Lived experiences of mental health and neurodiversity in parenthood

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Declaration

I hereby declare that this work has not been nor will be submitted partially or fully to another University for the award of any other degree. I also confirm and declare that this is my original work and appropriate referencing has been used throughout for sources.

Word Count

Section One: Systematic review

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Section Two: Empirical Study

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Lay Summary

Literature Review

Parenting is a rewarding but challenging experiences that comes with many life changes. Parents with higher parental stress have been found to be more likely to experience a mental health condition. Parents with mental health conditions have been found to experience more stigma and difficulties manging their and their children's needs. Most research focuses on impact to children with little known about parental experiences. Therefore, we aimed to explore published research in experiences of parenting with a mental health condition. Three databases were searched with twenty-five studies included and analysed using a method called thematic synthesis. Four themes were found overall, (1) 'the value of being a present parent', (2) 'being a parent is to protect and provide', (3) 'children's role and response to mental health', and (4) 'patients as parents'. Findings suggested parents with a mental health condition experienced a lot of stigma that led to feelings of shame and guilt about their parenting abilities. Mental health conditions often impacted parent's ability to provide physically, emotionally and financially for their children despite wanting too. Children often became the carer for their family and would adjust their needs in response to their parent's mental health. Peer and family support were identified as needed and valuable for future support.

Empirical Study

Autism Spectrum Condition is associated with difficulties in social communication and restricted and repetitive behaviours. Autistic women are often misdiagnosed and underdiagnosed compared to autistic males. There is a need in research to understand autistic women experiences. Pregnancy is a time that comes with many physical and emotional changes. Research has found autistic women can struggle with increased sensory sensitivity including light, smell, and taste. Autistic women have also been found to struggle to

communicate their needs with professionals, resulting in feeling misunderstood or unheard. Qualitative research is used to explore individual’s experiences. A qualitative design of Interpretative Phenomenological Analysis was used. Eight autistic women were interviewed, recruited from a research database and social media. Transcripts were analysed and three themes were found, (1) ‘reinterpretation of perinatal experiences after diagnosis’, (2) ‘the ups and downs of connecting to their maternal identity’, (3) ‘seeking support: need versus reality’. Findings suggested autistic women face additional barriers and challenges during pregnancy. Increased sensory sensitivities was found that impacted daily life. Feelings of confusion and disconnect from reality during birth were common. Participants felt communication with professionals was difficult and care was inconsistent. Stigma and expectations of motherhood led to feelings of inadequacy. Examples of compassionate care were discussed and consistency in care was considered important in future.

Acknowledgments

Firstly, I would like to thank my research supervisors Dr Megan Freeth and Professor Andrew Thompson. Your continued support, interest and knowledge has been invaluable throughout the research process. Megan, I wanted to thank you for your reliability and responsiveness as a supervisor, it’s been great to work with someone with such a passion for autism research. Andrew, thank you for your guidance and knowledge of qualitative methods particularly throughout your busy schedule at Cardiff. I also want to thank my clinical tutor, Dr Katharine Boon whose has continued to go above and beyond her role to support me, without her continual unrelenting compassion, care, and guidance the course would have been incredibly difficult to navigate.

Secondly, I wanted to say a huge thank you to my participants, without whom the research would have not been possible. I am sincerely grateful for your willingness and openness to share your pregnancy experiences. I hope to do your experiences justice and hope this research contributes the emerging field of understanding autistic women’s experiences.

Thirdly, to my fellow Trainees Lex, Margaret, Aditi, and Connie you made this course lighter and brighter, thank you for your endless support, debriefs laughs and good food. To my friends outside the course, particularly Alice and Beth, your love has kept me going amongst the trickiest times, you keep me sane and give me some much-needed fun throughout training! Thank you to my family for your unrelenting support to get to this point.

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Section One: Systematic Review

The Experiences of Parenting with a Mental Health Condition: A Systematic Review and Thematic Synthesis

Abstract

Objectives

The purpose of this review was to systematically appraise and synthesise qualitative research to investigate experiences of parenting with a mental health condition. Qualitative research has identified parenting to be a rewarding yet challenging experience, with mental health and stigma exacerbating pressures associated with parenting. Parents of all ages, gender and mental health diagnoses were included to explore in-depth the experiences of individuals across varying contexts.

Design and methods

Three databases were searched systematically for qualitative studies. In total twenty-five studies between 1998-2022 with 389 parents were included and analysed using thematic synthesis. The CASP appraisal tool was utilised to appraise quality.

Results

Four super-ordinate themes with nine subthemes were identified; ‘The value of being a present parent’, ‘Being a parent is to protect and provide’, ‘Children’s role and response to mental illness’ and ‘Patients as parents’.

Conclusions

Participants reported mental health as a barrier to being a present parent. Societal expectations of motherhood created intense feelings of guilt and shame. Participants reflected on the emotional and behavioural impact of mental health on their children and the presence of role reversal. Participants identified the need for peer support and a systemic approach within services to support families as a unit.

Practitioner Points

- Findings highlight the need for psychoeducation of parental mental health and systemic approaches to support the entire family.
- Future research should consider exploring experiences of parental mental health in the United Kingdom.

Keywords

Mental illness; Parenting; Thematic Synthesis; Qualitative; Systematic Review.

Introduction

Transitioning to becoming a parent is a multifaceted experience that is accompanied by a broad range of physical, financial, and emotional changes. Research suggests with the rise of technology, parenting is increasingly challenging and stressful in comparison to previous generations (Auxier et al., 2020). Parenting stress is defined as a psychological response to the parenting role that is distinctly different from other forms of stress, for example relational (Holly et at., 2019). Individuals undergo their own developmental experiences when becoming a parent, whilst also contending with the growing and ever-changing needs of their children (Respler-Herman et al., 2012). There has been a longstanding association between parenting stress and mental health conditions such as depression and anxiety (Rolle et al., 2017). It is estimated that around 68% of women and 57% of men who have mental health conditions are parents (Public Health England, 2021). With around 4% of parents having serious mental health illnesses (SMI) which is defined as having a diagnosis of psychotic disorders, bipolar disorder and major depression with psychotic symptoms or treatment-resistant depression (Evans et al., 2016; Stambaugh et al., 2017). Suggesting there is a significant proportion of parents who potentially face additional challenges whilst trying to navigate parenthood.

Children who grow up with parents with mental health conditions, particularly with high levels of parental stress are at significant long-term risk of experiencing chronic health and mental health conditions (Angelini et al., 2016). For children, early life is a crucial period of social, biological, and psychological development (Kamis, 2021). In accordance with attachment theory, infants develop their own capacity for emotional regulation from their parent’s availability to offer consistent support and safety (Bowlby, 1979). Therefore, it is important to consider how parental mental health may impact attachment and child development.

Central to attachment theory is the concept that similar attachment styles can be transgenerational, in that parent's attachment style can influence children's attachment development (Bowlby, 1979). This is influenced by the caregiver's availability to offer consistent support within their child's early experiences (Risi et al., 2021). There is evidence to suggest experiences of trauma may impede parental availability to be responsive to their children's needs, which may constrain secure attachment development (Lynegar et al., 2014). However, it is recognised as imperative to understand the exact mechanisms that may influence intergenerational attachment (Lynegar et al., 2014). Risi et al. (2021) found that parental mental health in particular parental depression, has a mediating influence on the relationship between both adult and child attachment. This suggests that parental mental health can impact attachment transmission as well as adulthood trajectories in children.

There has been an increased focus on guidelines for supporting children with parental mental health in recent years, for example the National Health Service (NHS) Long Term Plan (NHS, 2019). Most guidance has been acknowledged to neglect parental needs (Harries et al., 2023). Parents with mental health conditions report experiencing difficulties with disciplining their children, inconsistent boundaries, and role reversal (Ackerson, 2003). Parents have also reflected a struggle to meet the physical and emotional needs of their children when unwell (Dolman et al., 2013). This highlights the importance of further understanding experiences of parenting with a mental health condition.

The literature widely acknowledges that it is the severity or chronicity of mental illness, as opposed to the condition itself that can impact families and parenting (Kamis et al., 2021). Hosman et al. (2009) developed a theoretical model to explain the transgenerational transmission of psychopathology. This was based on the premise of developmental psychopathology, to understand the possible risk and protective factors for the impact of parental mental health. Hosman et al. (2009) highlighted that there are multiple interacting systems which include the parents, children, family, social support, and wider community with each factor having its unique protective and risk factors. Indeed, research indicates that parents with a mental health condition are also more likely to face difficulties with stigma, financial constraints, and single parenthood (Radley et al., 2022). Other mechanisms include parent-child interactions, family and social influences and the developmental stage for a child (Hosman et al., 2009). The parent-child interaction for example, has been highlighted as a mediator for adverse childhood experiences (Marie-Mitchell & Kostolanksy, 2019). This suggests parental functioning is influenced by a multitude systemic factors and is not limited to mental health in isolation.

The culturally constructed master narratives of parenting are important to consider, as according to the social constructionist theory these can unconsciously influence expectations and ideals a person holds (Kerrick & Henry, 2017). The dominant narratives of motherhood suggest expectations for unconditional love from the mother, which places significant pressure on the mother to develop such bond (Almond, 2010). Mothers from the United Kingdom (UK) have been found to adopt a “good mother” discourse along with ideals of how to achieve this (Guendouzi, 2006). These discourses intensify pressure on mothers to achieve this expectation, without consideration of additional challenges such as mental health and wider systematic factors.

To explore these systemic factors further, qualitative research has been used to increase understanding of parenting with mental health condition (Ackerson, 2003; Chen et al., 2021; Halsa et al., 2018; Perena et al., 2014). Most previous literature focused on the risks for families such as social isolation and custody battles (Jones et al., 2016). Recognising positive outcomes associated with parenting and mental health is also important, considering many parent with minimal adverse effects (Smith, 2003). Parenting is reported to bring a sense of pride and is a rewarding role, whilst also being a key motivator for recovery (Chen et al., 2021). Several studies have identified that motherhood is a central part of mother's identity, both in western and Asian cultures (Chen et al., 2021; Perena et al., 2014).

Qualitative studies have also been essential in gaining insight into specifically what aspects of parenting and managing mental health are challenging (Ackerson, 2003; Chen et al., 2021; Perena et al., 2014). Halsa et al. (2018) identified the numerous obligations of family life such as practical activities and routine for the children, were hard to balance alongside mental health appointments and treatment. Similarly, mothers and fathers describe how their symptoms can be debilitating at times and they struggle to parent to the standards they hold themselves too, based on societal expectations (Halsa, 2018; Mulvey et al., 2022; Parrott et al., 2015).

Harries et al. (2023) recently published the first systematic review and meta synthesis of qualitative research exploring experiences of parenting with a SMI. Parents described exacerbated pressures and restrictions of parenting with a SMI. Parents struggled to regulate their emotions experiencing them as overwhelming, such as easily becoming angry and using excessive discipline (Harries et al., 2023). Many children sacrificed their own needs for their parents and engaged in role reversal. Harries et al. (2023) extended previous literature by highlighting the interplay of complex systems on the impact of parenting with a mental health condition, such as social and financial constraints.

However, the review only included parents with SMI, therefore there is no current review exploring experiences of parenting with all mental health conditions. It is well known that one in three children live with a parent who experiences emotional distress such as depression or anxiety (Public Health England, 2021). Furthermore, maternal anxiety has been evidenced as a predictor for behavioural difficulties in children, while maternal depression increases a child’s likelihood of depression by three to four times (Brophy et al., 2021; Rao et al., 2021). This highlights the value of comprehensively exploring experiences of parenting with any mental health condition, which this review aims to do.

The findings from numerous qualitative studies can be amalgamated into a qualitative synthesis. Qualitative methods are valued for their potential contributions to inform practice and policy development (Hollier, 2020). Qualitative synthesis seeks to understand specific clinical questions by rigorously and comprehensively reviewing available literature, as opposed to qualitative literature reviews which offer a broad overview of current knowledge (Hollier, 2020). Over recent decades qualitative synthesis methods have been evolving, with evidence suggesting the larger scope of a synthesis is advantageous for informing policies and clinical practice (Popay, 2006). Thomas and Harden (2008) developed thematic synthesis, which is a qualitative process able to syntheses all qualitative methods based upon the same principles of thematic analysis (Thomas and Harden, 2008). These principles include analysing and integrating findings of all qualitative studies to identify prominent, overarching themes that best represent the experiences of the included participants (Braun & Clarke, 2012). This method was considered appropriate for this review, as it is inclusive of all qualitative methods, to explore in depth the experiences of individuals across varying contexts (Leeuwen et al., 2019).

Aims

The aim of this review is to synthesis the findings of qualitative studies to understand the experiences of parenting with a mental health condition.

Method

The protocol for this systematic review was registered on PROSPERO in January 2023 (reference: CRD42023382931). A systematic review protocol was developed to carefully consider the methodical construction of the review (see Appendix A). Booth et al. (2018) developed a framework with seven considerations for researchers to select a method for qualitative synthesis. The choice of synthesising methods is multifaceted and therefore requires the consideration of multiple criteria (Booth et al., 2018). This review consulted the RETREAT criteria and selected thematic synthesis (Thomas & Harden, 2008) as the chosen qualitative method. Thematic synthesis is an inclusive process considering a wide range of epistemological positions and qualitative methods, allowing the review to thoroughly consider the full breadth of the literature base (Thomas & Harden, 2008).

Search strategy

The PICo (population, phenomenon of interest and context) was used to develop the search strategy, which is an adaptation of the PICO tool for qualitative reviews (Stern et al., 2014). The PICo is considered the most appropriate to use with meta-synthesis as there is not pre-determined outcomes (Stern et al., 2014). Grey literature is regarded to broaden the scope of identified studies, however consensuses vary for robust methods to search grey literature (Mahood et al., 2014). Satisfactory papers were identified, therefore grey literature was not consulted.

Table 1

Research question identified with the PICo tool

Criteria	Description
Participant	Adults (>17) who are parents or primary caregivers to a child/children
Phenomenon of Interest	Qualitative lived experiences of parents (defined as mothers, fathers, or carers)
Context	Any diagnosed mental health condition/disorder

Three databases; Web of Science, PsychINFO and Scopus were systematically searched between January 2023 and March 2023. There were no restrictions placed on the dates of published research to include all relevant literature. Search terms were used with Boolean operators and the symbol * was used for truncation (Table 2). The titles, abstract and keywords were searched. Prior to the lead author (CG) beginning the searches, the search terms were discussed in supervision and checked by an external librarian at the university.

Table 2

Search Terms

Search Terms
Lived experience*" OR qualitative OR experience* OR interview* OR interpretative phenomeolog* OR template OR content OR narrative OR discourse OR grounded theory OR thematic **AND**

Parenting **AND**

Mental illness*" OR mental* illness OR mental* ill* OR "Mental* disorder*" OR "Mental condition

Study Selection

The inclusion and exclusion criteria are presented in Table 3.

Table 3

Inclusion and exclusion criteria

Inclusion Criteria

1. Adults (18 years plus) who are parents or primary care givers to a child (this includes biological parents, carers and adoptive parents). There is no limit on how long they have held a parenting role for after birth.
2. Studies exploring experience of parenting with a recognised mental health condition.
3. Use of a qualitative methodology and analysis or a mixed-method approach where qualitative data can be extracted.

Exclusion Criteria

1. Articles not written in English
2. Thesis articles
3. Studies about foster parents

Screening

All articles were imported to a reference management tool (Rayyan) for systematic reviews. Articles were screened by title and abstract with articles being excluded based on the inclusion and exclusion criteria. Once duplicates were removed full-text screening was completed. Forward searching using Scopus and backward tracking was completed. A total of 20% of articles were ratified by an independent researcher (AS) against the inclusion and exclusion criteria. Two discrepancies were resolved via discussion.

Data Extraction

The following data was extracted into a formatted table in Excel using an aggregative approach: author, year of publication, available sample characteristics, diagnosis and co-morbidities, recruitment, data collection, methodology, reflexivity, and findings.

Assessment of Quality

The critical appraisal of qualitative studies is a longstanding debate. The current consensus concludes although quality assessments should be completed, studies should not be excluded based on quality (Carroll et al., 2012). The exclusion of inadequate studies has no impact on the overall synthesis; however, it is important to acknowledge quality (Carroll et al., 2012). Sensitivity analyses have been implemented by similar literature to investigate the impact of lower quality studies on the methodological quality on reviews (Carroll et al., 2012; Coleman et al., 2017). However, as no study was rated as low quality, this was not completed in this analysis.

Studies were appraised using the Critical Appraisal Skills Programme qualitative checklist (Critical Appraisal Skills Programme, CASP, 2018). The CASP checklist is the most used tool to appraise qualitative studies (CASP, 2018). The checklist consists of ten items that are designed to evaluate the validity, rigour, and implications of research (Appendix B). CASP does not suggest a scoring system, however consulting other similar literature, numerical outcomes were attributed to concisely summarise quality (No=0, Can't tell=0.5, Yes=1) (Butler et al., 2020; Harries et al., 2023). Studies were categorised as high (>8-10), moderate (6-8) or low (<5).

All studies underwent appraisal by independent researchers (AS, LS) to ensure reliability. In total, there were ten discrepancies that were recorded and solved via discussion. Additionally, to support the transparency and quality of reporting the 'preferred reporting items for systematic reviews and meta-analyses (PRISMA, 2020) checklist and the 'enhancing transparency in reporting the synthesis of qualitative research' (ENTREQ) framework was completed by an independent researcher (AS) (See Appendix D & E).

Data Synthesis

Data was synthesised utilising Thomas and Harden's (2008) three step thematic synthesis approach. The first stage involves reading and re-reading the findings and importing these verbatim into an Excel spreadsheet. The lead researcher (CG) then engaged in inductive line-by-line coding to understand the meaning and content of each study. Through this a collection of codes were created allowing the development of themes. These themes were then compared across studies to create descriptive themes. Finally, these themes were organised into superordinate and subthemes of the experiences of parenting with a mental health condition. Supervision with the research supervisor (MF) was utilised to discuss each stage of this process.

Reflexivity

Qualitative research is contextual to the researcher's relationships between themselves and the participant. Therefore, transparency about such relationship is imperative for the credibility of qualitative findings (Dodgson, 2019). The lead researcher (CG) is a White British Trainee Clinical Psychologist in her mid-twenties with no children. The author has professional but no personal experience with individuals with mental health conditions.

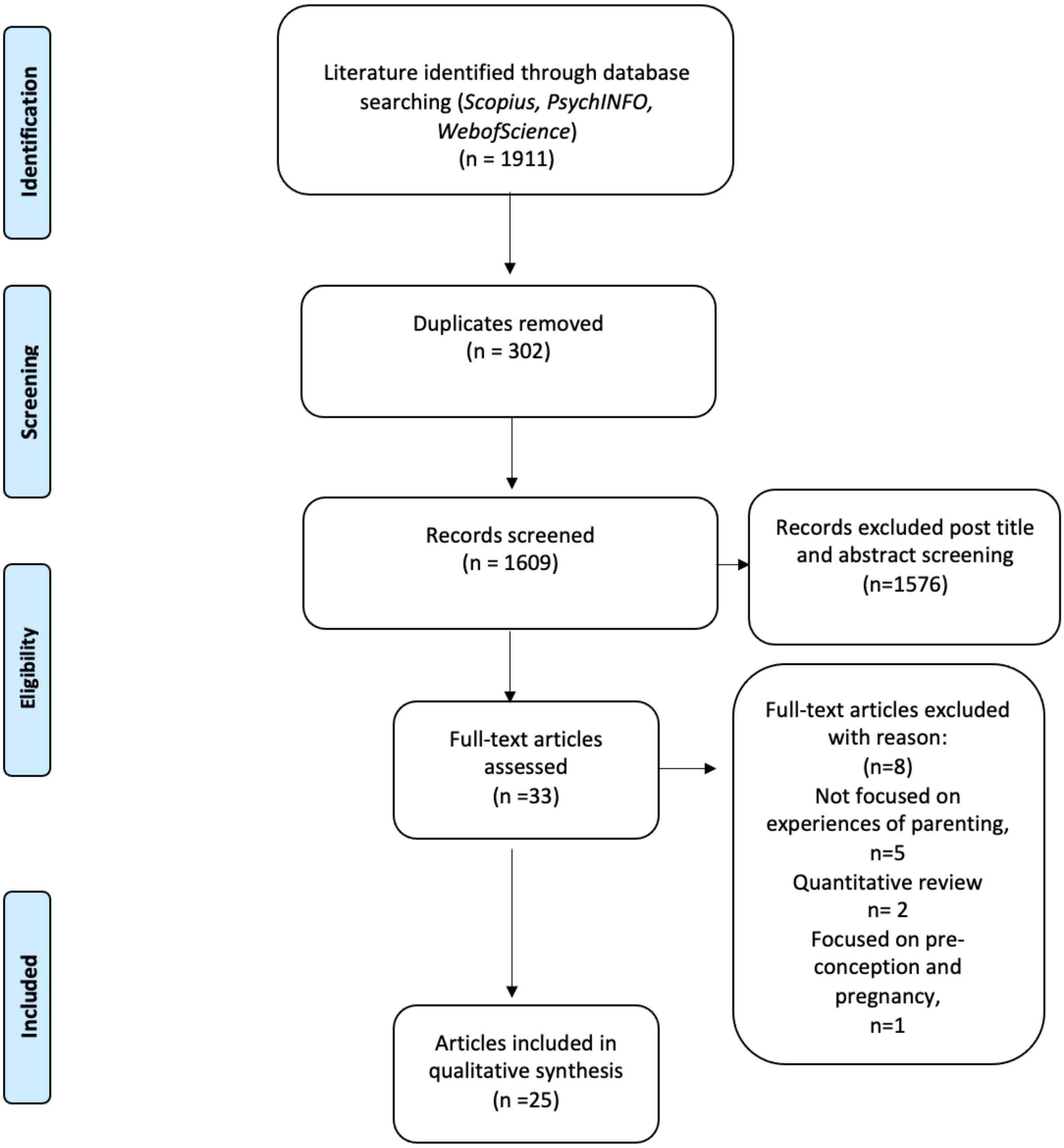
Results

Summary of Included Papers

A total of 1,911 studies were retrieved of which were 302 duplicates. Articles titles and abstracts were screened, with those not meeting the inclusion criteria excluded. The remaining 33 articles were read in full (Figure 1). Two papers were discussed in supervision and included. Overall, 25 studies met the inclusion criteria including 389 parents. Figure 1 detailed the PRISMA diagram of the screening process for included studies.

Figure 1

PRISMA Diagram, adapted from Moher et al. (2009)



The characteristics of each study were summarised within Table 4. The publication dates of the studies ranged from 1998-2022, with six studies being based in the United Kingdom and the rest United States, Canada, Europe, Ireland, Australia, Japan, and China. The included studies comprised of biological mothers and fathers only.

The majority of studies used semi-structured interviews (*n*=23) with the remaining using focus groups (*n*=2) to gather data. In total there were 389 parents (male= 85, female=304) between 18-79 years old. One study failed to report the exact number of participants; therefore, the overall number will be higher. Participants had between one and five children with ages ranging from 0-39 years old. Not all studies detailed the exact number of children each participant had or their ages. There was a mix of married, single, and widowed participants. Some participants lived full-time with their children, others had visitation, and some had no current contact.

There was a mixture of methods used for analysis, most studies used grounded theory (*n*=7) and thematic analysis (*n*=7), some used interpretative phenomenological analysis (n=6), framework analysis (*n*=1), discourse analysis (*n*=1) and the remaining used nondescriptive qualitative analysis (*n*=3).

Table 4

Summary of study characteristics

Author (Year)	Country	Recruitment	Participant Characteristics	Mental Health Conditions	Data Collection and Methodology	Reflexivity?	Findings and Themes
Ackerson (2003)	United States	Community mental health centres	13 parents (F=12, M=1) three currently married, remaining divorced, separated, or widowed. Seven parents lost custody temporarily or permanently	Psychotic disorder or severe mood disorder	Semi-structured interviews, Grounded theory	No	Eight themes were identified that represented parents feeling their experiences with mental health were interwoven with their relationships and parenting

Bassett et al. (1999)	Australia	Rehabilitation service	Females with children under 5 years old (number not specified)	Not detailed	Focus groups, qualitative exploratory descriptive design	Yes	Eight themes were found focusing on fear of losing custody and the stigma of parenting with a mental health condition
Chan et al. (2019)	China	Two integrated community centres of medical wellness	15 females age range between 26-50 years old, had between 1-2 children 2-22 years old	Major depressive disorders and schizophrenia spectrum disorders	Semi-structured interviews, Thematic analysis	Yes	Three main themes were identified focusing on doubting abilities as a parent and struggling for parental control
Chen et al. (2021)	China	Social media advertising	14 females between 20-49 years old with between 1-2 children 1-18 years old.	Anxiety, major depression, postnatal depression, schizophrenia, and bipolar disorder	Semi-structured interviews, Interpretative Phenomenological analysis	Yes	Seven super-ordinate themes alongside subthemes were identified that focused on motherhood being central to participants identity

Cremers et al. (2014)	Ireland	Not identified	6 females (M=42.3) between 37-62 years old. Four mothers were caring for their children (M=11.25)	Bipolar disorder and post-natal depression	Semi-structured interviews, Interpretative Phenomenological analysis	Yes	Five themes were identified around mental health overshadowing parenting and fear of judgement by others
Diaz-Caneja et al. (2004)	United Kingdom	Community mental health team from five geographical areas	22 females between 20-50 years old with children between 0-15 years old	Schizophrenia, bipolar disorder, or severe depression	Semi-structured interviews, thematic analysis	Yes	Seven themes were identified focusing on the difficulties of mothering with a mental health condition as well as the positives
Evenson et al. (2008)	United Kingdom	Community mental health teams	10 males (M=51) between 34-67 years old with between 1-3 children 1-33 years old	Psychosis, schizophrenia, schizoaffective disorder	Semi-structured interviews, Interpretative Phenomenological analysis	No	Three super-ordinate themes with subthemes were identified including psychosis impacting the father/ child relationship and what fathers felt parenting should entail

Hasla (2018)	Norway	Inpatient mental health hospital	16 females between 20-45 years old with between 1-5 children	SMI not specified	Semi-structured interviews, systematic text condensation	No	The findings are divided into two sections; "struggling for normality" which had three subsections and "dangerous mothers" also with three subsections
Klausen et al. (2016)	Norway	Three medical centres	10 females (M=41.7) between 31-40 years old. Had between 2 and 6 children	SMI not specified	Semi-structured interviews experience-orientated thematic analysis	No	Four themes were identified focusing on being able to understand the impact of parental mental health on children and mothers identity
Lumsden et al. (2016)	United Kingdom	Specialist community personality disorder service	8 males (M=37) between 28-44 years old with between 1-2 children 0-19 years old	BPD	Semi-structured interviews, Interpretative Phenomenological analysis	Yes	Three super-ordinate themes were identified around the process of becoming a father and the roles and responsibilities of fatherhood
McGraw et al. (2018)	Australia	Flyers in independent mental health practice	11 parents (M=9, F=2) between 31-51 years old (M=43) with 1-4 children between 1-18 years old	PTSD*	Semi-structured interviews, Interpretative Phenomenological analysis	No	Four super-ordinate themes with subthemes explored the transgenerational impact of parenting with PTSD and the emotional and behavioural impact

Mizock et al. (2018)	United States	Psychological rehabilitation centre	20 females (M=50) between 32-66	Major depressive disorders, PTSD, borderline personality disorder, schizophrenia, schizoaffective disorder, and high functioning autism/	Semi-structured interviews, Grounded theory	Yes	Four themes were identified centring around motherhood and mental illness
Montgomery et al. (2006)	Canada	Mental health hospital, acute and outpatient services	20 females between 20-39 years old with a total of 39 children between 2-15 years old	Schizophrenia, bipolar disorder, and major depression	Semi-structured interviews, grounded theory	No	The core category was identified to be having a meaningful relationship with their children and how they tried to achieve this
Mulvey et al. (2022)	United States	Women on the SMI probation caseload was offered a flyer	48 females (M=40) with between one and three children	Bipolar disorder, depression, psychotic disorder, anxiety disorder	Semi-structured qualitative life-course interviews, inductive approach	No	Five themes were identified focusing on how mental health impeded parenting ability and the parent's participants aspired to be
Nicholson et al. (1998)	United States	Women receiving case management services from the department	42 females (M=35.6) between 22-48 years old, average of 2.2	Anxiety disorder, bipolar disorder, psychotic disorder	Focus groups, thematic categories	Yes	Four thematic categories were identified focusing on stigma, custody and managing parenting with a mental health condition

		of mental health	children per family				
Parrott et al. (2015)	United Kingdom	Medium secure hospital	18 parents (M=10, F=8) (M=34) between 18-79 years old with between 1-5 children	Schizophrenia and personality disorder	Narrative interviews, Framework approach	No	Five themes centring around parenthood, identity and how mental health and offending interacted with these
Perera et al. (2014)	Australia	Public mental health service	8 females with children between -24 years old	Schizophrenia, major depressive disorder, and borderline personality disorder	Semi-structured interviews, grounded theory	No	The themes focused on positives and challenges to being a mother with a mental health condition, including identity as a mother and the parent child relationship

Radley et al. (2022)	United Kingdom	Early intervention in psychosis services and adult mental health teams	12 parents (F=10, M=2) between 20-59 with between 1-3 children aged 3-11 years old.	Psychotic disorders	Semi-structured interviews, grounded theory, and thematic analysis	Yes	Four themes were identified focusing on the interaction between parenting stress and psychosis
Reupert and Maybery (2009)	Australia	Posters in adult mental health clinics, community group settings and general practitioner wating rooms	11 males between 30-39 years old, children age ranged between 4-16 years old	Depression, schizophrenia, and bipolar disorder	Semi-structured interviews, Interpretative phenomenological analysis	No	Seven themes were identified focusing on fathering identity, child custody and stigma associated with mental illness
Sabella et al. (2022)	United States	Announcements within community mental health agencies and department of mental health providers	18 parents (M=3, F=15) between 25-30 years old (M=26) with between 1-4 children	Major depression, anxiety disorder, bipolar disorder, or schizophrenia	Semi-structured interviews exploratory and grounded theory approaches	Yes	Three themes were identified focusing on managing mental health whilst parenting and children being a source of motivation for recovery

Sherman et al. (2016)	United States	Combination of staff referrals, recruitment letters and presentations to groups	19 parents (F=2, M=17) between 27-57 years old (M=39.10) with between 1-5 children	PTSD	Mixed-method design with semi structured interviews and focus groups analysis used an inductive procedure	Yes	Participants identified themes categorised by children’s emotional and behavioural response to PTSD as well as the specific impact of PTSD symptoms on parenting ability
Strand et al. (2020)	Sweden	Outpatient clinics	15 parents (F=10, M=5) (M=42) with 17 children between them aged between 3-16 years old	Schizoaffective disorder, schizophrenia, psychotic disorder, and major depressive disorder	Semi-structured interviews, thematic analysis	Yes	Six themes overall were identified focusing on the unpredictability of parenting with a mental health condition
Ueno and Kamibeppu (2008)	Japan	One psychiatric hospital and two psychiatric clinics	20 females (M= 43.0), lived with mental health from between 2 and 37 years, 1-3 children between age of 3-20 years old	Schizophrenia, schizoaffective delusional disorder, delusional disorder, or mood disorder	Narrative interviews, modified ground theory approach	No	Five concepts were found that impacted the parenting practice of mothers, with the predominate being parenting whilst engaging in self-care

Wells et al. (2021)	United Kingdom	Medium and low secure forensic inpatient hospital	8 males (M=30.1) between 27-54 years old. Between one and three children aged 12-39 years old	Not specified	Semi-structured interviews, grounded theory	No	The central psychological concept that was identified was "paternal connection" and how this was maintained and constrained
Wilson and Crowe (2008)	United States	Not stated	5 parents (F=4, M=1)	Bipolar disorder	Sem-structured interviews, critical discourse analysis	No	Findings suggest parent’s identity was strongly related to societal standards and stigma. Parents felt their emotional regulation needed to be monitored

**SMI; serious mental illness PTSD; Post-traumatic stress disorder, BPD; Borderline personality disorder*

Quality Appraisal Results

Table 5 details the critical appraisal summary of the included studies using the CASP checklist. As per Thomas and Harden (2008) guidance no studies were excluded based on quality, therefore it is worth highlighting the specific limitations of included studies. Overall, 20 papers (80%) were found to be high quality and five (20%) moderate quality. Half of studies neglected to address reflexivity within their method. Additionally, two studies of lower quality failed to clearly detail study design and analysis. Finally, three studies also failed to report ethical considerations and one detailed consent but not ethical approval.

Table 5

Critical appraisal of the quality of included studies

Study Author	Clear research aims?	Appropriate method?	Appropriate design for aims?	Appropriate recruitment?	Data Collection?	Relationship between researcher and participants considered?	Ethical Issues considered?	Rigorous data analysis?	Findings clear?	Research valuable?	Overall Score	
Ackerson (2003)	✓	✓	✓	✓	✓	✕	✕	✓	✓	✓	8	Moderate
Bassett et al. (1999)	✓	✓	✕	✓	✓	✕	✓	✕	✓	✓	7	Moderate
Chan et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Chen et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Cremers et al. (2014)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	9.5	High

Diaz-Caneja et al. (2004)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Evenson et al.(2008)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9	High
Hasla (2018)	✓	✓	?	✓	✓	✗	✓	✓	✓	✓	8.5	High
Klausen et al. (2016)	✓	✓	✓	?	✓	✗	✓	✓	✓	✓	8.5	High
Lumsden et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
McGraw et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Mizock et al. (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Montgomery et al. (2006)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9	High
Mulvey et al. (2022)	✓	✓	?	✓	✓	✗	?	?	✓	✓	7.5	Moderate
Nicholson et al. (1998)	✓	✓	✗	✓	✓	✓	✗	✗	✓	✓	7	Moderate
Parrott et al. (2015)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9	High

Perera et al. (2014)	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	9	High
Radley et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Reupert and Maybery (2009)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9	High
Sabella et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Sherman et al. (2016)	✓	✓	?	✓	✓	✓	✗	✓	✓	✓	8.5	High
Strand et al. 2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Ueno and Kamibeppu (2008)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9	High
Wells et al. (2022)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10	High
Wilson and Crowe (2008)	✓	✓	✓	✗	✓	✗	✓	✓	✓	✓	8	Moderate

Thematic Synthesis

There were 90 codes in the ‘bank of themes’ (Appendix F) and 15 descriptive themes (Appendix G). Analysis produced four superordinate themes each with subthemes shown in Table 6, with a further table detailing contributions of studies to themes (Appendix H). The themes are a summary of the most prominent and relevant themes across the studies, as opposed to an exhaustive account (see Appendix I for additional quotes).

Table 6

Superordinate and Subthemes

Superordinate Theme	Subtheme
1.The value of being a present parent	*1.1 Barriers to present parenting* *1.2 Expectation to be a present parent*
2.Being a parent is to protect and provide	*2.1 The challenges to protecting* *2.2 The challenges to providing* *2.3 Children as motivators*
3.The impact of mental illness on children	*3.1 Children becoming carers* *3.2 Emotional, behavioural and physical impact*
4. Professional and social support needs	*4.1 Being recognised as parents by professionals*

The value of being a present parent

This super-ordinate theme identified the importance of participants of being present parents, grounded within societal expectations of parenting.

Barriers to present parenting

Across all studies participants described parenting with a mental health condition as “unpredictable” and “isolating” (Montgomery et al., 2006, p.23). Competing demands were often incompatible, “Just not being able to . . . fully concentrate on your family [. . .] there’s always this overshadow of . . . this problem, mental health problems” (Cremers et al., 2014, p.101). Parental responsibilities were complicated by mental health.

> You have to go to work. You have to come home. You have to deal with the kids and home… It’s hard to have a balance… I need to get out, but in the back of my mind I feel guilty that I need time alone (Nicholson, 1999, p.639).

> She [daughter] says why ain’t you phoned me? I don’t want to say on the phone really [child’s name] I feel suicidal today (Wells et al., 2021, p.159).

Parenting stress, for example lack of sleep triggered a decline in some participants wellbeing. Nearly half of studies recognised self-care as an important mechanism to maintain mental wellbeing. For participants in Ueno et al. (2008, p.525) this was recognising “I’ve got to take balance”.

There was often conflict for participants regarding caring for themselves or their children, “I almost had to get admitted to hospital yesterday. 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). In around half of studies there was a sense of sacrificing either theirs or their children's needs and struggling to find a balance.

> It makes it harder for me to put my child first and focus more on his wellbeing [...] I wish it would be better… My brain won't let me do it. It's just like I come first. Which I don't want to (Sabella et al., 2022, p.6).

Expectation to be a present parent

Across three quarters of studies participants perception of their parenting abilities were influenced by societal expectations. It was important to be regarded and be able to be a present parent "be there for them when they need you" (Wells et al., 2021, p.156). Participants were also concerned about being negatively judged and considered their self-presentation frequently, "So, you hide it. You try to be a good parent, you hide it when you are not well (Wilson et al., 2008, p.881).

Participants often reflected on longing to be what they perceived to be a 'normal' parent, "It's nice to know that sometimes I can go out and people come up to me and see me as a just an everyday-mother, it's a great feeling." (Perera et al., 2014, p.173). In over half of studies, this struggle for normality led to participants seeking to mask their difficulties "I won't let anyone think I can't cope" to reinforce they are the idealised "good mother". Inevitably holding themselves to these unrealistic standards left participants with feelings of "shame", "I am neither a good mother nor a good wife" (Chen et al., 2021, p.7).

Stigmatisation and judgement were common themes throughout all studies, "it's sort of like having `crazy bitch' stamped across my forehead, everybody treats you differently" (Basset, 1999, p.601). Many participants were concerned about how being stigmatised may impact their children’s social interactions. For one mother in Chen et al. (2021) her child had been excluded from a birthday party because of her mental illness, “If other mothers knew I had a mental illness, they might not allow their children to play with mine.” (Diaz-Caneja et al., 2004, p.477).

Being a parent is to protect and provide

This super-ordinate theme encompassed what parents felt the core meaning of being a parent was and how mental health could impede their ability to fulfil this.

The challenges to protecting

Over half of participants across studies identified the need as a parent to provide security and safety by protecting their child against harm. Particularly fathers in three studies defined this as the need to consistently “”be there” and “let your child know you are there for them” (Bassett et al., 1999, p.602). For most participants their mental health hindered their ability protect their children. Practically, participants would withdraw and “stay away for long periods” to prevent harm.

> I knew that when I heard voices that told me that something horrible was going to happen to them or that they [the children] had been sexually abused, I knew that wasn’t true, so I protected them from it. I kept quiet or stayed away (Strand et al., 2020, p.623).

Being sectioned was another example of a practical barrier, “I haven’t been there for them sometimes because I’ve been in hospital” (Evenson et al., 2008, p.634). In three studies, participants experienced loss of paternal relationships after sectioning “I wasn’t aware, that he’d [son] gone into care” (Wells et al., 2021, p.155). In over three quarters of studies, participants often attempted to conceal their illness and hide their symptoms from their children, “I’m trying to give them as normal a life as possible and you know, I would rather keep it to myself” (Radley et al., 2022, p.7). This was to emotionally protect children from feeling “worried” or “terrified” (Klausen et al., 2016, p.110).

Similarly, a fifth of studies drew on the felt need to hide the full extent of their illness from professionals. This was deemed protective for them and their children from loss of custody, “I hid being ill, because if the court knew that I had a mental illness, I would have to have a supervised visit with my son” (Reupert & Maybery, 2009, p.64). Another aspect that emerged in nearly all studies was that participants were “so afraid that my child has inherited my illness” (Chen et al., 2021, p.5). Many attempted to prevent this.

> I kind of read a little bit about this borderline thing coming about from a young age when people are not allowed to explore boundaries. So [...] I want to let him explore his boundaries (Lumsden et al., 2016, p.117).

The challenges to providing

Participants in nearly half of studies consistently stated to be a parent is to provide for your child, namely financially emotionally and practically. Nearly half of studies reflected on when participants were well, for example mothers in Chen et al. (2021, p.5) study reported being “tolerant”, “patient” and “energetic” and feeling able to engage in activities with their children. Conversely most participants felt their emotional availability to respond to their children’s needs was impeded by their mental state, “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 et al., 2004, p.476).

In around half of studies participants often expressed a longing to have connection with their children but struggling with emotional attachment. Lack of energy and fatigue because of mental illness and medication were attributed as significant causes. One participant in Everson et al. (2008, p.635) went as far as to say, “medication is a physical and emotional straight jacket”.

> I stopped being a parent to him [my son] and I become more of . . . somebody who doesn’t care . . . I completely shut my feelings off . . . I have no emotions at all (Sherman et al., 2016, p.405).

Nearly all studies identified the importance of financially providing, however mental health often restricted this due to not being able to work, “I haven’t got the money to buy him the things that I want to buy him” (Lumsden et al., 2016, p.116). All participants in every study reflected on the practicalities of juggling children’s schedules, to ensure they are provided with enriching social and educational activities and how difficult this can be, “It's a seven-day-a-week schedule, you know […] Keeping the entire home organised, keeping things moving smoothly” (Nicholson et al., 1998, p.639).

Children as motivators

A common theme across nearly half of studies was despite the challenges, children were motivators for recovery. Participants often described wanting to provide and care for their children no matter what, “I have always been strong, but now […] I don’t have any other choices because I have a kid” (Mulvey et al., 2022, p.1731). Children often represented a sense of hope for participants parenting abilities, which was much needed encouragement amongst the abundant feelings of guilt, “That having a mental illness and being a parent is possible […] you don’t have to be like ashamed” (Sabella et al., 2022, p.7).

Fathers in Lumsden et al. (2016, p.115) study were able to reflect on the challenges they had managed during fatherhood and how they prioritised their children's safety, "There's no shouting and roaring. [...] It's quite close to what I would call normal as possible". Parenthood bought joy "I just adored her" (Mizock et al., 2018, p.109) with "having someone to love, totally and unconditionally" (Parrott et al., 2015, p.264). For many participants, the importance and unbreakable bond of the parent-child relationship was clear, "I don't know what I would do without them. They are my everything" (Perera et al., 2014, p.173).

Maintaining connections was paramount across all studies, participants could often be separated from their children due to custody loss or sectioning. Daily telephone contact or visits were important, "[telling his father] what to cook them, what lotion to use on their skin" (Parrott et al., 2015, p.267). As well as travelling distances to have regular visitation, "it'll take me two buses to get there… and Saturday is [me] just hanging being a mommy. Just being a mom. (Mulvey at al., 2022, p.1723).

Children's role and response to mental illness

This super-ordinate them explored the impact parental mental health had on children in terms of emotional, behavioural responses and the roles they assumed.

Children becoming carers

In a fifth of the studies, participants reflected on the additional expectations placed on their children due to their mental illness. Many participants would describe their relationship with their children as a "special bond" that was characterised by "making us closer" because of their interdependence (Ackerson, 2003, p.114). Some participants failed to recognise the strain or responsibility placed on their children. Role reversal was present in two respects, firstly during symptom exacerbation older children assumed responsibility for siblings, “You know, she was doing the parenting! And she took care of [her brother] She became the little parent sometimes” (Ackerson, 2003, p.116).

The second was the child becoming for all intents and purposes, the caregiver “when I can’t get up because the medication has knocked me out, or I feel very unwell, my son has got to be in charge, he has got to know what to do” (Diaz-Caneja, 2004, p.476). In half of the studies, participants would draw on their children assuming responsibility of ensuring their parents took medication, “My daughter stays on me sometimes; I go to bed without taking my pill and she knows. She’s like, “No!” She says, “you’re taking your pill” (Mulvey et al., 2022, p.1729).

Emotional, behavioural and physical impact

In half of studies participants expressed concern regarding the negative impact of their mental illness on their children, including behaviourally, emotionally, and developmentally.

In Chen et al (2021, p.5) study participants identified delays in physical development namely body strength and co-ordination, as their children were unable to “crawl around and touch dirty floors”. Participants also noticed “very poor communication” from their children. Some children were noted to be anxious and insecure in response to their parent’s illness, “Is mom crying because of us fighting? We have to be silent, so we don’t disturb mummy” (Hasla, 2018, p.53).

In just under half of studies, participants observed how their children struggled with painful emotions in response to their parents such as “resentment” or “worry”. “I could feel genuine sadness in her (my daughter) . . . I've had a bigger impact on her than I thought." (Sherman et al., 2016, p.406).

A quarter of studies reflected on behavioural responses. These could be evident at school and socially and in some cases, mirror the symptoms they had observed in their parents, "I have no doubt her anger and the way she acts out at school—a lot of it has to do with me . . . my PTSD" (McGraw et al., 2018, p.258).

As well as these responses from children, participants in a fifth of studies found their children's need for comfort distressing for their mental health, "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" (Strand et al., 2020, p.623). While other participants noticed their children's sensitivity to their distress and how they may try to protect their parents, "I think he carries many hard things within himself that he doesn't talk to me about" (Strand et al., 2020, p.624). However, participants also felt their mental illness encouraged admirable qualities such as "compassion" by children adapting requests to consider parents need, "He is more like this, "Can we paint a little?" So, he adjusts, he becomes more responsive despite being so young. He understands" (Strand et al., 2020, p.624).

Professional and social support needs

The final super-ordinate theme reflects participants struggling with professionals not acknowledging or supporting them both as patients and parents. As well as what impedes access to support and what support participants felt would be invaluable.

Being recognised as parents by professionals

Nearly all studies acknowledged how incompatible the treatment for mental illness often was with their parenting role. There was a felt sense that professionals failed to acknowledge the unexpected side effects such as drowsiness and withdrawal and the impact this could have on parenting, “I would become drowsy after taking medication...they [other parents] would urge them [their children] to achieve more... if I could, I would have done the same” (Klaussen et al., 2016, p.112).

Generally, participants felt professionals failed to recognise that they were also a parent, “If you don’t say then they don’t ask” (Diaz-Caneja et al., 2004, p.477). Participants in Diaz-Caneja et al. (2004) study felt professionals failed to consider the practical challenges of managing mental health as a parent, for example attending appointments with no childcare. Participants could often be labelled as non-compliant as a result.

In nearly all studies, participants identified wanting specific parenting support or “emotional support” to discuss their parenting role within therapy, “I want to know I’m not alone or not necessarily having a negative impact on my child” (Chen et al., 2021, p.7). A recurring response from all participants across studies was the benefit of peer support or peer support programmes, to feel less isolated and more connected, “If there was a group out there where I could mix with single mothers that have a mental illness, it would help me” (Basset, 1999 p.600).

The importance of support

Nearly all studies identified potential support participants family could benefit from, as well as the nuances of struggles, depending on social support. There was a distinctive difference in narratives of studies, depending on whether participants were single-parents or had social support to draw upon “He [partner] just knows and understands all about my illness and he is there for me. Always" (Perera et al., 2014, p.174). As well as having wider support from family members if parents experienced an exacerbation of their mental health symptoms, "She's [mother] always there to help' and "looking after my child while I was in hospital" (Strand et al., 2020, p.626).

Participants with limited support or single parents, described an isolated system that extended to limited social networks for their children. This had significant impact on their perceived ability or resources to cope, "Sometimes the weekend feels like 20 years. Just no break and it's really hard" (Basset et al., 1999, p.600).

Over half of studies identified the value of psychoeducation for the whole family. Participants wanted support with communicating and managing their mental illness with their family, participants in Chen et al. (2021, p.7) said, "So that they understand that it's not their fault that mum or dad has an emotional problem ... [and] don't blame themselves" Participants felt their family often "need[ed] just as much support" drawing on specific peer support they felt their children would or have benefited from to "just be a kid" (McGraw et al., 2018, p.259), "They have had support. This was a fun experience: we went on a free camp with [name of organisation] when I was diagnosed as bipolar" (Strand et al., 2020, p.627).

In over half studies there was a sense that support should not just be focused with the onus on the individual to be effective long-term, "it shouldn't be just the guy or the girl sitting there, there should be the family there as well with them" (McGraw et al., 2018, p.260).

Discussion

The aim of this review was to identify, appraise and thematically synthesise qualitative research to understand the experiences of parenting with any mental health condition. From this review, four super-ordinate themes emerged: “The value of being a present parent”, “being a parent is to protect and provide”, “children’s role and response to mental illness” and “patients as parents”.

The first and second super-ordinate themes “the value of being a present parent” and “being a parent is to protect and provide” encapsulated participants expectations and core meaning of parenting. Participants felt parents needed to be fully present and attentive to their children’s needs physically, emotionally, and financially often conflicted with mental health. Participants frequently held themselves to unrealistically high internal standards and were met with intensive feelings of shame and self-criticism. This is consistent with previous literature, highlighting that mothers with mental health conditions labelled themselves as “bad mothers” (Scharp, 2017).

Participants were challenged with competing demands of engaging in self-care to manage their mental wellbeing, whilst balancing their children’s needs for attention and emotional connection. This dilemma often resulted in self-sacrificing of needs or profound feelings of guilt. Unsurprisingly, comparison with parents without mental illnesses were common alongside aspirations to achieve such idolised standards of parenting. These standards reflected the dominant discourse of western ideals for motherhood, whereby motherhood is expected to be intensive, emotionally consuming, and child-centred (Abrams & Curran, 2011). This finding aligns with social constructionist theory demonstrating how participants construct the meaning of motherhood based on social and cultural narratives (Guendouzi, 2005; Kerrick & Henry, 2017). Participants compared their parenting abilities to pre-existing mothering narratives and felt shame when mental health exacerbation made them feel unable to achieve societies perceived standard of parenting.

This struggle for normality within family life resulted in many participants concealing their symptoms to protect both themselves and their children. Participants attributed this to the existing stigma regarding parental mental illness. Alike Harries et al. (2023) all studies reported significant fear they would lose custody of their children. Parents were acutely aware of preconceived judgements other parents held and the impact this had on their children, for example social exclusion. Similarly, Reupert et al. (2021) found children's experience of stigma regarding parental mental health resulted in bullying, social isolation, and concealment of mental illness. In fact, Reupert et al. (2021) found existing stigma is compounded by societal expectations of parental abilities which parents are judged both internally and externally against. This suggests experience of stigma and societal norms are interconnected and perpetuate parental perceptions of incompetence, as well as feeling the need to prove themselves as parents.

The third super-ordinate theme "children's role and response to mental illness" described the emotional and behavioural consequences of parental mental illness on children. Children experienced a range of emotional responses including withdrawal, fear, and resentment towards their parents. Children were found to react in recognition of their parent's mental state by withdrawing or supporting parents. This was reinforced by found by Gladstone et al. (2011) in his review whereby children were aware of parental symptoms and behaviours and would adjust to support their parents. Children were exposed to strenuous demands, that often resulted in them assuming responsibilities incongruent with their developmental age. Role reversal was common with children caring for parents which is well documented in literature (Harries et al., 2023; Villatte et al., 2022). In some studies, children neglected their needs such as schooling during acute phases of parental mental illness, which has been found to increase risk of insecure attachment development (Risi et al., 2021). This aligns with attachment theory that argues secure attachment is built upon consistent and secure care (Bowlby, 1979). This consistent care is harder to provide during times of exacerbation of mental illness, leading to role reversal and emotional responses in children.

The final super-ordinate theme “patients as parents” reflected participants desire for their parental identity to be recognised by professionals. The theme also identified the complex systemic systems that influence availability of support for families. This review explored parental experiences across multiple cultures, socio-economical and marital statuses. The findings highlighted the systemic nature of mental illness and how strikingly contrasted parental narratives were dependent on support. Parents with spousal, familial or social support reflected how their ability to cope was underpinned by such support. In comparison to isolated or single parents who lived in persistent threat regarding exacerbation of mental illness and child custody. This supported Hosman et al. (2009) model which suggested the influence of multiple risk and protect factors regarding the impact of parental mental health, including wider social and community support.

These findings also highlighted the struggle to be recognised or understood as a parent within professional services. Alongside this came a lack of acknowledgement from professionals regarding the incompatible nature of treatment and parenting. Practical concerns were raised such as attending appointments with limited childcare, with parents often being deemed non-compliant. Parents wished to receive practical parenting support, as well as a space in therapy to discuss their parenting role. Nearly all studies identified the need for peer support as a valuable resource which was consistent with Harries et al’s. (2023) review. Peer support has been found to promote a sense of hope, empowerment, and recovery

(Shalay & Agyapong, 2020). Finally, participants identified a prominent need for psychoeducation for the whole family. This ranged from understanding of intergenerational risk of mental illness, communicating with children regarding mental illness, to helping children understand mental illness. Additionally, participants in many studies had the desire for them and their family to be seen as one and treated as a system. Participants recognised the benefit of the availability of support for the whole family and considered the impact of parental mental health systemically.

The findings of this review support Harries et al. (2023) notion of systemic threat in their review. Whereby societies stigmatisation of parents with mental illnesses, compound threat of child loss and self-critical parental identities, that can negatively impact parental-child relationships. An extension of this unique to this review, was the lack of acknowledgement of patients as parents by professionals, which subsequently exacerbated the narrative of judgement.

Summary of Methodological Quality in Studies

Stenfors et al. (2020) argued that there are four criteria used to widely appraise the quality of quantitative research: credibility, dependability, confirmability, and transferability. Nearly all studies adhered to the principles of credibility, dependability, and confirmability. They did so by justifying the chosen methodology, being transparent with design and data collection and comprehensively explored findings. All studies provided verbatim quotes to evidence data, and all studies were represented in the findings.

The most common methodological limitation across over half of the higher rated and moderately rated studies was transferability, including reflexivity. Reflexivity considers the contextual nature of qualitative research, occurring between two people at a specific time

(Dodgson, 2019). Therefore, it is argued to increase credibility of findings all quantitative research should consider reflexivity. Mitchell et al. (2018) emphasised the importance of transparency, for example providing rationale for the epistemological standpoint of the research, while also reflecting on the researchers positioning. It is worth noting while not all papers commented on reflexivity, Ackerson, (2003); Evenson et al. (2008); Reupert and Maybery, (2009) and Parrott et al. (2015) justified their chosen methodology which goes someway to addressing transparency. Four studies from the same country also failed to detail ethical approval, despite the ethical principles outlined in their countries National Research Act (Public law, 1974).

The two lowest rated studies Bassett et al. (1999) and Nicholson et al. (1998) were also the oldest studies, which failed to provide rationale for method or clear rigorous analysis. However, this could be considered reflective of the development of qualitative methodology in recent years and its use to understand topics that are exploratory in nature (Howitt & Cramer, 2010).

Clinical Implications

There are several implications that could be considered valuable for clinical practice. These implications will be based on the NHS model in the UK, where the lead researcher is based. Firstly, across all studies participants identified the value of peer support to negate feelings of isolation, guilt and shame as supported in literature (Harries et al., 2023; Shalay & Agyapong, 2020). The NHS currently has peer support workers who are trained to share their lived experience compassionately (NHS, 2023). Therefore, it could be useful to integrate peer support groups in community mental health services.

Secondly, parental support and acknowledgement of their parenting role was widely requested by participants. Adult mental health services could provide space within consultations and psychologically within assessments and formulations to consider parental identity. Additionally, training could be provided to staff regarding the impact of mental illness on parenting and identity. A flexible approach to facilitating treatment engagement is also needed, considering the practical barriers to accessing services such as medication side effects and childcare.

Finally, participants identified the need for psychoeducation and systemic support within families. This indicates the value of having individuals with lived experience contribute to policy, practice, and guidance as highlighted by the National Institute for Health and Care Excellence (NICE; 2017). There is potential value in the availability of systemic approaches to account for the wider systemic context. Family therapy interventions have been found to reduce parental distress and is recommended as an intervention for psychosis by NICE (Cluxton-Keller et al., 2015; NICE, 2014). Evidence is emerging for the benefit of family-focused practice, where psychoeducation, emotional, social, and psychological support is offered for the family in its entirety, emphasising a wraparound system of care (Lagdon et al., 2021). However more research needs to be completed to provide clarity on a universal definition, to consider its realistic applicability to practice.

Strengths, Limitations and Future Research Directions

This was the first systematic review exploring experiences of parenting with a mental health condition. In accordance with Tong et al. (2012) guidance transparency was utilised for the search strategy and analysis. The high to moderate quality appraisal ratings of all included studies was a strength of the review. Reliability was strengthened further with independent reviewers ratifying quality assessments.

The CASP checklist is the most commonly used tool and critical appraisal is widely acknowledged as beneficial for providing trustworthiness in clinical practice (Williams et al., 2020). However, there is existing contention regarding how to appraise qualitative studies, for example the CASP has been criticised for its weaker evaluation of methodological quality (Majid & Vanstone, 2018). For example, two studies were rated as high overall but failed to explicitly report all methodological aspects of their study (Hasala, 2018; Sherman et al., 2016). Although quality appraisal is a valuable aspect of the review process, it is important to consider how scoring and interpretation may have differed with other tools.

To ensure the review captured the breadth of literature available, no time limit was placed on publication dates. Research varied significantly in publication date from 1998-2022, which it notable with the oldest studies scoring as the lowest quality within the review. Similarly, evidence for thematic synthesis is dependent on quotes of which varied significantly between studies. Studies with more quotes contributed more towards the themes (Mulvey et al., 2022) and should be interpretated with this in mind.

The wide inclusion criteria accounted for limited synthesis of literature within the area. However, two studies included experiences of veterans with PTSD (McGraw et al., 2018; Sherman et al., 2016). Although the aim of qualitative research is not to generalise, it does aim to consider patterns across a similar phenomenon (Levitt, 2021). This could be considered a limitation of the review, as these experiences may have varied significantly from other parents, due to the origins of their mental health difficulties.

Included studies originated from a variation of countries, this is a strength as many cultural perspectives could be considered, in the context of most current literature being focussed on western cultures (Chen et al., 2021). Furthermore, variation of parental social-economic status was included, allowing for consideration of wider systemic factors on mental health. Future research could explore experiences of parenting with mental health within the

UK. Similarly, future research could seek to explore any potential similarities and differences within the above systemic factors.

Conclusions

This is the first meta-synthesis of experiences of parenting with a mental health condition, inclusive of any mental health condition from a range of cultures. The findings have potential to inform clinical guidance about support for parents with mental health conditions. The review highlighted how the societal pressure and stigma of motherhood ideals impact parental identity, leading to intensive feelings of inadequacy and guilt. These societal expectations created a narrative of being an intensive, present parent which mental health and support availability can act as a barrier to achieving. Parents recognised the emotional, behavioural implications for children as well as them assuming developmentally incongruent responsibilities. Support on a systemic, family focused level was an identified need alongside recognition from professionals of parental identities. Recommendations are made to provide a participatory approach to improving access to peer and systemic approaches, to support families as an entire system.

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Appendices

Appendix A

Review Protocol

PROTOCOL

Experiences of parenting with a mental health condition: A systematic review and thematic synthesis.

Protocol version 1.0
Date: 30.01.2023

Charlotte Grahame
(Trainee Clinical Psychologist)

University of Sheffield

Experiences of parenting with a mental health condition: A systematic review and thematic synthesis

Introduction

As of 2019 it was estimated that one in eight people experience a mental health condition in their lifetime, with this rising at least 28% within the first year of COVID-19 (World health organisation; WHO, 2022). Of that, one in 14 children live with a caregiver who has mental health difficulties (Wolicki et al., 2021). Parenting is multifaceted and demanding and those who experience poor mental health, often also contend with limited support, financial constraints, and stigmatisation (Montgomery et al., 2006). Particularly mothers but also fathers have been found to internalise stigma associated with mental illness which leads to poorer self-reported parenting experiences (Lacey et al., 2015). Research over recent years has been emerging to explore the experiences of parenting with a mental health condition. Understanding such experiences has been considered important as literature has highlighted that parental mental health during formative years in childhood relates to greater levels of distress in adulthood (Kamis, 2020). However, the majority of literature is yet to be synthesised, therefore, this review aims to contribute to an emerging body of literature exploring the experiences of parenting with a mental health condition.

Rationale

There is currently only one review exploring the experiences of parenting with a mental health condition. However, this review only includes parents diagnosed with; schizophrenia-spectrum disorders, psychosis, or bipolar disorder. Therefore, further synthesis is needed for qualitative data to consider what impact experiences of wider mental health conditions may have on parenting. This may inform future support in clinical practice. Especially considering the prevalence of depression and anxiety within the general population.

Objectives

Stage of review at this time of submission
Preliminary searches

Name, contact, email and address

Charlotte Grahame (Cgrahame1@sheffield.ac.uk)
Megan Freeth (m.Freeth@sheffield.ac.uk)

Conflict of interests

None

Collaborators

None

Searches
The following databases will be searched:

1. MEDLINE via Web of Science
2. PsycINFO
3. Scopus.

Backward searching will also be employed.
Searching will take place between January 2023 and April 2023.

The exclusion is as follows: Papers not written in English.

Phenomena of interest: "Mental illness*" OR mental* illness OR mental* ill* OR "Mental* disorder*" OR "Mental condition"

AND

Population: Parenting

AND

Context: "lived experience*" OR qualitative OR experience* OR interview* OR interpretative phenomeolog* OR template OR content OR narrative OR discourse OR grounded theory OR thematic

Types of study to be included

4. Qualitative journal articles written in English exploring experiences of parenting with a mental health condition.
5. Mixed method journal articles that contain relevant qualitative data that can be extracted.
6. Articles including parenting support will be included if qualitative data regarding parenting experiences can be easily extracted.

Condition or domain being studied

Any mental health conditions that meet corresponding diagnostic criteria are outline by the DSM-5 or ICD-10. Mental health condition can be formally diagnosed of self-diagnosed.

Participants/ population

Inclusion-

7. Adults (18 years plus) who are parents or primary care givers to a child (this includes biological parents, foster carers, adoptive parents). There is no limit on how long they have held a parenting role for after birth.

Exclusion:

8. Articles not written in English
9. thesis articles
10. Foster parents as their experience may differ due to the foster care process.

Intervention(s) exposure (s)

This is a qualitative review, therefore there is no intervention or exposure. The focus is to thematically synthesise the experiences of parenting with a mental health condition.

Comparator(s)/ control

None

Context

Main outcomes

There will be no set hypothesis or pre-determined outcomes for this thematic synthesis.

The main aim will be to explore the experiences of parenting with a mental health condition.

Data Extraction

The lead reviewer will select articles from database searching based upon the PRISMA guidance. Articles inclusion will be assessed based on the title and abstract by a single reviewer (CG).

At which point articles will be retrieved for full text searching against the inclusion and exclusion criteria, with duplicates being removed. Around 20% of the articles will be appraised by an independent second reviewer, with any disagreements being discussed.

A PRISMA diagram will be created alongside a table which will include the following information:

11. the author,
12. year
13. sample design
14. Number of participants
15. Description of sample (age, number of children, mental health cond)
16. Sampling
17. Data collection (interview and interview type, structured, semi-structured, case study, focus groups)
18. Method of analysis (IPA, thematic analysis, grounded theory etc)

19. Reflexivity
20. List of identified themes and sub-themes
21. Supporting verbatim quotes

Risk of bias (quality assessment)

The Critical Appraisal Skills Programme (CASP) guidelines for qualitative studies will be used to critically appraise the studies and assess research quality. The CASP checklist comprises of 10 questions, providing an overall score for each study. This tool is well recognised within qualitative synthesis. The strengths and limitations of selecting this approach will be discussed.

There will also be a second reviewer included to review the CASP checklist ratings of the included papers.

Strategy for data synthesis

Thematic synthesis will be used to explore the lived experiences of parenting with a mental health condition.

Thematic synthesis will be completed using a step-by-step approach guided by Thomas & Harden (2008) 3 step approach. Including:

22. immersion in the data and coding data line by line.
23. Searching for themes and developing descriptive themes
24. Generating analytical themes from the descriptive themes.

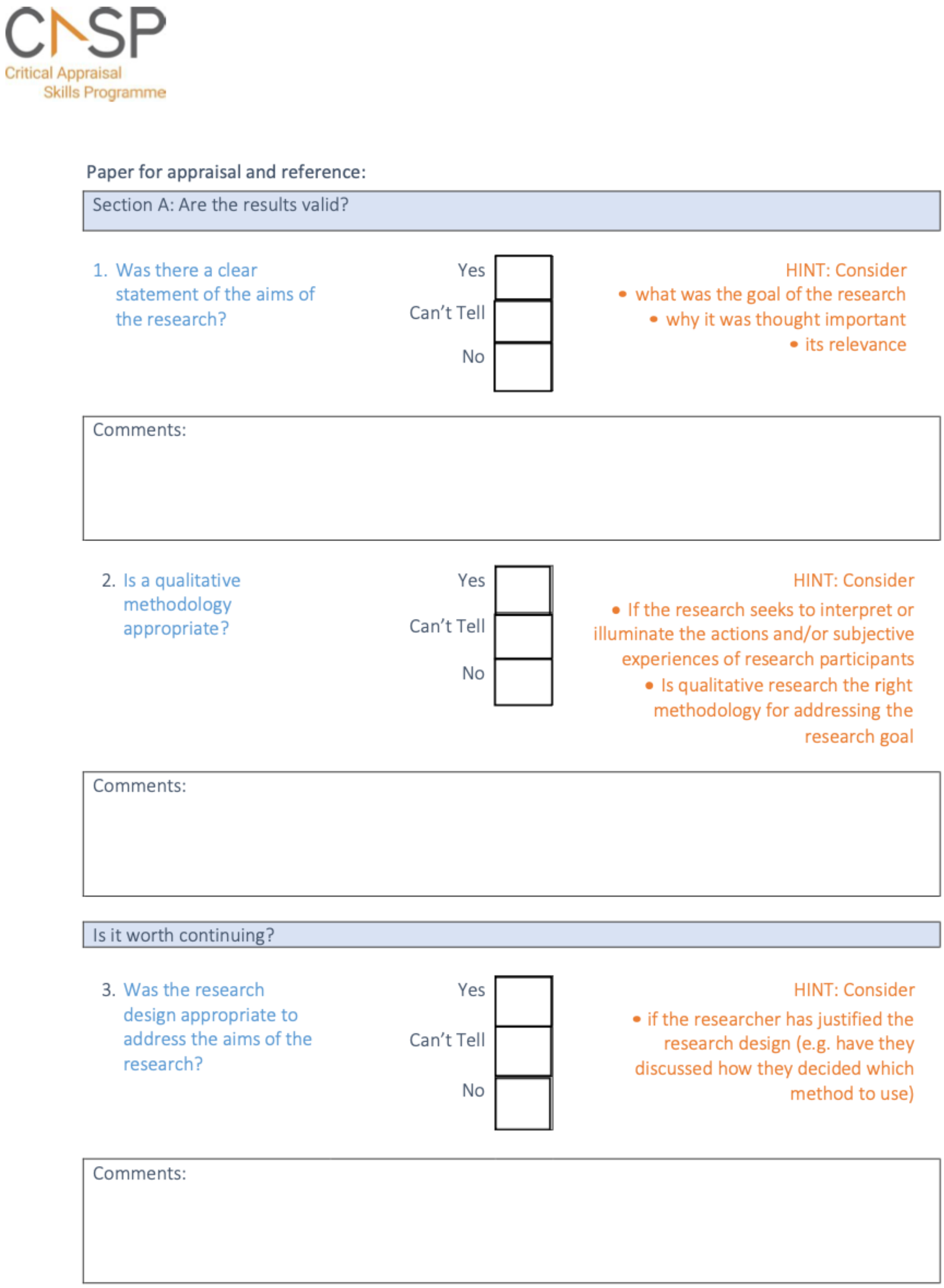
To record the verbatim quotes and results extracted data will be analysed using Microsoft Excel and Word by the primary investigator.

The primary investigator will search for similarities and differences across the codes generated and organise them into a hierarchical tree structure.

As the themes will be closely related to the original data, at this point each theme is examined in relation to the current review. This is when analytical themes begin to emerge and are developed.

Appendix B

CASP Quality Check List



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

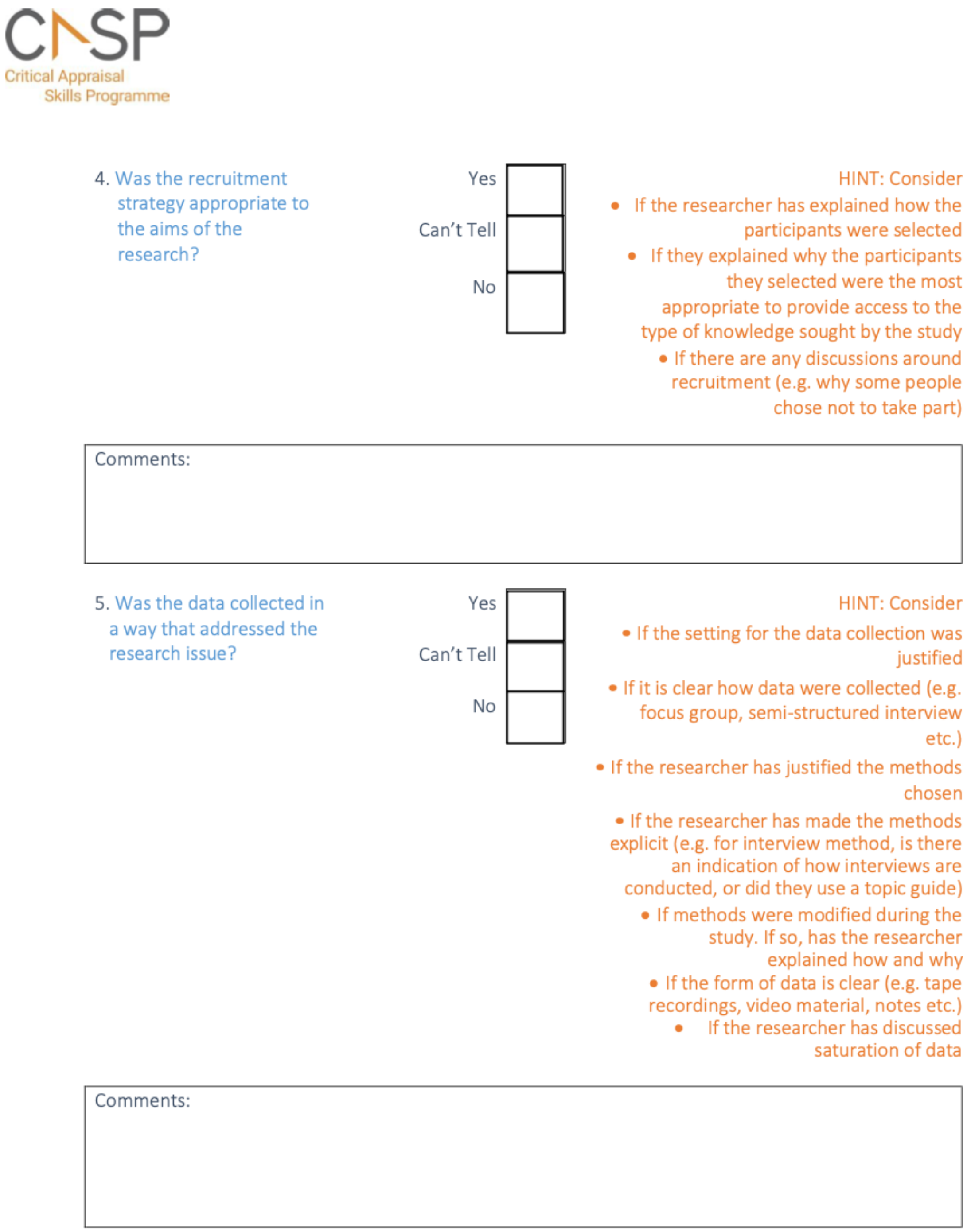
Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can’t Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher’s arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

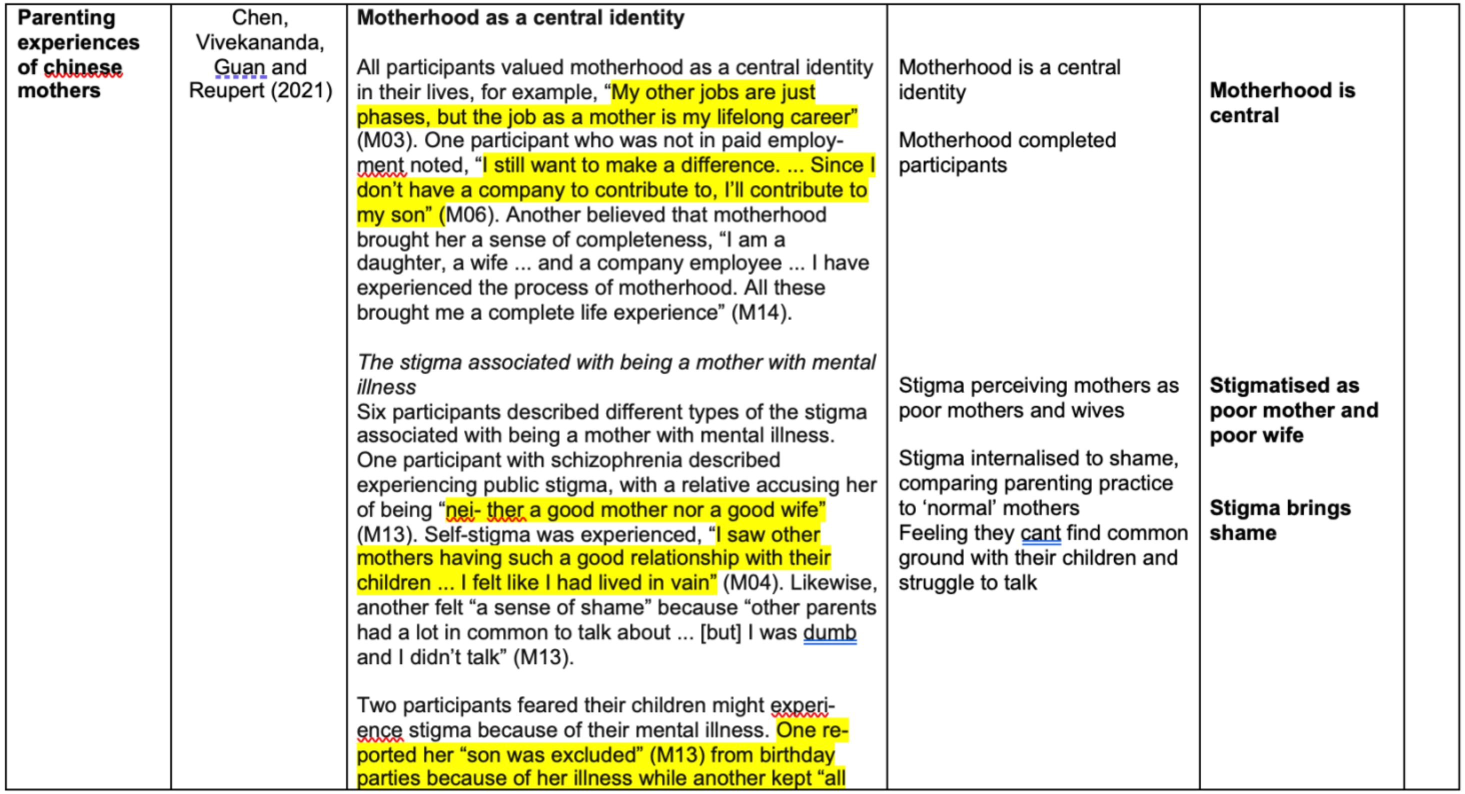
HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix C

Example of Analysis



Parenting experiences of chinese mothers	Chen, Vivekananda, Guan and Reupert (2021)	**Motherhood as a central identity** All participants valued motherhood as a central identity in their lives, for example, "My other jobs are just phases, but the job as a mother is my lifelong career" (M03). One participant who was not in paid employment noted, "I still want to make a difference. ... Since I don't have a company to contribute to, I'll contribute to my son" (M06). Another believed that motherhood brought her a sense of completeness, "I am a daughter, a wife ... and a company employee ... I have experienced the process of motherhood. All these brought me a complete life experience" (M14). *The stigma associated with being a mother with mental illness* Six participants described different types of the stigma associated with being a mother with mental illness. One participant with schizophrenia described experiencing public stigma, with a relative accusing her of being "nei- ther a good mother nor a good wife" (M13). Self-stigma was experienced, "I saw other mothers having such a good relationship with their children ... I felt like I had lived in vain" (M04). Likewise, another felt "a sense of shame" because "other parents had a lot in common to talk about ... [but] I was dumb and I didn't talk" (M13). Two participants feared their children might experience stigma because of their mental illness. One reported her "son was excluded" (M13) from birthday parties because of her illness while another kept "all	Motherhood is a central identity Motherhood completed participants Stigma perceiving mothers as poor mothers and wives Stigma internalised to shame, comparing parenting practice to 'normal' mothers Feeling they cant find common ground with their children and struggle to talk	**Motherhood is central** **Stigmatised as poor mother and poor wife** **Stigma brings shame**	

Appendix D

PRISMA checklist

Topic	No.	Item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1.
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 7-8.
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 8.
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 11, table 3.
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 10.
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Table 2

Topic	No.	Item	Location where item is reported
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 11.
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 11.
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 11.
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 11.
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 12.
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item 5)).	Page 13, Figure 1.

Topic	No.	Item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 13.
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Table 4 and 5.
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 13.
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Page 13.
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Table 5.
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 14-15.
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	NA

Topic	No.	Item	Location where item is reported
Study characteristics	17	Cite each included study and present its characteristics.	Table 4.
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 5.
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Page 14-15.
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Table 4 & 5.
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Results presented: 28-38.
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA.
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Page 12.
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	NA
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Table 39- 46.

Topic	No.	Item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	Page 45.
	23c	Discuss any limitations of the review processes used.	Page 45.
	23d	Discuss implications of the results for practice, policy, and future research.	Page 42-45.
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	PROSPERO (reference: CRD42023382931).
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Appendix.
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Appendix.
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	University of Sheffield.
Competing interests	26	Declare any competing interests of review authors.	None.
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendix.

Appendix E

ENTREQ Framework Audit

Item	Guide and Description	Reported on Page/ Table/ Figure	Signed off by independent researcher (AS)
Aim	Clearly stating the research question to address synthesis	19	✓
Synthesis Methodology	Identification of theoretical framework that is used for synthesis and the rationale for employing this framework	19, 23	✓
Approach to searching	Detailing comprehensive search strategy to seek all available studies	20,21	✓
Inclusion criteria	Identify the inclusion and exclusion criteria	21 Table 1	✓
Data sources	Describe the databases searched and information sources used	20	✓
Electronic search strategy	Describe the literature search	20,21	✓
Study searching methods	Describe how the study identified and screened studies	21,22	✓
Study characteristics	Inclusion of study characteristics of each study included	25,26, 27-35, Table 3	✓
Study selection results	Identify the number of studies screened and identify reasons for study exclusion	21,22,25,26 Figure 1 PRISMA	✓
Rationale for appraisal	Describe how studies were appraised and assessment of validity, robustness, and transparency	22,23	✓
Appraisal item	Identify the tools, criteria or framework used to appraise the included studies (e.g., CASP, COREQ, QARI)	22, CASP was used	✓
Appraisal process	Clarify how the appraisal was conducted and whether independent reviewers were involved	22,23	✓
Appraisal results	Results are presented of the quality assessment	36-38, Table 5	✓
Data extraction	Describe how the studies were analysed and how was the data extracted (e.g., all text under the headings results/ conclusions were extracted and entered into computer database)	39	✓

Software	Describe what software was used to analyse	39, Excel	✓
Number of reviewers	Identify who was involved in coding and analysis	23	✓
Coding	Detail process for how the data was coded	23	✓
Study comparison	Detail how comparisons were made within and across studies	23	✓
Theme development	Process of deriving themes	39,40, Table 6	✓
Quotations	Quotations are provided from the primary studies to illustrate themes	39-49	✓
Synthesis output	Results are presented that interpret and draw upon evidence, models and analytical frameworks.	50-57	✓

Appendix F

Bank of Codes Example

Bank of Codes	Bank of Codes	Bank of Codes
increase in severity with illness went hand in hand with difficulties parenting. Need to look after self as well as children simulatneously, sense of demand	Thoughts around pregnancy and parenthood overshadowed by mental health stigma	Sensitivity to how parenting with mental illness may impact their child
fusion of responsbilities as mother and responsibility to manage illness. Manging illness became part of caring for child	Worry about judgement overshadows feelings about parenthood	Feeling their distress is a burden to their children
recognition that mental health impacts parenting that being a painful thing to acknowledge, developing self care was a process but recognised as an important factor now	Fear of losing custody due to mental health stigma	Fear of judgement
Balancing needs of self and children	Feeling the need to prove themselves a good parents	Family separation and distress during admission
clear bond with child, evident love and affection obvious how much joy they bring to their life	Having to try twice as hard at parenting	Stigmatised society
mental health impacting emotional wellbeing of children. Concerned about impact on relationship and parenting, which had an influence of maternal confidence	Parents mental health being held accountable for children's behaviour	Child feeling shame for parental mental illness
Feelings of regret that they werent able to respond to both childs practical and emotional needs due to increase in mental health severity	Normalising daily stress of parenting	Mothers feeling shamed by society
Sense of disconnect from children mental illness severity can bring	Normative stress for all parents exacerbated by mental illness	Protection of children versus telling the truth

Appendix G

Descriptive Themes

Summary of Descriptive Themes

1. **The reciprocal relationship of parenting and mental health**

This was the most common theme, where participants reflected on how mental health could impact ability to parent, just as much as parenting itself could trigger mental health difficulties.

2. **Barrier to parenting**

There appeared to be both physical, psychological, and practical barriers to parenting. Physical was often fatigue and ability to juggle routines. Psychological related to emotional availability to respond to needs, whereas practical was participants struggling with discipline and being sectioned.

3. **Maintaining parent-child connection**

A lot of participants reflected on the strain mental health placed on their relationship with their child. This included being sectioned and participants reflected on ways they sought to maintain this connection when in crisis.

4. **Children motivating recovery**

Many codes related to the love and hope children bought into their parent's lives. Participants saw their children as a motivating factor to stay well and change their lives.

5. **Balancing of needs**

Many studies participants spoke about balancing the needs of themselves and their children, which were often conflicting. Participants often experienced fatigue and low mood and this impeded emotional availability to respond to their child's needs.

6. **Protection from mental health**

This theme focused on the participants feeling they needed to hide their mental health illness on many levels. This included from their children to protect them from the full effect, as well as from professionals so they weren't judged. Participants also wanted to protect their children from inheriting mental health conditions.

7. Impact on the child

Many themes spoke about the varying impact they felt their mental health condition had on their children including behavioural and emotional.

8. Children as parents

Participants often spoke of children assuming age-inappropriate responsibilities, including caring for other siblings as well as their parents for example ensuring they took medication.

9. Fear of judgement

Nearly all studies participants spoke about an inherent fear of being judged regarding their parenting ability based on their mental health.

10. Shame and guilt

All studies participants discussed internalised shame and guilt they felt because of not living up to the parental standards they or society had set themselves.

11. Being a 'normal' parent

Many studies spoke about parents longing to be a 'normal' parent and comparing themselves to the parenting norms society hold.

12. Family overshadowed by stigma

Participants spoke about the impact that stigma regarding mental health had on the whole family unit. Children would be isolated at school and some families would have minimal interaction outside the family unit.

13. Patients as parents

Participants often felt they weren’t acknowledged as parents by professionals when receiving support. There were a lot of treatment such as medication that interfered with practicalities of parenting.

14. The value of peer support

Participants often identified the potential value in peer support and identified this as an ongoing need for future.

15. Psychoeducation for children

Many participants identified support for parents about how to communicate with their children regarding their mental health would be useful. As well as psychoeducation for children regarding their parent’s mental health.

Appendix H

Contributions of Studies to Theme Development

Superordinate Theme	**Subordinate Theme**	**Study**	**Total**
The value of being a present parent			
	Barriers to present parenting	Reupert and Maybery (2009) Cremers et al. (2014) Klausen et al. (2016) Chan et al. (2019) Mulvey et al. (2022) Nicolson et al. (1999) Parrott et al. (2015) Diaz-Caneja et al. (2004) Radley et al. (2022) Sherman et al. (2016) Sabella et al. (2022) Evenson et al. (2008) Perena et al. (2014) McGraw et al. (2018) Wells et al. (2021) Mizock et al. (2019) Chen et al. (2021) Hasla (2018) Basset et al. (1999) Lumsden et al. (2016) Chen et al. (2021) Wilson et al. (2008) Strand et al. (2020)	25

		Montgomery et al. (2006)	
		Ackerson (2003)	
		Ueno and Kamibeppu (2008)	
			19
	Expectation to being a present parent	Reupert and Maybery (2009)	
		Cremers et al. (2014)	
		Klausen et al. (2016)	
		Chan et al. (2019)	
		Mulvey et al. (2022)	
		Nicolson et al. (1999)	
		Wells et al. (2021)	
		Mizock et al. (2019)	
		Parrott et al. (2015)	
		Lumsden et al. (2016)	
		Chen et al. (2021)	
		Wilson and Crowe (2008)	
		Hasla (2018)	
		Radley et al. (2022)	
		Sabella et al. (2022)	
		Perena et al. (2014)	
		Ueno and Kamibeppu (2008)	
		Montgomery et al. (2006)	
Being a parent is to protect and provide			
	The challenges to protecting	Reupert and Maybery (2009)	
		Klausen et al. (2016)	14
		Mulvey et al. (2022)	
		Nicolson et al. (1999)	
		Basset et al (1999)	
		Lumsden et al. (2016)	

		Chen et al. (2021) Hasla (2018) Strand et al. (2020) Radley et al. (2022) Evenson et al. (2008) Ackerson (2003) Cremers et al. (2014) Wells et al. (2021)	
	The challenges to providing	Reupert and Maybery (2009) Klausen et al. (2016) Mulvey et al. (2022) Nicolson et al. (1999) Mizock et al. (2019) Diaz-Caneja et al. (2004) Lumsden et al. (2016) Chen et al. (2021) Sherman et al. (2016)	9
	Children as motivators	Evenson et al. (2008) Mulvey et al. (2022) Nicolson et al. (1999) Mizock et al. (2019) Parrott et al. (2015) Lumsden et al. (2016) Sabella et al. (2022) Basset et al. (1999) Chen et al. (2021) Ackerson (2003)	10
The impact of mental illness on children	*Children becoming carers*	Ackerson (2003) Mulvey et al. (2022) Diaz-Caneja et al. (2004) Strand et al. (2020)	5

		Radley et al. (2022)	
	Emotional, behavioural and physical impact	Diaz-Caneja et al. (2004) Chen et al. (2021) Hasla (2018) Strand et al. (2020) Radley et al. (2022) Sherman et al. (2016) McGraw et al. (2018) Ackerson (2003) Strand et al. (2020) Mulvey et al. (2022) Nicolson (1999)	11
Professional and social support needs	*Being recognised as parents by professionals*	Reupert and Maybery (2009) Cremers et al. (2014 Klausen et al. (2016) Chan et al. (2019) Basset et al. (1999) Parrott et al. (2015) Diaz-Caneja et al. (2004) Chen et al. (2021) Hasla (2018) Strand et al. (2020) Wilson and Crowe (2008) Cremers et al. (2014) Sherman et al. (2016) Perena et al. (2014) McGraw et al. (2018)	15

	The importance of support	Klausen et al. (2016) Basset et al. (1999) Parrott et al. (2015) Diaz-Caneja et al. (2004) Chen et al. (2021) Hasla (2018) Radley et al. (2022) McGraw et al. (2018) Reupert and Maybery (2009) Diaz-Caneja et al. (2004) Strand et al. (2020) McGraw et al. (2018) Perena et al. (2014) Wells et al. (2021) Sherman et al. (2016) Perena et al. (2104)	16

Appendix I

Illustrative Quotes for Themes

Theme	Subtheme	Quote
The value of being a present parent	*Barriers to present parenting*	“If you can’t take care of yourself, you’re definitely not going to be able to take care of somebody else, and the first thing you have to do is take care of yourself” (Nicolson et al., 1999) “I always think about the needs of my child, my husband, or whole family, you know, it goes on forever. I mean, sometimes, I am so bad that I can’t help it. Well, it happens all the time, all I can do is neutralize them all, and taking balances well. I’ve got to take balance, if it doesn’t work well” (Ueno et al., 2008) “But with him, like I get aggravated also a lot. . . . . . being with him in maybe such a close range, right there in the same room, like it gets overwhelming. . . . . . before when he would aggravate me, I would feel like my triggers, and I would want to use. I’d be like I just want to get high. He’s just so annoying. I don’t want to deal with this. “(Sabella et al., 2022) “Four young children . . . all under 5 and that, and they’re flying about, large as life all the time. You know, as soon as I got home, after coming out of a quiet hospital, you know it was too much for me. I had to go back in” (Evenson et al., 2008). “Here’s disconnect where I cannot love them, I cannot hug them, I cannot touch them and even now if I try to hug one of the girls they go “Mum what’s wrong, what’s wrong,” because they’ve now got to that

		point where something must be wrong with me if I’m doing” (McGraw et al., 2018). “In periods when I feel good, it does not affect me, but during those periods when I’m extra weak and have more anxiety, it affects me because I do not have—I do not have the same energy. I do not have the same stamina. It’s hard to be with him, and it’s often then the big conflicts come, and everything gets much more difficult” (Strand et al., 2020).
	Expectation to be a present parent	“It is always the stigma of being mentally ill. When they go to the hospital to give birth, people immediately assume they cannot care for the child” (Nicolson et al., 1999) “I want to say, ‘See you’ when my child goes to school, so I have to wake up, but it was painful for me to wake up in the morning.” (Ueno et al., 2008) “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). “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 and Crowe, 2008). “She (sister-in law) had once scolding me in supermarket, in front of my husband, saying “just take your medication, you are mentally ill!” . . .Others in the streets would become scared of me, avoid me! I felt like I wanted to avoid it (from happening)” (Chan et al., 2018).

Being a parent is to protect and provide	*The challenges to protecting*	“I don’t live with my kids anymore… It’s just the way it goes I suppose, especially for someone with as many problems as me” “He’s never visited me. I’ve been admitted nearly every year since I’ve had him, you know, for at least a couple of months. I’ve never let him visit me. I can’t let him see what the kind of people that I’m living with, you know. I’m not well enough to see him. If I’m that unwell, I am sectioned, yeah?” (Evenson et al., 2008) “I have had compulsions that I want to kill him. I haven’t had those thoughts recently now, but I’m afraid they’ll come, so I think “I hope I do not think so now” and then it gets strange to be with him” (Strand et al., 2020). “If you can’t look after yourself, you can’t look after them” (Parrott et al., 2015).
	The challenges to providing	I had a long time in those early days when I felt really useless as a parent, really, really useless (Wilson and Crowe, 2008) I can’t sort of like be a father to him...I don’t feel fatherly to him at all...I feel isolated from him’ (Evenson et al., 2008) “If we had a new-born, I think that . . . my wife would have to bear the vast majority because I wouldn’t be able to cope with it, and it was one of the main reasons we chose not to have another child” (McGraw et al., 2018). “I’d like her to see more of the world. It can get a bit smothering here in the cosiness. But it’s the economy. To see the world and such things.

	But I have sickness benefits and some liabilities, so we live on subsistense, but it works” (Strand et al., 2020).
	“You’ve got to provide, that’s the way I was brought up; the men provide”.
	“You might not believe this – it’s the responsibility [I feel] – even though I haven’t got much, no contact. I save and send £100 each birthday and £40 a month” (Parrott et al., 2015).
	“I have been totally exhausted. Today, when life has calmed down, I am aware about how little surplus energy I have had for my children. I have taken care of them, got things organized, cooked food, and read a book for them. I have done it but without pleasure. I was not able to bring in happiness and enjoyment in the life of my children” (Hasla, 2018).
Children as motivators	After I had my son, it’s been like a situation where I refuse to like not [to] be able to provide for my son. And then being without me and it’s not just me anymore, my family, you know? Even though I have my depression and my anxiety that was like a weight on my legs. I still go forward. (Sabella et al., 2022)
	‘To see them grow up and keep well and that, you know, that’s what helps me to be a father . . . see that they’re helping their selves (Evenson et al., 2008).
	“It has helped me. I am proud to be a mother; I am happy to be a mother; I love being a mother” (Ackerson, 2003).
	“Cause this time I had this punishment this last five months, and I’m never going to jeopardize my family and kids again no matter how fat I

		get, no matter how tired and bored I get, I'm going to stick to it" (Mulvey et al., 2022).
The impact of mental illness on children	*Children becoming carers*	"She's really sensitive to loud noises and I don't know if that's because I am or that she actually is [like that]" (McGraw et al., 2018). "My kids have had to come home and, you know, had to help with the housework and "well, mom's not well so we have to fix supper tonight," or you know, things around the house ... and it was tough on me, having to ask my kids.... I mean, all of them helped a great deal. " (Ackerson, 2003). "My daughters would notice I was acting strange, and so my family, they would ask me questions, like "Are you okay? Are you, you know are you going through something?" You know, "what's wrong?" and I didn't really have an explanation for it. I didn't know what it was till I was diagnosed" (Mulvey et al., 2020). "I've given [my kids] certain things to say to help bring me back down . . . When they see that I'm going through something they'll come up and be like, 'Hey, it's okay; you're at home." (Sherman et al., 2016).
	Emotional, behavioural and physical impact	It seems that my children are generally aware of my condition. They seem to understand. They witness my episodes when I'm unstable, so they know about it." (Ueno et al., 2008). ''I was afraid to make another mistake. I felt I had caused so much… I was afraid actually of what to do'' (Cremers et al., 2014). "When I finally told her what happened to me, she was very sad . . . cried, just felt bad" (Sherman et al., 2016).

		"I am worried in the long term; I can see that he has changed in his mental attitude and he's actually learning things from me and becoming like a recluse. He does not want to mix with other children and it's affecting his schooling" (Diaz- Caneja et al., 2004).
Professional and social support needs	*Being recognised as a parent by professionals*	"They should recognise first and foremost that we are parents" (Parrott et al., 2015). "I think supports where you are still treated as an equal. So you are not going into a situation where you do feel lower than the person talking to you, where you feel like you're doing something wrong'' (Cremers et al., 2014). "I think it would be a group of people meeting up reg- ularly, 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 et al., 2004).
	The importance of support	"I needed days where they were in childcare so that I could be sane . . . I cannot go to my appointments if they're at home, and I cannot go and sit with a psych for an hour if I've got kids at home". "Someone to give them some sort of normal day. So, [with the] abnormal situation they found themselves in because of me . . . somebody there to go "just be a kid for today . . . let's go into the park and have a swing, let's go walk the dog" (McGraw et al., 2018).

	“Workers need to work with the whole family, with people like my [ex-]wife, so they understand what is happening and how they can help” (Reupert and Maybery 2009). “So, part of it is I feel that I am more aware of how stressors affect people’s lives ... having children and parenting has not been a particular stressor.... I have a wonderful support network; my husband is fabulous in being a support.... I would say that far and away is the most important thing. I couldn’t imagine doing it without that openness and support” (Ackerson, 2003).

Section Two: Empirical Project

The Lived Experiences of Pregnancy in Autistic Women: An Interpretative Phenomenological Analysis

Abstract

Objectives

Pregnancy is associated with a multitude of physiological and emotional changes that can be challenging for physical and mental health. There is limited literature investigating autistic women's experiences. Emerging pregnancy research suggests that additional challenges for autistic women exist, including heightened sensory sensitivity barriers to communication and overwhelming birth experiences. This study aims to investigate autistic women's experiences of pregnancy, specifically the connectedness to their child, sensory sensitivities, and support.

Design and Methods

A qualitative design: Interpretative Phenomenological Analysis was employed with eight autistic cisgender women who participated in semi-structured interviews.

Results

Three superordinate themes with eight subthemes were found; "reinterpretation of perinatal experiences after diagnosis", "the ups and downs of connecting to their maternal identity" and "seeking support: need versus reality"

Conclusions

Autistic women have similar pregnancy experiences to non-autistic women, whilst experiencing additional barriers and challenges. Most participants experienced disconnection from reality during birth, which led to confusion and distress. Societal stigma and perceived judgement negatively impacted maternal identities. Heightened sensory sensitivity was common and could interfere with daily life. Consistent support was valued but rarely experienced, all participants struggled to communicate their needs to professionals feeling uncared for, unheard and misunderstood.

Practitioner Points

- Findings highlighted the need for specific autism training for professionals in maternity services to support autistic women in communication and sensory needs.
- Future research should consider exploring experiences of perinatal or maternal services to inform practice.

Keywords

Autism; ASC; Pregnancy; Interpretative Phenomenological Analysis; Qualitative Research.

Introduction

Autism Spectrum Condition (ASC)[1] is a lifelong neurodevelopmental disorder that is characterised by difficulties with social communication and reciprocity, as well as restricted repetitive behaviours (American Psychiatric Association, 2013). Autistic adults are considerably more likely to experience co-occurring mental health conditions such as anxiety and depression as well as lower quality of life (Benevides et al., 2020; McConachie et al., 2018).

Recently there has been a burgeoning curiosity to investigate gender differences within autistic adults (Zener, 2019). Existing research highlights that autistic women[2] have been underdiagnosed and misdiagnosed in comparison to their male counterparts (Mandy & Lai, 2017). There is an identified need to understand the experience of autistic women, as this under-representation has led to delayed access to appropriate support (Leedham et al., 2020; Yau et al., 2023). Meaning there is a population of autistic women struggling to access services that potentially are ill-equipped to recognise their needs (Yau et al., 2023).

Indeed, late diagnosis has been found to lead to feelings of disempowerment and negative self-image (Leedham et al., 2020). Camouflaging, the process of modifying behaviour in social situations, has been theorised to be a substantial contributor to delayed diagnosis, as it has been suggested as more prevalent in autistic women (Cook et al., 2021; Hull et al., 2020). Autistic women describe camouflaging as an obligation to avoid stigmatisation, victimisation and to be accepted socially (Hull et al., 2017; Leedham et al., 2020). However, camouflaging has been found to increase psychological distress and have a detrimental impact on self-esteem (Cook et al., 2021; Leedham et al., 2020). This suggests that autistic women may not only feel pressurised to modify behaviour socially, but that

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[1] Autistic individuals prefer the term condition over disorder (Kenny et al., 2016).

[2] The term ‘woman’ will be used throughout as research suggests the term female in research is less personable (Joshi, 2014). However, in this context the use of the term ‘woman’ refers to those assigned female at birth with female reproductive organs. It is acknowledged a person may identify as a woman who was not assigned female at birth.

doing so may also be detrimental in relation to the recognition of their needs (Cook et al.,2021).

Many women, neurotypical and neurodiverse also experience profound physiological changes that can impact physical and mental health, during specific milestones such as puberty, pregnancy, and menopause (Koch & Mendle, 2022; Soltani et al., 2017). The nausea, pain, insomnia, and fatigue associated with pregnancy can limit women's daily functioning (Soltani et al., 2017). This can contribute to stress in pregnancy which has been linked to increased risk of mental health difficulties, namely depression and anxiety (Hampton et al., 2022; Herbell et al., 2019). Pregnancy can be a time of vulnerability considering the intense physical and mental challenges. Potentially even more so for autistic individuals, who have a higher prevalence of co-occurrent mental health conditions (Hampton et al., 2022).

Hampton et al. (2022) reported autistic parents had elevated stress, anxiety, and depression in comparison to non-autistic parents. The literature suggests that experiencing mental illnesses, limited social and spousal support within the perinatal period can impact attachment development (Bonari et al., 2004; McNamara et al., 2019). It is well understood that early attachment between mother and baby begins to develop during pregnancy (Sacchi et al., 2021). Attachment theory highlights the importance of the early attachment that children form with their primary caregivers, and how instrumental this is in forming their own attachment relationships (Bowlby, 1979).

Within perinatal attachment research Cranley (1981) coined the term 'maternal foetal attachment' (MFA) to define a mother's care towards and developing emotional bond with their unborn child. Development of MFA widened to also include the thoughts mothers have in relation to pregnancy and their baby (McNamara et al., 2019). Leifer (1977) suggested that MFA develops in stages during pregnancy, with lower levels observed in the first trimester, increasing with foetal movement in the following trimesters. Research has supported that experiencing movement sensations increases the depth of connection mothers felt (Malam et al; 2015; Soltani et al., 2017). Maternal bond has been associated with a multitude of pregnancy and postpartum outcomes, including maternal ability to care for their baby and child development (Abasi et al., 2020). Higher MFA is also associated with increased interactions with and imaginations about the baby (Eswi & Khalil, 2012). Thus highlighting the importance of MFA on subsequent parenting (Abasi et al., 2020).

Alongside attachment, evidence suggests that societal narratives around motherhood can influence expectant mothers' expectations of their maternal role (Kerrick & Henry, 2017). According to social constructionist theory, master narratives are culturally constructed by society and can unconsciously influence a person's ideals (Kerrick & Henry, 2017). Dominant narratives of motherhood suggest an expectation for unconditional love, which places significant pressure on the mother to develop this bond (Almond, 2010). Indeed, mothers from the United Kingdom (UK) have been found to adopt a "good mother" dominant discourse along with ideals of what constitutes to this (Guendouzi, 2005). Therefore, consideration should be given to how culturally constructive narratives impact mothers experience of their developing MFA. This is particularly poignant for autistic women, who have additional barriers and pressures to feel they need to be accepted within society (Cook, 2021; Leedham et al., 2020).

There have been several qualitative studies using interpretative phenomenological analysis (IPA) to understand experiences of pregnant women (Birtwell et al., 2015; Gagnon, 2021; Smith, 1999). Smith (1999) found when interviewing four women, that pregnancy acts as psychological preparation for motherhood. Gagnon (2021) reported varying perceptions of pregnancy, with some women reporting a profound sense of maternal responsibility and apprehension. Similarly, Birtwell et al. (2015) described women valuing their identity as a mother and noticing strong bonding when movements began, clinically supporting the notion that attachment begins pre-birth.

Research investigating pregnancy in autistic women is an emerging field, with only two systematic reviews published currently. These reviews include similar papers and explore sensory sensitivities, pregnancy and parenthood in autistic women (McDonnell et al., 2021; Samuel et al., 2021). Samuel et al. (2021) found heightened sensory sensitivity to the hospital environment such as lights and physical contact compounded stressful experiences. Heightened sensitivities were also reported to impact wellbeing resulting in overwhelming negative experiences described as ‘meltdowns’ (Samuel et al., 2021). Autistic women also felt they had a lack of control over their own bodies and their environment during birth. This is important to highlight for maternal care, considering autistic adults report feeling emotionally and physically unsafe during ‘meltdowns’, experiencing them as intently distressing and painful (Lewis & Stevens, 2023).

Currently, there are only two qualitative studies exploring the experiences of pregnancy. Rogers et al. (2016) used one case study, which similarly identified sensory overload in hospital, challenging communication both to and from professionals and feeling stigmatised because of her diagnosis. One unpublished thesis found stigma in autistic women was internalised as inadequacy and consequently impacted their identities as mothers (Burton, 2016). However, the experience of becoming a mother was cathartic, giving them a deep sense of connection and identity. This was suggested to potentially mediate the innate sense of difference and isolation autistic mothers often felt (Burton, 2016). Both studies had limited reflexivity and recruited from one country, providing a limited overview of pregnancy experiences.

Literature has identified that autistic mothers experience barriers to communication and felt they should be offered additional support (Dugdale et al., 2020; McDonnell et al., 2021; Rogers et al., 2016). Both Lum et al. (2014) and Pohl et al. (2020) found healthcare services were unable to meet autistic women’s needs. Autistic mothers reported difficulties communicating their pain and needs, as well as feeling birth was not explained clearly (Lum et al., 2014; Pohl et al., 2020) This led to feeling misunderstood, judged, and apprehensive about what to share (McDonnell et al., 2021; Samuel et al., 2021). Research understanding professionals' knowledge regarding supporting autistic patients is insubstantial, with many professionals reporting they lack sufficient training (Donovan, 2020; Hampton et al., 2021; Pohl et al., 2020). Autistic women reported valuing consistent and collaborative approaches to care as well (Samuel et al., 2021).

Currently, most literature is focused on postnatal experiences. Only two studies explicitly explore pregnancy; one being a case study and the other an unpublished thesis with two focused questions on pregnancy (Burton, 2016; Rogers et al., 2016). Therefore, this study aimed to investigate the lived experiences of pregnancy in autistic women. Given reported difficulties with mental health, sensory overload, and appropriate support, this study has potential clinical implications to facilitate the development of client-centred practices in perinatal services. There is also limited literature exploring the connectedness autistic mothers experience with their baby, which is important considering perinatal barriers and facilitators to developing attachment (Malam et al; 2015; McNamara et al., 2019; Soltani et al., 2017).

The use of qualitative research methods has become more common in autistic research. Specifically, IPA has been evaluated as an appropriate and useful approach with autistic individuals, serving as co-productive and insightful into understanding distinctive experiences of autistic individuals (MacLeod, 2019). IPA emphasises the significance of developing a detailed understanding of an individual's personal lived experiences and how the individual makes sense of this experience (Smith et al., 2021). IPA is ideographic in nature, focusing on the meaning of an experience and the significance this holds for the individual (Larkin & Thompson, 2012). This emphasises the individual as the expert in their own experiences (Larkin & Thompson, 2012). Research has suggested providing this equality of voice in IPA is advantageous in understanding how autism is experienced individually (Howard et al., 2019).

Aims

This study aims to gain a deeper understanding of autistic women's lived experience of pregnancy. Specifically, the current study seeks to understand individuals' experiences of their developing emotional connectedness with their unborn child, sensory sensitivities, and support both socially and from professional services.

Methodology

Design

The study used a qualitative design, IPA which is a phenomenological approach involving the examination of a participants lived world (Smith et al., 2021). IPA is a valuable method used more recently within Autism research (MacLeaod, 2019). IPAs ideographic nature gives a voice to individuals, while aiming to make sense of how individuals within specific contexts make sense of their situation (Larkin & Thompson, 2012; MacLeod, 2019). In IPA the researcher engages in double hermeneutics to immerse themselves within the participants world, simultaneously, as the participant is trying to make sense of their experiences (Smith et al., 2009). This deeper understanding of the connection between how people talk and think is important when researching lived experiences (Smith et al., 2021).

IPA was deemed the most appropriate method given its focus on understanding of individual experiences in particular contexts (Larkin & Thompson, 2012). This method was chosen over other methods, with less focus on experiences such as grounded theory. Grounded theory is concerned with developing conceptual theories regarding conscious or unconscious social patterns (Glaser et al.,1967).

Ethics

Ethical approval was obtained and granted by the University of Sheffield (see Appendix A).

Participants

Eight autistic cisgender women were recruited. The number of participants recruited was supported with existing IPA research (Dugdalde, 2021; Milward, 2006). Participants were recruited via purposive sampling. The inclusion and exclusion criteria are summarised in Table 1.

Table 1

Inclusion and exclusion criteria

Inclusion Criteria
1.Participants needed to be 18[3] years and older
2.Formal diagnosis of Autism
3.Experiences of pregnancy within the last 16 years[4]
Exclusion Criteria
1.Lacked capacity to consent to participate
2.Not fluent in English

A pregnancy cut-off was employed to limit extensive variability in recall. Demographic information was collected (Table 2). Participants were between the ages of 33 and 52 (*M*= 39.6). One participant was diagnosed with ASC pre-pregnancy and was pregnant during the interview. The remaining participants received their diagnoses post-pregnancy.

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[3] It is recognised that individuals under the age of 18 can experience pregnancy, however the inclusion criteria remained over 18 due to ethical considerations.

[4] The limit of 16 years was selected as research has suggested that many women are diagnosed with ASD alongside their children, whilst they are in school (Kanfiszer et al., 2017).

Four participants chose to discuss their multiple pregnancies. All names are pseudonyms for confidentiality.

Table 2

Demographic Information of Participants.

Participant	Ethnicity	Country of Residence	Age	Age at Diagnosis	Additional Diagnoses	Number of Children	Age of Children	Living with Children?	Relationship Status
Nora	White	Netherlands	52	51	Depression	3 (gave birth to one, two with husband and partner)	15,5,3	Yes	Married and together with their partner
Grace	White British	England	46	45	Chronic reoccurring stomach ulcers	1	12	Yes	Married
Ameillia	White British	England	34	34	Dyscalculia, Dyspraxia Dysgraphia, Visual and Auditory working memory processing disorder, Irlen Syndrome, Functional Neurological Disorder, Complex PTSD and Panic and anxiety disorder, Agoraphobia, Pennetta Phobia, Hypermobility and Fibromyalgia	3	15,12,8	Yes	Married

Olivia	White British	England	33	4	Anxiety, depression, and Fibromyalgia	1	Pregnant	Yes	Cohabitating
Clara	White Australian	Australia	35	34	Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder and Myalgic Encephalomyelitis	3	13,10,7		Cohabitating
Julia	White British	England	38	38	Depression	1	2	Yes	Married
Penny	White British	England	43	38	Childhood diagnosis of Anorexia	2	12,9	Yes	Cohabitating
Emily	White British	Australia	36	35		1	6	Yes	Single

Co-Production

Two autistic cisgender women were contacted by the lead researcher (CG) via the Sheffield Autism Research Lab, (ShARL). ShARL has details of autistic adults who consent to being contacted regarding research. They provided feedback on the interview schedule and information sheet (see Appendix B) and consent form (see Appendix C). Feedback can be seen in Appendix D.

Materials

Semi-structured one-to-one interviews are the recommended data collection method, based on IPAs aims of understanding an individual's story (Smith et al., 2021). A semi-structured interview schedule was developed considering the studies aims and Smith et al. (2021) guidelines (see Table 3). The interview was flexible to ensure participants discussed what they felt was important.

Table 3

Interview Schedule

Interview Questions	Additional Prompts
1. What was it like when you first find out that you were pregnant? (Which pregnancy are they referring too)	*How did you find out? (Test, symptoms) Where were you/ who did you tell? What did you do? Do you remember having any specific thoughts?*
2. How did you feel when you found out that you were pregnant?	
3. How were things for you during the first part of your pregnancy?	*What were the first changes you experienced? Could you tell me about your experiences of the different trimesters? Any sensory experiences? (Follow up by asking how interests may relate to sensory experiences if the participant is finding it difficult to answer) How did you manage?*

4. How were things as the pregnancy progressed?	*(Thoughts, feelings, sensations, and support, sensory sensitivities)*
5. How did you feel about becoming a parent?	*Did you experience a developing bond to your unborn child? could you feel them move and kick? How did this make you feel?*
6. Could you tell me about any specific support you had during pregnancy?	*Did you receive any support from a partner, family or friends?*
7. How did you find the support from medical professionals when you were pregnant?	*What experience did you have? Did you have scans (if so, how many?) were there any complications? How did you find the hospital environment? (Noise, light, support) do you feel this was influenced by your diagnosis? Did you feel appropriately supported by professionals when you were pregnant?*
8. Can you tell me about your experiences of the delivery of the baby?	*When did you have it? Where? How was the hospital? Who was with you? How were the professionals? How were the first few weeks?*
9. Was there anything particularly helpful or unhelpful for you at the time?	*How could you have been better supported? What was the communication like? Was there anything particularly helpful/ unhelp healthcare staff have done for you?*
10. Is there anything else you would like to share about your experience of pregnancy or giving birth?	*Difference and or similarities if multiple pregnancies*

Procedure

This study used three sources of recruitment including: Emailing from the ShARL database (*n*=1), and a recruitment poster on twitter (*n*=6), and Instagram (*n*=1). Several sources of recruitment were utilised to increase the reach of the study. Those who replied received an information sheet and consent form (see Appendix E). No participants withdrew or dropped out from the study. All interviews were conducted over university approved video technology between May and August 2022.

At the beginning of the interview the study, confidentiality, and withdrawal rights were explained. Video interviews were recorded, converted into an audio file and stored on the University secure drive. In total interviews lasted between 46.14 minutes and one hour 43 minutes. At the end of the interviews, participants were sent a debrief form. The first two and last interviews was transcribed by the lead researcher (CG). The remaining interviews were transcribed by an approved University of Sheffield transcriber.

Data Analysis

Reflexivity

Literature acknowledges that qualitative research is a reflexive process, Muecke (1994) noted that reflexivity is the influence of the researcher and the field reciprocally. The researcher engages in self-reflection to raise awareness of their values, and beliefs for potential influence on the research process (Darawsheh, 2014). Rigour as well as confidence in the credibility of the research is increased with researcher transparency (Anderson, 2008). Therefore, the lead researcher is a White British cisgender woman without ASC. In this case there were not any personal experience of the researcher that was used to inform the analysis (See Appendix F). To continually reflect upon the influences within the research, a reflexive journal was maintained throughout (Watt, 2007). This detailed personal influences and reflections on the interviews, themes, and interpretation, which was then discussed with the research supervisor (MF) (see Appendix G).

Coding and Analysis

After interviews were transcribed, the data was analysed using IPA in accordance with the approach as described by Larkin and Thompson (2012) and Smith et al. (2021). This involved six stages, with the first two stages focused on coding, where the primary researcher immersed themselves fully in the data. The second stage, initial noting involved examining language on an intricate level (see Appendix H; Smith et al., 2009). The third stage was the development of experiential statements, where an analytical shift occurred with the focus moving from descriptive summarises to the initial noting of experiences. Individual data was then arranged into conceptual maps and narrative summaries (see Appendix I & J). The fourth stage was searching for connections across experiential statements, which led to the fifth stage naming the personal experiential themes (PETs; Smith et al., 2021). These commonalities mapped to contribute to the final stage; looking for general experiential themes (GETs) across cases (see Appendix K). At this stage, Smith et al. (2021) recommended identifying which themes are super-ordinate in nature and highlights higher order concepts which other cases also share. The identified themes can be seen in Table 4 with participants contribution and illustrative quotes in Appendix L and M.

Validity and Quality Control

Traditional criterions for assessing quality of research are inappropriate for qualtitative research, as they focus on representative samples and reliable measures (Yardley et al., 2015). However, it is necessarily to consider how to evaluate validity in qualitative research. Smith et al. (2021) highlighted the importance of utilising general guidelines for ensuring validity and quality control within IPA research. Spencer and Ritchie (2011) identify core principles that underline the majority of concepts of quality, including Yardley et al. (2015). The following overarching principles of *contribution, credibility and rigour* were considered in this study to maintain validity. Triangulation has been discussed as a process of ascertaining validity. Utilising multiple methods to demonstrate validity has been suggested as diluting to the potential impact of each method (Thurmond, 2001). Therefore, triangulation was not employed within this study.

The first principal *contribution,* considered the relevance of the research and value of the evidence produced. This study ensured that links to theory, implications for future research and practice were made, considering how this may contribute to meaningful change within services.

Secondly, *credibility* was addressed by verbatim transcription of interviews, and analysis clearly recorded by table format. The details of the research process have been fully disclosed in terms of participant recruitment, interview procedures and outcome. Evidence of theme development and raw data have been included to demonstrate themes.

Thirdly, *rigour* was considered in terms of two primary methods, auditability, and reflexivity. Choice of method was clearly documented alongside supporting evidence and justification of the suitability of IPA. Additionally, an audit of each stage of the analytical process was conducted by (MF) and two independent researchers (AS, CN) on three transcripts (see Appendix N). A reflective log was completed throughout, enabling for recognition of potential personal biases in analysis

Finally, to establish quality and risk of bias within this study the Critical Appraisal Skills Programme (CASP) qualitative research checklist (CASP, 2018) was completed (see Appendix O).

Results

GETs and Subthemes

Data analysis produced three GETs with eight subthemes (Table 4). Each theme is discussed alongside illustrative quotes. The themes are not an exhaustive account of participant experiences, rather a demonstration of the narrative of several accounts (see Appendix M for additional quotations).

Table 4

Superordinate and Subthemes

Superordinate	Subthemes
1. Reinterpretation of perinatal experiences after diagnosis	1.1 Disconnect from reality during birth 1.2 Grief for expected journey 1.3 Battle with sensory experiences
2. The ups and downs of connecting to their maternal identity	2.1 Feelings of instant affection and love 2.2 Sense of not belonging 2.3 Expectation and pressure
3. Seeking support: Need versus reality	3.1 Feeling uncared for, unsupported and powerless 3.2 Containing, consistent, warm support

Reinterpretation of perinatal experiences after diagnosis

This GET explored participants feeling their diagnosis retrospectively contextualised their experiences, in terms of making sense of their internal worlds, communication, and the challenges they encountered perinatally, “Now you know, you’re autistic because […] so many things that made sense now” (Emily).

Participants also described a sense that their diagnosis added another layer of difficulty to some of their pregnancy experiences, “Like it’s hard for any woman, don’t get me wrong but why maybe it’s hard, hard in a different way because they don’t realise, they are autistic” (Penny). Nearly all participants felt if they had their diagnosis during pregnancy, they would have had a deeper understanding of self, “I think I could have advocated so much better for myself” (Emily). Conversely, for the participant who was diagnosed pre-pregnancy, pregnancy allowed her to be “a lot more accepting about being autistic… this is part of me” (Olivia).

Disconnect from reality during birth

Nearly all participants referred to being out of contact with reality “somewhere else completely” or “not in my body” (Penny) during birth. Participants struggled to make sense of what was happening during this time, feeling “oblivious” to their surroundings and like they “shut[ting] down” (Nora), “I keep looking back at that experience and thinking. Why was I so oblivious to everything? Because I remember in labour that I felt like I was out of contact with the world and with myself”. (Nora)

This disconnect meant many participants felt they were unable to “realise I [or the baby] was in danger at all” (Nora) during birth or “process” (Ameillia) the information professionals were giving them. Participants described being given “vague” (Penny) information and not “really knowing what was going on whilst I was in hospital” (Nora).

This meant participants struggled to make sense of their internal world but also externally during birth. Participants were unable to clarify or communicate their needs, feeling they became “really passive” (Nora).

Grief for expected journey

Some participants described a sense of grief for the loss of their expected birthing journey, “It took me a really, really long time to be ok with what happened, because it was different, and it wasn’t what I’d expected” (Clara). This was exacerbated by struggling to understand and connect with reality during birth, “I had planned for fully natural… I sort of feel like I missed his entry into the world” (Nora).

Nearly all participants felt they were unprepared and “didn’t get good advice” about what may happen during birth. This left residual “negative feelings about the experience” wanting a “more balanced” (Grace) understanding of their options. Furthermore, these feelings extended beyond birth “it really affected him and I for probably that first year of his life” (Penny).

Battle with sensory experiences

All participants reported noticing significant changes in their senses and “sensory issues” (Emily) that were overwhelming and confusing, “I didn’t know what was wrong with me but those sort of being oversensitive to everything” (Penny).

Nearly all participants identified smell as being the most prominent sensory change they noticed during pregnancy, “My sense of smell was phenomenal. It was outrageous” (Julia). For some participants, senses were “all-consuming” (Penny), and they were unable to carry out daily activities, “I could smell it and it would make my whole-body tense…and I just wanted to get away from it, it made going anywhere really, really difficult” (Penny).

Participants found they had associations with certain objects or clothing items, even years later post birth, “All the clo that I had from… the ones from the early phase of pregnancy I couldn’t wear. Because the association of nausea was so strong” (Grace).

Participants also described struggling with strong taste “if anything has got an overwhelming taste to it, I’ll get heartburn instantly, even now” (Ameillia). As well as seeking certain textures “my cravings have been totally sensory focused” (Olivia). Two participants connected childhood sensory experiences with diagnosis, “Well, I’m craving a bath sponge now what do you want me to do... and I remembered that’s something I used to do when I was younger” (Ameillia)

Some participants had positive memories of connecting pregnancy and senses, “I enjoyed it the same way that I enjoy some other sensory seeking kind of stuff “(Clara). As well as making associations between birthing experiences, “I struggled more with breastfeeding because its sensory” (Emily).

Another participant described how her birthing experience was accommodating for her sensory needs, “I was really lucky in that, their techniques really, really suited my sensory needs and, and what I didn’t get when I did transfer to the hospital”. Sensory overwhelm was a similar concern for Olivia, feeling “excessive stimuli” during her pending birth would lead to a “meltdown”.

The ups and downs of connecting to their maternal identity

This GET reflected the process participants went through to identifying as a mother, which came with unique positives and challenges. For some participants, this process was associated with a sense of difference they had always felt to others pre-diagnosis. For others, this was closely linked with the developing bond they nurtured with their baby, as well as internalised and externalised pressure to be a “better mother” (Grace).

Feelings of instant affection and love

Most participants described feeling “very attached” (Clara) with their baby. As well as a definitive, unquestionable sense of knowing “[I knew] that I wanted this baby and to be a mum” (Olivia, Emily). This sense of connection was personalised for each participant, some nicknamed their babies, “I really bonded with him, I called him [ ]” (Clara) and some connected through movement,

> I can remember the first time I felt her kick, we had been for a Chinese meal in XXX and then we had gone to see the Ramba in the [ ] … and I felt the first kick and that was really exciting. Erm I love dance so I kind of thought that was really cool (Grace).

Participants described feeling their baby was present in their daily life “I’d just tell him about things” (Nora), or they included them by talking about “anything really, just chit chat” (Julia). Participants also spoke about wondering about their baby’s personality, “My baby is gonna be such a little character and I just thought it was great, like oh my god this is gonna be so cool” (Grace).

However, two participants found they needed to “focus[ed] on the pregnancy rather than the baby” (Ameillia) due to pregnancy difficulties. Whether this was due to ill-health “I didn’t feel anything but ill” (Ameillia) or feeling overwhelmed. There were also some concerns about “connecting in the same way” (Penny) depending on the sex of the baby “I always got on better with boys” (Julia). Despite these challenges, participants connected with their babies meaningfully in their own way “I just kept distracting myself with telling […] to talk to her sister” (Ameillia). Alternatively, they had a moment where they felt their bond fell into place instantly, “Oh, he’s doing yoga… it kind of was a switch that flicked, and it was like oh we are the same” (Penny). Many participants retrospectively reflected how their bond strengthened as their “diagnosis came out of [him]” their children (Penny).

Sense of not belonging

For some participants they described an innate sense of “feeling different” and “not fitting in” but struggling to identify why, “I had a sense life was harder for me somehow” (Grace). This had implications for how they felt about becoming a parent. This led to a self-blaming narrative, with participants believing they were “just a bit crazy” (Clara) or a “freak” (Ameillia), “I had a very low opinion of myself, and I suppose they were just more sort of evidence that there was something wrong with me” (Penny).

Participants also reflected on messages from society or family that told them there was “something wrong with me” and that they “should be trying harder” (Grace). This further internalised the sense of difference and feeling they had “something missing my entire life” (Ameillia).

For some participants these feelings led to questioning their ability to “raise a child that’s not like me” or believing they were “not the kind of person that should raise a child” (Ameillia) not wanting to “pass my genes on”. Some also reflected they “didn’t want this baby to be like me” but had a “strong” determination that they “wanted their life to be very different to how mine had been” (Grace).

Pressure and expectation

Participants described a journey of “processing” (Grace) and “acceptance” (Clara) of their pregnancy, which was an integral point of identifying as a mother. Within this, participants reflected on intense internalised pressure and apprehension that they “wouldn’t be a good parent” (Julia).

For some participants, this journey included questioning if it was “fair for me to have a kid” (Ameillia) or recognising initially they “didn’t want to have kids” (Julia) but that changing. For others, they reflected on the pressure that they felt they “should be doing something differently” and “be a better mother” (Grace).

Seven participants reflected how this internalised pressure was compounded by external stereotypes, “being a new mum, you are made to feel like ‘crack on’” (Grace). Many participants reflected on feeling professionals were “expecting” that they were “not going to cope” (Julia) or “do the wrong thing” (Penny) feeling judged, based on previous mental health diagnoses. There was concern that being honest would be “held against me” (Clara). The “pressure” from professionals led to internalised beliefs such as, “You’re going to be a bad mother… because you’ve got an eating disorder, you’re not going to look after your baby” (Penny). Amelia reflected on feelings of “guilt” during pregnancy, “They said it was my fault my baby wasn’t growing” (Ameillia).

Participants also described feeling like they needed to maintain a persona during pregnancy to protect from judgement, “You’re happy about your pregnancy and you’re looking after your baby and everything’s fine and everything’s great” (Penny). Participants also described a “maternal instinct” arising and feeling a need to “protect” (Olivia) their children from danger. Olivia described feeling “vulnerable” being “autistic and a parent” worried autism would be “held against them” based on the stigma they had faced previously.

Seeking support: Need versus reality

The final GET theme explored participants experience of support throughout the perinatal period. Participants reported feeling “neglected” (Ameillia) and “dismissed” (Emily) with support being “unhelpful”, “awful” (Julia) and “impersonal” (Grace),

> It all felt a bit, not like I would, you know I felt like a very small cog in a very big machine that really wasn’t very interested, and I did feel like that all the way through (Grace).

Feeling uncared for, unsupported and powerless

Seven participants reflected on the inconsistent professional care they received, which consequently left them feeling unprepared for birth, “I’d see a different consultant every time, and they would just say different things every time” (Julia),

> It was so impersonal, and each member of staff seemed to be off doing their own thing, it wasn’t co-ordinated. I had no sense of seeing the same person twice and no sense that they were even singing from the same hymn sheet (Grace).

Some participants reported needing to be “guarded” (Olivia) with what they chose to share with professionals, through fear of judgement even if they were struggling. Nearly half of participants reported residual feelings about the care, they received “I am still angry” (Ameillia, Penny),

> But it was judging what things to mention when, because I knew that some things probably weren’t normal, so there were things that, I probably needed to keep to myself (Penny).

> I would be worried to speak out about certain things that I might have struggled with in case people said, “oh well, if you’re struggling now what are you gonna be like when the baby’s here (Olivia).

Participants described a sense of powerlessness, “I was so scared to say the wrong thing” (Penny) feeling unable to verbalise their distress or needs “I would have said no but I didn’t feel I could” (Penny). As well as feeling uncared for, “Oh, they were listening, they just didn’t care” (Ameillia). Some participants described feeling the support they did receive was bias, which gave them unrealistic expectations of birth, “Unhelpful was the sense of avoid medical intervention, you know until the last hour. So, I think it would have been helpful to have a more balanced view” (Grace).

That also led to feelings of guilt and inadequacy if their birth did not go to plan, “I had convinced myself it was my life’s work” (Grace). Some participants felt like they were "being a problem" if they did disclose distress and were ultimately left feeling dismissed and misunderstood. Experiences were genrealised as stereotypical pregnancy experiences "oh that happens to everyone" (Emily),

> Like over emotional or whatever, so I don't feel like they really took it seriously until basically I had that meltdown, and then they realised how much I actually was really struggling (Emily).

Furthermore, when information was provided to professionals about autistic needs, it was "acknowledged" but "I think they want me to feel like its normalised as well like; oh, it's okay, it's no different to whatever identities people can have, you know, it's no different to being asthmatic" (Olivia).

All participants reported needing clear communication from professionals that they felt, in hindsight would have prevented miscommunications they experienced during birth. Reflecting the language used was "ambiguous" and needing it to be "clearer",

> Obviously If they'd have known about my diagnosis that would have made a massive difference to how everyone there had treated me… I didn't feel like anyone explained anything clearly to me, everything, I was just expected to know (Penny).

Containing, consistent, warm support

Despite the difficulties all participants reflected on some "excellent" support from "really lovely people" (Nora). Participants also described what good support could look like. All participants recalled personal examples of "human connection" (Emily) and "warm support" (Nora) they shared with specific midwives, healthcare workers or consultants which they felt impacted their experience for the better, "He was just really funny. He just made me feel positive because I was laughing" (Emily).

One participant described her "personal", "consistent" (Clara) support to homebirth and how professionals considered her sensory needs. This support aligned with what other participants felt ideal support should be. It was important for support to have “more consistency” (Julia) and “continuity of care” (Penny).

The majority of participants felt “personalised” support was important and gave examples of how this could be achieved. Particularly feeling specific understanding of autistic individuals would be priceless, “it would be good to have a midwife who specialises in Autism” (Grace). Penny spoke of the value of the ‘after thoughts service’ coming away “feeling better” and knowing she had not “made more of it in my head”,

> I don't know how many autistic health care professionals there are around… being able to be supported by someone who understands some of the challenges around autism would be, priceless… (Nora).

Participants also reflected on how helpful it would have been to tell professionals they were autistic if they knew, to get the right support, “Erm, if you know that you're autistic, I think it's a really good idea to say something about it” (Nora).

> I think I’d have been able to communicate better if I’d have known because I’d have had a more, a better understanding of who I am and how I communicate, so I could have made alterations, like I have (Ameillia).

Indeed, Olivia spoke about how she was preparing to give professionals information about her needs that she felt they valued, “I’ve started putting together a birth plan and the, the National Autistic Society have a Self-Advocacy Booklet” (Olivia).

Discussion

The aim of this study was to understand the lived experience of pregnancy in autistic women. Three general experiential themes (GET) were identified with eight subthemes; ‘Reinterpretation of perinatal experiences after diagnosis’, ‘The ups and downs of connecting to their maternal identity’ and ‘Seeking support: need versus reality ‘.

The first GET ‘Reinterpretation of perinatal experiences after diagnosis’ reflected how participants felt “so many things made sense” after diagnosis, specifically difficulties with communication and sensory experiences. This new understanding provided space to acknowledge the additional challenges of having undiagnosed autism during pregnancy. This is consistent with both Leedham et al. (2020) and Wilson et al. (2022) studies. Participants reported diagnosis provided a new lens to understand difficult past experiences, that transformed personal narratives to be less self-critical and more compassionate.

Participants described a sense of disconnect from reality during birth, where they ‘shut down’ feeling ‘oblivious’ to their surroundings and needs of themselves or their baby. Similar to Donovan et al. (2020) and Nilsson et al. (2010; 2014) ‘shut[ing] down’ led to a difficult birth experience, where autistic women felt they were not present and consequently grieved the birth they expected. Comparable to Wilson et al. (2022) participants had a deeper self-understanding of their ‘meltdown type situations’ post diagnosis. This response appears to be different to non-autistic women, who experience feeling they are in a different place during birth to focus on contractions (Dixon et al., 2013). For autistic women there is a loss of connection to all aspects of the birth experience, including sensing need or danger which resulted in distressing, confusing experience.

Smell was identified as the most prominent sensory experience during pregnancy, which has also been reported by non-autistic mothers (Hampton et al., 2022). This experience is not uncommon in pregnancy of non-autistic women with both smell and taste in terms of sensitivity, aversion and nauseating responses reported (Cameron, 2014; Samuel et al., 2022). However, consistent with Hampton et al. (2022) and Samuel et al. (2022) heightened sensory sensitivity was experienced as “all-consuming” and had a detrimental impact on quality of life. Increased and emerging sensory sensitivities were reported that led to avoidance of environments due to noise, smell, and physical sensations (Samuel et al., 2022). Associations in some cases were so strong years post pregnancy, certain foods or clothing were still avoided due to the intense physiological response. The above suggests sensory sensitivity is a common experience in pregnancy, but for autistic women this can be so intense it interferes with coping with daily life.

The second GET ‘the ups and downs of connecting to their maternal identity’, considered the process of grappling with internal and external pressures contributing to participants emerging maternal identities. In his IPA study, Smith (1999) identified that pregnancy facilitated a process of changing self-perception, where all women discovered their role as a mother. Although participants described their feelings about motherhood, most felt judged about their ability to cope based on co-occurring or misdiagnosed mental health conditions. This in turn led to self-doubt about their competency and worth as a mother.

Additionally, some participants described feeling innately “different” to others and internalised the message from society they “should be trying harder” to conform. Autistic women have been found to have internalised beliefs they were flawed in comparison to others (Leedham et al., 2020). Wilson et al. (2022) found autistic women felt a burden to conform to expectations of being more neurotypical. Participants described needing to hide their true selves and executed caution disclosing to professionals through fear of judgement, much like camouflaging to reduce social stigma (Hull et al., 2017; McDonnell et al., 2021; Samuel et al., 2021). Burton (2016) also found stigma was internalised by autistic mothers as inadequacy.

These findings are supported by the social constructionism theory whereby individual knowledge of self and the world is developed culturally (Burr & Dick, 2017). In this case, the socially constructed narratives of needing to be a “good”, present mother and conform to this ideal, influenced participants internal representation they had of themselves (Kerrick & Henry, 2017). Although autistic women clearly experience a process of developing their maternal identity, this is heavily influenced by societal expectation and stigma. This stigma can create feelings of inadequacy, as well as a need to compare or conform to societies norms.

Social constructionist theory principles can also contextualise the varying experiences participants had in relation to their developing bond with their child. Some participants reported concerns about connecting with their child, holding the belief to be a good mother is to develop such connections, which only strengthened pre-existing self-criticism. These findings support the literature on the dominant co-constructed narrative of motherhood, that expects mothers to have immediate, positive connection to their child (Kerick & Henry, 2017). Prenatal attachment is theorised to be influenced by a women’s internal representation of how they view themselves as a caregiver (Laxton-Kane & Slade, 2002). Therefore, it is important to consider the reciprocal interaction between societal expectation and attachment development. Particularly with the known significance of the development of early secure attachments within attachment theory (Bowlby, 1979).

It is also important to acknowledge the instant connection many participants in this and previous studies felt to their child, whether this was through nicknames or movement (Dugdale et al., 2021). Increased recognition of foetal movement has too been associated with stronger MFA (Malm et al., 2016; Samuel et al., 2022). Indicating MFA development is multifaceted. However, for autistic women it is of particular significance to consider how additional stigma and sensory sensitivity, may interact with prenatal bonding and maternal identity.

The final GET ‘Seeking support: need verses reality’ encompassed experiences with professionals that left participants feeling invalidated and like they “didn’t care”. Autistic women have reported feeling disempowered and suppressed when communicating needs with professionals (Donovan, 2020). Power imbalances between healthcare professionals and patients have been found to impede shared decision making (Joseph-Williams et al., 2014). Participants described feeling “scared” through fear of judgement that meant they needed to be “guarded” when sharing information.

Similarly, Leedham et al. (2020) and Pohl et al. (2021) found autistic women felt misunderstood leading to intense self-doubt when sharing with professionals. Comparable to Samuel et al. (2021), participants also described feeling unprepared by professionals for birth or being given biased advice wanting more of a “balanced view”. Existing literature acknowledges that neurotypical and neurodiverse women can be socialised into certain models of childbirth, that are co-constructed intersubjectively by the media, society, and culture (Luce et al., 2016; Smith, 1999). Therefore, professionals should consider what birthing narratives are communicated and how this may contribute to expectant mothers understanding and beliefs. Particularly considering the experiences of suppression and disempowerment of autistic women, that may hinder shared decision-making during birth.

Furthermore, participants felt clearer communication and continuity of care would prevent feeling unheard and unsupported. Indeed, positive experiences within healthcare for autistic mothers has been correlated to a consistent, collaborative approach (Lum et al., 2014). Turner (2017) has made recommendations to consider using clear, explicit information and visual aids with autistic women during birth. Participants described limited information and ambiguous language led to misunderstandings about the health of themselves and their baby. Samuel et al. (2022) also found autistic women reported communication difficulties with healthcare professionals that negatively impacted birth experiences. Pohl et al. (2021) suggested that anxieties about needing to converse with professionals impeded communication, which was echoed in this study with fear of judgement by professionals. However previous literature highlights many professionals report they lack sufficient training to support autistic individuals (Donovan, 2020; Hampton et al., 2021; Pohl et al., 2020). This suggests that autistic women may struggle to communicate pain, distress, and sensory needs during birth, but professionals also lack the training to empower them to do so.

Strengths, Limitations and Future Directions

As far as the author is aware, this is the first study exploring in-depth experiences of pregnancy in autistic women. The multiple recruitment strategies allowed for wide reach of the study, which is a strength reflected in the various countries represented. Additionally, utilising auditing methods with independent reviewers increased the transparency of the findings.

IPA was selected as the chosen methodology because it allows for a deep exploration of the lived experiences of autistic women, which was suggested by previous literature (Leedham et al., 2020; Smith et al., 2021; Yau et al., 2023). There was however significant variability within participants, seven had not received a diagnosis prior to pregnancy, while one had received a diagnosis and was pregnant during the interview. Additionally, time since pregnancy varied considerably between one and 15 years which may have biased recall, despite the valid rationale for the inclusion criteria (Kanfiszer et al., 2017; Watkins et al., 2014). The findings sought to keep the idiographic nature of each participant, nevertheless the lack of homogeneity may have limited this. Although transferability is not the aim of qualitative research, it is worth considering how these factors impacted reported experiences.

Research suggests those who partake in studies have a particular interest in that subject matter, therefore participants may have had specific motivations to participate (Robinson, 2014). Findings should be considered cautiously, especially as the accounts expressed are not exhaustive of all autistic women.

The participants also varied in terms of their cultural backgrounds, with one participant being Australian, one Dutch and six British. This is advantageous as various cultural perspectives could be captured. However, all participants identified as White, and their experiences may differ from autistic women from other ethnicities. The National Autistic

Society (2014) reported that there is a lack of research regarding the experiences of autistic individuals from Black, Asian and minority backgrounds, which has significant impact on the ability to access support. Therefore, further research should endeavour to investigate experiences of pregnancy in autistic women from other ethnicities.

Additionally, future research should explore autistic women’s experiences of maternal healthcare services. Research thus far has highlighted barriers to communicating with professionals, as well suggested adaptations in services (Lum et al., 2014; Pohl et al., 2021; Samuel et al., 2022; Turner, 2017). However, research exploring healthcare experiences and viability to implement such adaptations is limited.

Clinical Implications

This study raised several implications for consideration in clinical practice. Participants highlighted the limited provisions available in maternity healthcare services for autistic women, which has also been identified as an area of concern by the Care Quality Commission (2022) in their state of healthcare report.

Firstly, participants reported inconsistent care with biased communication from professionals, that left them feeling unsupported. Participants suggested the value of specialist autism trained midwives and experts by experience in maternity healthcare roles, which could encourage co-production of service development. On a service level, specific training could be delivered on effective communication and use of language with autistic individuals. For example, as suggested in literature the use of clear, unambiguous language (Turner, 2017). Maternity services could also consider tailored material such as social stories to ensure autistic women feel informed for birth, which is currently happening within one NHS trust (East Suffolk and North Essex; NHS, 2023).

Secondly, findings from this study and previous literature highlighted how some autistic women experience a disconnect from reality during birth (Donovan, 2020; Samuel et al., 2022; Steward et al., 2018). Psychoeducation regarding this experience, alongside training for triggers, warning signs and strategies to support autistic women through this, would be beneficial for midwives. Especially as ‘meltdowns’ or ‘shutting down’ is now a well-known phenomenon reported in both literature and by autistic individuals (Lewis & Stevens, 2023). In both the examples above an easily accessible advocacy service for autistic women during birth would be valuable, to give power and a voice to communicate needs if they feel unable too.

Thirdly, participants drew on the emotional impact of their pregnancy and birth. Externalised stigma and societal expectations of motherhood created internalised beliefs, that obstructed their identity and perceived ability to bond with their baby. Indeed, the British Psychological Society (2016) acknowledge the need for increased access to services and equal support for women, for example those with neurodiversity. This could be achieved by psychologists being embedded within maternal services, as recommended by the National institute for Health and Care Excellence (NICE, 2014). Within a stepped-care approach psychologists could provide specialist training and supervision for maternity professionals. This could contribute to high quality psychological support and individualised care plans for autistic mothers (BPS, 2016). For example, to understand how additional barriers such as stigma, may interact with autistic women’s emotional wellbeing and developing MFA. This stepped care approach would also ensure access to psychological therapies for women with significant distress or trauma.

Conclusion

This study identified that autistic women have similar pregnancy experiences to non-autistic women, with individuals experiencing unique differences and additional barriers to accessing adequate support. Participants described heightened sensory sensitivities, specifically smell that led to aversion and avoidance years later. Disconnection during birth was common, resulting in miscommunication of needs and lasting emotional impact from their birthing experience. Many participants felt instantly bonded with their children, whilst some had concerns about their ability to connect. These concerns were exacerbated by pre-existing stigma which significantly impacted their maternal identities. Consistency and compassion in care was important and experienced minimally with participants feeling powerless and unheard. These findings have important implications and considerations for autistic perinatal needs in healthcare.

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Appendices

Appendix A

Ethical Approval

Downloaded: 18/05/2022 Approved: 19/01/2022

Charlotte Grahame
Registration number: 200183666
Psychology
Programme: Doctorate In Clinical Psychology

Dear Charlotte
PROJECT TITLE: Lived Experiences of Pregnancy in Autistic Women: An Interpretative Phenomenological Analysis

APPLICATION: Reference Number 044350

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 19/01/2022 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

University research ethics application form 044350 (form submission date: 18/01/2022); (expected project end date: 25/09/2023).
Participant information sheet 1101034 version 1 (18/01/2022).
Participant information sheet 1100812 version 1 (14/01/2022).

Participant information sheet 1099758 version 7 (18/01/2022). Participant consent form 1099759 version 2 (13/12/2021).

If during the course of the project you need to deviate significantly from the above-approved documentationplease inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.
Yours sincerely

Department Of Psychology Research Ethics Committee Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

The project must abide by the University's Research Ethics Policy:

https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure

The project must abide by the University's Good Research & Innovation Practices Policy:

https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf

The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.

The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Participant Information Sheet

Charlotte Grahame
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: Cgrahame1@sheffield.ac.uk

PARTICPANT INFORMATION SHEET

You are being invited to take part in a research project. Before you decide, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and ask me any questions you have.

Why have I been invited?

You have been invited to take part in this research project because you are autistic woman who has had experience of pregnancy within the last 16 years. We are asking for women to participant who have been pregnant in the past 16 years, to minimise any memory bias when reporting information.

Do I have to take part?

No, it is up to you whether you would like to take part. Participation in this study is voluntary. If you decide to take part, you can keep this information sheet and will be asked to sign a consent form. You can withdraw at any time without giving a reason.

What will happen if I take part?

You will be contacted via telephone or email (please indicate which is your preferred method) by the lead researcher within 3 weeks. You will be asked to take part in an hour-long interview where you will be asked some questions about your experience of pregnancy.

The interview will take place either online or if you prefer face-to-face. You are welcome to bring with you a supportive individual if this would help, however they are unable to participate during the interview.

This interview will be recorded and then transcribed using an approved University of Sheffield transcriber. Following this it will be analysed using Interpretative Phenomenological Analysis.

What are the benefits of taking part?

You have the opportunity to share your experience of pregnancy. A written report of the findings will be complied with the hope of providing information to ensure support is tailored to individuals and offered when needed.

What if there is a problem?

If you feel that there is a problem at any time, you can let the researcher know. This may be a topic that is difficult to talk about or could feel distressing. If you experience any distress whilst sharing your experience, the researcher will be able to discuss this with you and discuss what further support might be of help (e.g. contacting your GP). You can also ask to stop the interview at any time and decide you no longer wish to participate. Your data will not be included in the study.

Will all the information be kept confidential?

All the information we collect about you will be kept strictly confidential. You will not be identifiable in any reports or publications.

The only exception to this would be if during the interview the researcher became concerned about a risk of harm to yourself (e.g., suicidal risk), or someone (e.g. a child or another adult) you talk about (e.g. risk of neglect or physical harm). In such a situation the researcher would discuss the need to breach confidentiality with you; the aim of this would always be in order to support yourself and those you mention and ensure safety (for example, it may involve letting relevant services know about the situation, in order to help provide those involved with support).

Will I receive any reimbursement of expenses for taking part in this research?

There will be reimbursement of relevant travel expenses incurred by participating in this research (subject to providing receipts of travel), if interviews were face to face at the University of Sheffield.

What will happen to the results of the study?

The results will be submitted as part of the researcher’s doctoral thesis in May 2023. You can let the researcher know at the start of the study if you would like a copy of this and this can be sent to you. The results will also be submitted for hopeful publication.

The University of Sheffield is organising and funding this research. This project has been ethically approved via the University of Sheffield Clinical Psychology department, using the University of Sheffield’s Ethics Review Procedure.

What if I wish to complain about the way the study has been carried out?

In the first instance you can contact the lead researcher, Charlotte Grahame on cgrahame1@sheffield.ac.uk. Alternatively, you can contact the other researchers involved in the project; Megan Freeth, Lecturer and Researcher on m.freeth@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact Head of the Department; Liz Milne E.Milne@sheffield.ac.uk, or Jilly-Gibson-Miller; J.gibson@sheffield.ac.uk and Robert Schmidt; r.schmidt@sheffield.ac.uk who are Head of the ethics committee..

Contact Information

This research is being conducted by **Charlotte Grahame** Trainee Clinical Psychologist. **Megan Freeth,** is also part of the research team supervising the project. This research will be used to write a thesis which fulfils part of their doctoral training. If you have any questions about the research, you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and he will ask **Charlotte Grahame** to contact you.

Additional Information about your data

New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

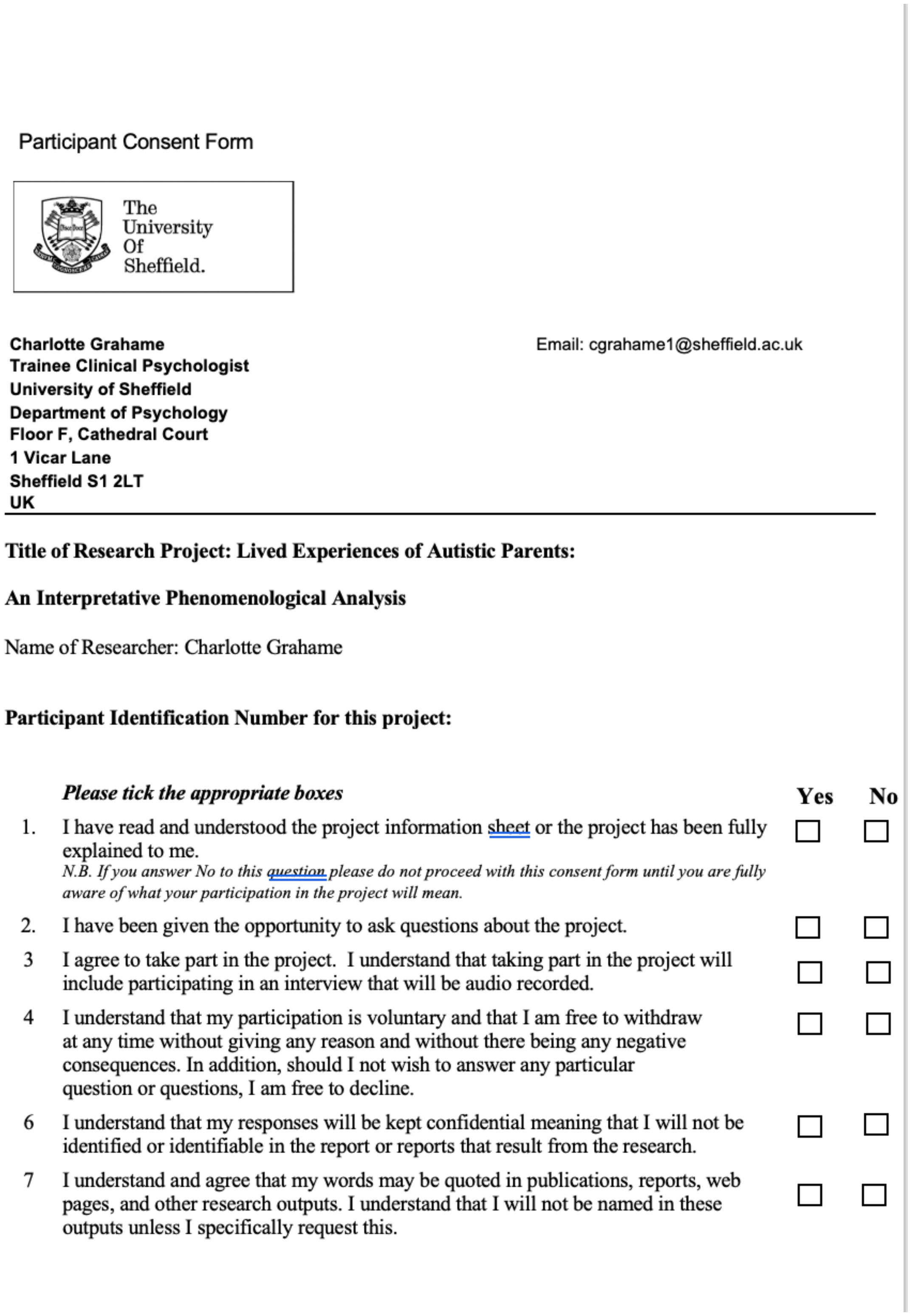
The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is ‘a task in the public interest’.

As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health, we also need to let you know that we are applying an additional condition in law: that the use of your data is ‘necessary for scientific or historical research purposes’.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University’s Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

Appendix C

Participant Consent Form



Participant Consent Form

The
University
Of
Sheffield.

Charlotte Grahame
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: cgrahame1@sheffield.ac.uk

Title of Research Project: Lived Experiences of Autistic Parents:

An Interpretative Phenomenological Analysis

Name of Researcher: Charlotte Grahame

Participant Identification Number for this project:

	Please tick the appropriate boxes	**Yes**	**No**
1.	I have read and understood the project information sheet or the project has been fully explained to me. *N.B. If you answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.*	☐	☐
2.	I have been given the opportunity to ask questions about the project.	☐	☐
3	I agree to take part in the project. I understand that taking part in the project will include participating in an interview that will be audio recorded.	☐	☐
4	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	☐	☐
6	I understand that my responses will be kept confidential meaning that I will not be identified or identifiable in the report or reports that result from the research.	☐	☐
7	I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐

8	I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
9	I agree for the data collected from me to be stored anonymously and potentially used in future research.	☐	☐
10 11	I confirm have a formal diagnosis of Autism Spectrum Condition. Detail of when diagnosed:___________and by: ____________(if remembered).	☐	☐
	I agree to take part in the above research project.		
12	I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

______________________	_______________	__________________
Name of Participant	Date	Signature
______________________	_______________	__________________
Lead Researcher	Date	Signature

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project's main record (e.g., a site file), which must be kept in a secure location.

Appendix D

Service User Feedback

Grammatical changes were made following feedback. One feedback point focused on advising that questions should be focused on individual's special interests to aid answering the questions. This point was raised in supervision and while considered extremely valuable, it was hard to conceive how this may form part of the interview schedule with interests being individualised.

Instead, questions regarding the individual's interests were added pre interview questions to encourage the building of a rapport. The participant was thanked for their valuable contribution and informed how this suggestion was implemented into the schedule.

Appendix E

Recruitment Poster

Advert for IPA Study

Are you a female (assigned at birth) with diagnosis of Autism and have had experience of pregnancy within the last 16 years?

I am looking for participants for a research study aimed at understanding the experiences of pregnancy for autistic women.

This study would involve participating in an hour-long interview about your experiences of pregnancy and how autism may have contributed to this experience.

We are hoping this research will be useful for ensuring individualised support is provided by services in future. I am a Trainee Clinical Psychologist and this project forms part of my thesis.

You will be eligible to take part if you:

- Have a formal diagnosis of Autism
- Are aged 18 or over
- Are a woman who has experienced pregnancy within the last 16 years
- Are able to consent to participating in research
- Speak fluent English

You are welcome to get in touch via email if you have any questions about the study or are interested in participating.

Charlotte Grahame: cgrahame1@sheffield.ac.uk

Appendix F

Reflexive Statement

The investigator is a cisgender female, in her mid-twenties who has not experienced pregnancy or birth. However, the investigator does have a diagnosis of Endometriosis and therefore has some experience with gynaecological and obstetrics services. It is worth acknowledging, that this is very different to the lived experiences of pregnancy and having a neurodevelopmental difference.

The primary investigator is a Trainee Clinical Psychologist and therefore has worked with autistic children and adults in her clinical work. This client group is a clinical area of interest the investigator would like to peruse in her future career. The primary investigator has also completed previous research on autistic people. The investigator has no personal experience with autism.

Appendix G

Reflexive Diary Extract

Participant 5

I was touched by how open she was about how she felt so powerless against the medical professionals, in terms of all the extra scans and support she needed because of her previous eating disorder. I noticed feeling like I could relate to her in this moment, I myself can feel powerless against medical professionals. It was important to recognise this as a bias for how I might emotionally respond to her story. I was also aware not to position myself as assuming a shared experience- having never experienced pregnancy or an eating disorder, it was a feeling I could relate to rather than say I had experienced it. I made sure I had the interview schedule next to me, to ground me back into my research. For the participant, these experiences in turn created this hypervigilance about having her children removed from her, because of how she was being treated and her and her husband's traumatic childhood experiences.

This participants experiences felt so different to my last interview, feeling she needed more consistency with who she was seeing. I needed to remind myself of the potential expectations or assumptions I had potentially made, from previous interviews so far. Each experience is different and unique, and it can be hard to treat as such when you have mentally, already started making connections of commonalities in your head.

She felt like she was seeing so many different professionals who she had to speak to and tell her story too. I noticed strong transference of fear from the participant. The pure sense of anxiety she felt by having so many internal examinations by so many different doctors and not being told why or who they were. She described feeling that she had been raped, 'so many different hands inside me' which was so awful to hear. Especially as the theme of feeling powerless came through so strongly from the beginning of the interview. The stark contrast of describing a euphoric feeling birthing her baby by being pulled back into reality with these examinations, thar she felt unable to say no to.

Participant 6

I wanted to be mindful that during this interview, I potentially introduced something into the mix with my position as a therapist. I like to think in my approach, I am a 'caring therapist'. I often find myself being chatty and friendly to help people feel comfortable and potentially, I suppose to also ease my own anxieties. This participant was quite blunt and to the point in her conversational style, which I found a stark contrast to my approach. I wanted to be mindful that my approach of 'chatty' may have had the opposite effect for this participant and just because I feel this approach is useful, doesn't mean it is best. XXX made lots of reference to her diagnosis in a serious and jovial way. I think this was useful to reflect on in broader terms, with the whole interview process. My interview style and approach will have been different and influenced by my experiences on clinical training. It can be hard to separate out the research and clinical sides, especially when you have spent so many years focusing specifically on the development of clinical skills.

Reflections on analysis:

I felt overwhelmed by the magnitude of trauma and difficulty that XXX experienced throughout all her pregnancies. Sometimes I noticed getting lost in the transcript and wanted to do her experiences justice, a lot came up for me when reading it I almost had to streamline my comments/ remember everything I wanted to write.

I was struck by the strong sensory experiences XXX had in terms of her smell and the associations she made or makes even now. I remember noticing the same during the interviews. I noticed there was a strong theme of pressure and self-blame XXX placed on herself throughout the interview. Feeling she was determined to make her children's life different to hers and needed to have more than one so they had each other. Similarly, anytime

XXX struggled physically she would place blame on herself and feel she needed to do more. The physical tole pregnancy took on her health meant she didn’t experience a developing bond to her children. A lot of concern about not wanting to raise a child that is like her, again a sense she was different but not knowing why. This felt contrasting to her starting to make links between some of her experiences and her recent diagnosis, almost retrospectively reviewing all her experiences. I felt the emotion behind XXX words of feeling invalidated, misunderstood and under supported by professionals which was a really powerful and awful experience. There was a strong message of the trauma she has been left with as a result, throughout.

Appendix H

Example of Initial Noting

Concern about bonding with baby that is different to her Feeling different/ isolated from others	P; definitely, definitely shock. I didn't, I've been a freak my entire life, I've never felt like I've fitted in anywhere and I was very concerned about how am I gonna raise a child that's not like me. Erm, I was absolutely terrified that I wouldn't be able to save my child from growing up the way that I did, although these fears have been very much put to rest now because she is exactly like me and I absolutely love it, she is a right little fire cracker, erm.	Primary emotion, memory of it is quite clear and profound Harsh critical language about self Sense of not belonging, feeling different Difference to baby impacting potential bond Difference in language, more positive Positive associations with self- bond with daughter has led to acceptance of self?
	I: (NAME – child 1) or (NAME – child 2)?	

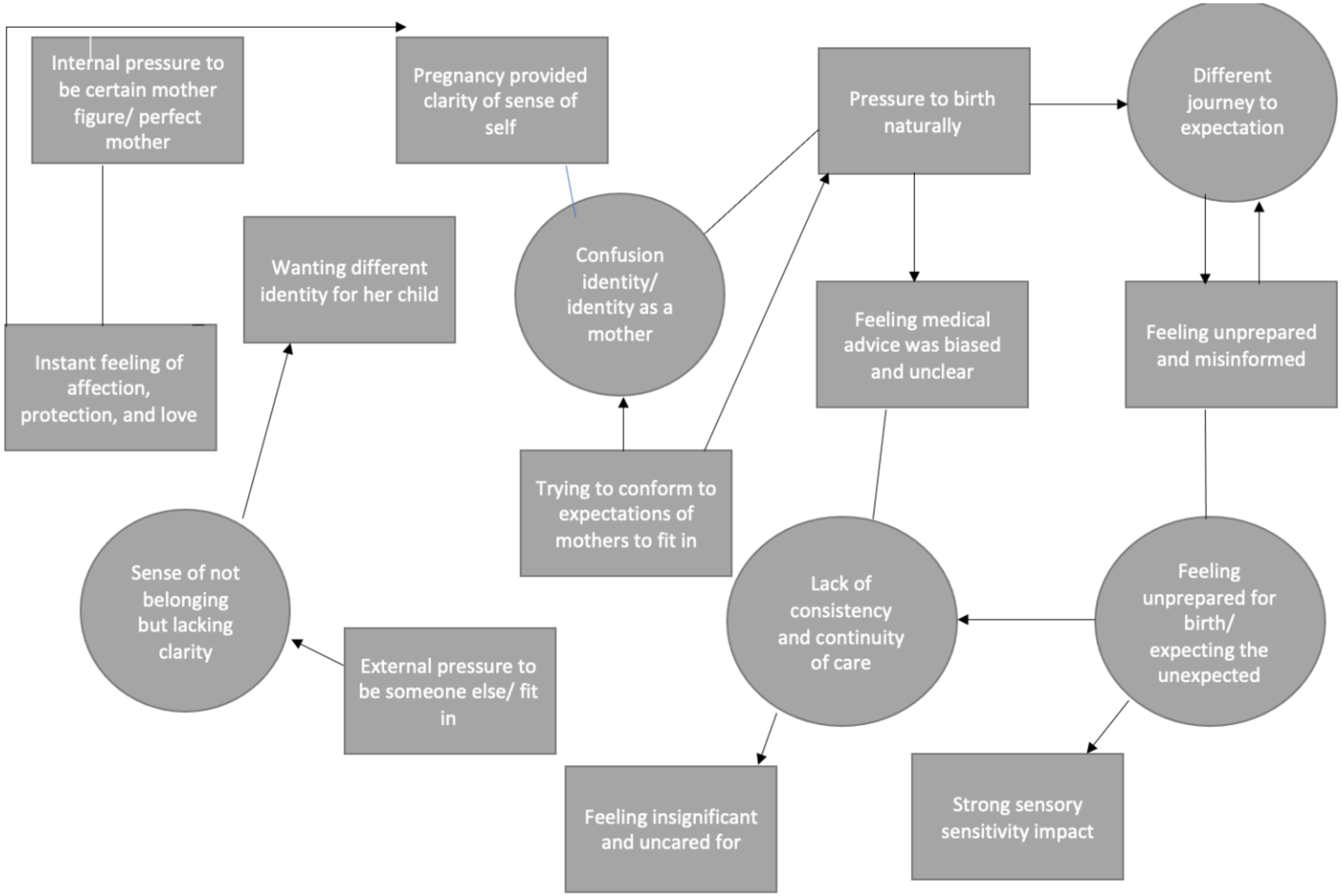
	P: (LAUGH) both of them.	
	I: Both of them?	
	P: Erm, but especially (NAME – child 1), in a lot of ways she is, I succeeded her in raising her in such a way that she is nothing like I was at her age and everything like I am now.	Proud language, did a good job as a mother Strong connection/ bond to how similar they are
	I: Yeah.	
Lack of sense of belonging or safety Motherly instinct- wanting to protect and keep children safe	P; She has the benefit of, I didn't have a very good childhood, even erm yeah I did get a lot of bullying at school, we know now it's because I'm autistic but even at home it was a very abusive upbringing, erm so I didn't have very many safe spaces so there are a lot of things that I should have learned during childhood that I didn't and I didn't learn them until I was in my mid to late 20's, erm and I learnt them because I stepped back and said "I'm not gonna	Parenting phyilosophy was influenced by her experiences Wanting children to have a different life to her

Wanting a different life for her children	do this to my kids, what is the best response here"? and I actually consciously parent rather than winning if you like like a lot of parents do, I mediate and ruminate on absolutely every decision that I make to make sure that I'm not making my children into another version of me and my trauma and what I had before, so that was my worry at the time was I don't want to raise a child who needs to recover from a childhood like I have to, erm I couldn't think of anything else, and that's why everybody kept telling me "if you just stop worrying about it you'll stop being sick", as if I was making myself ill by being so worried about it. Erm, which then added to the guilt, you know, my baby is not growing and she is not getting enough oxygen and it's all my fault because I can't stop worrying. Erm I had a mental break down after every one of my pregnancies, but that first one I genuinely believe because I was so anxious over, the baby	Internal monologue Wanting children to have difference experience. Wanting children to be different to her More accepting of herself now to help her children be more accepting of themselves? So they don't feel like they don't belong Self critical language Blaming herself for babies development. Feeling she is not doing a good job as a mother- when she is worrying

Inate sense there was something wrong with her Internal and external guilt and shame responsibility to not pass her genes onto her children shouldn’t be a mother protect children by not having them	part was easy, it was the after that, so yeah I just, I was so, so worried that I did, I did seriously consider terminating because I didn’t know if it would be fair for me to have a kid, I’d never wanted them because I didn’t think that I was the kind of person that should raise a child, even though I didn’t know I was autistic it was I’m a freak and there’s something *wrong* with me. I’d always been raise with this idea that there was something wrong with me and I didn’t want to pass that on, so yeah I was very panicked. But with (NAME – Child 2) it was just relief, because I’ve got six brothers and sisters, seven brothers and sisters, there’s eight of us all together, I don’t know how many that makes (LAUGH).	because she wants to protect her children which is what a mother does Repition and choice of word reflects anxiety “kind of person” not connecting to the idea of being a mother, didn’t think she was deserving of being a mother Internalised blame for being perceived as different Feeling responsible for potentially passing that onto others

Appendix I

Conceptual Map



Appendix J

Narrative Summary Example

Participant 4:

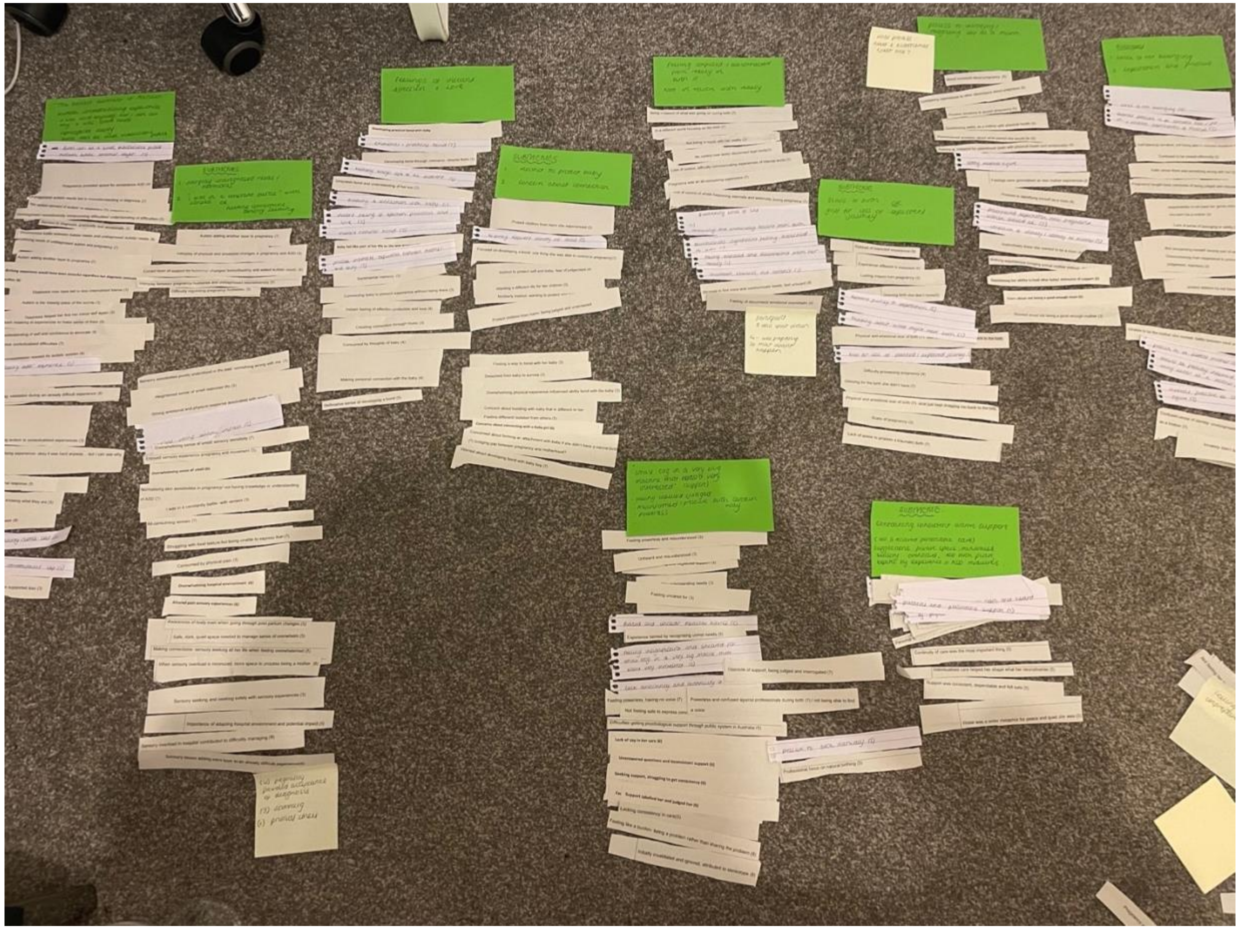
This participant held a lot of anxiety about her pregnancy and becoming a parent, she would pre-conceive how she might be judged. She described feeing the need to be guarded and consider how and what she said to medical professionals, through fear of judgement. The participant was very aware of her autism and considered how she may be judged due to her diagnosis. However, despite that there was a strong narrative of the journey she went through during her pregnancy. She described needing time to process her pregnancy and feel positive and excited about it. There appeared to be a process she needed to go through to recognise and accept herself as a mum, despite always wanting to be one. Throughout this process she also observed more acceptance of her diagnosis as well. This was mirrored in the support plans she had made and how she planned to advocate for herself and her birth.

Participant 5:

There was a strong narrative of the importance of individualised care throughout this interview. This participants experience was transformed by having a private midwife who helped create the participants perfect birth environment. By being so person centred, consistent and attentive this process helped the participant to make links regarding her own sensory and emotional needs. For example, needing a dark, quiet space to process information and overstimulation. There was a sense of the difficulty of having undiagnosed autism and going through pregnancy, with all the hormonal and physical related changes that happen to a woman. As a result, the participant attributed her experiences to mental health and assumed there must be something fundamentally wrong with her or her ability to parent. This highlighted that the lack of personalisation and understanding of individual needs led the participant to blame herself for struggling to manage her emotions/ hospital environments. The participant also spoke about the significance of the developing bond between her and her children and how she had symbolic memories or names from each pregnancy. The bond seemed to be instant and growing s the pregnancy progressed.

Appendix K

Grouping of Experiential Statements



Appendix L

Participants Contribution to Theme

PET and Subthemes	**Participants**							
	Nora	**Grace**	**Ameillia**	**Olivia**	**Clara**	**Julia**	**Penny**	**Emily**
Diagnosis contextualising perinatal experiences	X	X	X	X	X	X	X	X
Disconnect from reality during birth	X		X	X	X		X	X
Battle with sensory experiences	X	X	X	X	X	X	X	X
Grief of expected birth	X		X	X			X	
The ups and downs of connecting to their maternal identity	X	X	X.	X	X	X	X	X
Feelings of instant affection and love	X	X	X	X	X	X	X	X

Sense of not belonging		X	X		X		X	
Expectation and pressure		X	X	X	X	X	X	X
Seeking support: Need versus reality		X	X	X	X	X	X	X
Feeling uncared for, unsupported and powerless		X	X	X	X	X	X	X
Containing, consistent, warm support	X	X	X	X	X	X	X	X

Appendix M

Selection of Additional Participant Quotes per Theme

PET	Subthemes	Quote
Reinterpretation of perinatal experiences after diagnosis		*(Nora)* I think if I look back on it now with the diagnosis of autism, now I can understand, why I behaved the way I did when that happened. Because I think I shut down quite a lot. Erm, and I didn't I didn't really understand what was going on. I if I'd known then, that I was autistic, I would have said so and I would have said, I need you to explain things to me very clearly and patiently and make sure that I understand what you say. Erm, because I don't know with an experience like that, I think I went into some kind of shutdown. (*Grace)* erm, I was, I was just, I had always even before I was pregnant, I wanted children and I always felt really strongly that I wanted their life to be very different to how mine had been. Erm, and I, I, well, erm, you know, I had always been autistic but I had never known I was autistic, so I just felt different, felt different, like I didn’t fit in, you know kind of, had a sense that life was just, harder for me somehow and that whenever. *(Ameillia)* But I always know is there is something missing and my entire life has been me trying to figure out what the hell I’m missing. I never understood why people ignored me come up that will remind me and I’ll go “oh so that’s why I did that”.

Well I'm craving a bath sponge now, what do you want me to do", and the midwife looked and said "chew it but don't swallow it" (LAUGH). Erm, so that was funny, she gave me a bath sponge and kept putting it in water for me so that it was soft, and I'd sit and chew it. Which, looking back now, I didn't know it at the time but that was clearly stimming, but I didn't know about stimming at the time.

(Olivia) Erm (LAUGH) I still have that but what I have most noticed since being pregnant I, I had got so where I was a lot more accepting about being autistic. Growing up I was not okay about it, it was only really getting on for like about three or four years give or take where having support at work, and it just feels sort of safe and accepted and obviously having NAME- (partner) who has been incredible with it all, I felt okay being autistic. I don't have it in neon lights or anything, you know, I'm not just gonna suddenly start stimming left, right and centre cos I can but I just felt just this peace about it, like this is part of me, it is what it is, it's okay, erm but since being pregnant the mask is definitely up. Erm, I (SIGH), I'm certainly aware and I did feel vulnerable being autistic and being a parent, like I know it happens, like I've spoken to autistic women that have got kids and it's been really beneficial reaching out to them but they'd already had their children, so I was really worried that something would come up where my autism would be held against me, erm worrying about sort of what, I'd encountered enough stigma and negativity in my time but I would be worried to speak out about certain things that I might have struggled with in case people said things like "oh well, if you're struggling now what are you gonna be like when the baby's here", and just been on like red alert.

It's part of my whole life, you know, I've always been like it and it's a big part of my autism.

(Clara) Depression I did err get some medical support after both (NAME-child 1) and (NAME-child 3) were born, and I probably should have during my pregnancy with (NAME-child 1). None of them were technically, yeah as I say, none of them

		were pre or post-natal depression, it was more erm, you know, my pre-existing, what we didn’t know at the time, my pre-existing neurodiversity’s and I think anxiety disorders. easily fell into those really overwhelming emotions and meltdown type situations. I didn’t know they were meltdowns at the time, but I look back now and I go “oh that’s what that was”, a *(Penny)* Which was really, really difficult because the whole experience was really, really overwhelming, the entire thing of being pregnant, I’m sure it is for any woman but when you’ve also got the added, you know the added element of autism, it’s just a different level of overwhelm because, you know, things can happen outside your body and when I’m having a bad day I can still find a way to try and shut myself away from everything, you know, I can try and just read a book and just focus on that or I can, you know, wrap myself up in a blanket, you know, there’s things you can do but when you’re pregnant you can’t get away from those intense feelings. *(Emily)* And then so I kept testing it and it just was getting worse, if anything. Erm so they kept me in hospital basically just to try and stabilise that a little bit. So I think I was in hospital for, five days after. Erm, but I mean, I didn't know at the time, but now I would say I had a meltdown on like day three, I would say because I just couldn't, erm I just couldn't cope because it was just embarrassing So I basically would have had what you would call a really big meltdown. Just in tears and I just couldn’t, I couldn't carry on that way basically.
	Battle with sensory experiences	*(Nora)* and I noticed, I don't know whether I smelt stronger or whether my sense of smell was stronger, but I, I smelt different that I noticed that, that was quite marked to me, actually. And erm, I used to kind of jokingly referred to it as smelling like a hyaena. It's not that bad hahah, but it was like a kind of wild smell, and I really enjoyed that, you know, because it felt like a very natural thing

(Grace)
All the clothes I that I had from, well pretty much, the really big clothes wouldn’t fit me anyway, the ones that still fit me form the early phase of pregnancy I couldn’t wear. Because the association of nausea was so strong, I, I actually got to the point where I had a sliding wardrobe and you can see what’s in it.

(Ameilia) Smell was never friendly to me during preg, I mean I’ve got a very heightened sense of smell and with each pregnancy it got worse and never went back

It’s like I was in a constant battle between the two because there’s smells everywhere, you can’t get away from them.

(Olivia) My cravings have been totally sensory focussed, like it’s like I’m seeking the sensory, so erm (LAUGH) I have been craving water melon, oh I love it, it’s the texture, not so much the taste. I mean it’s great because it’s so hydrating and with the hot weather it’s just amazing, but it’s the texture, I need that sensory input, I need that texture.

(Clara) Erm, I think, looking back yeah, I think I did. You know I think that’s probably one of the reasons why I really enjoyed erm the second and third trimester because I loved the feeling of having the baby moving around in womb and everything, like I’ve just loved that so much and there’s nothing like it, you know there’s no other experience like it but it’s just a feeling that I really, really enjoyed and I think, looking back now I enjoyed it the same way that I enjoy some other sensory seeking kind of stuff, erm and so yeah, there was definitely that for sure.

(Julia) My sense of smell was phenomenal. It was outrageous. I remember, like we, i worked in a shared office at the time and it wasn't massive. It was kind of like a converted bungalow because it was on the old inpatient site that I worked on.

		Erm and I remember being right at the back of the shared office, and one of the one of my colleagues came in through the front door and I have to shout to her , XXX have you got sweetcorn for lunch again? *(Penny)* It just suddenly, it felt like all of my senses which already always felt so erm heightened, which I, and I didn’t know why. I had a very low opinion of myself and I suppose they were just more sort of evidence that there was something wrong with me. *I didn’t know what was wrong with me but those sort of being over sensitive to everything*, and other people’s reaction to that of me being fussy or me making a fuss about things or complaining about things. I could smell it and it just made my whole body just tense, you know just tensed and I just wanted to get away from it, and so it made going, it made going anywhere really, really difficult, you know we tried to go erm, well restaurants were not even, they were really difficult.
	Disconnection from reality during birth	*(Nora)* I think if I look back on it now with the diagnosis of autism, now I can understand, why I behaved the way I did when that happened. Because I think I shut down quite a lot. Erm, and I didn't I didn't really understand what was going on, erm, I think probably people might have explained it to me, but I don't recall them explaining what was happening and what it meant. So, I sort of felt like I didn't really know what was going on while I was in hospital And I just, I was oblivious. I didn't realise that I was in danger at all, even though it's quite a serious condition. And, erm they basically kept me in overnight and the next day they said, okay, we're going to induce you now .I still didn't understand then that I was in a serious position and I was just like, Oh, okay, can I find my mom, you know? *(Ameillia)* where I willingly gave up control. It had been taken from me my entire life so when I was old enough to actually take some it took a lot for me to give it

up but I was just quite happy for mum to do everything, to fight everything because I just did not know what I was doing, I felt like, I just felt like (SIGH).

I seem to shrink within myself and I can feel it, physically feel it happening, erm like I'm becoming smaller and lesser, erm and I always fought it whenever it happened, I didn't like it happening, it doesn't feel nice.

(Olivia) I worried so much that having that happen and any like excessive like stimuli going on that I'll meltdown and I worry the impact a meltdown will have on the baby and but then on the other extreme I'll worry that I'll shut down so that I can't get my needs and how can my birth partner's help me if they don't know what I need cos I can't tell them.

(Clara) easily fell into those really overwhelming emotions and meltdown type situations. I didn't know they were meltdowns at the time, but I look back now and I go "oh that's what that was".

(Penny) cos it was just like I was not there, I wasnt in my body, I was just somewhere else completely, erm it was like a trippy kind of

so I was going from like being like not there, just in another place and just birthing my baby and just focussing on that and just really kind of almost like a euphoria feeling, to then I was sort of pulled back into reality of having this examinations and it felt like as soon as they went.

Erm, but I still didn't get any incline that there was anything going wrong
I didn't think anything was made very clear to me so I didn't, I didn't know that you know, there was any danger or any issue.

I think they must have all just been a bit vague and expected me to understand.

The ups and downs of connecting to maternal identity		*(Clara)* I felt like a real warrior after, giving birth standing up. (LAUGH) and I think I had been squatting and I had an epidural when (NAME-child 1) was born and then so then yeah, having the peaceful water birth where I caught my own baby with (NAME-child 3) was pretty wonderful. So it was a full circle moment yeah sort of the Independent Midwives' did have that more focus on that natural birth and but err more sort of primal sort of urges and following women's body's and instincts and all of that sort of stuff, so they tended to create birthing spaces that were quiet and they were dark and I think also knowing what I know about other autistic people that the Midwife's approach to that might have been, there might have been a different autistic woman who had the complete opposite experience and actually not liked that dark sort of quiet experience.
	Feelings of instant affection and love	*(Nora)* Um, lots of loving and excited thoughts. I used to talk to him a lot. And try to encourage erm, other people or to talk around him, you know, so that he would get to know their voices. *(Grace)* I would just go lie on the sofa in the conservatory and just kind of, being with the baby inside me and just sort of, just thinking this is really special im going to remember this. I can remember the first time I felt her kick, we had been for a Chinese meal in Birmingham and then we had gone to see the Ramba in the hyperdrome so we were watching the ramba and I felt the first kick and that was really exciting. Erm I love dance so I kind of thought that was really cool *(Ameilia)* I didn't feel anything but ill and I just kept thinking this baby's trying to kill me. I tried not to think about it the entire time, I focussed on the pregnancy rather than on the baby. And then my husband, he used to lay on me with his head on my belly and he talked to all three of them, he talked to the babies, and he'd play music for them, and with (NAME – Child 1), it was Marilyn Manson, if she heard Marilyn Manson she'd instantly start squirming, erm which looking back now and knowing what we know about Marilyn Manson

(Olivia) You don't, until it happens, it really doesn't. It's like the most alien thing every (LAUGH), especially when you see it on the scan, it does look a bit like an alien, a very beautiful one, I love my little alien (LAUGH). Erm it can really feel like that.

(Clara) Erm, I think, looking back yeah, I think I did. You know I think that's probably one of the reasons why I really enjoyed erm the second and third trimester because I loved the feeling of having the baby moving around in womb and everything, like I've just loved that so much and there's nothing like it, you know there's no other experience like it but it's just a feeling that I really, really enjoyed and I think, looking back now I enjoyed it the same way that I enjoy some other sensory seeking kind of stuff, erm and so yeah, there was definitely that for sure.

(Penny) Before I explain about that is that with NAME – (child 1) I really wanted to know whether I was gonna have a boy or a girl because I thought that it would help, erm with like me bonding with him whilst I was pregnant with him like because then I could refer to the baby as he or she, and I wanted to be really, the thing I did really focus on, not parenting but about getting all of the stuff, I really focussed heavily on that and making his room absolutely like a work of art and erm and clothes and just all of that stuff. Erm, you know we had lots of trips to London to go to all sorts of places that I found, erm where I found like all one-off things.

Because my diagnosis came out of him, out of his diagnosis and were so, so similar, were so alike so, you know, and even before I had my diagnosis I understood him, just simplicity in a way that no one else could understand why he was behaving how he was, I just could understand it and we've always had that connection.

	Sense of not belonging	*(Grace)* I remember thinking, I wanted it to be a boy, because I felt like I don't want this baby to be like me. I don't want their life to be like my life and I couldn't really put my finger on what I meant by that, but I kind of felt like maybe if it was a boy it would be just, you know biologically quite different from me so that would be a good start, so yeah. *(Olivia)* I was just somehow determined to make it different so, ,knowing me I probably read an awful lot of books on baby care and kind of, how to give baby a good start and that sort of thing. So I had all the, I was definitely going to breastfeed, I was going to carry the baby in a sling constantly, you know every hippy dippy notion out there I was going to be doing and I had all these very positive, plans that I thought would give the child a different life to my life, Yeah yeah which actually now I am saying it to you feels like a lot of pressure and not a lot of realism *(Penny)* I had a very low opinion of myself and I suppose they were just more sort of evidence that there was something wrong with me. I didn't know what was wrong with me but those sort of being oversensitive to everything, and other people's reaction to that of me being fussy or me making a fuss about things or complaining about things.
	Expectation and pressure	*(Grace)* And there was always this sense of like, you should be doing something differently, you should be a better mother you should be you know more enlightened about this, but by the time she came I was just absolutely terrified… I wasn't able to have her naturally because you know, I had kind of convinced myself that this was, you know, my life's work and it was all going to go well, erm and I can remember just screaming get her out get her out get her out [PAUSE] it was just frightening.

		(Ameillia) They still said that there was nothing wrong with me and it was just my fault my baby wasn't growing and my umbilical cord was dying and that was my fault somehow. *(Clara)* Yeah, but I was really worried about that and I was worried that if I got upset at all that would be held against me. *(Julia)* Yeah, it was almost threatening. It's just oh well we'll have to do some questionnaires with you after you have the baby and make sure you're coping. And I thought, actually that's kind of inferring that you think I'm not going to, cope. (*Penny)* There was just the two of us and we didn't have that, and so it felt a bit, erm I suppose I sort of felt like in order to be (SIGH), a normal part of the wider family that's sort of something that we should have. I remember at the time really intensely feeling like there was people sweeping around me expecting me to do the wrong thing in my pregnancy, expecting me not to cope with weight gain, so therefore to not eat well, my baby not to grow properly and also a big expectation because I'd had problems with mental health all through my teenage years and twenties that I was bound to get postnatal depression.
Seeking support: Need versus reality	Feeling uncared for, unsupported and powerless	*(Ameillia)* So, in terms of my first pregnancy I'm still fucking angry because I'm still not, I'm still not recovered from that. I'm never gonna be well again in my entire life because of the neglect I suffered while I was pregnant with my eldest, so I'm very angry about it and the mental health support that I got afterwards was, again absolutely abysmal. I had mental break down after mental break down after mental break down. *(Emily)* Um. I think at first, probably when I was, like, so upset and struggling with everything. Erm, I think I was like, dismissed quite a lot by, like, the doctors and

erm, some of the midwives, like someone quite understanding erm, and nice about it, but some were quite like dismissive like oh this happens to everyone.

(Penny) I didn’t have the confidence to feel that I could say “hang on a minute, you don’t need to be so heavy handed”, I just let them do what they wanted to do and I just said “okay then, I’ll have the extra scans, and I’ll do this and I’ll do that”, erm and so I felt sort of, it made me hyper aware of everything.

I would have said no but I didn’t feel I could say no, it was just, erm you know, we are doing this thing and I felt that it would have been wrong to say no. So, there was that, and I, I had this intense nausea all the time, I just felt sick, just from the moment I opened my eyes to the moment I closed my eyes during the day.

But I was scared, I was always so scared to say the wrong thing because I was so frightened that, because they had from the word go kind of, they made me believe that I was definitely going to get post-natal depression, so I was so worried about that and I was also worried about anything, about my mood being, them picking up if I had a low mood during the pregnancy, so if I did I felt like I had to hide.

(Julia) Um, to be honest, my experience of the midwives was horrendous… While I was pregnant, I had, in our area, erm I think that had quite a lot of staff shortages, erm and retention issues and things. So I had a midwife that had been, I think she'd returned out of retirement. I don't, this is very judgmental, but I don't know if they bought her skills up to date when they did that. Every appointment I went to the first thing she asked me if I was anxious, and I said I'm not anxious. And she would say, are you sure you're anxious? Like I should have been? And I said, I'm not, but you're making me feel like I should have something to be anxious about because of the way you're asking me.

And I'd see different consultant every time. And they would just say different things every time.

	Containing, consistent, warm support	*(Nora)* So, I had like really excellent support from a really from really lovely people, right up until the baby was about to come. So, it was erm, it was a good support in terms of information, but also warm support. Yeah, like very personal *(Olivia)* My Midwife has been really lovely; she has been brilliant. She just had a really nice nature about her and she just listens and she just understood. *(Clara)* Erm, and I, the care that I received from her was amazing, you know it, it was, I mean to be fair to the Midwifery Group Practice Midwife's, they were also incredible but, you know the continuity of care that I got from (NAME-Midwife), her willingness to, you know was so personal and instead of feeling like a really clinical thing I felt more like erm I was working with a friend I suppose, you know, it was more, and that felt way more comfortable for me, I felt really Yeah, we were very, very lucky to have her, she was amazing and I will always be forever grateful that she was on shift that day. Yeah, yeah and that continuity of care I think was so important to me and it's one of the reasons they set up the Midwifery Practices. (*Julia)* I think just for me, just more consistency with the people that were looking after us and doing what they should have done, when they should have done it, really. Erm, that was the most stressful thing was just, you know, and, like consideration as well. So not having a room full, a tiny room full of people all at once when you had no sleep and then looking. *(Penny)* Which what I needed was continuity of care, I needed one person that I saw each time I went for my checks to say that, and also erm it made me, you know, seeing a different, not knowing who I was gonna see and then it being a different person, that was really scary not knowing, You know, like now, if I've got an appointment the person will like send me a photograph of them and, and so that I know what they're gonna look like.

	(Emily) So with the midwife, I felt like really supported and she was wonderful. And I'm really grateful that I had her. Just like really supportive and like he was particularly like humorous, but it just like, put you at ease and made you feel like, comfortable

Appendix N

Audit

Worthy Topic	
1. Is the topic of research relevant and justified?	**Yes** / Partially / No
Rich Rigor	
2. Does the study include clear theoretical constructs?	**Yes /** Partially / No
3. Does the study comprise of rich data?	**Yes** / Partially / No
4. Does the study describe the sample and provide demographic information?	**Yes** / Partially / No
5. Does the study describe how pregnancy is conceptualised (e.g time since birth)?	**Yes** / Partially / No **Yes** / Partially / No
6. Does the study sufficiently justify and describe the data analysis process?	**Yes** / Partially / No
7. Has the data been thoroughly coded adhering to the chosen analysis (6 steps for IPA)?	**Yes** / Partially / No
8. Has the researcher engaged in a reflexive process to define personal and group experiential themes?	**Yes** / Partially / No
Sincerity	
9. Does the researcher record self-reflexivity including values, biases, and personal experiences autism and or pregnancy?	**Yes** / Partially / No
10. Does the research address the chosen methods limitations?	

Credibility	**Yes** / Partially / No
11. Are participant quotes evidenced for themes and sub-themes?	**Yes** / Partially / No
12. Has the researcher engaged in appropriate supervision to support research quality?	**Yes** / Partially / No
Resonance	
13. Are the research findings documented clearly and insightfully?	**Yes** / Partially / No
Significant Contribution	
14. Does the study extend current knowledge of Autism and pregnancy?	**Yes** / Partially / No **Yes** / Partially / No
15. Do the study's provide implications clinical practice?	**Yes** / Partially / No
16. Does the study make recommendations for research?	
Ethical	**Yes** / Partially / No
17. Does the research have ethical approval?	**Yes** / Partially / No
18. Are the participants experiences appropriately represented?	**Yes** / Partially / No
	Yes / Partially / No
Meaningful Coherence	
19. Does the study achieve its reported aims?	
20. Does the study relate its findings with previous research?	**Yes** / Partially / No
	Yes / Partially / No

CGrahame
Name of Researcher Charlotte Grahame **Researcher Signature**
Name of Auditor Aditi Sharma **Auditor Signature**
Aditi Sharma

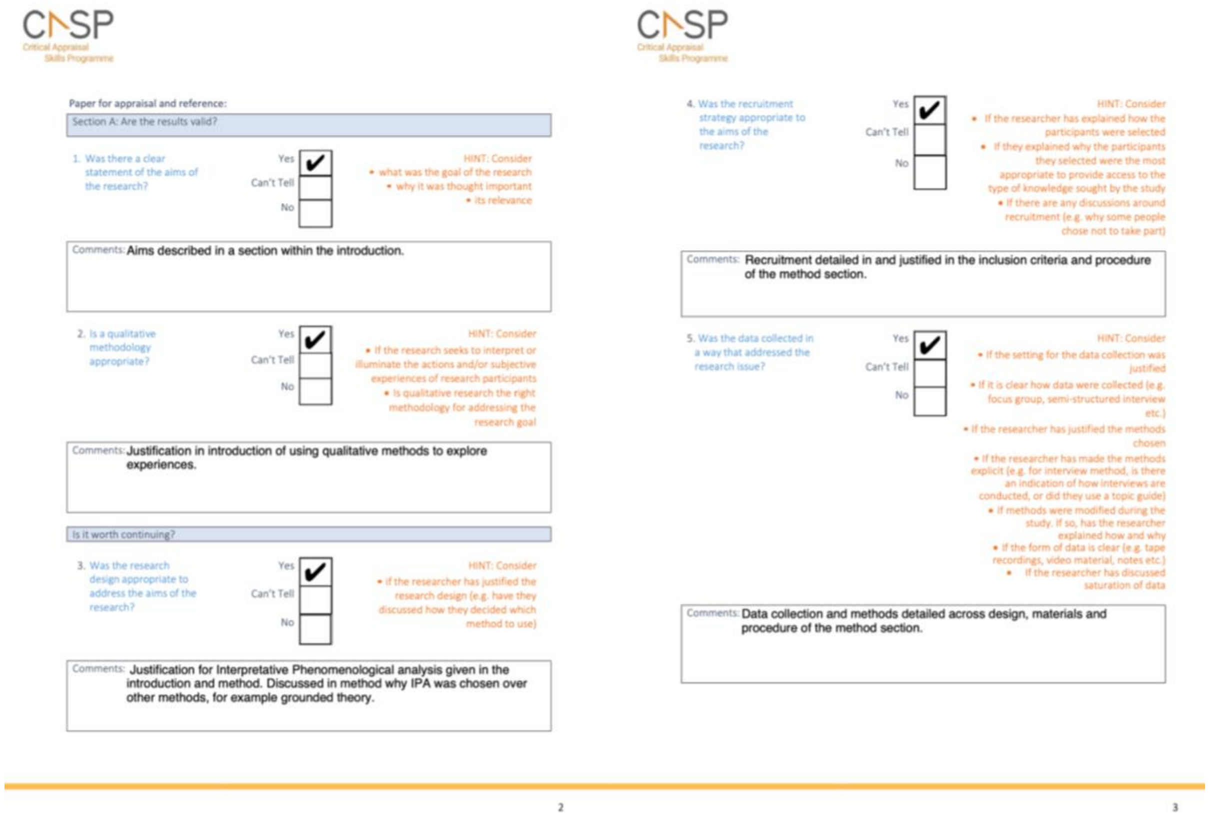
Worthy Topic	
1. Is the topic of research relevant and justified?	**Yes** / Partially / No
Rich Rigor	
2. Does the study include clear theoretical constructs?	**Yes** / Partially / No
3. Does the study comprise of rich data?	**Yes** / Partially / No
4. Does the study describe the sample and provide	**Yes** / Partially / No
demographic information?	
5. Does the study describe how pregnancy is conceptualised	**Yes** / Partially / No
(e.g time since birth)?	**Yes** / Partially / No
6. Does the study sufficiently justify and describe the data	**Yes** / Partially / No
analysis process?	
7. Has the data been thoroughly coded adhering to the chosen	**Yes** / Partially / No
analysis (6 steps for IPA)?	
8. Has the researcher engaged in a reflexive process to define	
personal and group experiential themes?	
	Yes / Partially / No
Sincerity	
9. Does the researcher record self-reflexivity including values,	**Yes** / Partially / No
biases, and personal experiences autism and or pregnancy?	
10. Does the research address the chosen methods limitations?	
Credibility	**Yes** / Partially / No
11. Are participant quotes evidenced for themes and sub-	
themes?	**Yes** / Partially / No
12. Has the researcher engaged in appropriate supervision to	
support research quality?	**Yes** / Partially / No
Resonance	
13. Are the research findings documented clearly and	
insightfully?	**Yes** / Partially / No

Significant Contribution	
14. Does the study extend current knowledge of Autism and	**Yes** / Partially / No
pregnancy?	**Yes** / Partially / No
15. Do the study’s provide implications clinical practice?	**Yes** / Partially / No
16. Does the study make recommendations for research?	
Ethical	**Yes** / Partially / No
17. Does the research have ethical approval?	**Yes** / Partially / No
18. Are the participants experiences appropriately represented?	**Yes** / Partially / No
	Yes / Partially / No
Meaningful Coherence	
19. Does the study achieve its reported aims?	
20. Does the study relate its findings with previous research?	**Yes** / Partially / No
	Yes / Partially / No

Name of Researcher Charlotte Grahame **Researcher Signature** CGrahame
Name of Auditor Connie Newcombe **Auditor Signature** CNewcombe

Appendix O

CASP Checklist



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Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments: Aims described in a section within the introduction.

2. Is a qualitative methodology appropriate?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: Justification in introduction of using qualitative methods to explore experiences.

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: Justification for Interpretative Phenomenological analysis given in the introduction and method. Discussed in method why IPA was chosen over other methods, for example grounded theory.

2

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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments: Recruitment detailed in and justified in the inclusion criteria and procedure of the method section.

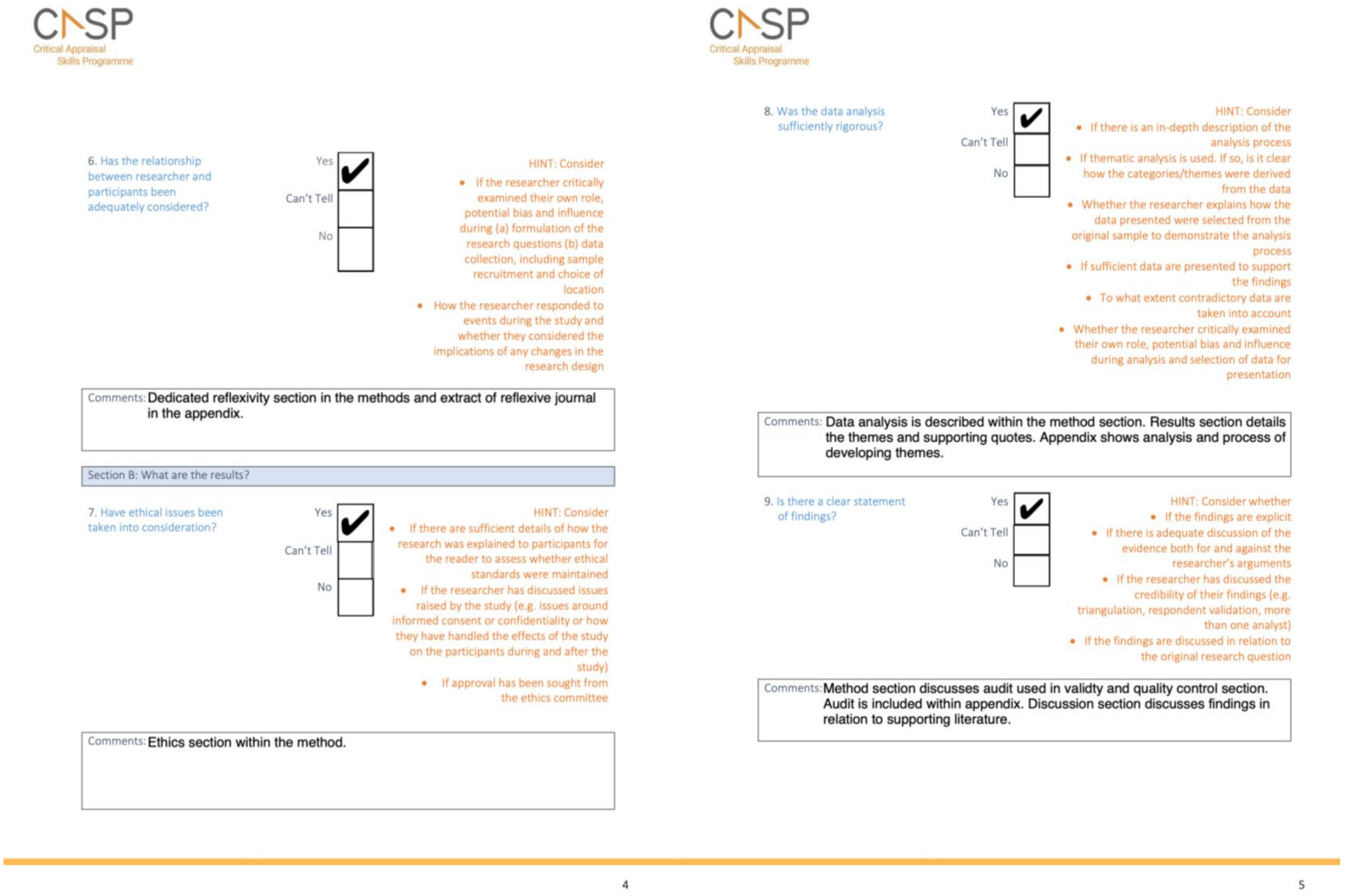
5. Was the data collected in a way that addressed the research issue?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments: Data collection and methods detailed across design, materials and procedure of the method section.

3



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6. Has the relationship between researcher and participants been adequately considered?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments: **Dedicated reflexivity section in the methods and extract of reflexive journal in the appendix.**

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: **Ethics section within the method.**

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8. Was the data analysis sufficiently rigorous?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments: **Data analysis is described within the method section. Results section details the themes and supporting quotes. Appendix shows analysis and process of developing themes.**

9. Is there a clear statement of findings?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: **Method section discusses audit used in validty and quality control section. Audit is included within appendix. Discussion section discusses findings in relation to supporting literature.**

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Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: Clinical and research implications discussed.