos et al., 2015; Clements et al., 2019; Maskill et al., 2010; Rusner et al., 2013).

When he died…the psychiatrist had actually said that he didn't think it was planned suicide…even though he had been telling me…he didn't want to live (Clements et al., 2019, p. 7).

Caregivers frequently encountered dismissive attitudes from healthcare professionals, who sometimes made decisions regarding the individuals' care without their input, leaving caregivers feeling like outsiders (Baruch et al., 2018a; Bauer et al., 2011; Rusner et al., 2012; Tranvåg et al., 2008). This exclusion left caregivers feeling like 'the problem', leading to further desperation. This was particularly problematic after inpatient discharges when caregivers felt they were left with little information on what to do (Tranvåg et al., 2008).

I have almost no communication with the people treating her. I feel as if they're saying: 'You're an outsider, we're the professionals, you must just stay out of it'. Nobody tells me how we are supposed to handle this after her discharge…I have a bag full of medicines I'm supposed to give her. That's the support apparatus we have (Tranvåg et al., 2009, p. 9).

Limited information from healthcare professionals regarding the individual's diagnosis, treatment, and prognosis resulted in caregivers seeking out information online (Baruch et al., 2018a; Bauer et al., 2011; Richard-Lepouriel et al., 2022; Speirs et al., 2023; Tranvåg et al., 2008; Van Den Heuvel et al., 2018). They also felt that healthcare professionals missed opportunities to check in on their wellbeing (Speirs et al., 2023).

I'm genuinely surprised that there was no mention or even a question of, how are you coping? Are you doing okay? Is there any support that we can give you?...if that person

supporting them isn't doing the best or doesn't know how to handle the circumstance, it's like a recipe for disaster (Speirs et al., 2023, p. 10).

Some caregivers highlighted services' openness to their involvement, which sometimes improved over time (Baruch et al., 2018a; Maskill et al., 2010; Tranvåg et al., 2008). They valued opportunities to discuss concerns and the forthcoming nature of healthcare professionals (Baruch et al., 2018a; Richard-Lepouriel et al., 2022).

3.3.2.2. Descriptive Theme: Barriers at every turn

Caregivers reported systemic, organisational, and institutional barriers when seeking support, adding to their frustration. Accessing appropriate mental health services was complex and confusing, especially during crises (Clements et al., 2019; Maskill et al., 2010; Rusner et al., 2012; Van Der Voort et al., 2009). Services for people with BD felt limited (Maskill et al., 2010). Admission to inpatient care was difficult and often followed by quick discharges, even when caregivers believed the individual was still unwell (Rusner et al., 2012). This was particularly challenging when caregivers felt there was a gap between acute crisis and 'stable' in terms of support available (Maskill et al., 2010). Caregivers also felt that obtaining updates and information was hindered by dysfunctional systems for sharing information (Rusner et al., 2012).

I rang about the medicine for my daughter, and it's not just about ringing to the doctor and asking, you have to first ring to the secretary, and then the secretary rings to the nurse, and then you have to wait for the nurse to ring you, and then you can talk to the nurse who approves that you can speak to the doctor (Rusner et al., 2012, p. 202).

Patient confidentiality posed another barrier, especially for parents whose child had turned 18, as they felt excluded from information sharing and decision making (Clements et

al., 2019; Rusner et al., 2012). Some caregivers also encountered barriers when managing the individual's finances (Rusner et al., 2012; Veltman et al., 2002).

I can't control how he spends his money…there is nothing in the system to let a wife take charge of the finances (Veltman et al., 2002, p. 111).

Many expressed dissatisfactions with the treatment and support provided to the individual with BD, citing issues with medication and misdiagnoses (Bauer et al., 2011; Maskill et al., 2010; Rusner et al., 2012; Speirs et al., 2023). Caregivers felt disheartened by the lack or refusal of guidance and signposting from services on accessing additional support for themselves, even when they were willing to pay (Clements et al., 2019). They felt let down by a system that seemed unresponsive to both their needs and those of the individual with BD, emphasising a need for organisational change at all levels (Chatzidamianos et al., 2015).

3.3.2.3. Descriptive Theme: What we need

Caregivers advocated for improved policies and collaborative practices between mental health services and caregivers (Richard-Lepouriel et al., 2022; Rusner et al., 2013; Speirs et al., 2023). Many expressed a desire to be more involved in care discussions, decision making, and crisis planning (Baruch et al., 2018a; Clements et al., 2019; Speirs et al., 2023). They also wanted to feel heard and have a space to express their emotions (Richard-Lepouriel et al., 2022).

The person who are close to a person with BD…they also need to be listened to, probably much more than the patient himself…they are the ones who are there with her everyday (Richard-Lepouriel et al., 2022, p. 188)

Healthcare professionals were seen as crucial in establishing transparent communication between caregivers and individuals with BD (Rusner et al., 2013). Caregivers recognised the key role of healthcare professionals in fostering joint responsibility, supporting caregiver involvement, and strengthening relationships (Rusner et al., 2013; Van Der Voort et al., 2009). They also emphasised the need for healthcare professionals to share information about BD symptoms, treatment, prognosis, and crisis management (Speirs et al., 2023; Van Der Voort et al., 2009).

The psychiatrist should invite the partner or children for a meeting and ask how they are doing, then they get information some patients do not give (Van Der Voort et al., 2009, p. 440).

They also expressed a desire for psychological skills and coping strategies to manage stress, practice self-care, set boundaries, and improve communication with the individual (Baruch et al., 2018a; Richard-Lepouriel et al., 2022; Speirs et al., 2023; Van Der Voort et al., 2009). Some caregivers called for places of respite to 'recharge their batteries' (Richard-Lepouriel et al., 2022).

3.3.3. Coping with the Shifting Landscape

The third analytical theme, comprising two descriptive themes, outlines the challenges caregivers face with the shifting nature of BD. Unpredictable and variable symptoms were difficult to navigate, leaving caregivers to feel constantly alert, further intensifying their burden. Some developed coping techniques that helped them manage.

3.3.3.1. Descriptive Theme: Riding the rollercoaster

Caregivers described the episodic nature of BD as being on a rollercoaster (Baruch et al., 2018a; Rusner et al., 2012; Speirs et al., 2023). Initial reactions to the diagnosis were filled with shock, fear, and confusion as they struggled to comprehend and manage the

significant changes in the individual (Baruch et al., 2018a; Bauer et al., 2011; Jönsson et al., 2011; Richard-Lepouriel et al., 2022; Tranvåg et al., 2008).

His behaviour was abnormal, completely different from the modest person we knew before. He turned into being supercilious and overconfident, and later…he became very timid and hesitant (Van Den Heuvel et al., 2018, p. 533).

Some caregivers described a feeling of 'treading on eggshells', unsure what to say or do during BD episodes (Baruch et al., 2018a; Speirs et al., 2023; Tranvåg et al., 2008; Van Den Heuvel et al., 2018). Transparent communication with the individual helped several caregivers better navigate BD's unpredictability (Rusner et al., 2013; Speirs et al., 2023). Others emphasised the importance of having knowledge about BD, understanding what to expect during and after episodes, and trusting the individual's ability to cope as essential for managing uncertainty and regaining hope and control (Baruch et al., 2018a; Van Den Heuvel et al., 2018). During manic episodes, caregivers often felt excluded and struggled with the out of character behaviours such as overspending, aggression, hurtful accusations, risky behaviours and sexual indiscretions (Baruch et al, 2018a; Bauer et al., 2011; Chatzidamianos et al., 2015; Jönsson et al., 2011; Maskill et al., 2010; Rusner et al., 2012; Speirs et al., 2023; Tranvåg et al., 2008).

His whole personality changed completely when the mania came. It was as though he was possessed by something alien. He 'disappeared' and 'someone else' took over…It was so frightening because I didn't understand….my brain was put out of action, had nothing to offer (Tranvåg et al., 2008, p. 8).

Many noted the need to mentally separate the person from the diagnosis to maintain a relationship (Richard-Lepouriel et al., 2022; Speirs et al., 2023; Van Der Voort et al., 2009). During depressive episodes, caregivers often felt useless and overwhelmed by the weight of

the individual's despair (Bauer et al., 2011; Rusner et al., 2012; Van Der Voort et al., 2009). These episodes brought worry about safety, powerlessness, and stress, which intensified during hospitalisations (Baruch et al., 2018a; Rusner et al., 2012; Speirs et al., 2023; Van Den Heuvel et al., 2018). The variability of symptoms caused heightened stress, vigilance, and exhaustion, as caregivers never knew when the next episode might occur and frequently felt one step behind (Baruch et al., 2018a; Bauer et al., 2011; Rusner et al., 2012, 2013; Tranvåg et al., 2008).

I experience the bipolar "emotional storms"…life is also a roller coaster for me…he's in the first carriage and experiences the up and down immediately. I am at the back and am perhaps still at the top when he rushes down and I don't understand at all what has happened because "everything" was fine…then I am still tired and sulky because I can't really get to him when he is on the way up again and thinks that I am boring and doesn't understand how good life is. It is not often that the train goes horizontally in a rollercoaster so we misunderstand each other all too often (Rusner et al., 2012, p. 205).

Some felt the individual's lack of insight into their diagnosis and or non-compliance with treatment compounded challenges (Bauer et al., 2011; Van Den Heuvel et al., 2018). One study highlighted how manic behaviours could be interpreted differently dependant on cultural contexts (Rusner et al., 2012). Several caregivers found that creating distance from BD specific situations allowed them to reflect and regain a sense of control (Richard-Lepouriel et al., 2022; Rusner et al., 2013). Maintaining routines, engaging in activities, and peer support also helped manage the unpredictable (Richard-Lepouriel et al., 2022; Rusner et al., 2013; Van Den Heuvel et al., 2018).

3.3.3.2. Descriptive Theme: Living on high alert

Caregivers described living in a state of hypervigilance, constantly monitoring for sudden and or unexpected changes in the individual's symptoms (Richard-Lepouriel et al., 2022; Rusner et al., 2012; Tranvåg et al., 2008; Van Den Heuvel et al., 2018).

I pay attention to everything because I'm careful that it does not go too high or too low, therefore I'm always a bit unstable…I'm always a bit in control (Richard-Lepouriel et al., 2022, p. 187).

This heightened vigilance was often a result of the unpredictable and variable nature of BD. Caregivers explained that this alertness sometimes created a sense of 'stability' amidst chaos, although it was fragile and often led to a near-constant fight or flight state (Rusner et al., 2012; Speirs et al., 2023).

There's such a chaotic situation here…which puts an even greater pressure on me never to be ill, never be aggressive, never act out…always be the stable person. That pressure is like a large bubble that makes it ache in my chest and threatens to burst (Rusner et al., 2012, p. 204).

Many caregivers tried to prevent BD episodes whilst respecting the individual's autonomy (Baruch et al., 2018a; Rusner et al., 2012; Van Den Heuvel et al., 2018). Some hesitated to suggest treatment, fearing that it would be perceived negatively (Baruch et al., 2018a; Rusner et al., 2012; Van Den Heuvel et al., 2018). Others developed communication strategies to facilitate these conversations (Baruch et al., 2018a; Van Den Heuvel et al., 2018). Caregivers became skilled at recognising early signs of episodes, sometimes before the individual was aware, although they sometimes struggled to differentiate between normal and abnormal behaviours (Van Den Heuvel et al., 2018).

When we read the information leaflet that summed up the features of BD, we recognised some things…symptoms appeared insidiously…that is the elusiveness of this disease; you never know when an episode will recur…that is why… if there is a sale at a store and he buys a thing or two…I have to be alert. Just in case (Van Den Heuvel et al., 2018, p. 535).

This chronic state of alertness left caregivers feeling perpetually on edge and burdened by the weight of responsibility.

4. Discussion

To our knowledge, this is the first review of qualitative studies to synthesise the experiences of caregivers supporting individuals diagnosed with BD. From this, three analytical themes were identified: 'burden of caregiving', 'healthcare system challenges', and 'coping with the shifting landscape'.

Consistent with existing literature (Van Der Voort et al., 2007), this review reveals the significant burden placed on caregivers, coupled with great responsibilities, challenges and sacrifices. They experience emotional and physical health impacts, often accompanied by new or worsening mental health difficulties. These feelings often led caregivers to question their role and whether to stay or leave. Some caregivers can feel they have no choice in the matter, which was reported by parents (Schulz et al., 2012). Reliance on psychological or pharmacological support was crucial, highlighting the importance of screening caregivers' wellbeing and responding to their needs (NICE, 2023). This is particularly pertinent when considering how caregivers described growing to accept their situation, emphasising the role of appraisal, grounding, and recognising the daily positives, all elements that psychological therapies and peer support can assist with (Baruch et al., 2018b; Perlick et al., 1999; Proudfoot et al., 2012; Steele et al., 2010).

Social withdrawal was common among caregivers, often due to their caring commitments and a perceived lack of support or understanding from friends and family. Compared to common mental health conditions such as depression and anxiety, BD is highly

stigmatised (Ellison et al., 2013; Perich et al., 2022). Many caregivers felt this stigma intensified their isolation and shame. Whilst attitudes towards BD vary globally (Latifian et al., 2023), caregivers in this review expressed a desire for greater public awareness, a need that organisations such as Bipolar UK (2022) are working to address.

Although not exclusive to BD (Cleary et al., 2020; Lillekroken et al., 2023), many caregivers felt excluded from care processes, with few noting openness from services. Key challenges included healthcare professionals providing inadequate information regarding BD and caregivers feeling unheard and uninvolved in treatment decisions, despite guidelines advocating for caregiver inclusion and information sharing (APA, 2002; Malhi et al., 2015; NICE, 2023; Yatham et al., 2018).

Several caregivers felt that certain structures were to blame for dissatisfaction with treatment, delayed access to support and information, and financial challenges. Whilst the UK has an Early Intervention in Psychosis pathway for first-episode psychosis (Neale & Kinnair, 2017), some caregivers expressed disappointment with the lack of BD equivalent care. The Bipolar Commission has been advocating for nationwide specialist services, recognising their effectiveness in some regions (Bipolar UK, 2022), however NICE (2020) guidelines do not explicitly recommend their implementation. Although these initiatives primarily target individuals with BD, it is evident that certain systemic shortcomings can result in caregivers bearing additional burdens (Kargar et al., 2021), a finding highlighted throughout this review. Caregivers advocated for improved collaborative practices with mental health services, including better information sharing, joint crisis planning, and access to psychological and or strategies to help manage stress. A lack of integrated frameworks for caregiver support, fragmented mental health services, limited training on caregiver inclusion, and or stretched resources may contribute to caregivers' negative experiences (Bipolar UK, 2022; Kargar et al., 2021; Ogilvie et al., 2005). Likewise, the nature of BD poses unique challenges, requiring mental health services to be both reactive and consistently responsive, unlike traditional models.

A key factor differentiating the experiences of these caregivers from those supporting individuals with other mental and or physical health conditions are the unpredictable and variable symptoms in BD (Chiao et al., 2015; El-Slamon et al., 2022; Highet et al., 2004; Kang et al., 2011; Lou et al., 2017). Caregivers were in a state of hypervigilance, monitoring any change in symptoms. Some described becoming skilled in recognising early warning signs, however, this often came with feelings of being on edge and increased responsibility. Others described having limited knowledge of what to expect during and after episodes or how to respond. Transparent communication helped with this, but individuals' lack of insight into their diagnosis and non-compliance with treatment complicated matters.

Confusion around cultural differences in understanding BD symptoms may increase stress for caregivers (Rusner et al., 2012), highlighting the importance of culturally sensitive frameworks to better equip caregivers for said challenges. A Care Quality Commission (2022) review found that nearly one in six patients in UK mental health services had their ethnicity recorded as 'not known' or 'not stated', hindering services' ability to address cultural needs. This, compounded by documented racial inequalities in BD treatment (Akinhanmi et al., 2018; Tchikrizov et al., 2023), raises concerns about whether ethnic and cultural factors receive sufficient attention in mental health care.

4.1. Limitations

This review's findings are based on a comprehensive and systematic search that incorporated various studies with differing methodologies and participants. Whilst offering an overview of the existing literature, we encourage readers to consult the primary studies for nuanced insights that may not be fully captured in this synthesis.

Although our findings provide valuable insights into caregivers' experiences, the decision to only include studies conducted in Western countries with individualistic cultures may limit the transferability of findings to other cultural contexts. Likewise, most studies did not report on participants' ethnicities, making it difficult to determine any cultural variations. This is particularly concerning given disparities in BD diagnosis and access to mental health

services among ethnic minority groups (Aggarwal et al., 2016; Bignall et al., 2019; Haeri et al., 2011).

Additionally, as this review only included studies published in English, relevant studies may have been omitted. As most participants were female, this may have influenced the findings, given documented gender differences in caregiving (Ogilvie et al., 2005; Sharma et al., 2016). Moreover, most studies did not report caregivers' time spent supporting the individual with BD, making it unclear how findings transfer to different 'levels' of caregiving. Lastly, we acknowledge that researchers' backgrounds and beliefs may have influenced the interpretation of findings, thus we ensured to adopt a triangulation approach by having discussions with reviewers (JH & BLT) at various stages.

4.2. Clinical and Research Implications

Given the challenges that caregivers face in working and communicating with healthcare professionals about diagnosis and ongoing treatment, mental health services could revisit their protocols regarding caregiver involvement. Greater involvement could reduce caregiver burden and stress, improve confidence to manage the unpredictable, strengthen communication with the individual, and foster trust in mental health services, ultimately bettering outcomes for all involved. As many caregivers experience high levels of stress due to BD's unpredictable nature, and its associated responsibilities, mental health services should proactively screen for mental distress and provide the appropriate support. As recommended in BD management guidelines (APA, 2002; Malhi et al., 2015; National Collaborating Centre for Mental Health, 2006; NICE, 2023; Yatham et al., 2018), this could include peer support, psychological therapies, and or information on self-care strategies.

Future research could explore caregiving experiences across diverse cultural and geographical contexts to better understand any differing experiences. A broader cultural understanding would not only fill gaps in the literature but also aid in the development of culturally sensitive support tailored to the unique needs of said caregivers. Similarly, future research would benefit from examining caregiving experiences by gender as well as

caregiving role (e.g., spouse, sibling), to help identify any specific needs, responsibilities, or challenges. Existing research has predominantly focused on spouses or grouped family members. Such insights could inform tailored support that better address the unique needs of different caregiver groups.

5. Conclusions

This review highlights the complex experiences caregivers face when supporting individuals with BD. They report emotional, practical, social, and health challenges due to the demands of caregiving and the nature of the condition. Some navigated the path to acceptance and implemented strategies to manage. Caregivers are met with unhelpful and judgemental comments, with many expressing a need for greater BD awareness. Challenges collaborating and communicating with mental health services were common, with calls for improvements in service delivery. Perceived barriers with service structures and protocols decreased care satisfaction. Professional support was welcomed, and services should continue to improve screening for caregiver's wellbeing, providing necessary support and or signposting. Services must also address caregiver-specific needs, adapting practices accordingly.

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Chapter 3: Bridging Chapter

The thematic synthesis in Chapter Two aimed to systematically identify, appraise, and synthesise qualitative studies exploring the experiences among caregivers supporting individuals with BD. This resulted in three analytical themes being generated.

The first analytical theme ‘burden of caregiving’ presented a multifaceted picture for caregivers, highlighting the burden, wellbeing challenges, and lack of social support and understanding from others. Whilst caregivers of those with BD typically face an uphill yet gradual adjustment over time, postpartum psychosis (PP) often presents unexpectedly and in a crisis context (Perry et al., 2021). Given the sudden onset of PP symptoms, it is unclear whether experiences would be comparable to those of BD. Likewise, if present, it calls into question how the experienced burden may feel in the long term should their partner be diagnosed with BD following a PP episode, go on to experience another PP episode, or struggle with their mental health. Additionally, in comparison to caregivers of individuals with BD, those supporting women through PP may receive greater support from family and friends due to the perinatal focus. This raises important considerations about how support structures respond differently across contexts, despite similarities in the presentation of symptoms during crisis.

The second analytical theme ‘healthcare system challenges’ highlighted the obstacles experienced by BD caregivers when navigating the healthcare system. They also noted difficulties collaborating with healthcare professionals and perceived them as unsupportive and unaware of their needs. Despite the Long Term Plan (NHS England, 2019a) highlighting the need for services to signpost partners (or fathers) to support and offer specialist assessment for their mental health, little is known about how they navigate and experience service-related care. Similar to BD, those supporting women with PP may be exposed to a variety of community and hospital-based mental healthcare (Roxburgh et al., 2023). Although, the onset of PP may be their first interaction with mental health services. This experience could shape their expectations and willingness to engage with services, which becomes particularly pertinent if the women later receives a BD diagnosis or

experiences subsequent PP episodes. Given the reported challenges caregivers of individuals with BD face with services, it is worth considering whether similar (or different) patterns emerge for those supporting women with PP, given the perinatal context and service set-ups.

The third analytical theme ‘coping with the shifting landscape’ underscores how the episodic and variable nature of BD, as outlined in Chapter One, feels like a rollercoaster ride for caregivers. This often left them feeling hypervigilant, constantly alert for changes in the individual’s mood or warning signs of relapse. This understandably led to increased burden, with some seeking ways to help them cope. In PP, it could be argued that hypervigilance appears as early as the first signs of deterioration (due to limited understanding, fear of baby’s wellbeing, uncertainty about accessing help) and or upon discharge from hospital when it may be perceived that the woman is on her path to recovery. Likewise, uncertainty about future PP episodes, BD diagnosis, or general deteriorations in the woman’s mental health could result in heightened vigilance for those supporting her. Thus, this raises questions about whether mental health services equip caregivers with the necessary support and information, and whether there are similarities in how caregivers across conditions respond to shifts in mood and escalating symptoms.

With these considerations in mind, as well as those outlined within Chapter One, Chapter Four presents a qualitative empirical study that primarily focuses on the experiences of care from mental health services among partners of women accessing support for PP. This study provides an opportunity to explore how caregiving and service interactions in PP compare to those in BD (and other SMI), highlighting both shared challenges and condition-specific differences.

Chapter 4: Empirical Research Project

Experiences of care from mental health services among partners of women accessing support for postpartum psychosis: a qualitative study

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Author guidelines can be found in Appendix E.

Abstract

Purpose: Postpartum psychosis (PP) affects one to two per 1,000 women and requires urgent intervention. Whilst PP primarily impacts women, it can place significant strain on partners, who often play a pivotal role throughout postnatal care and recovery. Little is known about how mental health services engage with and support partners during a PP episode. Therefore, this study aims to explore partners' experiences of mental health services to better understand their experiences and needs and inform service provision.

Methods: Semi-structured interviews were conducted with 12 partners of women who received support for psychosis following childbirth. Findings were analysed thematically.

Results: Three main themes were identified: 'understanding and responding to PP', 'partners' involvement in PP care' and 'the responsibilities undertaken and partner wellbeing'. Partners struggled to recognise PP and reported variability in healthcare professionals' knowledge of the condition. They urged for greater information and awareness of PP for partners, professionals and society. Most took on advocacy roles yet reported inconsistent involvement from services. Their ongoing responsibilities and PP related experiences significantly impacted their emotional wellbeing, with many finding services unresponsive to their needs. Some felt lucky to receive tailored support from charities and general practitioners. Many highlighted the need for improvements in integrated care frameworks for partners.

*Conclusions***:** These findings call for more inclusive and consistent care frameworks that actively involve, inform, and support partners. Further efforts are required to raise awareness of PP, improve staff training, and explore partners' needs from varying backgrounds, time points, and circumstances.

Keywords: Postpartum psychosis; Services; Partners; Fathers; Qualitative; Postnatal care

Introduction

Psychosis following childbirth, also known as postpartum psychosis (PP), affects approximately one to two per 1,000 women (Perry et al., 2021). Onset is often rapid and unexpected, with most cases emerging within two weeks postpartum (Heron et al., 2008). Symptoms include hallucinations, delusions, and disturbances in mood and cognition (Friedman et al., 2023). Recognised as a 'psychiatric emergency', PP often results in psychiatric hospitalisation (Heron et al., 2008; Jones et al., 2014). Despite its severity, PP is not classified as a distinct diagnosis in the DSM-5 (American Psychiatric Association, 2013) or ICD-11 (World Health Organization, 2019), instead, both include a specifier for 'postpartum onset' within four to six weeks after childbirth. Timely detection and treatment are crucial for a good prognosis, with early intervention leading to more favourable outcomes (Boyce & Barriball, 2010; Burgerhout et al, 2017; Jairaj et al., 2023). PP affects women from diverse backgrounds, with risk factors including pre-existing mental health conditions (namely bipolar disorder), previous PP episodes, obstetric complications, psychosocial stressors, immunological and genetic factors, and sleep deprivation (Işik, 2018; Jones et al., 2014; Perry et al., 2021). Experiencing PP can be life-changing and traumatic (Forde et al., 2020; Fusar-Poli et al., 2025; Heron et al., 2012), sometimes affecting maternal caregiving and bonding (Biaggi et al., 2021), which may affect child development (Plunkett et al., 2017). There is also an increased risk for maternal suicide, infant related accidents, and future psychiatric episodes (Brockington et al., 2017; Gilden et al., 2020).

Partners of women with PP often take on multiple responsibilities and roles as family dynamics shift, whilst also facing significant emotional and psychological challenges in navigating the condition (Doucet et al., 2012; Engqvist & Nilsson, 2011; Forde et al., 2020; Heron et al., 2012; Holford et al., 2018). PP can place strain on relationships (Wass et al., 2024), with research indicating that one in five marriages end following a PP episode (Blackmore et al., 2013). Conversely, some partners report that the experience of PP fosters greater understanding and support, leading to growth and positive change in their relationship (Boddy et al., 2017). Whilst partners often play a pivotal role in women's

postnatal care and recovery (Dolman et al., 2013; Grube, 2004; Jairaj et al., 2023; McGrath et al., 2013; Roxburgh et al., 2023), many express being excluded from care processes. They often feel uninformed about their partner's diagnosis, status, care plans, and prognosis (Boddy et al., 2017; Doucet et al., 2012; Holford et al., 2018). Specialist services such as Mother and Baby Units (MBUs) are perceived as more inclusive and responsive than general acute psychiatric wards and community care (Boddy et al., 2017; Roxburgh et al., 2023). Partners also urge for practical support, such as help with household tasks and infant care, although this has rarely been offered (Boddy et al., 2017; Doucet et al., 2012). It is, however, important to note that pre-existing relationship difficulties and conflict with the partner may pose additional barriers and or worsen perinatal mental health outcomes (Antoniou et al., 2021; Howard et al., 2013).

The NHS Long Term Plan (NHS England, 2019a), building on the Five Year Forward View (NHS England, 2016a), states that by 2023/24, partners of women accessing specialist perinatal mental health services should receive mental health checks, be incorporated into evidence-based psychological therapies, and have signposting to support as needed. Likewise, the National Institute for Health and Care Excellence (NICE, 2020) guidance outlines the need for healthcare professionals to consider the role of the partner in care plans, provide them with information and advice, and assess the impact of PP on the couple's relationship. However, many partners still lack access to the required specialist support, highlighting a critical gap between policies, guidelines, and service delivery. Ongoing work and resources to deliver targets set by the Long Term Plan are required to ensure this much needed care is provided (Maternal Mental Health Alliance, 2023; NHS England, 2021).

Although existing research provides valuable insights into the experiences of services among partners of women with PP, these studies were conducted before the implementation of the Long Term Plan; we would expect changes in service provision and inclusion of partners to have improved since then. To our knowledge, no previous studies

have solely explored in-depth partners' experiences of current service systems within the context of PP.

In the current study we aim to address these gaps in the literature by exploring how partners of women with PP experience mental health services, and what kind of care they would prefer. Gaining a deeper understanding of these experiences can further inform service provision for partners of women with PP, helping tailor care and enhance outcomes.

Methods

Design

This study adopted a qualitative design. Data were analysed using thematic analysis, following an inductive approach to identify commonalities and variations across transcripts (Braun & Clarke, 2006, 2019). This method was deemed appropriate given the exploratory nature of the research, facilitating a comprehensive analysis that extended beyond individual accounts to uncover patterns across the broader dataset (Braun & Clarke, 2006). A critical realist and contextualistic epistemological and ontological stance was assumed, recognising individuals' experiences as authentic yet shaped by their contexts, thereby producing knowledge that can inform meaningful change (Rogers & Rogers, 1997; Tebes, 2005). NHS ethics approval was obtained (reference: 24/SC/0013) (Appendix F).

Participants

Twelve partners of women who all self-reported having experienced PP were included in this study. Partners were purposively recruited through three charities (Action on Postpartum Psychosis [APP], Bipolar UK, and Dad Matters) and one NHS healthcare provider in the East of England to ensure diversity in demographic and socioeconomic factors, as well as service use. Inclusion criteria required partners to be 18 years or older; be the partner of a woman who received care for psychosis following childbirth (self-reported as PP by women) in the UK; and to have been in a relationship with the woman at the time of birth and throughout the postnatal period. Whilst partners views following relationship

breakdown are important, it was agreed that this criterion would provide the most homogenous and comparable insights. The PP episode must have occurred within the past seven years and more than six months ago. In line with previous studies (Doucet et al., 2012; Grube, 2004; Holford et al., 2018), a time frame of seven years was chosen to balance event recall with ensuring an adequate sample size given PP's low prevalence (Perry et al., 2021). This time frame also ensured that support was accessed following the release of the UK 2016 Five-Year Forward View (NHS England, 2016a). A six-month minimum since onset aimed to reduce distress and ensure partners had sufficient service experience and time for reflection. Partners who did not understand or speak fluent English were excluded. Participants meeting inclusion criteria who expressed an interest in participating were contacted by the first author to provide them with more information about the study, review informed consent, and schedule the interview. Participants were informed that their contributions would be kept confidential, with anonymity of quotations ensured. An incentive of £10 in the form of a voucher was offered.

Data Collection

Recruitment involved online and in-person leaflet advertisement (Appendix G) directing interested individuals to an online screening questionnaire. This questionnaire collected contact details, verified inclusion criteria, informed participants about the research, and obtained informed consent (see Appendix H and I). Interviews were semi-structured, using an interview schedule containing open questions to guide areas of discussion (Appendix J). This explored partners' wellbeing, and their views of the services accessed for the woman's PP throughout her entire care pathway. Characteristics pertaining to the participant and their partner (reported by participant) were obtained at interview stage. Interviews were conducted via Microsoft Teams between March and July 2024 and lasted approximately one hour and 30 minutes. The interview schedule was informed by existing research (e.g., Holford et al., 2018; Roxburgh et al., 2023) and developed by the research team. The interview scheduled, coupled with the advertisement of the study, were reviewed

by two partners of women who experienced perinatal mental health difficulties, with suggestions for refinement actioned. Interviews (n=12) were conducted by the first author, a clinical psychology doctoral trainee.

Analysis

Interviews were video recorded and transcribed verbatim by the first author (ER), which aided with data familiarisation (Riessman, 1993). Identifying features reported during interviews were anonymised. Interviews were then imported into NVivo 14 for analysis by ER. Thematic analysis (Braun & Clarke, 2006, 2019) was adopted, taking an inductive approach exploring meaningful comments and patterns in partners' experiences. Transcripts were read and re-read to identify initial codes which were then developed into themes. Themes were refined and restructured as the analysis progressed. To enhance rigour, a second researcher (JH) reviewed initial codes and read a subsample (n=3) of interviews. Regular discussions were held among the research team throughout the analytic process to revisit and adjust the thematic framework. Given the emphasis on reflexivity in qualitative research (Dodgson, 2019), the researchers regularly considered how their beliefs, biases, and positions might influence the data interpretation and theme development.

Findings

Participant Characteristics

Participants' characteristics are shown in Table 1, with additional information regarding their partners where relevant. Their mean age was 39 (range 31 to 45). Most participants were highly educated, full time employed, and from a white British background. All participants identified as male, were married, and living with their partner. There was variability in the mental health services accessed by women for their PP support, which is not uncommon (see Table 1). Of the 12 women, two did not access specialist perinatal support at any point. Table 2 provides details of the key services that participants reported

women accessing. Some women were reported to have engaged with more than one service at the same time during different stages of their care journey.

Table 1

Characteristics of participants and their partners (N=12)

Characteristics	**Category**	**Mean or *n***
Participant's age (years)	Mean Age	39
Gender	Male	12
Ethnicity	White British	8
	White Other	3
	Asian	1
Level of education	Postgraduate degree or above	8
	Undergraduate degree	2
	A-Levels	1
	GCSE	1
Employment status	Full time employed	9
	Part time/self-employed	3
Marital status	Married	12
Living with partner	Yes	12
Number of children	1	4
	2	6
	3+	2
Pre-existing mental health status in participant (self-reported)	Anxiety	3
	No prior experience	9
Psychiatric status in women (reported by participants)	First onset of postpartum psychosis (one woman with pre-existing schizophrenia)	10
	Second onset of postpartum psychosis	2

Services accessed in postnatal period by women (women could access more than one service)	Specialist perinatal	Mother and baby unit	7
		Perinatal community mental health team	8
	Non-perinatal	General acute psychiatric ward/psychiatric intensive care unit	5
		General community mental health team	4
		Early intervention in psychosis services	4
		Crisis resolution team/ home treatment team	7
Time since support accessed for first PP episode		1 year or less	4
		2-4 years	5
		5-7 years	3

Table 2

Details of mental health services accessed by women

Specialist perinatal or non-perinatal service	**Type of service**	**Description**
Specialist perinatal	Mother and baby unit	Specialist inpatient unit supporting women with severe mental health needs and their babies.
	Perinatal community mental health team	Multidisciplinary team supporting women in the community with severe mental health needs.
Non-perinatal	General acute psychiatric ward/psychiatric intensive care unit	Inpatient wards for adults with severe mental health needs/ providing higher security and

		intensive care. Women are admitted without their baby.
	General community mental health team	Multidisciplinary team supporting adults in the community with ongoing mental health difficulties.
	Early intervention in psychosis services	Multidisciplinary team supporting adults with a first episode of psychosis.
	Crisis resolution team/ home treatment team	Multidisciplinary team supporting adults in an acute mental health crisis.

Overview of qualitative findings

Three main themes were identified from the analysis: 'understanding and responding to postpartum psychosis', 'the responsibilities undertaken and partner wellbeing', and 'partners' involvement in postpartum psychosis care'. Table 3 shows subthemes for these, each described in detail in the text below.

Table 3

Themes and subthemes identified

Themes	Subthemes
Understanding and responding to postpartum psychosis	Recognising the early warning signs Staff awareness and communication Bridging the knowledge gap
Partners' involvement in postpartum psychosis care	Using their voice Partners in the picture Improving inclusive care frameworks
The responsibilities undertaken and partner wellbeing	Carrying the load The emotional toll on partners

Understanding and responding to postpartum psychosis

Many participants struggled to recognise their partner's mental health decline, often realising its severity when symptoms became extreme. Variability in healthcare professionals' knowledge of PP contributed to their frustration and confusion, further diminishing participants' confidence in the system. Many stressed the need for greater awareness and accessible information about PP, not only for partners and healthcare professionals, but also wider society.

Recognising the early warning signs

Recognising the early signs of PP proved difficult for many participants, as they struggled to understand the changes in their partner's mental health presentation. Some misattributed symptoms to physical health complications or medication side effects. Several participants only realised the severity of the situation once their partner reached crisis point.

> She was definitely low, getting worried, and her behaviours were becoming strange…it got to the point where I'd woken up one morning and she was wide awake, and I just turned around and said to (her) you ok? And she said, yeah we're dead, I think we're dead, and (name of child)…we are dead. And I think that's when I realised something was definitely not right. It wasn't just side effects of the tablets. (P09)

This lack of awareness often delayed help-seeking, leaving some questioning whether it had worsened their partner's prognosis. A few participants felt that their professional experiences had equipped them to recognise their partner's mental health decline and take appropriate action, noting that 'that's probably what made the difference' to their partner's prognosis (P03). Midwives often facilitated access to support services, whilst participants without such guidance relied on general practitioners (GPs) or attended Accident and Emergency (A&E), unaware of the support options available. In contrast, one

woman's pre-existing schizophrenia diagnosis ensured she was already under the care of services. Participants vividly recalled these early events, reflecting confusion, urgency, and, at times, regret over delayed action.

> It was like in a movie…on my way home, I didn't really know what was going to be there. And I was worried that the children will be dead, like literally, in the washing machine or something because I knew that she was, she wouldn't even recognise me over the phone. (P03)

Staff awareness and communication

Participants described disparities in healthcare professionals' awareness and communication of information regarding PP from conception through to postnatal care. Several were surprised by the lack or absence of information on severe mental health conditions during antenatal and National Childbirth Trust (NCT) classes, describing these as missed opportunities to raise awareness.

> …they could have flagged it up a bit more the kind of mental health impacts that having a baby can have… that there's potential that you can experience a serious mental illness…it would be good to know that that's a possibility…I would have just like to have been a lot more alert to the possibility that this could take a real toll on my wife's mental health and that it's not just stress. (P12)

Many felt healthcare professionals lacked expertise in recognising PP, with some highlighting instances when their partner was misdiagnosed with postnatal depression (PND). Of the 12 women, eight were told by healthcare professionals that they were experiencing PP, although this information was sometimes not relayed to participants. One woman was told that she was exhibiting PP symptoms, but this was never officially confirmed. Whilst another woman's symptoms were managed as a relapse of her pre-

existing schizophrenia, despite the participant's efforts to highlight how different this episode felt in comparison to previous relapses. Two were later diagnosed with bipolar disorder, with murmurings of PP-like symptoms by healthcare professionals earlier in the woman's care. The lack of clarity regarding their partner's presentation added to participants' confusion, with some attributing this to perceived delays in appropriate care.

> I think that they weren't aware of the severity of the situation. I certainly wasn't, and I think them as the professionals, albeit midwives, weren't aware, or at least didn't have enough awareness. I know they're not mind readers…but I think that perhaps if they'd had more…of an awareness, they could have given me more of an awareness. (P06)

Many emphasised the importance of reassurance about the prognosis of PP, which few felt was adequately provided. Some sought information online or via charities like APP or Bipolar UK, often on their own initiative due to limited signposting from services.

Bridging the knowledge gap

Many participants lacked prior knowledge of maternal mental health conditions, with nearly all having not heard of PP before. They emphasised the need for greater awareness not only among healthcare professionals but also for partners and wider society. Suggestions included providing practical resources, such as leaflets or emails directed at partners, with clear information about warning signs, potential presentations of PP (and other conditions), and support systems available.

> I expressed this in many moments of frustration, even if the staff are not aware in detail of the intricacies of mental health challenges around perinatal period, surely at the very least there could just be a pack that gets given to every expected mother to take home to share with their partners that has, you know, here's the links to the

> websites, here's the phone numbers for perinatal teams if you need to contact them...it gives them a point to try and start accessing the system. (P08)

Participants believed having this information pre and post birth could have made them more alert and responsive to their partner's mental health needs. However, some acknowledged that these materials might not have always been read and retained.

Partners' involvement in postpartum psychosis care

Participants provided unique insights into their partner's condition and often advocated on her behalf when she could not due to the severity of her PP symptoms. They experienced varied levels of involvement from services, highlighting the need for better integrated care frameworks to support their active role.

Using their voice

Participants were pivotal in both advocating for their wife's needs and taking initiative to ensure care progressed smoothly. For example, they ensured services followed previously established care plans or requested changes to new ones and arranged appointments and care in the initial stages and during relapses.

> She (healthcare professional from crisis team) said…I got your wife booked for Tuesday. And I said, no…this is something that needs to be treated for immediately, so I would really appreciate if she was seen today. And actually the same day at around 12, we had...a psychiatric consultant and mental health nurse coming in. (P03)

One participant took the lead in securing an ambulance to transport his partner to an MBU. Several participants also led discussions with healthcare professionals when their partner's PP symptoms were severe. Whilst attending services, partners often served as

emotional anchors, stepping in to support their partner during acute episodes. Despite their efforts, some partners hesitated to speak up, feeling unsure of their role or deferring to healthcare professionals. Familiarity with the system helped some gain confidence to advocate more effectively.

> I've learned so much more about how you…navigate the system…which leavers to pull and buttons to push to get the right outcomes…hopefully…this conversation is part of a drive to make it so that people don't have to learn it the hard way as much. (P08)

Partners in the picture

The involvement of participants in PP care varied greatly across services and individual experiences. Participants described feeling valued and included in many instances but ignored and overlooked in others, with unclear reportings of either more or less favourable outcomes in more recent years.

> …she was like and what is (wife) like normally?…I hadn't really expected it based on the experiences I'd had up to that point for me to be asked anything other than when does (baby) need feeding…so that was good. (P01, MBU)

Several participants noted missed opportunities for updates, invitations to discharge planning or care meetings, and inclusion in care decisions. Whilst COVID-19 posed challenges, some felt it did not justify the lack of involvement or support they experienced. Participants' involvement was sometimes facilitated by their partner requesting their presence. In other cases, they felt PP symptoms caused their partner to doubt their intentions.

> I've been a little worried to contact the MBU because I don't want the same thing to repeat again, like my wife accusing me of having an affair with the staff members. (P11)

Many participants spoke positively about MBUs and acute wards for acknowledging and promoting family involvement, although others had less favourable experiences. Meanwhile, perinatal teams were praised for their support but also criticised for their shortcomings, as participants sometimes felt 'on the outside' of care. This was also the case for crisis and general community mental health teams, where participants reported positive experiences of feeling seen and heard, with other reports of being kept in the dark. These varied experiences highlight potential inconsistencies in how participants have been involved in PP care, even when supported by the same type of service.

Improving inclusive care frameworks

Participants highlighted the need for improved care frameworks that actively involve them not only throughout the PP care process but also from conception.

> …not living in like the old age times where the mums are doing everything type thing…just being involved…or like being looked at when those discussions are happening rather than feeling like you, you're sort of sat on the side or in the corner or going out to do the tea or coffee run. (P01)

Whilst two participants expressed appreciation for the NHS and access to specialist support, others shared concerns with the system, such as feeling like services were designed only with women in mind, healthcare professionals lacking knowledge of women's mental health history, and disorganisation and delays in obtaining transport to inpatient facilitates. Staffing issues and confidentiality policies were cited as barriers to accessing

information. There were also calls for better communication between and within services, alongside improved community care models for including women's partners.

> …perhaps pick up some points from the MBU…because that…was 10 out of 10…and putting that into the community model…would be really, really, really helpful…it would make the recovery better for mum…and make the whole process more efficient and reassure dad as well. (P06)

Participants also emphasised the need for services to acknowledge their role and proactively involve them by providing information, signposting resources, and actively listening to their concerns.

> …it would be more helpful if the onus was actually on the doctors and nurses to call you, to give you the updates rather than you to be chasing them, probably a couple of reasons for that, one of them…there comes a point when you're like, I'm just harassing them, and they've got more to do than just speak to me and I got to the point where I realised I wasn't going to get much out of calling them, so I just stopped calling them. (P09)

The Responsibilities Undertaken and Partner Wellbeing

Most participants faced diverse and overwhelming responsibilities when their partner was unwell, sometimes shaped by systemic factors. These demands, coupled with the experience of PP, often affected their wellbeing, with some feeling supported whilst others felt left to manage alone.

Carrying the load

It was common for participants to take on significant responsibilities whilst managing their partner's PP. Many assumed childcare duties, especially when their partner was not admitted to an MBU, often relying on family or friends for essential support.

> It was a logistical nightmare…my mum's only a 10 minute walk down the road now 'cause she moved to help with everything that happened. (P06)

Participants also managed feeding, household chores, picking up prescriptions, finances, and implementing care advice from community teams to ensure the safety of their partner and child(ren). They were also sometimes required to step into the role of decision-maker on behalf of their partner. Long distance travel to inpatient wards or MBUs added to the strain. Some participants sought childcare solutions to continue working, although this could be challenging, whilst others found work to be an escape.

> I'm in a situation where my wife is in the adult psychiatric ward. I have a 5 month baby to look after. I'm unable to go to work. I don't have any childcare in place. It's way too expensive…I requested social services to help me…I'm in a situation neither I'm able to go to work, neither am I getting childcare, neither am I getting an MBU…I had a breakdown, what do I do? (P11)

The emotional toll on partners

The experience of PP had a profound emotional impact on many participants, sometimes resulting in mental health difficulties such as depression, anxiety, or PTSD.

> …there are lots of things that my wife doesn't remember about everything that happened….whereas I can't forget any of it. I saw it all…there's no forgetting for us. (P05)

The strain also affected relationships, with couples therapy often proving beneficial but typically sought privately rather than signposted by services. Many participants adopted a ‘head down, just get on with it’ mentality, immersing themselves in supporting their partner and managing responsibilities.

> …bit of a typical bloke…I also feel like I just need to crack on…there's stuff that I need to deal with here, and yeah I feel a bit down, but it’ll pass and we’ll just crack on and get the job done. (P04)

Whilst this approach helped them cope, some felt it reinforced the ‘stereotypical man’ image, which some thought led services to assume they were coping. Participants frequently described feeling overlooked by services, with few having received check-ins, signposting, or support for their wellbeing. Barriers such as time-limited GP appointments, online referrals, and uncertainty about where to access support hindered help-seeking. Many were frustrated with services’ inadequate signposting and advertisement of APP, which was often the only source of support accessed by participants. Some accessed other charities like Dad Matters and Bipolar UK, received support via their employer, or self-referred to talking therapy services. Two participants praised their GP’s for proactively and consistently checking in on their wellbeing. Delayed mental health declines commonly emerged after their wife stabilised, during subsequent pregnancies, or when no further episodes occurred.

> …they said everything was absolutely fine (wife’s mental health after second pregnancy) and I went into the garden and sobbed…I just realised how much I had been gearing myself up for this next fearful fight. (P02)

Participants tended to downplay their struggles but urged services to be more direct with check-ins and to provide hope during PP episodes.

Discussion

This study aimed to build upon existing research by exploring in-depth partners' experiences of current service systems following the implementation of the Long Term Plan within the context of PP care, whilst also focusing on better understanding what kind of support they would prefer. In line with previous research (Boddy et al., 2017; Engqvist & Nilsson, 2013; Forde et al., 2019), partners struggled to recognise and make sense of their wife's mental health decline, with some attributing changes in mood to physical health complications post birth. This occasionally delayed help-seeking, which is particularly problematic in the context of PP, given the immediate need for intervention to mitigate risks and improve outcomes (Boyce & Barriball, 2010; Burgerhout et al, 2017). Symptoms of PP can further hinder women's abilities to seek support themselves, placing greater reliance on partners (Roxburgh et al., 2023).

Aside from their own lack of awareness of PP, partners reported perceived disparities in healthcare professionals' knowledge of the condition across the perinatal period, comparable to existing findings (Lyons et al., 2024). This sometimes led to misdiagnosing PP for PND (Holford et al., 2018), further exacerbating existing confusion among partners. Heterogeneity of PP poses significant diagnostic challenges (Sharma et al., 2022), potentially hindering healthcare professionals' confidence in detecting, responding to, and informing partners about the condition. Calls for greater societal awareness regarding PP were prevalent among partners, something that organisations like APP are working hard to address.

Partners can play a critical role throughout the journey of PP, providing essential support, advocating during women's care, and offering stability. Contrary to prior research (Boddy et al., 2017; Doucet et al., 2012; Lever Taylor et al., 2018; Holford et al., 2018), many partners felt that services embraced their role, reflecting progress towards the NHS Long Term Plan's (NHS England, 2019a) objectives to enhance partner involvement in perinatal mental health care by 2023/24. However, systemic barriers to care and variability in involvement across services and individual experiences remained, indicating the need for

further efforts to ensure these frameworks are consistently and effectively implemented across all settings.

Additionally, it is important to recognise the role either PP related symptoms (such as delusions and paranoia) and or pre-existing difficulties within romantic relationships (such as mistrust, lack of support, abuse) may pose for partner involvement. As reported within this study and pre-existing research (Forde et al., 2020), women may become more sceptical of their partner's intentions during their care, a key differentiating factor between PP and other perinatal mental health conditions when considering tailored support (Fusar-Poli et al., 2025; O'Hara & Wisner, 2014). Ensuring adequate information gathering throughout antenatal care (e.g., routine midwife appointments) could prove vital in recognising any potential strains within the relationship. Likewise, decisions regarding partner involvement should not be static, given the variability of a PP presentation. Thus, embracing a dyadic way of working and reassessing partner involvement at different points in the woman's care could be helpful. Partners stressed the importance of inclusive care frameworks that acknowledge their role from conception through recovery, aligning with guidelines proposed by NICE (2020) and NHS England (2021). Similarly, as highlighted in a qualitative systematic review conducted by Lyons et al. (2024), the need for healthcare professionals to provide reassurance and information on PP was reiterated by several partners.

Consistent with previous research (Boddy et al., 2017; Doucet et al., 2012; Heron et al., 2012; Holford et al., 2018), the significant responsibilities placed on partners often left them feeling overwhelmed, with many adopting a 'just get on with it' mentality to cope. Whilst this approach appeared to help them manage immediate demands, it may have masked the emotional toll of their experiences, with mental health challenges often emerging once things seemed to settle (in line with previous research by Heron et al., 2012). This period is also accompanied by partners attempting to rebuild trust in their relationship after witnessing distressing events during the acute phase of PP (Boddy et al., 2016; Holford et al., 2018; Wyatt et al., 2015). Partners also reported difficulty expressing their struggles to services, sometimes hindered by systemic factors such as complicated referral processes and time-

limited appointments. It is important that healthcare professionals remain alert to these dynamics.

Women who experienced PP have recognised the psychological impact it can have on their partner and their need for psychological support (Heron et al., 2012; Roxburgh et al., 2023). However, repeated gaps in services' recognition of and offerings of support for partners have been highlighted (Doucet et al., 2012; Holford et al., 2018; Roxburgh et al., 2023), findings echoed in this study. A recent Maternal Mental Health Alliance (2023) report further underscores this, noting that as of 2023, only 42% of services offered mental health assessments and signposting for partners. Therefore, there remains an urgent need for more consistent and proactive approaches within services to ensure healthcare professionals are effectively identifying and supporting the mental health needs of partners. There also needs to be greater attention paid to addressing the strain that PP places on relationships, with services signposting to relevant support rather than leaving it to be sought privately, as noted by partners in this study.

Limitations

Whilst this study provides unique insights into partners' experiences of care during PP, several limitations must be acknowledged. Data analysis was conducted by the first author, but regular discussions with the research team ensured a triangulation approach to enhance rigour. Additionally, despite efforts made to mitigate recall bias, the time elapsed and distress caused by the episode may have influenced participants' recall. The sample consisted predominantly of white British, highly educated, married male partners, thus limiting the transferability of findings to partners from other backgrounds, gender identities, or relationship status. Findings are also limited to those who have not experienced relationship dissolution following a PP episode. Likewise, as participants were recruited predominantly through charities, they may represent a more proactive group and not speak to the views of those unable to access such support. As partners accessed services across the UK, findings are likely to be most transferable to these settings, although they may hold

relevance for international contexts. Lastly, half the sample experienced PP during the COVID-19 pandemic. Whilst some partners felt the pandemic did not influence their experiences, the extent to which service pressures impacted care remains unclear.

Implications

Providing partners with accessible and tailored information regarding maternal mental health, including PP where appropriate, during antenatal (e.g., midwife appointments and NCT classes) and postnatal care is an important consideration for improving their awareness and preparedness. Also, ensuring standard information gathering is undertaken during antenatal appointments to better understand relationship dynamics. Midwives are well positioned to facilitate these discussions due to their regular contact with families throughout the perinatal period. They would also benefit from further training to build their confidence in recognising and responding to PP. Likewise, despite classification complexities regarding PP, training could also be extended to healthcare professionals across all perinatal care disciplines to enhance consistent recognition and management of PP. This would not only improve timely and appropriate care for women but also provide clarity and reassurance to partners.

Greater societal awareness of PP is required, and although charities like APP have made significant progress in this area, continued efforts are required to support earlier recognition of symptoms and encourage timely help-seeking. As outlined in NHS England's (2021) guidance, the necessity to 'think family', 'remain curious', and maintain a 'perinatal frame of mind' is underscored by partners in this study, reiterating further efforts required to ensure the smooth running of said principles in current care frameworks. Likewise, services need to ensure that confidentiality policies do not inadvertently exclude partners, and that care adopts a family centred approach as recommended by NICE (2020). Due to partners known delayed mental health decline and help seeking, further efforts should be made to proactively offer mental health assessments, tailored interventions, and signposting to relevant organisations (e.g., APP) at various time points.

Given the predominantly white British, highly educated partners in this study, future research would benefit from exploring the experiences of partners from diverse sociocultural and economic backgrounds, whose perspectives remain underrepresented. This is particularly pertinent as partner characteristics in this study (e.g., stronger social set ups) may have offered protective effects (Roxburgh et al., 2023), raising the question of whether partners from different backgrounds might experience greater challenges. Likewise, existing research highlights that ethnic minority women face significant barriers when accessing perinatal mental health support, such as stigma, language barriers, and a lack of culturally relevant information and care (Watson et al., 2019). Such insights could help tailor support to better address the needs of partners from diverse backgrounds.

Additionally, further research investigating the longer-term impacts of PP on partners is warranted, given the strain PP can place on relationships, the delayed mental health impact of these experiences, and uncertainties around future pregnancy, conception, and potential relapse. Likewise, understanding how partners manage the shift from the woman's PP episode to an established diagnosis of bipolar disorder, particularly within the context of mental health services and the recognition of their caregiving role and needs, could offer valuable insights.

Conclusions

This study explored partners' experiences of mental health services in the context of PP, highlighting the roles they can play in caregiving, advocacy, and sustaining the family unit. Partners face significant emotional and practical strain, emphasising the need for services to proactively offer support and signposting for their wellbeing. Whilst some progress has been made, ensuring consistent involvement of partners across all settings remains essential. Greater awareness of PP among the public, healthcare professionals, and partners is necessary to ensure those involved are better informed and equipped to effectively manage PP episodes. Future research is needed to examine the experiences and

needs of partners within the context of PP, particularly those from diverse backgrounds, differing relationship status, and at various stages of the caregiving journey.

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Chapter 5: Additional Methodology

This chapter aims to elaborate on the methods section within the empirical research project. This includes further consideration of the researcher's ontological and epistemological stance, additional insight into reflexivity within the context of this research, elaboration on the recruitment process, how the interview schedule was constructed, and a more detailed outline of ethical considerations.

Ontological and Epistemological Stance

As outlined in Chapter Four, a critical realist and contextualistic epistemological and ontological stance (Fletcher, 2017) was assumed throughout the empirical research project, but also the systematic review and thematic synthesis. This positioning acknowledged that mental health services, caregiving roles, diagnoses, and systemic and organisational influences exist as real entities, rather than socially constructed concepts. Likewise, individuals were seen to interpret and engage with these realities in different ways based on their social, cultural, and personal backgrounds. This approach recognised that there was no experience 'truer' than another, it allowed for the diverse ways in which caregivers made sense of and responded to their experiences. Thus, resulting in the ability to inform service provision and real-world change. It is also important to note that this positioning was held in mind throughout various stages of the research, such as when choosing the design (qualitative), during data collection (semi-structured interviews designed to explore caregivers' personal experiences and their interactions with real entities), and throughout data analysis and interpretation (thematic analysis and synthesis to identify commonalities and variations across datasets).

Reflexivity

Acknowledging the researcher's position, underlying assumptions, and perspectives throughout the research process is crucial for enhancing credibility, rigour, and transparency in how the research is developed, conducted, and analysed (Dodgson, 2019). The main

researcher therefore wishes to acknowledge that she is a 29-year-old white British woman completing her Doctorate in Clinical Psychology, thus grounded in specific bodies of knowledge through her academic, research and clinical training. Prior to her current training, she completed a Master's in Clinical Mental Health Sciences and published research exploring women's experiences of mental health services in the context of PP. The current research topic was selected due to her previous work and interest in improving service provision and equity of care.

Furthermore, the researcher's lack of direct clinical experience working with women with PP or their partners positioned her as an 'outsider' in some respects, possibly enabling participants to articulate their experiences without assumptions about shared knowledge. However, her broader understanding of mental health systems and prior research shaped her approach to the topic. Although the researcher does not have any children or personal experience of PP, she experienced pregnancy loss and subsequently became pregnant again during data collection and analysis. These personal experiences of service interactions may have heightened her empathy and sensitivity toward participants' experiences but could have also introduced unconscious biases when interpreting partners' perspectives. Reflexivity was therefore emphasised throughout the research process, supported by regular supervision and the use of a reflective journal (see Appendix K for examples). It is therefore important to consider how her personal experiences may have influenced both her approach to interviews and the interpretation of data.

Recruitment

The leaflet advertising the research (Appendix G) was also uploaded to the charities Match of the Dads and Get Me Out The Four Walls social media platforms (Facebook and Twitter) and official websites. The authors (ER) social media platforms (X, LinkedIn, Facebook, and Instagram) were also used to advertise the research. Two NHS healthcare providers in the East of England supported with the identification of participants (although only one identified a participant), by advertising the research within general acute psychiatric

wards and MBUs. Women often access general acute psychiatric wards because of the limited availability on MBUs (Roxburgh et al., 2023). Falling within the above healthcare providers, ER also liaised directly with clinical leads and or team managers from community-based mental health services such as early intervention in psychosis services, community mental health teams, and specialist perinatal community mental health teams. A person of contact was identified within each service who then informed staff working with women who were or had experienced PP to hand them a leaflet (when on a home visit or scheduled meeting elsewhere) containing information about the research, which they would then choose to pass onto their partner.

Alternatively, if partners were present for said visit, and able to provide consent to be contacted (Appendix L), clinicians obtained the partners contact details and then emailed ER with their details. ER then contacted the partner to discuss what the research entailed and directed them to the screening questionnaire (Appendix M). ER ensured that all individuals expressing an interest to take part in the research completed the screening questionnaire. ER would then contact them via telephone to arrange a time and date for the interview (if there was no response, an email was sent to schedule a time to talk over the telephone), review the screening questionnaire responses, and answer any questions (see ethical considerations for further information). ER attended multidisciplinary team meetings to promote the research.

Interviews

As noted in Chapter Four, the interview schedule (Appendix J) was discussed within the research team, which included two clinical psychologists, both of whom had an interest in the field of perinatal mental health research. No refinements were suggested. Likewise, the two partners of women who experienced a perinatal mental health difficulty who provided feedback on the interview schedule were selected following a public and patient involvement advertisement (Appendix N) on two charities (e.g., Dad Matters and Get Me Out The Four Walls) social media platforms. The two partners emailed ER, from this, an email exchange

took place to arrange a time and date to meet via Microsoft Teams for an hour. During the meetings, one partner highlighted how he preferred the questions around partner wellbeing to be situated last, as he felt that talking about these experiences towards the beginning of the interview could be uncomfortable. The other partner emphasised that starting with a question about when they first noticed difficulties (PP) would help establish a timeline, making it easier to recall events in a logical order. Both suggestions were taken onboard, no further recommendations were provided. Partners felt there were sufficient follow up questions, and said they understood the wording of the questions.

Ethical Considerations

NHS ethics approval was obtained (reference: 24/SC/0013; see Appendix F) and a copy of all approved documentation was sent to the Research and Development (R&D) offices within the two NHS healthcare providers used for the identification of participants to obtain confirmation of Capacity and Capability. All sites and R&D offices were provided with the required updates throughout the research stages. Approval to promote the research was obtained from charities via email.

Participants were informed as to the purpose of the research at the screening stage. Consent was also obtained at this stage for screening purposes, contacting participants after completing the screening process (if deemed eligible), and to participate in the interview. The information sheet and consent form were revisited before the interviews commenced (see Appendix H and I). Capacity to consent to the terms outlined was also considered due to the sensitive topics discussed. Participants were reminded of their right to withdraw from the research up until data analysis commenced, as their data would be included, and it would not be possible to withdraw data at this point.

No risk concerns were highlighted whilst the research took place. However, a plan was put in place should any risk have been identified. For example, if someone disclosed suicidal ideation and or self-harm during any correspondence between the first point of contact with ER and the interview stage, this would have been investigated further to ensure

an informed decision could have been made regarding their suitability to participate in the study. If the decision to not involve the participant was reached based on suicidal ideation and or self-harm, appropriate mental health signposting and guidance would have been provided (see Appendix M), as well as encouragement to contact their GP. The same process would have applied to those disclosing suicidal ideation and or self-harm during the interview.

If there was an immediate risk, ER would have asked the participant if she could call the emergency services (999) and obtain the address of their current location. Alternatively, she would have encouraged them to attend A&E. If this was met with resistance, ER would follow the steps outlined above by providing them with the required support services and emergency contacts information. A collaborative safety plan would also have been completed.

If participants disclosed risk to others (e.g., woman and or child), ER would have remained non-judgemental and calm and reiterated that she is responsible for ensuring the safety and wellbeing of all people involved. An attempt to gather further information about the disclosure would have been explored with caution and empathy. An offer to contact their GP to inform them on their behalf would have been offered. If this was met with resistance, ER would have reiterated the support available and encouraged them to contact their GP. ER would have also consulted the research team to discuss the situation and seek guidance on how best to proceed. Safeguarding processes would have been followed where required (according to https://nhssafeguarding.app/raising-concerns/s1-01/). At this stage, ER would have had the participants contact details (such as name, telephone number and email address) if any follow up was deemed necessary. The opportunity for reflections and debrief would have been available with the research team, and the ability to discuss any additional steps required to be put in place to support the participant or others involved.

Participants provided their name, email address, and telephone number at the screening stage for the purpose of contacting them to arrange the interview. They were allocated an ID number (e.g., P01) at interview stage and identifiable information was

deleted once the interview had finished. Of the 12 participants, 10 requested the research findings once available; thus, consent was obtained to retain their email address on the UEA OneDrive (mentioned below). Participants were assured anonymity of quotations and in the reporting of results. Following the transcription of the data, the video recordings were deleted and any identifiable information within the recordings was changed. For example, if any references were made to their partner's names, this was replaced with 'partner's name'. If they mentioned their own name, this was replaced with 'participant name'. If they mentioned the names of any children, this was replaced with 'name of first child', and so forth. If a specific service or healthcare professional was named, this was replaced with 'type of service, e.g., CMHT' or 'healthcare professional role, e.g., Nurse'. If a specific location was referenced, this was changed to 'Location in England'.

We recognised that the interview schedule contained questions that could evoke strong emotions from participants, questions of this nature were inevitable given the aim of the research. The researcher ensured to be compassionate and attentive to how questions were asked. Breaks, the opportunity to not answer certain questions, and the option to reschedule the interview were offered, although no participant felt any of these were required. At the end of the interview, participants were debriefed (Appendix O), asked if they would like to be contacted with the findings of the research, and were offered the opportunity to ask any questions. They were also signposted to information regarding PP and mental health support.

Data were saved by the screening questionnaire software (JICS), downloaded, and exported onto the UEA OneDrive with double password protection. The same applied to the interview recordings, transcripts, and participant information. Only ER and the research team had access to the shared files. Files were not downloaded onto any personal laptops or desktops. All data was collected and managed in accordance with the Data Protection Act 2018 and the UEA Research Data Management Policy 2019.

Chapter 6: Discussion and Critical Evaluation

The final chapter provides a summary of the findings from both the thematic synthesis and the empirical research project. They are then considered collectively within the context of previous research and the wider literature. Following this, strengths and weaknesses of both papers will be explored and implications for clinical practice and research considered. The chapter ends with an overall conclusion of the thesis portfolio.

Summary of Findings

The systematic review aimed to thematically synthesise qualitative studies exploring the experiences of caregivers supporting individuals diagnosed with BD. From this, three analytical themes were identified, comprising six descriptive themes, with three supporting subthemes. The first analytical theme 'burden of caregiving' introduced 'the weight of care' (descriptive theme one) experienced by caregivers when caring for someone with BD. There was a 'hidden cost' (subtheme one) to caregiving, which highlighted the emotional, physical, and mental health difficulties that were experienced. They often felt 'alone in the struggle' (subtheme two), noting high social isolation and withdrawal, typically made worse by others' unhelpful remarks or stigma. The process of 'coming to terms' (subtheme three) with the BD diagnosis involved caregivers actively accepting the situation for what it was, rather than what they wanted it to be, with hope being crucial in this process.

Analytical theme two 'healthcare system challenges' noted how caregivers felt 'left out of the loop' (descriptive theme two) by healthcare professionals during the individual's BD care. Despite being privy to key information, they felt overlooked and dismissed, sometimes resulting in heightened uncertainty regarding how best to care for the individual with BD. They experienced 'barriers at every turn' (descriptive theme three), noting how systemic, organisational, and institutional obstacles often got in the way of seeking support for the individual with BD. Many expressed dissatisfaction with treatments provided, felt services for those with BD were limited, and stated how it was difficult to navigate how to support the individual in-between acute and 'stable' periods. This resulted in caregivers

highlighting ‘what they need’ (descriptive theme four), advocating for improved policies, collaborative practices among caregivers and services at various stages of care, and a desire for greater support for themselves.

The third and last analytical theme ‘coping with the shifting landscape’ explained how caregivers ‘ride the rollercoaster’ (descriptive theme five) that is the episodic and variable nature of BD. They noted equally challenging feelings when the individual was experiencing either a manic or depressive episode. Caregivers were often in a chronic state of ‘living on high alert’ (descriptive theme six) because of this, constantly monitoring for any changes in mood. Many found it challenging to flag any perceived mood fluctuations or treatment suggestions, whilst others developed communication tools to aid this process.

The empirical research project explored the experiences of care from mental health services among partners of women accessing support for PP. Three main themes were identified from the analysis, encompassing eight subthemes. The first main theme ‘understanding and responding to PP’ focused on how partners struggled to ‘recognise the early warning signs’ (subtheme one) and changes in the woman’s mental health. This sometimes resulted in delayed help-seeking, with many not knowing who or where to turn to for support. The ‘staff awareness and communication’ (subtheme two) of SMI was perceived as poor, with partners noting various missed opportunities to notify them of said risks. They also felt staffs’ knowledge of PP was limited, which in turn hindered the much-needed reassurance about the prognosis of PP. Partners noted how there is a need to ‘bridge the knowledge gap’ (subtheme three), calling for greater awareness and information regarding PP.

The second main theme ‘partner’s involvement in PP care’ highlighted how partners often ‘used their voice’ (subtheme four) throughout the woman’s care, to advocate on her behalf and ensure she received the appropriate care. ‘Partners in the picture’ (subtheme five) revealed how the involvement of partners in PP care varied widely across services and individual experiences. Experiences ranged from being overlooked and dismissed, to acknowledging the importance of their role. ‘Improving inclusive care frameworks’ (subtheme

six) was underscored by many partners, with some noting how systemic and organisational barriers were to blame.

The last and third theme ‘the responsibilities undertaken and partner wellbeing’ explained how partners often ‘carry the load’ (subtheme seven) when the woman is unwell with PP, undertaking many (additional) responsibilities. Family and friends were sometimes relied upon for extra support. The experience of PP also took a (sometimes) delayed ‘emotional toll on partners’, which resulted in mental health difficulties for a few partners. Most were not offered any support for their wellbeing, although some noted how their ‘just get on with it’ mentality may have resulted in services perceiving them to be coping well.

When considered together, the review and empirical study shed light on the commonalities and variances between caregiver experiences within the context of differing diagnoses, caregiver relations and backgrounds, and time periods in one’s life. Caregivers across both papers highlighted the necessity to undertake additional responsibilities and roles whilst caring for the individual with either BD or PP. It has been documented that caregivers of those with SMI often feel obliged to provide this level of care (Rowe, 2012), something that parent caregivers noted in the review. However, despite the challenges, most partners of women with PP described embracing this position (similar to Holford et al.’s 2018 findings). This could be seen as a natural extension of their role as a new parent, whilst also being a defined life stage where caregiving is somewhat expected. Caregiver identity can take time to develop (Carers UK, 2022b). Given the acute and often time-limited nature of PP, partners may be less inclined to see themselves as caregivers, which may pose additional barriers to their beliefs about accessing support. This calls into question whether identifying with the ‘caregiver’ title could help shift perceptions away from the male stereotype of ‘just getting on with it’ discussed in Chapter Four. Likewise, it prompts consideration of when a ‘partner’ transitions into a ‘caregiver’ role if the woman is diagnosed with a SMI following a PP episode.

Furthermore, despite the chronicity of BD in comparison to the acute nature of PP (Friedman et al., 2023; Mignogna & Goes, 2024), all caregivers expressed emotional and or

mental health difficulties, consistent with previous research investigating caregiver burden in SMI (Cham et al., 2022; Von Kardorff et al., 2016). This emotional toll, and the demands associated with caregiving in the context of SMI, can strain relationships to the point where partners either leave or consider doing so. This was evident in the review and is underscored in the PP literature (Blackmore et al., 2013; Wass et al., 2024). This highlights that regardless of illness duration, the pressures of caregiving (coupled with the experiences throughout) can lead to relationship dissolution. Previous research has also highlighted that relationship quality is important for both caregiving experiences and the wellbeing of individuals with SMI (Labrum et al., 2024). Thus, it is important to consider differences in caregiver relationships and how these variations may affect outcomes. Whilst common among caregivers (Carers UK, 2021; Hajek et al., 2021), those supporting individuals with BD reported higher levels of social isolation and withdrawal than those caring for women following a PP episode. It could be argued that given the perinatal context and time-limited nature of PP, family and friends are more inclined to provide practical and emotional support, as well as a listening ear.

Caregivers across both papers noted challenges (such as being excluded from care processes and not being provided with information or updates) with mental health services and professionals, although this was more commonly reported among BD caregivers. It could be argued that due to the advancements in service provision and specialist perinatal mental health care in the UK (Chin & Lim, 2022; NHS England, 2019c), that partner involvement was perceived more favourably. Nonetheless, a lack of involvement reported by caregivers, across differing countries and diagnoses, suggests a broader systemic issue that is more widespread. Likewise, countries will differ with regards to their caregiver inclusion frameworks (Zarzycki et al., 2024), with this being a key area for improvement in the UK, as acknowledged by the NHS Long Term Plan (NHS England, 2019a), Carers UK (2019), and the Lord Darzi's report (2024). Caregivers across both papers also urged for improved collaborative practices with mental health services.

Most caregivers also emphasised the need for healthcare professionals to provide them with more proactive wellbeing check-ins, offer psychological support and signposting, as well as strategies and skills to manage daily life. This is going to be even more critical for those supporting individuals with SMI, as the shift towards community-based mental health care could (inadvertently) place greater demands on caregivers if frameworks are not well established (NHS England, 2019b). It could be argued that specialist perinatal services have a historically 'built-in' family focus, whereas it may be less embedded within the service model of generic community mental health teams (where those with BD often receive support), resulting in changes to caregiver involvement and support perhaps taking longer to be recognised by healthcare professionals.

Similarities in caregiver hypervigilance can be observed among those caring for individuals with BD (as noted in the review) or following a PP episode. Research has shown that partners of women with PP find the recovery process challenging, noting how they second guess and sometimes misinterpret humour or increased energy for the return of manic symptoms (Holford et al., 2018). This suggests that hypervigilance is a shared burden for caregivers, and that it extends beyond time-limited episodes, even if the woman does not receive a BD diagnosis. It also highlights the need for clear classifications of conditions and psychoeducation for caregivers so they can be better equipped to manage in the future (Lyons et al., 2024).

Lastly, findings relating to caregiver burden (and other wellbeing outcomes) across both papers can be understood through the lens of the Carer Stress and Burden Model (Sörensen et al., 2006), an integrative framework of both the Appraisal Model (Lawton et al., 1991) and the well-known Stress-Process Model (Pearlin et al., 1990). The Stress and Burden Model comprises six interrelating elements: 1. Primary stressors (direct challenges as a result of caregiving demands, e.g., intensity and variability of symptoms, tasks performed), 2. Secondary stressors (indirect challenges as a result of caregiving, e.g., relationship challenges, financial strain, social isolation), 3. The appraisal, a personal evaluation of their situation (demands vs resources available), which results in 4. The

outcomes (e.g., burden, emotional distress, physical and or mental health difficulties). The linear sequence of the model can be influenced by 5. Exacerbating and mitigating factors (e.g., stigma, lack of or increased social support, coping strategies, formal support systems, caregiver characteristics inclusive of attachment styles [Dark-Freudeman et al., 2016; Tricarico et al., 2024]), consisting of all other influences aside from the primary and secondary stressors. Finally, 6. Background and contextual factors (e.g., socioeconomic, demographic, cultural) can also inform the caregiver's experiences.

The above framework allows for an enhanced comparison and understanding of both the commonalities and variances in SMI caregiving. For example, as previously mentioned, social isolation was less prevalent among caregivers of individuals with PP in comparison to BD, and stigma was a reported area of concern in BD caregiving but not in PP. This highlights how the model can capture differences and specific challenges dependent on the condition. This also extends beyond SMI caregiving, whereby conditions such as dementia may present its own unique challenges. For example, differences in primary stressors, such as the progressive nature of the illness, accompanied by secondary stressors like an increase in caregiving tasks over time (Engel et al., 2022), may be less prominent in SMI caregiving. Likewise, a recent systematic review (Lindeza et al., 2020) highlighted how positive aspects in dementia caregiving were attributed to effective support from services (exacerbating and mitigating factors), which was a particular area of concern reported by caregivers across both papers.

Despite the model serving to highlight distinctions across conditions, it also underscores a deeper understanding of caregiver experiences and outcomes, whereby individual differences are recognised as important. As highlighted in these findings, caregiver relation and background appeared to influence outcomes. Thus, despite reports of similarities among caregiver experiences across mental health conditions (Cruz et al., 2024), the model encourages the recognition of nuances in caregiving experiences and the need for personalised care (especially as the same condition may result in differing outcomes for caregivers).

Strengths and Limitations

To the authors knowledge, this is the first thematic synthesis and qualitative study investigating the experiences of caregivers (inclusive of partners) supporting individuals diagnosed with BD and receiving mental health support for PP, thus complementing previous research. Combining the thematic synthesis with a qualitive study provided a multifaceted understanding of caregiver experiences across diagnoses, synthesising existing literature whilst also producing new insights. The use of thematic synthesis and thematic analysis ensured consistency with the analytic processes, facilitating a coherent integration of findings (Thomas & Harden, 2008). Moreover, the commitment to transparency throughout the research process was a real strength, from pre-registering the protocol on PROSPERO to systematically documenting and reporting amendments. Therefore, ensuring to adhere to best practices (Kolaski et al., 2023; PLoS Medicine Editors, 2011). Furthermore, whilst challenges have been reported in conducting literature searches of qualitative research (Methley et al., 2014; Shaw et al., 2004), this was not a limitation in the current review. The search strategy, developed in consultation with a specialist librarian and piloted to ensure the SPIDER tool (Cooke et al., 2012) retrieved sufficient papers, effectively captured relevant studies.

The regular use of supervision provided external perspectives and exploratory discussions, whilst the use of a reflective journal (during the empirical study) facilitated ongoing critical thinking and time for reflection, all important aspects to embrace when undertaking qualitative research. Furthermore, the empirical study not only recruited participants through various avenues of recruitment, but also conducted interviews online, which facilitated nationwide coverage. Thus, this led to a wide range of service use among participants, as well as enhancing the diversity of experiences. Although, recognition is paid to the limitations that may accompany online based research (such as access and capability).

Another potential limitation to acknowledge is how the researcher's philosophical position influences the generation and interpretation of themes. As noted in Chapter Five, the researcher's critical realist stance assumes a reality exists, but that understanding of it is shaped by one's own experience and interpretation (Fletcher, 2017). With this in mind, it is important to consider whether themes relating to concepts such as burden or emotional wellbeing have been best captured by the thematic frameworks generated, as experiences could be shaped by both real systemic barriers and by individual interpretation. Furthermore, in the review, it could be argued that the classification of what was deemed a western country with an individualistic culture was subjective, and informed by an outdated framework (Hofstede, 1984; albeit used widely). Although, there remains no universally agreed upon definition, some countries could be viewed as mixed, and globalisation may be influencing certain shifts in said classifications. Interpretations and transferability of findings should be considered with caution.

Due to time and resource restraints relating to training, both papers were limited to the English language, potentially missing valuable experiences of other caregivers. Most caregivers in the empirical study were of a White background, whilst most studies in the review failed to report on participants' ethnicities (and other socio-demographic characteristics). This limits the transferability of the empirical study's findings, and in the review, it remains unknown whose experiences are best represented based on ethnicity alone. Likewise, as the empirical study was unable to recruit same sex partners, unique caregiver experiences may have been omitted, as well as the opportunity to better understand the needs of caregivers supporting those with SMI identifying as LGBTQIA+. Lastly, we acknowledge that a second reviewer was not involved during the title and abstract screening process, despite this being recommended when conducting a systematic review (Stoll et al., 2019). Although, efforts were made to include a second reviewer at full text screening, determining study selection, and quality review.

Research Implications

Despite the empirical study and review filling gaps in the wider literature, there is still much to learn about caregiver experiences within the context of SMI. The researcher undertook their best efforts to include the voices of diverse caregiver groups, however, some caregivers may not be well represented by these findings. Future research would benefit from exploring the experiences of same sex partners (caregivers) in the context of PP. Of particular interest, to see how the 'male stereotype' of delayed help-seeking reported in the empirical study is (if at all) present in those identifying as female. As well as to see if there are any reported differences in how mental health services interact and engage with female partners.

Further research is warranted where socioeconomic and demographic status is recorded to explore any differences this may present in caregiver experiences, especially given the significant challenges faced by individuals from underserved groups (Davies et al., 2024; Schulz & Sherwood, 2008). It is also important to broaden our understanding of how caregivers from non-western countries with collectivist cultures (or those residing in western countries who embrace collectivist values) experience their role in the context of SMI. A qualitative systematic review may be a good option for exploring this, as it offers a rich understanding of the data. Also, future reviews would benefit from including studies published in various languages to capture a broader range of caregiver experiences within the context of SMI and reduce language bias.

Another area for further exploration would be that of different caregiver relationships when supporting an individual with SMI, given the known disparities in how burden, roles, and responsibilities are undertaken and or experienced. Recognising the effects that caregiving can have on individuals, looking into the experiences of those who chose to leave the romantic relationship and or discontinue their caregiving responsibilities would be of value. This could provide further insights into what led them to make these decisions and whether such insights could inform family interventions and approaches within services.

Furthermore, investigating how partners coped in the period following the first episode of PP through to and including a subsequent episode, or how they navigated a partner's transition to a SMI diagnosis after a first episode of PP, could prove valuable. This could specifically shed light on the role of hypervigilance in these contexts, as well as provide insight into the transition from specialist perinatal services to general CMHTs. Lastly, gaining an increased awareness from male caregivers (or partners) into their perceptions of the term 'caregiver' (particularly within the perinatal context), and how this may or may not influence help-seeking behaviours, could enhance our understanding and inform tailored care. All the above recommendations will prove detrimental in further informing service provision plans to involve and support caregivers of those with SMI in the future.

Clinical Implications

Ensuring healthcare professionals understand what constitutes an 'informal caregiver' is essential to ensuring they are properly informed and can be responsive to the individuals' needs. Healthcare professionals should be mindful of how caregiving experiences and their implications may vary depending on the diagnostic pathway of the person receiving care. For example, a caregiver supporting an individual following a prolonged journey to receiving a BD diagnosis (e.g., an average of nine and a half years; Bipolar UK, 2021) may have experienced delayed recognition and support. In contrast, a caregiver to a woman who experienced an acute PP episode followed by a swift BD diagnosis may have encountered more immediate support and recognition. In line with guidance (NHS England, 2019b), healthcare professionals should continue to proactively check caregivers' wellbeing and offer the most appropriate support. Likewise, they should also remain responsive to individual differences and the multifaceted elements of caregiving, across and within conditions, as understood through the lens of the Model of Carer Stress and Burden (2006).

Furthermore, specialist perinatal teams and MBUs are to ensure they are providing adequate psychoeducation on relapse recognition and prevention towards the end of the

woman's care. This way the partner (caregiver) can feel more prepared and aware of what may constitute a relapse and what recovery may entail (Lyons et al., 2024). However, this raises concerns for if women are not supported by a specialist perinatal service (which is not uncommon, Roxburgh et al., 2023) and whether other services (early intervention in psychosis services or CMHTs) feel equipped with the required knowledge (McConachie & Whitford, 2009) and provisions to offer this for partners (caregivers). Especially given the debated classification of PP and BD (Sharma et al., 2022).

Moreover, it is important for healthcare professionals to be attuned to any cultural and ethnic differences in caregivers' beliefs and needs and provide the required adaptations. However, there are notable differences in how NICE guidelines approach addressing this within SMI. Whilst guidance for psychosis and perinatal mental health difficulties acknowledges the need for culturally informed care (NICE 2014; 2020), no such recognition exists in BD guidelines (NICE, 2023). Findings from the review would suggest that there are notable differences in how caregivers from different cultural backgrounds interpret BD symptoms. Likewise, this difference in guidance may be due to the known racial disparities, whereby individuals from Afro-Caribbean communities are more likely to be diagnosed with schizophrenia than BD (Akinhanmi et al., 2018; Bignall et al., 2019).

Mental health services should remain attentive to relationship dynamics (pre and post diagnoses) between the caregiver and the individual with SMI (Labrum et al., 2024). Depending on the service accessed, care-coordinators are well positioned to obtain this information, ensuring a dyadic way of working, considering both perspectives. Similarly, healthcare professionals should be mindful of how the caregiver's relationship to the individual with SMI influences their experiences, given the reported differences in the sense of obligation and burden between parents and partners in this research. Likewise, to also recognise that acute time-limited caregiving can also result in high levels of distress, thus length of caregiving is not always representative of caregiver's burden.

Furthermore, CMHTs (among other services supporting those with SMI) should remain responsive to the evolving climate of the NHS Long Term Plan (NHS England,

2019a) and its implementation, reviewing guidance for working with caregivers as required. Likewise, as the shift towards community-based care becomes more embedded within the UK and other parts of the world, it is important to consider different ways in how this may affect caregivers. Despite the Long Term Plan's best intentions, transitions in service provision and care can take time to become fully established. During this period, caregivers may unintentionally face increased levels of burden.

Healthcare professionals such as general practitioners (GPs) are going to be key in the transition to increased community care, as they can often act as a primary point of contact, especially when an individual with BD is 'stable' and not under a CMHT. This in turn places GPs in a gatekeeping role, where they must recognise and respond to any changes in mood. Training for GPs is therefore crucial to ensure they feel confident in managing individuals with SMI, especially given GPs documented challenges of working with this population (Fleury et al., 2012). Likewise, GPs must be proactive in identifying caregivers, especially if barriers such as difficulties with caregiver self-identification are present (Peters et al., 2020). Also, ensuring GP practices remain responsive to caregiver's unique needs (e.g., appointment timings) is important (NHS England, 2016b).

Conclusions

The thesis portfolio aimed to develop a deeper understanding of caregiver experiences within the context of SMI, specifically on PP and BD. The systematic review and thematic synthesis focused on holistic caregiver experiences when supporting an individual with BD, highlighting specific caregiver needs. The empirical research project narrowed in on one particular aspect of caregiving, the interaction with and support from mental health services. This exclusively focused on partners experiences and needs, within the context of PP. Together, the review and empirical paper shed light on the commonalities and variations between caregiver experiences across differing diagnoses, caregiver relations and backgrounds, and time periods in one's life. Overall, caregivers across both papers reported high levels of burden and emotional distress, great sense of responsibility and advocacy,

and challenges with healthcare professionals and mental health services. Differences in themes mostly emerged around the early stages of PP and the ongoing nature of BD, and in relation to social support networks and stigma. These findings are of importance for future clinical and research practices, with a much-needed emphasis on individual differences and caregiver inclusion in SMI as the movement towards community-based mental health care becomes established.

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Appendix A

Journal of Affective Disorders Author Guidelines

Guide for authors

About the journal

Aims and scope

Official Journal of the International Society for Affective Disorders *The Journal of Affective Disorders* publishes papers concerned with affective disorders in the widest sense: depression, mania, mood spectrum, emotions and personality, anxiety and stress. It is interdisciplinary and aims to bring together different approaches for a diverse readership. Top quality papers will be accepted dealing with any aspect of affective disorders, including neuroimaging, cognitive neurosciences, genetics, molecular biology, experimental and clinical neurosciences, pharmacology, neuroimmunoendocrinology, intervention and treatment trials.

Journal of Affective Disorders is the companion title to the open access Journal of Affective Disorders Reports.

Article types

The Journal primarily publishes:

Full-Length Research Papers

(up to 5000 words, excluding references and up to 6 tables/figures)

Review Articles and Meta-analyses

(up to 8000 words, excluding references and up to 10 tables/figures)

Short Communications

(up to 2000 words, 20 references, 2 tables/figures)

Correspondence

(up to 1000 words, 10 references, 1 table/figure).

At the discretion of the accepting Editor-in-Chief, and/or based on reviewer feedback, authors may be allowed fewer or more than these guidelines.

Peer review

This journal follows a single anonymized review process. Your submission will initially be assessed by our editors to determine suitability for publication in this journal. If your submission is deemed suitable, it will typically be sent to a minimum of two reviewers for an

independent expert assessment of the scientific quality. The decision as to whether your article is accepted or rejected will be taken by our editors. Authors who wish to appeal the editorial decision for their manuscript may submit a formal appeal request in accordance with the procedure outlined in Elsevier's Appeal Policy. Only one appeal per submission will be considered and the appeal decision will be final.

Read more about peer review.

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- have been written by family members or colleagues.
- relate to products or services in which they have an interest.

Any such submissions will be subject to the journal's usual procedures and peer review will be handled independently of the editor involved and their research group. Read more about editor duties.

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- the article's publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out.
- if accepted, the article will not be published elsewhere in the same form, in English or in any other language, including electronically, without the written consent of the copyright-holder.

To verify compliance with our journal publishing policies, we may check your manuscript with our screening tools.

Authorship

All authors should have made substantial contributions to all of the following:

1. The conception and design of the study, or acquisition of data, or analysis and interpretation of data.
2. Drafting the article or revising it critically for important intellectual content.
3. Final approval of the version to be submitted.

Authors should appoint a corresponding author to communicate with the journal during the editorial process. All authors should agree to be accountable for all aspects of the work to ensure that the questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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- Any addition, deletion or rearrangement of author names in the authorship list should only be made prior to acceptance, and only if approved by the journal editor.
- Requests to change authorship should be made by the corresponding author, who must provide the reason for the request to the journal editor with written confirmation from all authors, including any authors being added or removed, that they agree with the addition, removal or rearrangement.
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Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants, scholarships and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

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- Generative AI and AI-assisted technologies should only be used in the writing process to improve the readability and language of the manuscript.
- The technology must be applied with human oversight and control and authors should carefully review and edit the result, as AI can generate authoritative-sounding

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The use of generative AI and AI-assisted technologies in scientific writing must be declared by adding a statement at the end of the manuscript when the paper is first submitted. The statement will appear in the published work and should be placed in a new section before the references list. An example:

- Title of new section: Declaration of generative AI and AI-assisted technologies in the writing process.
- Statement: During the preparation of this work the author(s) used [NAME TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.

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- age
- gender
- race
- ethnicity
- culture
- sexual orientation

- disability or health condition

We recommend avoiding the use of descriptors about personal attributes unless they are relevant and valid. Write for gender neutrality with the use of plural nouns ("clinicians, patients/clients") as default. Wherever possible, avoid using "he, she," or "he/she."

No assumptions should be made about the beliefs of readers and writing should be free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions.

These guidelines are meant as a point of reference to help you identify appropriate language but are by no means exhaustive or definitive.

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There is no single, universally agreed-upon set of guidelines for defining sex and gender. We offer the following guidance:

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- Sex and/or gender dimensions of the research should be addressed within the article or declared as a limitation to the generalizability of the research.
- Definitions of sex and/or gender applied should be explicitly stated to enhance the precision, rigor and reproducibility of the research and to avoid ambiguity or conflation of terms and the constructs to which they refer.

We advise you to read the Sex and Gender Equity in Research (SAGER) guidelinesand the SAGER checklist (PDF) on the EASE website, which offer systematic approaches to the use of sex and gender information in study design, data analysis, outcome reporting and research interpretation.

For further information we suggest reading the rationale behind and recommendeduse of the SAGER guidelines.

Definitions of sex and/or gender

We ask authors to define how sex and gender have been used in their research and publication. Some guidance:

- Sex generally refers to a set of biological attributes that are associated with physical and physiological features such as chromosomal genotype, hormonal levels, internal and external anatomy. A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth") and is in most cases based solely on the visible external anatomy of a newborn. In reality, sex categorizations include people who are intersex/have differences of sex development (DSD).
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You are required to provide a concise and factual abstract which does not exceed 250 words. The abstract should briefly state the purpose of your research, principal results and major conclusions. Some guidelines:

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- Avoid references. If any are essential to include, ensure that you cite the author(s) and year(s).
- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

Keywords

You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

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Highlights

You are required to provide article highlights at submission.

Highlights are a short collection of bullet points that should capture the novel results of your research as well as any new methods used during your study. Highlights will help increase the discoverability of your article via search engines. Some guidelines:

- Submit highlights as a separate editable file in the online submission system with the word "highlights" included in the file name.
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You are encouraged to provide a graphical abstract at submission.

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will help draw more attention to your online article and support readers in digesting your research. Some guidelines:

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- Our preferred file types for graphical abstracts are TIFF, EPS, PDF or MS Office files.

We encourage you to view example graphical abstracts and read about the benefits of including them.

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- Submit math equations as editable text, not as images.
- Present simple formulae in line with normal text, where possible.
- Use the solidus (/) instead of a horizontal line for small fractional terms such as X/Y.
- Present variables in italics.
- Denote powers of e by exp.
- Display equations separately from your text, numbering them consecutively in the order they are referred to within your text.

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Tables must be submitted as editable text, not as images. Some guidelines:

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- Cite all tables in the manuscript text.
- Number tables consecutively according to their appearance in the text.
- Please provide captions along with the tables.
- Place any table notes below the table body.
- Avoid vertical rules and shading within table cells.

We recommend that you use tables sparingly, ensuring that any data presented in tables is not duplicating results described elsewhere in the article.

Figures, images and artwork

Figures, images, artwork, diagrams and other graphical media must be supplied as separate files along with the manuscript. We recommend that you read our detailed artwork and media instructions. Some excerpts:

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- Cite all images in the manuscript text.
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- Submit each image as a separate file using a logical naming convention for your files (for example, Figure_1, Figure_2 etc).
- Please provide captions for all figures, images, and artwork.
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Artwork formats

When your artwork is finalized, "save as" or convert your electronic artwork to the formats listed below taking into account the given resolution requirements for line drawings, halftones, and line/halftone combinations:

- Vector drawings: Save as EPS or PDF files embedding the font or saving the text as "graphics."
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Reference to a chapter in a book:

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Reference to a website:

Cancer Research UK, 2023. Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/ (accessed 13 March 2023).

Reference to a dataset:

Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T., 2015. Mortality data for Japanese oak wilt disease and surrounding forest compositions [dataset]. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.

Reference to software:

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- All references in the article text are cited in the reference list and vice versa.

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Appendix B

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	See title page for SR
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	See page 16
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	See pages 18-19
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	See page 19
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	See pages 21-23
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	See page 20
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	See pages 20-21
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	See pages 22-23
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	See page 25
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	See pages 25-30
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	See pages 25-30
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	See pages 24-25 and 32-34
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	See page 31
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	NA
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	See pages 36-37
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the	See page

Section and Topic	Item #	Checklist item	Location where item is reported
		model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	31
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	See pages 24-25 and 32-34
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	See pages 23-24
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	See page 24
Study characteristics	17	Cite each included study and present its characteristics.	See pages 24-30 and 31-32
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	See pages 24-25 and 32-34
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	See pages 51-53
	23b	Discuss any limitations of the evidence included in the review.	See pages 53-54
	23c	Discuss any limitations of the review processes used.	See pages 53-54 and 116
	23d	Discuss implications of the results for practice, policy, and future research.	See pages

Section and Topic	Item #	Checklist item	Location where item is reported
			54-55
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	See pages 19-20
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	See pages 19-20
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	See pages 21-22
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	See below
Competing interests	26	Declare any competing interests of review authors.	See below
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	See manuscript

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Supporting 'other information' submitted to Journal of Affective Disorders:

Funding Sources

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Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper

Appendix C

PROSPERO Protocol for Systematic Review

Experiences of informal caregivers supporting individuals diagnosed with bipolar disorder: A systematic review and thematic synthesis

Emily Roxburgh, Joanne Hodgekins, Billie Lever-Taylor

Review methods were amended after registration. Please see the revision notes and previous versions for detail.

Citation
Emily Roxburgh, Joanne Hodgekins, Billie Lever-Taylor. Experiences of informal caregivers supporting individuals diagnosed with bipolar disorder: A systematic review and thematic synthesis. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42023487273

REVIEW TITLE AND BASIC DETAILS

Review title
Experiences of informal caregivers supporting individuals diagnosed with bipolar disorder: A systematic review and thematic synthesis

Review objectives
Main research question:
What are the experiences of informal caregivers supporting individuals diagnosed with bipolar disorder?
Sub-research question:
What are the emotional/practical/informational support needs of informal caregivers?
Bipolar disorder, which affects more than 1% of the world's population, is a persistent mood disorder marked by the occurrence of manic or hypomanic episodes, alternating with periods of depression (Grande et al., 2016). Caregivers of people diagnosed with bipolar disorder play a crucial role in providing ongoing support and stability for their loved ones. Research shows that caregivers of people with bipolar disorder experience high burden, depression, anxiety, and distress during their caregiving experiences (Van der Voort et al., 2007). Likewise, as community-based and psychosocial care becomes more embedded in the UK and other parts of the world, there is a need to acknowledge the potential additional strain(s) that caregivers may experience because of these changes (NHS Long Term Plan, 2019; NHS Mental Health Implementation Plan 2019; World Health Organisation, 2022).

Keywords
Bipolar disorder, informal caregivers, systematic review, thematic synthesis

SEARCHING AND SCREENING

Searches
We will search through the following electronic databases: MEDLINE (Ovid) / Scopus (ELSEVIER) / PsycINFO (EBSCO) / CINAHL (EBSCO). The search strategy was informed by the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke et al., 2012). This strategy helped formulate the research question. Searches will be from 1980 (due to the updated classification of bipolar disorder; Mason et al., 2016) to present. Searches will be limited to English language. The reference lists of any included studies will be hand searched for any additional studies that meet our inclusion criteria. Forward citation searching will also be conducted.
Searches will be re-run prior to the final analyses and any further relevant studies will be retrieved for inclusion.

Study design
Inclusion criteria:
-Qualitative studies which explore informal caregivers' experiences supporting individuals diagnosed with bipolar disorder.
-Mixed methods studies will be included, but only qualitative data will be extracted and included in the synthesis.
-Studies exploring the experiences of informal caregivers which encompass bipolar disorder amongst other mental health conditions, but only data clearly pertaining to bipolar disorder will be extracted and included in the synthesis.
-Studies exploring the experiences of informal caregivers which encompass other stakeholders' views, but only data clearly pertaining to informal caregivers' experiences will be extracted and included in the synthesis.
-Studies published in peer-reviewed journals.
Exclusion criteria:
-Studies which only use a quantitative research design.
-Studies exploring evaluation of interventions (e.g., support groups, programmes).
-Studies not available in the English language.
-Studies reported in book chapters, conference papers, editorials, or letters.
-Studies that do not include the views of informal caregivers.
-Systematic reviews or thematic or meta-synthesis.

ELIGIBILITY CRITERIA

Condition or domain being studied
Bipolar disorder. Caregivers' experiences.

Population
Inclusion criteria:
-Informal caregivers of someone diagnosed with bipolar disorder.
-Informal caregivers relationship includes either parent (where the young person is 14 years old or over), adult child, sibling, spouse/partner, other relative, and close friend or neighbour.
-Informal caregivers are identified as having a close relationship to the individual with bipolar disorder and/or provides substantial support (e.g., emotional, practical).
-Studies published in English.
-Informal caregivers above the age of 18 years old.
-Informal caregivers from western countries and individualistic cultures.
Exclusion criteria:
-Informal caregivers under the age of 18 years old.

Intervention(s) or exposure(s)
This systematic review and thematic synthesis will include all studies pertaining to informal caregivers' experiences of supporting individuals diagnosed with bipolar disorder. Mixed-methods studies will also be included, but only qualitative data will be extracted and included in the synthesis.

Comparator(s) or control(s)
Not applicable

Context
Studies conducted within Western countries characterised by individualistic cultures will be eligible for inclusion.

OUTCOMES TO BE ANALYSED

Main outcomes
The primary outcome of this systematic review and thematic synthesis will be to answer the following research question: What are the experiences among informal caregivers when supporting individuals diagnosed with bipolar disorder? No pre-defined outcome has been identified.

Additional outcomes
Not applicable

DATA COLLECTION PROCESS

Data extraction (selection and coding)

Study selection:

- All References will be imported into Rayyan and duplicates will be removed.
- Titles and abstracts will be screened (by ER) against the inclusion and exclusion criteria.
- Full text screening will be conducted (by ER) for eligible studies meeting the inclusion criteria.
- If it is unclear whether studies meet the inclusion criteria by screening the title or abstract, full text screening will be conducted.
- A second reviewer will conduct full text screening on 20% of included studies, and if any opposing views arise regarding the final selection of studies included, this will be discussed until a consensus is reached among the reviewers.

Data extraction:

A pre-designed data extraction form will be used in Excel, which will be piloted on two eligible studies prior to implementing this for the subsequent eligible studies. Items will be amended accordingly to ensure they are relevant and capture the required data for the review. The following data items will be extracted for each study (if they are available):

1. Reviewer
2. Basic study information
- Title
- Author and year
- Country
- Sample size
- Aims and objectives of the study
3. Participant characteristics
- Informal caregiver relationship to individual diagnosed with bipolar disorder
- Age
- Gender
- Ethnicity
- Employment
- Living situation
- Time caring for individual diagnosed with bipolar disorder
- Type of support provided to individual diagnosed with bipolar disorder
4. Characteristics of individual diagnosed with bipolar disorder
- Age
- Gender
- Ethnicity
5. Data collection method and setting (e.g., questionnaire, interview, focus group etc.,)
6. Data analysis approach (e.g., IPA, Thematic Analysis, Grounded Theory etc.,)
7. Key themes and findings
8. Quotations or excerpts
9. Additional notes

Data extraction will be conducted by one reviewer (ER).

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) will be used to guide each stage and will be documented in the PRISMA flow chart.

Risk of bias (quality) assessment

The Critical Appraisal Skills Programme (CASP) for Qualitative Studies Checklist will be used by one reviewer (ER) to assess the quality of identified studies. All studies meeting the inclusion criteria will be included in the review, irrespective of their quality rating. Quality assessment will be cross-checked by a second reviewer on 20% of the studies, and if any opposing views arise, these will be discussed until a consensus is reached among the reviewers. Results from the CASP will be tabulated and displayed in the final review paper.

PLANNED DATA SYNTHESIS

Strategy for data synthesis
Thematic synthesis (Thomas & Hardens, 2008) will be used to analyse the qualitative data extracted from the eligible studies. This approach comprises of 3 key stages:
1. Coding of text 'line by line'
2. Developing 'descriptive themes'
3. Generating 'analytical themes'
Data synthesis will be completed by one reviewer (ER).

Analysis of subgroups or subsets
Not applicable

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Mrs Emily Roxburgh, University of East Anglia
- Dr Joanne Hodgekins, University of East Anglia
- Dr Billie Lever-Taylor, Kings College London

Review affiliation
University of East Anglia

Funding source
Not applicable

TIMELINE OF THE REVIEW

Review timeline
Start date: 02 October 2023. End date: 25 September 2025

Date of first submission to PROSPERO
28 November 2023

Date of registration in PROSPERO
28 November 2023

Appendix D

Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Studies

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	

5. Was the data collected in a way that addressed the research issue?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	

8. Was the data analysis sufficiently rigorous?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	
9. Is there a clear statement of findings?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)* • *If the findings are discussed in relation to the original research question*	
Section C: Will the results help locally?	
10. How valuable is the research?	☐ Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	

Appendix E

Community Mental Health Journal Author Guidelines

Instructions for Authors

Types of Papers

The journal welcomes Articles with a length not exceeding 16 pages. This does not include references, tables and figures.

The journal welcomes Brief Report articles with a length not exceeding 10 pages. Submissions of this type should not include any figures or tables.

Submissions should be double spaced and use a normal, plain font (i.e., 10 point Times New Roman) as further described in the "Text" section of these Guidelines.

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Supplements

The Journal is dedicated to rapid dissemination of research on therapeutic treatments or preventive interventions. Supplements to the Journal can be used to publicize findings newly presented at conferences or symposia.

Please contact the Managing Editor for information about supplemental issues of the Journal.

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Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

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Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript. The use of an LLM (or other AI-tool) for "AI assisted copy editing" purposes does not need to be declared. In this context, we define the term "AI assisted copy editing" as AI-assisted improvements to human-generated texts for readability and style, and to ensure that the texts are free of errors in grammar, spelling, punctuation and tone. These AI-assisted improvements may include wording and formatting changes to the texts, but do not include generative editorial work and autonomous content creation. In all cases, there must be human accountability for the final version of the text and agreement from the authors that the edits reflect their original work.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

Please note: For some articles (particularly, systematic reviews and original research articles), 250 words may not be sufficient to provide all necessary information in the abstract. Therefore, the abstract length can be increased from the 250-word limit (to up to 450 words) if the topic dictates, and to allow full compliance with the relevant reporting guidelines.

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration, followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Acknowledgements

An Acknowledgment section may be included to acknowledge, for example, people who have assisted with aspects of the work (but who do not qualify as authors), disclaimers, collaborations, etc.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

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Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.

- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

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References

Citation

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. “https://doi.org/abc”).

- Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture, 8*(3), 207–217. https://doi.org/10.1037/ppm0000185
- Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. https://doi.org/10.1097/PHM.0000000000001435
- Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research*(4th ed., pp. 115–129). Routledge.
- Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

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Tables

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

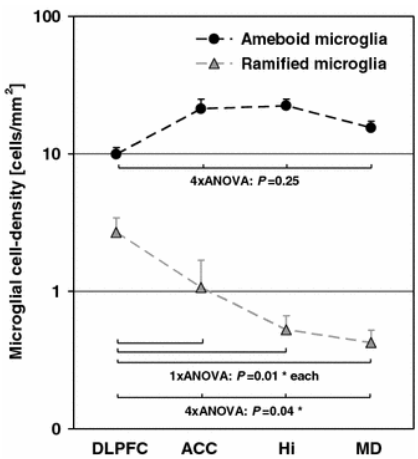
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Artwork and Illustrations Guidelines

Electronic Figure Submission

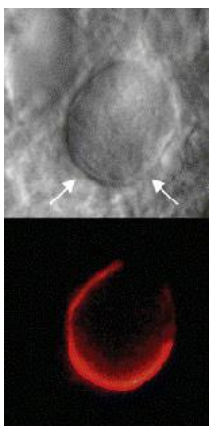
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- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

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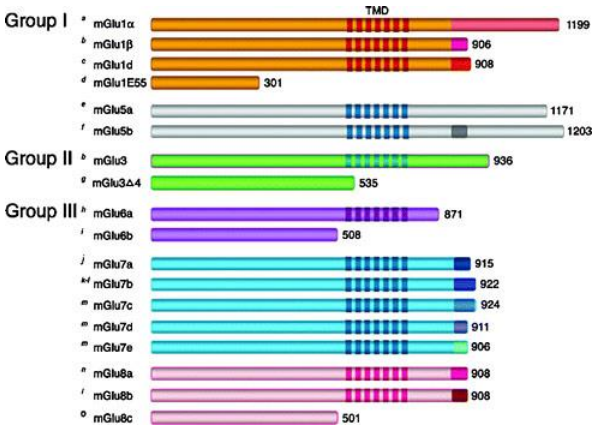
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- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.
- Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art



- Definition: Photographs, drawings, or paintings with fine shading, etc.
- If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.
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Combination Art



- Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.
- Combination artwork should have a minimum resolution of 600 dpi.

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- Color art is free of charge for online publication.
- If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.
- If the figures will be printed in black and white, do not refer to color in the captions.
- Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

- To add lettering, it is best to use Helvetica or Arial (sans serif fonts).
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- All figures are to be numbered using Arabic numerals.

- Figures should always be cited in text in consecutive numerical order.
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- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
- Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

- Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.
- When preparing your figures, size figures to fit in the column width.
- For large-sized journals the figures should be 84 mm (for double-column text areas), or 174 mm (for single-column text areas) wide and not higher than 234 mm.
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- Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)

- Any figure lettering has a contrast ratio of at least 4.5:1

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Springer accepts electronic multimedia files (animations, movies, audio, etc.) and other supplementary files to be published online along with an article or a book chapter. This feature can add dimension to the author's article, as certain information cannot be printed or is more convenient in electronic form.

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Submission

- Supply all supplementary material in standard file formats.
- Please include in each file the following information: article title, journal name, author names; affiliation and e-mail address of the corresponding author.
- To accommodate user downloads, please keep in mind that larger-sized files may require very long download times and that some users may experience other problems during downloading.
- High resolution (streamable quality) videos can be submitted up to a maximum of 25GB; low resolution videos should not be larger than 5GB.

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- Aspect ratio: 16:9 or 4:3
- Maximum file size: 25 GB for high resolution files; 5 GB for low resolution files
- Minimum video duration: 1 sec
- Supported file formats: avi, wmv, mp4, mov, m2p, mp2, mpg, mpeg, flv, mxf, mts, m4v, 3gp

Text and Presentations

- Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.
- A collection of figures may also be combined in a PDF file.

Spreadsheets

- Spreadsheets should be submitted as .csv or .xlsx files (MS Excel).

Specialized Formats

- Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

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- It is possible to collect multiple files in a .zip or .gz file.

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- Name the files consecutively, e.g. “ESM_3.mpg”, “ESM_4.pdf”.

Captions

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In order to give people of all abilities and disabilities access to the content of your supplementary files, please make sure that

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- The manuscript should not be submitted to more than one journal for simultaneous consideration.
- The submitted work should be original and should not have been published elsewhere in any form or language (partially or in full), unless the new work concerns an expansion of previous work. (Please provide transparency on the re-use of material to avoid the concerns about text-recycling ('self-plagiarism').
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- Concurrent or secondary publication is sometimes justifiable, provided certain conditions are met. Examples include: translations or a manuscript that is intended for a different group of readers.
- Results should be presented clearly, honestly, and without fabrication, falsification or inappropriate data manipulation (including image based manipulation). Authors

should adhere to discipline-specific rules for acquiring, selecting and processing data.

- No data, text, or theories by others are presented as if they were the author's own ('plagiarism'). Proper acknowledgements to other works must be given (this includes material that is closely copied (near verbatim), summarized and/or paraphrased), quotation marks (to indicate words taken from another source) are used for verbatim copying of material, and permissions secured for material that is copyrighted.

Important note: the journal may use software to screen for plagiarism.

- Authors should make sure they have permissions for the use of software, questionnaires/(web) surveys and scales in their studies (if appropriate).
- Research articles and non-research articles (e.g. Opinion, Review, and Commentary articles) must cite appropriate and relevant literature in support of the claims made. Excessive and inappropriate self-citation or coordinated efforts among several authors to collectively self-cite is strongly discouraged.
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Upon request authors should be prepared to send relevant documentation or data in order to verify the validity of the results presented. This could be in the form of raw data, samples, records, etc. Sensitive information in the form of confidential or proprietary data is excluded.

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- If the manuscript is still under consideration, it may be rejected and returned to the author.
- If the article has already been published online, depending on the nature and severity of the infraction:

  - an erratum/correction may be placed with the article

- an expression of concern may be placed with the article

- or in severe cases retraction of the article may occur.

The reason will be given in the published erratum/correction, expression of concern or retraction note. Please note that retraction means that the article is **maintained on the platform**, watermarked “retracted” and the explanation for the retraction is provided in a note linked to the watermarked article.

- The author’s institution may be informed
- A notice of suspected transgression of ethical standards in the peer review system may be included as part of the author’s and article’s bibliographic record.

Fundamental errors

Authors have an obligation to correct mistakes once they discover a significant error or inaccuracy in their published article. The author(s) is/are requested to contact the journal and explain in what sense the error is impacting the article. A decision on how to correct the literature will depend on the nature of the error. This may be a correction or retraction. The retraction note should provide transparency which parts of the article are impacted by the error.

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Authors are welcome to suggest suitable reviewers and/or request the exclusion of certain individuals when they submit their manuscripts. When suggesting reviewers, authors should make sure they are totally independent and not connected to the work in any way. It is strongly recommended to suggest a mix of reviewers from different countries and different institutions. When suggesting reviewers, the Corresponding Author must provide an institutional email address for each suggested reviewer, or, if this is not possible to include other means of verifying the identity such as a link to a personal homepage, a link to the publication record or a researcher or author ID in the submission letter. Please note that the Journal may not use the suggestions, but suggestions are appreciated and may help facilitate the peer review process.

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Authorship principles

These guidelines describe authorship principles and good authorship practices to which prospective authors should adhere to.

Authorship clarified

The Journal and Publisher assume all authors agreed with the content and that all gave explicit consent to submit and that they obtained consent from the responsible authorities at the institute/organization where the work has been carried out, **before**the work is submitted.

The Publisher does not prescribe the kinds of contributions that warrant authorship. It is recommended that authors adhere to the guidelines for authorship that are applicable in their specific research field. In absence of specific guidelines it is recommended to adhere to the following guidelines*:

All authors whose names appear on the submission

1) made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data; or the creation of new software used in the work;

2) drafted the work or revised it critically for important intellectual content;

3) approved the version to be published; and

4) agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

* Based on/adapted from:

ICMJE, Defining the Role of Authors and Contributors,

Transparency in authors' contributions and responsibilities to promote integrity in scientific publication, McNutt at all, PNAS February 27, 2018

Disclosures and declarations

All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate).

The decision whether such information should be included is not only dependent on the scope of the journal, but also the scope of the article. Work submitted for publication may have implications for public health or general welfare and in those cases it is the responsibility of all authors to include the appropriate disclosures and declarations.

Data transparency

All authors are requested to make sure that all data and materials as well as software application or custom code support their published claims and comply with field standards. Please note that journals may have individual policies on (sharing) research data in concordance with disciplinary norms and expectations.

Role of the Corresponding Author

One author is assigned as Corresponding Author and acts on behalf of all co-authors and ensures that questions related to the accuracy or integrity of any part of the work are appropriately addressed.

The Corresponding Author is responsible for the following requirements:

- ensuring that all listed authors have approved the manuscript before submission, including the names and order of authors;
- managing all communication between the Journal and all co-authors, before and after publication;*
- providing transparency on re-use of material and mention any unpublished material (for example manuscripts in press) included in the manuscript in a cover letter to the Editor;
- making sure disclosures, declarations and transparency on data statements from all authors are included in the manuscript as appropriate (see above).

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Author contributions

In absence of specific instructions and in research fields where it is possible to describe discrete efforts, the Publisher recommends authors to include contribution statements in the work that specifies the contribution of every author in order to promote transparency. These contributions should be listed at the separate title page.

Examples of such statement(s) are shown below:

• Free text:

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Example: CRediT taxonomy:

• Conceptualization: [full name], …; Methodology: [full name], …; Formal analysis and investigation: [full name], …; Writing - original draft preparation: [full name, …]; Writing - review and editing: [full name], …; Funding acquisition: [full name], …; Resources: [full name], …; Supervision: [full name],….

For **review articles** where discrete statements are less applicable a statement should be included who had the idea for the article, who performed the literature search and data analysis, and who drafted and/or critically revised the work.

For articles that are based primarily on the **student's dissertation or thesis**, it is recommended that the student is usually listed as principal author:

A Graduate Student's Guide to Determining Authorship Credit and Authorship Order, APA Science Student Council 2006

Affiliation

The primary affiliation for each author should be the institution where the majority of their work was done. If an author has subsequently moved, the current address may additionally be stated. Addresses will not be updated or changed after publication of the article.

Changes to authorship

Authors are strongly advised to ensure the correct author group, the Corresponding Author, and the order of authors at submission. Changes of authorship by adding or deleting authors, and/or changes in Corresponding Author, and/or changes in the sequence of authors are **not** accepted **after acceptance** of a manuscript.

- **Please note that author names will be published exactly as they appear on the accepted submission!**

Please make sure that the names of all authors are present and correctly spelled, and that addresses and affiliations are current.

Adding and/or deleting authors at revision stage are generally not permitted, but in some cases it may be warranted. Reasons for these changes in authorship should be explained. Approval of the change during revision is at the discretion of the Editor-in-Chief. Please note that journals may have individual policies on adding and/or deleting authors during revision stage.

Author identification

Authors are recommended to use their ORCID ID when submitting an article for consideration or acquire an ORCID ID via the submission process.

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For cases in which a co-author dies or is incapacitated during the writing, submission, or peer-review process, and the co-authors feel it is appropriate to include the author, co-authors should obtain approval from a (legal) representative which could be a direct relative.

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In the case of an authorship dispute during peer review or after acceptance and publication, the Journal will not be in a position to investigate or adjudicate. Authors will be asked to resolve the dispute themselves. If they are unable the Journal reserves the right to withdraw a manuscript from the editorial process or in case of a published paper raise the issue with the authors' institution(s) and abide by its guidelines.

Confidentiality

Authors should treat all communication with the Journal as confidential which includes correspondence with direct representatives from the Journal such as Editors-in-Chief and/or Handling Editors and reviewers' reports unless explicit consent has been received to share information.

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Compliance with Ethical Standards

To ensure objectivity and transparency in research and to ensure that accepted principles of ethical and professional conduct have been followed, authors should include information regarding sources of funding, potential conflicts of interest (financial or non-financial), informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals.

Authors should include the following statements (if applicable) in a separate section entitled "Compliance with Ethical Standards" when submitting a paper:

- Disclosure of potential conflicts of interest
- Research involving Human Participants and/or Animals
- Informed consent

Please note that standards could vary slightly per journal dependent on their peer review policies (i.e. single or double blind peer review) as well as per journal subject discipline. Before submitting your article check the instructions following this section carefully.

The corresponding author should be prepared to collect documentation of compliance with ethical standards and send if requested during peer review or after publication.

The Editors reserve the right to reject manuscripts that do not comply with the above-mentioned guidelines. The author will be held responsible for false statements or failure to fulfill the above-mentioned guidelines.

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Competing Interests

Authors are requested to disclose interests that are directly or indirectly related to the work submitted for publication. Interests within the last 3 years of beginning the work (conducting the research and preparing the work for submission) should be reported. Interests outside the 3-year time frame must be disclosed if they could reasonably be perceived as influencing the submitted work. Disclosure of interests provides a complete and transparent process and helps readers form their own judgments of potential bias. This is not meant to imply that a financial relationship with an organization that sponsored the research or compensation received for consultancy work is inappropriate.

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they declare this in the competing interests section on the submitted manuscript. If they are an author or have any other competing interest regarding a specific manuscript, another Editor or member of the Editorial Board will be assigned to assume responsibility for overseeing peer review. These submissions are subject to the exact same review process as any other manuscript. Editorial Board Members are welcome to submit papers to the journal. These submissions are not given any priority over other manuscripts, and Editorial Board Member status has no bearing on editorial consideration.

Interests that should be considered and disclosed but are not limited to the following:

Funding: Research grants from funding agencies (please give the research funder and the grant number) and/or research support (including salaries, equipment, supplies, reimbursement for attending symposia, and other expenses) by organizations that may gain or lose financially through publication of this manuscript.

Employment: Recent (while engaged in the research project), present or anticipated employment by any organization that may gain or lose financially through publication of this manuscript. This includes multiple affiliations (if applicable).

Financial interests: Stocks or shares in companies (including holdings of spouse and/or children) that may gain or lose financially through publication of this manuscript; consultation fees or other forms of remuneration from organizations that may gain or lose financially; patents or patent applications whose value may be affected by publication of this manuscript.

It is difficult to specify a threshold at which a financial interest becomes significant, any such figure is necessarily arbitrary, so one possible practical guideline is the following: "Any undeclared financial interest that could embarrass the author were it to become publicly known after the work was published."

Non-financial interests: In addition, authors are requested to disclose interests that go beyond financial interests that could impart bias on the work submitted for publication such as professional interests, personal relationships or personal beliefs (amongst others). Examples include, but are not limited to: position on editorial board, advisory board or board of directors or other type of management relationships; writing and/or consulting for educational purposes; expert witness; mentoring relations; and so forth.

Primary research articles require a disclosure statement. Review articles present an expert synthesis of evidence and may be treated as an authoritative work on a subject. Review articles therefore require a disclosure statement. Other article types such as editorials, book reviews, comments (amongst others) may, dependent on their content, require a disclosure statement. If you are unclear whether your article type requires a disclosure statement, please contact the Editor-in-Chief.

Please note that, in addition to the above requirements, funding information (given that funding is a potential competing interest (as mentioned above)) needs to be disclosed upon submission of the manuscript in the peer review system. This information will automatically

be added to the Record of CrossMark, however it is **not added** to the manuscript itself. Under 'summary of requirements' (see below) funding information should be included in the '**Declarations**' section.

Summary of requirements

The above should be summarized in a statement and included on **a title page that is separate from the manuscript** with a section entitled "**Declarations**" when submitting a paper. Having all statements in one place allows for a consistent and unified review of the information by the Editor-in-Chief and/or peer reviewers and may speed up the handling of the paper. Declarations include Funding, Competing interests, Ethics approval, Consent, Data, Materials and/or Code availability and Authors' contribution statements. **Please use the title page for providing the statements.**

Once and if the paper is accepted for publication, the production department will put the respective statements in a distinctly identified section clearly visible for readers.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

When all authors have the same (or no) competing interests and/or funding it is sufficient to use one blanket statement.

Examples of statements to be used when funding has been received:

- Partial financial support was received from [...]
- The research leading to these results received funding from […] under Grant Agreement No[…].
- This study was funded by […]
- This work was supported by […] (Grant numbers […] and […]

Examples of statements to be used when there is no funding:

- The authors did not receive support from any organization for the submitted work.
- No funding was received to assist with the preparation of this manuscript.
- No funding was received for conducting this study.
- No funds, grants, or other support was received.

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- **Financial interests:** Author A has received research support from Company A. Author B has received a speaker honorarium from Company W and owns stock in Company X. Author C is consultant to company Y.

  Non-financial interests: Author C is an unpaid member of committee Z.

- **Financial interests:** The authors declare they have no financial interests.

Non-financial interests: Author A is on the board of directors of Y and receives no compensation as member of the board of directors.

- **Financial interests:** Author A received a speaking fee from Y for Z. Author B receives a salary from association X. X where s/he is the Executive Director.

  Non-financial interests: none.

- **Financial interests:** Author A and B declare they have no financial interests. Author C has received speaker and consultant honoraria from Company M and Company N. Dr. C has received speaker honorarium and research funding from Company M and Company O. Author D has received travel support from Company O.

  Non-financial interests: Author D has served on advisory boards for Company M, Company N and Company O.

Examples of statements to be used when authors have nothing to declare:

- The authors have no relevant financial or non-financial interests to disclose.
- The authors have no competing interests to declare that are relevant to the content of this article.
- All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.
- The authors have no financial or proprietary interests in any material discussed in this article.

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Research involving human participants, their data or biological material

Ethics approval

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

Retrospective ethics approval

If a study has not been granted ethics committee approval prior to commencing, retrospective ethics approval usually cannot be obtained and it may not be possible to consider the manuscript for peer review. The decision on whether to proceed to peer review in such cases is at the Editor's discretion.

Ethics approval for retrospective studies

Although retrospective studies are conducted on already available data or biological material (for which formal consent may not be needed or is difficult to obtain) ethics approval may be required dependent on the law and the national ethical guidelines of a country. Authors should check with their institution to make sure they are complying with the specific requirements of their country.

Ethics approval for case studies

Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on **Informed Consent**.

Cell lines

If human cells are used, authors must declare in the manuscript: what cell lines were used by describing the source of the cell line, including when and from where it was obtained, whether the cell line has recently been authenticated and by what method. If cells were bought from a life science company the following need to be given in the manuscript: name of company (that provided the cells), cell type, number of cell line, and batch of cells.

It is recommended that authors check the NCBI database for misidentification and contamination of human cell lines. This step will alert authors to possible problems with the cell line and may save considerable time and effort.

Further information is available from the International Cell Line Authentication Committee (ICLAC).

Authors should include a statement that confirms that an institutional or independent ethics committee (including the name of the ethics committee) approved the study and that informed consent was obtained from the donor or next of kin.

Research Resource Identifiers (RRID)

Research Resource Identifiers (RRID) are persistent unique identifiers (effectively similar to a DOI) for research resources. This journal encourages authors to adopt RRIDs when reporting key biological resources (antibodies, cell lines, model organisms and tools) in their manuscripts.

Examples:

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Cell Line: RST307 cell line **RRID:CVCL_C321**

Antibody: Luciferase antibody DSHB Cat# LUC-3, **RRID:AB_2722109**

Plasmid: mRuby3 plasmid **RRID:Addgene_104005**

Software: ImageJ Version 1.2.4 **RRID:SCR_003070**

RRIDs are provided by the Resource Identification Portal. Many commonly used research resources already have designated RRIDs. The portal also provides authors links so that they can quickly register a new resource and obtain an RRID.

Clinical Trial Registration

The World Health Organization (WHO) definition of a clinical trial is "any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes". The WHO defines health interventions as “A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions” and a health-related outcome is generally defined as a change in the health of a person or population as a result of an intervention.

To ensure the integrity of the reporting of patient-centered trials, authors must register prospective clinical trials (phase II to IV trials) in suitable publicly available repositories. For example www.clinicaltrials.gov or any of the primary registries that participate in the WHO International Clinical Trials Registry Platform.

The trial registration number (TRN) and date of registration should be included as the last line of the manuscript abstract.

For clinical trials that have not been registered prospectively, authors are encouraged to register retrospectively to ensure the complete publication of all results. The trial registration number (TRN), date of registration and the words 'retrospectively registered’ should be included as the last line of the manuscript abstract.

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Springer Nature advocates complete and transparent reporting of biomedical and biological research and research with biological applications. Authors are recommended to adhere to the minimum reporting guidelines hosted by the EQUATOR Network when preparing their manuscript.

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Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Ethics approval'.

Examples of statements to be used when ethics approval has been obtained:

• All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

• Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

• This research study was conducted retrospectively from data obtained for clinical purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

• This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of University B approved this study.

Examples of statements to be used when no ethical approval is required/exemption granted:

• This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required.

• The data reproduced from Article X utilized human tissue that was procured via our Biobank AB, which provides de-identified samples. This study was reviewed and deemed exempt by our XYZ Institutional Review Board. The BioBank protocols are in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.
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Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images.

Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing

characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person.

Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.

Exceptions where it is not necessary to obtain consent:

• Images such as x rays, laparoscopic images, ultrasound images, brain scans, pathology slides unless there is a concern about identifying information in which case, authors should ensure that consent is obtained.

• Reuse of images: If images are being reused from prior publications, the Publisher will assume that the prior publication obtained the relevant information regarding consent. Authors should provide the appropriate attribution for republished images.

Consent and already available data and/or biologic material

Regardless of whether material is collected from living or dead patients, they (family or guardian if the deceased has not made a pre-mortem decision) must have given prior written consent. The aspect of confidentiality as well as any wishes from the deceased should be respected.

Data protection, confidentiality and privacy

When biological material is donated for or data is generated as part of a research project authors should ensure, as part of the informed consent procedure, that the participants are made aware what kind of (personal) data will be processed, how it will be used and for what purpose. In case of data acquired via a biobank/biorepository, it is possible they apply a broad consent which allows research participants to consent to a broad range of uses of their data and samples which is regarded by research ethics committees as specific enough to be considered “informed”. However, authors should always check the specific biobank/biorepository policies or any other type of data provider policies (in case of non-bio research) to be sure that this is the case.

Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not have been fully informed, extra care will be taken by the editor and may be referred to the Springer Nature Research Integrity Group.

Consent to Publish

Individuals may consent to participate in a study, but object to having their data published in a journal article. Authors should make sure to also seek consent from individuals to publish their data prior to submitting their paper to a journal. This is in particular applicable to case studies. A consent to publish form can be found

here. (Download docx, 36 kB)

Summary of requirements

The above should be summarized in a statement and placed in a ‘Declarations’ section before the reference list under a heading of ‘Consent to participate’ and/or ‘Consent to publish’. Other declarations include Funding, Competing interests, Ethics approval, Consent, Data and/or Code availability and Authors’ contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for **"Consent to participate"**:

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

Sample statements for **“Consent to publish”**:

The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

Sample statements if identifying information about participants is available in the article:

Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

Images will be removed from publication if authors have not obtained informed consent or the paper may be removed and replaced with a notice explaining the reason for removal.
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Appendix F

NHS Ethics Approval (with REC Favourable Opinion Letter)

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mrs Emily Roxburgh
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Email: approvals@hra.nhs.uk

09 February 2024

Dear Mrs Roxburgh

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study**
IRAS project ID:	**332391**
REC reference:	**24/SC/0013**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **332391**. Please quote this on all correspondence.

Yours sincerely,
Deanna Herron

Approvals Specialist
Email: approvals@hra.nhs.uk
Copy to: *Mrs Tracy Moulton*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [CPFT MODEL NON-COMMERCIAL PARTICIPANT IDENTIFICATION CENTRE AGREEMENT (SPONSOR TO PIC)]	1	07 December 2023
Contract/Study Agreement template [NSFT MODEL NON-COMMERCIAL PARTICIPANT IDENTIFICATION CENTRE AGREEMENT (SPONSOR TO PIC)]	1	07 December 2023
Copies of materials calling attention of potential participants to the research [Leaflet for recruitment]	Version 1	13 November 2023
Copies of materials calling attention of potential participants to the research [Leaflet for recruitment]	Version 2	23 January 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers, public and products liability and professional indemnity]	1	07 December 2023
Interview schedules or topic guides for participants [Interview Schedule Guide]	1	13 November 2023
IRAS Application Form [IRAS_Form_11122023]		11 December 2023
Letter from sponsor [I&I cover letter - from sponsor]	1	07 December 2023
Other [Timeline of events - interview]	1	13 November 2023
Other [Participant debrief sheet]	1	13 November 2023
Other [Consent to contact form for PIC]	1	13 November 2023
Other [Good clinical practice certificate]	1	16 October 2023
Other [Screening questionnaire questions]	1	07 December 2023
Other [Project protocol feedback UEA]	1	28 July 2023
Other [Secondary supervisor CV]	1	07 December 2023
Participant consent form [Consent form]	Version 1	13 November 2023
Participant consent form [Consent form (tracked)]	Version 2	23 January 2024
Participant information sheet (PIS) [PIS]	Version 1	23 November 2023
Participant information sheet (PIS) [PIS (tracked)]	Version 2	23 January 2024
Research protocol or project proposal [Project protocol]	Version 3	23 January 2024
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	07 December 2023
Summary CV for supervisor (student research) [CV Primary Supervisor]	1	07 December 2023

Health Research Authority

South Central - Oxford B Research Ethics Committee
Health Research Authority
2 Redman Place
Stratford
E20 1JQ

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

09 February 2024

Mrs Emily Roxburgh
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Dear Mrs Roxburgh

Study title:	**Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study**
REC reference:	**24/SC/0013**
IRAS project ID:	**332391**

Thank you for your letter of 31/01/2024, responding to the Research Ethics Committee's (REC) 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.

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.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

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

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) 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 HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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 research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

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).

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, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

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

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Leaflet for recruitment]	Version 1	13 November 2023
Copies of materials calling attention of potential participants to the research [Leaflet for recruitment]	Version 2	23 January 2024
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Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	07 December 2023
Summary CV for supervisor (student research) [CV Primary Supervisor]	1	07 December 2023

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.

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: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

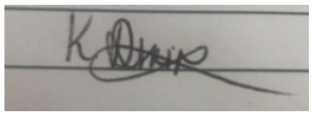
We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 332391 Please quote this number on all correspondence

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

Yours sincerely

p.p.



Dr Maria Breen
Chair

Email:oxfordb.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval

Copy to: Mrs Tracy Moulton

Northern Ireland: research.gateway@hscni.net

Appendix G

Participant Advertisement Leaflet

University of East Anglia

NHS

POSTPARTUM PSYCHOSIS

DADS AND PARTNERS, WE WANT TO HEAR FROM YOU!

Emily Roxburgh, Trainee Clinical Psychologist, invites you to take part in her study as part of her Doctorate in Clinical Psychology.

The project

We want to explore partners' care experiences from mental healthcare services; were you involved, supported, or informed throughout the woman's care? You'll be invited to complete a brief screening questionnaire and take part in a 1:1 confidential interview via Microsoft Teams. We believe the findings from this study could contribute to improving services and tailored care for partners of women with postpartum psychosis.

You can take part if:

- You are currently or were the partner of a woman who experienced postpartum psychosis.
- The woman received mental healthcare support for postpartum psychosis in the UK in the past 7 years.
- You were in a relationship with the woman at the time of birth and throughout the time she was receiving mental health support after birth.
- It has been more than 6 months since the postpartum psychosis began.
- You are aged 18 years old or over.
- You speak and understand fluent English.

Interested?

1. Scan the QR code:
2. Or visit: https://app.onlinesurveys.jisc.ac.uk/s/uea/screening-questionaire
3. Or email the study researcher, Emily Roxburgh, (e.roxburgh@uea.ac.uk) for more information.

Receive a £10 Love2shop gift vougher for participatin

If you decide to take part, your details will be kept confidential and anonymous. No one will be able to link you to what you tell us, no names will be used in the final report. All data will be collected and managed in accordance with the Data Protection Act 2018 and the UEA Research Data Management Policy 2019. This study has received NHS Ethics Approval (24/SC/0013).

Appendix H

Participant Information Sheet

IRAS Project ID: 332391, Version 2, Version Date 23/01/24

University of East Anglia

Faculty of Medicine & Health Sciences
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
United Kingdom

Participant Information Sheet

Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study

You're being invited to take part in our study because we're keen to learn about your experiences with mental healthcare services. Specifically, we want to hear your thoughts on the care you received when your partner had psychosis after giving birth.

Before you decide whether or not you want to take part it is important for you to understand why the study is being done and what it will involve. Please take the time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information.

Why are we doing this study?
We know that partners of women who had psychosis after giving birth play a big part in the mum's recovery, helping the family, and making tough choices. It can also be hard on relationships and the partners own happiness. We hope to get at least 10 partners from across the UK to take part to tell us about their care experiences from mental healthcare services during this time.

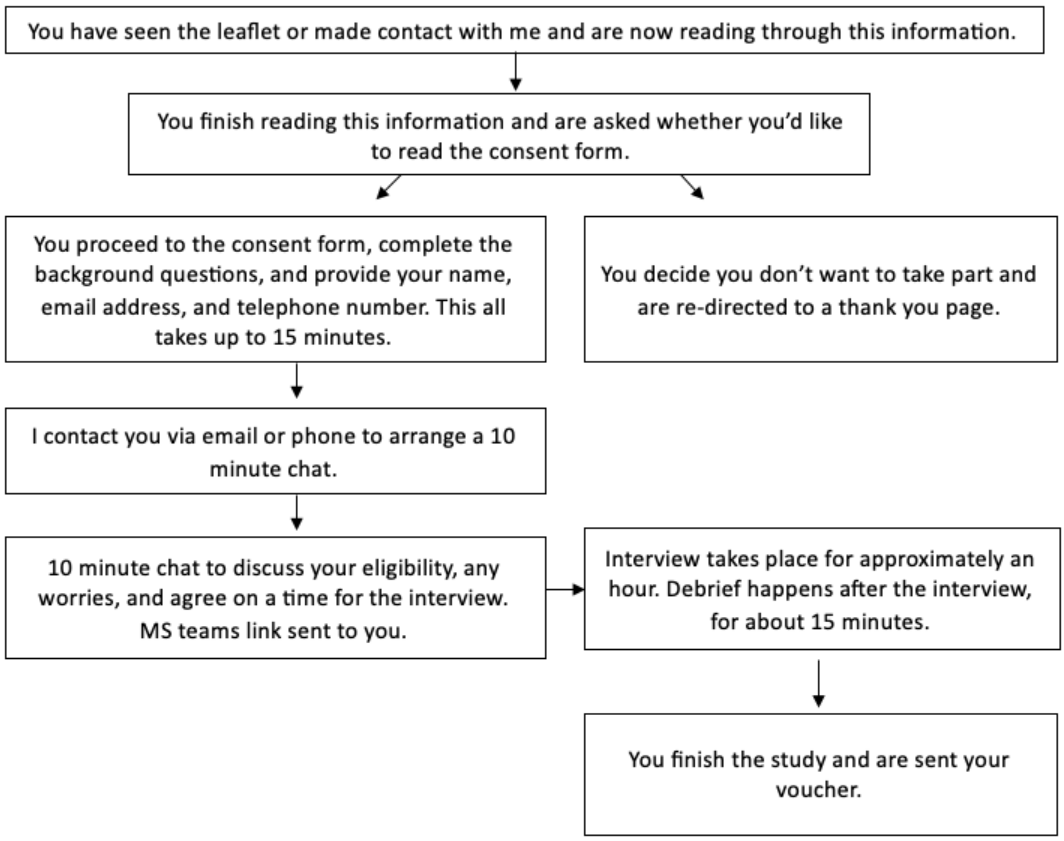
What will taking part look like?
You will be asked to read and complete a consent form after reading this information. This is to make sure you are happy to take part. You will be asked to type your initials, full name twice (once for a signature), and the date. Then, you'll answer some questions to check if you're eligible to take part in the interview. We'll also need your contact details (name, phone number, and email address) so we can get in touch if you're eligible and to send you a signed copy of the consent form. An email address is essential to take part in the study. The researcher will then reach out to you by phone or email to set up a quick 10-minute chat. This is a chance for you to ask questions, share any worries, and for the researcher to check your answers to the questions. You'll also pick a time for the interview on Microsoft Teams (MS Teams). We'll be flexible with the timing to fit around your childcare or work schedule. We suggest having childcare during the interview, but if that's not possible, we'll try our best to make the interview work around this. If you find it difficult to access MS Teams, we can look into finding local support to help you join.

Once you click on the MS Teams link (sent to you in the chat), the researcher will go over this information again and make sure you still want to take part. The interview will start with the researcher asking about your background (your level of education, if you work, how many children you have, if you have difficulties with your mental health, if you're getting support for this, if you're married, and your ethnicity). They will also ask about your wellbeing, if you were offered support, what you thought of healthcare professionals, what it was like getting support for your partner, and how involved you felt. You don't have to answer every question, and you can refuse to answer without giving a reason. The interview will be recorded on video and then typed into a word document to be analysed. If you're not comfortable being on video, we can turn it off and record just audio.

If you're not eligible to take part, we'll explain why and point you in the direction of how to get mental health support. Feel free to reach out if you have more questions.

How much time will this take?
The first set of questions you'll answer will take around 10-15 minutes. The interview and the wrap-up talk afterward will be about one hour and 15 minutes. The time might change a bit depending on how much you want to share for each question.

Here's a flowchart to show you what happens:



Do I have to take part?
It is your choice if you want to take part or not. If you decide to take part, you can stop anytime. You do not need to tell us why you don't want to take part.

What good things could happen if I take part?
The best thing about taking part is that you get to share your experiences in as much detail as you want. They will be listened to, recorded, and might help make services and care better for partners of women who experience psychosis after birth. You will also get a £10 Lovetoshop voucher when you finish the interview.

What might not be so good about taking part?
Sometimes, the questions we talk about in the interview might make you feel sad or worried. If that happens, you can take a break, pick a different time for the interview, or stop it completely. The researcher will do their best to be understanding and kind when asking questions.

Will any further support be offered?
After the interview, you will have a debrief. This means the researcher will be there to talk about any questions or worries you have about what we talked about. You'll also get information on where to find mental health support if you need it.

How will we use your information?
We will need to use information from you for this study. This includes your name, telephone number, and email address, which we'll get from you when we check if you can take part in the study. Only the people doing the research or checking to make sure things are done right will see these details. Others won't know who you are. We'll keep everything about you safe, and once the interview happens, we'll delete your name, email address, and phone number. However, we will need to ask for your email address again at the end of the interview so we can send you the £10 Lovetoshop voucher.

The interview will be confidential. This means that what you say won't be linked back to you. The researcher will give a number to your interview write-up, and any names or details mentioned during the interview (like family names or locations) will be changed to something general (like 'partner' or 'location'). Recordings of your interview will be deleted once the interview is written into a word document. We might use short quotes from your interview, but it won't show it's from you, and we won't use any names. If you don't want your quotes to be used, please tell the researcher during the interview. We will write our report in a way that no-one can work out that you took part in the study.

It's important to know that sometimes we might have to break the confidentiality agreement. That is, if you tell us that you or somebody else might be at risk, we have a duty of care to make sure everyone is safe. We would talk as a research team and take steps to keep everyone safe. It this happens, you might not be able to continue taking part in the study. We'll keep you updated and involved if this happens.

All the information we collect will be stored securely according to the Data Protection Act and the UEA Research Data Management Policy. Only the main researcher and research supervisors will have access to this. Once we have finished the study, we will keep some of the data (interview transcripts) so we can check the results.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?
You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to dataprotection@uea.ac.uk, or
- by ringing us on 07824527234 (data protection at the UEA)

What will happen to the results?
The main researcher will ask you at the end of the interview if you want to read the results of the study when it's finished. You can also ask for this by emailing e.roxburgh@uea.ac.uk. The results of this study will be given to you as a summary. We will also write a report for an academic journal and present our findings in the form of a presentation with NHS services. It will not be possible to identify you in anything we write.

Who has reviewed this study?
All research that is carried out in the UK must be reviewed by an ethics committee. The South Central - Oxford B Research Ethics Committee has given a favourable opinion of the study.

Who is carrying out the study?
This study is being conducted by Emily Roxburgh, Postgraduate Researcher in the Doctorate in Clinical Psychology Programme (ClinPsyD) at Norwich Medical School, UEA. The primary supervisor is Dr Joanne Hodgekins; Clinical Associate Professor in Clinical Psychology at the UEA ClinPsyD, and the second supervisor is Dr Billie Lever-Taylor; Clinical Psychologist at King's College London.

What if I have a complaint or any concerns with how the study is being conducted?
If you wish to make a complaint or have any concerns about the way this study is being conducted, please contact me at e.roxburgh@uea.ac.uk. Please contact Professor Sian Coker, at the UEA, at s.coker@uea.ac.uk if you want to speak to someone who is independent from the study.

What if I would like further information about the study?
Should you need any more information about the study, please do not hesitate to contact me at e.roxburgh@uea.ac.uk and raise any questions you may have.

Thank you for reading this information

Appendix I

Participant Consent Form

IRAS Project ID: 332391, Version 2, Version Date 23/01/24

University of East Anglia

Faculty of Medicine & Health Sciences
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
United Kingdom

Participant Consent Form

Study title: Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study

Lead researcher: Emily Roxburgh, UEA

I give my consent and confirm that *(please type your initials in each statement):*

	Initials
I have read and understood the participant information sheet.	
I have had the opportunity to ask questions about the study.	
I understand that my participation is voluntary and that I can withdraw at any time, without giving any reason.	
I understand I cannot see, change, or withdraw the data I have shared with the research team (even when I've withdrawn from the study).	
I consent to the interview with me being audio or video recorded.	
I consent to a written transcript and audio or videorecording of the interview being stored securely and treated confidentiality.	
I understand that if risk to myself or others is mentioned, the confidentiality agreement may need to be broken to make sure everyone is safe.	
I consent to my data being written up for publication. My name and other identifying details will not be shared and it will not be possible to identify me from any publications.	
I understand that I will be given a £10 Love2Shop e-voucher for my participation in this study once I have taken part in it.	
I agree to take part in the study.	

Name of participant:
Signature of participant (please insert your full name):
Date:

Appendix J

Interview Schedule

IRAS Project ID: 332391, Version 1, Version Date 13/11/23

Demographic information:

Age

Ethnicity

Employment status

Highest level of education

How many children have you got

Marital status

Living status with partner

How you experienced any MH difficulties?

Did partner have MH difficulties before the birth?

1. **When did you first notice the difficulties starting (Postpartum Psychosis)?**

1a) Did anyone tell you about PP before the difficulties started?
1b) Were you aware of what PP was before the difficulties started?
1c) Who 'diagnosed' it as PP in the first instance?
1d) How did you react/ feel?

2. **Were you provided with any information regarding maternal postnatal mental health conditions when your partner became pregnant / or following birth?**

2a) What information would you have liked to have had?
2b) When do you think the information provided would have been most helpful for you?
2c) Why do you think having this information would have been useful?

3. **What were your experiences of accessing support for postpartum psychosis?**

3a) Difficult/ easy process?
3b) Did you receive any support with this by a healthcare professional?
3c) Did they involve you in decision making/ the process of accessing support?

4. **What was your experience of healthcare professional's post-birth? (Please specify the type of service they worked for)**

4a) Why do you think (INSERT EXPERIENCE) stood out for you in particular?
4b) If supported by various teams, why was one more helpful than the other?

5. **What was your experience of being involved by services/ healthcare professionals in your partner's care?**

5a) Did you feel involved in decision making?
5b) Were you invited to reviews or appointments?
5c) Did you feel that your concerns were being taken seriously, why?
5d) Is there anything they could have done better/ that would have made you feel more supported/ involved?
5e) Did they explain or talk through any of the symptoms that your partner was exhibiting?
6f) Did they speak about future planning, what this may look like?

6. **Were you offered any mental health support / other support? (Please specify what type of support/ what service was offering this if known)**

6a) Is this something you took up / something you would consider?
6b) Why did you not go ahead with the support offered?
6c) Did the support feel tailored to what you were experiencing?
6d) Were there any barriers in you accessing this support?

7. **Do you feel as though your partners PP experience affected your own wellbeing?**

7a) What could have been put in place to facilitate this for you?
7b) What was most challenging about this for you?
7c) Did this have any knock-on effects elsewhere in your life/lives?
7d) Do you feel it affected your relationship with your wife in any way?

8. **What would you like to have been offered / seen more of during these times from services?**

8a) Do you think anything could be tailored better for partners?
8b) Do you think there could be any barriers to this?

9. **What did a typical day look like for you during these times?**

9a) Did you feel you took on more responsibility?

9b) What was it like being 'dad and mum'?

9c) Did you have support from anyone else in the family?

9d) Did you still work during this time?

10. **Is there any additional information you would like to share that has not been covered and you think might be helpful/important for us to know?**

Appendix K

Examples of Reflective Journal Entries

“I did my first interview today. The participant was really forthcoming with their experiences which was so helpful. I recognised that he had a lot to share. I sometimes struggled to keep us on track. I didn’t want him to feel as though I was shutting him down, when he was so openly wanting to talk about his experiences. In hindsight, I felt I perhaps focused on building a rapport in the early stages of the interview. I think conducting interviews again will take some getting used to. I’m conscious I want to ensure I’m collecting rich data but also balancing this with the natural flow of the interview.”

“The interview today was difficult. I felt it was very hard to interrupt and ask further follow up questions. Similar to the other interviews, he naturally took the lead in wanting to tell me about his experiences and guide the interview. I noticed that when I went to interrupt him, I didn’t want him to think I wasn’t interested in what he was going to say. Where appropriate, I’d apologise and say that we’ll come back to the topic he was discussing. Sometimes I’d also say that I was conscious of time and wanted to ensure that we were able to capture all relevant points. I also felt it was important to validate that there must be a lot that he wanted to share given the experiences he has had, but that unfortunately this was not going to cover all aspects. I spent some time reflecting after the interview, perhaps I need to ‘let go’ a bit more throughout the interview process, as long as I’m confident that I’m still collecting rich data.”

“Today I noticed that I could sometimes take on a ‘clinical role’ during the interviews due to the emotional responses from partners. They would often push themselves to continue talking despite crying. I wanted to ensure they felt comfortable, and that they felt seen for how resilient they were for sharing their experiences. I made sure to offer breaks, although no one has agreed to one yet. It reminded me of a previous reflection where I noted how

they might be finding the interviews therapeutic? I've also noticed that humour can sometimes work for them, a lot of partners would naturally use humour as a way of 'easing in' so this is something that (within reason) I utilised."

"I had the final two interviews today and I'm really pleased with how they went. I feel much more confident in myself and feel I have developed as an interviewer. I recognise that not everything has to go to plan, something I still need to work on at times. For some time now, I have felt that I am beginning to hear some patterns of what is being said and experienced, as well as differences. I have also been transcribing at the same time which may have facilitated this."

Appendix L

Consent to Contact Form

IRAS Project ID: 332391, Version 1, Version Date 13/11/23

CONSENT TO CONTACT FORM FOR RESEARCH

Please complete this form if you are happy for the researchers from the Norwich Medical School (MED) at the University of East Anglia (UEA) to contact you to discuss your participation in research.

Research participation will involve taking part in a screening questionnaire and interview.

1. I agree that the researchers from the MED at the UEA can contact me to discuss my participation in research, using my contact details below.

2. I understand that personal contact details below will be stored securely, in line with the Data Protection Act and General Data Protection Regulations.

Full Name of participant:

Signature:

Date:

Address:

Telephone / Mobile:

Email:

Preferred Time to be contacted: Morning Afternoon Evening (please circle)

Preferred Method of contact: Morning Afternoon Evening (please circle)

Now tear off this section of the form, and return to the member of the public

I agree that the researchers from the Norwich Medical School (MED) at the University of East Anglia (UEA) can contact me to discuss my participation in research. Participation is voluntary, and I can withdraw my interest at any time. If I withdraw my interest, and decide not to take part, the research team will destroy any copies of my personal details, and my clinical care will not be affected in any way.

Name:
Signature:
Date:

The main researcher can be contacted on e.roxburgh@uea.ac.uk and the MED at UEA on med.reception@uea.ac.uk or by calling 01603 593061.

Appendix M

Screening Questionnaire (JISC)

Screening questionnaire

Participant Information Sheet

Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study

You're being invited to take part in our study because we're keen to learn about your experiences with mental healthcare services. Specifically, we want to hear your thoughts on the care you received when your partner had psychosis after giving birth.

Before you decide whether or not you want to take part it is important for you to understand why the study is being done and what it will involve. Please take the time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information.

Why are we doing this study?

We know that partners of women who had psychosis after giving birth play a big part in the mum's recovery, helping the family, and making tough choices. It can also be hard on relationships and the partners own happiness. We hope to get at least 10 partners from across the UK to take part to tell us about their care experiences from mental healthcare services during this time.

What will taking part look like?

You will be asked to read and complete a consent form after reading this information. This is to make sure you are happy to take part. You will be asked to type your initials, full name twice (once for a signature), and the date. Then, you'll answer some questions to check if you're eligible to take part in the interview. We'll also need your contact details (name, phone number, and email address) so we can get in touch if you're eligible and to send you a signed copy of the consent form. An email address is essential to take part in the study. The researcher will then reach out to you by phone or email to set up a quick 10-minute chat. This is a chance for you to ask questions, share any worries, and for the researcher to check your answers to the questions. You'll also pick a time for the interview on Microsoft Teams (MS Teams). We'll be flexible with the timing to fit around your childcare or work schedule. We suggest having childcare during the interview, but if that's not possible, we'll try our best to make the interview work around this. If you find it difficult to access MS Teams, we can look into finding local support to help you join.

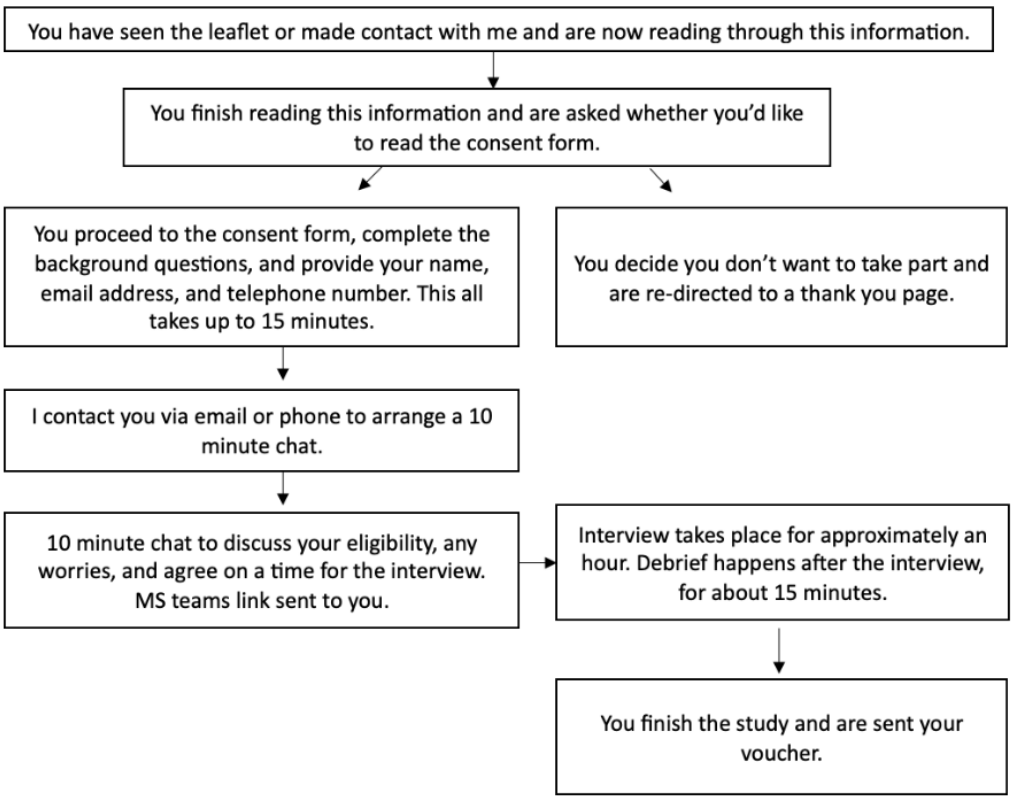
Once you click on the MS Teams link (sent to you in the chat), the researcher will go over this information again and make sure you still want to take part. The interview will start with the researcher asking about your background (your level of education, if you work, how many children you have, if you have difficulties with your mental health, if you're getting support for this, if you're married, and your ethnicity). They will also ask about your wellbeing, if you were offered support, what you thought of healthcare professionals, what it was like getting support for your partner, and how involved you felt. You don't have to answer every question, and you can refuse to answer without giving a reason. The interview will be recorded on video and then typed into a word document to be analysed. If you're not comfortable being on video, we can turn it off and record just audio.

If you're not eligible to take part, we'll explain why and point you in the direction of how to get mental health support. Feel free to reach out if you have more questions.

How much time will this take?

The first set of questions you'll answer will take around 10-15 minutes. The interview and the wrap-up talk afterward will be about one hour and 15 minutes. The time might change a bit depending on how much you want to share for each question.

Here's a flowchart to show you what happens:



Do I have to take part?

It is your choice if you want to take part or not. If you decide to take part, you can stop anytime. You do not need to tell us why you don't want to take part.

What good things could happen if I take part?

The best thing about taking part is that you get to share your experiences in as much detail as you want. They will be listened to, recorded, and might help make services and care better for partners of women who experience psychosis after birth. You will also get a £10 Lovetoshop voucher when you finish the interview.

What might not be so good about taking part?

Sometimes, the questions we talk about in the interview might make you feel sad or worried. If that happens, you can take a break, pick a different time for the interview, or stop it completely. The researcher will do their best to be understanding and kind when asking questions.

Will any further support be offered?

After the interview, you will have a debrief. This means the researcher will be there to talk about any questions or worries you have about what we talked about. You'll also get information on where to find mental health support if you need it.

How will we use your information?

We will need to use information from you for this study. This includes your name, telephone number, and email address, which we'll get from you when we check if you can take part in the study. Only the people doing the research or checking to make sure things are done right will see these details. Others won't know who you are. We'll keep everything about you safe, and once the interview happens, we'll delete your name, email address, and phone number. However, we will need to ask for your email address again at the end of the interview so we can send you the £10 Lovetoshop voucher.

The interview will be confidential. This means that what you say won't be linked back to you. The researcher will give a number to your interview write-up, and any names or details mentioned during the interview (like family names or locations) will be changed to something general (like 'partner' or 'location'). Recordings of your interview will be deleted once the interview is written into a word document. We might use short quotes from your interview, but it won't show it's from you, and we won't use any names. If you don't want your quotes to be used, please tell the researcher during the interview. We will write our report in a way that no-one can work out that you took part in the study.

It's important to know that sometimes we might have to break the confidentiality agreement. That is, if you tell us that you or somebody else might be at risk, we have a duty of care to make sure everyone is safe. We would talk as a research team and take steps to keep everyone safe. It this happens, you might not be able to continue taking part in the study. We'll keep you updated and involved if this happens.

All the information we collect will be stored securely according to the Data Protection Act and the UEA Research Data Management Policy. Only the main researcher and research supervisors will have access to this. Once we have finished the study, we will keep some of the data (interview transcripts) so we can check the results.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to dataprotection@uea.ac.uk, or
- by ringing us on 07824527234 (data protection at the UEA)

What will happen to the results?

The main researcher will ask you at the end of the interview if you want to read the results of the study when it's finished. You can also ask for this by emailing e.roxburgh@uea.ac.uk. The results of this study will be given to you as a summary. We will also write a report for an academic journal and present our findings in the form of a presentation with NHS services. It will not be possible to identify you in anything we write.

Who has reviewed this study?

All research that is carried out in the UK must be reviewed by an ethics committee. The South Central - Oxford B Research Ethics Committee has given a favourable opinion of the study.

Who is carrying out the study?
This study is being conducted by Emily Roxburgh, Postgraduate Researcher in the Doctorate in Clinical Psychology Programme (ClinPsyD) at Norwich Medical School, UEA. The primary supervisor is Dr Joanne Hodgekins; Clinical Associate Professor in Clinical Psychology at the UEA ClinPsyD, and the second supervisor is Dr Billie Lever-Taylor; Clinical Psychologist at King's College London.
What if I have a complaint or any concerns with how the study is being conducted?
If you wish to make a complaint or have any concerns about the way this study is being conducted, please contact me at e.roxburgh@uea.ac.uk. Please contact Professor Sian Coker, at the UEA, at s.coker@uea.ac.uk if you want to speak to someone who is independent from the study.
What if I would like further information about the study?
Should you need any more information about the study, please do not hesitate to contact me at e.roxburgh@uea.ac.uk and raise any questions you may have.
Thank you for reading this information

Consent Form

Do you want to take part in this study? *

- ◯ Yes, I'd like to go ahead and read the consent form before I take part.
- ◯ No, I don't want to take part.

If answered no, redirected to:

You have been re-directed to this page because you either don't wish to take part in this study or you don't meet the inclusion criteria. If you have any questions or concerns, please contact Emily Roxburgh, at e.roxburgh@uea.ac.uk. For support with mental wellbeing, please visit the **Action for Postpartum Psychosis**, **MIND**, or **NHS Talking Therapies** website by typing this into google. Or call 116 123 or email: jo@samaritans.org for Samaritans, or "SHOUT" to 85258 for SHOUT crisis text line.

Consent Form

I give my consent and confirm that (please type your initials in each statement):

I have read and understood the participant information sheet. *

I have had the opportunity to ask questions about the study. *

I understand that my participation is voluntary and that I can withdraw at any time, without giving any reason. *

I understand I cannot see, change, or withdraw the data I have shared with the research team (even when I've withdrawn from the study). *

I consent to the interview with me being audio or video recorded. *

I consent to a written transcript and audio or videorecording of the interview being stored securely and treated confidentiality. *

Screening question 1

Please answer yes or no to the following 5 questions to see if you're eligible to take part.

Did your partner receive support for postpartum psychosis in the UK in the last 7 years? *

- ◯ Yes
- ◯ No

Screening question 2

Was your partners postpartum psychosis episode more than 6 months ago? *

- ◯ Yes
- ◯ No

Screening question 3

Were you in a relationship with your partner at the time of birth and throughout the postnatal period when she experienced postpartum psychosis? *

- ◯ Yes
- ◯ No

Screening question 4

Are you 18 years old or older? *

- ◯ Yes
- ◯ No

Screening question 5

Do you speak and understand fluent English? *

- ◯ Yes
- ◯ No

Contact details

Please enter your contact details so I can contact you to arrange a quick chat. This is so we can arrange a time/date for the interview, and to answer any questions you may have.

What is your full name? *

What is your email address? *

What is your telephone number? *

Appendix N

Public and Patient Involvement Advertisement Leaflet

University of East Anglia

NHS

PERINATAL MENTAL HEALTH

DADS AND PARTNERS, WE NEED YOUR HELP!

We are going to interview partners of women who have accessed support for postpartum psychosis, and we want to get dads and partners feedback on our interview questions and how we are advertising our research.



You will be reimbursed £25/hour or £12.50/half hour for your time and contributio.

If you're the partner of a woman who has experienced a perinatal mental health difficulty and are interested in helping us, please contact Emily Roxburgh (main researcher) on: e.roxburgh@uea.ac.uk

We will help you schedule an online call to discuss.

Appendix O

Participant Debrief Sheet

IRAS Project ID: 332391, Version 1, Version Date 13/11/23

Debrief Letter

University of East Anglia

Faculty of Medicine & Health Sciences
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
United Kingdom

Debrief Letter

Study title: Experiences of care from mental healthcare services among partners of women accessing support for postpartum psychosis: a qualitative study

Dear Participant,
Thank you for participating in this study looking at care experiences from mental healthcare services among partners of women treated for postpartum psychosis. If you wish to receive feedback about the overall findings of this study when it is finished, please request this at e.roxburgh@uea.ac.uk. The findings of this study will be shared with you in the form of a brief lay summary.

If you wish to withdraw your data from the study, please do so between the time you completed the interview up until August 2024 – as this is when the analysis of the findings will take place. If you have experienced any distress or require further support following the study, please see the below signposting for mental health support and guidance.

-Samaritans, call 116 123 or email: jo@samaritans.org for a reply within 24 hours
-Shout, text "SHOUT" to 85258 to contact the Shout Crisis Text Line, or text "YM" if you're under 19
-Please click here to be redirected to the Mind website.
-Please click here to be redirected to the Talking Therapies NHS website.
-Please click here to be redirected to the Action for Postpartum Psychosis charity website.

If you have any concerns or would like to raise any complaints, please contact me at e.roxburgh@uea.ac.uk or if you wish to contact someone independent of this study please contact Professor Sian Coker at s.coker@uea.ac.uk.

Kind regards,
Emily Roxburgh
Trainee Clinical Psychologist
Doctorate in Clinical Psychology (ClinPsyD)
Email: e.roxburgh@uea.ac.uk