

**The Experiences and Service Needs of Parents who Experience
Significant Mental Health Difficulties: A Qualitative
Exploration**

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical
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Abstract

This thesis qualitatively explored the experiences and parenting support needs of parents who experience significant mental health difficulties. Three papers are presented. Paper 1 presents a metasynthesis of qualitative research that explored parents' perceptions of the impact of Serious Mental Illness (SMI) on parenting and their corresponding support needs. Twenty-eight studies were included involving 550 parents across 14 countries, spanning 27 years of research. Six themes were derived following thematic synthesis: 1) *The Constrained Parent*, 2) *Parenting Difficulties*, 3) *The Strained Child*, 4) *Inescapable Threat*, 5) *Combatting Threat*, and 6) *Wrap-around Support Needs*. The centrality of SMI-related parenting challenges and inescapable threat perceptions on strained parent-child relationships were highlighted. To improve support for parents experiencing SMI, systemic practice change initiatives were recommended: families should be put at the centre of support decisions and surrounded by compassionate, non-stigmatising support.

Paper 2 explored the lived experiences of parents who experience psychosis using Interpretative Phenomenological Analysis (IPA) because remarkably little is known about how parenting is experienced by these parents. Eight semi-structured interviews were conducted, and three main themes were identified: 1) *Living with the Struggle: Painfully Disconnected*, 2) *Desired and Vulnerable Position: Comfortably Connected* and 3) *Exposed: Parenting Under a Spotlight*. Experiences of psychosis were found to exacerbate parenting difficulties and parental perceptions of vulnerability and disconnection from their children and system supports as a result of misaligned parent and service priorities and inescapable experiences of exposure and judgment. Recommendations were made for systemic, parent-centred interventions that target stigma, decrease risk-focused support and promote meaningful connections between parents and the systems around them.

Paper 3 presents a critical reflection of the research process for Paper 1 and Paper 2, including the challenges faced, lessons learned and clinical and research implications.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Paper 1

Parenting and Serious Mental Illness (SMI): A Systematic Review and Metasynthesis

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The following paper has been prepared for submission to *Clinical Psychology Review*. Author guidelines can be found in Appendix A. Please note, there have been deviations from the guidelines, such as the presentation of figures and tables in the main text rather than in supplementary materials for thesis submission. The word count is within the limits for *Clinical Psychology Review*.

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Abstract

The consequences of Serious Mental Illness (SMI) on parent and child outcomes can be profound. Supporting parents to manage their caregiving roles alongside parental SMI successfully has been recognised as a public health priority. To meet this priority and develop effective and acceptable interventions, it is imperative that parents' experiences and support needs are understood. This systematic review aimed to synthesise qualitative research that explored parents' experiences and perceptions of the impact of SMI on their parenting and their corresponding support needs. The Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines were followed. Five databases were searched for terms associated with SMI, parenting and qualitative research. Twenty-eight studies involving 550 parents who experienced SMI met inclusion criteria, and the methodological quality of included studies was appraised using the Critical Appraisal Skills Programme. After findings were synthesised using thematic synthesis, six themes were identified: 1) *The Constrained Parent*, 2) *Parenting Difficulties*, 3) *The Strained Child*, 4) *Inescapable Threat*, 5) *Combatting Threat*, and 6) *Wrap-around Support Needs*. Novel insights into the centrality of SMI-related parenting difficulties and system-wide threat perceptions on strained parent-child and distanced parent-support relationships were highlighted. Systemic practice change initiatives via compassionate and inclusive system-wide support were recommended.

Keywords: Schizophrenia; bipolar disorder; psychotic disorders; motherhood; service provision; family focused practice.

Highlights

- The impact of experiences of SMI on parenting needs to be understood.
- Experiences of SMI significantly strains parent-child relationships.
- Systemic factors present additional challenges to parents who experience SMI.
- Systemic interventions may improve parent and child outcomes.

Introduction

Parenting is complex and multifaceted, impacted by a multitude of personal and environmental factors. Around 4% of parents experience Serious Mental Illness¹ (SMI; Stambaugh et al., 2017), such as psychosis, schizophrenia, and bipolar disorder, representing a large group of parents who face additional and often complex challenges when navigating parenthood (Dolman et al., 2013). Factors such as social, emotional, and economic burden (e.g., Chen et al., 2021) have been associated with an increased risk of adverse outcomes in families within which a parent experiences SMI, including disrupted attachment relationships, social exclusion, child emotional difficulties, and parental suicidality (Dubreucq et al., 2021; Gregg et al., 2021; Perera et al., 2014). Despite this, much remains unknown about how parents who experience SMI experience parenting and what their professional healthcare, practical and peer support needs are in relation to parenting. In particular, parents' experiences of navigating relationships with their children and wider systems, and their ideas about parenting support, are not yet fully understood. Consequently, parental needs are often disregarded by services, leaving parents feeling unheard and unsupported (David et al., 2011; Goodyear et al., 2022).

There has been an increase in research and policy guidance over the last 15 years focusing on the challenges that families face related to parental experiences of SMI (e.g., Bee et al., 2014; Foster et al., 2019; Reedtz et al., 2021). Although positive advances have occurred, the focus has largely been on supporting children and other family members cope with the challenges of parental SMI and parental experiences have been largely neglected (Radley et al., 2022). Major documents outlining practice change initiatives, including the National Health Service (NHS) Long Term Plan (NHS England, 2019), fail to consider the support needs of parents who experience SMI adequately. Furthermore, the

¹ The authors of this paper prefer to use the term mental health difficulties. However, the term SMI has been used throughout this paper due it being a widely recognised term in the wider literature.

inadequate implementation of family-focused practice (FFP) within countries that have legislation mandating its use (Furlong et al., 2021) highlights the insufficiency of policy maker decisions alone in promoting practice change. Given that parent and child outcomes are inherently linked (Kahng et al., 2008), it is imperative that parental perceptions about the impact of SMI on parenting and their support needs are better understood to improve service provision for this priority group.

To better understand the experiences of mothers with SMI, Dolman et al. (2013) conducted a metasynthesis of 23 studies exploring 355 maternal experiences and eight studies exploring 143 healthcare professionals' (HCPs) views. These studies, published between 1995 and 2011, reported on mothers' experiences of preconception decision-making, pregnancy and motherhood with SMI, and HCPs experiences of providing support for these mothers. Guided by principles of metaethnography (Noblit & Hare, 1988), Dolman et al. (2013) identified two main themes, namely 1) *experiences of motherhood* and 2) *experiences of services*. However, despite insightful findings, the included studies are now more than a decade old. Moreover, the aims of that review were very broad: both pre- and post-conception experiences and mothers experiences of post-partum psychosis – a presentation with distinct clinical features that occurs in a discrete post-partum period (Spinelli, 2021) – were included, and the integral role of fathering was not considered. Thus, the applicability of findings to non-gendered SMI parenting experiences outside of the distinct perinatal period appears limited.

Prior to Dolman et al.'s (2013) review, Oyserman et al. (2000) reported a mixed review of 67 quantitative and qualitative studies published between 1980 and 2000. The authors described that parental SMI was associated with disrupted attachment relationships and less attuned parenting. Although a relatively large number of studies was included, a synthesis of included studies was not reported. Furthermore, the included studies largely focused on mothers who experienced low mood or depression: only 9.3% of studies

specified diagnoses of schizophrenia or psychosis and 9.7% of bipolar disorder. Other reviews have focused on parenting in the context of specific diagnostic characteristics. For example, in a mixed review of five quantitative and two qualitative studies published between 1969 and 2012, Engur (2017) reviewed parent ideas about the impact of experiences of psychosis on parenting. Engur (2017) found that parents experienced communication difficulties and disorganised parenting. However, little detail was provided, and the seven included studies were not synthesised. Similarly, other mixed reviews have limited their focus to specific presentations of bipolar disorder (Stapp et al., 2020), and qualitative reviews have restricted their focus to presentations of post-partum psychosis (Forde et al., 2020) or SMI in Chinese cultures (Chen et al., 2021).

Although the reviews outlined above offer helpful insights into how parenting can be affected among parents with specific diagnostic or cultural characteristics during discrete time periods, limited up-to-date and cross-cultural insights remain regarding how both mothers and fathers perceive their parenting to be impacted by their experience of SMI and what their parenting support needs are. To guide clinical practice for parents experiencing SMI effectively, an up-to-date and comprehensive qualitative understanding of how parenting is experienced in the context of SMI is required, in line with the Medical Research Council guidelines for the development of complex interventions (Skivington et al., 2021). Therefore, this metasynthesis aimed to synthesise parents' experiences and perceptions of the impact of SMI on parenting to improve our understanding of their personal and professional support needs. We specifically addressed the question 'What are parents' experiences and perceptions of the impact of SMI on parenting and what support needs are indicated?'. The outcomes of this metasynthesis can be used to inform policy, future research and clinical practice.

Methods

This metasynthesis was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al., 2009). The protocol was registered with PROSPERO on 01/12/2021 (Ref: CRD42021295443; https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021295443).

Search Strategy

The search strategy was developed in consultation with the University of Manchester library service using the categories of Sample, Phenomenon of Interest, Design, Evaluation, and Research type (Cooke et al., 2012; see Table 1). Medical Subject Heading terms were used to identify synonyms and Boolean operators (“AND”, “OR”) were used to combine terms and concepts. Five databases, relevant for this topic area, were searched: CINAHL, MEDLINE, EMBASE, PsychINFO and Web of Science. Databases were searched in December 2021 for articles published from inception that contained the terms outlined in Table 1, either in the title, abstract or keywords. The search was updated in April 2022 which identified one new study for inclusion. Google Scholar and reference lists of included studies were searched (Horsley et al., 2011).

An outline of the systematic search process is illustrated in Figure 1. Identified references were imported into EndNote (Clarivate Analytics UK Ltd [Version 20], 2020). Duplicates were removed, and titles, keywords, and abstracts were assessed for eligibility against the inclusion and exclusion criteria by the first author. A second independent reviewer assessed a sample of 10% ($n = 688$) of the total number of studies for inclusion ($N = 6881$). Agreement between reviewers was substantial (99.85%, $\kappa = 0.67$). Any discrepancies were resolved through discussion. Next, the first author reviewed the full text of studies that were not excluded during the screening stage. In the instance of uncertainty, two other authors jointly reviewed the studies and discussions were held to

reach agreement. Corresponding authors of included studies were contacted via email to resolve any data queries.

Table 1: Search terms and limits

1.	S-sample	(Parent* or Mother* or Father* or Caregiv* Guardian* or Carer* or Kinship or Stepparent* or foster parent*)
2.	PI-phenomenon of Interest	(Serious Mental Illness* or SMI or Severe Mental Illness* or Enduring Mental Illness* or Serious Mental Health Difficult* or Serious Mental Health Problem* or Psychos* or Schizophr* or Mental Health or Mental Illness* or Persistent Mental Illness* or Bipolar* Disorder* or Bipolar*)
3.	D-design	(interview*, focus group*, case stud* or observ*)
4.	E-evaluation	(view* or experience* or opinion* or attitude* or perce* or belie* or feel* or know* or understand* or Perspective*)
5.	R-research type	(Qualitative* or mixed method* or IPA or Grounded Theory or Thematic Analys* or Narrative*)
6.	1 AND 2	
7.	3 OR 4	
8.	5 AND 6 AND 7	
Limits: Human, Peer-reviewed, English & German language		

Inclusion and Exclusion Criteria

Papers were included if they 1) were written in English or German (as the research team was fluent in these languages), 2) included qualitative data from qualitative or mixed-methods studies that could be extracted, 3) involved parents (mothers, fathers, stepparents, guardians, foster parents, or kinship parents) who experienced SMI defined as psychosis, schizophrenia, schizophrenia-spectrum disorders or bipolar disorder not limited to the perinatal period (conception to the child’s second birthday), 4) focused on parenting experiences and 5) were published in a peer-reviewed journal. Papers were excluded if they focused on parenting in the perinatal period only or included parents who no longer had contact with their children only.

Methodological Quality and Risk of Bias Assessment

Each included study's methodological quality/risk of bias was appraised using the widely used 10-item Critical Appraisal Skills Programme (CASP, 2018) for qualitative research. As the CASP does not offer a summary scoring system (Long et al., 2020), a numerical system was used (No=0, Partially Agree=0.5, Yes=1). Methodological quality was categorised as high (>8-10), moderate (6-8) or low (≤ 5 ; see Butler et al., 2020). To ensure reliability of assessment ratings, another independent reviewer rated 100% of the included papers. Substantial agreement was achieved between reviewers (96.32%, $\kappa = 0.76$). Any disagreements were resolved by discussion.

Data Extraction and Analysis

The text from included studies under the headings 'results' or 'findings' were extracted into Microsoft Word and analysed using Thomas and Harden's (2008) thematic synthesis. This approach promotes the integration of qualitative findings from multiple studies via the identification of common themes across studies. The approach has been identified as promoting consideration of the appropriateness and acceptability of service provision (Barnett-Page & Thomas, 2009); thus, allowing policy and practice to be informed.

The synthesis followed three overlapping stages (Thomas & Harden, 2008). The first author led on all stages and began by reading each included study several times before line-by-line coding the extracted data using pen and paper methods, from which 1840 preliminary codes were developed. Next, descriptive themes were developed inductively across papers using 'post-it' notes. Sub-themes and analytical themes were developed in the final stage by interpreting consistent and inconsistent themes across papers, relying on researcher inference and judgment. To minimise potential bias, another author independently analysed five of the included studies, which were randomly selected. The research team discussed the analytical themes to ensure that the final themes were

plausible, coherent and appropriately derived from the data. A critical realist epistemology underpinned the analysis (Fletcher, 2017), allowing for inferences about psychosocial processes around parenting to be made, while recognising that inferences are bound by the context of the research; that psychosocial phenomena can exist independently of theory, but that meaning can be constructed from the experiences reported within the included studies. Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guidelines were followed (Tong et al., 2012; Appendix B).

Reflexivity Statement

The authors were all white European women who ranged in ages and three were parents. The first author was a trainee clinical psychologist with several years of experience working in clinical and research roles with people experiencing SMI. The second author was an academic psychologist specialising in health psychology research with an interest in parenting. The third author was an academic psychologist specialising in psychosis research with an interest in family-focused practices. The fourth author was an academic and clinical psychologist with an interest in understanding and supporting mothers who experience SMI. A reflective diary, research team discussions, and a rigorous research process were utilised to minimise the potential for biased interpretations.

Results

Study Characteristics

Twenty-eight studies were identified and synthesised (see Figure 1). These studies were conducted in 14 countries between 1995 and 2022 and reported on the parenting experiences of 550 mothers and fathers who experienced SMI (see Table 2). Most studies reported mothers' experiences ($n = 16$), 11 reported mothers' and fathers' experiences, and one study reported fathers' experiences only (Evenson et al., 2008). Most studies detailed

participant age, sex and number of children, but few other socio-economic demographic characteristics were reported. For example, only nine of the 28 studies (32.14%) reported on the ethnicity of participants. Sample sizes ranged from five to 57. Of the 25 (89.28%) studies that detailed diagnoses, 46.17% of participants had diagnoses of schizophrenia or psychosis and 21.95% had diagnoses of bipolar disorder. Diagnoses were verified by self-report ($n = 4$), the Diagnostic and Statistical Manual of mental disorders, fourth edition (DSM-IV; American Psychiatric Association [APA], 1994; $n = 1$), the DSM-IV-text revised (DSM-IV-TR; APA, 2000; $n = 2$) or the International Classification of Diseases, 10th edition (ICD-10; World Health Organisation [WHO], 1993; $n = 2$). However, 19 studies did not state how diagnoses were verified clearly. Qualitative data were derived from interviews ($n = 27$) or focus groups ($n = 1$), and a range of analysis methods were used.

Methodological Quality of Included Studies

Overall, the methodological quality of the 28 studies was assessed as being high ($n = 12$) or moderately high ($n = 16$; see Table 3). However, only one study adequately considered the researcher-participant relationship (Chan et al., 2019), 15 studies (53.57%) adequately took ethical issues into consideration, and five studies (17.86%) demonstrated an absence of ethical considerations. Chan et al. (2019), Sabella et al. (2022), Chen et al. (2021) and Montgomery et al. (2006) received the highest methodological quality ratings of 9.5/10 or above, whereas Sands (1995), Thomas and Kalucy (2002) and Venkataraman and Ackerson (2008) received the lowest quality ratings of 7/10 or lower. As no widely accepted approach for excluding qualitative studies on the basis of quality exists (Dixon-Woods et al., 2006; Thomas & Harden, 2008), no studies were excluded from this review.

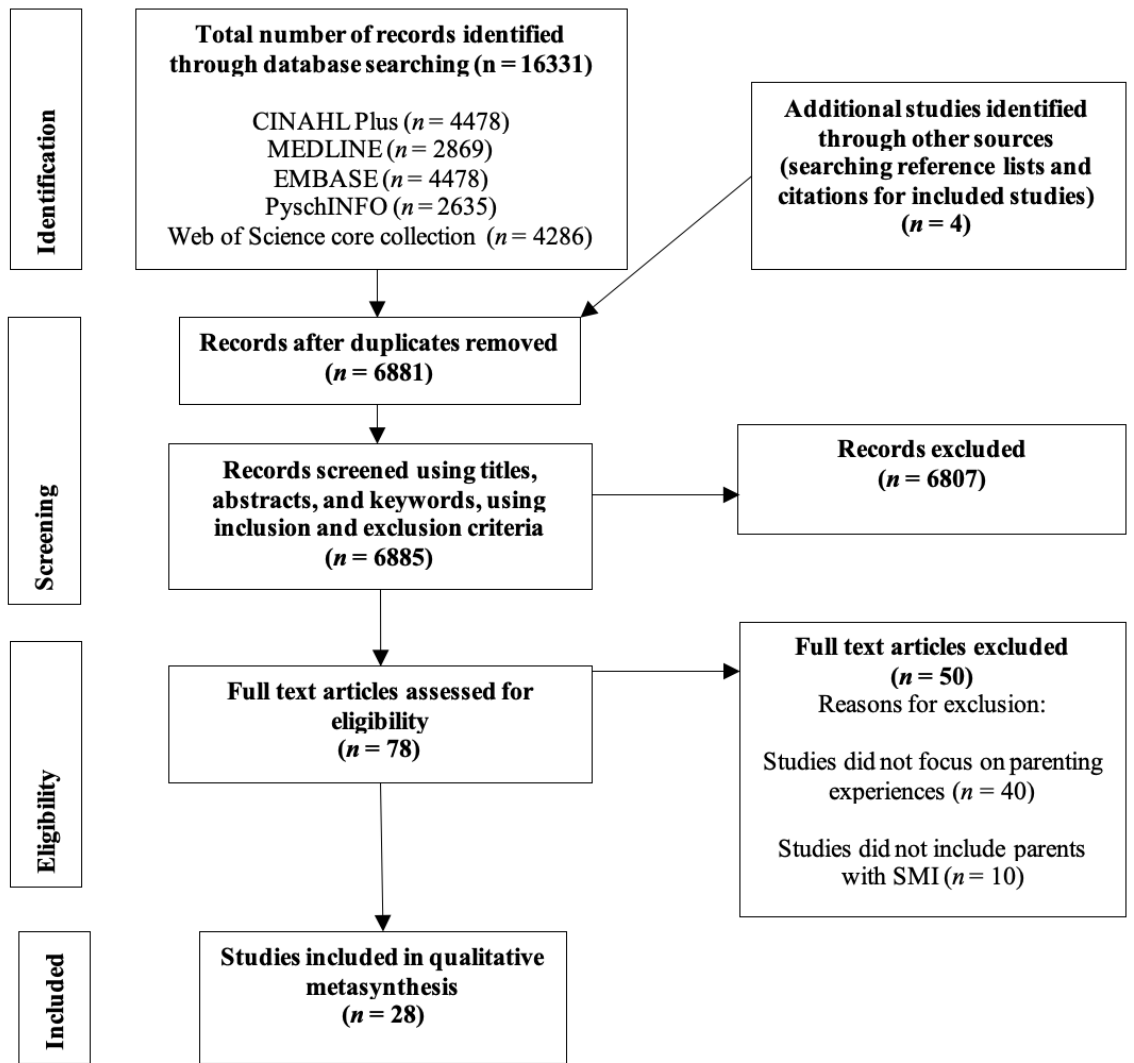


Figure 1: PRISMA Flow Diagram

Table 2: Characteristics of included studies presented in chronological order

	Study: Authors, Year, Location	Study Aim	Sample Description			Verification of Diagnosis	Recruitment Method	Data Collection^a / Analysis	Main Theme Titles
			Parental Mental Health Difficulty	Other Socio-demographic Information	Child Information				
1.	Sabella et al. (2022) USA	To understand the experiences of young adult parents with SMI	Anxiety (<i>n</i> = 15), MDD (<i>n</i> = 13), PTSD (<i>n</i> = 9), BD (<i>n</i> = 9), schizophrenia (<i>n</i> = 1), schizoaffective disorder (<i>n</i> = 1), ED (<i>n</i> = 5), BPD (<i>n</i> = 1)	Mothers (<i>n</i> = 15) and fathers (<i>n</i> = 3). Age (years): Mean age 26 Ethnicity: non-Hispanic white (<i>n</i> = 10), non-Hispanic black (<i>n</i> = 2), Hispanic (<i>n</i> = 3), mixed/other (<i>n</i> = 3) Relationship status: married/cohabiting (<i>n</i> = 5), divorced/separated (<i>n</i> = 3), never married (<i>n</i> = 10) Living: independently (<i>n</i> = 9), with own parents (<i>n</i> = 6), homeless shelter/group home (<i>n</i> = 3) Income: average income <\$10,000 Education: high school (<i>n</i> = 8), college (<i>n</i> = 7), degree (<i>n</i> = 3)	Number of children: 1 (<i>n</i> = 9), 2 (<i>n</i> = 7), 3 (<i>n</i> = 1), 4 (<i>n</i> = 1). Ages ranged from “several weeks” to 12 years	Unclear	Community centres, social services, homeless shelters and social media advertisement	Semi-structured interviews / GT (Strauss & Corbin, 1998)	<ul style="list-style-type: none"> - Managing symptomatology while parenting - Children as sources of motivation and recovery - Experiences of discrimination and feelings of stigma
2.	Chen et al. (2021) China	Explore the experiences of family life and parenting of Chinese mothers, in the context of mental illness	Schizophrenia (<i>n</i> = 1), BD (<i>n</i> = 3), Anxiety (<i>n</i> = 2), MDD (<i>n</i> = 4), PND (<i>n</i> = 3), Anxiety and Depression (<i>n</i> = 1)	Mothers (<i>N</i> = 14) Age (years): 20-29 (<i>n</i> = 1), 3-39 (<i>n</i> = 8), 40-49 (<i>n</i> = 5) Relationship status: Married (<i>n</i> = 12), divorced (<i>n</i> = 1), new relationship (<i>n</i> = 1) Employment: employed (<i>n</i> = 11), part-time (<i>n</i> = 1), freelance (<i>n</i> = 1), housewife (<i>n</i> = 1) Ethnicity: Chinese (<i>n</i> = 14) SES status: not reported	Number of children: 1 (<i>n</i> = 9), 2 (<i>n</i> = 5). Aged 1-6 (<i>n</i> = 5), 7-12 (<i>n</i> = 10), 13-18 (<i>n</i> = 4)	Self-report	Social media	Semi-structured interviews / IPA (Smith et al., 2009)	<ul style="list-style-type: none"> - Motherhood as central identity - The stigma associated with being a mother with MI - The impact of MI on parenting - Perceptions about the impact of MI on children - Experience of talking to children about MI - How having children impacts mothers’ MI and their recovery - Support obtained and needed
3.	Mulvey et al. (2021) USA	To explore how mothers involved in the criminal justice system with significant and long-term mental illness describe their experience of mothering	Bipolar/depression type disorder (<i>n</i> = 31), psychotic disorder (<i>n</i> = 14) and anxiety type disorder (<i>n</i> = 3)	Mothers (<i>N</i> = 48). Age (years): Mean age 40 Ethnicity: from white (<i>n</i> = 30), black (<i>n</i> = 10), Hispanic (<i>n</i> = 4), or other (<i>n</i> = 4) backgrounds Custody: never lost custody (<i>n</i> = 18), partial/family custody (<i>n</i> = 11), and lost custody at some point (<i>n</i> = 19) SES: not reported	The number of children participants had: 1 (<i>n</i> = 12), 2 (<i>n</i> = 13), 3 (<i>n</i> = 10) or 4 or more (<i>n</i> = 13)	DSM IV-TR diagnoses	SMI probation caseloads within the criminal justice system	Semi-structured interviews / Unspecified inductive approach inspired by GT	<ul style="list-style-type: none"> - “Normative” Mothering - Aspiring to Break the Cycle - Constrained Mothering - “Failure” and State Intervention - Children as Parents - Children as Catalyst for Change
4.	Boström and Strand (2021) Sweden	To explore parent-infant relationships and parent and child mental health perceptions	Schizoaffective disorder (<i>n</i> = 4) and schizophrenia (<i>n</i> = 2)	Mothers (<i>n</i> = 4) and fathers (<i>n</i> = 2) Age (years): 38-47 Family environment: cohabiting with other parent (<i>n</i> = 2), single parent (<i>n</i> = 1), shared custody (<i>n</i> = 2), child in foster care (<i>n</i> = 1) Ethnicity and SES: not reported	Children: five girls and two boys aged 8-15	Not stated	Four outpatient services for people who experience psychosis	Semi-structured interviews / IPA (Smith et al., 2009)	<ul style="list-style-type: none"> - An unclear image - An incoherent story - Illness as part of ordinary life - A non-hierarchical parent-child relationship - Attunement of the parent-child relationship and child wellbeing

5.	Strand et al. (2020) Sweden	To explore parents' experiences of how psychosis affects their parenting	Schizoaffective disorder ($n = 8$), schizophrenia ($n = 2$), psychotic disorder ($n = 3$) and MDD with psychotic episodes ($n = 2$)	Mothers ($n = 10$) and fathers ($n = 5$). Age (years): 36-56 ($M = 42$) Relationship status: married/cohabiting ($n = 8$), single, divorced ($n = 7$) Employment: employed ($n = 2$), parental leave ($n = 1$), sick leave ($n = 12$) Custody status: lived with child/ren ($n = 10$), joint custody ($n = 3$), access rights ($n = 2$). Ethnicity and SES: not reported	Participants had 17 children between them (11 boys and 6 girls), aged 3-16 ($M = 10$)	Not stated	Psychosis outpatient clinics	Semi-structured interviews / TA (Braun & Clarke, 2006)	<ul style="list-style-type: none"> - Protection - Reciprocity - Control - Guided learning - Group participation - Unpredictable absences
6.	Chan et al. (2019) Hong Kong	To explore the experiences of parenting and self-stigmatisation of Chinese mothers with SMI	MDD ($n = 11$) or a schizophrenia-spectrum disorder ($n = 4$)	Mothers ($N = 15$). Age (years): 26 - 50 Relationship status: divorced ($n = 8$), married ($n = 5$), widowed ($n = 2$) Employment status: unemployed ($n = 10$), part-time ($n = 4$), full time ($n = 1$) Ethnicity and SES not reported	Participants had between 1 and 6 children between them, aged between two and 22 years	Not stated	Two mental health support centres	Semi-structured interviews / TA (Braun & Clarke, 2006)	<ul style="list-style-type: none"> - Distancing and being distanced - Doubting myself - Struggling for control
7.	Awram et al. (2017) Australia	To understand the strategies women with mental illness use to balance the demands of mothering with mental health recovery	Depression ($n = 6$), BD ($n = 3$), schizoaffective disorder ($n = 2$), PND ($n = 1$), post-natal psychosis ($n = 1$), anxiety ($n = 4$), PTSD ($n = 3$), OCD ($n = 1$)	Mothers ($N = 10$) Relationship status: separated ($n = 4$) living with partner ($n = 6$), Childcare arrangements: children in mothers' full-time care ($n = 6$), part-time care ($n = 3$), or both ($n = 1$) Ethnicity and SES status not reported	Mothers had between 1 and 4 children aged 2-25 years ($M = 12$)	Not stated	Three community mental health organisations	Semi-structured interviews / GT and constant comparison (Charmaz, 2014)	<ul style="list-style-type: none"> - Recovery and motherhood intertwined - Seeing the bigger picture - Strategies of balancing mothering and recovery - Supports and resources
8.	Klausen et al. (2016) Norway	To understand mothers' stories about motherhood in relation to being admitted as mental health service users	Psychosis ($n = 2$), suicidality ($n = 2$), somatic illness ($n = 1$), overdose ($n = 1$), depression ($n = 1$), "request from doctor" ($n = 1$), not disclosed ($n = 2$)	Mothers ($N = 10$) Age (years): 31-70 Relationship status: single ($n = 3$), married ($n = 3$), had a partner ($n = 4$) Ethnicity and SES not reported	The number of children participants had: 2 ($n = 5$), 3 ($n = 3$), 4 ($n = 1$), and 6 ($n = 1$). Age of children not specified	Unclear	Psychiatric hospital services	Semi-structured interviews / TA (Riessman, 2008)	<ul style="list-style-type: none"> - Being able to put oneself in the child's shoes - The emotional impact of being admitted - Being open with the children about the admission - Being an emotionally available and present mother
9.	van der Ende et al. (2016) Netherlands	To understand the successful strategies of parents with mental illness	Mood disorder ($n = 9$), anxiety ($n = 1$), psychotic disorder ($n = 6$), addiction ($n = 2$), PD ($n = 7$), and ADHD ($n = 2$)	Mothers ($n = 19$) and fathers ($n = 8$) Age (years): 19-59 Relationship status: married/relationship ($n = 14$), divorced/widowed ($n = 5$), unmarried ($n = 8$) Living arrangements: independent living ($n = 21$), sheltered/supported accommodation ($n = 6$) Employment status: employed or had "regular daytime activity" ($n = 14$) SES and ethnicity not reported	Participants youngest children were aged between 6 months and 18 years old. 18 had 1-2 children and 9 had 3-6 children	Not stated	Expert by experience groups, providers of mental health services, and volunteers	"open-ended" interviews / TA (Miles & Huberman, 1994)	<ul style="list-style-type: none"> - Effects of MI on parenting – mothers - Effects of MI on parenting – fathers - Strategies for successful parenting

10.	Parrott et al. (2015) UK	To understand experiences of parents parenting roles maintained during admission to a secure forensic hospital	Of the total secure hospital population: schizophrenia ($n = 100$), PD ($n = 7$), Affective disorder ($n = 4$), unconfirmed ($n = 4$)	Mothers ($n = 8$) and fathers ($n = 10$) Living arrangements: medium secure hospital without children ($n = 18$) Other demographic information from the qualitative study was not provided	Fathers had 41 children between them (range=1-5; median=1). Mothers had 20 children between them (range=1-3; ($M=2$))	Not stated	Ward staff	Semi-structured interviews / Framework approach (Ritchie & Spencer, 1994; Pope et al., 2000)	<ul style="list-style-type: none"> - Parenthood and self-identity - Impact of MI on parenting - Parental concepts of offending and risk - Parenting from within the unit-maintaining relationships - Explaining MI and detention to children
11.	Rampou et al. (2015) South Africa	To explore and describe the parenting experiences of mothers with a chronic mental illness	Schizophrenia ($n = 4$), BD ($n = 4$), and MDD ($n = 2$).	Mothers ($N=10$). Age (years): 40-49, ($n = 6$), 30-39 ($n = 3$), and 20-29 ($n = 1$) Relationship status: single, separated or widowed ($n = 8$), unknown ($n = 2$) Employment: employed ($n = 1$), unknown ($n = 9$). SES and ethnicity not reported	Number and ages of children were not supplied	Not stated	Outpatient mental healthcare treatment and rehabilitation services	Individual interviews / Tesch's descriptive method (Creswell, 2009)	<ul style="list-style-type: none"> - Challenges for mothers with regard to caring for their children. - Family support needs.
12.	Perera et al. (2014) Australia	To explore positive and challenging experiences of mothers with MI, from perspectives of mothers and HCPs	Primary diagnoses: schizophrenia ($n = 5$), MDD with psychotic symptoms ($n = 2$), BD ($n = 1$)	Mothers ($N=8$). Relationship status: in relationship ($n = 5$), single ($n = 3$) Background: "Various cultural backgrounds including Polynesian and Indigenous Australian". Ethnicity and SES not reported	Mothers had a total of 20 children between them, aged 1-24 years. 13 children were under the age of 10	Not stated	Adult public mental health service	Semi-structured interviews / GT (Charmaz, 2006)	<ul style="list-style-type: none"> - Positive aspects of motherhood for women living with MI - Challenging aspects of motherhood
13.	Tjøflåt and Ramvi (2013) Norway.	To understand parenting with bipolar disorder	BD ($N = 6$)	Mothers ($n = 5$) and fathers ($n = 1$) Age (years): 31-50 ($M=41$) Relationship status: married and shared parental responsibility ($n = 3$) divorced ($n = 3$) Employment: employed full or part time ($n = 3$), "national insurance" ($n = 3$). Living arrangements: renting ($n = 3$) own home ($n = 3$) Ethnicity and SES not reported	Parents had 11 children between them, aged 1-18 years. Parents had between 1 and 3 children each	Not stated	Community mental health centres	Semi-structured interviews / IPA (Smith & Osbourne, 2003)	<ul style="list-style-type: none"> - Balancing bipolar disorder and parenting - The need for support versus perceiving stigma - Dependence on their children - Change and growth
14.	Jungbauer et al. (2011) Germany	Explore the impact of parental schizophrenia on family members	Schizophrenia ($N = 57$)	Mothers ($n = 40$) and fathers ($n = 17$) Age (years): 19 – 54 ($M=38.3$) Living arrangements: same household as child/ren ($n = 36$), separated from children ($n = 18$) Ethnicity and SES not reported	38 children took part aged 7 – 18 ($M = 12$; 19 males, 19 females)	ICD-10	Inpatient and outpatient psychiatric care facilities	Semi-structured interviews / GT and CA (Mayring, 2010)	<ul style="list-style-type: none"> - Everyday family life between crisis and normalisation - The perspective of sick parents - Effects on the couple relationship - Coping with stress and the consequences of stress in children - Family constellations
15.	Montgomery et al. (2011) Canada	To explore the experience of "hitting bottom" from the perspectives of mothers with SMI	Diagnoses were not detailed. The most common diagnosis was MDD	Mothers ($N = 37$) Age (years): 19-38 Living arrangements: lived with child/ren ($n = 22$), separated from child/ren ($n = 10$), un-specified ($n = 5$) Ethnicity and SES not reported	Children were aged 2-15	Not stated	N/A - secondary qualitative analysis	Semi-structured interviews / Narrative Analysis (Riessman 2008)	<ul style="list-style-type: none"> - Storytellers - Stories of bottom

16.	Jungbauer et al. (2010) Germany	To investigate the experience of parenthood in parents with schizophrenia with young children and their needs for assistance	Schizophrenia (<i>n</i> = 17) and schizoaffective disorder (<i>n</i> = 9)	Mothers (<i>n</i> = 21) and fathers (<i>n</i> = 5) Mean age (years): 39.7 Living arrangements: lived with child/ren (<i>n</i> = 15), separated from children (<i>n</i> = 11), Employment: employed (<i>n</i> = 6), part-time (<i>n</i> = 5) Income: disability benefits (<i>n</i> = 13), unemployment benefit (<i>n</i> = 5), child-raising allowance (<i>n</i> = 1), no income (<i>n</i> = 1) Ethnicity not reported	Parents had an average of 1.8 children between the ages of 1 and 30 (<i>M</i> = 12.8)	ICD-10	Inpatient, semi-inpatient and outpatient psychiatric facilities	Interview and oral survey / GT (Glaser, 1998) and CA (Mayring, 2010)	<ul style="list-style-type: none"> - Positive aspects/resources in the perception of parenthood - Negative aspects/burdens in the perception of parenthood - Support requests regarding parenting/upbringing
17.	Khalifeh et al. (2009) UK	To explore experiences, treatment preferences, and needs of mothers who were treated at home as an alternative to hospital admission for an acute severe mental health crisis	MDD (<i>n</i> = 10), BD (<i>n</i> = 6) and Schizophrenia (<i>n</i> = 2)	Mothers (<i>N</i> = 18) Age (years): 21-30 (<i>n</i> = 1), 31-40 (<i>n</i> = 9), 41-50 (<i>n</i> = 7) and 51-60 (<i>n</i> = 1) Ethnicity: White (<i>n</i> = 12), Black (<i>n</i> = 3) or Asian (<i>n</i> = 3) Living arrangements: alone (<i>n</i> = 9), with the child's father (<i>n</i> = 8), with another male (<i>n</i> = 1) 5 children aged 12-18 also participated. SES not reported	Mothers had 1 (<i>n</i> = 6), 2 (<i>n</i> = 3), 3 (<i>n</i> = 5), or 4 (<i>n</i> = 4) children aged 0-1 (<i>n</i> = 3), 2-5 (<i>n</i> = 8), 6-11 (<i>n</i> = 13), 12-18 (<i>n</i> = 16) or >18 (<i>n</i> = 3)	Not stated	Crisis resolution team	Semi-structured interviews / TA (Braun & Clarke, 2006)	<ul style="list-style-type: none"> - Mothers' experiences: advantages and disadvantages - Child experiences
18.	Wilson and Crowe (2009) New Zealand	To explore how parents with bipolar disorder construct their role as parent, and how bipolar disorder is constructed in texts	BD (<i>N</i> = 6)	Mothers (<i>n</i> = 5), fathers (<i>n</i> = 1) No other socio-demographic details provided Ethnicity and SES not reported	"Young children" (ages not reported). Number of children not reported	Self-identified diagnosis	Unclear	Semi-structured interviews / Critical discourse analysis (Titscher et al., 2000)	<ul style="list-style-type: none"> - Monitoring and Emotional Regulation
19.	Ueno and Kamibeppu (2008) Japan	To understand mothers' perceptions of what experiences influence them or their parenting practices	Schizophrenia (<i>n</i> = 13) and mood disorders (<i>n</i> = 7)	Mothers (<i>N</i> = 20) Mean age (years) = 43 Relationship status: married (<i>n</i> = 14), separated or divorced (<i>n</i> = 4), widow (<i>n</i> = 1), never married (<i>n</i> = 1) Living arrangements: with children (<i>n</i> = 20) Ethnicity and SES not reported	Mothers had between 1 and 3 children, ranging from 3 to 20 years old	DSM-IV-TR diagnosis	One psychiatric hospital and two psychiatric clinics	Semi-structured interviews / Modified GT (Kinoshita, 2003)	<ul style="list-style-type: none"> - Parenting while performing self-care - Balancing responsibilities - Feeling of affection for the child - Frustration with poor parenting - Feeling the child's compassion
20.	Evenson et al. (2008) UK	To explore the experiences of fathers with psychosis	Schizophrenia (<i>n</i> = 7), schizoaffective disorder (<i>n</i> = 2), and delusional disorder (<i>n</i> = 1)	Fathers (<i>N</i> = 10) Age (years): 34-67 (<i>M</i> = 51) Relationship status: married (<i>n</i> = 5), cohabiting (<i>N</i> =2), divorced (<i>n</i> = 1), single (<i>n</i> = 2) Ethnicity: "white" Living arrangements: with child/ren (<i>n</i> = 6), with partner/wife without child/ren (<i>n</i> = 2), alone (<i>n</i> = 2) SES not reported	Participants had 21 children between them (7 girls, 14 boys aged 1-44 years)	Not stated	CMHTs	Semi-structured interviews / IPA (Smith & Osborn, 2003)	<ul style="list-style-type: none"> - Psychosis undermines the father-child relationship and the work of parenting - Pre-fatherhood aspirations - Fears for the children - Impact of psychosis on fathers

21.	Venkataraman and Ackerson (2008) USA	To understand the strengths, challenges and service needs of mothers with BD	Bipolar-I disorder (<i>n</i> = 8) and Bipolar-II disorder (<i>n</i> = 2)	Mothers (<i>N</i> = 10) Age (years): 21-49 Relationship/living status: never married (<i>n</i> = 4), divorced (<i>n</i> = 1), widowed (<i>n</i> = 1), married/cohabiting (<i>n</i> = 4) Employment status: unemployed (<i>n</i> = 2), "lower level" jobs (<i>n</i> = 4), "higher level" jobs (<i>n</i> = 2), "a couple" were students SES: "low" (<i>n</i> = 7), "middle" (<i>n</i> = 3) Ethnicity: "white" (<i>n</i> = 10)	The number of children in each family ranged from 1-4. Children were aged 1-30	Not stated	Community mental health centres and support groups	Semi-structured interviews / GT (Strauss, 1987)	- Strengths in Parenting - Challenges in Parenting - Service Needs
22.	Montgomery et al. (2006) Canada	To describe experiences of mothers with SMI and how they manage their mothering circumstance	Schizophrenia (<i>n</i> = 3), BD (<i>n</i> = 4), MDD (<i>n</i> = 9), and unspecified (<i>n</i> = 4)	Mothers (<i>N</i> = 20) Age (years): "early 20s to late 30s" All had contact with their children and 16 were living with their children Ethnicity and SES not reported	39 children between mother, aged 2-15 years. Mothers had between one and four children	Self-identified	Referred by psychiatrists or "designate"	Unstructured formal interviews / GT (Glaser, 1998)	- Core category: appearing normal, creating security, being responsible - Keeping close: masking, censoring speech, doing motherwork, seeking help
23.	Diaz-Caneja and Johnson (2004) UK	To understand the experiences of mothers with SMI and their views of the services they receive	Schizophrenia (<i>n</i> = 8) BD (<i>n</i> = 10) and severe depression with psychotic symptoms (<i>n</i> = 4)	Mothers (<i>N</i> = 22) Age (years): 20-29 (<i>n</i> = 2), 30-39 (<i>n</i> = 9), 40+ (<i>n</i> = 11) Ethnicity: White (<i>n</i> = 13), White European or South American (<i>n</i> = 3), Black UK (<i>n</i> = 1), Black Caribbean (<i>n</i> = 1), Black African (<i>n</i> = 1), Asian (<i>n</i> = 2), Mixed (<i>n</i> = 1) Relationship status: married/cohabiting (<i>n</i> = 3), previously married and living alone (<i>n</i> = 11), widow (<i>n</i> = 1), never married (<i>n</i> = 7) Living arrangements: local authority (<i>n</i> = 21), privately renting (<i>n</i> = 1). Employment: part-time (<i>n</i> = 1), unspecified (<i>n</i> = 22). SES not reported	Mothers had a total of 41 children 9 mothers had child/ren aged under 9 and 17 had child/ren aged 10-17 Child living arrangements: both parents (<i>n</i> = 2), mother only, (<i>n</i> = 9), father only (<i>n</i> = 4), other family member (<i>n</i> = 2), foster care (<i>n</i> = 4), adopted (<i>n</i> = 1)	Not stated	CMHT	Face to face semi-structured interviews / TA (Richards & Richards, 1998)	- Positive aspects of motherhood - Difficulties associated with motherhood - Effect of MI on children - Stigma - Views about services
24.	Savvidou et al. (2003) Greece	To explore the influence of the diagnosis of SMI on mother's lives and relationships for mothers hospitalised on a psychiatric unit	Schizophrenia (<i>n</i> = 10), delusional disorder (<i>n</i> = 1), BD (<i>n</i> = 1), MDD (<i>n</i> = 3), and BPD (<i>n</i> = 2)	Mothers (<i>N</i> = 20) Age (years): 28-53 Living arrangements: hospitalised (<i>n</i> = 20); with child/ren (<i>n</i> = 13), without child/ren (<i>n</i> = 7) Relationship status: divorced (<i>n</i> = 10), unspecified (<i>n</i> = 10) Custody: lost custody (<i>n</i> = 10), regular contact (<i>n</i> = 1), full custody (<i>n</i> = 9) Ethnicity and SES not reported	Mothers had a total of 32 children between them, aged 3.5-18 years	DSM-IV diagnosis	Unclear	Face-to-face semi-structured interviews / Discourse Analysis (Burman & Parker, 1993; Parker, 1992)	- The discourse of "parenthood" - The discourses of "Mental Illness" and "Mentally Ill" parent - Relationship with partner, family, and social environment - MI and parenthood

25.	Ackerson (2003) USA	Explore how parents coped with the dual demands of parenthood and experiencing SMI	“Severe and persistent mental illness” (psychotic disorder or severe mood disorder); diagnostic information was not supplied	Mothers (<i>n</i> = 12), fathers (<i>n</i> = 1) Relationship status: married (<i>n</i> = 3), separated, widowed, or divorced (<i>n</i> = 10) Ethnicity and SES not reported	Children’s ages were not stated	Self-identified or ‘documented’ diagnosis	Community mental health centres or mental health consumer groups	1:1 semi-structured / structured interviews / Guided by GT (Glaser & Strauss, 1967)	<ul style="list-style-type: none"> - Problems with diagnosis and treatment - Stigma and discrimination - Chaotic interpersonal relationships - The strain of single parenthood - Custody issues - Relationship with children: discipline, boundary issues, role reversal - Social support - Pride in being a parent
26.	Thomas and Kalucy (2002) Australia	To explore the views of parents and their families about the impact of mental illness on their families, especially their children	BD (<i>n</i> = 11), MDD (<i>n</i> = 10), schizoaffective disorder (<i>n</i> = 8), schizophrenia (<i>n</i> = 3), PD (<i>n</i> = 2), or PND (<i>n</i> = 1)	Mothers (<i>n</i> = 28) and fathers (<i>n</i> = 7) Age (years): 30-67 (<i>M</i> = 44.6) Living arrangements: separated from child/ren completely (<i>n</i> = 12), lived with some of their child/ren (<i>n</i> = 4) Ethnicity and SES not reported	Parents had 88 children between them (48 daughters and 40 sons) aged 2-36 years	Not stated	Inpatient and outpatient mental health services and consumer groups	Semi-structured interviews / Unspecified qualitative methodology	<ul style="list-style-type: none"> - Impact on daily life - Family concerns - Hospitalisation - Ongoing management - Participant recommendations
27.	Nicholson et al. (1998) USA	Understand the parenting experiences of women with mental illness from the perspectives of mothers and case managers	Affective disorder (<i>n</i> = 23), psychotic disorder (<i>n</i> = 8), anxiety disorder (<i>n</i> = 6), or “other/don’t know” (<i>n</i> = 5)	Mothers (<i>N</i> = 42) Age (years): 22-48 (<i>M</i> = 35) Relationship status: married/cohabiting (<i>n</i> = 19), previously married (<i>n</i> = 20), never married (<i>n</i> = 3) Living arrangements: private home (<i>n</i> = 38), with father (<i>n</i> = 18), foster care (<i>n</i> = 6), adopted (<i>n</i> = 10), with relatives (<i>n</i> = 10), independently (<i>n</i> = 5) Ethnicity: Caucasian (<i>n</i> = 35), African American (<i>n</i> = 5), Hispanic/Latina (<i>n</i> = 1), Native American (<i>n</i> = 1)	97 children between mothers with an average of 2.2 children per family. Living: with mother/mother and partner (<i>n</i> = 38), with father (<i>n</i> = 18), foster care (<i>n</i> = 6), adopted (<i>n</i> = 10), with relatives (<i>n</i> = 10), independently (<i>n</i> = 5)	Not stated	Case management services/ Unspecified thematic analysis	Face to face focus groups / Unspecified TA	<ul style="list-style-type: none"> - The stigma of MI - Day-to-day parenting - Managing MI - Custody of and contact with children
28.	Sands (1995) USA	To examine mothers’ perceptions of themselves as mothers and persons with mental illness, their psychosocial issues, and their receptivity to support programs	Schizophrenia (<i>n</i> = 6), schizotypal personality disorder (<i>n</i> = 1), MDD (<i>n</i> = 1), BD (<i>n</i> = 1) and unknown (<i>n</i> = 1)	Mothers (<i>N</i> = 10) Age (years): 21-37 (<i>M</i> = 27) SES: low-income (<i>n</i> = 10) Living arrangements: community supervised apartment (<i>n</i> = 10). Mothers’ children were living with them (<i>n</i> = 5) or in foster care or with a relative (<i>n</i> = 5). Ethnicity: African American (<i>n</i> = 7) or White (<i>n</i> = 3) 8 mothers without SMI were included as a comparison group	Ages and number of children not specified	Not stated	Support services	Informal conversations and semi-structured interviews / Unspecified TA	<ul style="list-style-type: none"> - Experience of motherhood and MI - Programme demands - Psychosocial issues

^a Other methods of data collection may have been used but only data gathered from interviews or focus groups are included in the review.

Note. SES = socio-economic status, BD = Bipolar Disorder, MDD = Major Depressive Disorder, PND = Post-natal Depression, BPD = Borderline Personality Disorder, PTSD = Post-Traumatic Stress Disorder, OCD = Obsessive Compulsive Disorder, PD = Personality Disorder, ADHD = Attention Deficit Hyperactivity Disorder, CMHT = Community Mental Health Team, TA = Thematic Analysis, GT = Grounded Theory, CA = Content Analysis, IPA = Interpretive Phenomenological Analysis; MI = Mental Illness.

Table 3: Methodological quality assessment of included studies

	Study: Authors and year	Was there a clear statement of the aims of the research	Is a qualitative methodology appropriate	Was the research design appropriate to address the aims of the research	Was the recruitment strategy appropriate to the aims of the research	Was the data collected in a way that addressed the research issue	Has the relationship between researcher and participants been adequately considered	Have ethical issues been taken into consideration	Was the data analysis sufficiently rigorous	Is there a clear statement of findings	How valuable is the research	Quality Appraisal (total score)
1	Sabella et al. (2022)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9.5)
2	Chen et al. (2021)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9.5)
3	Mulvey et al. (2021)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	No (0)	PA (0.5)	PA (0.5)	Yes (1)	Yes (1)	Moderate (7.5)
4	Boström and Strand (2021)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
5	Strand et al. (2020)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
6	Chan et al. (2019)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (10)
7	Awram et al. (2017)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
8	Klausen et al. (2016)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Moderate (7.5)
9	van der Ende et al. (2016)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Moderate (8.5)
10	Parrott et al. (2015)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
11	Rampou et al. (2015)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
12	Perera et al. (2014)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Moderate (8.5)
13	Tjoflåt and Ramvi, (2013)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
14	Jungbauer et al. (2011)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
15	Montgomery et al. (2011)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Moderate (8)
16	Jungbauer et al. (2010)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	No (0)	Yes (1)	Yes (1)	Yes (1)	Moderate (8)
17	Khalifeh et al. (2009)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Moderate (8.5)
18	Wilson and Crowe (2009)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Moderate (8)
19	Ueno and Kamibeppu (2008)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Moderate (8.5)
20	Evenson et al. (2008)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Moderate (8)
21	Venkataraman and Ackerson (2008)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	Yes (1)	PA (0.5)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Moderate (7)
22	Montgomery et al. (2006)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9.5)
23	Diaz-Caneja and Johnson (2004)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	High (9)
24	Savvidou et al. (2003)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	PA (0.5)	PA (0.5)	Yes (1)	Yes (1)	Moderate (8)
25	Ackerson (2003)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	Yes (1)	No (0)	No (0)	Yes (1)	Yes (1)	Yes (1)	Moderate (7.5)
26	Thomas and Kalucy (2002)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	Yes (1)	No (0)	No (0)	PA (0.5)	Yes (1)	Yes (1)	Moderate (6.5)
27	Nicholson et al. (1998)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	Yes (1)	No (0)	PA (0.5)	PA (0.5)	Yes (1)	Yes (1)	Moderate (8)
28	Sands (1995)	Yes (1)	Yes (1)	Yes (1)	PA (0.5)	PA (0.5)	No (0)	No (0)	PA (0.5)	Yes (1)	PA (0.5)	Moderate (6)
	Percentage of studies rated 'Yes' (1)	96.4%	100%	75%	78.5%	85.7%	3.5%	53.57%	78.5%	100%	96.4%	

Note. PA = Partially Agree.

Thematic Synthesis

Six themes were conceptualised to represent how parenting is influenced by experiences of SMI: 1) *The Constrained Parent*, 2) *Parenting Difficulties*, 3) *The Strained Child*, 4) *Inescapable Threat*, 5) *Combatting Threat* and 6) *Wrap-around Support Needs*. A conceptual model was developed (Figure 2), illustrating the relationship between the six main themes and 14 sub-themes. The model depicts the centrality of SMI-related parenting difficulties in generating strain on parent-child relationships, the all-consuming and invasive role of threat on parenting, and the strategies that parents use to combat such difficulties. The need for comprehensive and inclusive system-wide support is indicated. Illustrative quotes are provided within the text in italics (Appendix C presents additional exemplar quotes). A matrix of themes (Appendix D) illustrates which themes were present in the included studies.

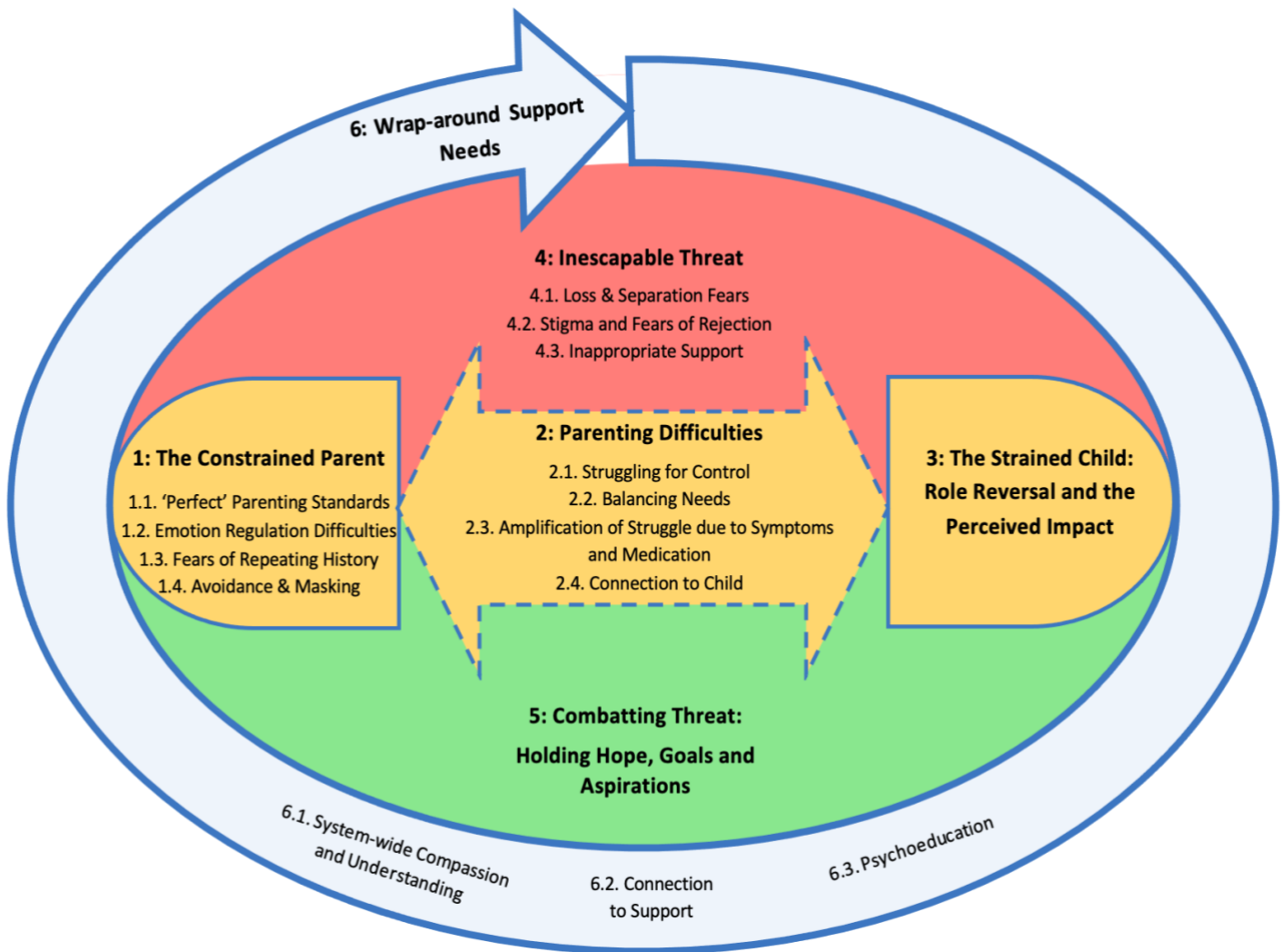


Figure 2: Conceptual model depicting themes and subthemes

Theme 1: The Constrained Parent

Feeling bound by the impact of experiences of SMI was a common theme across studies. Parents perceived the “*overwhelming*” (Mulvey et al., 2021, p.18) nature of SMI to exacerbate the “*pressure*” (Perera et al., 2014, p.174) associated with being a parent: “*Parenting at the best of times is hard, but with a mental illness...it is harder*” (Awram et al., 2017, p.152). There was often a sense that parents felt hopeless and frustrated; feelings that compelled parents to adopt “*self-restrained*” (Chen et al., 2021, p.6) parenting. This constrained parenting style was conceptualised to be a protective defence, consequent of parental comparisons to idealised parenting standards, difficulties regulating emotions, and worries about negatively impacting children. This theme consisted of four sub-themes.

Subtheme 1.1: “Perfect” Parenting Standards

Parents appeared bound by a “*tremendous guilt*” (Montgomery et al., 2011, p.4) about their identity of being a parent who experienced mental health difficulties. Societal ideas about “*perfect*” and “*ideal*” parenting (Chen et al., 2021, p.5) were conceptualised as unattainable standards that served to perpetuate parental perceptions of inadequacy and incompetence. A sense of threat and vulnerability associated with such perceptions existed for many. By ‘hiding’ themselves during periods of significant distress, including from their children, parents attempted to protect their valued parenting identities. However, distance in the parent-child relationship could be an unintended consequence, serving to further perpetuate parental perceptions of failure: “*I fail both as a person and mother*” (Chan et al., 2019, p.532). Resultantly, parents would “*second guess*” their capacity to be “*good*” parents (Perera et al., 2014, p.177), which conflicted with parental instincts to protect and be close to their children.

“When I was psychotic, I stayed away for long periods. I didn’t want her [child] to see me in such bad shape” (Strand et al., 2020, p.623).

Subtheme 1.2: Emotion Regulation Difficulties

Parents frequently struggled to manage difficult feelings associated with “*stressful*” (Sabella et al., 2022, p.6) and “*scary*” parenting circumstances (Strand et al., 2020, p.628), which in many cases perpetuated isolation and disconnection. Difficult emotions and circumstances were regarded as inescapable for some, leading to feelings of being trapped and reflecting “*helplessness*” (Chen et al., 2021, p.5). Such powerful feelings were often internalised: “*You have so much pain you do not know where it goes so you turn it inward on yourself*” (Montgomery et al., 2011, p.5). An overwhelming desire to escape this pain was frequently reported. For some, avoidance and substance use provided temporary relief, while others perceived suicide to be their only option.

“When my first son was 1 year old, I was suicidal. I felt bad as a parent. I could not fulfil the mother role” (van der Ende et al., 2016, p.90).

Other parents demonstrated an externalisation of uncontrollable emotions. This was often associated with a limited window of tolerance during which parents reported getting “*angry very easily*” with their children (Venkataraman & Ackerson, 2008, p.398). Often, parents appeared to struggle with managing difficult emotions and situations effectively. This could sometimes result in excessive child discipline, further distancing parents from their children: “*I couldn’t control myself. I couldn’t even after I hit her*” (Chan et al., 2019, p.533).

Subtheme 1.3: Fears of Repeating History

Pervasive parental fears about passing on difficult mental health experiences to their children were common and could be conceptualised as an unwelcome family legacy: “*I feel as it goes from son to son this thing you know?*” (Evenson et al., 2008, p.636).

Parenting style was shaped profoundly by such fears, while a sustained impact of parents’ own experience of being parented was also evident. For some, a lenient parenting style was

adopted, driven by fears of exposing children to painful emotions related to neglectful or abusive parenting they had themselves suffered, particularly when painful memories involving shame reactions were triggered by interactions with their children. Parents' own apparent insecure attachment representation led some to seek an especially close bond with their children and many parents wished to protect their children from the adverse childhood experiences they had endured themselves. Across studies, parents valued secure, safe, and consistent care. When this was absent in their childhood, providing this for their children was considered a priority.

“...It [childhood home] was just not a safe place...so for [daughter], I have tried to provide her with like a really safe place to be that is clean and I am always there”
(Venkataraman & Ackerson, 2008, p.395).

Subtheme 1.4: Avoidance and Masking

Attempting to remedy stigma, fear and shame, parents described using a “*shield*” (Jungbauer et al., 2010, p.236) and “*tried to hide*” their authentic selves (Tjoflåt & Ramvi, 2013, p.87), creating an illusion of ‘perfect parenting’ to satisfy the expectations held by themselves, their children and society to “*pretend that things were OK*” (Montgomery et al., 2011, p.4). In the presence of perceived power figures, parents could become exhausted “*trying to entertain everyone in the room*” (Parrott et al., 2015, p.266), particularly when a pressure to demonstrate parenting capacity to child protection services was experienced.

Avoidance and withdrawal were strategies enlisted when parents described feeling overwhelmed. Some found such strategies helpful, offering themselves time to self-regulate and subsequently return to parenting: “*I would walk away, take a toilet break or drink a cup of water. Then I would deal with our emotions later*” (Chan et al., 2019, p.532). However, some parents recognised such strategies were only temporarily effective and emotions remained unprocessed and burdensome. In the face of difficult symptoms,

some parents learnt specific strategies to manage difficult symptoms, while others adapted a “*mechanical*” parenting mode (Montgomery et al., 2006, p.24) to persevere parental functioning.

“...I was depressed enough so that I just kind of went through life. I didn’t feel anything, I just, you know, did the grocery shopping, did the cooking, took care of their needs, but I wasn’t happy...” (Venkataraman & Ackerson, 2008, p.397).

Theme 2: Parenting Difficulties

The impact of parenting difficulties on the positioning of parent and child roles, which were often polarised, was conceptualised within this theme. Parenting difficulties were impacted by specific SMI-related factors including symptom and medication effects, alongside other factors including connection, understanding, and parent-child bonding. This theme consisted of four sub-themes.

“You have to go to work. You have to come home. You have to deal with the kids, deal with your own home. Your own problems, you know, really start piling up” (Nicholson et al., 1998, p.639).

Subtheme 2.1: Struggling for Control

Mothers and fathers who parented at home as well as from inpatient settings struggled with asserting boundaries, maintaining discipline, and managing routines. Exhaustion and fatigue were frequently referenced and parents often reported feeling depleted of the energy required to assert boundaries: *“The children walked over me; I could not keep standing because of the burden of my depression”* (van der Ende et al., 2016, p.91).

Although this often led to parental withdrawal, the persistence of children’s needs could result in conflictual guilt and resentment between parent-child dyads. Some parents managed by displacing responsibilities onto their children, or by directly communicating their vulnerability. However, when communication difficulties existed, some parents used

excessive discipline to regain control. Conversely, some parents avoided asserting boundaries entirely, describing themselves as being “*too kind*” (Boström & Strand, 2021, p.72) which could lead to blurred parent and child roles. In such cases, parents’ desire to be unconditionally loved and accepted appeared to inhibit their ability to assert boundaries: “*I think sometimes I am more of a friend and I think that’s my downfall...*” (Venkataraman & Ackerson, 2008, p.400).

Subtheme 2.2: Balancing Needs

Parents were significantly challenged by the competing demands of parenting while experiencing SMI. Parents recognised the dilemma of balancing their own needs for respite with their children’s needs for attention, comfort, and connection: “*What comes first? Me sleeping or me being available for my child?*” (Perera et al., 2014, p.176). The energy required to sustain adequate balancing of demands was easily depleted. Trapped in an unsustainable tug of war, parents experienced profound guilt and perceptions of inadequacy when defeated by exhaustion.

“I try to keep my balance, for when I am terribly tired and feel bad, I push myself as much as I can, and I feel bad, it hurts not to have enough strength for my children...” (Tjoflåt & Ramvi, 2013, p.82).

Although parents largely recognised the importance of meeting their own needs to be able to meet the needs of their children, their ability to effectively balance was thwarted by the confines of busy family lives. Consequently, parents’ own needs were often neglected. “*...I couldn’t run the whole struggle, not even look after myself, much less to look after a child*” (Khalifeh et al., 2009, p.637).

Subtheme 2.3: Amplification of Struggle due to Symptoms and Medication

Parental mental health difficulties were associated with an amplified parenting “*struggle*” (Evenson et al., 2008, p.637) that some conceptualised as “*a living hell*” (Montgomery et al., 2006, p.23). Parenting ability could be negatively impacted by cognitive difficulties, particularly during periods of significant psychological distress “*Sometimes I would forget to bath them for 4 or 5 days*” (Thomas & Kalucy, 2002, p.42). Fear, shame, and guilt appeared to be felt profoundly when parents did not understand why their children were incorporated into their symptoms, particularly when thoughts of harming their children conflicted with their instincts to protect.

“...regardless of how I loved my [child] I had thoughts of hurting her, so I have to put her down and I couldn’t understand why I had these thoughts” (Montgomery et al., 2006, p.24).

Emotional and physical closeness within parent-child dyads appeared to be influenced by parental reactions to these threatening experiences. Some parents responded by seeking closeness to their children due to fears of custody loss or other harm coming to their children, while others distanced themselves to protect their children from their thoughts. When children themselves were perceived as being the threat, harm to children could arise.

“...I was hallucinating that there was demons inside of him so I took a, a knife sharpener and just pressed it on his chest...So I didn’t really attack him, in my mind I was protecting myself” (Mulvey et al., 2021, p.14).

A widely recognised parenting difficulty involved fatigue and low motivation which often impacted parent-child interactions. Medication side effects were frequently reported to amplify exhaustion, which could compound parenting difficulties. For some, medication was conceptualised as a “*mental straitjacket*” (Evenson et al., 2008, p.635), further constraining parents’ sense of control. However, symptom effects were positively

conceptualised when parents had increased energy, for example, during manic episodes. In such circumstances, parents benefited from energy related to their experience of mania that had been previously depleted, while children benefited from parents who were more physically present.

Subtheme 2.4: Connection to Child

Parents' desire to be "*close*" (Montgomery et al., 2006, p.23) to their children was often thwarted by parental feelings of being overwhelmed and "*consumed*" (Perera et al., 2014, p.175) by their mental health difficulties. Consequently, parents often appeared unable to co-regulate and emotionally connect with their children: "*It's very difficult when you're wrapped up in your own emotional needs to look at the emotional needs that your children have*" (Diaz-Caneja & Johnson, 2004, p.476). For some parents, their ability to feel connected with their children was compounded by an absence of emotional connection, which could result in perceptions of polarised and emotionally distanced parent-child relationships:

"...it is as if we are somehow not together; you know, it is as if I am in my own world, pondering on things and then the children wonder why you are so distant"
(Tjoflåt & Ramvi, 2013, p.82).

Other studies reported parental difficulties in distinguishing their child's emotions from their own. A 'special bond', within which children could be conceptualised as parents' "*soul mates*" (Ackerson, 2003, p.115) was experienced by some, and appeared to represent parents' desire to attain unconditional acceptance. Whether parents were "*insightful*" (Parrott et al., 2015, p.265) about their own and their children's needs played a central role in parental approaches to communicating with their children about mental health difficulties. When knowledge was perceived to be lacking, avoidance of discussions was often reported:

“They don’t really understand my illness, and I don’t understand my illness either, so it’s so hard to talk about it...” (Khalifeh et al., 2009, p.637).

Others avoided discussions due to shame, fear of damaging their child, or believing that discussions were unnecessary, which could create a communication barrier between parent-child dyads. However, other parents reported it was important for children to be informed about their mental health difficulties, and foster age-appropriate conversations with their children that were *“less scary”* (Awram et al., 2017, p.154).

Theme 3: The Strained Child

All studies reflected that family relationships were strained. The *“chaos”* (Montgomery et al., 2006, p.23) of parenting was frequently displaced onto children who became strained with the heavy demands placed upon them to satisfy roles that were often incongruous with their developmental age. Parental shame and guilt were felt profoundly when the impact on children was realised, particularly where parent-child role-reversals were experienced:

“I’m reliant on him physically to go to bed, physically to get up, emotionally because he’s my one and only contact. And it’s almost like sometimes I am the child, and he’s the parent” (Khalifeh et al., 2009, p.636).

Parents often relied on their children to meet their needs. When parents conceptualised themselves as vulnerable and child-like, parents reflected that their children often sacrificed their own needs to care for them. Reflective of heightened threat perceptions, parents perceived their children to be fearful of harm coming to family relationships and observed their children to adopt strategies intended to protect by assuming parenting roles. Parent-child role confusion was felt profoundly when parents attempted to transition back into parenting positions following acute episodes of psychological distress. For example, following hospital admissions during which parents

and their children lived separately, the restatement of boundaries and control was particularly difficult to navigate.

“...my daughter got herself a little job, she left school ... she was like running the show, being the mum, and I was just like a puppet” (Perera et al., 2014, p.175).

Parental guilt and shame were heavily cited across studies in relation to parents' worry about the impact of their mental health difficulties on their children's social, emotional and academic development. Although the voices of children were not included in the current review, some parents described believing that their expressions of distress placed unfair strain on their children, with difficulties *“invading their lives”* (Montgomery et al., 2011, p.4). These parents observed their children to demonstrate particular concern and responsibility for relieving their distress. However, children's responses to parental distress varied across families. Some parents perceived their children to be *“sick and tired”* (Thomas & Kalucy, 2002, p.45) of the unpredictability of their mental health difficulties, and some observed that their emotional and physical absences could leave their children feeling isolated and alone:

“She [daughter] felt like she was living on an island. She missed the support she needed from me, during my depression” (van der Ende et al., 2016, p.90).

Some parents described profound emotional distress to be experienced by their children; a possible manifestation of parents lacking knowledge about how to support their children emotionally. Some parents conceptualised child behavioural difficulties to be deliberate attempts to exacerbate their own stress, rather than their child's attempt to communicate their own distress. This lack of parental understanding and possible co-dysregulation could serve to further isolate children and their emotional needs.

“...Because he has been depressed, down in the dumps. He got hold of knife two weeks ago and had it close to his wrist and ready to cut himself and I asked him why he did it ‘I don't know mommy’” (Venkataraman & Ackerson, 2008, p.402).

Theme 4: Inescapable Threat

A relentless and inescapable power of threat permeated across multiple areas of parents' lives. Parenting difficulties appeared to be amplified by constant and dominating fears of child loss, profound negative self-perceptions, inescapable stigma, and overwhelming feelings of being inappropriately supported and unsafe in the systems they lived within. The role of inescapable threat appeared to cause parents to become increasingly consumed by fear and less able to seek support, further perpetuating feelings of being constrained and bound by parenting difficulties. Three sub-themes were established.

Subtheme 4.1: Loss and Separation Fears

A fundamental and widespread barrier to parents talking about their mental health difficulties and seeking support were profound fears of custody loss: *“Every mother’s fear is that her children will be taken into care”* (Diaz-Caneja & Johnson, 2004, p.477). Parents experienced contact with child protection agencies as *“traumatic”* and *“intimidating”* (Perera et al., 2014, p.177), fearing the consequences of being negatively evaluated. Parents frequently avoided services and hid their authentic selves, attempting protect custody of their children.

“I didn’t want to go to a psychiatrist because I thought he would lock me up and I wanted to raise my kids” (Ackerson, 2003, p.112).

When separations did occur, parents reported feeling imprisoned and isolated; consumed by sadness and shame: *“My heart is in chains. It never gets easy, not for any mother; that pain never completely goes away”* (Nicholson et al., 1998, p.639). While separations threatened parent-child relationships, parents largely remained committed to contact with their children, demonstrating their need to remain emotionally and physically connected. Some parents recognised when custody arrangements were in their children’s best interests; however, parents commonly reported experiencing shame and humiliation during the process of attempting to re-gain child contact. Together, these experiences

served to act as powerful barriers to parents accessing services and talking about their needs, serving to further isolate parents and children from accessing support.

Subtheme 4.2: Stigma and Fears of Rejection

Integral to parenting capacity was how safe and secure parents felt, both within themselves, their family systems, and wider society. A significant barrier to safety was dominant discourses about parents with mental health difficulties being “*dangerous*” (Savvidou et al., 2003, p.395). Parents demonstrated pervasive self-defeating perceptions, which appeared to be exacerbated by idealised societal perceptions of parenting. Negative self-perceptions caused parents to lack parenting confidence, which appeared to trigger feelings of hopelessness: “*I’m never going to be able to be the person I’m meant to be to raise them*” (Perera et al., 2014, p.176). Parents reported feeling alienated from parenting peers, choosing to avoid parenting networks; bound by fears of negative social consequences.

“If other mothers knew I had a mental illness, they might not allow their children to play with mine” (Diaz-Caneja & Johnson, 2004, p.477).

Parental fears were, however, a reality for some, with potent stigma permeating across generations: “*...She [child] said their mothers told them not to play with her because her mother was crazy*” (Rampou et al., 2015, p.124). Consequently, parents’ authentic selves remained hidden, bound by a powerful desire to be seen as “*ordinary people*” (Tjoflåt & Ramvi, 2013, p.88).

Subtheme 4.3: Inappropriate Support

Across studies, parents largely reported feeling alone without the support of systems around them: “*It may be important that you know that sometimes the structure around us fails*” (Strand et al., 2020, p.627). Parenting status was perceived to be largely

unrecognised by HCPs, serving to undermine parental trust in service provision.

Furthermore, parents whose needs did not fit precise service entry criteria remained unsupported and vulnerable to the powers of services that they hoped would support them.

“...Then they would say ‘Your case does not fit,’ why should I keep trying?” (Chan et al., 2019, p.532).

Often, HCP and family fears about child safety, based on diagnostic heuristics, resulted in increased parental observations. This risk-focused approach threatened parents’ sense of control, exacerbating perceptions of powerlessness and inadequacy which could distance parents from accessing support. Among parents living within services, significant threats to the integrity of parent-child relationships were posed by the combination of child access limitations and inappropriate visiting facilities: “*The hospital is not the right environment for them*” (Diaz-Caneja & Johnson, 2004, p.478). Although respite associated with inpatient care was a welcome relief for some, many parents believed the support received did not adequately prepare them to return to parenting at home.

Wider socio-economic factors further threatened parents’ sense of security.

Reliance on other people for financial support were degrading experiences. Several studies (Ackerson, 2003; Chan et al., 2019; Rampou et al., 2015; Sabella et al., 2022) reported that the systems around parents and their children could threaten their basic human needs.

Theme 5: Combatting Threat: Holding Hopes, Goals and Aspirations

Parents were largely able to sustain their parenting roles, adopting “*small tricks*” (Tjoflåt & Ramvi, 2013, p.87) to combat the challenges presented to them. System-wide support helped parents to manage their difficulties, while having hope, aspirations, and parenting goals supported parents to reduce the impact of threat to support their parenting. Many parents reported finding solace, pride and comfort in their parenting roles, with children enriching their lives and promoting a sense of hope, “...*sort of quite life affirming. It jogs me out of the depression that used to sort of get me down*” (Evenson et al., 2008, p.637). In

addition, children were often perceived to offer hope of meeting parents' relational needs for reciprocated love: *"I felt that I loved this little person completely, and this little person would love me"* (Diaz-Caneja & Johnson, 2004, p.475).

Parents who reported feeling hopeful and optimistic for their future lives with their children demonstrated increased commitment to change. This finding was particularly evident in parents who had been separated from their children and who were supported to re-gain contact and parental responsibility. The integrity of the parent-child relationship was highly regarded and considered a priority goal. Themes of aspiring for security and comfort prevailed across parental goals and aspirations, offering parents a sense of optimism and hope for the future: *"I want to get stable. You know, get settled in my relationship with [my son]..."* (Mulvey et al., 2021, p.20).

Theme 6: Wrap-around Support Needs

Parents and children were situated within complex systems spanning family, peer, and wider socio-political contexts. It was clear that those who parented without support experienced the most significant challenges, and some considered it unrealistic to raise a child alone: *"I believe it takes a village to raise a child"* (Ackerson, 2003, p.116). Parents considered it crucial for services to recognise and provide early, multi-disciplinary and system-wide support. Three sub-themes were established.

"Mental health professionals and the children and family social services department have to be more incorporated. They have to become more of a joint body and have some kind of co-ordination and co-operation going fully" (Diaz-Caneja & Johnson, 2004, p.479).

Subtheme 6.1: System-wide Compassion and Understanding

A fundamental need to trust, be understood by, and connected to family, peer and professional systems was reported by many parents across studies. While HCP support was

variable, parents valued respectful and consistent approaches within which they felt understood “*without judgments*” (Montgomery et al., 2006, p.25). A compassionate approach appeared to be necessary in supporting parents to feel empowered and understood; an important step in targeting power differentials that often underpinned barriers to parents accessing support. Relatedly, parents wished to receive support from people who they felt would understand their position due to their lived experience, both from HCPs, “*I wanted a mum as a GP...*” (Awram et al., 2017, p.155), and peer support groups. Parents hoped such support would allow them to feel “*less burdened*” while simultaneously promoting parenting support by helping parents “*learn some lessons from other people*” (Chen et al., 2021, p.7).

Furthermore, although guilt and shame often limited parents from feeling able to make time to meet their own needs, parents who reported feeling empowered to consider their own needs experienced richer connections both with themselves, and their children.

“So once I learnt that, that made a huge...like light bulb moment so that I knew ‘ok if I start looking after me and my mental health and my physical health then I’ll be able to look after my family” (Awram et al., 2017, p.152).

Subtheme 6.2: Connection to Support

A dominant theme across studies was the need for parents to feel able to rely on systems around them to meet their children’s needs when unable to do so alone: “*...If only there was someone there to help me look after my children...I could only try my best to stay at home and control myself*” (Chan et al., 2019, p.532). Parents who were part of supportive family networks reported having an additional “*backbone*” (Tjoflåt & Ramvi, 2013, p.84), providing additional strength to support their parenting. Parents placed significant weight on remaining the primary carer of their children during acute periods of psychological distress and believed that separations during inpatient stays could be avoided. There was a

sense that mothers in particular felt bound by the powers of child custody authorities but wished that services would support children remaining with them during inpatient stays.

“If it was possible that when you are admitted at the hospital and your child doesn't have anybody to take care of him/her, they should allow us to sleep with them in the hospital until we are discharged” (Rampou et al., 2015, p.124).

Parents valued being close with their children, but also needed space for self-care. The idea of family-focused support, within which both parents and their children could be simultaneously supported both therapeutically and socially, was considered a valuable system-wide intervention. Aligning parent and child support with specific parental mental health difficulties was an important service consideration. Parents reflected that services that supported respite care for children would be helpful in promoting space for parental self-care.

“I think there needs to be like a place where we could take our kids to take them somewhere because we need time to ourselves but I mean for just bipolar, you know” (Venkataraman & Ackerson, 2008, p.404).

Across studies, parents reflected that support should be extended to their children; it was not enough for parents to receive support alone.

“As much as I have to go to a psychiatrist or a psychologist and chat, the kids have to be allowed to go...they've got so many thoughts in their heads” (Klausen et al., 2016, p.112).

Subtheme 6.3: Psychoeducation

The need for psychoeducation for parents, children, and their families, alongside wider peer and professional networks was frequently reflected as necessary to promote inclusion and connection and reduce blame, stigma and fear. Parents wished to understand their symptoms: *“I want to know more about bipolar...why I become irritable like this”*

(Rampou et al., 2015, p.124). With such an understanding, parents could be afforded more control over their parenting, with alternative parenting strategies becoming more comprehensible and accessible. Professional mental healthcare support that specifically targeted parenting difficulties was regarded as important for some in alleviating distress and potential adverse outcomes for children. Practical advice and information were sought about how to approach specific parenting circumstances, including balancing control and managing emotions.

“Let’s say I get angry at my child...how can I manage that with my child? Or is it okay if I don’t deal with it? If I need to deal with it, then what should I do?” (Chen et al., 2021, p.7).

The role that psychoeducation could offer for children was particularly welcomed for parents who worried that children would “*blame themselves*” (Chen et al., 2021, p.7) for parental emotional difficulties. Largely, HCPs were considered best placed to provide family-focused psychoeducation: “*It would be nice if nurses talked about the transference of psychiatric problems to the children*” (van der Ende et al., 2016, p.90).

Discussion

This systematic review of 28 studies was the first to comprehensively synthesise qualitative research exploring mothers and fathers’ experiences and perceptions of the impact of SMI on parenting and their support needs that was not restricted to specific cultures or specific mental health presentations within the SMI umbrella. The aims of the review were fully met because we enhanced our understanding about how parents experienced SMI to impact their parenting and their corresponding support needs. Key themes were identified regarding the challenges that parents who experience SMI are faced with, factors that contribute to and maintain parenting difficulties, parental coping strategies, and parental support needs. Novel insights were provided into the interplay

between parental perceptions of inescapable, system-wide threat, and parents' current and desired use of family, peer, and professional support.

The current review consolidates and extends findings featured in previous reviews of mothers who experience SMI (Dolman et al., 2013) and parents who experience bipolar disorder (Stapp et al., 2020), and significantly enhances findings regarding the centrality of parenting difficulties in the lives of parents who experience SMI and the aversive impact of stigma and fears of child loss on parenting relationships. The current review extends findings by revealing similarities in the experiences of mothers and fathers across cultures, childcare and living contexts. Across contexts, parenting challenges and relationships appeared situated within complex systems underpinned by persistent threat, further compounding SMI-related parenting challenges, regardless of parent gender and living arrangements.

Novel insights into factors impacting the polarisation of parent-child relationships and role reversals are presented; a finding that augments recent research highlighting that children can perceive themselves as parenting figures when supporting parental SMI (Villatte et al., 2022). The influential role of systemic threat was clearly communicated throughout participants' narratives, in which systems that parents perceived to neglect and threaten their parenting identities exacerbated their difficulties and fears. In turn, strain was placed on parent-child relationships which increased parental feelings of guilt and shame, resulting in distance between parents, their children and the systems around them. These findings support previous reports highlighting the central role of power, threat, and deficiency of sense making among people who experience psychosocial distress (Johnstone & Boyle, 2018).

Previous research has highlighted factors that inhibit parents from accessing support, including lack of policy and practice guidelines, lack of integration between adult and child services, crisis-orientated service provision, fears about child loss and

approaches that present a parenting ‘fix’ (Jones et al., 2016; Mulligan et al., 2020; Mulligan et al., 2021; van Esch & de Haan, 2017). The current review consolidates such findings and offers insights into how to target such barriers, by moving away from siloed and risk-focused approaches in which practitioners and policymakers are at the centre of decisions, and towards a system in which practitioners and other stakeholders scaffold compassionate, goal-based and collaborative support around parents and the systems they live within. Echoing Bronfenbrenner’s *Ecological Systems Theory* (Bronfenbrenner, 1992) that views psychosocial processes to be influenced by multiple levels of the surrounding environment, this finding highlights that change is needed at multiple systemic levels to promote better relationships between parents and their children, families, HCPs, and wider cultural and political networks. In line with recent calls for a ‘village’ approach of social connectedness for families who experience multiple adversities (Goodyear et al., 2022; Reupert et al., 2022), a shift in practice approach is indicated, particularly given that FFP is not widely implemented even within countries that mandate it (Falkov et al., 2016; Furlong et al., 2021). A strengths-based approach could shift system-wide perceptions of threat, promoting parents’ sense of safety and connection to the communities they live within, supporting better access to, and use of, support. In turn, this could increase parent-child and system communication and connectedness, for example, by targeting the well-referenced barrier of stigma (Lacey et al., 2015).

Clinical Implications

The current review highlights key aspects relevant to the successful implementation of evidence-based policy and practice that are grounded in qualitative data and driven by the voice of parents (Skivington et al., 2021). The present review should prompt parents, practitioners, commissioners, and policymakers to consider the implications for practice, in line with a systems’ approach that places parenting support in a wider systemic context

(Allchin et al., 2022; Bauer et al., 2021; Falkov et al., 2016; Mytton et al., 2014). A system-wide FFP approach is indicated, putting families at the centre of support decisions, promoting layers of support around parents, and decreasing social adversity and threat; a factor reported to be more detrimental to parenting than SMI itself (Gladstone et al., 2011). Such an approach has the potential to decrease risk of adverse outcomes for parents and children, reduce referrals to child protection services and the need for reactive and crisis-based interventions (Nicholson et al., 2019) and promote better communication and connection between parents, their children, and the systems they live within. Recommendations based on parents' reported experiences and support needs are provided in Table 4. However, given that the current review did not include studies reporting on the views of children, HCPs or commissioners, caution should be given when considering these recommendations.

Strengths, Limitations and Future Research

A comprehensive systematic search was conducted, and data were synthesised from 28 studies reflecting the voices of 550 mothers and fathers experiencing SMI across 14 countries, spanning 27 years of research. A range of childcare, living arrangements, and socio-cultural factors were represented within parent samples, allowing for the analysis and interpretation of a diverse range of parental views and experiences, representing a strength of the review. However, only 32.14% of the included studies reported on ethnicity, which limits the transferability of findings across ethnic groups. Future research should explore and report on ethnicity, especially given the higher prevalence and poorer outcomes for people experiencing mental health difficulties among ethnic minority groups (Maura & Weisman de Mamani, 2017).

Although it was not possible to explore specific parental experiences, and specific diagnostic characteristics were deliberately not explored, it was necessary to first establish

this comprehensive and broader understanding of the impact of parental SMI and support needs to guide future research, policy, and interventions for more specific presentations and parenting challenges. The current review was restricted to peer-reviewed studies published in English or German as the research team was fluent in these languages, and due to time limitations and translation costs. Clear location, publication, and selection biases are possible, and caution is advised when transferring findings. Future reviews should be even more comprehensive, include more languages and seek to consider specific parenting challenges and mental health difficulties, for example hearing voices or experiencing mania, to explore what support needs might be indicated. Future research should explore parental barriers to accessing services across specific geographic locations and settings, and should include the views of families, HCPs and policy makers. Although it is not possible to transfer findings from the current review across geographic regions or mental health difficulties, strong themes emerged from the data irrespective of setting, location, and mental health difficulty, highlighting key recommendations for practice and future research.

The use of thematic synthesis allowed multiple qualitative approaches and findings to be synthesised, promoting new interpretations to inform policy and practice. The themes derived from the synthesised data are acknowledged to be influenced by researcher lived experience, position, and insights. However, the trustworthiness, methodological rigour, and credibility of the review findings were enhanced through the process of independent review at stages of study selection, quality assessment, and theme identification (Tong et al., 2012), and due to the high or moderately high methodological quality ratings of all included studies.

Table 4: Suggested clinical implications and recommendations

Area of the system	Recommendation
Parents	<ul style="list-style-type: none"> • Psychoeducation should be provided to normalise parents’ experiences, reduce guilt and stigma, promote integration with community networks, support system-wide conversations about mental health and support parent-child attachment relationships. • Parents should be supported to access peer networks to tackle parental isolation. • Parents’ psychological and practical support needs should be considered from an early stage to avoid crisis escalation and restrictive interventions. A strengths-based approach could support parental hope and goal-based parenting outcomes. • Longer term psychological support could support parents to make sense of experiences of threat, supporting parents to re-gain their sense of control and connection with their children, families and wider networks. • Emotion regulation support should be considered, if necessary, to support parent-child relationships by reducing shame and self-defeating behaviours by supporting parental recognition and management of their own and their children’s emotional needs. • Practical parenting support and respite care should be considered, particularly for parents without system supports. Practical factors should be considered, including childcare provision and flexible service access arrangements.
Children and family	<ul style="list-style-type: none"> • Consideration should be given to providing respite care for children, particularly children who have been identified as experiencing increased responsibility to care for their parent(s). Community support groups could also provide connection and containment for these children and other family members. • Child and family wellbeing should be monitored to promote signposting and joined-up support to appropriate healthcare and community services. • Psychological support for children should be considered, providing opportunities for safe and supportive exploration, sense making, and management of psychosocial difficulties.
Healthcare services	<ul style="list-style-type: none"> • Specialist training, support and supervision should be offered across parent and child services to ensure that necessary knowledge, skills, confidence, competence, and compassion underpins service delivery. This could help reduce practitioner fear and risk-orientated responses, in turn fostering parental hope and trust in services. • HCPs should hold in mind the centrality of parenting identity in the lives of people who experience SMI. Parenting status should be asked about and considered by all HCPs. • Consideration should be given to socio-cultural and political contexts within which parents live, promoting a cultural fit of service delivery. • Sensitivity to parental distress and fears of social service involvement is required. Services should address parental concerns to alleviate fears and promote engagement.
Policy and legislation	<ul style="list-style-type: none"> • Services and communities should be adequately funded to ensure suitable provision of staff, training, and resources to meet parents needs as outlined above. • Public awareness of experiences of SMI should be increased to target stigma and promote non-judgmental, compassionate, and connected system-wide support. • Socio-economic disadvantage, adversity and wider systemic influences should be accounted for.

Conclusions

This was the first review to comprehensively synthesise qualitative research exploring mothers and fathers' experiences regarding the impact of SMI on parenting and their support needs, that was not restricted by specific cultural characteristics. Parental perceptions of inescapable threat profoundly impacted parent-child relationships, which were strained and centred around SMI-related parenting difficulties. The need for system-wide support, placing parenting in a compassionate systemic context is emphasised. Key recommendations for clinicians and policymakers are highlighted. Future research should consider the experiences and needs of parents with specific parenting and mental health challenges across different geographic locations.

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***References marked with an asterisk indicate studies included in the synthesis.**

Paper 2

Parents Who Experience Psychosis: A Qualitative Exploration

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The following paper has been prepared for submission to *Frontiers in Psychiatry*. Author guidelines can be found in Appendix E. Please note, there have been deviations from the guidelines, such as use of APA referencing rather than Vancouver referencing for thesis submission.

**Word Count: 7,745 (main text; excluding figures, and references); 250 (abstract);
10,161 (complete text).**

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Abstract

Psychosocial difficulties and symptoms associated with psychosis can exacerbate parenting challenges. Although significant adverse psychosocial outcomes for parents who experience psychosis have been reported, remarkably little is known about how parenting is experienced by these parents. Without understanding parental experiences and needs, evidence-based service provision remains limited. Therefore, this qualitative study aimed to understand the lived experiences of parents who experience psychosis, including how parenting support was experienced. Eight biological parents (five mothers and three fathers) who experience psychosis were recruited and interviewed from Early Intervention in Psychosis services in the Northwest of England. Using Interpretative Phenomenological Analysis (IPA), three superordinate themes and six subordinate themes were identified. Theme 1 '*Living with the Struggle: Painfully Disconnected*' captured a persistent parenting struggle that distanced parents from their children and support due to all-consuming experiences of psychosis, fear, and risk-focused service support. Theme 2 '*Desired and Vulnerable Position: Comfortably Connected*' captured parental experiences of symptom relief through connection with their children, alongside parental need to be integrated with the systems around them. Theme 3 '*Exposed: Parenting Under a Spotlight*' represented parental experiences of inescapable observation and judgment from the systems around them. Novel insights into the role of misaligned parent and service priorities in parental perceptions of powerlessness, shame and disconnection from their children, valued parenting identities, and system supports are presented. Systemic interventions that target stigma, provide system-wide psychoeducation, and promote person-centred, compassionate, and meaningful connections between parents and the systems they live within are needed to promote better parenting outcomes.

Keywords: *Schizophrenia; serious mental illness; family focused practice; psychotic disorders; interpretative phenomenological analysis.*

Introduction

Approximately 440,000 adults in the UK experience psychosis (McManus et al., 2016) and more than half are parents (Bee et al., 2014). Parents who experience psychosis face a multitude of challenges (Campbell et al., 2018), including difficulties with managing parenting responsibilities (Montgomery et al., 2006; Strand et al., 2020), boundaries (Khalifeh et al., 2009) and relationships (Ackerson, 2003; Gregg et al., 2021). Parenting difficulties have been associated with adverse social, emotional and behavioural outcomes in the children of parents who experience psychosis (Mowbray et al., 2006; Rasic et al., 2014). However, much of the parenting research is framed within the context of Serious Mental Illness (SMI; e.g., Chen et al., 2021; Dolman et al., 2013; Harries et al., in preparation; Oyserman et al., 2000) an umbrella term capturing mental health difficulties that have clinical features that are distinct from psychosis, including major depression, bipolar disorder and anxiety disorders (Evans et al., 2016). Thus, despite the prevalence of parents who experience psychosis and the recognised adverse parenting outcomes, remarkably little is known about how these parents experience and navigate parenthood, including their experiences of receiving parenting support (Radley et al., 2022; Strand et al., 2020). Consequently, the support needs of parents who experience psychosis remain inadequately understood (Bee et al., 2014), presenting a significant barrier to the development and implementation of evidence-based practice (Skivington et al., 2021).

To our knowledge, only three studies using qualitative methodologies that focused specifically on psychosis and were published in English sought parental views about how experiences of psychosis *per se* impacts parenting. In Sweden, Strand et al. (2020) explored the experiences of 15 parents who experienced psychosis using Thematic Analysis (Braun & Clarke, 2006), while Boström and Strand (2021) explored the experiences of six parents who experienced psychosis and their seven children using Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003). In the UK,

Evenson et al. (2008) analysed the narratives of ten fathers who experienced psychosis using IPA. Across these three studies, challenges in managing the parent-child relationship alongside experiences of psychosis itself were highlighted. However, none of these studies specifically sought parental views about their receipt of parenting support. Additionally, studies that have explored parenting in broader SMI parenting samples have mostly restricted their focus to maternal experiences (Dolman et al., 2013). Thus, the integral role of fathers has been largely overlooked (Bakel & Hall, 2020). Moreover, only one qualitative study exploring parenting experiences in psychosis was conducted in the UK (Evenson et al., 2008), where significant socio-economic and political change has occurred in the 14 years since its publication. In particular, the impact of parenting has become more recognised (Allen, 2011), Early Intervention in Psychosis services (EIPs) have become embedded in mental healthcare provision (National Institute for Health and Excellence [NICE], 2016) and the National Health Service (NHS) have committed to improving service provision for parents and their children (The NHS Long Term Plan; NHS England, 2019).

If we are to improve parenting outcomes and support the implementation of evidence-based family-focused practice (FFP) approaches (Bee et al., 2014; Gregg et al., 2021), as the NHS long-term plan proposes (NHS, 2019), an in-depth and up-to-date understanding of how parenting is experienced by mothers and fathers who experience psychosis, including their experiences of parenting support, is required. We therefore undertook an investigation of the lived experiences of parents who experience psychosis. The primary aim was to explore how these parents experienced parenting, the meanings they assigned to their experiences, and the support offered to them. We specifically addressed the question ‘What is it like to be a parent who experiences psychosis?’.

Method

Design

This qualitative, interview-based study employed IPA (Smith & Osborn, 2003) because it promotes in-depth exploration of the personal, lived experiences of individuals with complex emotional experiences (Larkin et al., 2006; Michie et al., 1999; Smith et al., 2009) and allows exploration of patterns and divergences within and across participant narratives (Murray & Wilde, 2020). Given the lack of current qualitative research into parents who experience psychosis, IPA is particularly suitable (Smith et al. 2009).

Ethical Approval

Relevant approvals were obtained from the local NHS Research Ethics Committee (REC) and Health Research Authority (HRA) (reference 21/WA/0010; Appendix F), the local NHS Trust Research and Innovation department (reference: x505; Appendix G), and The University of Manchester Research Governance department. Experts by experience were consulted during the research design process in November 2020, in line with best practice UK legislative frameworks (HRA, 2021).

Participant Inclusion and Exclusion Criteria

Participants were eligible if they were a biological, stepparent or kinship parent to children aged 0-18 who they had at least weekly contact with. Participants had to have experienced non-affective psychosis within the preceding two years as determined by a Diagnostic and Statistical Manual of mental disorders, fifth edition (DSM-V) symptom checklist (American Psychiatric Association [APA], 2013; Appendix H), were able to give fully informed consent and were registered with a general practitioner to ensure appropriate risk management. Due to the requirement of IPA for individuals to talk in detail about their

experiences (Smith et al., 2009), participants were excluded if they were not proficient in English.

Recruitment

Participants were recruited from EIPs in the Northwest of England. With the assumption that parents who experience psychosis are a hard-to-reach group (Wolfenden et al., 2022) due to stigma (Lacey et al., 2015), we adopted a convenience sampling approach which was informed by purposive sampling to ensure participants were recruited who could provide data relevant to the study aims.

Practitioners working at EIPs identified eligible parents via caseload review, facilitated by a collaborator from the participating NHS Trust. Practitioners contacted and provided eligible participants with a study advert (Appendix I) and a participant information sheet (Appendix J). Participants were required to complete a consent to contact form (Appendix K) to indicate their interest in taking part, following which the first author made contact to determine eligibility, describe study procedures and discuss ethical considerations. Participants had 24 hours to consider their participation, before being contacted again, when an interview was arranged for a time and location convenient for the participant.

Data Collection and Analysis

Time was spent upon meeting with participants to encourage them to feel as comfortable as possible. Informed consent was verbally obtained over the telephone or in person (Appendix L) and was audio-recorded using an encrypted recording device. Demographic information was collected to contextualise individual narratives and the overall sample (Appendix M). The first author conducted in-depth, semi-structured interviews with all participants, which were recorded separately to consent procedures. A topic guide

(Appendix N), which was developed in consultation with the literature, the research team and experts by experience, was used flexibly to explore areas most salient to participants (Smith et al., 2009; Smith & Osborn, 2003). It consisted of open-ended questions to encourage participants to lead discussions and verbal prompts to promote deeper exploration of participant stories. The first author conducted a pilot interview with a member of the research team to test the appropriateness of the topic guide, allowing for refinements, while enhancing researcher interview skills (Malmqvist et al., 2019). Following the interviews, participants were given time to reflect on their participation and were provided with a debrief sheet (Appendix O) and signposted to support organisations. Participants were offered a £10 Amazon voucher for taking part.

The recommended dynamic stages of IPA were employed (Smith & Osborn, 2003). The first author listened to each interview several times to ensure content familiarisation, following which they transcribed each interview verbatim and subsequently checked it against the audio recording. To promote participant anonymity, participants were assigned a pseudonym and all identifiable information was omitted. The first author re-read each transcript multiple times and “bracketed” any pre-existing assumptions, beliefs, and initial reflections to avoid interfering with participants’ narratives and analysis (Smith et al., 2009). The second author also read each transcript and noted their own reflections.

The first author subsequently commenced line-by-line coding of each transcript using Microsoft Word, in which descriptive, linguistic and conceptual comments were made (Smith et al., 2009; Appendix P). Using these comments, patterns were explored within individual transcripts using Microsoft Excel (Appendix Q), resulting in the development of exploratory comments and emerging subordinate and superordinate themes for each participant (Appendix R). Themes were then re-checked against each transcript to ensure the derived themes reflected participants’ narratives. The second author independently undertook this stage with two randomly selected transcripts. Next, the first

author led on exploring higher level convergences across all transcripts using ‘post-it’ notes (Appendix S), following which superordinate and subordinate themes were defined. This stage involved in-depth discussion between the first and second author, and wider discussions with the research team. The final step involved translating the themes into a narrative account within the write up.

To encourage ‘insider perspective’ of parents’ experiences, a double hermeneutic phenomenological approach was employed. To support this process, the first author kept a reflective diary and discussions were held with the wider research team. This encouraged exploration and acknowledgment of the first author’s own world and interpretive account in relation to parents’ attempts to make sense of their own personal and social experiences (Smith, 2004; Tuffour, 2017).

Reflexive Positioning

Acknowledging that qualitative research is influenced by researcher experiences, preconceptions and knowledge (Smith et al., 2009), reflexivity and considering the subjective positioning of researchers was an important process. Authors varied in age, gender, ethnicity, and clinical experience. The first author, a white British practicing trainee clinical psychologist, had several years of experience working with people who experienced psychosis, including parents. Two authors were practicing clinical psychologists working in perinatal mental health and psychosis services, and two authors were academic psychologists specialising in health psychology and psychosis research. The authors had a variety of personal experiences of parenting. Acknowledging that the research team were all interested in improving service provision for parents who experience psychosis, caution was applied to ensure this subjective position did not influence interpretative accounts of the data towards a suggestion for parenting support that was not reflected in parents’ narratives.

The research was approached from a critical realist (Bhaskar, 1978) positioning, underpinned by a constructivist epistemology. The role of human agency and language use in constructing social realities and experiences, while assuming that people's actions are shaped and constrained by societal mechanisms and structures that are independent of thoughts or perceptions, underpinned the epistemological assumptions of this research. This positioning enabled consideration of why participants drew upon certain discourses to construct their realities, exploration of the impact of societal mechanisms and structures on discursive processes, and consideration of the position of participants discourses within the societal structures and systems that they negotiate. The use of a reflective diary and regular discussions with the research team supported these processes.

Trustworthiness and Rigour

To ensure that themes were 'trustworthy' and grounded in the data, the approach to analysis was iterative and reflexive (Tobin & Begley, 2004). The first two authors ensured that their interpretations of participant narratives were similar on a case-by-case basis. In-depth discussions between the first two authors following each interview facilitated this process, ensuring that interpretation of themes was consistent with participants' stories, thus minimising risk of interpretations being influenced by researcher values and experiences (Smith et al., 2009). A reflective log and discussions with the research team supported the reflexive process (Yardley, 2000), particularly in promoting the incorporation of multiple perspectives to ensure broad and balanced data interpretations, the uncovering of unconscious biases, and in supporting the first author in remaining 'true' to narratives while applying a 'critical analytic lens' (Braun & Clark, 2013). The analysis process has been evidenced in the appendices to ensure transparency.

Results

Participant Characteristics

Eight biological parents (five mothers and three fathers) participated, representing a sample size deemed adequate to achieve rich phenomenological insight (Noon, 2018; Smith et al., 2009). Depending on participant preference and COVID-19 restrictions, interviews took place over the telephone ($n = 6$), in a mental healthcare clinic ($n = 1$) or in the participant's home ($n = 1$). Interviews lasted between 67 and 93 minutes ($M = 77$, $SD = 9$) and took place between April 2021 and March 2022.

Participants were aged 25 to 43 years ($M = 33$, $SD = 6.6$). Participants had between 1 and 4 children each ($M = 2.6$, $SD = 1.2$), with a total of 16 children between them (female = 8; male = 8). Children were aged 1 to 18 years ($M = 7.6$, $SD = 5.2$). Three parents lived with their children and partner, two lived with their children only and three lived alone. The majority were white British ($n = 5$), two were black African and one was white European. Five were single and three were married or in long-term relationships. Two lived in social housing, one lived with their parents and four rented privately. Four were unemployed, three worked part-time and one worked full-time. Education was completed to GCSE ($n = 1$), A-level ($n = 3$), university ($n = 1$) and adult diploma ($n = 3$) level.

Qualitative Findings

Three superordinate themes were identified: 1) *Living with the Struggle: Painfully Disconnected*, 2) *Desired and Vulnerable Position: Comfortably Connected*, and 3) *Exposed: Parenting Under a Spotlight*. Figure 3 represents the relationship between the three superordinate themes and six subordinate themes. The figure represents the influence of a persistent parenting struggle on a precariously balanced, hard-to-reach and hard-to-maintain desired position of parenting with comfort and connection: a vulnerable position

threatened by inescapable experiences of exposure. The need for systemic intervention to promote parental experiences of connection, stability and security is indicated. Illustrative quotes are provided to highlight parent voice (see Appendix T for additional exemplar quotes).

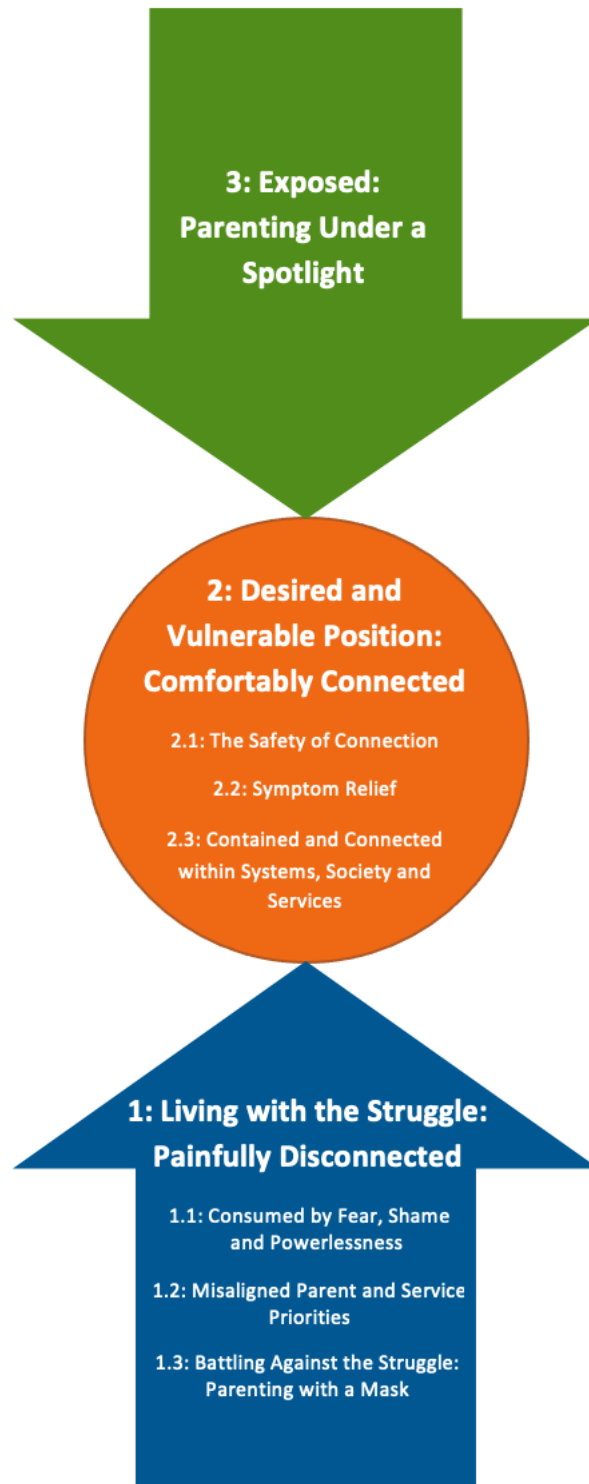


Figure 3: Conceptual model depicting superordinate and subordinate themes

Superordinate Theme 1: Living with the Struggle: Painfully Disconnected

Parents described a persistent and sometimes unmanageable parenting struggle impacted by intolerable distress and fears associated with experiences of psychosis, concerns about negatively impacting or losing their children, and perceptions of powerlessness and shame. An incongruence between parental support needs and parental experiences of receiving risk-focused support served to further exacerbate parents' sense of helplessness and a polarised sense of self. Consequently, parents experienced exhaustion, leaving them feeling disconnected from their children and a valued parenting identity and were caught between hiding, performing and proving parenting to sustain their parenting role. This theme consisted of four subordinate themes.

“It is a struggle. You...I don't even know how I get through the day sometimes. Sometimes I think, ‘wow, that was like... [hand explosion]’” (Lauren).

Subordinate Theme 1.1: Consumed by Fear, Shame, and Powerlessness

All parents described feeling consumed by an inescapable sense of fear and shame that thwarted their sense of safety and comfort. The fast pace that parents adopted to speak about fears of separation or harm coming to their children reflected a sense that they felt desperate to escape the entrapment of fear. Several parents described feeling hopeless and defenceless to voices that exploited their biggest fears, principally harm coming to their children, resulting in a *“very strong sense of impending doom”* (Darren). This fear was unbearable for some, including Vanessa, who described feeling powerless to fears of losing her son:

“Frightened! Because some silly voice in your head, it can take my boy away. Very frightened, very not in control and not empowered. Very hopeless” (Vanessa).

Parents who were separated from or unable to have contact with their children reflected feeling painfully distanced and alone. Janet described feeling inconsolable,

desperately longing for reconnection: *“I was crying the whole time...I found myself calling her name at night”*. For some, the pain of disconnection led to contemplation of suicide.

For others, fears about separation prevented parents from getting close to their children:

“It’s hard work. Especially when you’ve got like loads of paranoia and when you think that someone’s gonna hurt your children all the time. You’re kind of like distancing yourself away from your children so like you don’t get hurt” (Sharon).

Parents’ narratives about the emotional consequences of parenting while experiencing psychosis contained notable pauses, sighs, and tearfulness, particularly around descriptions of *“stress, “guilt”, “fear”, “anxiety” and “depression”*. Experiences of psychosis served to exacerbate parenting challenges and exhaustion, resulting in parents feeling overwhelmed and defeated: *“I struggle to keep up with the speed that she goes”* (Darren). Age-incongruent responsibilities could be displaced onto children, increasing parental guilt and shame, particularly when their children’s worry was evident:

“They’d be worrying about me cause I was walking like a zombie, so that had an impact on them...Because they think, ‘look, my lovely bubbly mum is all of a sudden not alright, what’s happening, are we doing anything wrong?’” (Vanessa).

Profound guilt and shame were associated with perceptions of parenting failure, particularly when parents were unable to maintain child contact, felt unable to manage the demands of parenting, or felt consumed by thoughts and voices that exploited perceptions of *“failure”*. In such cases, distance between parents and their children could arise:

“I wasn’t sort of as present as I could have been...because it was covid as well, we were sort of home schooling I found it quite difficult to ignore the voices that I was hearing” (Lucy).

An unremitting fear of negatively impacting their children was experienced by all parents. Janet described being consumed by *“worry that [daughter] will be bullied”* after she had *“meltdowns”* in her neighbourhood. A sense of shame often accompanied fear,

including for Lucy, who described feeling haunted by images of her son witnessing her distress and worried about the impact of this:

“I sort of had a bit of a moment when I was sort of crying, shouting, ‘oh they’re filming me, they’re filming me. We need to ring the police’. And sort of he witnessed that. And it’s just a bit scary to think of the impact that might have on him” (Lucy).

Fathers reflected particularly profound experiences of feeling “*ashamed*” and “*embarrassed*” about a ‘limited’ ability to “*provide*”. This served to exacerbate fathers’ perceptions of powerlessness, reflecting a possible double male-based stigma associated with psychosis and gendered parenting roles. Chris reflected:

“I know it plays on my head as if, if I didn’t have these mental health issues, if I didn’t have the psychosis, I wouldn’t be in this position. I’d be still in work, I’d still be working and I’d be providing everything I could for her [voice quivers]”
(Chris).

Some parents described having lost their parenting identity entirely to psychosis and reflected feeling isolated, desolate, and hopeless, stripped of their identity:

“I’m not a parent anymore. Because of the psychosis. I feel like psychosis has destroyed my life” (Sharon).

Subordinate Theme 1.2: Misaligned Parent and Service Priorities

Parents reflected that their parenting difficulties were exacerbated by an absence of compassionate and meaningful service support. Parents described feeling as though their parenting needs were not adequately considered, which contrasted with the centrality of their parenting identity in their lives. Amir reflected a sense of confusion, wondering why his parental role had been overlooked by inpatient and outpatient mental health services: “*I don’t know why they don’t ask me*”. Fathers in particular perceived services to discount the

contribution of parenting to the distress they experienced. They described being treated as individuals living independently, rather than parents living within family systems, which they felt missed a fundamental part of their identity:

“Nothing really came up about being a dad I don’t think whilst I was in hospital. Cos they were very much trying to sort of look at you as an individual, and yeah they didn’t really ask me about what it was like missing my daughter” (Darren).

Chris reflected feeling consumed by frustration and disappointment about the lack of support available to single fathers, which served to distance himself from connection with his children and resulted in him feeling despondent and unsupported by a system that he perceived to be stigmatising: *“The amount of help you get as a single dad with mental health is shocking...There’s nothing there at all. Literally”* (Chris).

A number of parents reflected that services unhelpfully focused on risk: an aversive threat-focus that was associated with perceptions of fearful mental health practitioners. Many parents perceived this focus to be *“overkill”*, serving to distance them from the compassionate support they desired, while exacerbating parental perceptions of *“failure”*. A barrier to talking about parenting difficulties was presented, serving to distance parents from accessing support while intensifying experiences of mistrust, worry and paranoid thoughts:

“Even though every day is a struggle for me, it doesn’t necessary mean that he’s in danger. And I feel like when, when you first come round from, when you first come out with ‘listen I’m struggling and I’m being honest’, straight away all of these alarms start going off with social services. It makes you worse” (Lauren).

All but one parent reflected feeling exasperated by repeated risk-focused questions being asked by healthcare providers that served to undermine their sense of being heard and understood. Vanessa reflected:

“You feel like screaming. You feel like saying like, ‘now listen, just help’. You just, you just wanna say, excuse my language, ‘shut up, and can you please try to understand’”.

Parents reflected a fundamental need to remain close to their children; a consideration that was not perceived to be wholly supported by services. Sharon demonstrated significant frustration and distress associated with feeling that her parenting needs were disregarded, leaving her feeling isolated, unheard and desperately yearning for services to grant her parental custody rights: *“No one’s listening to me about what my children need. They need to come home”.*

Subordinate Theme 1.3: Battling Against the Struggle: Parenting with a Mask

The language that parents used to describe how they coped with the dual demands of parenting while experiencing psychosis conveyed a sense of endurance; a challenging ‘parenting performance’ that was fronted by a parenting façade that parents hoped would protect themselves, their children and their parenting identity:

“I try to stay strong, so a lot of people don’t know about my mental health. In fact nobody does. Cos I wear a face full of make-up and I put a strong, strong act on”
(Lauren).

The parenting struggle was amplified for single parents who faced parental challenges without family or peer network support. Among these parents, there was a sense of dependence on the ability to use a mask: different “hats” that allowed them to function without feeling consumed by emotional pain and perceptions of defeat. Janet reflected:

“As a single parent you just put on a hat, and you’re like, I have to play both the roles. So feeling helpless is not acceptable”.

Other parents reflected detaching from emotional pain and attempting to “*project a happy persona*” (Darren), to allow themselves to fulfil their parenting roles to combat distress and promote connection with their children. Lucy described:

“I think there’s an element of faking it...fake it until you make it, where you’re faking sort of being happy and positive, but from it, it sort of turns into real happiness” (Lucy).

Parents often faced the parenting battle alone. Fears about parenting “*failure*” and losing their children amplified parent’s needs to “*prove*” and “*protect*” their parenting status. Societal stigma and lack of system supports served to further exacerbate parents’ perceptions of threat. A sense of hiding to protect was represented in parents’ narratives. For some, hiding represented “*staying inside*” to protect themselves and their children from threatening voices and paranoid thoughts about threats of the outside world. For others, hiding represented concealing their mental health difficulties from their children, family, peers and services by meticulously monitoring their words and actions. Chris described battling against displaying emotional distress in front of his daughter, attempting to protect a “*strong*” parenting identity by repressing and pushing down sadness and hiding tearfulness.

Superordinate Theme 2: Desired and Vulnerable Position: Comfortably Connected

This theme captured parents desired parenting position: an environment within which they felt safely connected to their children and their parenting identity and supported by the systems around them. However, this position was vulnerable, difficult to balance and could be easily tipped by the conditions around parents which could cause parents to quickly move back into the struggle. This theme consisted of three subordinate themes.

“I can be a good mum again. Cos I was a really good mum and I know I was. It’s just that when I got poorly after my last child, you know I got depressed and stuff, I just, and with the psychosis, I just, everything just went downhill” (Sharon).

Subordinate Theme 2.1: The Safety of Connection

Parents’ relationship with their children and family networks were central to their sense of safety. When describing their feelings about relationships with their children, parents used a notably softer tone of voice, reflecting a sense of relief and comfort, with words including “joy”, “love”, “pure”, and “hope” featuring heavily. When describing being with her children, Sharon reflected: *“It feels like I’m at home, like I’m safe”*.

The safety that parents felt by being close to their children was held in stark contrast to the fear of disconnection or damaging their children that played a central role in the struggle. Safety and comfort, when experienced, were conceptualised as cherished states that had to be protected at all costs. For many parents, the fear of other people and systems infringing on this cherished state led to “*protective*” parenting stances. Several parents, including Lauren, noted a desire to stay especially close to their children to combat fears about harm coming to their children and their relationship: *“I’m very erm protective over him”*. Several parents reflected that their desire to ensure a close relationship with their children stemmed from painful memories of their own childhoods, within which relationships with their parents were insecure or threatened by abuse. For these parents, being close with their own children offered an opportunity to remedy the pain of their past:

“I kind of missed a full family unit, which is why I decided my family is gonna be full” (Vanessa).

Physical closeness to children was particularly important, especially for parents who lived apart from their children either due to service intervention or parental separations. Parents’ fears about being more permanently disconnected from their children

and family networks were distressing experiences. Some parents, including Darren, described utilising experiences of psychosis to promote a sense of resolve and reconnection; a product of feeling desperately fearful about the prospect of long-term disconnection:

“I thought my wife had killed herself, and I thought my baby was like motherless and someone was looking after her. But, yeah, then I sort of did this thing where I sort of re-started time and made time go backwards so my wife wasn’t dead again” (Darren).

Some parents described experiencing an especially close relationship with their children that was held in particularly high regard. For many, this was due to the protective function of their children: *“That my little boy is my saviour. He saves me”* (Lauren). Children represented safety for many parents, pulling them away from suicidal ideation and behaviours, or thoughts about being *“worthless”*:

“I love it, I love it. Cos it’s like, sometimes in my head I could be the worst person in the world. But then to have her there, clinging to me and everything like that, it reminds me I’m not [voice quivers]” (Chris).

Moments of joy with their children were highly valued by all parents. Parents projected pride when describing such memories, reflecting a valued parenting identity: *“the moments of love and joy that you have, and pride”* (Lucy). Many parents described a *“special”* relationship with their children within which their needs for social connection were met: *“He’s my best mate...it’s like we’ve just got like a little bond”* (Lauren).

Subordinate Theme 2.2: Symptom Relief

Parents reflected openly on the *“relief”* from distressing symptoms that their children afforded them. A sense of wonder was represented in parents’ narratives when they described the powerful respite from distress that they experienced when they were with

their children. For some, psychotic symptom relief was experienced only through relationships that they held with their children and was not replicated by other close relationships, including partner relationships. Crucially, parents reflected that significant symptom relief was experienced only when they were physically with their children and that having relationships with their children from a distance did not serve the same alleviative function. Amir reflected:

“When I’m with my children, I hear nothing. But when I’m on my own I can hear those voices” (Amir).

Some parents reflected insight into the influential role that relational comfort and security with their children played in promoting symptom relief. Chris described experiencing respite from paranoid thoughts and hearing distressing voices when he was with his children, conceptualising the contact as a ‘cure’: *“It pretty much just like mends my head”*. Other parents reflected that contact with their children provided temporary distraction from emotional distress. These parents, including Lucy, recognised that relief from distress was a temporary, but valuable escape:

“I think because you’re sort of engaging in sort of activities with him, and sort of playing and joking around, it can just sort of make you forget about the negatives for a bit” (Lucy).

The relief from distress that children provided parents with was conceptualised by some as a special “*power*”; a tool to fight emotional suffering promoted by the responsibility of parenthood. Some conceptualised parenthood as a “*turning point*”, presenting them with a chance to develop strength and resilience following difficult life experiences: *“I’m a better person now. I think it’s definitely strengthened me as a person”* (Darren). Vanessa reflected a tremendous drive to overcome setbacks that being a parent offered her. In this sense, a reciprocal parent-child ‘saviour’ role was presented in which children offered parents drive and resilience, while parents protected children from harm:

“The mother, er, in the moment of er crisis, she can lift a car and get the child from under. You’re getting that amazing power from inside” (Vanessa).

Although relief from distress was conceptualised as a welcome experience among all parents, many reflected guilt associated with a sense of reliance on their children to alleviate their distress. Chris reflected: *“I can’t use my daughter as a crutch”*. A sense of shame was demonstrated in these parents’ narratives, reflecting the overpowering pull of the parenting struggle. Thus, a delicate balance between appreciating relief from distress and feeling guilt for relying on children was presented. Darren summarised: *“It’s been both a blessing and curse”*.

Subordinate Theme 2.3: Contained and Connected within Systems, Society and Services

Feeling connected to and contained within the systems parents lived within was highly valued within parent narratives: *“I know that people are around me, so I’m safe”* (Amir). However, parents’ experiences of being held and supported with compassion were largely absent experiences.

Parents described longing to be understood by their family and peer networks to *“fit in”* and combat experiences of being ostracised due to stigma and limited societal understanding about psychosis. Vanessa described the first step in promoting her own understanding was to *“name it”*, allowing her to *“become real”*. Here, an opportunity for promoting understanding was suggested, in which *“being seen”* was a decision, rather than a consequence of others’ exposing actions. One parent described feeling grateful for being offered family-focused support that aimed to promote her mother’s understanding about psychosis, *“so that my mum could understand it”* (Lauren). However, this experience was short-lived due to rigid service attendance policies. The legacy of this experience was profound, exacerbating feelings of abandonment and disconnection.

The desired role of compassionate and dependable others featured heavily in parental reflections about the desired characteristics of supportive others. Parents described a desire to be supported by professionals and peer support workers who were on their “level” and “wavelength”, and who they felt they could “click with” to promote a trusting, secure and open relationship. A compassionate approach was seen as particularly important for professionals to harness when approaching conversations about parenting difficulties. Janet reflected that the nurturing approach of a dependable social worker had the power to eradicate experiences of shame that had previously prevented her from talking about her parenting needs:

“She was like a mother figure. And that, this was when I opened up to her about the voices” (Janet).

Similarly, several parents reflected a strong desire to be connected to groups of other parents and children with lived experience of psychosis to promote a sense of being ‘accepted’ and supported, and to reduce feelings of ‘difference’ and disconnection. These parents reflected a desire to be integrated with parenting communities, while simultaneously learning strategies to manage the parenting struggle. Chris reflected:

“It would just give her [daughter] a better grasp on things. Just hearing it...and seeing other people and other people interacting with their kids that are the same. And it’s just, yeah it would make her realise that her daddy’s not the only one, it’s not weird” (Chris).

Across parent narratives, a need to be able to rely upon and be held by the systems parents and their children lived within was evident. For parents who had close family networks, a sense of relief was communicated when they described being able to rely on others for childcare support. However, many parents were not afforded the support of family systems: *“I wish there was something there that I could just grasp for help” (Chris).*

Among these parents, a strong message of parents requiring additional, reliable and consistent service support was notable:

“For me, the most important thing, erm, if the person is going through that alone, is having someone that they can count on” (Janet).

Superordinate Theme 3: Exposed: Parenting Under a Spotlight

This theme conceptualised how parents experienced the seemingly inescapable watch of peer, family and wider service networks. Parenthood itself was experienced as a confronting and exposing experience which challenged parents’ sense of identity and selfhood, while experiences of psychosis subjected parents to further observation and judgment.

Parents’ narratives reflected a sense of frustration and anger about being unfairly judged about their parenting ability. For some, experiences of psychosis served a double-edged exposing function, in which they were subjected both to increased observation due to stigma and societal fears about the ability of parents who experience psychosis to adequately care for their children, in addition to paranoid thoughts about being observed.

“It’s horrible. Because I think everyone’s judging me. Even down to like my mental health team that I’m under. I don’t want that. I think, ‘you all think I can’t deal with it. You think I’m not...you all think I’m bad’. Cos of this social service thing now, I think they’re all...feel like they’re watching me” (Lauren).

The stigma associated with mental health difficulties, and psychosis in particular, caused parents to feel “*really small*” (Darren). Resultantly, parents could feel disconnected from their authentic selves and their valued parenting identity, “*because people look down on it*” (Chris). Some parents acknowledged the role of psychiatric diagnoses in generating additional pressure to ‘perform’, and parental expressions of distress could be pathologised:

“I feel like I can’t say anything. Because I’m scared that they’re gonna think I’m poorly. Cos once you’ve been poorly they’re constantly looking out for it”

(Sharon).

In such cases, parents felt exposed and their connection to a desired position of being comfortably connected to their children was thwarted, causing parents to easily slide back into the struggle. Several parents reflected that services that were intended to support them were experienced as threatening, causing an amplification of parental fear. The language that Lauren used to describe her experiences with mental health services reflected exasperation; a lasting legacy of mistrust and disengagement following experiences within which she described feeling misinformed and trapped by surveillance: *“You go to one service and you’ve got a million behind you that are coming in”*. Similarly, Sharon described feeling as though she was living under constant examination, unable to escape supervised contact with her daughter due to others’ perceptions of her being a *“dangerous”* mother.

Several parents noted experiencing an increase in paranoid thoughts following social services involvement. Some described feeling exposed and vulnerable when service staff talked about their parenting difficulties in front of their families. Consequently, several parents described feeling undermined and forced back into the parenting struggle; stuck between proving their parenting worth and hiding to protect:

“I feel like I’m on a dive line. And I feel like if I step out of place in the slightest, that’s it” (Lauren).

Several parents described parenthood as being a revealing experience within which their previously unwanted, hidden traits became hard to hide. Some parents, including Darren and Chris, reflected feeling haunted by pre-parenthood identities that did not align with their desired parenting identities. Their tone of voice and hesitations within their

narratives suggested a sense of defeat yet frustration about being unable to fulfil parenting roles they perceived to be traditionally valued by society:

“It sort of made me want to, er, change myself completely. Cos, I knew that my old lifestyle was not compatible with having a child” (Darren).

The “*label*” of being a parent who experienced mental health difficulties was experienced as particularly challenging for fathers. Chris demonstrated a sense of shame and described wishing to conceal his distress from his daughter to avoid feeling painfully exposed and risk damaging his valued parenting identity: *“I don’t like to admit that I’ve got like mental health issues with my daughter”*. Similarly, Amir reflected on the importance of being respected as a father within his community. However, he was presented with a dilemma within which he enjoyed the exposure associated with a respected fathering status, but wished for his experiences of psychosis to remain hidden to protect his respected parenting identity:

“Because people, they recognise and respect you. And they, they, they will show more respect because they know you are not like other people that do not have kids” (Amir).

Discussion

To the authors’ knowledge, this study was the first to explore the lived maternal and paternal experiences of parents who experience psychosis using IPA in the UK. The aims of the study were met fully; this study provides novel insights into how parenting with psychosis is experienced and how parents experience the support offered to them. Three key themes were identified. Parents experienced a polarised and vulnerable sense of parenting identity and connection to their children and wider systems they lived within; a polarisation that was pulled by the gravity of parents’ perceptions of powerlessness and shame consequent of distressing experiences of psychosis and fears of parenting ‘failure’.

Parents' attempts to balance relief with reliance on their children to alleviate distressing experiences of psychosis, including hearing threatening voices and experiencing paranoid thoughts about harm coming to their parenting relationship, thwarted their sense of parenting security and satisfaction. Parents' desire to protect their connection with their children and parenting identity was further compromised by an inescapable sense of observation resultant of societal stigma and threatening service contact that was perceived to be misaligned with their parenting needs.

Novel insights into factors that influence parental experiences of security, comfort, and connection with their children and their parenting identity in the specific context of psychosis are presented. In particular, the respite from distressing experiences of psychosis that parents were afforded through contact with their children was experienced as both a relief and burden: a polarising pull resulting in an oscillation between experiences of relief and shame that impacted parents' sense of connection with their children and parenting identity. This finding augments previous research highlighting the influence of shame on parents' sense of security with their children, as identified in parents with broader experiences of SMI (Chan et al., 2019; Chen et al., 2021; Montgomery et al., 2006; Tjoflåt & Ramvi, 2013). The centrality of parental fear and shame, particularly around parents' perceptions of the negative impact of psychosis on their children and the threat of disconnection, also echoes findings seen in studies and reviews of parents who experience SMI (Ackerson, 2003; Dolman et al., 2013; Harries et al., in preparation; Mulvey et al., 2021). These findings parallel recent research suggesting that children of parents who experience SMI can experience an inflated sense of responsibility to support their parents (Strand et al., 2020; Villatte et al., 2022), which may contribute to parents' sense of shame seen in SMI parenting populations, including mothers and fathers who experience psychosis.

The adverse impact of stigma on parents' sense connection to their authentic selves and desired parenting identities found within the current psychosis-specific parenting sample extends findings from previous studies of mixed samples of mothers and fathers who experience SMI (e.g., Chen et al., 2021; Diaz-Caneja & Johnston, 2004; Nicholson et al., 1998; Parrott et al., 2015; Savvidou et al., 2003). Although both mothers and fathers experiencing psychosis reported significant parenting challenges, including battling against fear and the threat of disconnection with their children that compromised their ability to connect to a valued parenting identity, fathers appeared to experience the most significant challenges. Fathers perceived particularly negative perceptions of their ability to 'provide', which appeared to be exacerbated by barriers uniquely impacting fathers, including perceived service access limitations; a possible gendered stigma (Reupert & Maybery, 2009; Reupert et al., 2021) posing additional challenges and barriers to pre-existing mental health stigma facing fathers who experience psychosis.

The powerful role of an aversive practitioner-led risk-focus in thwarting both mothers' and fathers' ability to connect with service support, communities around them, and a secure parenting identity enhances previous research that highlights that crisis-orientated services can pose a barrier to parents accessing service support (Jones et al., 2016; Mulligan et al., 2021). This finding suggests that services which are led by threat perceptions, a possible a product of practitioner burnout (Johnson et al., 2018), can exacerbate perceptions of difference and divide, and amplify problem-based narratives, both for parents, families and services. These perceptions and narratives appear to actively distance parents who experience psychosis from the support they need. This finding suggests a possible systemic and trans-generational attachment function (Bowlby, 1969, 1988) that healthcare providers and wider networks might play in supporting, or undermining, parents' capacity to feel connected and secure in themselves and their relationship with their children and the systems around them (Reupert & Mayberry, 2007).

Clinical Implications

Our findings suggest that systemic practice change is needed, in line with recent calls to reduce stigma and promote social and systemic connectedness for parents experiencing multiple adversities (Goodyear et al., 2022; Reupert et al., 2022). Psychoeducation could promote practitioner ability to understand and connect with individual parent needs, as opposed to viewing parents who experience psychosis through risk-based lenses. Systemic intervention that targets stigma, promotes understanding, and increases compassionate and meaningful connections between parents and the systems around them, could promote parents' sense of safety and security in exploring relationships with their parenting identity, their children and the communities they live within, promoting a 'safe base' for parents to explore and manage the complex demands of parenting in the context of psychosis (Ainsworth & Bell, 1970). A framework of compassionate and inclusive support for mothers and fathers who experience psychosis, facilitated by parents with lived experience of psychosis, could help to target pervasive stigma that appears to underpin system-wide fears that serves to undermine the integrity of parents' sense of security in their parenting roles. Given recent reports suggesting that FFP is not adequately implemented regardless of the legislation that mandates it (Falkov et al., 2016; Furlong et al., 2021), a system-wide shift to promote parents' sense of security and comfort across multiple levels of the system (Bronfenbrenner, 1992) is indicated.

Strengths, Limitations and Future Research

The study findings significantly contribute to the dearth of qualitative literature exploring parenting experiences of mothers and fathers who experience psychosis, including their experience of service support. The inclusion of both mothers and fathers experiencing psychosis in the present study represents a strength, allowing for in-depth exploration of

maternal and paternal experiences of psychosis and the support offered to them in a UK healthcare context.

Although in-depth exploration of parents' narratives using IPA methodology allowed for a deeper exploration and understanding of participant experiences compared to other qualitative approaches, such as Thematic Analysis (Braun & Clarke, 2006; Murray & Wilde, 2020), some limitations should be considered. The sample was small and consisted of predominantly white British biological parents, thus possibly limiting the transferability of study findings to other parenting populations. A small number of fathers were included, and although in-depth exploration of these fathers' narratives was undertaken, the transferability of study findings to other fathers who experience psychosis may be limited. Future research should aim to explore the experiences of broader samples of fathers who experience psychosis.

The purposive nature of sampling for this study also represents a possible limitation, within which parents who participated might have been especially knowledgeable or interested in the topic of parenting and psychosis, compared to other parents who did not volunteer. Thus, it is difficult to establish whether the experiences reported were representative of the wider population of parents who experience psychosis. Furthermore, the relationship between the interviewer and participant is important to acknowledge. Given discourses of power imbalance that are often present in relationships between people who experience psychosis and healthcare professionals (Eassom et al., 2014), the interviewer-participant relationship may have presented a barrier to parents talking more openly about their experiences, particularly if participants perceived the interviewer to be aligned with healthcare services.

Although IPA is deemed a suitable methodology for exploring the experiences of small samples (Larkin et al., 2006; Tuffour, 2017), future research should replicate the findings across mothers and fathers living in different socio-political contexts and

healthcare systems internationally before the study findings can be considered transferable to other contexts, especially those outside of EIPs in the Northwest of England. Future research should consider parents' experiences of receiving support from services that actively promote FFP, given that the NHS long term plan (NHS; 2019) advocates for the implementation of family-focused support across mental health services.

Conclusions

The present study provided novel insights into the interplay between parental perceptions of exposure and disconnection on how mothers and fathers who experience psychosis experienced and navigated their parenting role and support from services. Parents who experience psychosis need to be compassionately supported by, connected to, and contained within family, peer, and service networks to ensure the provision of appropriate and accessible parenting support. The integral role of reliable and relatable others in promoting parental engagement with support and optimism for better parent and child outcomes is indicated.

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Paper 3
Critical Appraisal

Claire I. Harries

This paper is a reflective piece and not intended for publication.

Word count: 6,000 (main text; excluding references)

Introduction

This paper provides an overview and critical evaluation of my attempts to explore and understand the experiences of parents who experience significant mental health difficulties, including psychosis, and their parenting support needs. This paper will consider the process of conducting a systematic review and empirical study, including the development of research questions, conducting interviews and interpreting data. Strengths and limitations of the research will be considered. The challenges faced, lessons learned, and my reflections regarding the contributions of this research to the evidence base, future research, implications for clinical practice and my own personal and professional development will be presented.

Paper 1: Systematic Review

Rationale for the Topic

My clinical interest in supporting parents who experience mental health difficulties inspired me to undertake research that aimed to better understand parental mental health difficulties and parenting support needs. This was in line with the interests of the review team, who recognised that multi-million-pound investments were being made nationally to support families within which a parent experiences mental health difficulties through the promotion of Family Focused Practice (FFP, Goodyear et al., 2015; 2017; Grant et al., 2018) in line with commitments from the National Health Service's (NHS) Long Term Plan (NHS England, 2019). However, upon recognising that the experiences and service preferences of parents who experience significant mental health difficulties were not well-understood (Radley et al., 2022; Strand et al., 2020), the notion of evidence-based practice was questioned, and a research-practice gap was identified (Ennis & Wykes, 2013; Gillard et al., 2012; Skivington et al., 2021). Therefore, a systematic review that focused upon

better understanding parenting experiences for those with significant mental health difficulties and their support needs was considered an important research area to address.

Parenting in psychosis was considered as a potential review topic. Initial literature scoping revealed that much psychosis research focused upon quantitative child and family outcomes consequent of parental experiences of psychosis (e.g., Campbell et al., 2018; Donatelli et al., 2010; Goldstein et al., 2010) and reviews already existed highlighting the influence of parent factors on the psychosocial wellbeing of children (Bee et al., 2014; Dretzke et al., 2009). It was less clear, however, how parenting was experienced in the context of psychosis, and no review existed that had synthesised qualitative literature of parents who specifically experienced psychosis. Despite this, initial exploratory database searches using Google Scholar and PsychInfo revealed very few qualitative studies exploring parenting experiences among parents who experienced psychosis only (Appendix U). This was considered striking given that the impact of parental mental health difficulties on parenting outcomes is becoming increasingly recognised (Allen, 2011; Goodyear et al., 2022; National Institute for Health and Excellence [NICE], 2016; NHS, 2019). However, given the lack of qualitative research, the value of conducting a meaningful appraisal and synthesis of parenting experiences in psychosis only appeared limited (Higgins & Green, 2008). It was therefore considered necessary to first establish a comprehensive and broader understanding of the parenting experiences and support needs of parents who experience other Serious Mental Illnesses (SMI), including psychosis, schizophrenia and bipolar disorder.

Advanced exploratory searches revealed a substantial research-base of quantitative literature focusing upon clinical outcomes among parents who experience SMI. However, qualitative parenting experiences and support needs had been less widely reported. Previous reviews of parenting experiences among parents who experience SMI revealed a focus on mothers (Dolman et al., 2013) or parenting in specific cultures (Chen et al., 2021).

The essential role of fathering had been overlooked, perhaps reflective of societal associations of parenting with mothers (Lacey et al., 2015). Cross-cultural and up-to-date insights regarding the experiences and support needs of mothers and fathers who experience SMI was lacking, which was considered significant given FFP initiatives and the intentions of the NHS long term plan (2019). The chosen review topic – to explore the experiences and support needs of parents who experience SMI – was thought to offer novel contributions and meet an important research-practice gap.

Throughout the process of choosing a review topic, I learned valuable lessons in considering practice guidelines, policies and legislation in relation to clinical need. I utilised clinical supervision and a research diary to support this learning process, as indicated as good practice by Boland et al. (2017).

Searching the Literature

I acknowledged that retrieval of relevant literature for reviews is reliant on a sound search strategy (Cooper, 1998), and that developing a broad but focused strategy can be a challenge (Smith et al., 2011). In generating search terms, a list of synonyms was first developed in relation to the key concepts of '*serious mental illness*' and '*parenting*'. This stage proved more challenging than anticipated given the breadth of terms related to SMI. Preliminary testing of search terms returned a huge number of results. I utilised supervision and consultation with the University of Manchester (UoM) library service to support search strategy refinement, which supported consideration of how to effectively combine search terms using the SPIDER tool (Cooke et al., 2012). The terms '*hallucinations*', '*delusions*', and '*mania*' were removed and were considered not needed given the other over-arching terms. I became aware that some studies identified through initial literature scoping did not specify a qualitative methodology in the title, abstract or keywords and would have therefore been missed during searching. To avoid missing any relevant studies,

the concepts of 'design' and 'evaluation' were combined using the Boolean operator 'OR'. Discussion was held with the review team before the search strategy was finalised (see Paper 1, Table 1). Test searches returned a comprehensive but manageable number of articles to review.

Four additional studies were identified through forward and backward searching of reference lists of included studies (Horsley et al., 2011) that were not retrieved from search results. Although this may indicate that other relevant studies were not retrieved in the search process, it is acknowledged that a search of qualitative literature should aim for 'conceptual saturation' (Doyle, 2003) rather than locating every available study. Given that 6,881 records were identified through database searching, and that 28 studies were included in the review, the review was considered to be comprehensive. Furthermore, a reviewer independent of the research team screened a random sample of 10% of search results against inclusion criteria. Substantial agreement was reached between myself and that reviewer, suggesting a robust and sound screening process.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were developed to be clear and specific to ensure inclusion of studies that were in line with the aims of the review. The decision to include studies that utilised mixed methodologies but reported qualitative findings was made to avoid missing relevant parental experiences. The inclusion criteria specified that only studies that specifically focused on parenting experiences could be included to avoid inclusion of studies reporting on parenting experiences in the context of specific parenting interventions, because the aim of the review was to establish a broad understanding of parenting experiences and support needs. The decision was made to exclude studies focusing on parenting experiences that were restricted to the perinatal period only because

the perinatal period is a period that presents unique parenting challenges compared to other parenting periods (Howard & Khalifeh, 2020; Nelson, 2003; NICE, 2014).

The operational definition of SMI was discussed at length with the review team, given that the umbrella term of ‘SMI’ is a socially constructed concept (Martínez-Martínez et al., 2020) developed as a tool to identify individuals considered to be ‘most vulnerable’. The lack of agreement in the operational definition of SMI in the research literature was considered (Bye & Partridge, 1997; Kessler et al., 2003). Given the review aims, the research team believed that it was important to explore how SMI had been operationalised in clinical practice guidance, which revealed that diagnoses of psychosis, schizophrenia and bipolar disorder were considered ‘SMI’ (NICE, 2014). Thus, we defined SMI as psychosis, schizophrenia, schizophrenia-spectrum disorders and bipolar disorder. However, I became aware that samples of parents in several studies had included parents with additional mental health diagnoses, including anxiety and low mood. Following discussion with the review team, the decision was made to include studies that involved samples of parents with diagnoses other than schizophrenia-spectrum disorders or bipolar disorder, because we did not wish to exclude data that may have been relevant to the aims of the review.

Only studies published in peer-reviewed journals were included. The review team debated the inclusion of grey literature in systematic reviews due to its potential to moderate publication bias (Dwan et al., 2008; Haddaway & Bayliss, 2015; Martin et al., 2005). Given time limitations and because quality appraisal methods do not always align with grey literature presentation (Adams et al., 2017), it was decided that it was not necessary to broaden the literature search beyond academic, peer-reviewed articles. Time constraints and financial resources also did not permit translation of studies that might have been published in languages other than English or German (languages that the review

team were fluent in). This is a recognised limitation of the review because further cross-cultural insights may be missing.

Appraising the Methodological Quality of Included Studies

The debate around assessing the methodological quality of qualitative research (Thomas & Harden, 2008) was considered with the review team. We reflected on the complex “*interrelationship between research quality and truth claims*” (Thorne et al., 2004, p.1362) and considered whether qualitative research can or should be assessed. When reflecting on my clinical practice, I acknowledged that ‘good quality’ formulations that accurately capture complex psychological processes can be helpful for individuals and systems, but that ‘poorer quality’ formulations can be unhelpful or even harmful (Johnstone & Dallos, 2006). I reflected on the parallels with good and poor quality research, within which poor methodical quality can thwart the merit of reported findings (Tong et al., 2012). It was decided that appraising the methodological quality of included studies would be helpful in promoting systematic rigour. However, no studies would be excluded based on low quality appraisal scores because 1) there is no widely accepted approach for excluding studies based on ratings (Dixon-Woods et al., 2006), and 2) it was clinically important to not exclude the parent voice based on author methodology.

I was motivated to ensure the choice of quality appraisal tool was appropriate for the review. I consulted the review team and reviewed articles exploring quality assessment tools (e.g., Majid & Vanstone, 2018). The Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative studies (available from <https://casp-uk.net>) was selected and deemed an appropriate tool. The CASP is a widely used quality appraisal tool in qualitative research (Long et al., 2020) and permits key issues of methodological validity and rigour to be appraised. Although the CASP offers a framework for reflecting upon methodological quality, it does not offer a summary scoring system to promote the identification of higher

or poorer quality studies. Therefore, a summary scoring system was used, similar to the review by Butler et al. (2020), to facilitate clear summary ratings, allowing ease of comparison of methodological quality ratings between included studies.

The process of appraising studies using the CASP supported me to understand the included studies more comprehensively. However, challenges were encountered. The level of subjective judgment involved in the appraisal process was notable, and I had not anticipated the sustained concentration required. My fluctuating concentration and fatigue may have increased the potential for biased ratings (Higgins et al., 2011). It was therefore important for an independent rater to complete the quality appraisal process to promote rigour and confidence in the rating process. The independent rater and myself piloted the appraisal process using the CASP together. Although it is acknowledged that subjective judgment can impact CASP judgments, the rater independently assessed all 28 of the included studies, and substantial agreement was reached, suggesting confidence in inter-rater judgments.

Analysis

The nature of the review question was reflected upon with the review team when considering choice of methodology. Data analysis was guided by Thomas and Harden's (2008) thematic synthesis, an approach that aims to uncover patterns within qualitative findings across studies. In line with the aims of the review, thematic synthesis can offer an appropriate method of addressing questions related to the development of policy and clinical practice (Barnett-Page & Thomas, 2009; Tong et al., 2012).

A large number of studies was included in the review. Although this was considered a strength, I initially felt somewhat overwhelmed by the amount of data presented for synthesis. I utilised supervision to discuss how best to approach data analysis and was helpfully encouraged to consider methods suited to my learning style to promote

data emersion. Upon recognising that I have previously benefited from using visual methods to manage large amounts of information, I decided not to use computer software. Instead, I used paper and pen methods to undertake line-by-line coding (Appendix V), following which individual codes were typed into Microsoft Word and printed out to allow visual development of descriptive themes (Appendix W), following which analytical themes and subthemes were developed using 'post-it' notes (Appendix X). Although time consuming, I felt that this approach allowed me to become immersed in the data and promoted thorough exploration of patterns across studies. The challenge of remaining sensitive to idiosyncrasies within and between studies was acknowledged, particularly given that the parents included in the review could be considered a relatively heterogenous sample. Future research could consider whether differences exist in parenting experiences between specific diagnoses under the SMI umbrella, including psychosis.

A further challenge was remaining aware of my own subjective bias when interpreting data and being sensitive to not placing undue emphasis on some findings over others. Conducting a metasynthesis involves the reconceptualisation of study findings, which has been considered a controversial process given the reliance on judgments of individual reviewers (Thomas & Harden, 2008). It was therefore important to consider my reflexive positioning (Berger, 2015). Use of a reflective diary and regular supervision supported this process. Reflective conversations were held about the potential impact of my social position, personal experiences around parenting, professional beliefs about clinical psychology and wider political beliefs to ensure that concepts that were derived from the analysis were reflective of the data and not unduly influenced by my own positioning. Without such reflective discussions, an increased risk of biased interpretations may have been presented. To further minimise risk of bias, five randomly selected included studies were independently analysed by a member of the research team which revealed similar interpretative accounts of the data. Although the likelihood of subjective

bias could have been reduced further if all included studies were independently analysed and extracted data was checked (Sargeant & O'Connor, 2014), time and resource limitations did not allow for this.

Trustworthiness and Credibility

The Enhancing Transparency in Reporting the synthesis of Qualitative research ENTREQ checklist (Tong et al., 2012) was used. The ENTREQ framework ensured that a number of steps were taken to promote trustworthy and credible review findings, including 1) the use of an independent reviewer to screen 10% of search results, 2) the use of an independent reviewer to quality appraise 100% of included studies, 3) the clear and comprehensive presentation of study characteristics, 4) the use of a second author independently coding and analysing five included studies, 5) the use of substantive quotes to support review findings, and 6) the development of a conceptual model to visually represent thematic synthesis results. Appendix B demonstrates that all ENTREQ items were met.

Summary

The systematic review was the first comprehensive synthesis of qualitative literature exploring mothers and fathers' experiences and perceptions of the impact of SMI on parenting and their support needs that was drawn from diverse samples and not restricted to specific cultures. The review aims were met fully. Future reviews should include studies written in diverse languages and consider specific parenting challenges and mental health difficulties to explore what support needs might be indicated. Throughout the review process, steps were taken to ensure that the review was undertaken with methodological rigour to enhance the credibility of findings. Recommendations for clinical practice and service delivery were highlighted, reflecting a strength of the review.

The experience of conducting a systematic review has encouraged me to reflect on my learning style and has promoted my confidence in seeking and utilising advice and guidance from professionals from multiple backgrounds; learning that I will take forward in my clinical work. Although challenging, I enjoyed the process of conducting in review and found the results and implications for practice compelling. Since conducting the review I have noticed an increase in my motivation to discuss research implications with colleagues, particularly regarding ideas about promoting compassionate approaches to supporting parents who experience multiple adversities and targeting stigma. In summary, I have gained valuable clinical, research, and personal lessons throughout the systematic review process, and feel inspired to implement change, improve my clinical practice and support wider service developments for parents who experience multiple adversities.

Paper 2: Empirical Study

Rationale for the Topic

The empirical study was closely aligned with the aims of the systematic review and my own clinical interests and ambitions, within which I have a keen interest in supporting parents who experience mental health difficulties. When considering empirical research topics with the research team, I was struck by the apparent lack of awareness about parenting in services that support people who experience psychosis (e.g., Early Intervention in Psychosis [EIP] teams). This was evidenced in a recent audit that demonstrated a lack of EIP clinician adherence to asking clients about parenting (Tuck et al., 2020, unpublished audit). I was interested to hear anecdotal reflections about the difficulties that colleagues working with parents in EIP teams faced when thinking about how parenting might be impacted by psychosis. I felt drawn to understanding and connecting with the experiences of parents who experience psychosis, including their

experience of support, which consolidated my motivation to explore this research area further.

I was surprised when exploring the literature to discover the significant lack of research exploring parenting experiences in the context of psychosis (Radley et al., 2022; Strand et al., 2020), particularly in the UK for both mothers and fathers (Evenson et al., 2008). The national drivers to better support parents with mental health difficulties, including psychosis (Goodyear et al., 2015; 2017; Grant et al., 2018; NHS England, 2019), were reflected upon with the research team. We recognised the significant research-practice gap and considered the clinical and research need to better understand parenting experiences and support needs in the context of psychosis, by highlighting parent voice and understanding parenting experiences, to inform clinical practice and future research. Thus, the study aimed to explore how parents who experience psychosis experienced parenting and the support offered to them.

Design and Methodology

The study sought to explore parental experiences, so a qualitative methodology was deemed appropriate. Different qualitative methods were considered when choosing the methodology that would allow the research question to be answered, including Thematic Analysis and Grounded Theory. Although qualitative approaches all share similarities, in that they attempt to make sense of the accounts of individuals that experience a given phenomenon (Noblit & Hare, 1988), theoretical and methodological differences exist between approaches. Interpretative Phenomenological Analysis (IPA; Smith & Osbourne, 2003) was selected, which unlike Thematic Analysis and Grounded Theory, promotes in-depth exploration of the lived experiences of small group of people (Smith, 2004; Smith & Osbourne, 2007; Smith et al., 2009). IPA promotes the development of analytic themes to describe meanings assigned to the group being studied while also acknowledging that

unique experiences are presented within the sample (Tuffour, 2017). Given the lack of qualitative research into parents who experience psychosis, the need for an in-depth understanding of a group of parents experiencing psychosis, and with the research team aiming to ‘give voice’ (Larkin et al., 2006) to mothers and fathers experiences, IPA was considered particularly suitable. As IPA was a new methodology to me, it presented a unique learning opportunity.

The topic guide was designed in line with IPA methodology, within which questions were designed to encourage participants to lead discussions. An individual with lived experience of psychosis was consulted which helped consideration of how to support participants to feel empowered to communicate their experiences to support deeper explorations of the phenomena that participants discussed.

Patient and Public Involvement (PPI)

Consultation with an individual with lived experience of psychosis made a valuable contribution to design procedures, including processes for promoting participant comfort and language use within the topic guide. Feedback from consultation was incorporated into study processes, including spending time at the beginning of interviews supporting participants to feel comfortable, and revision of the topic guide by incorporating ‘less formal’ language. When reflecting on the rich narratives that participants shared within interviews, the benefits of PPI involvement were further appreciated. In line with national strategic plans that highlight the importance of PPI in clinical research (Centre for Research in Public Health and Community Care [CRIPACC], 2018), I aim to promote service user participation in my future clinical and research work.

Recruitment

During initial research presentations to staff working in participating organisations, feedback suggested that many clinicians were supporting parents who experienced psychosis. However, challenges in successfully recruiting participants were soon realised. In accordance with the NHS Research Ethics Committee (REC) and the local Research and Development (R&D) department approved study protocol, recruitment followed a multi-stage approach, which on reflection, presented significant challenges and contributed to slow recruitment rates. Participants were firstly contacted by service staff who shared information about the study, following which a consent to contact process took place. Thus, recruitment of participants relied on service staff, many of whom reflected being “*over-stretched*” consequent of busy caseloads and supporting clients in particularly challenging situations throughout the COVID-19 pandemic.

I wondered whether service staff might have been reluctant to initiate discussions about the study with service users due to fears of detecting risk issues that they felt under-resourced to adequately manage (Mulligan et al., 2021; van Esch & de Haan, 2017). I also wondered whether parenting was not a topic perceived to be important to service staff, possibly resulting in the study being considered less important compared to other larger scale psychosis studies. In addition, I wondered whether the initial slow recruitment might have been influenced by staff reservations about contacting parents who experienced more severe difficulties. This might have resulted in important experiences being missed from the presented data due to selected exclusion (Emanuel et al., 2000). In supervision, I reflected that clinical psychology training had equipped me with the skills and confidence to manage complex risk situations. I wondered whether other staff might have had a lower tolerance for risk and resultantly excluded participants from consideration. Future research may benefit from providing training or support to staff around risk and safeguarding prior

to commencing research studies to build their confidence around managing risk, thus possibly increasing recruitment rates and minimising inclusion biases.

To facilitate recruitment, it was decided with the research team that I would spend a morning each week ‘embedding’ myself with the staff team of a collaborating EIP. Although this approach proved helpful, it was very time intensive. Additionally, I reflected on the notion that recruiter characteristics can influence recruitment (Newington & Metcalfe, 2014), and considered a possible selection bias of participants within which service staff may have approached parents with certain characteristics that aligned with their biases or my perceived personality traits. Additionally, although purposive sampling promoted identification of parents who were able to provide rich narratives about their experiences, this sampling strategy may have limited the variety of parental experiences reported. The participants who volunteered might have represented a particular subset of parents who were especially insightful, articulate or interested in the topic of parenting and psychosis. On reflection, recruitment via social media platforms may have offered a wider platform to reduce selection bias and reduce reliance on clinician referrals.

Five mothers and three fathers took part, which is an appropriate sample size for IPA (Noon, 2018; Smith et al., 2009). Five participants were white British, two were Black African and one was White European, and they ranged in their age, number of children, educational background, relationship status and living arrangements. The sample was fairly heterogenous. Future research, involving different research sites across different geographic locations, and using different recruitment methods, may support the development of an increased understanding of differences among experiences of parents who experience psychosis to increase the transferability of study findings. It would be particularly important to further explore fathers’ experience given the relatively low number of fathers included in the study.

Data Collection

Before interviews began, time was spent engaging participants in general conversation unrelated to the research area, with the aim of reducing perceptions of power imbalance and to support participants to feel comfortable and at ease. Time was also spent explaining my role as a researcher, with the aim of reducing associations between myself and mental health services to encourage participants to be open and reflective about their experiences. Following consent procedures, the interview was semi-structured which is the most widely used qualitative interview format (Smith et al., 2009). The structure allowed an interview focus that aligned with the aims of the research while allowing flexibility and encouraged participants to lead discussions and discuss aspects of parenting that were most important or salient to them.

I considered my previous experience of working clinically with parents who experience multiple adversities and conducting qualitative interviews in previous researcher roles to be helpful in building participant rapport and being able to use open and reflective questions to facilitate engagement. However, I recognised challenges in terms of researcher and clinician role confusion. I acknowledged that I had to remain within my researcher role to facilitate rich interviewee narratives, but I recognised a ‘pull’ to facilitate therapeutic change, particularly when parents described feeling ‘stuck’ with their difficulties. I also wondered how participants’ previous experiences of engaging with services and mental health practitioners might have influenced their interaction with myself. I reflected on imbalanced power dynamics that often exist between individuals who experience psychosis and healthcare professionals (Eassom et al., 2014), and made efforts to minimise my position as a professional and adopted a curious, not knowing stance, supporting participants to share their experiences as experts in their own lives (Larner, 2000). The use of a reflective diary and supervision supported me in separating research and clinical roles to minimise risk of the data being influenced by positioning. I

recognised the benefit of listening to recordings and transcribing interviews, which afforded me with additional opportunity to reflect and develop my interviewing skills.

The opening question was considered an important contextualising foundation for the rest of the interview. The first four interviews were opened with “*could you tell me about your experience of parenting?*”. Although participants offered discussions about their parenting, it was recognised that this question did not offer an initial foundation for parents to consider their experiences of psychosis alongside parenting. Thus, the remaining interviews opened with “*could you tell me about your experience of psychosis?*”. It was interesting to notice how experiences of psychosis appeared to underpin parental narratives within the subsequent interviews, highlighting the importance of the contextual positioning of questions and language content in participants’ attempts to make sense of their experiences.

Interviews were conducted over the telephone, in mental health services, or in participant homes. Precautions relating to the COVID-19 pandemic mandated that most interviews were conducted over the telephone. Although I was initially apprehensive that telephone interviews may not have promoted data as ‘rich’ in quality as those conducted face-to-face, and that building rapport may have been more challenging, this appeared not to be the case, in line with suggestions from Carr and Worth (2001). Despite this, it was not possible to determine non-verbal information over the telephone, which might have provided additional information to support the sense-making process (Smith et al., 2009). A further limitation of telephone interviews was the presence of distractions, within which interviews could be interrupted by children or partners. Although efforts were made to reduce the impact of this occurring, the presence of others during interviews may have impacted parents’ ability speak openly about their experiences.

Data Analysis

All interviews were transcribed by myself from the Dictaphone recording and analysis followed IPA guidelines (Smith & Osbourne, 2003). During the process of transcription, I benefitted from gaining a sense of ‘closeness’ to the data, within which elements of the data that I had not previously noticed were realised (Smith et al., 2009). The process of analysing data was more time exhaustive and challenging than I had anticipated; however, the value of supervision throughout the analysis process was invaluable in supporting me to reflect upon and work through challenges. For example, I initially planned to use NVivo software (QSR International Pty Ltd [Version 12], 2020) to support coding of transcripts; however, I encountered challenges with visualising patterns within participant narratives using this software and found that I benefitted more from using computer software that I was more familiar with. The process of line-by-line coding was time consuming given the volume of codes produced. However, the use of supervision and my reading of published guides on IPA research (e.g., Smith et al., 2009) were valuable in normalising these experiences. I was encouraged in supervision to reflect on my learning style when searching for patterns across transcripts and noted that I had found ‘post it’ note methods beneficial in previous qualitative research. I found this visual approach containing and promoted flexible exploration of the connections between themes.

Although IPA was considered well-aligned with the aims of the study, some limitations were discussed with the research team. Much consideration was given to minimising the impact of bias. In particular, the subjective nature of IPA methodology – a feature of many forms of qualitative methodology (Ritchie & Spencer, 2002) – within which there exists risk that interpretations may be unduly influenced by the internal world of analysts (Smith et al., 2009) was considered. Reflective discussions within supervision were facilitated about the process of ‘double hermeneutics’, within which participants attempt to articulate and make sense of their experiences, while the researcher

simultaneously attempts to make sense of this process. To avoid interfering with participants' narratives, I engaged in reflexive bracketing (Ahern, 1999), within which I noted my own assumptions and beliefs about parents' experiences and statements to avoid undue influence of my own interpretative world on the analysis (Smith et al., 2009). It was also important for me to recognise and consider my reflexive positioning (Berger, 2015). The use of a reflective diary and regular supervision supported the uncovering of unconscious biases within the reflexive process (Yardley, 2000) to promote balanced and comprehensive data interpretations. This process supported me in remaining aligned with participant stories, while also allowing me to view the data through a 'critical lens' (Braun & Clark, 2013).

The analysis was approached from a position of critical realism (Bhaskar, 1978), which was underpinned by a constructivist epistemology. Use of a reflective diary and regular supervision supported discussions and considerations about the a 'real world' existing independently of theory and perceptions, and constructions and meaning that is built from 'observable' experiences (Creswell & Plano Clark, 2017). Although this epistemology was considered appropriate, it is acknowledged that a contextualist epistemology might have promoted further exploration of the meanings and experiences of parents in the context of societal influences, which may have been more in line with my preference for systemic thinking.

I was motivated to ensure trustworthiness and credibility of the analysis process and I aimed to ensure the analysis was iterative and reflexive (Tobin & Begley, 2004). To facilitate this process, in depth discussions were held between myself and a second author regarding each interview. The process of generating codes and themes was also conducted by myself and that author independently for two participants to ensure that valid codes and themes were generated. Interpretations of participant stories were compared on a case-by-case basis for all participant narratives and all themes were discussed and agreed with the

research team to ensure that the findings were credible. I found supervision to be invaluable throughout the analysis process in ensuring that analytical themes were aligned with participants experiences and helping me to build a coherent story of the themes to support the write up.

Summary

The empirical study was the first in the UK to seek maternal and paternal experiences of psychosis and their parental support needs using IPA. Novel insights were presented regarding the interplay between parental experiences of psychosis, parent-child connections and wider systemic relationships, and parental support needs. The study findings highlighted the integral need for non-stigmatising, reliable and inclusive system-wide support.

The process of conducting this research was closely aligned with my clinical interests and has promoted my motivation to pursue a career in supporting parents who experience multiple adversities. I learned valuable lessons in qualitative research methodology, including the importance of considering reflexivity and hermeneutics, which I will take forward in my practice.

Overall Reflections of Completing a Large-Scale Research Project

Impact of Research and Dissemination

Throughout the research process I have been motivated to conduct research that could ultimately benefit parents who experience significant mental health difficulties by developing a better understanding of their experiences and support needs with the potential to inform policy and clinical practice guidelines. Within the empirical study, parents provided emotive, in-depth accounts of their experiences and I am driven to respect and honour their voices and utilise their experiences to positive effect. In my clinical work, I

aim to highlight the parent voice and their needs to bring the topic of parenting into focus among practicing clinicians, in line with the aims of the NHS Long Term Plan (2019). The findings from the systematic review and empirical study can help inform FFP approaches and national guidelines related to clinical care for parents who experience significant mental health difficulties.

The majority of parents consented to be informed about the empirical study results, and a written lay summary will be provided. Additionally, several referring clinicians requested information about the study outcomes, and I have offered to present the findings and implications for practice within team meetings. The empirical study and systematic review are planned to be disseminated to the wider academic community by 1) presenting results at a research conference at the University of Manchester (UoM) in June 2022, 2) publicising findings on UoM and relevant NHS Trust websites including the Perinatal Mental Health and Parenting Research Unit (PRIME-RU), and 3) submitting manuscripts to the named journals.

Overall Reflections

The research process has important implications for my clinical practice. I have gained skills and confidence in designing and conducting research, throughout which my appreciation of working within a scientist-practitioner model has grown and my understanding of the role of research in facilitating change has developed. I am grateful for the experience I gained in a qualitative methodology that was new to me, and for the skills I developed in connecting with participants and their narratives. Throughout the process of conducting interviews, listening to audio-recordings, transcribing, and analysing interviews, I became aware of the importance of language and cues in connecting with experiences and others, which has helped develop my ability to listen and ‘be with’ individuals in my clinical work. Relatedly, I have recognised the integral role of critical

reflection, within which bringing conscious awareness and reflection to my thoughts, feelings, perceptions and biases has promoted a sense of being more self-aware and able to challenge my internal world to facilitate empathic attunement to the individuals that I work with clinically. Supervisory support has been invaluable throughout this process.

I have learned a tremendous amount, both personally and professionally throughout the research process. The nature of balancing research, clinical and academic work alongside my personal life, particularly during a global pandemic, has been challenging. However, I feel a great sense of pride and achievement for having completed this project. I have recognised the value of working to my strengths, naming my limitations, and seeking advice, support, and guidance from supervisors, colleagues, and wider networks of peers and my family.

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Appendices

Appendix A. Author Guidelines for Clinical Psychology Review



CLINICAL PSYCHOLOGY REVIEW

AUTHOR INFORMATION PACK

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Clinical Psychology Review publishes substantive reviews of topics germane to **clinical psychology**. Papers cover diverse issues including: psychopathology, psychotherapy, behavior therapy, cognition and cognitive therapies, behavioral medicine, community mental health, assessment, and child development. Papers should be cutting edge and advance the science and/or practice of clinical psychology.

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Appendix B. Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Checklist (Tong et al., 2012)

No.	Item	ENTREQ guide/description	Present?
1	Aim	State the research question the synthesis addresses.	✓
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (<i>e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis</i>).	✓
3	Approach to searching	Indicate whether the search was pre-planned (<i>comprehensive search strategies to seek all available studies</i>) or iterative (<i>to seek all available concepts until they theoretical saturation is achieved</i>).	✓
4	Inclusion criteria	Specify the inclusion/exclusion criteria (<i>e.g. in terms of population, language, year limits, type of publication, study type</i>).	✓
5	Data sources	Describe the information sources used (<i>e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists</i>) and when the searches conducted; provide the rationale for using the data sources.	✓
6	Electronic Search strategy	Describe the literature search (<i>e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits</i>).	✓
7	Study screening methods	Describe the process of study screening and sifting (<i>e.g. title, abstract and full text review, number of independent reviewers who screened studies</i>).	✓
8	Study characteristics	Present the characteristics of the included studies (<i>e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions</i>).	✓

9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (<i>e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development</i>).	✓
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (<i>e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings</i>).	✓
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (<i>e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting</i>).	✓
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	✓
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	✓
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (<i>e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software</i>).	✓
15	Software	State the computer software used, if any.	✓
16	Number of reviewers	Identify who was involved in coding and analysis.	✓
17	Coding	Describe the process for coding of data (<i>e.g. line by line coding to search for concepts</i>).	✓
18	Study comparison	Describe how were comparisons made within and across studies (<i>e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary</i>).	✓

19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	✓
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author's interpretation.	✓
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. <i>new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct</i>).	✓

Appendix C. Table of the Six Main Themes, 14 Subthemes and Additional Exemplar Quotes

Theme	Subtheme	Additional Exemplar Quotes
1. The Constrained Parent	1.1. 'Perfect' Parenting Standards	<p>"I was possibly asking myself to be more perfect [as a mother]. I couldn't accept that I wasn't able to be extra good to her [the child] with all my heart and soul." (Chen et al., 2021).</p> <p>"You never tell people you have got bipolar disorder, because they think you are nuts, that you go completely Jesus Christ, run up and down the street naked" (Wilson & Crowe, 2009).</p> <p>"I had a long time in those early days when I felt really useless as a parent, really, really useless" (Wilson & Crowe, 2009).</p>
	1.2. Emotion Regulation Difficulties	<p>"I would get really angry. There was so much going on in my head, and it was so loud and I didn't know that wasn't normal, and it would make me snap and get angry and just everything seemed to be coming at me at once. Um, and that. . . being a mom, it was hard cause I would feel so bad, I would yell at my kids or you know, just get frustrated and I wouldn't be able to focus. . . cause there was so much thought going on. . . it [her anxiety] definitely affected me in a lot of ways and it was just overwhelming I think" (Mulvey et al., 2021).</p> <p>"I would hit him. It served him right. . . I didn't know why I could not stop. . ." (Chan et al., 2019)</p> <p>"I feel guilty a lot of the time because I get irritable with them, I get impatient and I don't know whether that is my illness or whether that is normal at times, it is hard to work out" (Wilson & Crowe, 2009).</p>
	1.3. Fears of Repeating History	<p>"I have a great fear that they too will suffer from mental illness, either genetically (my mother also had mental health problems) or socially because of what they have been through" (Diaz-Caneja & Johnson, 2004).</p> <p>"I get reminded of when I was a little, and I don't want him to experience the same. . . He gets sad when we play games and he loses. . . so I let him get what he wants" (Strand et al., 2020).</p>
	1.4. Avoidance and Masking	<p>"So you hide I – you try to be a good parent, but you hide it when you are not well. . ." (Wilson & Crowe, 2009).</p> <p>"I feel like with child welfare authorities that they really. . . like follow me with their eyes, how I am, how I seem to be. . . if I have a bad or good day, so I try-yes, to feel good. . ." (Klausen et al., 2016).</p>
2. Parenting Difficulties	2.1. Struggling for Control	<p>"I was not good at saying no, because I felt sorry for them [because they had been through so much] ... I tried to make their life easier" (Ackerson, 2003).</p> <p>"I found that there were no boundaries. . . . I didn't feel like cooking, so what I would do is spend money that I didn't have, and just give them money to buy takeaways and things like that, and letting them play out[side] when normally I would put my foot down" (Khalifeh et al., 2009).</p>
	2.2. Balancing Needs	<p>"It is hard to do anything being a full-time mother, you are running around after them all the time, cleaning up and you don't have time for yourself" (Perera et al., 2014).</p> <p>"There was a point where I just managed, and there was a point where I knew I couldn't do it anymore. I couldn't run the whole struggle, not even look after myself, much less to look after a child." (Khalifeh et al., 2009).</p>

	2.3. Amplification of Struggle due to Symptoms and Medication	<p>“. . .when I have those slips of memory, which are part of my illness, something major will get lost . . . and when it relates to the kids, that makes it hard to be a dad. I feel ashamed of having fallen short of my standards . . .” (Evenson et al., 2008).</p> <p>“Oh, they love it. They love it because we are at the park every- day, and I go around like animal with them, and then, you know, just going up and down the slide, you know, they love it, because mommy is so happy, you know, hey, if mommy has got all this energy, that most parents don’t have, you know...” (Venkataraman & Ackerson, 2008).</p> <p>“For me, it’s sad, but it makes it harder for me to put my child first. And makes it harder for me to focus more on his well-being than what I want to do for myself. Which sounds really bad. It sounds really sad. But it’s like if you want the honest to God truth, that’s the honest to God truth. And I wish that it would be better. And I wish that I could put more focus on to him in making sure that he’s good before anything else. But sometimes it’s just like my brain won’t let me do it. It’s just like I come first. Which I don’t want to. He’s my baby” (Sabella et al., 2022).</p>
	2.4. Connection to Child	<p>“when you are mentally unwell, you don’t spend as much time with your child because you are so consumed by your mental health” (Perera et al., 2014).</p> <p>“It’s difficult when my son gets anxious, I think. It’s hard not to go in and mix it up with myself, to project my feelings on him. It’s hard to see him as an individual...” (Strand et al., 2020).</p>
The Strained Child: Role Reversal and the Perceived Impact		<p>“I think he carries many hard things within himself that he doesn’t talk to me about. He talks to my care provider about it, and he doesn’t say it to me. He doesn’t want to hurt me, he wants to protect me and not make me sad” (Strand et al., 2020).</p> <p>“She became the little parent sometimes, and because she had that little bit of responsibility or something, it made it even worse for me to parent her!” (Ackerson, 2003).</p> <p>“Your mother is a patient. I don’t have the energy to discipline you ... So, you better manage yourself”, (Chen et al., 2021).</p> <p>“If you're feeling not too good in yourself, it seems like the kids, they sense it. And then they act out more” (Nicholson et al., 1998).</p> <p>"T [Son] then withdrew completely and didn't come any more. And A. [daughter] was overwhelmed and cut herself and all sorts of things. And then somehow during the follow-up consultation with the child psychiatrist she just said that she couldn't stand it with me any longer” (Jungbauer et al., 2010).</p>
3. Inescapable Threat	3.1. Loss and Separations Fears	<p>“If I did anything that made them think I was going crazy then they’d take my daughter away” (Diaz-Caneja & Johnson, 2004).</p> <p>“I think I would die if my daughter was every taken away from me, especially for the wrong reasons - you know, incompetence” (Nicholson et al., 1998).</p> <p>“I always thought they wanted to take my kids away from me. I saw everything in a negative way” (Jungbauer et al., 2011).</p>
	3.2. Stigma and Fears of Rejection	<p>“It is quite hard to ask for help when you need it because everybody thinks, oh she’s a bad mother, she can’t do this . . .” (Diaz-Caneja & Johnson, 2004).</p> <p>“I went to maintenance court so that he [the father] can support the children. He is supporting them but some months he doesn't and it becomes difficult for me to buy food for the children” (Rampou et al., 2015).</p>
	3.3. Inappropriate Support	<p>“Before my daughter was born I went to therapy and this information was passed on to Child and Youth Care. It [the information] followed its own course. Instead of being supportive, they kept me under strict control, based on the psychiatric diagnosis in my file” (van der Ende et al., 2016).</p> <p>“I was a bit worried about what they [children] might see, a lot of people wander around in a daze and look a bit nutty ... I was worried that they might think I was like that too” (Tjoflåt & Ramvi, 2013).</p>

		<p>“I’ve definitely been discriminated against by the judge. It was horrible. They’d talk to me like I was five. They looked at me like I was a disease of a father. I wanted to be there for my kid but was never given the opportunity by the courts to do it” (Sabella et al., 2022).</p>
4. Combatting Threat: Holding Hope, Goals and Aspirations		<p>“I want them to grow up in a decent, pleasant, lovable environment that doesn’t have any fighting, arguments, you know any kinda physical abuse. I want to have a nice home where I can own some day...I’d like to just live the rest of my life out with my kids in peace...” (Sands, 1995).</p> <p>“I want to get stable. You know, get settled in my relationship with [my son]. . .I mean, like re-establish. . .Slowly, confidently, you know, so he can be confident that I’m not gonna get, you know [crazy] again” (Mulvey et al., 2021).</p>
5. Wrap-around Support Needs	5.1. System-wide Compassion and Understanding	<p>“My mother saw that I was isolating myself, that my world became small and that I got stressed by raising my child. She said to leave him [her child] with her so I could breathe” (van der Ende et al., 2016).</p> <p>“...Having a work setting that accommodates day care, parental concerns, makes a big difference” (Ackerson, 2003).</p> <p>“I need a GP. I wanted a mum as a GP ... Cos I would say to her, “Is this a normal mother problem or is this a crazy mother problem?”” (Awram et al., 2017).</p>
	5.2. Connection to Support	<p>“I think there needs to be like a place where we could take our kids to take them somewhere because we need time to ourselves but I mean for just bipolar, you know” (Venkataraman & Ackerson, 2008).</p> <p>“I think it would be a group of people meeting up regularly, and perhaps the opportunity for their children to be there. Somewhere where you could talk, where you could have outings as well as get families together. And support from professional people there, not just people talking, but professional people helping them to cope as well...” (Diaz-Caneja & Johnson, 2004).</p>
	5.3. Psycho-education	<p>“I had a serious diagnosis, but I didn’t understand it, and perhaps neither did my therapists or my doctor. I was alone with my children, I was manic and psychotic and we didn’t get any help. Had they understood it and had my children been in kindergarten, it would have helped, both for my children and me . . . it’s quite as simple as that” (Tjoflåt & Ramvi, 2013).</p> <p>“It would be nice if nurses talked about the transference of psychiatric problems to the children. They should make it clear that we have to deal with it . . . although it is hard to do it.” (van der Ende et al., 2016).</p>

Appendix D. Matrix of Theme Representation within the Included Studies

	Study: Authors and year	Theme 1: The constrained Parent				Theme 2: Parenting Difficulties				Theme 3: The Strained Child: Role Reversal and the Perceived Impact	Theme 4: Inescapable Threat			Theme 5: Combatting Threat: Holding Hope, Goals and Aspirations	Theme 6: Wrap-around Support Needs		
		Perfect Parenting Standards	Emotion Regulation Difficulties	Fears of Repeating History	Avoidance and Masking	Struggling Control	Balancing Needs	Amplification of Struggle due to Symptoms and Medication	Connection to Child		Loss and Separation Fears	Stigma and Fears of Rejection	Inappropriate Support		System-wide Compassion and Understanding	Connection to support	Psycho-education
1	Sabella et al. (2022)	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-
2	Chen et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓
3	Mulvey et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓
4	Boström and Strand (2021)	✓	✓	✓	✓	✓	-	✓	✓	✓	-	-	-	✓	-	✓	✓
5	Strand et al. (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓
6	Chan et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-	-	✓	✓
7	Awram et al. (2017)	✓	-	-	✓	-	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓
8	Klausen et al. (2016)	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	-
9	van der Ende et al. (2016)	✓	✓	✓	✓	✓	✓	✓	✓	-	-	✓	✓	✓	✓	✓	✓
0	Parrott et al. (2015)	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓	✓
11	Rampou et al. (2015)	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓
12	Perera et al. (2014)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	-
13	Tjoflåt & Ramvi, (2013)	✓	✓	✓	-	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓	✓
14	Jungbauer et al. (2011)	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-	✓	✓
15	Montgomery et al. (2011)	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	-
16	Jungbauer et al. (2010)	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓
17	Khalifeh et al. (2009)	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	-
18	Wilson & Crowe (2009)	✓	✓	-	✓	-	✓	✓	-	-	-	✓	✓	-	-	-	-
19	Ueno & Kamibeppu (2008)	-	✓	-	✓	-	✓	✓	✓	✓	-	✓	-	✓	-	-	-
20	Evenson et al. (2008)	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	-	-
21	Venkataraman & Ackerson (2008)	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓	✓	✓	✓
22	Montgomery et al. (2006)	✓	✓	-	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓	✓	-
23	Diaz-Caneja & Johnson (2004)	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
24	Savvidou et al. (2003)	✓	✓	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-
25	Ackerson (2003)	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	-
26	Thomas & Kalucy (2002)	-	✓	-	✓	✓	✓	✓	✓	✓	✓	-	✓	-	✓	✓	✓
27	Nicholson et al. (1998)	✓	✓	✓	-	✓	✓	✓	✓	-	✓	✓	✓	-	-	-	-
28	Sands (1995)	✓	✓	-	-	✓	✓	✓	✓	✓	✓	✓	✓	✓	-	✓	✓

Note. ✓ = Theme identified; - = Theme not identified

Appendix E. Author Guidelines for Frontiers in Psychiatry

Manuscript Formatting Guidelines

1. General standards

1.1. Article Type

Frontiers requires authors to carefully select the appropriate article type for their manuscript and to comply with the article type descriptions defined in the journal's "Article Types" page, which can be seen from the "For Authors" menu on any Frontiers journal page. Please pay close attention to the word count limits.

[Original Research

Original Research articles report on primary and unpublished studies. Original Research may also encompass confirming studies and disconfirming results which allow hypothesis elimination, reformulation and/or report on the non-reproducibility of previously published results. Original Research articles are peer-reviewed, have a maximum word count of 12,000 and may contain no more than 15 Figures/Tables. Authors are required to pay a fee (A-type article) to publish an Original Research article. Original Research articles should have the following format: 1) Abstract, 2) Introduction, 3) Materials and Methods, 4) Results, 5) Discussion.]

1.2. Templates

If working with [Word](#), please use our [Frontiers Word templates](#). If you wish to submit your article as LaTeX, we recommend our [Frontiers LaTeX templates](#).

For LaTeX files, please ensure all relevant manuscript files are uploaded: [.tex](#) file, PDF, and [.bib](#) file (if the bibliography is not already included in the [.tex](#) file).

During the [Interactive Review](#), authors are encouraged to upload versions using "Track Changes." Editors and reviewers can only download the PDF file of the submitted manuscript.

1.3. Manuscript Length

Frontiers encourages the authors to closely follow the article word count lengths given in the "Article Types" page of the journals. The manuscript length includes only the main body of the text, footnotes, and all citations within it, and excludes the abstract, section titles, figure and table captions, funding statement, acknowledgments, and references in the bibliography. Please indicate the number of words and the number of figures and tables included in your manuscript on the first page.

1.4. Language Editing

Frontiers requires manuscripts submitted to meet international English language standards to be considered for publication.

For authors who would like their manuscript to receive language editing or proofreading to improve the clarity of the manuscript and help highlight their research, Frontiers recommends the language-editing services provided by the following external partners:

EdiPage

Frontiers is pleased to recommend the language-editing service provided by our external partner [EdiPage](#) to authors who believe their manuscripts would benefit from professional editing. These services may be particularly useful for researchers for whom English is not the primary language. They can help to improve the grammar, syntax, and flow of your manuscript prior to submission. Frontiers authors will receive a 10% discount by visiting the following link: <https://editpage.com/frontiers/>.

The Charlesworth Group

Frontiers recommends the Charlesworth Group's author services, who has a long-standing track record in language editing and proofreading. This is a third-party service for which Frontiers authors will receive a 10% discount by visiting the following link: <https://www.cwauthors.com/frontiers/>.

Frontiers推荐您使用在英语语言编辑和校对领域具有悠久历史和良好口碑的查尔斯沃思作者服务。此项服务由第三方为您提供，Frontiers中国作者通过此链接提交稿件时可获得10%的特别优惠: www.cwauthors.com.cn/frontiers/.

Note that sending your manuscript for language editing does not imply or guarantee that it will be accepted for publication by a Frontiers journal. Editorial decisions on the scientific content of a manuscript are independent of whether it has received language editing or proofreading by the partner services, or other services.

1.5. Language Style

The default language style at Frontiers is American English. If you prefer your article to be formatted in British English, please specify this on the first page of your manuscript. For any questions regarding style, Frontiers recommends authors to consult the Chicago Manual of Style.

1.6. Search Engine Optimization (SEO)

There are a few simple ways to maximize your article's discoverability. Follow the steps below to improve search results of your article:

- include a few of your article's keywords in the title of the [article](#);
- do not use long article [titles](#);
- pick 5 to 8 keywords using a mix of generic and more specific terms on the article subject(s);
- use the maximum [amount](#) of keywords in the first 2 sentences of the abstract;
- use some of the keywords in level 1 headings.

1.7. CrossMark Policy

[CrossMark](#) is a multi-publisher initiative to provide a standard way for readers to locate the current version of a piece of content. By applying the [CrossMark](#) logo Frontiers is committed to maintaining the content it publishes and to alerting readers to changes [if and when](#) they occur. Clicking on the [CrossMark](#) logo will tell you the [current status](#) of a document and may also give you additional publication record information about the document.

1.8. Title

The title should be concise, omitting terms that are implicit and, where possible, be a statement of the main result or conclusion presented in the manuscript. Abbreviations should be avoided within the title.

Witty or creative titles are welcome, but only if relevant and within measure. Consider if a title meant to be thought-provoking might be misinterpreted as offensive or alarming. In extreme cases, the editorial office may veto a title and propose an alternative.

Authors should try to avoid, if possible:

- titles that are a mere question without giving the [answer](#);
- unambitious titles, for example starting with "Towards," "A description of," "A characterization of," "Preliminary study on;"
- vague titles, for example starting with "Role of...," "Link between...," "Effect of..." that do not specify the role, link, or [effect](#);
- include terms that are out of place, for example the taxonomic affiliation apart from species name.

For Corrigenda, General Commentaries, and Editorials, the title of your manuscript should have the following format:

- "Corrigendum: Title of Original Article"
- General Commentaries
 - "Commentary: Title of Original Article"
 - "Response: Commentary: Title of Original Article"
- "Editorial: Title of Research Topic"

The running title should be a maximum of 5 words in length.

1.9. Authors and Affiliations

All names are listed together and separated by commas. Provide exact and correct author names as these will be indexed in official archives. Affiliations should be keyed to the author's name with superscript numbers and be listed as follows: Laboratory, Institute, Department, Organization, City, State abbreviation (only for United States, Canada, and Australia), and Country (without detailed address information such as city zip codes or street names).

Example: Max Maximus¹

¹Department of Excellence, International University of Science, New York, NY, United States.

Correspondence:

The Corresponding Author(s) should be marked with an asterisk in the author list. Provide the exact contact email address of the corresponding author(s) in a separate section.

Example: Max Maximus*

maximus@iuscience.edu

If any authors wish to include a change of address, list the present address(es) below the correspondence details using a unique superscript symbol keyed to the author(s) in the author list.

Equal contributions:

The authors who have contributed equally should be marked with a symbol (†) in the author list of the doc/latex and pdf files of the manuscript uploaded at submission.

Standard statements to include in the author list:

Example: Max Maximus^{1†}, John Smith^{2†} and Barbara Smith¹

These authors have contributed equally to this work and share first authorship

1.10. Consortium/Group and Collaborative Authors

Consortium/group authorship should be listed [in the manuscript](#) with the other author(s).

In cases where authorship is retained by the consortium/group, the consortium/group should be listed as an author separated by ", " or "and, ". The consortium/group name will appear in the author list, in the citation, and in the copyright. If provided, the consortium/group members will be listed in a separate section at the end of the article.

For the collaborators of the consortium/group to be indexed in PubMed, they do not have to be inserted in the Frontiers submission system individually. However, in the manuscript itself, provide a section with the name of the consortium/group as the heading followed by the list of collaborators, so they can be tagged accordingly and indexed properly.

Example: John Smith, Barbara [Smith](#) and The Collaborative Working Group.

In cases where work is presented by the author(s) on behalf of a consortium/group, it should be included in the author list separated with the wording "for" or "on behalf of." The consortium/group will not retain authorship and will only appear in the author list.

Example: John Smith and Barbara Smith on behalf of The Collaborative Working Group.

1.11. Abstract

As a primary goal, the abstract should render the general significance and conceptual advance of the work clearly accessible to a broad readership. In the abstract, minimize the use of abbreviations and do not cite references, [figures](#) or tables.

For Clinical Trial articles, please include the Unique Identifier and the URL of the publicly accessible website on which the trial is registered.

1.12. Keywords

All article types require a minimum of 5 and a maximum of 8 keywords.

1.13. Text

The entire document should be single-spaced and must contain page and line numbers [in order to](#) facilitate the review process. The manuscript should be written using either Word or LaTeX. For templates, see [1.2. Templates](#).

1.14. Nomenclature

- The use of abbreviations should be kept to a minimum. Non-standard abbreviations should be avoided unless they appear at least four [times](#) and defined upon first use in the main text. Consider also giving a list of non-standard abbreviations at the end, immediately before the Acknowledgments.
- Equations should be inserted in editable format from the equation editor.
- Italicize gene symbols and use the approved gene nomenclature where it is available. For human genes, please refer to the HUGO Gene Nomenclature Committee ([HGNC](#)). New gene symbols should be submitted [here](#). Common alternative gene aliases may also be [reported](#) but should not be used alone in place of the HGNC symbol. Nomenclature committees for other species are listed [here](#). Protein products are not italicized.
- We encourage the use of Standard International Units in all manuscripts.
- Chemical compounds and biomolecules should be referred to using systematic nomenclature, preferably using the recommendations by IUPAC.
- Astronomical objects should be referred to using the nomenclature given by the International Astronomical Union provided [here](#).
- Life Science Identifiers (LSIDs) for ZOOBANK registered names or nomenclatural acts should be listed in the manuscript before the keywords. An LSID is represented as a uniform resource name (URN) with the following format:
`urn:lsid:<Authority>:<Namespace>:<ObjectID>[:<Version>]`

For more information on LSIDs please see the [Code](#) section.

1.15. Sections

The manuscript is organized by headings and subheadings. The section headings should be those appropriate for your field and the research itself. You may insert up to 5 heading levels into your manuscript ([see](#) 3.2.2.1.2 Heading Title).

For Original Research articles, it is recommended to organize your manuscript in the following sections or their equivalents for your field:

INTRODUCTION

Succinct, with no subheadings.

MATERIALS AND METHODS

This section may be divided by subheadings and should contain sufficient detail so that when read in conjunction with cited references, all procedures can be repeated. For experiments reporting results on animal or human subject research, an ethics approval statement should be included in this section (for further information, see the [Bioethics](#) section.)

RESULTS

This section may be divided by subheadings. Footnotes should not be used and must be transferred to the main text.

DISCUSSION

This section may be divided by subheadings. Discussions should cover the key findings of the study; discuss any prior research related to the subject to place the novelty of the discovery in the appropriate context, discuss the potential shortcomings and limitations on their interpretations, discuss their integration into the current understanding of the problem and how this advances the current views, speculate on the future direction of the research, and freely postulate theories that could be tested in the future.

For further information, please check the descriptions defined in the journal's "Article Types" page, which can be seen from the "For Authors" menu on any Frontiers journal page.

1.16. Acknowledgments

This is a short text to acknowledge the contributions of specific colleagues, institutions, or agencies that aided the efforts of the authors. Should the content of the manuscript have previously appeared online, such as in a thesis or preprint, this should be mentioned here, in addition to listing the source within the reference list.

1.17. Contribution to the Field Statement

When you submit your manuscript, you will be required to briefly summarize in 200 words your manuscript's contribution to, and position in, the existing literature in your field. This should be written avoiding any technical language or non-standard acronyms. The aim should be to convey the meaning and importance of this research to a non-expert. While Frontiers evaluates articles using objective criteria, rather than impact or novelty, your statement should frame the question(s) you have addressed in your work in the context of the current body of knowledge, providing evidence that the findings—whether positive or negative—contribute to progress in your research discipline. This will assist the Chief Editors to determine whether your manuscript fits within the scope of a specialty as defined in its mission statement; a detailed statement will also facilitate the identification of the editors and reviewers most appropriate to evaluate your work, ultimately expediting your manuscript's initial consideration.

Example Statement on: [Markson K and Markson H \(2010\) The Intense World Theory – a unifying theory of the neurobiology of autism. Front. Hum. Neurosci. 4:224. doi: 10.3389/fnhum.2010.00224](#)

Autism spectrum disorders are a group of neurodevelopmental disorders that affect up to 1 in 100 individuals. People with autism display an array of symptoms encompassing emotional processing, sociability, perception, and memory, and present as uniquely as the individual. No theory has suggested a single underlying neuropathology to account for these diverse symptoms. The Intense World Theory, proposed here, describes a unifying pathology producing the wide spectrum of manifestations observed in autists. This theory focuses on the neocortex, fundamental for higher cognitive functions, and the limbic system, key for processing emotions and social signals. Drawing on discoveries in animal models and neuroimaging studies in individuals with autism, we propose how a combination of genetics, toxin exposure and/or environmental stress could produce hyper-reactivity and hyper-plasticity in the microcircuits involved with perception, attention, memory and emotionality. These hyper-functioning circuits will eventually come to dominate their neighbors, leading to hyper-sensitivity to incoming stimuli, over-specialization in tasks and a hyper-preference syndrome. We make the case that this theory of enhanced brain function in autism explains many of the varied past results and resolves conflicting findings and views and makes some testable experimental predictions.

2. Figure and Table Guidelines

2.1. CC-BY Licence

All figures, tables, and images will be published under a [Creative Commons CC-BY licence](#), and permission must be obtained for use of copyrighted material from other sources (including re-published/adapted/modified/partial figures and images from the internet). It is the responsibility of the authors to acquire the licenses, follow any citation instructions requested by third-party rights holders, and cover any supplementary charges.

For additional information, please see the [Image Manipulation](#) section.

2.2. Figure Requirements and Style Guidelines

- Frontiers requires figures to be submitted individually, in the same order as they are referred to in the manuscript; the figures will then be automatically embedded at the end of the submitted manuscript. Kindly ensure that each figure is mentioned in the text and in numerical order.
- For figures with more than one panel, panels should be clearly indicated using labels (A), (B), (C), (D), etc. However, do not embed the part labels over any part of the image, these labels will be replaced during typesetting according to Frontiers' journal style. For graphs, there must be a self-explanatory label (including units) along each axis.
- For LaTeX files, figures should be included in the provided PDF. In case of acceptance, our Production Office might require high-resolution files of the figures included in the manuscript in EPS, JPEG or TIF/TIFF format.
- ~~In order to~~ be able to upload more than one figure at a time, save the figures (~~labeled~~ in order of appearance in the manuscript) in a zip file and upload them as 'Supplementary Material Presentation.'

Please note that figures not in accordance with the guidelines will cause substantial delay during the production process.

2.2.1. Captions

Captions should be preceded by the appropriate label, for example "Figure 1." Figure captions should be placed at the end of the manuscript. Figure panels are referred to by bold capital letters in brackets: (A), (B), (C), (D), etc.

2.2.2. Image Size and Resolution Requirements

Figures should be prepared with the PDF layout in mind. Individual figures should not be longer than one page and with a width that corresponds to 1 column (85 mm) or 2 columns (180 mm).

All images must have a resolution of 300 dpi at final size. Check the resolution of your figure by enlarging it to 150%. If the image appears blurry, jagged or has a stair-stepped effect, the resolution is too low.

- The text should be legible and of high quality. The smallest visible text should be no less than 8 points in height when viewed at actual size.
- Solid lines should not be broken up. Any lines in the graphic should be no smaller than 2 points wide.

Please note that saving a figure directly as an image file (JPEG, TIF) can greatly affect the resolution of your image. To avoid this, one option is to export the file as PDF, then convert into TIFF or EPS using a graphics software.

2.2.3. Format and Color/Image Mode

- The following formats are accepted: TIF/TIFF (.tiff), JPEG (.jpg), and EPS (.eps) (upon acceptance).
- Images must be submitted in the color mode RGB.

2.2.4. Chemical Structures

Chemical structures should be prepared using ChemDraw or a similar program. If working with ChemDraw please use our [Frontiers ChemDraw template](#). If working with another program please follow the guidelines given below:

- Drawing settings: chain angle, 120° bond spacing, 18% width; fixed length, 14.4 px; bold width, 2.0 px line width, 0.6 px margin width, 1.6 px hash spacing, 2.5 pt. Scale 100% Atom Label settings: font, Arial; size, 8 pt.
- Assign all chemical compounds a bold, Arabic numeral in the order in which the compounds are presented in the manuscript text.

2.3. Table Requirements and Style Guidelines

- Tables should be inserted at the end of the manuscript in an editable format. If you use a word processor, build your table in Word. If you use a LaTeX processor, build your table in LaTeX. An empty line should be left before and after the table.
- Table captions must be placed immediately before the table. Captions should be preceded by the appropriate label, for example "Table 1." Please use only a single paragraph for the caption.
- Kindly ensure that each table is mentioned in the text and in numerical order.
- Please note that large tables covering several pages cannot be included in the final PDF for formatting reasons. These tables will be published as supplementary material.

Please note that tables which are not according to the guidelines will cause substantial delay during the production process.

2.4. Accessibility

Frontiers encourages authors to make the figures and visual elements of their articles accessible for the visually impaired. An effective use of color can help people with low visual acuity, or color blindness, understand all the content of an article.

These guidelines are easy to implement and are in accordance with the [W3C Web Content Accessibility Guidelines \(WCAG 2.1\)](#), the standard for web accessibility best practices.

A. Ensure sufficient contrast between text and its background

People who have low visual acuity or color blindness could find it difficult to read text with low contrast background color. Try using colors that provide maximum contrast.

WC3 recommends the following contrast ratio levels:

- Level AA, contrast ratio of at least 4.5:1
- Level AAA, contrast ratio of at least 7:1

Level AA
Contrast ratio 4.6:1

Level AA
Contrast ratio 9.5:1

You can verify the contrast ratio of your palette with these online ratio checkers:

- [WebAIM](#)
- [ColorSafe](#)

B. Avoid using red or green indicators

More than 99% of [colorblind](#) people have a red-green [color](#) vision deficiency.

C. Avoid using only [color](#) to communicate information

Elements with complex information like charts and graphs can be hard to read when only [color](#) is used to distinguish the data. Try to use other visual aspects to communicate information, such as shape, labels, and size. Incorporating patterns into the shape fills also make differences clearer; for an [example](#), please see below:

3. Supplementary Material

Data that are not of primary importance to the text, or which cannot be included in the article because they are too large or the current format does not permit it (such as videos, raw data traces, powerpoint presentations, etc.), can be uploaded as Supplementary Material during the submission procedure and will be displayed along with the published article. All supplementary files are deposited to Figshare for permanent storage and receive a DOI.

Supplementary Material is not typeset, so please ensure that all information is clearly presented without tracked changes/highlighted text/line numbers, and the appropriate caption is included in the file. To avoid discrepancies between the published article and the supplementary material, please do not add the title, author list, [affiliations](#) or correspondence in the supplementary files.

The Supplementary Material can be uploaded as Data Sheet (Word, Excel, CSV, CDX, FASTA, PDF or Zip files), Presentation (PowerPoint, [PDF](#) or Zip files), Image (CDX, EPS, JPEG, PDF, PNG or TIF/TIFF), Table (Word, Excel, CSV or PDF), Audio (MP3, WAV or WMA) or Video (AVI, DIVX, FLV, MOV, MP4, MPEG, MPG or WMV).

Technical requirements for Supplementary Images:

- 300 DPIs
- RGB color mode

For Supplementary Material templates (LaTeX and Word), see our [Supplementary Material templates](#).

4. References

Frontiers journals use one of two reference styles, either Harvard (Author-Date) or Vancouver (Numbered). Please check [this page](#) to find the correct style for your target journal.

- All citations in the text, figures or tables must be in the reference list and vice-versa.
- The names of the first six authors followed by et al. and the DOI (when available) should be provided.
- Given names of authors should be abbreviated to initials (e.g., Smith, J., Lewis, C.S., etc.)
- The reference list should only include articles that are published or accepted.
- [Unpublished data](#): submitted manuscripts or personal communications should be cited within the text only, for the article types that allow such inclusions.
- For accepted but unpublished works use "in press" instead of page numbers.
- Data sets that have been deposited to an online repository should be included in the reference list. Include the version and unique identifier when available.
- Personal communications should be documented by a letter of permission.
- Website URLs should be included as footnotes.
- Any inclusion of verbatim text must be contained in quotation marks and clearly reference the original source.
- Preprints can be cited [as long as](#) a DOI or archive URL is available, and the citation clearly mentions that the contribution is a preprint. If a peer-reviewed journal publication for the same preprint exists, the official journal publication is the preferred source. See the [Preprints](#) section for more information.

4.1. Harvard Reference Style (Author-Date)

Many Frontiers journals use the Harvard referencing system, to find the correct reference style and resources for the journal you are submitting to please go to [this page](#). Reference examples are found below, for more examples of citing other documents and general questions regarding the Harvard reference style, please refer to the [Chicago Manual of Style](#).

Appendix F. HRA Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Dr Anja Wittkowski
Clinical Psychology Office, 2nd Floor Zochonis Building
The University of Manchester, Brunswick Street,
Manchester
M13 9PL

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

08 February 2021

Dear Dr Wittkowski

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

Study title:	The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.
IRAS project ID:	288806
Protocol number:	1
REC reference:	21/WA/0010
Sponsor	University of Manchester

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 **288806**. Please quote this on all correspondence.

Yours sincerely,



pp
Mr Gurmel Bhachu
Approvals Manager

Email: HCRW.approvals@wales.nhs.uk

Copy to: *Ms Lynne Macrae*

Appendix G. Greater Manchester Mental Health NHS Foundation Trust Capacity and Capability Approval Letter



**Greater Manchester
Mental Health
NHS Foundation Trust**

Miss Claire Harries
Division of Psychology and Mental Health
The University of Manchester
2nd Floor Zochonis Building
Brunswick Street
Manchester
M13 9PL

Research & Innovation
1st Floor, Harrop House
Bury New Road
Prestwich, Manchester
M25 3BL

Tel: 0161 271 0607
Email: researchoffice@gmmh.nhs.uk
Date: 19 April 2021

Confirmation of Capacity & Capability at GMMH

Re: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.

IRAS Reference: 288806

Research & Innovation Reference: x505

Sponsor: University of Manchester

Dear Miss Harries

On behalf of Greater Manchester Mental Health NHS Foundation Trust, I am pleased to confirm Capacity and Capability for the above research to commence at our site.

It is a condition of approval that Rory Allott must be a co-author on any publications to ensure the Trust involvement is appropriately reflected and confidentiality is maintained.

Approved Documents

Protocol Version 2 dated 01/02/2021 is recognised as the most current to date.

The documents approved for use at this Trust are as listed in the Health Research Authority Letter dated: 08/02/2021.

Any subsequent, relevant amendments are additionally approved to date.

Metrics and Recruitment

First Participant Target	Total Target Recruitment	Recruitment Target Date
16/05/2021	6-12	31/05/2022

Recruitment Updates

To help R&I monitor the progress of the study, and recruitment activity within GMMH, please record your recruitment data on the attached spreadsheet. We ask all study teams to complete this on a monthly basis and return it to researchoffice@gmmh.nhs.uk by the 01st of each month.

We will then update our study database, R-PEAK, and report on trust-wide recruitment to the R&I Committee.



C&C Letter Template non-portfolio & non-interventional studies
version 02 05/08/2020

Study Staff

The CV and relevant training of the PI has been reviewed.

Conditions of Approval

The following conditions apply to this approval:

- a) The study is conducted in compliance with all the relevant legislation and the relevant GMMH Policies and R&I SOPs. These can be found on the R&I website: www.gmmh.nhs.uk/standard-operating-procedures-sops-and-guidance-documents
- b) All staff working on the study have the appropriate training and experience and have responsibilities formally delegated to them. A Research Passport is required for non-GMMH staff that require access to GMMH services or facilities.
- c) Serious Breaches of GCP or the protocol will be notified to Research & Innovation within one working day of awareness.
- d) All relevant documents will be maintained and will be made available to R&I personnel, to facilitate compliance checks, formal audits and regulatory inspections.
- e) You will notify R&I of any subsequent protocol amendments.
- f) You will promptly inform R&I of the end of the study and share a copy of the end of study notification.

I wish you every success with the study.

Yours sincerely, _____



Mark Dawson
Research Initiation and Delivery Manager (Operations)



Appendix H. Symptom Checklist



Eligibility/Symptom Checklist

Study Title: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.

Date:

18+: Y/N **Child aged 0-18: Y/N** **Weekly+ contact: Y/N** **GP: Y/N** **Fluent English: Y/N**

Must meet two or more of Criterion A (or one if delusions are of a bizarre nature or if hallucinations consist of a voice keeping a running commentary or two or more voices conversing).

Any diagnosis?

Criteria	Description
A	Delusions
A	Hallucinations
A	Disorganised Speech <i>E.g., frequent derailment or incoherence</i>
A	Grossly disorganised or catatonic behaviour
A	Negative symptoms <i>E.g., diminished emotional expression, low motivation etc.</i>
B	Social/occupational dysfunction
C	Duration <i>At least 6 months, including at least 1 month of Criterion A symptoms</i>
D	Mood disorder exclusion
E	Substance use / medication effects exclusion
F	Relationship to pervasive developmental disorder <i>If history of PDD, symptoms of psychosis must be prominent and present for at least a month.</i>

Version 1.2 27/11/2020
IRAS ID: 288806



Are you a parent who experiences psychosis?

We would like to talk to you about being involved in a research project.

We aim to explore what it's like to be a parent who experiences psychosis. We aim to find out about the challenges that parents with psychosis are faced with, and what support would be valued. This is important because we do not yet know exactly how people with psychosis experience parenting, what support they would like, and how they would like support to be delivered.

What would you be asked to do?
The project will involve speaking to a researcher for about an hour about your experience of parenting with psychosis and what support you would value from services. You will also be asked to complete a short questionnaire.

We would like to talk to you if you:

- Are aged 18+
- Have experienced psychosis as a primary difficulty in the last 2 years
- Are a biological, step parent, or kinship parent of a child aged 0-18
- Have contact with your child on at least a weekly basis
- Are registered with a GP
- Speak fluent English

You will be reimbursed for taking part.

This project is being conducted as part of a Clinical Psychology Doctoral Programme at The University of Manchester.



If you would like to find out more about taking part, please contact:
claire.harries@postgrad.manchester.ac.uk
or
07437925920

Appendix J. Participant Information Sheet



Participant Information Sheet (PIS)

Title of the project: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.

Research team: Claire Harries (Trainee Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust), Dr Anja Wittkowski (Senior Lecturer, University of Manchester and Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust), Dr Lynsey Gregg (Lecturer, University of Manchester), Dr Debbie Smith (Lecturer, University of Manchester), Dr Rory Allott (Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust).

You are being invited to take part in a research study that aims to explore the lived experiences of parents who experience psychosis. This research is part of a Doctorate in Clinical Psychology (ClinPsyD) at The University of Manchester.

Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish.

Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

The research project will be led by Claire Harries and supervised by Dr Anja Wittkowski, Dr Lynsey Gregg, Dr Debbie Smith and Dr Rory Allott. This research is being conducted as part of a Clinical Psychology Doctorate programme (ClinPsyD) at The University of Manchester. The research is sponsored by The University of Manchester.

What is the purpose of the research?

We aim to explore the lived experiences and challenges that parents with psychosis are faced with when it comes to parenting. We want to find out about how people have managed and coped, and also what parents think about the support they have received. This project is important because we do not yet know exactly how and when psychosis affects parenting, what support parents feel they need, and how parents would like support to be delivered. The findings will help us learn how to better support parents with psychosis. Findings will be shared with health care professionals and researchers to help people's understanding and to inform the delivery of services.

Why have I been invited?

You have been invited to take part because you have a child or children, you experience psychosis, and a health care professional has spoken to you about this research. We aim to speak to about 6-12 parents around the North-West of England. Due to the relatively small number of participants required, it is possible that some individuals may like to take part but may not be interviewed. This is to ensure that we speak to people from a range of backgrounds and who have a range of parenting experiences. We acknowledge that it might feel disheartening and we would like to thank all individuals who take the time to consider this research study; we appreciate your contribution.

Will the outcomes of the research be published?

The interviews will be listened to, transcribed and analysed by the Principal Researcher (Claire Harries) or a University of Manchester staff member with whom a confidentiality agreement will be signed.

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This research is part of a doctoral thesis and will be supervised by a team of researchers and clinicians. The findings will be written up as a thesis for submission to The University of Manchester ClinPsyD programme. We plan to publish the results of the research in an academic research journal as well as sharing the findings with researchers at relevant conferences. The findings will also be shared with health services. *It will not be possible to identify you from the information in any reports and publications (see Data Protection and Confidentiality below for more information).* If you wish to have a summary of the results, these will be made available to you at the end of the study. With your consent, we will retain your contact details which will allow us to contact you in the future to share these with you.

Disclosure and Barring Service (DBS) Check

A DBS check reviews a person's history ensuring they are suitable and safe to work with different people, including vulnerable groups. The researcher who will be in contact with participants has an appropriate DBS check obtained by Greater Manchester Mental Health NHS Trust.

Who has reviewed the research project?

All research in the NHS is reviewed by a Research Ethics Committee which is made up of an independent group of people who protect the rights, safety, dignity and well-being of participants. This study has been reviewed and approved by the HRA and Health and Care Research Wales Research Ethics Committee (21/WA/0010).

Who is funding the research project?

This study is funded by The University of Manchester.

About your Participation

What would I be asked to do if I took part?

If you would like to take part, you will be contacted by telephone and invited to attend an interview (an informal conversation) with the Principal Researcher (Claire Harries). The research will tell you about what taking part will involve, and you will have the opportunity to ask the researcher any questions. The researcher will complete a brief screening questionnaire with you to check that you meet the criteria for participating in the study, including having at least weekly contact with your child/children. Unfortunately, if you do not meet the study criteria, we will not be able to include you in this study because we aim to find out about the experiences of parents with particular characteristics. We acknowledge that this may feel disappointing and would like to thank all people who take the time to consider this research; your interest in this research is very much valued. Before the interview, you will have the opportunity to ask any further questions and you will be asked to provide your consent to take part.

An interview may be arranged to take place with you either via video call (Zoom), over the telephone, or in person depending on your preference and in line with government, University, and NHS guidelines relating to COVID-19 (see COVID-19 section). Interviews in person will take place in health care centres, at a neutral place of convenience, or in your home. Your preferred location will be accommodated where possible. Due to the personal nature of the interviews, the research team recommend a quiet and private location, without children being present where possible.

Prior to the interview you will be given the opportunity to ask any further questions. If you are happy to participate, you will be asked to provide consent to take part. If you chose to complete the interview over a video or telephone call, the researcher will read aloud a consent form and all of your answers will be audio recorded. This will be recorded separately to your interview to protect your confidentiality. If the interview takes place in person, you will be asked to give written consent.

During your participation, you will be asked to complete a demographic checklist that should take no longer than ten minutes. It will include questions about your age, gender, how many children you have, and some brief questions relating to your experience of psychosis and experiences with services. We recognise that this information is personal and sensitive; it will be closely protected and is only collected to understand the context of your experience of parenting and to ensure that the findings of this research can be applied to the wider population. This information will be stored separately from your name and contact details to protect your confidentiality.

Following this, you will be interviewed by Claire Harries (Principal Researcher). It is hoped that this will be a relaxed and informal experience. It is expected that the interview will last between 45-90 minutes and it will be audio recorded. The interviewer will ask you some questions that will allow you to share your experiences freely.

During the interview you may be asked questions about the following:

- Your experience of parenting and times when experiences of psychosis have impacted parenting.
- Your experiences of parenting support and your thoughts about what support you would value.

It is possible that during the interview you may feel emotional. If you need to take a short comfort break at any time, please let the researcher know. If you feel uncomfortable, do not wish to answer a certain question or you would like to stop the interview, you can do so at any time without having to give a reason. Additionally, you can decide to withdraw from the study at any point (see "What happens if I do not want to take part or if I change my mind?"). Following the interview, you will be given time and space to discuss anything the interview brought up for you as well as being provided with information on where to access further support if it is required.

Will I be compensated for taking part?

Participants who take part in the study will be offered a £10 e-voucher to thank them for their time. This will be sent electronically to participants via email following participation.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form (a copy of which you will be given to keep) or your consent will be audio-recorded. If you decide to take part, you are still free to withdraw at any time during the interview and up to 48 hours following your participation, without giving a reason without any detriment to yourself. It will not be possible to remove your data from the project at the analysis stage as we will not be able to identify your specific data because it will be anonymised. Data analysis will commence 48 hours after your participation, which means you can withdraw your data from the study up to 48 hours following your participation. This does not affect your data protection rights. If you decide not to take part, you do not need to do anything further.

Audio-recordings of interviews are essential for this research project and therefore it would be an essential part of your participation. It is important to us that you feel comfortable with the recording process at all times. If you feel uncomfortable with the recording at any point during the interview, you are free to stop the recording at any time.

Will anyone know I am taking part?

With your consent, we will inform your GP or relevant healthcare professional (e.g., care coordinator if you have one) that you are taking part in a study about parenting and mental health. We will collect your date of birth and address for this purpose. We will give minimal details about what the project involves, protecting your rights. Your contact details will be securely destroyed at the end of

this study, unless you consent to being contacted about future research opportunities; but this is optional, and you do not have to consent to this in order to take part.

What you say in the interview will be kept confidential, but someone will need to be informed if you say something that suggests there is a risk to either yourself or others. If there are circumstances when information needs to be shared outside of the research team, we will aim to involve you throughout and will seek your consent wherever possible. This is to ensure everyone is kept safe.

What support will be available to me afterwards?

We will check if you have any concerns following your participation in the study. The Principal Researcher is a trainee clinical psychologist and can talk to you about what to do next and what support is available. You can also speak with your responsible clinician (e.g. GP, key worker, care co-ordinator), crisis services, or contact voluntary and professional support organisations such as:

Samaritans	24 hour helpline	0330 094 5717/116 123
Mind	24 hour helpline	0300 123 3393

What are the good things about taking part?

You will be contributing to an important area of research that is currently under-studied. The findings will help improve understanding about how people with psychosis experience parenting, and what support parents would value. Also, some people enjoy taking part in research that can help inform future research or service development. There is added the benefit from having the opportunity to talk to somebody about your experiences.

Are there any disadvantages or risks of taking part?

Although not expected, you may find some of the questions asked in the study uncomfortable or upsetting to answer. The interviewer will be mindful of this. You are free to have a break or end the interview at any time should you feel upset or distressed. If there are any questions you do not wish to answer you can leave them unanswered. Additionally, you would need to find a convenient time to complete the interview, which could be difficult with, for example, work commitments or arranging child-care. The Principal Researcher will discuss and plan this with you over the telephone and will aim to work around your needs.

COVID-19

Due to the current COVID-19 pandemic, we will ensure we are adhering to the latest government advice in relation to social distancing as well as taking all reasonable precautions in terms of limiting the spread of the virus. You should carefully consider all of the information provided below before deciding if you want to take part in this research study. If you have any additional queries about any of the information provided, please speak with a member of the research team.

Are there any additional considerations that I need to know about before deciding whether I should take part?

Wherever possible, we would like to conduct interviews by video conferencing or telephone to limit risk of spreading or contracting the virus. However, we understand that this will not be possible for everybody. Therefore, there is the option of meeting with the researcher in person. This could occur either at your home, on NHS premises, or at another community centre, depending on practicalities and your preferences. However, meeting in person carries additional risk of contracting or spreading the virus due to coming into contact with the researcher and other people in the community. We would also ask you to sign a consent form in person, which would mean touching the same piece of paper that the researcher had touched.

What additional steps will you take to keep me safe while I take part?

- We would complete a brief screening checklist with you to screen for health vulnerabilities. If you are considered to be in a vulnerable group, you should not take part in face-to-face research but could take part either over the telephone or via video-teleconferencing.
- Before meeting with the researcher, both you and the researcher will be screened for COVID-19 symptoms. If either you or the researcher has symptoms, the research will not be able to go ahead on that day, and we will ask to rearrange the interview with you.
- The researcher will not use public transport on their journey to meet with you. This will reduce risk of picking up and passing on COVID-19.
- You will be asked to use a pen to sign a consent form. You can either use your own pen, or the researcher will sanitise a pen to give to you. The researcher will use a different sanitised pen.
- The researcher will ensure that there is good air circulation within any premises that you meet.
- The researcher will wear a face covering and you will be asked to wear one too. The researcher will have a face covering to give you to wear, or you can use your own if you would prefer.
- The researcher will keep alcohol-based hand sanitiser with them at all times. They will use this before and after meeting with you. You will also be asked to use sanitiser. The researcher will ensure that there is a minimum 2 meters in between themselves and you.

Is there any additional information that I need to know?

If it is organised for the interview to take place in person, please arrive on time (not early or late). This is because it will avoid too many people being in the same place at once. The researcher will ask for you for contact details to NHS Track and Trace if necessary.

What if government guidance changes?

If government guidance changes, we will contact you to via your preferred method of contact to discuss the best possible course of action. This may include postponing the appointment.

About Data Protection and Confidentiality

What information will you collect about me?

In order to participate in this research project we will need to collect information that could identify you, called "personal identifiable information". This will include:

- Name
- Ethnicity
- Contact number
- Employment status
- Age
- Sexuality
- Contact address
- Email address
- Gender
- Marital status
- Socioeconomic status

This information is optional and will benefit the research by recognising if it is generalisable to the wider population. Only provide this information if you feel comfortable doing so.

To be contacted further with regards to your participation or to receive a summary of the study findings, you will need to provide your name and a contact address/phone number. If you would like to be contacted about future research opportunities, there is an option for the research team to keep your contact details for this purpose, although this is optional. This information will be destroyed when it is no longer needed.

The interviews will be conducted on an individual basis and will be audio-recorded. Audio-recordings of the interview will consist of voice only. The whole interview will be audio-recorded unless you request to pause or stop at any point. The researcher will notify you when the audio-recording begins and stops. The recording will be deleted once it has been transcribed and anonymised.

Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific

reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our Privacy Notice for Research Participants (<http://documents.manchester.ac.uk/display.aspx?DocID=37095>).

Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, the University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind.

Audio (such as consent procedures for telephone interviews or interviews) will be recorded using a University of Manchester approved encrypted device. If the interview has been conducted in person, the device with the audio recording on will be securely stored in a locked box before being transferred to a secure University of Manchester network. As soon as possible after the recording is made, the audio will be transferred to a secure University of Manchester network; it will then be checked and permanently deleted from the audio recording device. The audio data will be stored in an .mp3 format using encryption and password protection which will only be known by the research team.

The University of Manchester requires identifiable data to be anonymised as soon as the objectives of the project allow. The audio recording will be transcribed as soon as possible after the completion of the interview by the Principal Researcher or by a University of Manchester staff member. This staff member will be reminded of the guidelines regarding confidentiality and will be asked to sign a copy of a 'Confidentiality Agreement'. The Chief Investigator (Dr Anja Wittkowski) and Academic co-supervisor (Dr Debbie Smith) will have access to your recording for supervision and data preservation and storage purposes.

Your interview will be transcribed after a 48-hour-period following your interview. During transcription, your information will be pseudo-anonymised, which means that your personal identifiable information will be taken out and replaced with an identifier code (e.g. 'parent1', 'child 1', 'location 1'). This will be used for saving the transcribed document and for any quotations from the interview that may be used in the write-up to protect your confidentiality. Following transcription, the audio recording will be permanently deleted. Once your data has been pseudo-anonymised it will no longer be possible to identify your specific data set and therefore it will not be possible to withdraw it from the study after that time.

The transcription will be transferred to a University of Manchester secured electronic storage system and the original file will be deleted from the encrypted device. Once transcription has been completed, audio-recordings will be erased. Transcripts will be analysed by all members of the research team. It is important that multiple members of the research team are involved in the analysis process to make sure the analysis is accurate.

If the interview takes place in person, this research will involve lone working. Therefore, the research team will follow a lone working procedure to ensure everybody's safety. This includes

sharing some of your personal data such as your name and contact number and where you live. This information will only be shared with another member of the research team and will be securely destroyed/deleted after the interview has been completed and the lone worker returns to base.

All personal identifiable information will be stored separately from your anonymised interview transcript. All personal identifiable information will be securely destroyed/deleted as soon as it is no longer needed. If you would like to be contacted about future research opportunities, there will be the option of the research team retaining your contact details for the purpose of contacting you about future research opportunities that you may be interested in. However, this is completely voluntary, and you do not have to agree to this. If you would prefer to not be contacted about future research then your contact details will not be kept on file for future research purposes, the information you provide will only be used for the purpose of this study and will not be used to contact you regarding any other matter. Your contact details will not be shared with anyone outside of the research team unless for reasons outlined. The information you provide will not be used to make decisions about future services available to you.

When we write up the research and present the results, we will use anonymised direct quotes from people who take part in this research. This means that things you say in the interviews may be published. However, your personal details will not be linked to your quotes and your real name will not be used, so your identity will be protected. There will be the option for you to choose whether your anonymised data can be used in future research. However this is completely optional, and you do not have to agree to this.

If you wish to be sent a copy of the research findings, a copy of your contact details (e.g. email or postal address) will be kept electronically, stored securely and separately from anonymous data.

The standard retention period for data once anonymised is 5 years following publication of the research. As such, research data will be kept for a minimum of 5 years and consent forms or audio recordings of consent will be kept for a minimum of 2 years after the research has ended. After this time the data will be securely destroyed/deleted.

Breaks in confidentiality

All personal identifiable information you provide will remain strictly confidential and will not be shared outside the research team. If circumstances occur when the researcher needs to disclose information outside of the research team, you will be kept involved wherever possible. Such occasions include:

- In the event the researcher is concerned about your safety or the safety of others. They may need to share this information with others (such as the research team, GP, care team, children's services or a family member).
- When there is a professional obligation to report misconduct/poor practice. The researcher may need to inform their employer or professional body.
- If during the study you disclose information about any current or future illegal activities, there is a legal obligation to report this to the relevant authorities (e.g. police).

Individuals from The University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data, but all individuals involved in auditing and monitoring the study, will have a strict duty of confidentiality to you as a research participant.

About the complaints procedure

If you have a complaint that you wish to direct to members of the research team, please contact: **Dr Anja Wittkowski** who you can email at anja.wittkowski@manchester.ac.uk or contact via telephone on **0161 306 0400**.

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact: The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the Information Commissioner's Office about complaints relating to your personal identifiable information using the telephone number **0303 123 1113**. You can find out information about the complaints procedure at <https://ico.org.uk/make-a-complaint/>. In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester, Greater Manchester Mental Health or Pennine Care NHS Foundation Trust, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

About Further Contact

What do I do next if I wish to take part?

If you require an additional information or are interested in taking part in this project, please contact the Principal Researcher, Claire Harries (trainee clinical psychologist) on the below details:

Email: claire.harries@postgrad.manchester.ac.uk **Telephone:** 07340555067

Alternatively, you can complete the consent to contact form and email it to claire.harries@postgrad.manchester.ac.uk, or you can complete the consent to contact form and return it to your healthcare professional who will then give this to Claire Harries. You will then be contacted by Claire Harries via your preferred method to answer any additional questions, check that you are eligible to take part and consider an appropriate time and date for an interview. After this you will be given 24 hours to think about whether you would like to take part. The Principal Researcher will contact you once again to finalise arrangements.

Who do I contact for more information?

If you require any further information or have any questions about the study before you decide to participate, please contact Claire Harries, trainee clinical psychologist at The University of Manchester on the email address claire.harries@postgrad.manchester.ac.uk.

Claire Harries

Lead researcher for this study
Trainee Clinical Psychologist
The University of Manchester, 2nd Floor
Zochonis Building, Brunswick Street,
Manchester M13 9PL
0161 306 0400
Claire.harries@postgrad.manchester.ac.uk

Dr Anja Wittkowski

Chief Investigator for this study
ClinPsyD research supervisor
The University of Manchester, 2nd
Floor Zochonis Building, Brunswick
Street, Manchester M13 9PL
0161 306 0400
anja.wittkowski@manchester.ac.uk

Dr Lynsey Gregg

Second supervisor for this study
ClinPsyD research supervisor
The University of Manchester, 2nd
Floor Zochonis Building, Brunswick
Street, Manchester M13 9PL
0161 306 0400
Lynsey.gregg@manchester.ac.uk

Dr Debbie Smith

Academic co-supervisor for this study
ClinPsyD research supervisor
The University of Manchester, 2nd Floor
Zochonis Building, Brunswick Street,
Manchester M13 9PL

0161 306 0400
Debbie.Smith-2@manchester.ac.uk

Dr Rory Allott

Field supervisor for this study
Clinical Psychologist
Early Intervention Service,
Crossgate House, Cross Street,
Sale, Cheshire
M33 7FT
0161 358 1390
Rory.Allott@nhs.uk

Thank you for considering taking part in this study.

Appendix K. Consent to Contact Form



Consent to Contact Form

Study Title: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis

Principal Investigator: Claire Harries

If you are interested in taking part in this project and would like somebody from the research team to contact you to talk about the project in more detail, please give your details on the next page. You should only provide the information if you are happy to be contacted in that way. For example, if you do not want to be contacted by email then do not provide an email address.

Please note the following points in relation to the processing of your data:

- Data will be held securely by the research team on behalf of the University of Manchester according to the University's data protection and information security policies. A copy of the University's Privacy Notice can be found at: { HYPERLINK "<http://documents.manchester.ac.uk/display.aspx?DocID=37095>" }
- Access to the data will be restricted to the research team for the sole purpose of contacting you about this study.
- Your data will not be shared with any third party without your written permission.
- The details collected will only be stored for as long as required to find out if you wish to take part in this specific research. Once no longer needed, that data will be destroyed securely.
- If you decide to change your mind about being contacted about the study or would like your details to be destroyed, you can contact Claire Harries via email on: claire.harries@postgrad.manchester.ac.uk

Once you have completed your details (on the next page), please ensure that you have added your signature and return the form by **either**:

- Returning the form to person who gave it to you (e.g., a staff member), who will then pass your details to Claire Harries.

or
- Sending this form directly to Claire Harries by emailing a scanned copy to: { HYPERLINK "<mailto:claire.harries@postgrad.manchester.ac.uk>" }.

or
- Emailing Claire Harries ({ HYPERLINK "<mailto:claire.harries@postgrad.manchester.ac.uk>" }) to ask her to send you a copy of this form, so that you can complete the form electronically and send it back to her.

I am happy **to provide/for my health care professional to provide** (delete as appropriate) my personal details so that I can be contacted about the study called "The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis"; IRAS ID 288806. /

Name (please give your full name)	
Signature	
Today's date	

Please complete the details below or hand back to your health care provider to complete on your behalf.

Contact by letter	Address	
	Post Code	
Contact by phone	Preferred contact number	
	When would you prefer to be contacted? (please circle)	Morning / Afternoon/ Evening / Don't Mind
	Can an answerphone message be left?	Yes / No
Contact by email	Email address	
How you would prefer to be contacted (please circle): Letter / Telephone / Email		

Appendix L. Consent Form



Consent Form

Title of the project: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis (IRAS ID: 288806).

Research team: Claire Harries (Trainee Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust), Dr Anja Wittkowski (Senior Lecturer, University of Manchester and Clinical Psychologist; Greater Manchester Mental Health NHS Foundation Trust), Dr Lynsey Gregg (Lecturer, University of Manchester), Dr Debbie Smith (Lecturer, University of Manchester), Dr Rory Allott (Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust)

	Activities	Initials
1	I confirm that I have read the attached information sheet (Version 2, Date 01/02/2021) for the above study. I have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw my data until 48 hours after the interview without giving a reason and without detriment to myself. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis.	
3	I agree to my interviews and my verbal consent to take part being audio recorded on an encrypted audio-recorder device, if this research takes places remotely.	
4	I understand that audio recordings will be retained until the transcript is validated by the research team.	
5	I agree that any data collected may be published in anonymous form in academic books, reports and journals or presented at conferences or used in teaching. This includes direct anonymised quotations from interviews.	
6	I understand that data collected during the study may be looked at by responsible individuals from The University of Manchester, the NHS, or regulatory authorities, when it is relevant to my taking part in research. I give permission for these individuals to have access to my data.	
7	I agree that anonymised data may be shared with members of the research team who are at different institutions (NHS & University of Manchester).	
8	I agree to my General Practitioner and/or clinical care team being informed of my participation in the study.	
9	OPTIONAL: I agree that the researchers may retain my contact details in order to provide me with a summary of the findings for this study. If initialled, a 'Contact Form for Summary of the Research' will need to be completed)	
10	OPTIONAL: I agree to be contacted about future research and my contact details can be retained for this purpose.	
11	OPTIONAL: I agree that my anonymised data can be used in future research.	
12	I understand that there may be instances where during the course of the interview information is revealed which meant that the researchers will be obliged to break confidentiality, and this has been explained in more detail in the information sheet.	
13	I agree to take part in this study.	

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IRAS ID: 288806

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the Privacy Notice for Research Participants ([HYPERLINK "https://manchester.ac.uk/discover/privacy-information/data-protection/privacynotices/"](https://manchester.ac.uk/discover/privacy-information/data-protection/privacynotices/)).

Signed:

-----	-----	-----
Name of participant	Signature	Date
-----	-----	-----
Name of person taking consent	Signature	Date

Copies: One for the participant; one copy for the study file (original); one copy for service records if required.

Appendix M. Demographic Checklist



Date :

Background Checklist

Study Title: *The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.*

This questionnaire collects information about you and your family. Please read and answer every question. All information provided will be treated in strict confidence.

1. Age today.....

2. What gender do you identify with?

<input type="checkbox"/>	Female
<input type="checkbox"/>	Male
<input type="checkbox"/>	Prefer not to say
<input type="checkbox"/>	Other Please describe

3. What is your current relationship status?

Single	<input type="checkbox"/>	If so, how long for?.....
Married	<input type="checkbox"/>	If so, how long have you been married?
Living together	<input type="checkbox"/>	If so, how long have you been living together?
Separated or divorced	<input type="checkbox"/>	If so, do you have a partner?
Widowed	<input type="checkbox"/>	If so, how long for?.....
Other	<input type="checkbox"/>	Please describe

4. What is your highest level of education?

No qualifications	<input type="checkbox"/>	To end of year
GCSEs, CSEs, or O-levels	<input type="checkbox"/>	
A levels/ BTEC	<input type="checkbox"/>	
Trade/apprenticeship	<input type="checkbox"/>	
University degree	<input type="checkbox"/>	
Other	<input type="checkbox"/>	Please specify.....

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5. What is your current employment status?

Full time employment	<input type="checkbox"/>	
Part time employment	<input type="checkbox"/>	If so, how many hours per week?
Home duties	<input type="checkbox"/>	
Receiving benefits	<input type="checkbox"/>	
Voluntary work	<input type="checkbox"/>	If so, how many hours per week?
On maternity leave	<input type="checkbox"/>	If so, please also indicate your employment status prior to your leave.....
Unemployed	<input type="checkbox"/>	

6. Who are you currently living with?

<input type="checkbox"/>	Living alone
<input type="checkbox"/>	Living with partner
<input type="checkbox"/>	Living with children How many children live with you?..... How many children don't live with you.....
<input type="checkbox"/>	Living in shared accommodation How many people do you share with?.....
<input type="checkbox"/>	Living with relatives

7. How many people live with you (including children)?

8. What are you current living arrangements?

<input type="checkbox"/>	Home owner
<input type="checkbox"/>	Privately renting
<input type="checkbox"/>	Social Housing
<input type="checkbox"/>	Living in a care home
<input type="checkbox"/>	Living in a hostel/shelter
<input type="checkbox"/>	Homeless/no fixed abode

9. Which ethnic group do you identify with? Please tick

<p>White</p> <p><input type="radio"/> English / Welsh / Scottish / Northern Irish / British</p> <p><input type="radio"/> Irish</p> <p><input type="radio"/> Gypsy or Irish Traveller</p> <p><input type="radio"/> Any other White background</p>
<p>Mixed / Multiple ethnic groups</p> <p><input type="radio"/> White and Black Caribbean</p> <p><input type="radio"/> White and Black African</p> <p><input type="radio"/> White and Asian</p> <p><input type="radio"/> Any other Mixed / Multiple ethnic background</p>
<p>Asian / Asian British</p> <p><input type="radio"/> Indian</p> <p><input type="radio"/> Pakistani</p> <p><input type="radio"/> Bangladeshi</p> <p><input type="radio"/> Chinese</p> <p><input type="radio"/> Any other Asian background</p>
<p>Black / African / Caribbean / Black British</p> <p><input type="radio"/> African</p> <p><input type="radio"/> Caribbean</p> <p><input type="radio"/> Any other Black / African / Caribbean background</p>
<p>Other ethnic group</p> <p><input type="radio"/> Arab</p> <p><input type="radio"/> Any other ethnic group (please <u>state</u>)_</p> <p>.....</p>

10. Do you have a mental health diagnosis?

Yes No

Please state your diagnosis (if any)

.....

11. What was your age when you first had symptoms of psychosis?

.....

12. How many children do you have?

.....

13. What is/are the age(s) and sex of your child/children? (please list below)

Age	Sex

14. What is your relationship to your child/children?

<input type="checkbox"/>	Biological Mother
<input type="checkbox"/>	Biological Father
<input type="checkbox"/>	Non-biological mother (please <u>describe</u>).....
<input type="checkbox"/>	Non-biological father (please <u>describe</u>).....
<input type="checkbox"/>	Other.....

15. Do you currently receive any childcare support?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<input type="checkbox"/>	N/A

Please briefly describe what childcare support you receive

.....

16. Have you previously received any childcare support?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<input type="checkbox"/>	N/A

Please briefly describe the childcare support you previously received

.....

17. How would you rate your current mental health? (please circle)

1 2.....3.....4.....5.....6.....7.....8.....9.....10

Not at all good

Excellent

18. Are you receiving any current support for your mental health or psychological difficulties?

Yes No

If yes, what support are you receiving?

Medication Talking therapy Inpatient admission

Other (please specify)

19. Have you previously received any support for your mental health or psychological difficulties?

Yes No N/A

If yes, what support did you receive?

Medication Talking therapy Inpatient admission (how many?.....)

Other (please specify)

Thank you for taking the time to fill in this checklist.

Topic Guide

The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis (Version 3. November 2020)

Study Title: *The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.*

This topic guide is not intended to be followed in a linear manner and is not exhaustive. Flexibility should be given to the order in which questions are asked, and the exact content of the questions. It is not expected that all questions will be asked. This topic guide may be developed alongside ongoing analysis.

Before progressing with interview:

1. Thank the participant for agreeing to be interviewed. Introduce self.
2. The purpose of this research is to explore your experience of being a parent with psychosis, experience of services and considering how experiences of services could be improved.
3. Everything you say in this interview will be anonymous and your confidentiality maintained.
4. Ask if they are still OK for us to tape record this conversation.
5. Remind them that it is OK to stop or take a comfort break at any point or refuse to answer any questions during this interview.
6. Ask if they have any concerns or questions before we start.

- **How would you describe yourself as a parent?**
 - o Possible prompts: How do you feel about being a parent? How you feel about your child/ren? How do you feel about yourself? How do you think other people see you as a parent?
- **Can you describe how you have managed at different points throughout being a parent?**
 - o Possible probes: What are the challenges? What are the positives? How have things changed over time? How do you feel about this?
- **Can you tell me about your experience of having psychosis and being a parent?**
 - o Possible prompts: How do you feel? How do you cope? How do you think your children feel? How do they cope?
- **Please can you tell me about your experience of receiving support for parenting with psychosis?**
 - o Possible probes: Could your experience have been improved with different support? Can you describe the aspects of parenting that you would value support with? What impact would that have on you? What impact would that have on your children?
 - o Possible prompts: When? Where? How? Who should be involved? What are current barriers?

General prompts:

- Can you tell me more about that?
- Tell me what you were thinking?
- How did you feel?
- Could you tell me an example?
- What was that like for you?

Summary

- Do you have any further points that you would like to make?
- Can you think of any other questions that could be asked in future interviews?
- Any questions?

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Appendix O. Debrief Sheet



PARTICIPANT DEBRIEF SHEET

Study Title: The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.

Research Team: Claire Harries (Trainee Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust), Dr Anja Witkowski (Senior Lecturer, University of Manchester and Clinical Psychologist; Greater Manchester Mental Health NHS Foundation Trust), Dr Lynsey Gregg (Lecturer, University of Manchester), Dr Debbie Smith (Lecturer, University of Manchester), Dr Rory Allott (Clinical Psychologist, Greater Manchester Mental Health NHS Foundation Trust).

Thank you for taking the time to participate in this research. We hope that you have found it interesting to take part.

Purpose of the study

We want to improve our understanding of the lived experiences of parents who have psychosis, and what support they would value from services. To do this, we asked you to complete an interview to share your experiences. We are aware that every parent has a different experience of parenting, and that experiencing psychosis might impact parenting; but we don't yet know exactly how psychosis impacts parenting, and what support parents with psychosis would like. For this reason, we wanted to hear about your thoughts and feelings as well as the types of support that you would value with parenting. We hope to use this information to inform and guide child and family services when parents may have similar experiences.

Summary of findings

A summary of the findings can be sent to you once all the interviews have been analysed. If you would like a copy, please let the interviewer know if the research team can retain your contact details. These details will be stored securely at the University of Manchester and destroyed once they are no longer required. Alternately, if you want to request this at a later date or if you change your mind, please send an email to { [HYPERLINK "mailto:claire.harries@postgrad.manchester.ac.uk"](mailto:claire.harries@postgrad.manchester.ac.uk) }.

Giving feedback

People react differently after taking part in research studies. Please let us know any thoughts or feelings you have about the study. Honest feedback from you will help us learn. It also gives us a chance to explain parts of the study that may still be confusing. If you would like to give feedback on your interview experience, please send an email to { [HYPERLINK "mailto:claire.harries@postgrad.manchester.ac.uk"](mailto:claire.harries@postgrad.manchester.ac.uk) }.

If you are or become upset as a result of joining this study

If you feel upset or distressed by any part of the study, please let us know. We want to do everything we can to ease any discomfort and to help you manage this safely. On the following page you will find a list of voluntary and professional organisations who can provide advice and support.

If you have any further questions, please feel free to ask now or contact me at { [HYPERLINK "mailto:claire.harries@postgrad.manchester.ac.uk"](mailto:claire.harries@postgrad.manchester.ac.uk) }.

Support Sheet

Study Title: *The experiences and service preferences of parents experiencing psychosis: an interpretative phenomenological analysis.*

Listed below are some of the professional and voluntary organisations you can contact to get help in a crisis, or if you have been experiencing periods of low mood, stress or anxiety and wish to seek further support.

You can always contact your GP or another healthcare professional for advice. If a health professional has given you a specific number to call when you are concerned about your condition, continue to use that number.

If you are concerned that your life or someone else's life is in immediate danger you should visit your nearest Accident and Emergency department (A&E) or call for an ambulance by dialling 999.

NHS 111



Available 24 hours a day, 365 days a year and calls are free from landlines and mobile phones.

You can call NHS 111 if you think you need to go to A&E or need another urgent care service, if you don't know who to call or don't have a GP, or if you need health information or reassurance about what to do next. The service is staffed by a team of fully trained advisors who can give you the healthcare advice you need or direct you straight away to the local service that can help you best. Where possible, the NHS 111 team will book you an appointment or transfer you directly to the people you need to speak to.

If NHS 111 advisers think you need an { HYPERLINK "http://www.nhs.uk/NHSEngland/AboutNHSservices/Emergencyandurgentcareservices/Pages/Ambulanceservices.aspx" }, they will immediately arrange for one to be sent to you. { INCLUDEPICTURE

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Mind



0300 123 3393



supporterrelations@mind.org.uk

An independent mental health charity committed to improving the lives of people with mental health needs. They promote the health and wellbeing of people affected by mental distress and take a positive approach to mental health, challenging stereotypes and discrimination

{ HYPERLINK "https://www.mind.org.uk" }

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Samaritans



116 123



jo@samaritans.org

Confidential, non-judgmental support available 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide.
{ HYPERLINK "https://www.samaritans.org" }

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"C:\\var\\folders\\9x\\pgdqjzvj7ndcqqxf3rpd2l3h0000gn\\T\\com.microsoft.Word\\WebArchiveCopyPas
teTempFiles\\Z" * MERGEFORMAT } Greater Manchester Self Help Services

Works actively with people in the Greater Manchester area on a number of difficulties including anger, anxiety and depression. The website also provides information to local Sanctuary services which can be contacted at night if you are in a crisis.

{ HYPERLINK "https://www.selfhelpservices.org.uk" }

UNODC – Parenting through COVID-19



A webpage that has provided access to many different support materials relevant to parenting and COVID-19. These resources have been developed under the Listen First Program.

{ HYPERLINK "https://www.unodc.org" }

Appendix P. Example of Line-by-Line Coding

<p>Grief of lost mothering responsibilities. The guilty, fearful mother. Ruminative thinking.</p>	<p>son to school. I wouldn't be able to take him erm, just to the park to play and things like that. Erm. I think you worry as well, because I was in hospital at that time, like how much was it affecting him. Erm, sort of, I suppose it's hard to know, and what, what opinions staff thought of me. Or sort of what, what they understand is going on.</p> <p>I Worry. Could you tell me a little bit more about that if you can?</p>	<p>Taking son to school – a responsibility not able to meet. Guilt of limiting son's need for exploration. Recognition of importance of play. Worry. Distance from child = worry about impact amplified. Amplification of worry if unable to see child. Fears about the impact – the guilty parent. Perceptions of others at forefront of mind. The struggle of determining others perceptions. Others opinions about parenting are highly valued. Others understanding about her mental health are highly valued. Do other others misunderstandings highlight her lack of understanding and therefore doubt about parenting ability? The need for system-wide understanding is highlighted? Erm – unsure of herself. Sort of – hesitation/stumbling = finding it hard to understand/describe? What, what – what is it? Hard to put words to her experience?</p>
<p>Fearing criticism and judgement. Fear of impact on child: shame. The pain of accessing memories. The prominence of paranoia.</p>	<p>P Yeah, so I suppose [clears throat] erm, just Child1 being aware that I wasn't leaving the house, um I was a bit worried what, what he was thinking, or sort of what effect I would have on him. And before I went to hospital, so I had a bit of a episode where I sort of came, um him, he was playing with my partner, um they were playing the dining room, but, I sort of [coughs], had a bit of a moment when I was sort of crying, shouting, "oh they're filming me, they're filming me. We need to ring the police".</p>	<p>Suppose – not concrete – being unsure. Clears throat – hard to say? Nervous? Fear of child's perception of her as a mother. Dominance of others perceptions/judgments about her parenting ability, including perceptions from son. Acknowledging the potential impact on her son. Worry about son's perception of her as a mother. Enwined perceptions = exacerbation of shame as a mother. Fear about impact on child. The pain of describing how her experience may have impacted son. Bit of an episode – minimising to protect herself? There is a sense that she is deeply shamed about psychotic episode, images and memories of herself are deeply painful to access; possibly images of herself in that situation with her son. Crying and shouting alongside prominent memories of her distress in front of her son. Paranoia is prominent. Painful recollections of son witnessing psychotic episode. Fear of the potential impact on son is prominent. Fear of others in paranoia translated to fear of impact on child? Coughs – hard to say? Disrupted flow of explanation – is not clear for her? Or hard to say?</p>

A	B	C
The powerless, observed mother	(the prevailing role of power)	
	<i>Trapped in exposure (a fickle sense of strength)</i>	
		Inescapable scrutiny / observation
		Mothering exposure
		Under the control of others / powerless
		Hopelessness
		The trapped mother
		Shame and guilt
		<i>A vulnerable parenting identity (the battle with selfhood)</i>
		Self-defeating perceptions
The feared legacy of psychosis		Fragile / unreachable parenting identity
		Failed mothering perceptions / confidence
		Discounting own relational needs
		<i>The fear of harm (fearful mother/family)</i>
		Fear of impacting child
		The protective paradox of fear
		Meta fear and worry / entwined psychological processes
		Proximity dictates distress
		Aversive parenting uncertainty
Surviving Parenting		
		<i>Unattainable mothering standards</i>
		Parenting standards
		Parenting responsibilities
		The absent mother
		<i>Fearful others</i>
		Unnecessary risk focus
		Partner support
		The protective child
		Intrusive support
Surviving Parenting		
		<i>The masked mother</i>
		Strategies of protection: avoidance, masking, escape
		Performing Parenting / stamina
		<i>The need for closeness, safety, and certainty (closeness as an antidote to pain)</i>
		Education support strategies / Need for parent-child communication
		The need for a safe environment
		Insight into needs required
		External gateways to freedom
		Closeness to child / bond
	The gains of sharing / processing pain	
	The need for compassion + connection	
	The power of joy + love ; emotional contagion	
	<i>Timeliness of support</i>	
	Timeliness of support	
	Timestamps / journey of pained motherhood	
	Adequate support	
	Mixed feelings of support	

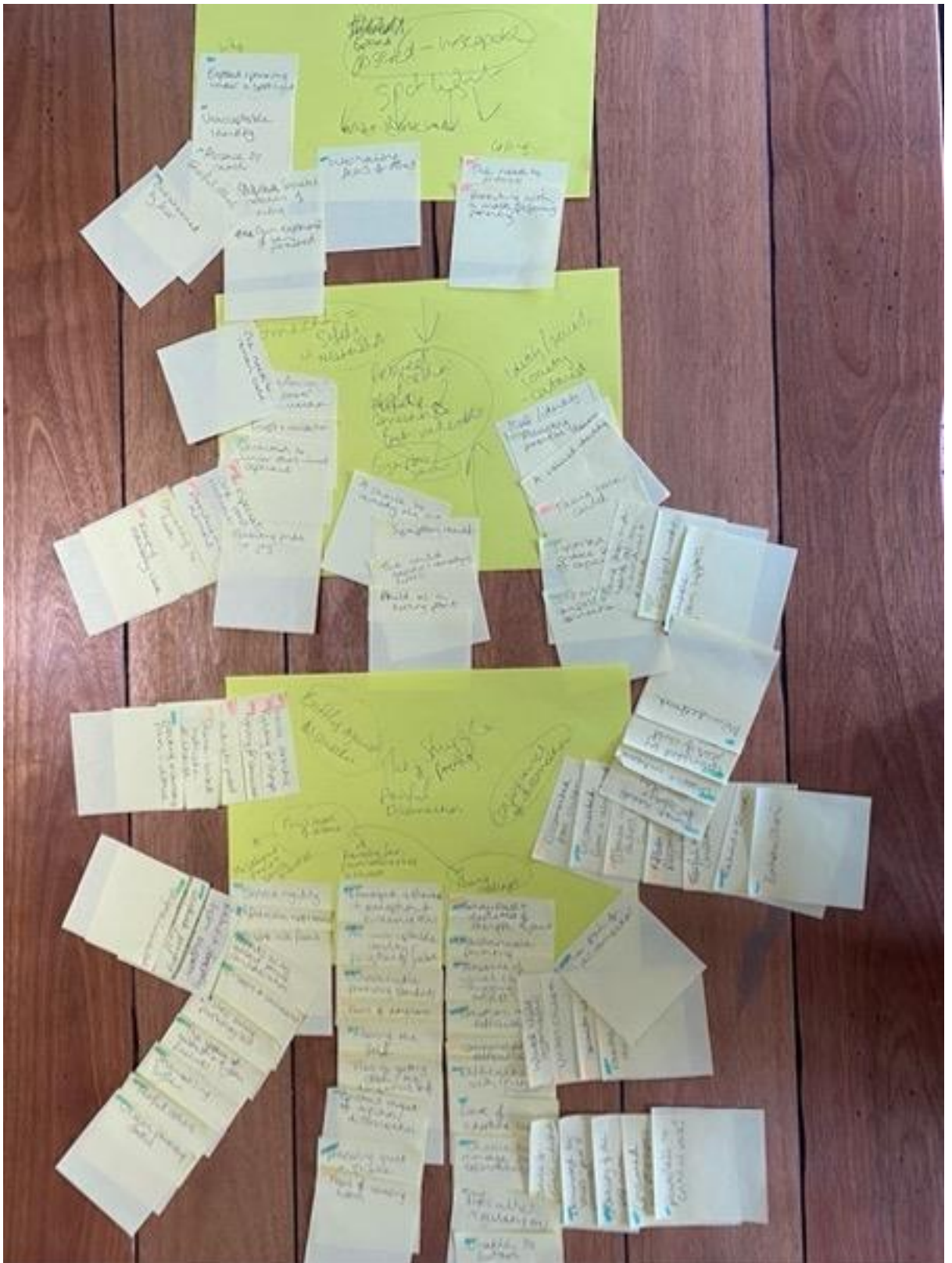
Appendix R. Searching for Themes Across Participants

<p>1</p> <p>Systemic influences:</p> <ul style="list-style-type: none"> - Neighbourhood and socio-economic threats - The legacy of one's own parenting culture - Trapped in a powerful, unresponsive, and stigmatising system - Misaligned parent and service priorities: an aversive risk focus 	<p>Parenting under threat:</p> <ul style="list-style-type: none"> - The pain of disconnection - Alone with the threat and control of voices: child removal and emotional disconnection - Unhelpful coping: hiding and avoidance to protect - Fears of impacting child: desire to avoid history repeating itself - Performing mothering: observed, exhausted and isolated - Emotion regulation difficulties - Inhibiting connection with child 	<p>The hidden child:</p> <ul style="list-style-type: none"> - Fearful, alone and longing for connection - Responsibility behind closed doors: role reversal - Absorbing parenting distress 	<p>Parallel experiences:</p> <ul style="list-style-type: none"> - Trapped and compliant - Fears of disconnection and rejection - Valuing resilience - Conflict avoidance - Desire for safety and security 	<p>The journey of change: becoming empowered and connected:</p> <ul style="list-style-type: none"> - The transformative power of trust and connection - Being held and supported: practical support, MDT and lived experience - Taking back control, responsibility and pride - Being heard and supported to make sense of experiences - Compassionate, reliable connection with others
<p>2</p> <p>Powerless and afraid</p> <ul style="list-style-type: none"> - The pain of disconnection - Reliant, stuck and yearning for independence - Powerless to external control: voices, service decisions and gendered parenting norms - Unseen and threatened by desertion - The fear of causing harm to daughter 	<p>Battling for control:</p> <ul style="list-style-type: none"> - Protecting the fathering identity: proving parenting - Fighting for security: battling against stigma and discrimination - Yearning for connection and validation - Fighting to overcome a misunderstood past - Fighting against hierarchy and structures 	<p>The empowered father:</p> <ul style="list-style-type: none"> - The salvation of parenting: child as saviour - The power of parenting connection in alleviating distress from psychosis - Parenting with pride - The role of comparison in boosting esteem 	<p>The need for systemic change</p> <ul style="list-style-type: none"> - The need for a shift in gendered parenting assumptions - System-wide education needed - The desire for parenting validation and support through connection with parents with psychosis - The need for service shifts away from a risk focus 	
<p>3</p> <p>The prevailing role of threat</p> <ul style="list-style-type: none"> - Inescapable threat of voices - The exhausted, helpless and fearful mother: desperate to be seen - A vulnerable parenting identity: parenting with a transparent mask - The unseen, distanced family - The aversive, surface level and risk-focused support 	<p>Parenting Power:</p> <ul style="list-style-type: none"> - A chance to remedy the past - The prevailing role of power - The success imperative: the desire to teach values and lessons - Fearful and compliant children - Promoting empowerment among children: remedying parenting doubt 	<p>An especially close connection:</p> <ul style="list-style-type: none"> - Dominated by mutuality of child's experience: overwhelmed by fear - Closeness as an antidote to threat: the protective mother - The power of being seen and heard - The impenetrable family unit - The need to be understood and unconditionally accepted 		

<p>4</p> <p>Inescapable Threat:</p> <ul style="list-style-type: none"> - Lost and powerless to psychosis: unsustainable parenting demands - Trapped by fears of child removal - The exposed, yet hidden/ misunderstood mother - Fears of impacting son - The legacy of mistrust and system failures 	<p>Misaligned Parent and Service Priorities:</p> <ul style="list-style-type: none"> - The barrier stigma - Silenced by an aversive risk focus: the risk paradox - Missing containment, consistency, and compassionate care - Lack of system flexibility 	<p>Protecting the Parenting Identity</p> <ul style="list-style-type: none"> - Parenting with a mask - Psychosis amplifies the need to protect: remaining hidden and unseen - The role of reassurance 	<p>Surviving Parenting in the Context of threat</p> <ul style="list-style-type: none"> - The need to be close: the child saviour remedying distress - The role of system support: security and containment - The power of being seen, heard and connected - The need for a new approach: compassionate and informed care 	
<p>5</p> <p>The powerless parent:</p> <ul style="list-style-type: none"> - Trapped in exposure - A vulnerable parenting identity: the missing responsibility - The centrality of the self-critic: inescapable guilt and shame - Unable to sustain parenting: exhaustion and fatigue 	<p>Distance arising from fear:</p> <ul style="list-style-type: none"> - The fear of doing harm: hiding to protect - Unattainable mothering standards - The missing role of communication - Misaligned parent and system perspectives: fearful others 	<p>Surviving parenting:</p> <ul style="list-style-type: none"> - Parenting in the moment - Parenting with a mask - The need for closeness, safety, and parenting security - The need for system-wide psychoeducation 		
<p>6</p> <p>Unprocessed trauma: Voices capitalising biggest fears</p> <ul style="list-style-type: none"> - The prevailing guilt - The dominance of child loss fears - Trapped and powerless to psychosis: scared and alone - The impact of "tunnel vision" - Parenting routine challenges 	<p>Tug of War: caught between closeness and distance</p> <ul style="list-style-type: none"> - The need to protect - The mutual pain of disconnection - Fears of getting close - The battle with mothering identity - Under-recognised parenting status: unheard and unsupported - The resolution of distress with child contact 	<p>The "dangerous mother"</p> <ul style="list-style-type: none"> - Fearing the self - The pathologisation of distress: the misunderstood, distanced mother - Unhelpful risk focus: misaligned parent and service priorities - The straightjacket of systems approach: distanced and alone - The need to prove parenting 	<p>The missing role of containment and connection</p> <ul style="list-style-type: none"> - Helpless, stuck and alone: the need for system support - The need to be close - Powerless to the system - Psychoeducation needs - The need for consistent, contained community care 	

7	<p>The threat of disconnection</p> <ul style="list-style-type: none"> - Consumed by critical voices: powerless, fearful and alone - The parallel increase in parenting distance and distress from psychosis - The unseen, disconnected father: feeling unsafe without system supports - Emotional control difficulties - Parent and child fears driven by limited understanding 	<p>The need to remain connected: 'there is a light'</p> <ul style="list-style-type: none"> - The safety and remedy of connection: psychotic symptom relief - The need to maintain valued, respected parenting identity - Attempting to remedy distress with positive mood induction - The hope of a better, connected future - The need for a community parenting support approach 			
8	<p>Parenting: "both a blessing and a curse"</p> <ul style="list-style-type: none"> - Child as a turning point: the desire to realign parenting identity - Struggling to adjust: overwhelmed and distanced from usual coping - Trapped and unable to manage parenting expectations and demands - The hope and relief from entrapment: the child saviour 	<p>The exposed parent: unable to hide</p> <ul style="list-style-type: none"> - Exposure of an unacceptable identity: parenting under a spotlight - The impossible search for an acceptable identity - Inescapable threat: powerless to entrapment - Intolerable distress: absence of control and the need to distance - Absence of adaptive coping - Masking to protect: performing parenting 	<p>The overpowering fear of parenting failure</p> <ul style="list-style-type: none"> - Failing to meet the desired parenting identity - Damaged and ashamed: unable to sustain parenting - Avoidance and hiding as coping - Internalising the fears of others - Shame-based motivation for change 	<p>The disconnected parent</p> <ul style="list-style-type: none"> - The pain of parenting from a distance - Parenting as an absent service consideration - Stigma and fears of rejection - The absence of understanding: disconnected from the self and others - The need for system support - Relief from entrapment: compassion, connection and acceptance 	

Appendix S. Searching for Higher-order Superordinate and Subordinate Themes



Appendix T. Overview of the Three Superordinate Themes, Six Subordinate Themes and Additional Exemplar Quotes

Superordinate theme	Subordinate theme	Exemplar Quotes
1: Living with the Struggle: Painfully Disconnected	1.1: Consumed by Fear, Shame and Powerlessness	<p>“There is loads of challenges. It’s loads of challenges. Because you can’t concentrate. You’re just exhausted all the time. And kids don’t know that you’re exhausted, you’re supposed to be there for them. They do understand why you’re tired every now and then, but if it goes day to day, you just can’t” (Vanessa).</p> <p>“I just felt like so guilty. Like, it was my fault that I was away from my children. It was my,- it was my doing” (Sharon).</p> <p>“Yeah, it’s just sort of, erm, I felt upset and it,- you just sort of feel it in the pit of your stomach. You just feel sort of regret. Um, and I just felt, I felt bad for [Partner] that he was having to do everything on his own” (Lucy).</p> <p>“I didn’t want to be a failure I think. And er, having psychosis, it felt like I’d failed” (Darren).</p> <p>“Sometimes, I’m not on a good day all, all the time, and I’m being snappy. And I feel disgusting about that, because I shouldn’t be snappy to kids. Because it’s not their fault if there’s something going on in my life, you know what I mean” (Vanessa).</p> <p>“There is loads of challenges. It’s loads of challenges. Because you can’t concentrate. You’re just exhausted all the time. And kids don’t know that you’re exhausted, you’re supposed to be there for them” (Vanessa).</p> <p>“At the moment, it just feels like [Partner] organises [clears throat], everything. ... It just makes me feel a bit less worthy. As a parent I just feel a bit less involved, and not as competent” (Lucy).</p> <p>“So say if the kids wanted their tea, and I was too paranoid and too fixated on the voices calling me a crap mum and stuff like that. That, I just felt like, that I couldn’t be a Mum” (Sharon).</p>
	1.2: Misaligned Parent and Service Priorities	<p>“But a single Mum, they get everything. Absolutely everything [emphasis]. They’ll get a house, everything. Where, they just don’t take into account, even though I’ve been signed off of work and everything like that, due to mental health, I’ve not been able to see my son and everything, it’s deteriorated my mental health. If I had a house where I could have my kids all the time, it’d help. But they don’t take that into account. They just see it as, ‘single guy? Oft, hostel’” (Chris).</p> <p>“I’ve got my, I’ve got my own problems to deal with, and you give me another problem questioning my parenting. Is this how it goes? Like. So that’s another problem. That’s not help” (Vanessa).</p> <p>“They say, ‘right ok, we’re just gonna let the social services know that you’ve got a child in the house’. And you think, ‘right ok. No one said I was gonna hurt my son, or that I’m gonna do anything in front of my son’. Erm, and that’s when all the alarms start going and you think, ‘wow, why are they doing this? What they doing? Why are they doing this? Are they trying to make me worse?’” (Lauren).</p> <p>“When I was um under, I think it was called the crisis team, erm, I was getting visits every day, but they sort of asked the same questions about risk. Erm. I think, I can’t remember exactly, but, they sort of had a list of questions, about ‘are you a risk to yourself, are you a risk to others?’, um which I wasn’t. So it might have been better to just have someone to have someone to talk to um without it being so risk focused” (Lucy).</p> <p>“Some, like, some services don’t understand that, that I am a parent” (Lauren).</p>

	1.3: Battling Against the Struggle: Parenting with a Mask	<p>“I wasn’t really there to be honest with you. It was like I was in a dream. It was like just there was a mask over me, and I was just done” (Lauren).</p> <p>“Protecting them [children] from me. Cos I feel that everything bad happens when I’m around” (Sharon).</p> <p>“I suppose I didn’t really cope too well. My, um, my sort of us staying inside to avoid, that kind of thing” (Lucy).</p> <p>“So me talking about my mental health, erm you know, if I said “ah I felt really sad that day”, and [Child] was there, or [Child] was to hear it and he was playing in a different room, he would come in and say, “Mummy are you ok?”. And I couldn’t, I couldn’t, I couldn’t let him hear that. And I couldn’t let him know that- [pause]. I,- my job is to protect him and make sure that he’s happy in life, and not feeling how I feel” (Lauren).</p>
2: Desired and Vulnerable Position: Comfortably Connected	2.1: The Safety of Connection	<p>“I want them to be close to me so we know what’s happening. So I’m not gonna wake up one day and all of a sudden I don’t know my children” (Vanessa).</p> <p>“We both know like,- you know there’s days where he’ll be having a bad day where he’s like, his mates have picked on him, or something at school. Or like, I don’t know, he’s been shouted at by the teacher for doing something. And I’ll support him. And it’s just,- he’s,- it’s like he’s supporting me but he doesn’t know he’s supporting me. And that’s what it’s like. I know he feels what I am” (Lauren).</p> <p>“It’s hard, because you want to be together. Which I hope, I hope in the future we’re gonna be together. Yeah, cos you want to live, to be with them together all the time. Not just to talk with them on the phone or just with them sometimes. You want to be with them all the time, to know what they’re doing” (Amir).</p> <p>“I would not, I would not want to go in hospital. Because that’s what made me lose my children going in hospital. I’d want to have something done at home. Like home-based treatment team or something. I didn’t think going into hospital was the right thing... Yeah. I think it destroyed my life” (Sharon).</p> <p>“I feel very privileged to have as much time with my daughter as I do though, cos not a lot of dads get, you know, get to spend all that time with their daughter, their child. So yeah, I love spending time with her. She makes my days go by faster” (Darren).</p> <p>“I love it with my little pals. It’s a joy to chat with them, and you know. They’re so funny as well, the way they talk, and,- yeah. It is, it makes me feel good. It makes me feel younger as well, because they’re my pals, so I’m like a friend to them. So I don’t feel like I’m an old woman and have to cook and clean. Err I feel like a part of their life” (Vanessa).</p> <p>“I love it. I took her abroad with me [laughs], everything. I take her everywhere with me, literally [laughs]. She’s literally like my little,- she’s literally just a little girl version of me.” (Chris).</p>
	2.2: Symptom Relief	<p>“I was really tired and I couldn’t sleep, I couldn’t,- I I was mumbling like drunk to the stage that even my speech was blurry. I was so tired. So er, they went to the shop, they got popcorn, they put a movie on, they sat around me all day with me, watched the movie. I didn’t speak a lot because I was too tired and stuff like that. But just having them around me. And to be very fair, that day, because they’d all been around and talking, lovely, bubbly and chatting to themselves, I fell asleep. So they put me to sleep!” (Vanessa).</p> <p>“Even though I was having these sort of negative thoughts, being around him and seeing,- cos we would still have moments of joy together, and you know, you, you can’t really sort of build too much of a negative when you’re spending time,- so when I</p>

	<p>was spending time with [Child] we would still have good times together, and still have,- I don't know just that love that you feel for your child as well, it's um, sort of, yeah,- it sometimes overwhelms the negative by spending,- by spending time with him, yeah" (Lucy).</p> <p>"Like he [son] just literally, just every day just pulls me through the day. Literally pulls me through. Every single day" (Lauren).</p> <p>"My psychosis is a way of dissociating myself from certain situations. So when I start getting stressed and they [voices] start piping up, that's why. So when I'm with my daughter, when I'm with my kids, I'm not stressed.... And it's,- I feel relaxed, I feel calm, I feel peace. Yeah, it's nice" (Chris).</p> <p>"She's, she's been the thing that kept me alive to be honest. Um [pause] if I hadn't have had a daughter, um, I don't think I'd have, I don't have much to look forward to in life. She's been the er, light in the darkness" (Darren).</p> <p>"Yeah what happens [when with his children], is my feeling is I see there is a light. There is no darkness. There is feeling happy. I can enjoy and I can feel I can understand. I'm alive. Not like I'm in the dark, not like I'm a dead person. I'm an alive person" (Amir).</p>
<p>2.3: Contained and Connected within Systems, Society and Services</p>	<p>"Sometimes it's nice just to talk to someone about, about you know,- and not judge you about hearing voices and stuff. It's nice" (Amir).</p> <p>"That lady [mental health worker] who was like a mother to me, she was very patient. She listened to me. She made me laugh. You know, she would be so comfortable that I was able to open up to her. So, I think we might not have all the staff in the world, but that little bit of compassion goes like, a really, a really long way. You know, but just because of that lady and her attitude towards me... her attitude, it made me focus on my problem as, 'you know what, this is a problem that can be fixed'" (Janet).</p> <p>"It's just sometimes I see someone and I click with someone, I feel like she's [healthcare worker] just more on my level. She's just more on my wavelength with things. She understands,- I feel like she understands me. Like I'll go in and I'll have a chat with her, and she'll take off all the pressure, and I'll leave there feeling better. Whereas I'll come and see [care coordinator], and I leave and think, I feel drained" (Lauren).</p> <p>"It's like, parent and child classes. But like, not classes, like groups with other people with their psychosis who have kids. Do you know what I mean? Because I don't know,- I literally don't know anyone else. Personally, I don't know anybody [emphasis] who has the same issues I do with a kid,- and then has kids. So it's like to meet other people like that would be refreshing, to see how they deal with things" (Chris).</p> <p>"Yeah, it's just to have someone to be there to help with anything that might come up. Um, if I'm if I'm struggling with something, at least there's someone else there that's, you know, I'm not on my own, um, having to deal with something" (Darren).</p> <p>"Yeah I feel comfortable. I feel that nothing can happen to me if I'm safe. Nothing can happen to me... yeah cos I know that people are around me, so I'm safe. Not like I'm on my own" (Amir).</p>
<p>3: Exposed: Parenting</p>	<p>"I've asked for help, and then you're just, you feel like you're being criticised. so you feel like they're looking at you, 'well, you've got all these issues, how are you looking after your kids', like, and you're thinking, 'pretty fucking easy', so" (Chris).</p>

Under a
Spotlight

You've got many people coming and you just feel like, you're not helping, you're not helping! And each visit you're thinking, "I'm not gonna talk to you, I'm not gonna do it", it, you're doing a step back every time you don't feel comfy" (Vanessa).

"I felt really helpless at first. And I felt very vulnerable because you're exposing and you're presenting yourself to people you don't know" (Janet).

"It's horrible [supervised visits with children]. Even though my sister does it, I feel like, - cos I'm dead close with my sister anyway I feel like she's just hanging around, you know, we're just hanging out together. But, I'd like to take my daughter for a walk without someone being there" (Sharon).

"I used to be a skater-stoner. And now I've got to sort of re-define myself a little bit. And as a parent as well especially, um, I've gotta re-define myself. Because [laughs] you can't be a teenager all of your life. And er, I'm very much, you know, I'm still, I'm still a teenager in my head" (Darren).

"Just living in this dream that I'm in. It's just a dream that I'm in. I feel like everyone knows. I feel like I'm sort of like, - they're, they're normal, - like it's it's just different" (Lauren).

"I can't explain. It's stressing me out because I feel like no ones listening to me. And then I feel like I'm, me saying that sounds like I'm being paranoid. And I'm scared that, I'm scared that people are gonna think that I'm poorly again" (Sharon).

**Appendix U. Preliminary Literature Scoping: Table Detailing Percentage of Samples
with Psychosis within Initially Identified Studies**

Study: authors, year, location	Percentage of Sample with psychosis	10% +	20% +	30% +	33% +	40% +	50% +	60% +
Boström and Strand (2020) Sweden	100%	Y	Y	Y	Y	Y	Y	Y
Strand et al. (2020) Sweden	86.6%	Y	Y	Y	Y	Y	Y	Y
Chan et al. (2019) Hong Kong	26.66%	Y	Y					
Klausen et al (2016) Norway	20%	Y	Y					
Awram et al. (2017) Australia	20%	Y	Y					
Van der Ende et al (2016) Netherlands	22.2%	Y	Y					
Parrot et al (2015) U.K.	91.7% of total population; diagnostic information pertaining to the qualitative sample was not supplied.	Y	Y	Y	Y	Y	Y	Y
Rampou et al (2015) South Africa	40%	Y	Y	Y	Y	Y		
Perera et al. (2014) Australia	62.5%	Y	Y	Y	Y	Y	Y	Y
Montgomery et al. (2011) Canada	?							
Khalifeh et al. (2009) UK	11.1%	Y						
Ueno & Kamibeppu (2008) Japan	65%	Y	Y	Y	Y	Y	Y	Y
Evenson et al. (2008) UK	100%	Y	Y	Y	Y	Y	Y	Y
Montgomery et al (2006) Canada.	15%	Y						
Sands et al. (2004) USA	15%	Y						
Diaz-Caneja & Johnson. (2004) UK	36.36%	Y	Y	Y	Y			
Savvidou et al. (2003) Greece	50%	Y	Y	Y	Y	Y	Y	
Ackerson et al. (2003) USA	?							

Thomas & Kalucy. (2002) Australia	31.4%	Y	Y	Y				
Nicholson et al. (1998) USA	19%	Y						
Sands (1995) USA	60%	Y	Y	Y	Y	Y	Y	Y

Appendix W. Searching for Descriptive Themes Across Included Papers



Appendix X. Searching for Analytical Themes and Subthemes

