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Exploring the experiences and needs of children living with a parent with a mental health issue

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Variation of research portfolio due to COVID-19

Due to recruitment difficulties, the following MRP (n=4) has a lower than planned for sample size (protocol planned for 6-10 participants). Recruitment difficulties related to the reduced availability of clinicians to support recruitment. The clinicians who recruited to the study noted low participant numbers themselves due to generally higher difficulties in contacting and engaging young people during the COVID-19 pandemic. Due to the nature of analysis undertaken (Interpretative Phenomenological Analysis), it is not considered that the low sample size negatively impacts the final data set. It is recommended that doctoral level IPA projects aim to sample 4-10 participants (Smith, Flowers, & Larkin, 2009, p52).

Chapter 1

Systematic Review

Protecting and needing protection: A metasynthesis exploring the current needs of children living with parental mental illness

Prepared in accordance with the author requirements for the Journal of Child and Family Studies

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Abstract

Introduction

There are gaps in our knowledge with regards to how to support young people living with parental mental illness (PMI). The current review aimed to review and extend current knowledge regarding the experiences and needs of this population.

Methods

A systematic search of qualitative research about children living with PMI (published between 2015-2022) was executed across four databases: EMBASE, CINAHL, Medline, and PsychInfo. The final papers were appraised, and the results synthesised using meta-ethnography.

Results

Findings from twelve papers highlighted that young people living with PMI require support to make sense of PMI and must be recognised as having their own care needs. They need support to maintain a sense of 'normality', but at times require protection from harm.

Conclusions

The needs of young people living with PMI may be addressed using a whole-family approach which supports young people, both as children and where they wish, as carers, using flexible service design that responds to need in a personalised manner.

Keywords

Parental mental illness, young carers, parent-child relationship

Introduction

Recent estimations suggest that 68% of women and 57% of men with mental health conditions are also parents (The Royal College of Psychiatrists, 2016). Children living with parental mental illness (PMI) are at greater risk of developing social, emotional, cognitive, and behavioural difficulties (Brockington et al., 2011). PMI related factors include symptoms, severity, and duration. Children may be exposed to parental emotional distress, unpredictability and unusual behaviour, and these symptoms may challenge parents' ability to provide consistent boundaries, and emotional availability to their children (Brockington et al., 2011). Parents with mental illness are also more likely to face health and social inequalities, including poverty, homelessness, stigma, and domestic violence, which may further impact parenting and child outcomes (Brockington et al., 2011). Young people living with PMI are often considered to be young carers, where they participate in caring for parents. Recent prevalence estimates suggest up to 50,000 young people may be carers of PMI (Dearden & Becker, 2004).

Young carers (aged 0-25 years) are young people who help to care for someone with an illness, disability, mental health condition, or addiction (Carers Trust, 2022). As a large, heterogeneous population, recent estimations suggest there are up to 800,00 young carers aged 5-17 years (The Children's Society, 2022), and 376,00 young adult carers (Carer's Trust, 2022) within the UK. Caregiving duties are highly specific to family context but are understood to fall under instrumental (shopping, cleaning, caring for siblings), or emotional (providing emotional support for parents, family) categories.

Emotional caregiving, which is thought to be particularly characteristic of PMI contexts (Aldridge, 2003), is thought to be one risk factor impacting long-term outcomes (Hooper, 2008). Other factors include age, coping style, mental health literacy, stigma, and relationships with others (Yamamoto & Keogh, 2018). The continued 'hidden' nature of this population results from a combination of poor identification by statutory services, lack of clear definition regarding the type of care that qualifies as 'caregiving', and family reluctance to self-identify, in part due to stigma (Aldridge, 2018). Despite research on this population spanning two decades, young people's accounts continue to be poorly represented, within research or services seeking to meet their needs (Aldridge, 2018). It is therefore pertinent that we review current knowledge regarding the lived experiences and needs of young people living with PMI.

Meta-syntheses are helpful for promoting evidence-based practice, because they synthesise findings from multiple qualitative studies, leading to enhanced reliability, deepened understanding, and diversity of perspectives, (Dam & Hall, 2016). Wahl, Bruland, Bauer, Okan, & Lenz. (2017)'s recent review of child and parent needs concluded that children need services to recognise their role, support autonomy, knowledge, social, emotional, and practical needs. However, their review synthesised mixed method research, which can compromise reliability, with large sample sizes risking loss of primary research findings (Sattar, Lawton, Panagioti, Johnson, 2021). Yamamoto & Keogh's (2018) review found young peoples' understanding of PMI varied, and that their relationship with their parents, coping strategies, and social connections were both a source of risk and resilience. However, this review only included children's views, and recommended the future inclusion of other stakeholders. Neither review included families living with parental substance use disorder (SUD). Therefore, it would be helpful to systematically review the recent qualitative literature on the views of multiple stakeholders about the experiences and needs of young people living with PMI.

Aims and Questions

The current review aimed to update, extend, and synthesise current evidence relating to the perspectives of young people, parents, and clinicians, with regards to the following question:

- What do the experiences of young people living with PMI tell us about their needs?

Methods

The review was carried out according to a protocol, which was reviewed and agreed upon (June 2021) prior to study selection, and data extraction (beginning February 2022). The protocol was not pre-registered, but is available on the Open Science Framework (OSF): https://osf.io/hj8aq/?view_only=3e96f69efe504ef89e109d7761dfc6a1

Search strategy

Systematic searches were run across four electronic databases: Medline (OVID); Embase (OVID); Cinahl (Ebscohost); PsychInfo (Ebscohost). Articles were retrieved between April – May 2021 (date parameter 2015-2021). The search was updated in April 2022, using the same strategy but updating the 'date' parameter.

Search Terms

Search terms (Table 1) were based upon a modified SPIDER (Methley et al, 2014). Guidance during the modification and scoping searches was provided by the supervising researcher and a subject librarian at the University of Glasgow. The 'Phenomenon of interest' was separated, creating two separate criteria relating to mental illness and the parent-child relationship. This generated higher specificity, as scoping searches indicated there would be a high number of irrelevant returns (e.g parent carers of children with illness). Example MeSH terms, keywords, and synonyms are presented below (full example, Appendix 1.2).

Table 1 Search Terms

Subject	”Adolescent” or ”child” or ”child of Impaired Parents” or ”young carer”

Phenomenon of **I**nterest	”Parent” or ”parent-child” AND ”Parental mental illness” or ”Mental illness”
Design	”Interview” or ”focus group”
Evaluation	”Caregiver burden” or ”personal experience”
Research type	”Qualitative method”

***Inclusion Criteria**:* Empirical primary research published in English between 2015 and 2022 was included. This date parameter was chosen due to the aim of the current synthesis to update Yamamoto and Keogh’s (2018) recent synthesis, in addition to extending their methodology (Noblit & Hare, 1988). Research was included where the research aims and focus of the data was centred upon the experiences of young people aged 25 or under, living within the PMI context (≥50%), including parents with SUDs (drugs, alcohol), and where these studies incorporated focus group or interview designs.

Exclusion criteria: Research was excluded where it utilised quantitative, single-case study, or retrospective accounts (pertaining to adults’ reflections of childhood experiences). Studies that utilised secondary data, the coding of written accounts, or the evaluation of an intervention were also excluded. Studies using qualitative data, but within the context of predominantly quantitative methods, were excluded, to ensure primary focus of the metasynthesis upon qualitative epistemologies. Studies where the experiences of young people living with PMI were not explicitly focused upon, where accounts related mostly to the experiences of young people living with a parent with a physical illness or disability only, or where studies focused upon adult caregivers, were excluded. Studies were also excluded where most (≥50%) care recipients were not parents. Review articles, dissertations, editorials, discussion papers, or conference abstracts were also excluded.

Framework for qualitative research appraisal

The Walsh & Downe (2006) appraisal tool (Appendix 1.3) acknowledges the limitations of qualitative research, whilst resisting the application of positivist assumptions regarding quality scores as representative of objective 'truths' about research (Walsh & Downe, 2006). Rather, the tool places emphasis upon "integrity, transferability, and transparency of findings", providing a framework for identifying strengths and weaknesses.

It was agreed that a qualitative description of papers would be provided, detailing an overview of relative strengths and weaknesses. Papers were scored using a categorical traffic light system (Appendix 1.4). Papers were not excluded based upon scoring.

To reduce bias, two recent graduates of the Doctorate in Clinical Psychology independently rated three papers (McGaw & Reupert, 2022; McGibbon, Spratt, & Davidson, 2019; Gullbra et al., 2016a), after initial discussion to calibrate judgements using the appraisal tool and traffic light system (present, partially present, absent). Calculations indicated an item agreement level of 67%. Areas of disagreement were debated, with final ratings assigned. Areas of disagreement generally related to whether an item qualified as 'present' or 'partially present'.

Reflexivity

Reflexivity is promoted within qualitative research as a means of bringing into awareness, and managing, the impact of the researchers cultural, social, and personal assumptions upon data analysis (Clancy, 2013). These same assumptions are likely to be in operation during the systematic review process (Newton, Rothlingova, Gutteridge, LeMarchand, & Raphael, 2011). The main researcher was a white, female, Scottish, trainee clinical psychologist, with several years of practise and research experience regarding the review population. Throughout the development of the search strategy, study selection, extraction, and analysis, the researcher practised reflexivity, by way of reflective notetaking, audit trails, and on-going review of the these within research supervision.

Method of Synthesis

The metasynthesis was informed by Noblit & Hare's (1988) meta-ethnographic approach. This approach is suitable for synthesising qualitative findings utilising diverse approaches (Seers, 2012). The synthesis can involve integrating and summarising themes, as per Yamamoto & Keogh (2018). It can also take a more interpretative approach, by comparing themes, generating higher order interpretations, and new theory (Seers, 2012). The current study took the latter approach. This was informed by Sattar et al.'s (2021) stepped guidance (Appendix 1.5). Audit trails were kept detailing each step, the material of which was reviewed during research meetings to ensure fidelity to the process.

Results

Search Outcome

The search returned 28,776 articles (Figure 1). Duplicates were removed, followed by screening titles and abstracts of 15,755 articles. The full texts of 127 articles were reviewed for eligibility, with 12 articles selected. In cases of ambiguity, full texts were independently reviewed by the supervising researcher, and suitability discussed using the inclusion/exclusion criteria.

Summary of included studies

Twelve studies, published between 2015 and 2022, were included (Table 2). Nine studies recruited young people. One study included parents and children. Two studies recruited parents. In total 200 participants (167 children, 33 parents) were included. Six papers explored PMI, four explored SUD's, and two explored both. Specific mental illnesses included: substance misuse, parental alcohol dependency, bipolar disorder, personality disorder, developmental disorder, schizophrenia, schizoaffective syndrome, psychosis, post-traumatic stress disorder, and multiple personality disorder. Broader categorisations included: ‘mood problems’, anxiety problems, and ‘stress’. Three papers did not specify type of mental illness. Four studies assessed PMI using parental self-report, with the addition of symptom checklists being used within two studies. Within two studies, diagnostic and clinical characteristics reported, but the source of this information was not stated. Six studies did not specify that assessment had taken place. Studies were conducted in the UK, USA, Western Europe, and India.

Figure 1 Prisma Search results

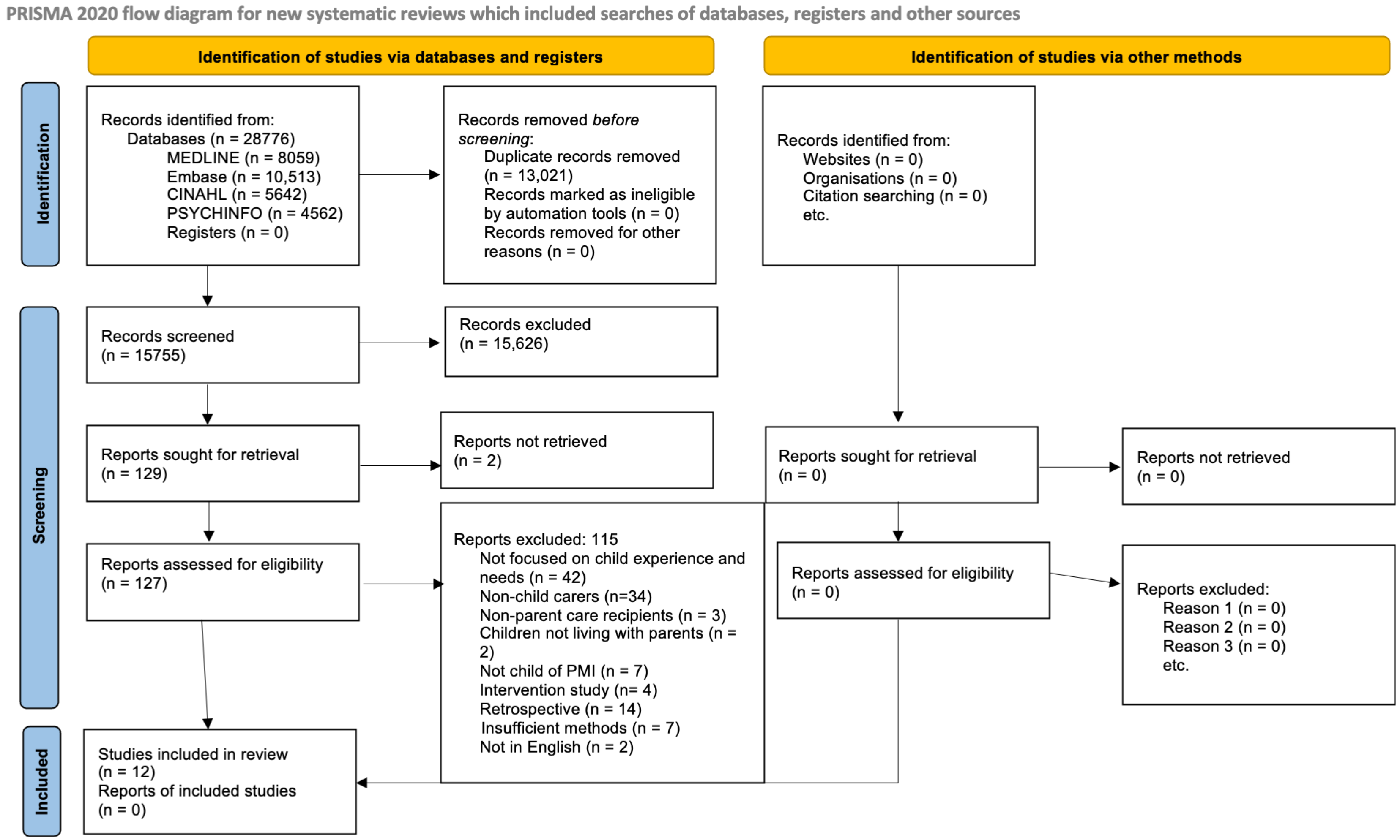


Table 2 Study Characteristics

Authors, year and country	**Sample characteristics**	**Care-recipient type & diagnoses**	**Method of PMI assessment**	**Data collection; method of analysis**	**Themes (subthemes)**
1. Alexanderson & Näsman, (2017), Sweden	N= 23 Age range = 6-19 years Mean age = Individual ages not stated Gender = Mixed Ethnicity = Not stated	Substance Misuse	Not stated	Qualitative 1:1 semi-structured interviews; Qualitative analysis, informed by Grounded Theory	- When parents live together - When parents have separated
2. Backer, Murphy, Fox, Ulph, & Calam, (2017), UK	N=10 Age range = 4-12 years Mean age = 7 years Female = 1 Male = 9 Ethnicity: White = 100%	Bipolar disorder	Parental self-report	Qualitative 1:1 interviews, carried out using computer assisted interview technology 'In my shoes'; Thematic Analysis	- Perceptions of parents (Parent with bipolar disorder; Well parent) - Knowledge and awareness of bipolar disorder (BD) (Communication about illness; Description of illness) - Managing family life with a bipolar parent (Emotional effects on child; 'Independent child'; Sources of support; Avoidance and coping) - Living in a family with BD

3. Bosch, Riebschleger, & Van Loon, (2017), Netherlands	N = 18 Age range = 13-21 years Mean age = 17 years Female = 11 Male = 7 Ethnicity = Not Stated. 'Dutch Youth'	Mental illness Mood problems = 5 (38.5%) Anxiety Problems = 2 (15.4%) Stress = 2 (15.4%) Personality disorder = 1(7.7%) Developmental Disorder = 4 (30.8%) Schizophrenia/Psychosis = 1 (7.7%)	Parent self-report using standardised measures: General Health Questionnaire (scoring ≥3), Hospital Anxiety and Depression Scale (scoring ≥8), Problem Drinking Questionnaire CAGE (scoring ≥2)	Qualitative 1:1 semi-structured interviews; Qualitative Thematic Analysis (QTA)	- Feeling Guilty - Not feeling ashamed - Making behavioural adjustments - Articulating that guilt and shame do not usually impair the parent-child relationships
4. Boström, &Strand, (2021), Sweden	N=13 Parents = 6 parents. Age range = 38-47 years. Mean age = 44 years Female = 4 Male = 2 Children = 7 Age range = 8-15 years Mean age = 11 years Female = 5 Male = 2 Ethnicity: Not Stated	Schizophrenia = 2 Schizoaffective syndrome = 4	Diagnostic and clinical characteristics presented within study, but source of information not stated.	Qualitative 1:1 semi-structured interviews; Interpretative Phenomenological Analysis	- An unclear image - An incoherent story - Illness as part of ordinary life - A non-hierarchical parent-child relationship - Attunement of the parent-child relationship and child well-being (An attuned parent-child relationship; Child's emotional independence)
5. Gullbrå, Smith-Siversten, Graungaard, Rortveit,	N = 15 Age range = 16-25 years	Mental illness = 5 Substance Misuse = 5 Cancer = 5	Not stated	Qualitative Focus groups using semi-structured question schedule; Systematic Text	- Living with unpredictability - The struggle for an ordinary adolescence - Experiences and expectations from encounters with the GP

Hafting, (2016) (a), Norway	Mean age = Individual ages not stated. Female = 12 Male = 3 Ethnicity: Not stated			Condensation (STC), informed by Shibbeye's theories on recognition	
6. Gullbrå, Smith-Sivertsen, Rortveit, Anderssen, Hafting, (2016) (b),Norway	N = 12 (parents) Age range = Not stated Mean age = individual ages not stated. Female = 9 Male = 3 Ethnicity: Not stated	Mental illness = 7 Addiction problems = 2 Somatic illness = 3	Not stated	Qualitative 1:1 semi-structured interviews; Systematic Text Condensation (STC)	- The importance of being an ordinary family (Making everyday life normal for the children; Being a competent parent) - In need of professional support (Counselling and support form a helper close at hand; the children's specific needs for information and emotional support; information about support services – a task for the GP)
7. Hagström, & Forinder, (2019), Sweden	N=19 Age range (point one) = 6-12 years Mean age= 7 years Age range (point two) = 10-16 years Mean age = 11 years Age range (point three) = 16-20 years Mean age = 16 years Female = 8 Male = 11	Parental alcohol dependency	Not stated	Qualitative 1:1 unstructured interviews completed across three time points spanning thirteen years; 'Narrative' analysis.	- The children's social situation - The two faces of the alcohol-dependent parent - Positioning oneself as a 'vulnerable' victim Experiences of parental neglect; Experiences of violence) - Positioning oneself as a 'competent agent'

	Ethnicity: Not Stated				(Controlling or preventing the alcohol-dependent parent from drinking; Confronting the parent with the alcohol misuse problem) - Practicing the role of young carer (Caring for the alcohol-dependent parent; Caring for younger siblings; Caring for oneself) - Disclosing the family secret and seeking help
8. Hill, (2015), UK	N = 30 Age range = 9-20 years Mean age = Ages not stated. Female = 16 Male = 14 Ethnicity: White Scottish	Parental alcohol misuse. (One young person did not disclose who the family member was).	Not stated	Three distinct phases. 1. Group reflections about conducting research on the impact of alcohol problems in families 2. Group work exploring parental alcohol problems (film making, spider diagrams) 3. Interviews during task-based activities such as drawing (individual, paired,	- Choosing to talk (All in the past…perhaps; Use of treatment services; Where I live) - Choosing to talk indirectly

				or small group depending upon preference); Inductive approach via thematic analysis	
9. McGaw & Reupert, (2022), Australia	N = 8 Age range = 12-17 years Mean age = 15 years Female = 4 Male = 4 Ethnicity = Caucasian (N=7), Mixed ethnicity (N=1)	Post-Traumatic Stress Disorder (PTSD) (associated with being a Veteran Parent)	Parental self-report of formal diagnosis by psychiatrist; verification via PTSD checklist for DSM-5 (PCL-5)	Qualitative 1:1 semi-structured interviews; Interpretative Phenomenological Analysis	- Growing in Silence (Taking care; Self-reliance; A family disconnected; "Our Family")
10. McGibbon, Spratt, & Davidson, (2019), Northern Ireland, UK	N = 22 Age range = 8-18 years Mean age = 14 years Female = 18 Male = 4 Ethnicity = Not stated	Mental illness Physical illness and/or disability Developmental problem Numerous care-recipients reported, over 50% of care recipients were parents, over 50% of difficulties related to mental illness	Not stated	Qualitative 1:1 semi-structured interviews; Thematic Analysis	- Caring for parents experiencing mental illness - Caring for parents experiencing physical ill health and/or disability (data not included within review) - Caring for siblings living with developmental disorders (data not included within review)
11. Nattala, Murthy, Weiss, Leung,	N = 15 Age range = 10-19 years Mean Age = 14 years	Fathers with alcohol dependence	Fathers met ICD-10 Criteria for alcohol dependence for at least three years (confirmed	Qualitative 1:1 semi-structured interviews; Analysed	- Explanations of fathers drinking (Perceived causes; Perceived ability of their father to control drinking; Perceived quality of

Christopher, (2022), India	Female = 10 Male = 5 Ethnicity = Not stated		through direct interview of father, or where not available, mother).	‘manually’ in order to identify themes	father’s behaviour and character if not drinking; Concept of an ideal father) - Experiences related to father’s drinking (Witnessing destructive behaviour; Physical abuse – experienced or witnessed; Neglect and deprivation) - Reactions to father’s drinking (Physiological symptoms; Imposed responsibilities; Impact upon school performance/learning; Social impact, emotional reactions and resilience; Efforts to curb father’s drinking; Dealing with father when he comes home drunk; Futility of help-seeking)
12. Nolte & Wren, 2016, UK	N= 15 (parents) Age range = 25-50 years Mean age = 39 years Female = 13 Male = 2 Ethnicity White British = 3 African Caribbean Asian = 1 Black African = 4	Schizophrenia (6), Bipolar disorder (3), Depression/post-natal depression with psychosis (3), substance-use induced psychosis (2), multiple personality disorder (1)	Diagnostic and clinical characteristics presented within study, but source of information not stated.	Individual interviews Interviews, transcription, and analysis carried out using Interpretative grounded theory	Results constructed as 4 social processes: - Protecting and being protected (Protecting their children; Being protected by their children) - Responding to children’s search for understanding (Seeing children as mature; Seeing children as knowledgeable about parent with mental health problem (PMHP) - Prioritising family life

	Mixed race (Caribbean & White) = 1 Kurdish = 1 Algerian = 1 Turkish = 1 Orthodox Jewish = 1				(Staying close and connected; Hoping for a secondary relationship with MHP) - Relating to others

Qualitative Research Appraisal

The scope, purpose, and aims of the research, were stated within all papers, focusing upon concepts of risk and resilience (Backer et al., 2017; Bosch et al., 2017; Boström & Strand, 2021; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Nolte & Wren, 2016; Nattala et al., 2022), or the rights of the child (Alexanderson & Näsman, 2017; McGibbon, Spratt, & Davidson 2019). Relevance and transferability were clearly demonstrated through contextualising findings within broader research and policy.

Eight papers provided clear rationale for qualitative design including the under-researched nature of the study population, and to understand 'lived experience' (Backer et al., 2017; Bosch et al., 2017; Boström & Strand, 2021; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Hagström & Forinder, 2019; Hill, 2015; McGaw & Reupert, 2022). Six papers stated utilising specific methods, for example IPA (Boström & Strand, 2021; McGaw & 2022), grounded theory (Nolte & Wren, 2016), narrative methodologies (Hagström & Furindor, 2019), or designs developed for use within certain age and social contexts (Backer et al., 2017; Hill, 2015).

All papers took a purposive strategy to recruitment, which is considered appropriate for recruiting 'hard to reach' populations (McGaw, 2022). Ten papers recruited through a single source, such as social services, 'young carer' support groups, or online support organisations, (Alexanderson & Näsman, 2017; Backer et al., 2017; Boström & Strand, 2021; Hagström & Furindor, 2019; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Hill, 2015; McGibbon, Spratt, & Davidson, 2019; Nolte & Wren, 2016; Nattala et al., 2022). Two studies used multiple recruitment sources, including internet forums, schools, and previous research samples (Bosch et al., 2017; McGaw & Reupert, 2022).

Processes for carrying out analyses were transparently reported in six papers, detailing specific rationale, steps of data analysis, involvement of multiple researchers to aid reliability, and consideration of issues such as saturation, member checking, and bracketing (Backer et al., 2017; Bosch et al., 2017; Gullbrå et al., 2016a; Gullbrå et al., 2016b; McGaw & Reupert, 2022, Nolte & Wren, 2016).

All papers clearly demonstrated transparency about how raw data led to interpretations and conclusions, using verbatim interview quotes. However, few papers mentioned using audit trails. Five papers lacked transparency about how the social, physical, and interpersonal contexts of data collection may have impacted final interpretations (Alexanderson & Näsman, 2017; McGaw et al., 2022; McGibbon et al., 2019; Nolte & Wren, 2016; Nattala et al., 2022). For example, McGaw et al., (2022) did not consider how data collection strategies (in-person, telephone, virtual) may have impacted data or interpretations.

One major finding is that transparency regarding the use of reflexivity was generally lacking. Eight papers (Alexanderson & Näsman, 2017; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Hagström & Forinder, 2019; Hill, 2015; McGibbon, Spratt, & Davidson, 2019; Nattala et al., 2022; Nolte & Wren, 2016) did not clearly report having carried out this practice. Four papers (Backer et al., 2017; Bosch et al., 2017; Boström & Strand; McGaw & Reupert, 2022) reported using reflexivity with some discussion about steps taken to reduce researcher bias. This is an important finding given the central role of reflexivity for enhancing trustworthiness.

Awareness of strengths and weaknesses with regards to transparency, transferability, and integrity, provided an initial impression of the reporting patterns between papers. This informed the interpretation of primary author data during the synthesis. Primary author awareness of social context is relevant for meta-ethnography, and integrated where appropriate, within the reciprocal synthesis. Papers were synthesised from newest to oldest – in acknowledgement that the first papers to be synthesised would have a greater influence upon the synthesis (Sattar et al., 2021) – as per the synthesis aims to provide update of recent meta-syntheses. The results of the appraisal provided further weight for this strategy as methodological strength generally improved over time.

Meta-synthesis

The synthesis involved using constant comparison to compare themes between different studies, which allowed the translation of one study into another, aided by translation tables and summaries (Appendix 1.6-1.8). The papers were deemed sufficiently alike to allow for reciprocal synthesis, leading to 7 third order constructs under two headings: *The process of meeting family needs in relation to fluctuating PMI;* and *processes that suggest young people seek to meet their own needs* (Appendix 1.9). Primary author quotes are presented in plain text, with participant quotes italicised. A lines-of-argument synthesis presents theory about the needs of young people living with PMI.

The process of meeting family needs in relation to fluctuating PMI

The young people's experiences, represented within three higher order subthemes, describe ways they met family needs as part of adapting to the fluctuation of PMI.

Relational silence

Half of the studies concluded that PMI was expressed within families both explicitly, and implicitly, but that the dominant process was to remain silent (McGaw & Reupert, 2022; Boström & Strand, 2021; Backer et al., 2017; Nolte & Wren, 2016; Hill, 2015). The aim in staying silent, driven by the parent, was to prevent exposure to PMI. For two papers (Nolte & Wren, 2016; Gullbrå et al., 2016b), this protective strategy related to the young age of the child, who was presumed to be "innocent" and less aware of PMI (Nolte & Wren, 2016): One example is Nolte & Wren (2016,p735):

> "There was a sense that, as "the cause" of the child's difficulties, they were in some way harmful or even "toxic" to the child, and "contaminated" as a parent…"

Some young people reported that parents only talked openly during acute crisis, and that they themselves also preferred to remain silent about PMI (McGaw & Reupert, 2022). Hill (2015) surmised that remaining silent about parental SUD's might function to express loyalty, but that young people appeared comfortable discussing PMI indirectly (drawing, third person vignette). Silence was also played out within the study context, where some researchers did not directly ask about PMI in respect of parent's wishes (Backer et al., 2017). Hill (2015) expressed the importance of clinicians considering communication preferences for exploring PMI.

Despite the aims of silence as a protective relational process, some studies concluded that this strategy negatively impacted the parent-child relationship by compromising young people's ability to express, and develop understanding, perpetuating distress and uncertainty associated with PMI (Boström & Strand, 2021; Backer et al., 2017; Nolte & Wren, 2016).

Fluctuations in the flow of care: trying to attune to the parent's needs

Four papers proposed a change in the assumed normative direction of care provided within the parent-child relationship, during which the child attempted to emotionally attune to their parent's needs rather than the reverse (McGaw & Reupert, 2022; Boström & Strand, 2021; Hagström & Furinder, 2019; McGibbon et al., 2019). Young people attempted to soothe their parent's distress (McGaw & Reupert, 2022; McGibbon et al., 2019), or control their drinking (Nattala eta al., 2022; H Hagström & Furinder, 2019). One paper conceptualised young people as "competent agents" (Hagström & Furinder, 2019), however they could become overwhelmed by emotional distress, feelings of incompetence, and the unpredictability of PMI, with parent-child relationships characterised by feelings of apathy, anger, worry, mistrust, and abandonment (Nattala et al., 2022; Hagström & Furinder, 2019). For example, Hagström & Furinder (2019,p12):

> "…she took it on herself to…'to make her well again' – at the same time she was filled with frustration and anger due to her position as an abandoned child. In retrospect, Julia

> expressed sadness that her childhood had been so limited and filled with concern for and control of her alcohol-dependent mother."

Boström & Strand (2021) argued that the child's focus upon their parents' emotions constituted parent-child emotional "enmeshment", whilst McGibbon et al, (2019) indicated they believed they had to be "strong" for their parents. Some participants believed that expressing need could cause distress (McGibbon et al., 2019; Bosch et al., 2017). For example, McGibbon et al, (2019,p1168):

> "…several young carers recalled how, when they tried to discuss issues…including family breakdown or the loss of a parent…care-recipients would often become tearful and feel unable to offer them reassurance or meet their emotional needs"

Considering these adaptations within the parent-child relationship, some papers conceptualised a "non-hierarchical" family structure, leading to "role-reversal" where the child attempted to perform the role of the parent (Boström & Strand, 2021; Hagström & Furinder, 2019; McGibbon et al., 2019). However, parent-child connections were also characterised by love and compassion (McGibbon et al., 2019; Nolte & Wren, 2016).

Protector: processes for protecting parents and self

Young people reported numerous emotional and behavioural responses. One response was to disconnect, by not needing care, defined as "acting in a mature way", "independence", "self-reliance", and "patterns of parentification" as a means of caring for parent's considered to be "vulnerable", and in need of "protecting" (McGaw & Reupert, 2022; Boström & Strand, 2021; Hagström & Furinder, 2019; McGibbon et al., 2019; Alexanderson & Näsman, 2017; Backer et al., 2017; Bosch et al., 2017). Disconnection was self-protective and sometimes associated with better mental health, especially where participants had relationships with other 'well' adults, peers, or positive leisure or school opportunities (Boström & Strand, 2021; Hagström & Furinder, 2019; Alexanderson & Näsman, 2017; Backer et al., 2017; Bosch et al., 2017).

Caregiving was described, including emotional caregiving; medication support; crisis support; hiding evidence of drinking; providing self-care; caring for siblings; daily chores; providing structure and routine (McGaw & Reupert, 2022; Boström & Strand, 2021; Hagström & Furinder, 2019; McGibbon et al.,2019; Alexanderson & Näsman, 2017; Bosch et al., 2017; Gullbrå et al., 2016a; Nolte & Wren, 2016). Hagström & Furinder, (2019,p14) provide an example of safeguarding:

> *'I figured that if I whistled in her ear, she'd wake up. That way I could check that she was alive…If she didn't wake up, I laid her down and put lots of pillows on top. I laid close and then I fell asleep.'*

Five papers reported mental, physical, and academic problems, and emotions including worry, frustration, shame, guilt, sadness, and feelings of "obligation" (Nattala et al., 2022; McGibbon et al., 2019; Backer et al., 2017; Bosch et al., 2017; Gullbrå et al., 2016a). PMI was unpredictable, and perpetuated anxiety (Nattala et al., 2022; McGibbon et al., 2019; Alexanderson & Näsman, 2017; Gullbrå et al., 2016a), with one participant comparing it to being on a *'rollercoaster'* (McGibbon et al., 2019), leading to ambivalence (Gullbrå et al., 2016a,p363):

> *"…when I enter a room…many questions coming to my mind: How should I behave right now? How is Mum? How is Dad? Is the atmosphere good or bad? What can I say, what can I not say? I always have this sensation – it is really stressful."*

Processes that suggest young people seek to meet their own needs

Young people sought to meet their own needs within the context of PMI, represented within four higher order subthemes.

Struggling to make sense alone

At times understanding about PMI was multifactorial (influence of others, genetics, childhood trauma) (Nattala et al., 2022; McGibbon et al., 2019). However, seven papers concluded that building understanding alone contributed to inaccuracies, emotional difficulties, and perpetuated worry for parents (Nattala et al., 2022; Boström & Strand, 2021; Hagström & Furinder, 2019; McGibbon et al., 2019; Backer et al., 2017; Gullbrå et al., 2016b; Nolte & Wren, 2016).

Narratives constructed by young people were often unclear, partial, and constructed through observation rather than discussion (Boström & Strand, 2021; Backer et al., 2017). Boström & Strand's (2021) authors found young people intertwined their parent with their illness, leading to fragmented understanding: *'[she's] funny, she can have funny ideas/…/in periods she goes for a lot of walks."* (p71), and young people sometimes blamed their parents for being unwell (Nattala et al., 2022). In contrast, Hagström and Furinder (2019) conceptualised parents as having "two faces" facilitating love, and the expectation of affection, from the sober parent, whilst looking for signs of the parent becoming the 'drunk parent'.

Two papers concluded that inaccurate narratives were perpetuated by the parent's ambivalence about discussing PMI, although they were open to other trusted adults helping (Boström & Strand, 2021; Gullbrå et al., 2016b). Age was also identified as a factor leading to inaccurate narratives, characterised by self-blame:

> "Younger children attributed much of their parent's mood and behaviour to themselves, for example because they had been naughty..." (Backer et al., 2017,p217)

Fragile normality

Seven papers concluded that PMI had become part of families' 'normal', which felt de-stigmatising and provided a protective sense of continuity for identity and relationships

(McGaw & Reupert, 2022; Boström & Strand, 2021; McGibbon et al., 2019; Backer et al., 2017; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Nolte & Wren, 2016b). Three papers described 'normality' as the enactment of everyday activity, including eating dinner, receiving pocket money, and sibling rivalry (McGaw & Reupert, 2022; McGibbon et al., 2019; Backer et al., 2017). However, underlying this was a sense of emotional disconnection between family members: '*Someone would cook dinner and then we'd have that and he, then we'd just all go to our rooms…'* (McGaw & Reupert, 2022,p27). Whilst young people described 'normality' as conditional upon parental wellness (McGaw & Reupert, 2022; McGibbon et al.,2019; Gullbrå et al., 2016a), some parents believed that 'normality' continued regardless (Gullbrå et al., 2016b; Nolte & Wren, 2016).

Ensuring normality, despite the fluctuating nature of PMI, came at a price for young people. Two papers described feelings of stress and mistrust, and a constant "balancing act", in response to fluctuating PMI (McGaw & Reupert, 2022; Gullbrå et al., 2016a). Whilst normality was protective, it could prevent open communication, as families minimised (Boström & Strand, 2021), or avoided discussing PMI whilst well, for fear of destabilising their fragile sense of normality (Nolte & Wren, 2016).

Normality was also associated with the enduring love between family members, which reinforced their commitment to sustaining normality and family survival despite PMI (McGaw & Reupert, 2022; Boström & Strand, 2021; Backer et al., 2017; McGibbon et al., 2017; Alexanderson & Näsman, 2017). During 'well' periods family relationships functioned well for all family members (McGaw & Reupert, 2022; Boström & Strand, 2021; Backer et al., 2017) as illustrated in Alexanderson & Näsman (2017,p37):

> "…It is clear from the interviews that in the middle of the misery there may also be bright spots…children, although not all, clearly stated that they love their parents in spite of the addiction problems."

Accessing support

Young people often felt ignored by those from whom they sought support (Nattala et al., 2022; Hagström & Furinder, 2019; McGibbon et al., 2019; Alexanderson & Näsman, 2017; Backer et al., 2017; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Nolte & Wren, 2016; Hill, 2015). Support was sometimes unhelpful, and at times helpers perpetuated, or caused harm, by not intervening, which minimised experiences and reinforced silence (Nattala et al., 2022; Hagström & Furinder, 2019; Alexanderson & Näsman, 2017; Gullbrå et al., 2016a). Whilst a 'well' parent could act as a buffer for PMI (Alexanderson & Näsman, 2017; Backer et al., 2017), Alexanderson & Näsman (2017) concluded that the 'well' parent could be compromised by their own PMI, or experiences of abuse.

"Disclosure stigma" (Hagström & Furinder, 2019) drove shame and silence, to prevent the experience of 'othering', losing friendships, and opportunities (Nattala et al., 2022; Hagström & Furinder, 2019). Younger children - being more dependent upon adults for protection - were more likely to disclose, than older children who would physically distance themselves from the 'ill' parent (Hagström & Furinder, 2019; Alexanderson & Näsman, 2017; Backer et al., 2017).

Formal services including GP's, support groups, and informal supports including family or friends, had been beneficial in providing understanding about emotional support for young people (Alexanderson & Näsman, 2017; Backer et al., 2017; Gullbrå et al., 2016a; Gullbrå et al., 2016b; Nolte & Wren, 2016; Hill, 2015). Hill's (2015) participants believed intervention was only for parents, however the authors concluded the context of data collection – young person support group – may have led to the assumption that the benefit of support for them was implied. Most participants wished for formal support to take a whole-family approach, in a flexible and personalised manner, in response to fluctuating PMI (Gullbrå et al., 2016a; Gullbrå et al., 2016b; Nolte & Wren, 2016; Hill, 2015). Hill, (2015,p348) illustrated fluctuating need:

> *'I used to live with my mum, but she got a bit ill so we moved into Gran's house. Then she got better (sighs), so we moved back down, and then she got a bit ill again, and then she got better…'*

Surviving

Hagström & Furinder reported abuse and neglect with caution, to avoiding further stigmatising a highly stigmatised population. Within the current review it is noted that these experiences were reported in only four papers, and within these papers not all participant's reported abuse (Nattala et al., 2022; Hagström & Furinder, 2019; McGibbon et al., 2019; Alexanderson & Näsman, 2017). However, some young people did experience physical, sexual, and emotional abuse, and neglect (Nattala et al., 2022; Hagström & Furinder, 2019; McGibbon et al., 2019; Alexanderson & Näsman, 2017). Nattala et al. (2022) reported based gender-based violence (P289).

Young people reported complex emotions including loneliness, self-blame, shame, fear, and relational mistrust. One young person stated: *'... he doesn't hit us anymore, but he'd be more verbally abusive and emotionally abusive which is probably the most difficult to deal with ... he'd call me worthless and just a waste of space and like, a fat slob …It really upsets me…'.* (McGibbon et al., 2019, P1171). Hagström & Furinder (2019) found confusion due to "…uncertainty over the roles the parent and child might play in the family dynamic; for example, depending on whether the parent is drunk or sober, angry or happy, passive or violent" (p11). In response, young people developed awareness of early warning signs and responded by protecting themselves and others, for example by shielding and comforting them, or dissociating their 'parent' from the 'abuser' (Nattala et al., 2022; Hagström & Furinder, 2019). Disclosing abuse could lead to retaliatory abuse, reinforcing silence (Alexanderson & Näsman, 2017).

Line-of-argument synthesis

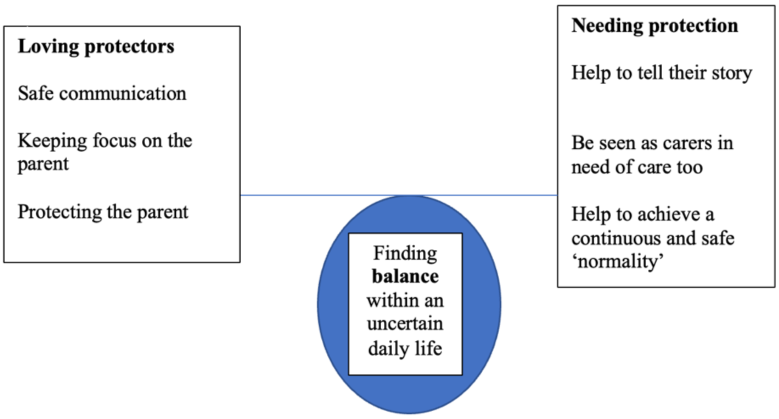
The interrelationship between processes for meeting they, and their family's needs, implied a dialectic positioning young people are protectors, who at times also need protection. This interrelationship is underpinned by a constant search for balance, due to fluctuating PMI (Figure 2).

Communication about PMI was often steeped in fear, with families expressing preference for silence, as a protective measure. Parents' feared knowledge about PMI could cause harm to their child. However, this created an empty communicative space between parent and child, inhabited by PMI. Despite silence, young people continuously built meaning, but doing so alone led to misunderstanding and misplaced blame, that reinforced worry, mistrust, and uncertainty. Young people and their families require support to tell their story, and label experiences and emotions, in a way which feels helpful, rather than harmful.

At times, young people's attempts to attune to parents' emotional needs – 'role reversal' – led to increased stress within a context where they felt unable to have their needs reciprocally met. In other cases, focusing upon parents needs could lead to emotional "enmeshment". At times feeling unsupported by others left them feeling alone. Therefore, they need to feel 'seen' within their situation, both as "capable agents", but also as individuals with needs. Supporters must be aware that stigma and shame may prevent overt help-seeking.

Young people played the role of self-reliant "protector" of their family, by caregiving, identified by some authors as "parentification". In many cases caregiving was driven by bonds of reciprocal love, but at times it became burdensome. Building a sense of 'normality' was protective for well-being, but difficult to maintain as PMI fluctuated. As such, families require support to build and sustain normality and relationships. Part of support may mean facilitating distance from "caring" roles whilst supporting appropriate levels of ownership. In extreme cases, they require safeguarding to survive and thrive, to protect against abuse and neglect. The needs must be met in a way which does not cause further stigma or trauma to families.

Figure 2 Illustration of line-of-argument synthesis



Discussion

The synthesis findings were summarised within seven higher order constructs, sitting under two headings, leading to theory relating to children with PMI meeting their own, and their families' needs within a fluctuating living context.

The findings, including both parent and child views, gives insight into the complexity of communicating about PMI. Fear and loyalty perpetuated silence, leaving the child to make sense of PMI alone. This aligns with previous findings indicating children develop a sense of what is permitted to be discussed about PMI with parents (Van Parys & Rober, 2013). Grove, Riebschleger, Bosch, Cavanaugh, & Van der Ende (2017) promote the importance of services for supporting family understanding of PMI in a way which reduces inaccuracies, shame, and uncertainty, which can otherwise reinforce worry and self-blame. Attachment theory conceptualises the role of primary caregivers in the development of children's "internal working models" of self, and others, allowing children to develop coherent narratives about events and relationships in their lives (Oppenheim, 2006). Within the current findings, constructing narratives alone left young people vulnerable to confusion, and misattribution of blame to themselves or their parents.

Young people tried to attune to their parent's emotional needs, without expecting it to be reciprocated, and they feared that expressing needs could cause parents distress (Boström & Strand, 2021; McGibbon et al., 2019). Conceptualized as 'role-reversal' this led to the subjugation of their own emotional needs within the parent-child relationship (Byng-Hall, 2008). A related process within the current review was 'emotional enmeshment', where generational boundaries blur and emotions between child and parent merge. This may impact the development of self-identity, separate from the parent (Byng-Hall, 2008), and is a process sometimes associated with parents with childhood trauma histories (Krieg, 2005), such as within the current review.

The current findings suggest young people continue to have difficulty accessing help, and at times the response of others felt minimising, or enabling of harmful family contexts. The findings also emphasise the reinforcement of shame and secrecy by experiences of "disclosure stigma". Dobener, Fahrer, Purtscheller, Bauer, Paul and Christiansen (2022) found stigma-by-association to be a mechanism of intergenerational transmission of mental illness and argued for the importance of anti-stigma campaigns. Whilst campaigns are undoubtedly important, current findings emphasise the role of shame within the reinforcement of, and not only the product of, internalised stigma. Therefore, intervention must also target the experience of shame within families, which can confer barrier for service engagement.

The current findings replicated previous findings regarding the varied tasks that young people living with PMI undertake, evoking a sense of children as protectors (Yamamoto & Keogh, 2018; Dam & Hall, 2016), who may present as self-sufficient. Broszormenyi-Nagy and Spark (1983) described the family systems concept "parentification", involving children taking on 'adult' roles within the family. However, George & Solomon (2011) propose that "parentification" is one process through which the intergenerational impact of trauma occurs, where a parent's sense of vulnerability leads to role inversion. Kerig (2005) cautions against the assumption that even well-functioning, competent, young people will not be subject to 'sleeper' effects, with longitudinal data suggesting risk of later physical and mental health issues (Rudd, Doan, & Yates, 2021; Schier, Herke, Nickel, Egle, & Hardt, 2015). This would support our conclusions that young people are both vulnerable, and competent, and require support towards positive outcomes.

Lastly, the drive for ‘normality’ was a clear theme, with children and parents maintaining daily balance to ensure the continuity of normal family life, during which they were happy and well-functioning. The consistency and structure associated with ‘normality’ was a protective factor, in counterbalance to PMI which felt unpredictable, as reported elsewhere (Power et al., 2016), however in the current study emotional disconnection sometimes underlay apparently well-functioning family life.

Strengths and Limitations

A strength of the current metasynthesis is its highly systematic process, which resulted in up-to-date theory about children living with PMI. This process allowed for a high degree of representation of the findings from included papers within the final third order constructs, enhancing trustworthiness (Dam & Hall, 2016). Another strength is the inclusion of papers focused upon children of parents with SUDs, a marginalised subpopulation of PMI, and a context which is increasingly reported (NSPCC, 2020).

On limitation is that despite planning to include clinician perspectives, none fulfilled the inclusion criteria regarding sufficient focus upon young peoples’ experiences, instead focusing upon own experiences and practise. Therefore, it is unclear how current views, particularly those about lack of support, would compare with those who provide support. Secondly, papers were not excluded based upon appraisal rating and were not synthesised strictly in order of strongest to weakest, possibly leading to methodologically less transparent papers having a greater influence upon the findings. There are several ways to synthesise papers, each with their own merits and drawbacks, with the use of appraisal within qualitative syntheses under continued debate (Sattar et al., 2021). Demographic related weakness includes the wide age range of children (4-25 years), and only one non-Western paper. This could limit the transferability of the synthesis findings. Lastly, the review was not pre-registered prior to data extraction, however the approved protocol is available on OSF.

Methodological limitations were identified within the studies themselves, which is important given the poor reporting standards regarding use of reflexivity. Studies were often unclear with regards to the demographic and clinical characteristics of their participants. For example, ethnicity often wasn't stated, meaning it is unclear how representative the data is of different ethnic groups. However, young carers are more likely come from ethnic minority groups, and families from these communities are at higher risk of mental ill-health (The Children's Society, 2013; Independent Mental Health Task Force, 2016). Additionally, the assessment of PMI was often based upon non-standardised measures, meaning that the comparability of PMI between papers is unknown. Overall, the quality appraisal highlighted that methodological transparency in one area appeared to lead to limitations elsewhere. For example, whilst Hill's (2015) design was highly transparent, they lacked clarity regarding the synthesis of their diverse data. However, their transparency regarding the impact of social context upon their data informed the reciprocal synthesis theme 'Relational Silence'. Together, these limitations may impact the trustworthiness and transferability of the findings, and subsequently the current synthesis.

Clinical & Policy Implications

Services must consider ways of supporting young people in maintaining healthy attachments with their parents, where safeguarding is not indicated. Policy drivers at national and local levels are renewing focus upon early intervention, namely through infant mental health teams (Scottish Government, 2020). The underlying assumption is that supporting the development of secure early parent-child attachment during the formative years provides long-term protection. The current findings suggest that intervention may be required intermittently across childhood, to support attachment in line with fluctuating PMI.

Findings from the current review contrast with a previous review in that hospitalisation was not a significant part of children's experience of PMI (Yamamoto & Keogh, 2018). This may reflect a general shift within society away from hospitalisation for acute mental health crisis, towards community care. Khalifeh et al., (2009) have suggested this shift may lead to greater exposure of young people to the more acute and distressing aspects of PMI, such as self-harm and suicidal behaviour. Current findings suggest children continue to require more significant consideration within parent's care-at-home plans.

Lastly, young people and their families need support to build 'normality' whilst ensuring young caregiving tasks are developmentally appropriate. Aldridge (2018) argues that supporting young carers *in* their role as caregiver should not supersede the commitment of services to adequately support parents, to prevent children having to provide significant levels of care in the first place. In this sense, any such support would be best delivered in a way which is flexible and responsive to parent need, rather than considering child need as caregiver.

Conclusions

This metasynthesis explored the experiences of young people living with PMI, leading to theory about current need. Findings highlighted that young people living with PMI require support to understand PMI and that their own care needs require recognition. They need support to maintain a sense of 'normality', but at times require protection from harm. The needs of young people living with PMI may be addressed using a whole-family and individualised approach which supports young people both as children and where they wish, as carers, using responsive and flexible service design in acknowledgement of the fluctuation of PMI.

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Chapter 2

'Yeah trying to catch where his mind's at sometimes is hard...': The experiences of young people living with a parent with a mental health condition during the COVID-19 pandemic.

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Abstract

Background: Children and young people living within the context of parental mental illness (PMI) often help to care for their parent during periods of illness and are at increased risk of poor developmental outcomes. The current study explored the experiences of young people living with PMI during the COVID-19 pandemic.

Method: Four young people participated in semi-structured interviews, with the data analysed using Interpretative Phenomenological Analysis.

Results: The first superordinate theme reflected participants' experiences of PMI, their own mental health, and the impact of COVID-19 upon receiving help. The second reflected participants' caregiving and emotional responses, and how the pandemic limited access to previously helpful strategies. The third reflected participants' accounts about uncertainty relating to PMI, family roles, and relationships, drawing parallels with COVID-19.

Conclusion: Findings emphasised the complex and varied experiences with regards to how PMI impacts emotions, identity, and relationships. The findings highlight the need for further recognition of the needs of this population, within broader research, clinical, and policy contexts, to support positive family coping.

Keywords: parental mental illness, young carers, interpretative phenomenological analysis

Plain Language Summary

Background: Children living with parents who experience mental illness (PMI) often try to care for their parent when they are struggling, but are themselves at risk of difficulties in their identity, relationships, and mental health. Young carers have seen more of their parents' illness during COVID-19 due to being at home more but have had less access to the things that support them (Blake-Holmes & McGowan, 2020). It is unclear how children living with PMI specifically, experienced the COVID-19 pandemic. It is important we continue to develop our understanding of this group of young people so that we can provide appropriate help.

Aims: The current study wanted to learn about how young people make sense of living with a parent with a mental health difficulty, during the COVID-19 pandemic.

Method: Four young people, aged 16-18 years, took part in the study. Participants provided informed consent. Each interview was audio-recorded and typed, exactly as spoken. The interviews were analysed using a method called Interpretative Phenomenological Analysis (IPA). IPA focuses upon individuals' experiences and how they make sense of their experiences. Therefore, participants' own language and personal meanings are of importance.

Findings: Three main themes were created from the transcribed data. The first one was titled *'... if you're already like this [shows angled hand] a winds gonna knock you further*', which is about parent and participant mental health during COVID-19. The second was titled; *'…trying to catch where his mind's at sometimes is hard...yea'* which relates to participant caregiving and emotional responses to PMI, and how COVID-19 has limited access to previous supports. The third is titled *'[] having to like shut the curtains [] we realised that that sorta helped my mum [] every single night the fire was on',* which relates to participant experiences of uncertainty, how this felt similar to uncertainty related to COVID-19, and adapting to PMI despite this.

Conclusion: Participants talked about the difficulties they had faced in living with PMI during the pandemic. Whilst they wished to care for their parent, out of feelings of mutual love, caring could take its toll upon their mental health, particularly where they felt that their needs were not met in return. The themes developed highlighted these difficulties, and it is hoped they will direct us regarding the support needs of these young people and their families, to prevent caring from becoming too much for the young person.

Reference: Blake-Holmes, K., & McGowan, A. (2020) 'It's making his bad days into my bad days': The impact of coronavirus social distancing measures on young carers and young adult carers in the United Kingdom, *Child and Family Social Work,* 27, p22-29, doi: 10.1111/cfs.12877

Introduction

Approximately 68% of women and 57% of men with mental health conditions are also parents (The Royal College of Psychiatrists, 2016), with recent estimations suggesting one in four UK children (0-16 years) have experienced parental mental illness (PMI) (Abel et al., 2019). Certain demographic groups experience a higher proportion of mental illness, including people from ethnic minority backgrounds, those with disabilities, carers, and those who experience socio-economic disadvantage (Mental Health: Population Factors, 2019). Whilst mental illness may include anxiety, depression, personality disorder, and psychosis, users of mental health services also include those impacted by emotional distress or environment-related stress such as trauma, unemployment, or poverty. Poor resourcing, and training prevents UK services from adopting a consistent, whole-family approach for identifying and supporting children living with PMI, despite being identified as an 'at-risk' population (Foster et al., 2012; Brockington et al., 2011). These difficulties have likely been further complicated by the COVID-19 pandemic.

The long-term sequelae of Adverse Childhood Experiences (ACE's), of which PMI is one, predicts a dose-response relationship for negative social, economic, psychological, and physical outcomes, making ACE's a central focus for UK health and social policy (Children's Commissioner, 2019). Risk relating to PMI may include exposure to symptoms including parental distress, unpredictability, unusual behaviour, or due to the impact of PMI upon the parent's ability to provide consistent boundaries, supervision, and emotionally responsive parenting (Brockington et al., 2011). PMI is one risk factor for the intergenerational transmission of mental illness, with between 16%-79% of children treated through UK Child and Adolescent Mental Health Services (CAMHS) having a parent with PMI, (Campbell et al., 2020). Poor child outcomes include socioemotional and cognitive problems, obesity, and drug misuse, however the relationship with PMI is unclear, as it is known that PMI may co-occur with other known risk factors such as family dysfunction, deprivation, domestic violence, and parental alcohol misuse (Adjei et al., 2021).

When parents struggle with PMI, young people may take on caring roles for their parents or siblings. This role can become harmful where the child's own psychological and developmental needs are not adequately met (Stein et al., 2014), a process sometimes referred to as parentification (Hooper, L'Abate, Sweeney, Gianesini, & Jankowski, 2014). Young carers as a population are acknowledged to be subject to social, economic, educational, and health inequalities, stigma relating to their association with someone with mental illness (Aldridge, 2018). It is important to continue developing the evidence base regarding the lived experiences of children living with PMI.

National strategies for containing the transmission of COVID-19 posed further challenges for young people with regards to these inequalities. Social distancing and self-isolation lead to loneliness and isolation, reduction in social support and daily structure for vulnerable populations of young people, including young carers (Crawley et al., 2020). Although the UK is now considered to be in a transitionary phase, post-lockdown there continues to be significant adjustments to services that it is acknowledged will continue to disproportionately effect those experiencing social and health inequalities (Scottish Government, 2020). Within the current context young people living with PMI have been living with greater exposure to the more serious parts of their parent's illness, but without the previous protections afforded by attendance at school (Blake-Holmes & McGowan, 2020). Therefore, young people living with PMI may be uniquely impacted in a way that has not yet been reflected within policy, research, and clinical contexts. The current study sought to explore how young people make sense of living with PMI during the COVID-19 pandemic.

Design, Method, & Analysis

Ethical Approval

Ethical approval was provided by the West of Scotland Research Ethics Committee (21/WS/0016), (Appendix 2.1) and managerial approval by NHS Lanarkshire Research and Development team (L19045, Appendix 2.2).

Design

The current study utilised Interpretive Phenomenological Analysis (IPA) to explore the experiences and sense making of participants. Husserl's philosophy, upon which IPA is based, conceptualises humans as active, sense-making beings, who construct and attach meaning and significance to people and events as they generate their unique understanding of the world (Smith, Flowers, & Larkin, 2009). IPA is inductive and ideographic (Smith et al., 2009), making it suited to investigating the lived experience of young people living with PMI, with 1:1 semi-structured interviews undertaken to generate data which had the required depth and richness. Data was collected used video-conferencing technology, in line with health care delivery during the COVID-19 pandemic.

Sampling and Recruitment

Participants were recruited between March-August 2021 from a Tier 3 NHS service that provides support for children with moderate to severe mental health difficulties, where PMI is thought to contribute to their difficulties. This sampling strategy was chosen to allow exploration of the accounts of young people living with PMI who also have their own mental health issues, where previous qualitative research predominantly recruits form young carer organisations. The current sample is therefore not intended to be considered representative of all young people living with PMI. The study aimed to recruit a homogenous sample of participants aged 12-18, who were living with PMI during the COVID-19 pandemic. Those considered to be too mentally unwell, based upon the clinical opinion of their keyworker, were not considered for participation. The main researcher liaised with CAMHS clinicians and attended team meetings to provide information about the study.

Potential participants were identified and approached by their CAMHS case clinicians, who provided them with study information. Consenting young people were contacted by the main researcher and sent a participant information sheet (PIS) (Appendix 2.3), consent form (Appendix 2.4), and a link for a remote information session via the NHS remote videoconferencing platform, ‘Attend Anywhere’. Participants were given at least 24 hours to consider participation, before the main researcher made contact to schedule interviews. The main researcher had no previous relationship with participants.

Four young people aged 16-18 years (3 she/her, 1 they/them) agreed to participate in the study, (table 3). Preferred pronouns are used throughout the study, with pseudonyms used to protect anonymity. Two additional participants noted interest in participation however one was deemed too unwell, and the other did not provide consent prior to the end of study.

Table 3 Table of participant demographics

Participant Pseudonym	Age	PMI (Based on participant self-report)
Lisa	18	Bipolar disorder
Alex	17	Borderline personality disorder, 'trauma',
Gem	16	Generalized Anxiety disorder, Borderline Personality disorder, Obsessive Compulsive disorder, Seasonal Affective disorder
Emily	18	Borderline personality disorder, 'trauma'

Interview Procedure

Informed Consent

Participants provided informed consent – written or audio recorded - prior to participation. Parental consent was not required due to participant ages. To support informed consent, PIS were provided prior to participation, detailing the aims of the study, procedures, information about consent, confidentiality (and its limits), anonymity, and the right to withdraw consent. Participants were informed that consent related to participation, and the use of anonymised quotations for the purposes of dissemination. The PIS were discussed during the online information session, also attended by the participant's CAMHS clinician, according to preference (three participants).

Topic Guide

A topic guide (Appendix 2.5) was developed by the main researcher following IPA guidance (Smith et al., 2009), which probed areas of significance as highlighted by the relevant literature. The interview questions were refined through discussion with the main supervisor, field supervisor, and local clinicians, who between them had expertise in both IPA and working with young people living with PMI.

Interview Protocol

Interviews took place remotely, at a time and location of the participant's choosing, on the condition that locations were quiet and private. Interviews were conducted via 'Attend Anywhere' remote platform. The topic guide was used flexibly to ensure the participant's discussion dictated direction. Interviews lasted between 56-90 minutes. Participants were instructed on the steps to take in the event of poor internet connection. After interviews participants were taken through a debriefing sheet, during which they were given the opportunity to reflect upon areas of interest or emotional difficulty. The main researcher offered to contact their clinician for additional support. No participants requested this support.

Data Analysis

The data were analysed using an IPA framework (Smith et al., 2009). Initially, each interview was treated as a single case. Firstly, the interview was transcribed verbatim, with the transcript read repeatedly to allow immersion within the participant's data. Transcripts were considered alongside reflective comments made by the researcher during the interviews. The next stage involved making initial comments in the transcript margin, relating to linguistic, descriptive, and conceptual characteristics (Appendix 2.6). Based upon these comments, initial themes were constructed, with effort taken to ensure they reflected participant experiences and meanings. Themes were clustered to produce superordinate themes representing the significant aspects of their account. Throughout this process, superordinate themes were considered alongside the transcript, codes, and subthemes, to ensure adherence to idiography. The researcher engaged in 'bracketing' throughout, to manage the influence of researcher bias upon the analysis (Fischer, 2009), and shared excerpts of coding, theme, and superordinate theme generation with the research supervisor, to ensure fidelity to the IPA process. An individual case summary was then written and reviewed with the research supervisor. Case-by case analysis was repeated for all participants.

The final analysis involved looking for patterns across the whole sample. Whilst this stage required a greater emphasis upon researcher interpretation, close attention remained upon the idiographic case summaries, as per the hermeneutic cycle. Themes were generated across participants, which after clustering, allowed the generation of superordinate themes, illustrated within a thematic map (Appendix 2.7). The researcher was iterative in their approach, continuously reflecting upon the entire data set, codes, themes, and case studies, as part of the generation of the map, which was discussed with the research supervisor and refined until no further superordinate themes were generated. Superordinate themes and subthemes were listed in evidence tables with transcript evidence (Appendix 2.8) and shared with the research supervisor.

Reflexivity

Within IPA, researchers use reflexivity and bracketing to bring into awareness the impact of their cultural, social, and personal assumptions upon their interpretation of participant accounts (Clancy, 2013). To regulate the impact of my unconscious biases during interpretation, and to support validity, I carried out bracketing, and kept a reflective diary, to maintain a reflexive stance.

I am a white Scottish, middle class, female clinical psychology trainee, with prior research and professional experience involving the study population, having previously worked in a young carer's organisation. I found the deep level of interpretation involved in case-by case analysis provided opportunity for me to consider, and bracket, similarities and difference between my own childhood experiences, and the participants. As a child of a parent with acquired brain injury, I resonated with Lisa's experience of trying to '*catch'* her dad's *'mind'*, and her willingness to do this to ensure the continuity of their bond. Gem's whole-family approach to supporting her mother resonated with my own experiences. Lastly, I recognised the uncertainty and loss caused by self-isolation, stay-at-home orders, and the virus itself.

Results

Experiences of PMI were intertwined with those of COVID-19, and some participants drew parallels between the two. Three superordinate themes were developed based upon eight subthemes. Superordinate themes were: *'... if you're already like this [shows angled hand] a winds gonna knock you further*', *'...trying to catch where his mind's at sometimes is hard...yea',* and *'[] having to like shut the curtains [] we realised that that sorta helped my mum [] every single night the fire was on'*. Themes are discussed below, supported by transcript quotes ('L' refers to line number within participant transcripts). Emphasised words within quotes are bold, pauses are indicated using ellipses, and square brackets indicate omitted material. Pseudonyms are used to protect anonymity.

1 *‘… if you’re already like this [shows angled hand] a winds gonna knock you further’ (Gem, L847-849)*

Participants accounts highlighted how they attached meanings to their experiences of PMI. They understood PMI in terms of the vulnerabilities they observed and were vocal about how COVID-19 had compounded their families’ difficulties. This theme also incorporated participants’ own mental health experiences. Three subthemes were identified: *‘[] some people doze off and stuff but it’s different with my mum…so weird to explain []’, ‘...I feel like we [family] all felt like, a bit lost without the usual things that we rely on.’* and *‘[] I don’t mind listening…I just don’t like talking about my own things’.*

1.1 ‘[] people doze off and stuff but it’s different with my mum…so weird to explain []’ (Gem, L618-619)

Participant experiences of PMI were characterised by periodic loss of their parent through withdrawal. Alex described their mother’s withdrawal:

> *She [mother] gets like confined to the house uhm…and-or unless we’re with her, and like she hates- any time we go to even just [the shops] up the road like uhm she hates it and when she comes back she’ll sleep for a bit [] she’s drained []’* (Alex, L607-608)

Alex’s use of *‘confined’* suggests PMI traps their mother, with *‘drained’* expressing the cost of freedom. Periodic loss of their mother is magnified by their perceived failure to help, stating they feel *‘[] bad because [] I couldn’t really do anything…’* (Alex L238-244). For Alex and Emily, her mother’s withdrawal is associated with the impact of childhood trauma. Stating that *‘[] it all kinda stems from there []’* (Alex, L220), and *‘[]*

it was something that kind of…you know, ruin their lives, or make it difficult for them' (Emily, L75-79), the past impacts the present, keeping their parents, and by extension them, confined. Gem experiences withdrawal whilst she and her mother watch TV:

> *'[] you'll just be like 'oh mum did you like, see that' and she'll go 'oh sorry, am not really watching it'…and you're kinda like [in high pitched voice] 'ok so what are you doing then, because you were looking at it!'[] people doze off and stuff but it's different…so weird to explain []'* (Gem, L617-619)

Gem panics when her mother disconnects from their shared activity. Her psychological absence, despite physical presence, feels confusing, illustrated by Gem's search for understanding and heightened pitch in her voice.

Another broad experience of PMI related to the unpredictable fluctuation of PMI, described by Emily as *'ups and down days'* (Emily, L184). Lisa's experience of fluctuation relates to her father's bipolar disorder symptoms, characterised by highs and lows in mood, and energy:

> *'[] we'd [Lisa and father] start loads of different things [] [pace quicker] we'll paint, we'll paint the fence, we'll do this, we'll draw, we'll cook this we'll, and it's loads of these different things all the time but...you never fully finish them [] it's quite...quick sometimes [] quite snappy, and then the next day it's like no I'm not doin that...like opposites, polar opposites yea.'* (Lisa, L325-331)

Lisa's expressed, through quickened pace, the feeling of being uncontrollably swept up by her father's activity. The constant activity change, followed by withdrawal, feels jarring. Emily experiences her mother's moods as unpredictable:

> *'[] sometimes when she [mother] does kind of…what's the word, when she like…snaps, I guess I could say it's like ehm [] I do get that kind of, kind of scared feeling of, the argument* ***is*** *gonna happen []'* (Emily, L197-199)

Emily expresses fear when her mother *'snaps',* communicating powerlessness and anticipatory anxiety. The most extreme manifestation of unpredictable fluctuation related to parental self-harm. Alex now mistrusts periods of stability, driving them to remain close, to keep their mother safe:

> *'[] I'd feel really bad [] .in times before when she's self-harmed uhm [quieter: attempted suicide], and I've been the one to find her been the one to help her. So like, if I'm not here, I feel like, even if she's fine, something'll change []'* (Alex, L572-576)

To varying degrees, participants understand their parents separately from PMI. This protects Lisa's relationship with her father, preventing feelings of rejection, stating (Lisa, L492-494): *'[] we're doing something and he [father] gives up or whatever and I just think [] it's not me that he's taking the frustration out of and it's not what we're doing, its- its his Bipolar that's like taken that away from you []'.* However, whilst Alex understands PMI drives withdrawal, they also express blame towards their mother, stating: '*...I think she just couldn't be bothered going up to bed []'* (Alex, L229-232).

1.2 '...I feel like we all felt like, a bit lost without the usual things that we rely on.' (Lisa, L148)

Participant's felt that mental illness constituted an additional vulnerability during COVID-19, which was broadly associated with loss.

Emily vividly described her mother's deteriorating mental health during the pandemic, using scale to juxtapose COVID-19 as *'this big thing'* causing her world to become *'small'* (Emily, L343-345), as her thoughts became consumed by COVID-19:

> *'…she's [mother] just constantly just in a state of mind of… just constantly thinking about it so she was in kind of like bed more so it was almost like she would just think like a…a small area…of just like worry'* (Emily, L347-349)

Lisa attributed her father's withdrawal during lockdown to loss of motivation, leading him to disconnect from his club:

> *'in real life] you can't just pretend they're not there or ignore them or just shut off, but when you're at home online you can just turn the computer off and that's it, it's gone, it's dealt with.' (Lisa, L292-299)*

Lisa's statement, *'…that's it, it's gone, it's dealt with'* feels abrupt, expressing frustration at her father's inability to adapt. Lisa expressed sadness, stating (L419-421): *'[] I feel bad for my dad sometimes because if he wants to do this extravagant thing one day and he can't []'*. Alex did not express clear COVID-19 impact, stating (L605): '*my mum...never left the house before unless she had like appointments*'. Their family clearly experienced significant multi-generational physical and mental health issues, possibly leading them to play a larger part in Alex's sense-making than the pandemic.

The participants also described COVID-19 in terms of loss for themselves. The parts of life that that were a source of protection had reduced, whilst the stressful parts had increased. They described loss in temporal terms, by comparison pre-COVID life versus now, including a loss of face-to-face socialising, attending school, and hobbies. Emily had previously used time with friends to escape conflict with her mother (L270-274). School was not central to participants' reflections, but most indicated that online schooling had led to burnout (L380-384). Emily described her experience of stay-at-home orders:

> *'[] it's just hard, to find something to like, watch, or play, that'll take my mind off of like covid or my mum…it's just like a constant like circle of thinking about like two things…and it kinda just drags time*'. (Emily, L295-301)

Describing the *'drag'* of time, evokes a sense of being controlled by her worries, as boredom leads to rumination. The emotional toll of stay-at-home orders led Alex's mental health to deteriorate:

> *'[] I would, dissociate really bad []I ended up, I started self-harming [] was just staring at the same four walls all the time an- not talkin to anyone [] No fresh air, I didn't go outside...for like months'* (Alex, L374–390)

Gem constructed what the onset of the COVID-19 pandemic meant for her family:

> *'[] normal people are here [gestures a lower level with her hand][] during covid everyone else's emotions were heightened to about here [hand gestures higher][] and like families who have like people with mental health issues...are already always here [gesturing to higher height] so when everything happened they went up to like [hand gestures higher height]…also the added thing of my mum []it's like stacking dominoes'* (Gem, L837-844)

Gem communicated, through gesture, the belief that due to PMI their baseline day-to-day emotional difficulty sits higher than *'normal'* families, such that they were disproportionately impacted by COVID-19. Her use of the metaphor *'stacking dominoes'* represents the interrelation between family members where one member's mental health difficulties impact the others.

1.3 *'[] I don't mind listening…I just don't like talking about my own things'* (Emily, L472-473)

Participants had their own mental health needs and communicating these to parents could feel difficult. This dynamic was complicated by changes in CAMHS remotely during the pandemic.

Lisa and Gem are comfortable sharing thoughts and feelings with their parents, who they feel are more able to empathise due to PMI. However, Gem reflected that seeking care triggers her mother's self-blame for her difficulties (L917-920). Although Lisa feels supported, her father's advice to remain hypervigilant provokes fear:

> *'[] it's a bit quite scary sometimes [] dad puts a lot of emphasis on that like 'don't follow what I done because it isn't always the greatest thing to over work yourself. [].kinda like, not scaremongering me into not...but kinda like that..'.* (Lisa, P24, L554-447)

In contrast, Alex and Emily worry about causing others burden by sharing feelings:

> *'I just don't like putting, like what I'm going through on other people…I'd rather just kind of keep it to myself…[signal interference 2 secs] [] sometimes there's the odd slip*

> *up with her [mother], like I'll be talking to her and I just, like start crying for no reason but, that's probably about it'* (Emily, L478-480)

Emily deals with emotions in isolation to avoid causing burden. Seeking help is expressed as *'the odd slip up',* evoking the idea of failing, through clumsiness, or loss of control. Alex describes help-seeking for mental illness as *'very competitive'* (P30, L676), suggesting their total family need overwhelms the available caring resource, leaving Alex feeling rejected and invalidated:

> *'I know the things, like- or eating disorders as well, uhm because my...middle sister's got one [] even try to say anything to like, my Gran, uhm, about maybe the fact that I can't do school, or can't leave my bed...my Gran will always make it about her'* (Alex, L685-688)

Difficulty expressing need within families was compounded by the participants' experiences of receiving remote therapy. Despite expressing gratitude to their clinicians, the participants feel unseen at times. Emily expressed preference for in-person therapy, due to enhanced emotional connection (L604-605): *'[] I can kind of, gauge more with the person [therapist][]...know what they're feeling as well as what I'm feeling []'*. Lisa questions her therapeutic engagement:

> *'[] if you don't []want to say 'oh I'm feeling anxious or upset', you can just not say it and they [therapist] won't know...you have to be really open online and tell- tell people how you feel, because they can't tell just by seeing your face []'* (Lisa, L663-666)

Lisa's assertion that you *'can just not say'* suggests a dilemma between choosing to hide or share emotions, echoing the dilemma faced by participants within families. Gem described the embodied experience of therapy from her bedroom:

> *'[]I've got a sticker on my desk if I was looking at that whilst I was talking [to the therapist] if I looked at that later on I'd go [sad sound] 'oh' but whereas if I was in like- if I was in like a therapy office, [] I'd be going home.'* (Gem, L891-893)

Difficult feelings, discussed during therapy, become absorbed within objects in her room, taking on new meaning such that looking at them later causes her to psychically relive them, in a manner which feels intrusive. In comparing this experience with the imagined experience of containment associated with a therapy office, she speaks of discomfort with remote therapy which allows the lines between therapy and life to become uncomfortably blurred.

2 *'Yeah trying to catch where his mind's at sometimes is hard...yeah' (Lisa, 348)*

Participants described ways that they responded to PMI. Caring was driven by love for their family members. However, at times there were negative emotional consequences, magnified by COVID-19 restrictions. Three subthemes were identified: *'[]she'll [mother] be like I'm useless"[] I'm like "but you're not though!"[]', '[]I think it's being willing to doing...what like they [parent] want…yeah',* and *'[] I wish that COVID didn't happen and that we could bond over something []'*

2.1 *‘[]she’ll [mother] be like I’m useless” []I’m like “but you’re not though!”[]’* (Gem, L220-227)

Participants described ways they provide care to support parents’ well-being. Broadly speaking, these efforts required the management of proximity. Lisa joins her father’s activity:

> *‘[]he [father]would start something and not finish it and you’d be like but I wanted to keep going...or he would start something, you wouldn’t wanna do it and then he’d be like oh but why not. It’s kinda that...trying to catch up or like…trying to catch where his mind’s at sometimes is hard...yea’* (Lisa, L343-348)

Lisa’s description of trying to *‘catch’* her father’s mind, when his drive often fluctuates as a result of bipolar disorder, evokes the sense that at times his mind is just out of her grasp, moving to its own tempo and unaware of her efforts to stay connected. Gem’s response to PMI also involves attunement, stating she can *‘[] tell when I’ve talked to my mum about things you can see her going ‘what could I have done to have stopped that?’* (L516-517). Gem is hypervigilant to signs of self-blame, guilt, or feelings of uselessness, and responds with strong opposition, as a means of reassuring her mother:

> *‘[] I…was with her [Gem’s friend] through all of it like and then [laughs] ehm as soon as she starts to feel better she broke up with me [] I was suicidal I was- it was not a good time in my life [voice rises in pitch] and none of that was too do with my mum! But my mum likes to think it is! [laughs] I’m like ‘NO!’* (Gem, L465-468)

For Alex, staying close provides their mother with emotional and relational regulation:

> *‘[]I-I’m like the...mediator I guess so I’ll sit at the table with them [laugh] [mother and partner] and talk to them about their issues [laugh][]I’ve never been in a proper like relationship the way that they are and I’m like ‘you know you just have to compromise, you need to watch what you say, coz if you throw it in the air my mum will pick it up completely different []’* (Alex, L531-536)

Alex understands their role using the term *‘mediator’,* evoking a sense of caring through involvement in their mother’s romantic relationship. Alex’s assertion that the fiancé must *‘watch what he’* says suggests Alex has learnt how to communicate with their mother in a way which protects their relationship. In opposition, creating distance during conflict helps Emily’s mother to emotionally regulate:

> *‘Ehm it’s a bit of a panic moment, coz it’s like urghhh…how do I thingwy it back down []its like I say something else and it makes things worse and then I just…I have to like retreat before…I make it worse essentially’* (Emily, L254-256).

Emily’s use of *‘retreat’* evokes a sense of accepting defeat, and powerlessness to respond in any other way. Throughout her interview, Emily described means of creating not only physical but also emotional distance, stating sleep provides *‘[]time to like…regain everything…’* allowing her mother a ‘[] *fresh and clear head []’* (L241-242).

2.2 *‘[] I think it’s being willing to doing...what like they [parent] want...yeah’ (Lisa, L473)*

Participants felt responsible for their parents, at times evoking several strong emotions including self-blame and burden.

Participants were vulnerable to feelings of self-blame when they perceived themselves as failing to help. Lisa spoke about her tendency to automatically attribute her father's low mood to herself, stating (L248-249): *'[] you think ohhh have I done something, you start to overthink even though it's nothing to do with you []'.* Emily's self-blame was articulated through her language, stating she tries not to say the '*wrong'* thing or '*start something'* (L189). Describing her effort to not let her mother *'get riled up'* through giving her space continues to locate blame within herself:

> *'It doesn't…it lets her [mother] like…not…like get riled up or…she can just sit and watch a show or something and I'm [not] bothering her…and it's not gonna start…like an argument or something, bad'* (Emily, L193-194)

Emily describes herself as part of a *'waiting game'* (L283-216), representing uncertainty associated with conflict and the sense that resolution is on her mother's terms. Gem experiences self-blame at the thought of being the object of her mother's distress:

> *'[]I feel like my mum sort of wants to be able to go 'oh, I could've been able to prevent that' and sometimes it really frustrates me because I'm like…[] you could've kept me in bubble wrap my entire life' and this probably still would've happened.'* (Gem, L505-506)

Feeling failure to influence her mother's drive to self-blame became exasperating for Gem and speaks of a sense of powerlessness linked with the sense of being the object of her mother's distress. Stating (L459-463): *'it-it upsets me because I'm like it's not* *my mum's fault and nothing, like ever, has been mum []'* suggests that in convincing her mother, she is also protecting herself.

Secondly, the participants expressed notions of choice in relation to their caring role. Emily spoke about having to *'step up'* and look after her mother (Emily, L54). Alex spoke about parental self-harm occurring once when they refused to help:

> *'[] at the beginning of covid []I was over at my Gran's at the time, and I was like 'oh for goodness sake, I can't have anything, like, no peace' []she [mother] was like texting me like 'oh, I want him out the house' and [] Gran was like 'don't get involved coz you'll be the bad guy', so I stayed and then that happened []'*(Alex, L556-563)

Alex expresses that they must care, to their mother keep safe. The belief that they can't have *'peace'* expresses a sense of obligation to sacrifice their own need for time away. For Lisa, having no choice is about accepting the parameters of connection with her father, that *'[] if I wanted to keep going I would have anyone, to keep going with []'* (L356-357), later constructing meaning about reciprocity within their relationship:

> *It kind of feels like []Why...why not do this? [].you just continuously question and over analyse [] and it makes you think uhhh a bit lonely or...a bit frustrated sometimes but you know it's not, their fault []it's just what is...'* (Lisa, L365-368)

Lisa's repetition of *'why',* without ever finding an answer, evokes a sense of lack of reciprocity when her father is unwell, associated with feelings of loneliness and frustration that sits in tension with the knowledge that '*[] if I wasn't willing to do everything []it wouldn't be as big of a strong connection []'* (L500-501).

2.3 *'[] I wish that COVID didn't happen and that we could bond over something []'* (Lisa, L419-422)

Participants articulated ways that the COVID-19 pandemic impacted their ways of coping with PMI. They lost access to previously helpful strategies, negatively impacting both family relationships and participants' wellbeing. Emily, associated the stay-at-home orders with growing pressure:

> *'[] during covid it was a case of we [family] couldn't kind of like leave the house [] we were constantly together and it was like a- I felt like it was kind of a* ***tension*** *thing…it wasn't like arguments every now and then it was arguments like…like* ***constantly*** *[]there was like… no escape []'* (Emily, L113-118)

Her emphasis of *'tension'* and *'constantly'* represents the relentless nature of relational stress during lockdown. Gem also spoke of the growing psychological pressure associated with lockdown, expressed through metaphors such as *'cabin fever'* and *'claustrophobia',* to represent the intensity of family relationships (Gem, L683-689). In contrast, Alex described a continuation of prior arrangements for providing care, stating (L344): '[] *not that I had a place to like escape before, but I don't now, at all'.*

Staying at home was not only associated with increased pressure and tension within relationships. Internally, Gem spoke of increased exposure to her mother's symptoms leading to heightened hypervigilance and worry:

> *'[] I was noticing more things in my mum and my mum was like 'it's fine' am like 'but it's not', and my mum's like 'yes it is' like…because it's like a normal thing that I don't see all the time* (Gem, L651-652)

Gem's hypervigilance is associated with increased exposure to behaviours whilst schools were closed, increasing uncertainty and worry about her mother's health. Emily also spoke about increasing worry about her mother's safety, which alongside increasing pressure incurred from online learning overwhelmed her capacity to concentrate*,* stating (L138-141): '[] *I was thinking about what she [mother] was doing, and if she was ok []I was thinking about the argument…there was Spanish work I needed to get done…then it was just like a, kinda overwhelming feeling [] pressure, from like everything'*. Lisa's uncertainty related to her changed relationship with her father:

> *'…do we [Lisa and father] depend on…like doing things to be together?...is there not another connection we have that doesn't include doin this [] our connections a bit…not as much because of COVID as well-'* (Lisa, L448-450)

Lisa felt she had lost part of their relationship due to stay-at-home orders. Repetition of *'connection'* emphasises her grief for what she worries is lost, as a result of no longer being able to do *extravagant'* things (L420) or '*be spontaneous'* (L446).

3 *'[] having to like shut the curtains [] we [family] realised that that sorta helped my mum [] every single night the fire was on…'* (Gem, L740-744)

Participants sought to make sense of self-identity, family, and roles within an uncertain living context, and some identified parallels between PMI and COVID-19. Despite this, the participants respond adaptively. Two subthemes were identified: *'[] it was so easy for me, but [] I don't feel like I have a mum',* and *'[] I think everyone was feeling the same so somethin...we could do together...kinda helped []'.*

3.1 *'[] it was so easy for me, but []I don't feel like I have a mum'* (Alex, L270-271)

Articulating the impact of PMI upon family roles was challenging for participants. In stating (Alex, L24-28): *'[] they [family] see me as the parent [] my youngest sister used to tell me all the time that she wishes I was [] everyone tells me I've grew up a lot, to look after them…',* Alex expresses the feeling their self-identity is dependent upon their purpose to others, as reinforced by others. Being many roles was later expressed:

> *'[] we'd [Alex and mother] say that I was like her sibling, or most of the time like her mum [laughs] so uhm, yea so she'll just talk to me she still does now [] she wouldn't tell anyone else, it'd just be me.* (Alex, L249-251)

Alex had difficulty understanding the role they play for their mother, leading them to identify with multiple role types. Their assertion that *'...we'd say…'* suggests their roles are co-negotiated. Their later assertion that *'[] I felt like I was having to be a lot older [] people would always forget that I was like 15…[]'* (L260-263), suggests they felt abandoned, without support in return, when they were caring for multiple individuals. Some participants described sorrow and loss about unmet expectations of the parent-child relationship. Lisa's asserted that (L237-241): '*[] you don't want to see someone that, is meant to be always happy an caring for you upset or…angry…[]'*, whilst Alex feels that they don't *'have a mum [] someone to look up to* (L270-271).

In contrast, Gem has constructed strongly defined boundaries regarding how family members should relate with one another, often referring to assumed universal norms, using statements such as *'[] me an my dad get on...pretty well, for like...families…*' (L52-58). Her relationship with her mother was expressed in terms of the flow of care running from parent to child, through accounts such as how *'[] [I] fell asleep on my mum yesterday [] coz I wasn't feeling very well []'* (L113-114).

When considering the impact of PMI upon their sense of self, the participants expressed the sense that they experience their parent's bad days alongside them:

> *'[] if the person's low [] it kinda bums your mood down a bit [] like you don't know why you feel that way but it's because they [father] feel that way []'* (Lisa, L611-613)

Lisa's statement evokes a sense of experiencing her father's difficulties, articulated throughout her interview as feelings being 'projected' onto her due to the emotional impact of seeing her father's low mood. Whilst Alex expressed that caring provided them a positive source of self-identity, they also expressed difficulty trying to *'[] identify different emotions [] figure out what my actual personality is []'* due to often being focused on what others need of them (L458-459).

3.2 '[] I think everyone was feeling the same so somethin...we could do together...kinda helped []' (Lisa, L123-124)

Uncertainty within parent-child relationships was central to participant sense-making. Gem discussed the impact of this upon her sense of security and otherwise robust sense of family boundaries:

> *'...it literally can be like one tiny thing will happen, and it's [] like the walls of the house have just collapsed [] one of us will like leave a cup in the livingroom and it's*

> *just so happened that my mum's had a really bad day and that cup, is, just the final straw and oh my god []' (Gem, L353-355)*

Gem's compares her mother's deterioration to the collapse of her home, representing the sense of relational threat that PMI can cause. Emily describes a parental relationship often in flux, for which Emily doesn't always know the correct '*...flips and switches to **make** it better...'* during conflict (L228). Lisa drew parallels between her relationship with her father, and COVID-19-related uncertainty:

> *'[] it's just wondering when [] when's the next time we [Lisa and father] can do something [together] and I think that's the same with COVID as well, wondering when's the next time we'll be able to do something that's not...in the house doing nothing [laughs] []'* (Lisa, L407-411)

Despite the multiple sources of uncertainty that the participants are currently faced with, they and their families responded in flexible, adaptive, and resilient ways. Emily can compartmentalise difficult days in a way which is protective, and on good days her and her mother are *'[] constantly talking like we're laughing like we'll watch a bit, TV show together []'* (L198-201). Gem faces the uncertainty introduced by her mother's Seasonal Affective Disorder with imagination, despite additional struggle during winter lockdown:

> *'[] having like the curtains shut so she [mother] couldn't see how dark it was getting outside [] [picking up pace] our livingroom felt like we were in a Christmas film [laugh] like the curtains were shut, the fire was on, like it was like, our livingroom just constantly felt like we were in a Christmas movie'* (Gem, L747-750)

In shutting out the dark, Gem protects her mother from the outside. She felt positive about how she and her family worked together to evoke a happy time of year, and experienced emotional benefits herself (L788-791): '[] *I was happy, it was good, it was nice seeing her…really like happy about something, like because the year had been so bad []'.* Lisa's account suggested acceptance of her father's difficulties:

> *'...you have to think like, 'well* ***I'll*** *take a break from it and when he's [father] willing to do it again or...do something with me again I'll take that opportunity, seize the opportunity basically.'* (Lisa, L492-496)

Lisa's acceptance is expressed in her awareness that she must look to reconnect with her father, when possible. Her use of *'seize'* speaks of a sense of empowerment within this situation, and determination to drive the continuation of their relationship despite the difficulties incurred by PMI.

Discussion

The current study explored young peoples' experiences living with PMI during the COVID-19 pandemic. Four interviews were conducted and analysed using IPA. Eight themes, sitting within three superordinate themes were generated.

The unpredictability inherent to PMI is a proposed mechanism of risk, due to its impact upon the parent-child attachment, impacting the parent's ability to be consistently emotionally available (Brockington et al., 2011). Current participants expressed great uncertainty relating to PMI. They understood parental changes, such as withdrawal or fluctuating presentation, to indicate increased vulnerability, evoking feelings of rejection, powerlessness, sadness, anxiety, and fear, echoing previous findings (Trondsen, 2012). A recent review interpreted fear of parental death to be at times related to misunderstanding about PMI (Yamamoto & Keogh, 2018), however within the current study, fears about death by suicide were based upon past experience.

The current findings also suggested that participants responded to PMI by providing care. Parentification literature describes caregiving, which is excessive, causes parent-child role reversal, and may compromise children's development (Byng-Hall, 2008). Emotional parentification, which can include the child playing the role of confidant, emotional supporter and family mediator (Hooper et al., 2014), was evidenced within this study. The current findings may be associated with participants' parents' childhood experiences (ACE's), as early experience of trauma is seen to predict role confusion within their later relationship with their children (Linde-Krieger & Yates, 2021). However, participants also spoke positively of their families' proactive coping and adaptation to PMI, particularly when previous sources of protection were not available due to the pandemic. It is acknowledged that parentification is not inherently damaging, and where children's caregiving duties are not excessive, burdensome, or represent a permanent shift within the family system, can contribute to healthy development (Byng-Hall, 2008).

Current participants expressed self-blame, and burden in response to PMI. Self-blame is a common experience reported within this population and drives the call for children to be adequately informed about PMI (Yamamoto & Keogh, 2018). However, self-blame within the current study was related to feelings of incompetence, rather than misunderstanding. Caregiving was also associated with burden and lack of choice. Such experiences have been reported within retrospective research (Van Parys, Bonnewyn, Hooge, De Mol, Rober, 2015) and is an aspect of parentification through which poorer outcomes may occur (Hendricks, Vo, Dionne-Odom, & Bakitas, 2021). Just as participants felt burdened, they avoided causing burden, by avoiding use of the parent-child relationship when distressed. Hiding distress may constitute a way of caring for parents and protecting the parent-child relationship (Van Parys & Rober, 2013).

Participants reported that they and their parent's mental health had suffered during the pandemic. This is in line with the current literature around the impact of the COVID-19 pandemic upon mental health within the UK, with societal action for containing infection rates disproportionately impacting young people, including those living with PMI who are already subject to health and social inequalities (Crawley et al., 2020). Giebel et al., (2021) associated poorer mental well-being amongst carers of individuals with dementia, with reduced access to support services. The current study provides insight into these closures from the perspective of young people living with PMI, where participants were not only impacted by reductions in statutory and health services, but by increased exposure to their parents' difficulties, and indirectly by the limitations placed upon their parents' lives. In this sense, the current findings view that families with PMI were disproportionately impacted due to their higher level of baseline vulnerability, echoing current policy outlining that the pandemic has highlighted and exacerbated social and health inequality within marginalised communities in general (Onwumere et al., 2021).

Clinical and policy implications

Despite the challenges described within our findings, the Scottish Government's 'Recovery and Transition strategy', does not adequately address the disproportionate impact of the pandemic upon young carers (Scottish Government, 2020a). It is imperative that their needs are also included within planned 'actions', as part of the current review of the Mental Health Strategy (2017-2027) (Scottish Government, 2017).

With pressure upon mental health services likely to continue, it is vital that innovative responses to mental distress utilise collaborative working with third sectors, including young carers groups that provide sources of positive social connection and support (Gough & Gulliford, 2020). However, during the pandemic it is estimated that a quarter of charities have had at least 40% reductions to funding, deductions which are greater in magnitude than those made during the 2008 financial crash (Clifford, Mohan, & Rutherford, 2021). Furthermore, within the current study, despite all providing care, none of the participants strongly identified as 'young carers' and only one had previously attended such a group. This provides weight to the notion of young carers as a 'hidden population', and the need to develop effective means for identifying and supporting young people that don't necessitate them to identify as carers.

One finding related to the participants' experiences of remote and teletherapy. Carers in general face significant disadvantage as a result of remote service provision, as they experience higher ratees of technology poverty, and the loss of opportunity to express their thoughts, feelings, and needs, within a private setting away from the care recipient (Onwumere et al., 2021). Payne et al's (2020) review found that young people within Tier 3 CAMHS express preference for face-to-face therapy. The current study participants spoke positively of their clinician's but experienced reduced satisfaction regarding therapy. Future research could investigate the phenomenology of remote therapy from multiple stakeholder perspectives, to ensure both effective care and choice remain the driving principles of health care provision.

Strengths & Limitations

The findings contribute nuanced, phenomenological data, about the transgenerational transmission of trauma and mental illness within the context of PMI. Participants were recruited within an NHS CAMHS setting, expanding upon previous research which predominantly recruits from third sector organisations. Whilst information about PMI is certainly helpful for these families, current findings add to our knowledge about additional drivers of psychological distress, including identity, and family relationships. The current research also provides understanding of the unique experience of living with PMI during the COVID-19 pandemic.

One limitation is that time constraints prevented consultation with young people during the project development, possibly leading to issues pertinent to the study population remaining unexplored. Member reflections did not take place, which may have provided opportunity for further elaboration of the data as part of the analytic process. Collecting the data remotely may have limited the extent to which participants felt able to express themselves honestly, replicating the difficulties they expressed regarding their therapeutic experiences.

There are also limitations relating to the sample. Utilising clinicians as part of the recruitment strategy may have led to a gatekeeping approach and introduced bias, with some young people not having the opportunity to consent. The population of young people living with PMI is highly heterogeneous, thus the small sample size, from one NHS service, means there may be communities, for example based upon gender, social economic status, sexuality, ethnicity, or clinical characteristics (young people without a mental health condition, those living with varied severity of PMI), that remain unrepresented within the current study. This is important given the unequal experiences that young carers might experience based upon their positioning within the intersection of inequalities such as race, class, and disability (Alexander, 2021). Lastly, the sample size is below what was planned, due to pandemic-related recruitment challenges. There is little consensus about methods for estimating appropriate sample size, however, IPA epistemology places emphasis upon depth of understanding of a small number of accounts. Sebele-Mpofu (2020) argues that considering sample size alone is insufficient, and Malterud, (2016) outlines the importance of “informational power”, relating to data richness. The current study data generated using case-by-case analysis, is rich and nuanced, ensuring high fidelity to the IPA process (Smith et al., 2009).

Conclusions

This study explored the experiences of young people living with PMI during the COVID-19 pandemic. Findings emphasised complex and varied experiences with regards to how PMI impacts emotions, identity, and relationships. The findings highlight the need for further recognition of the unmet needs of this population, to support positive family coping, within broader research, clinical, and policy contexts.

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Appendices

Appendix 1.1 Author guidelines for submission to the Journal of Child and Family Studies

Link to Journal Quick guide for manuscript preparation for authors

Link: https://resource-cms.springernature.com/springer-cms/rest/v1/content/17815186/data/v5

Appendix 1.2 Example search strategy: Medline (ovid)

S - Sample	Define using two sets of terms Adolescent/ or child/ or young adult/ or child of Impaired Parents/ or Caregivers/ or young carer OR (Child* or Teen* or Young adult* or Adolescen* or offspring or Care?givers or COPMI or CAPRI or COPE-MHD or (young adj3 car*)).ti,ab.
PI – Phenomenon of interest (parent aspect)	Parent/ or Parents/ or Parenting/ or parent-child/ or parent-child relations/ or Parent-child relationship/ or child parent relation/ or family relation/ or family relations/ or family OR (parent* or parent-child or relation* or relative* or family or (parent-child adj3 relation*)).ti,ab.
PI – Phenomenon of interest (mental illness aspect)	Parental mental illness/ or Parental illness/ or Mental illness/ or family illness/ or mental health/ or Mental disorders/ or Anxiety/ or Major depression/ or depression/ or mental stress/ or Bipolar disorder/ or personality disorder/ or psychosis/ or Schizophrenia/ or substance-related disorders/ or alcohol abuse OR (mental or Schizo* or psycho* or Bipolar or Obsessive Compulsive or Depress* or Anxiety or substance or alcohol or abuse or misuse or (parent* adj5 mental) or (mental* adj3 parent) or (mental adj3 ill*) or (parent* adj3 illness) or (severe adj3 mental) or (ill* adj3 family) or (family adj3 ill*)).ti,ab.
D - Design	Interview/ or Interviews/ or Interviews as topic/ or Participation/ or participatory/ or participate/ or focus group/ or focus groups/ or Participate/ or participation/ or narrative OR (((semi-structured or semistructured or informal or in-depth or indepth or face-to-face or guide) adj5 (interview* or discussion*)) or group* or focus-group or qualitative or informant or Interview* or participa* or observation).ti,ab.
E - Evaluation	Caregiver burden/ or personal experience/ or caregiver attitudes/ or Caregiver Attitudes In Adolescence/ or attitude of health personnel OR (view* or experienc* or attitude* or perce* or belie* or accounts or feel* or know* or understand* or needs or help-seeking or barriers or facilitate* or awareness or (caregiver adj3 burden) or perspective* or multiperspectival).ti,ab.
R – Research Type	Qualitative/ or Qualitative method/ or Qualitative Research/ or interpretative phenomenological analysis/ or thematic analysis/ or phenomenological/ or narrative/ or qualitative analysis/ or qualitative studies OR (qualitative or interpretative or phenomenological or thematic or narrative or action-oriented or phenomenological-hermeneutic analysis or grounded theory).ti,ab.

Appendix 1.3 Walsh & Downe (2006) Qualitative Research Appraisal Tool

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Table 4 Summary criteria for appraising qualitative research studies.

Stages	Essential criteria	Specific prompts
Scope and purpose	Clear statement of, and rationale for, research question/aims/purposes	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated
	Study thoroughly contextualised by existing literature	• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
Design	Method/design apparent, and consistent with research intent	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate
	Data collection strategy apparent and appropriate	• Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
Sampling strategy	Sample and sampling method appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
Analysis	Analytic approach appropriate	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	Context described and taken account of in interpretation	• Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena
	Clear audit trail given	• Sufficient discussion of research processes such that others can follow 'decision trail'

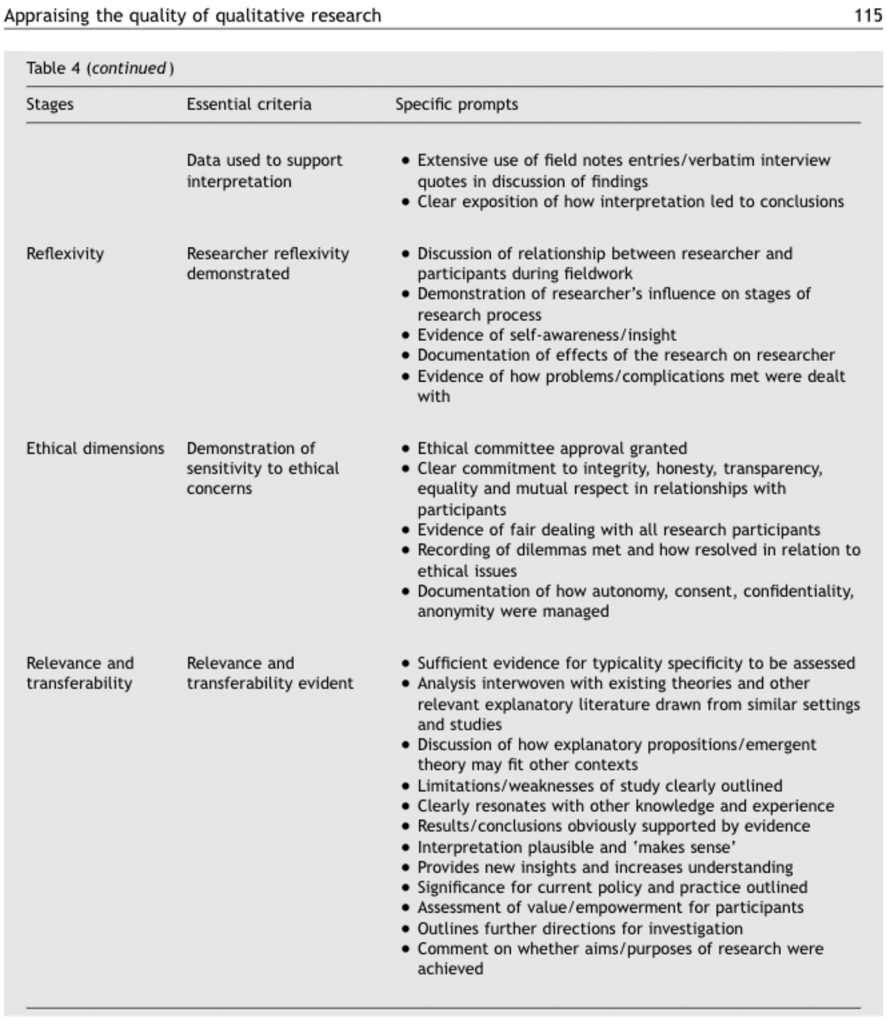


Table 4 (*continued*)

Stages	Essential criteria	Specific prompts
	Data used to support interpretation	• Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions
Reflexivity	Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with
Ethical dimensions	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance and transferability	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and 'makes sense' • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved

Appendix 1.4 Qualitative research appraisal outcome

	Scope and purpose		Design		Sample strategy	Analysis	Interpretation			Reflexivity	Ethical Dimensions	Relevance and transferability
	1. Statement of rationale/aims/Research question	2. Contextualised by existing literature	3. Method/design consistent with research intent	4. Data collection strategy clear & appropriate	5. Sample and sampling strategy methods appropriate	6. Analytic approach appropriate	7. Context described and taken account of in interpretation	8. Clear audit trail	9. Data used to support interpretation	10. Reflexivity demonstrated	11. Sensitivity to ethical concerns	12. Relevance and transferability evident
1. Alexanderson & Näsman (2017)	🟩	🟩	🟧	🟩	🟧	🟧	🟧	🟥	🟩	🟥	🟥	🟩
2. Backer, et al., (2017)	🟩	🟩	🟩	🟩	🟧	🟩	🟩	🟧	🟧	🟧	🟩	🟩
3. Bosch et al., (2017)	🟩	🟩	🟩	🟩	🟧	🟩	🟩	🟧	🟩	🟧	🟩	🟧
4. Boström, & Strand, 2020	🟩	🟩	🟩	🟩	🟧	🟧	🟩	🟥	🟩	🟧	🟩	🟩
5. Gullbrå et al., (2016a)	🟩	🟩	🟩	🟧	🟧	🟩	🟩	🟧	🟩	🟥	🟧	🟩
6. Gullbrå et al., (2016b)	🟩	🟩	🟩	🟧	🟧	🟩	🟩	🟧	🟩	🟥	🟧	🟧
7. Hagström, & Forinder (2019)	🟩	🟩	🟩	🟩	🟧	🟧	🟩	🟥	🟩	🟥	🟧	🟩
8. Hill, (2015)	🟩	🟩	🟩	🟩	🟧	🟥	🟩	🟥	🟧	🟥	🟩	🟧
9. McGaw &Reupert (2022)	🟩	🟩	🟩	🟧	🟩	🟩	🟧	🟥	🟩	🟩	🟧	🟩
10. McGibbon et al., 2019	🟩	🟩	🟧	🟧	🟩	🟧	🟧	🟥	🟧	🟥	🟧	🟧
11. Nattala et al (2022)	🟩	🟩	🟥	🟩	🟧	🟥	🟧	🟥	🟩	🟥	🟩	🟧
12. Nolte & Wren, 2016)	🟩	🟩	🟥	🟩	🟧	🟩	🟧	🟧	🟩	🟥	🟧	🟩

Appendix 1.5 Steps of Meta-ethnography (Sattar et al., 2021

Phase
1. Getting Started
2. Defining focus on the synthesis; locating relevant studies; including/excluding studies; quality appraisal
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising the translations (reciprocal, refutational synthesis, and lines-of-argument synthesis)

Appendix 1.6 Example of Phase 3 Data Extraction Table

Study: Children and parents with psychosis – Balancing between relational attunement and protection from parental illness
Authors: Bostrom & Strand (2021)
Objective: 'To explore parent and child mental health and the parent-child relationship from the perspectives of children and their parents with psychosis.'
Themes: An unclear image, An incoherent story, Illness as part of ordinary life, A non-hierarchical parent-child relationship, Attunement of the parent-child relationship and child well-being (An attuned parent-child relationship, Child's emotional independence)

Themes (also known as key concepts)	Participant Quotes (First Order Constructs)	Primary author interpretations (Second Order Constructs)
3.1 An unclear image	"funny, she can have funny ideas/ …/in periods she goes for a lot of walks." …/in periods she goes for a lot of walks."	Several of the children's descriptions presented an unclear image of their parent and the parent's illness. Despite some awareness, none of the children used words, such as psychosis, hallucinations, or delusions, and few described having been told about psychotic symptoms. Some children's descriptions of the parent's illness were intertwined with their perceptions of the parent as a person.
	"I know that she had the illness, that is, it was inside her, but it did not come out. And then when my granny died, it all came out. That's when she got ill."	Some children seemed to have constructed their own understanding to make sense of the parent's illness.
	Ivar's mother: Before, we didn't have a microwave, because I was so afraid of radiation/…/and that affected the children, but I tried to explain it in an easy way. 'Mummy has this illness that makes her a bit weird sometimes.' I don't really say it in a very serious way	
	Alva: My dad doesn't really talk about his illness. I don't quite understand why he gets like that. I can't really grasp what the illness is/…/I think I would like to ask my dad how it is/…/He might have told me once when I was in second grade. When we were on our way to school, he said 'I have an illness'. I was shocked and thought he must be joking. But it was true.	Even if some of the children recalled having been informed about the illness by the parent or the mental health services, the child's image still seemed fragmented
	: "Partly it's that I am ashamed of my illness, but schizophrenia, you could use other words, you could say mental illness."	Alva's father described that he avoided speaking to her about his frequent voice hearing experiences. Instead, he referred to symptoms he considered more acceptable:
	Elliot: She is really kind. Interviewer (I): She is really kind. Can you think of a time when you thought she was really kind? E: Yes, like now. I: What do you think she is doing now then? E: Now she just is, and she talks and is probably kind. I: Is there anything else that your mother does that you think is a really kind to do? E: She cooks food sometimes.	Some children were vague when asked to describe their parent: "I can't think of anything" or "I don't know." Other children's descriptions lacked authentic examples of situations or parental behaviors

	“He understands problems really well, because it feels like he has been through stuff/…/I was in an argument with a friend and he understood everything and told me what to do to make it better.”	In contrast to his vague description of his mother, Elliot's descriptions of his father with whom his mother said he had a closer relationship, were quite rich. Other children also gave more distinct and elaborate descriptions of the other parent.
		The children's somewhat unclear image of their parent's illness was confirmed by parents' descriptions of restricted communication. The lack of communication about the illness could explain why some children perceived symptoms as being part of the parent's character. Furthermore, the relationship between the ill parent and the child seemed marked by a certain distance as there were aspects of the parent's behavior that remained concealed
3.2 An incoherent story		Some children's interviews were characterized by incoherence. The incoherence could be within some answers, between parts of some children's interviews, and between children's interviews and those of their parents. Incoherence in some children's interviews that could be attributable to the child's young age was not included in this theme.
	Sara: I go upstairs to get changed in the bathroom I eat breakfast and get dressed I go downstairs and he has three kids one little girl and she has cancer and you have to have a tube through the nose and it's easier if we bring them because these boys in school help. You look very, very, you have such, you look so much like my ice skating teacher, I could take it as Tuesday today.	Sara, a 12-year-old girl, had lived with several foster families and at various institutions over the past four years as both her parents were suffering from mental illness. She expressed her own mental health problems both implicitly and explicitly. Her speech was characterized by an unfiltered rush of words and gave a disorganized impression
	Ivar's description of his health seemed unproblematic: “I think I'm fine, actually. Yes, just fine” (laughter), while his mother described him as anxious, fearful and insecure, having found a suicide note recently that Ivar had written.	She also spoke about experiences of depression, anxiety, phobias, and mood problems. In contrast to Sara's troubled accounts, her father claimed her health had improved and that she was managing well despite her previous difficulties. This kind of disagreement between parents' and children's perceptions of the child's mental health was found in other families as well.
3.3 Illness as part of everyday ordinary life	“An ordinary day at home means that I am sitting in my room checking out my mobile and mummy is lying on the couch all day” (Ivar).	Most children seemed to focus on improvements in the parent's health and avoided discussing the more severe problems described by the parents. For instance, children would describe the parent's symptoms as minor problems of daily life
	Interviewer: Okay, what do you think about your mum's health? Elliot: She's fine, she is. I: Do you think she's always fine or that she is unwell sometimes? E: She can be not well sometimes. I: What happens then? E: Or she doesn't get that happy really but it's always when we are playing or playing cards or something. You're usually not happy when you lose or get bad cards.	

	Elliot's mother: No, we are doing really well. Sometimes you have problems and then you get over it and get somewhere better/…/Cause I mean, when I was Ill before it was a bit hard too, but we got through it and we are grand now/…/I am pleased. Those things happen, and then you're happy again.	Elliot's approach to his mother's illness was similar to that of his mother, who seemed to focus on improvements
	Lovisa: I'm not sure if she was always like that, but before, I didn't think about it. But now it has become a problem, because this flat has thin walls and she shouts a lot, and that disturbs me when I'm reading or something. […] But it doesn't usually go on for very long, which is good.	Another child, Lovisa, described being disturbed by her mother's shouting while she was reading, but expressed little emotion in relation to her mother's temper tantrums
	Lovisa's mother confirmed that her shouting may be one reason her daughter often stayed out, but she downplayed its impact: “It could be that, a tiny bit.”	Both parents and children seemed to use strategies, such as normalizing or minimizing the impact of the parent's illness on everyday life while keeping a focus on improvements.
3.4 A nonhierarchical parent–child relationship	“So, she usually doesn't say no. And so, if I say, “I want a chocolate sandwich,” then she doesn't say “No.””	Both parents and children described the participating parents as permissive, exercising little controlling parenting behavior. For example, Ivar said that his mother usually did not set limits.
	Ivar's mother confirmed this description of herself as permissive and repeatedly described herself as “too kind” and “a mother with few rules.”	
	. “If I argue too much, she can't cope anymore, so she tells my [older] brother, and he comes in and then we fight” (Ivar)	In some families, older siblings were reported to take over the ill parent's responsibilities for household chores and for dealing with conflicts with the younger child.
	Alva described the parent–child relationship as mutual and warm, and her father as “really kind, funny/…/like a five-year-old, I'm not kidding!”	In addition to the low level of control, some parents were described as childlike.
	Her description was confirmed by her father. “When I was growing up with her, I was very introverted/…/ A child teaches the parent to become a good parent,”	indicating a nonhierarchical, or perhaps even reversed, parent–child relationship
	Alva: I say, take a headache tablet then maybe we can go out and play some basketball together? Lie down and rest for a while or something. I comfort him in different ways, ask him if he wants to play a game of cards, and perhaps he will feel better if thinks about something else. I think it's the money matter that doesn't work so well. He thinks mostly about money, also when he has a headache; he gets like anxiety.	Alva, among other children, also provided explicit examples of reversed roles (Table 4, Q8). The descriptions of nonhierarchical parent–child relationships indicated that the children and their siblings had to manage responsibilities beyond their level of maturity as the parent could not be fully relied upon periodically.

3.5 Attunement of the parent–child relationship and child well-being		This theme describes the interplay between the child's well-being and the degree of closeness and emotional dependency in the parent–child relationship. It includes the two subthemes: An attuned parent–child relationship and Child's emotional independence.
3.5.1 An attuned parent–child relationship	: “I think it's hard when he has anxiety. It's hard not to mix it up with my own feelings. I do know what it is like to feel ill. It's easy to be too empathic.”	Johannes' and Sara's descriptions indicated that they were both emotionally involved with and highly focused on their ill parents, despite their different family contexts. Johannes lived with his mother every other week as his parents had separated, and Sara, who was in foster care, saw her father once a month. Neither Johannes nor Sara described any close relationships other than with their ill parents. Sara did not seem to have formed any close attachments since leaving her birth parents. Although Johannes spent as much time at his father's home as his (ill) mother's, he described his father as somewhat hostile and unable to understand Johannes' emotions. Both he and his mother described their emotional closeness. His mother worried that she might not be able to separate her own problems from her son's:
	Johannes: No, it's like she shakes, and that happens to me too when I'm stressed. Interviewer: What happens then? J: I shake a bit all the time, but I don't think about it. But when I hold something when I'm stressed, I shake like that. I: And that used to happen to your mum when you were little? J: Yes. I: Was your mum conscious of it? J: It was as if she was conscious, but I think it's the same that happens to me when I'm stressed.	Johannes and Sara were attuned not only to the ill parent, but also to the illness itself; both displaying symptoms and personality characteristics similar to the parent's. Although Johannes' mother said she had never spoken to her children about her psychosis, Johannes' described his own symptoms similar to his mother's
	“You can get ill from moving around a lot, and get mood swings and panic disorder like I have/…/but I also suffer from depression and I don't dare to go out on my own.”	When Sara talked about her own difficulties, she used the same words she used to describe her father's problems, such as “mood-swingy.” She also used psychiatric language to describe herself: “
	“I need to get out more and activate myself.”	Johannes frequently used psychiatric language and spoke of himself as a patient: “
	Ivar's mother: He is carrying a lot of heavy stuff that he doesn't dare or want to speak to me about./…/I think it makes him anxious and afraid. He always asks ‘How long will it take before you get well again?’	To some extent, Ivar also fit the pattern of emotional dependence and attunement to his mother's state, although his mother was more likely to make this interpretation than Ivar himself. She was concerned about his mental health and she described him as a sensitive, anxious, considerate boy who was highly receptive to her needs

3.5.2 Child's emotional independence	When Ida was asked what she would normally do when she was angry, she said “I prefer to be alone.”	Some of the children seemed to manage their own emotional reactions by keeping some distance from the illness and the parent. For example, they would retreat to their rooms when they were angry, or they would avoid disturbing their parent if they woke up at night.
	her mother, who described her as having “a lot of integrity/…/If she is sad or angry, she just wants to leave.”	
	offered limited responses about her family (e.g., ‘I don't remember'), became more engaged when talking about school: “I have fun, I enjoy school/ …/There are these stumps in the school yard that you can do tricks on. That's good fun. And the bars are fun.”	Some children responded sparsely to questions about family life. Instead, they provided richer descriptions of contexts outside the home, with friends, or at school.
	Alva and Lovisa both described the importance of other adults and friends in their lives. Alva described her relationship with her father, living with psychosis, as mutual and warm. However, her support family, who were also her relatives, seemed vital to her everyday sense of well-being and stability	
	The importance of Alva's social network was also confirmed by her father, who described her as “extroverted” and “solid” in situations involving her friends.	
	. Lovisa described a genuinely close relationship with her healthy father and, talking often about her close friends, gave the impression she had a large social network.	
		Children who seemed emotionally attuned to their ill parents and their symptoms also presented the most severe mental health problems. In contrast, other children who displayed fewer mental health problems seemed more emotionally independent and paid less attention to their parents' illness. These children had also at least one other close relationship with an adult (e.g., the other parent) and described being part of a social network

Appendix 1.7 Example phase 5. Translating studies into one another

Example of primary data synthesis of author interpretations

1) **Doing communication about PMI (Below are themes from the review papers that sit under the current theme 'cluster')**

- Growing in silence (no talking with family, parent, with others), (McGaw & Reupert, 2022)
- An incoherent story (Bostrom & Strand, 2021)
- Communication about illness, (Age related) description of illness (Backer et al., 2017)
- Protecting their children (hiding the illness, not talking, monitoring impact upon child, fear of damaging child) age related (Nolte & Wren, 2016)
- All in the past…perhaps (past talk as distancing and protective of loyalties), Choosing to talk indirectly (methods for communicating indirectly, extensive knowledge about alcohol problems; using the third person; using a hypo- thetical scenario; talking about their own lives with the impact of parents' alcohol problems implied, rather than stated; and finally, talking about a collective experience) (Hill, 2015)

Findings from paper McGaw & Reupert (2022) describe an absence of inherent need to share or discuss their or their parent's experiences, instead living within a context of general silence. Despite appearing comfortable talking within the context of the interview, this default tendency towards silence appeared to mirror the silent stance of the parent whereby they only spoke openly about their PTSD at the point of crisis.

Bostrom & Strand (2021) also found that young people, and their parents, were comfortable talking within the context of the interview. However, they found that the communication style of participant's was characterised by incoherence, in terms of linguistic style. Incoherence was also situated within the context of a general incongruence between parent and child narratives about how the child's mental health was doing, within the context of PMI.

Backer et al., (2017) found that there was variation, partly by age, regarding communication that young people reported from their parents, with some remembering, and some reporting having forgotten. Whilst 7-10 year olds sometimes knew their parent's illness by label, or articulated that their parent was 'ill', or mentioned some physical manifestations of their illness, younger children (aged 4-6) did not appear to have such awareness. Most were not asked directly, however some had noticed aspects of their parents within the context of family life, indicative of BD (bipolar disorder) symptoms. Additionally, Backer et al., (2017) noted that uncertainty was a commonality inherent within most young people's descriptions of parent's BD, and similarly to Bostrom & Strand (2021), their narratives were not clear and complete, for example, relaying awareness of the diagnostic label without knowing what this meant, or drawing understanding of their parent's PMI through comparison between how by they experience their parent now, versus pre diagnosis.

Similarly to Backer et al,. (2017), findings relating to young person experiences, Nolte & Wren's (2016) participant parents expressed age related assumptions that younger children (under 8years), were unaware and unable to understand their illness, and so actively hid this from them as a means of protecting them by providing them a 'normal' life. This was also similar to McGaw & Reupert's (2022) participant experiences of parents staying silent about their PTSD within the family until the point of crisis. In addition, Nolte & Wren (2016) findings suggested that hiding, through staying silent, was part of the parent's overall attempt to monitor and prevent impacting their child in a way that might be damaging. This is similar to Backer et al., (2017)'s study where some of the participant's interview questions about PMI were limited by the parent's not providing consent to ask directly about BD. At times Nolte & Wren (2016) spoke about openly talking to children about PMI. However, this generally functioned to provide reassurance that they were not negatively impacting children, which was driven by a worry that they as parents, could damage their children. Talking and staying silent, in general, was motivated by the wish to protect from damage.

Lastly, Hill (2015) found that particularly in relation to communicating about parental alcohol misuse, that young people appeared more able to openly acknowledge difficult experiences if they were in the past, rather than reflective of current difficulties, which if talked about, may have been considered as 'disloyal', or critical of the parent. Underlying this communication style is an inherent tendency towards staying quiet, and to give less information about current circumstances that are difficult, similarly to McGaw & Reupert, 2022). Additionally, Hill (2015) found that most of the discussion about parent's difficulties happened indirectly, with experience implied, for example through drawings about the impact of alcohol use, through developing thoughts and feelings for a third person vignette about a young person experiencing alcohol use, and through hypothetical discussion about the future if it is to involve parental alcohol use. Inherent within this communication style is a preference to not talk directly about their parent's difficulties, and to generate information about their parent's well-being through observation rather than talking (McGaw & Reupert, 2022).

Appendix 1.8 Example phase 5. Translating studies into one another: translations table

Descriptor (groups of similar concepts clustered together/broad thematic headings	First order data	Second order themes
1. **Doing communication about PMI**	“it’s nature [natural] for [us] to keep things hidden, to keep things to ourselves ... because nobody else— normal people —can’t really understand the situation” (Ben) “we/they/I do not talk about that stuff,” both within and outside of their family.	Growing in Silence (no talking with family, parent, with others) (McGaw & Reupert, 2022)
	Sara: I go upstairs to get changed in the bathroom I eat breakfast and get dressed I go downstairs and he has three kids one little girl and she has cancer and you have to have a tube through the nose and it's easier if we bring them because these boys in school help. You look very, very, you have such, you look so much like my ice skating teacher, I could take it as Tuesday today. Ivar's description of his health seemed unproblematic: “I think I'm fine, actually. Yes, just fine” (laughter), while his mother described him as anxious, fearful and insecure, having found a suicide note recently that Ivar had written.	An Incoherent Story (self-narrative – within answers, within interviews, between child and parent accounts) Bostrom & Strand (2021)
	P: Err she’s told me a tiny bit about it but I’ve forgotten. Int: Aah right can you tell me a bit more about that? P: Mmm I’ve forgotten most I’ve forgotten nearly all of it, I can’t remember any anything else about it. (Michael, aged 7)	Communication about illness (Backer et al., 2017)
	Five of the older children (aged 7–10) knew that their parent had a mental illness called ‘bipolar’. Some of these children referred to it as simply ‘an illness’, ‘being ill’, or ‘unwell’ and only referred to it as ‘bipolar’ when asked whether they knew what the illness was called. One child referred to physical symptoms such as headaches and stomach aches her mother experienced, linking these to BD later in the interview. Four of the younger children (aged 4–6) did not know about their parent’s BD and so were not questioned directly, but described aspects of their parent and family life in ways which indicated bipolar symptoms. Yeah it’s like a mental illness. Quite complicated to understand’ (Michael, aged 7). Another discussed her mother’s bipolar symptoms in the context of it not being their fault ‘Erm when my mum feels irritable, but I know it’s not her fault, she she probably sat on the sofa cos she	(Age related) description of illness (Backer et al., 2017)

	um I don’t know if she thinks it’s her fault but I don’t think it is’ (Alice, aged 10). In one family, the mother had been diagnosed when her children were young, and two siblings from this family were able to make comparisons between their mother before and after bipolar ‘... there wasn’t a single problem with her. Erm basically she was just normal’ (Michael, aged 7) One of the children made reference to her age and adjustment to her mother’s disorder ‘Mmm I’ve probably got used to it when I turned ten’ (Alice, aged 10).	
	Faith,[1] mother of three children under 7 years of age, stated: “They have no idea. They are still very young – they won’t understand any- thing like that. When they are big, I’ll explain everything to them.” It was quite a long time ... that they were out of the house so I don’t know if we can say children forget what their parents are like but, you know, it was . . . the same mother, I looked exactly the same ... um ... so when they came home I was with them and ... there was nothing different. (Omette, mother of thee young children who stayed with family for a while after she became acutely unwell). I think [my son] was more affected. . . but he don’t talk, he’s introvert, he won’t want to talk to no one. [He] experienced me going through an addiction. . . um, so he’s probably got a lot of resentments, angry, you know what I mean? And not able to express it. I want him to be able to. . . express any frustrations or anger. “and with the children I left it for a while and I wasn’t going to (bring it up). . . I don’t want to remind them.” I worry that I am a bad influence on her, that I will be detrimental to her long term. . . health, happiness, mental state [sad laugh] And that she um yeah that it’s not good for her around me. (Karen, mother of a 15-year old daughter). It is important to note here that it is not the case that some parents talked to their children to protect them while others remained silent. Rather, most parents experienced both these positions at different times and in different circumstances. Thus, where parents were concerned about their children and the impact of their MHP on them and wished to protect them,	Protecting their children (hiding the illness, not talking, monitoring impact upon child, fear of damaging child) age related (Nolte & Wren, 2016)

	both talking and keep- ing silent could at times be ways to respond to these worries.	
	Homer explained, ‘my mum use to have an alcohol problem’ Rob explained that ‘my ma’s stopped now. She’s on tablets...she cannae drink at all’. Paige adding, ‘my mum was an alcoholic, she’s not really an alcoholic now’. ...she’s has cut down to one bottle a day, and it’s not even a bottle a day, it’s half a bottle, maybe not even that, a couple of glasses out of it which is really, really good.	**All in the past…perhaps** (past talk as distancing and protective of loyalties), Hill, 2015
	As Taz and Rosie’s bottle visually shows, alcohol is a poi- son and ‘you can die’ (see Figure 1). Many of the bottles included descriptions of how people behaved when drinking in negative terms: some participants spoke about a person being sad, getting upset and even feeling suicidal. Others identified drinking alcohol with increased aggressiveness and being violent. Rosie explained why she wrote feeling scared: ‘because people are violent when they’ve been drinking’ Jessica even paraphrases what Amy is thinking, ‘I think she is kind of like “oh no, not again, has she been doing it again” and all that’. Some participants highlighted similarities, such as Audrey who said, ‘her life is totally different but not that different’; Jessica said: ‘there are quite a lot of people like Amy’.	**Choosing to talk indirectly** (methods for communicating indirectly, extensive knowledge about alcohol problems; using the third person; using a hypothetical scenario; talking about their own lives with the impact of parents’ alcohol problems implied, rather than stated; and finally, talking about a collective experience) (Hill, 2015)

	Ronaldinho felt that ‘Amy’s story’ was good ‘cos it gives you something to build on’. Therefore, it appeared that the use of a third person was intrinsically useful. In a paired discussion, siblings Jodie and Ronaldinho talk about alcohol, ‘If you get addicted to it you’re not going to have any time to go out, you’re just going to be in your house all day drinking. Bart shares his worry about his mum’s drinking in the future, ‘if one day she starts getting really heavy’. Luke explained: ‘I was the only other person living there so I was having to bunk off school’.	

Appendix 1.9 Phase 6 Final third order constructs, distribution of study findings across themes

The process of meeting family needs in relation to fluctuating PMI
Relational silence
Fluctuations in the flow of care: trying to attune to the parent's needs
Protector: processes for protecting parents and self

Table 4 Higher order themes under construct one

	The process of meeting family needs in relation to fluctuating PMI		
Studies	**Relational Silence**	**Fluctuations in the flow of care**	**Protector**
Alexanderson & Nasman, (2017)			X
Backer et al., (2017)	X		X
Bosch et al., (2017)		X	X
Bostrom & Strand (2021)	X	X	X
Gullbra et al., (2016a)			X
Gullbra et al., (2016b)			
Hagstrom & Furinder (2019)		X	X
Hill, (2015)	X		
McGaw & Reupert, 2022	X	X	X
McGibbon et al., (2019)		X	X
Nattala et al., (2022)		X	X
Nolte & Wren, (2016)	X	X	X

Processes that suggest young people seek to meet their own needs
Struggling to make sense alone
Fragile normality
Accessing support
Surviving

Table 5 Higher order themes under construct two

Studies	***Processes that suggest young people seek to meet their own needs***			
	Struggling to make sense alone	**Fragile normality**	**Accessing support**	**Surviving**

Alexanderson & Nasman, (2017)			X	X
Backer et al., (2017)	X	X	X	
Bosch et al., (2017)				
Bostrom & Strand (2021)	X	X		
Gullbra et al., (2016a)		X	X	
Gullbra et al., (2016b)	X	X	X	
Hagstrom & Furinder (2019)	X		X	X
Hill, (2015)			X	
McGaw & Reupert, 2022		X		
McGibbon et al., (2019)	X	X	X	X
Nattala et al., (2022)	X		X	X
Nolte & Wren, (2016)	X	X	X	

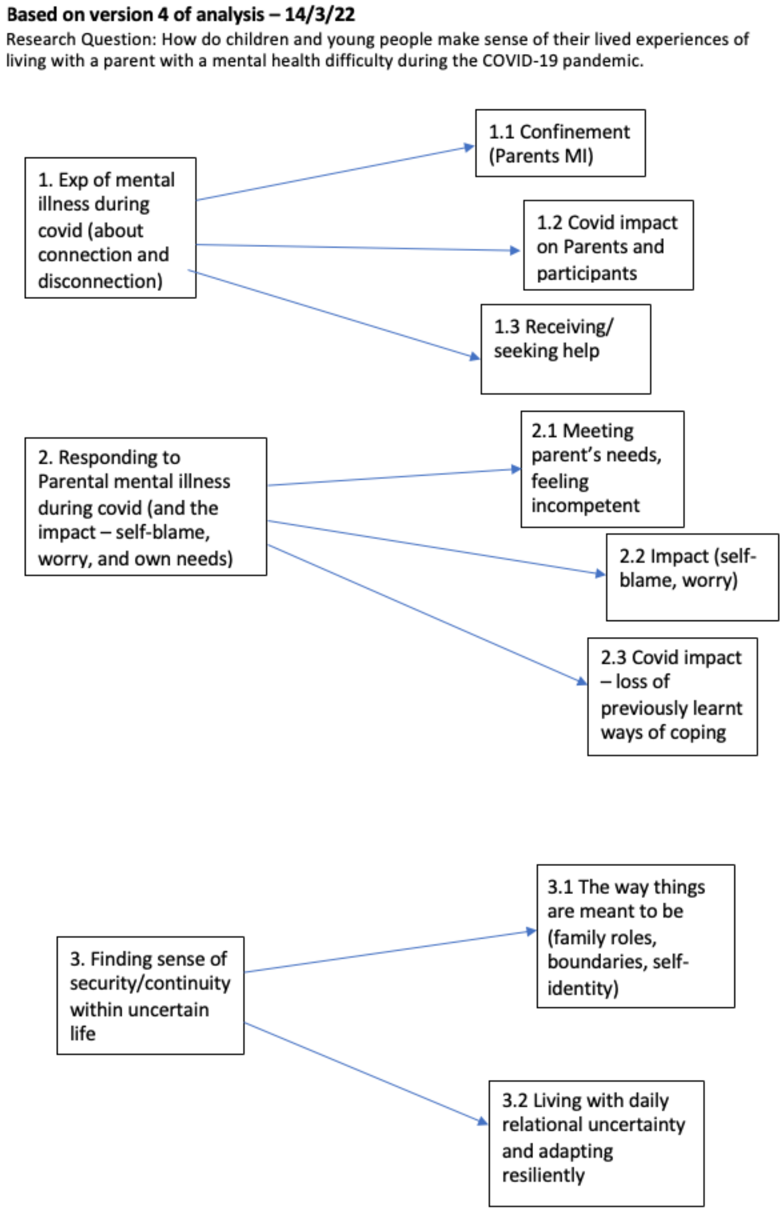
Appendix 2.6 Example of initial coding

No.	Emergent themes	Transcript excerpt	Exploratory Codes: *Linguistic – italics,* Descriptive, Conceptual – *underlined* Situational
		Jen: Yea?...Do you have any questions before we start?...Oh no it's the start of the funny signal! [*Discussion about signal issues, alternative plans for interview etc if required. Between interviewer and participant....during which signal resolves itself*] Shall we get start? Lisa: Yea fine 00:03:02 **Jen: Yea? And you've got no questions? Coz I think I asked if you had any questions then we all froze...** [Lisa and Jen Laugh]	Signal freezing, impacting interaction *Laugh – opportunity to build rapport*
1	Highly valued connection through 'Doing' activities to /relationship building L61-63, P3	**Jen: Tell me a bit about them?** Lisa: Ehm it's really good because I feel like...me and my dad have a really, like...a really strong connection because we're both really into like drawing and creative things...and we like...like DIY's and stuff and, doin that so its quite, for bonding to do together, ehm...	*Repeat of 'really' – emphasise strength of relationship* Lisa values the relationship Bond derived from shared interests and activity Activity facilitates relational connection
2 3	Doing what Dad likes during Lockdown L66-67, P3 Sense of strong Connection with PMI L69-70, P4	**Jen: That sounds really interesting, tell me more about...the drawing and the DIY and all that stuff?** 00:04:29 Lisa: Ehm, well he does like...photography as well...so... one time we like made like a dark room, where you...filter all the pictures and stuff...an that was during lockdown we done that together **Jen: Riiiight** Lisa: Ehm...an we like goin out, taking pictures....an... doin stuff like that an drawing, coz we're really into...stuff like that so... **Jen: That sounds like mega bonding...** Lisa: [laughs] Yea...	Dad likes photography Doing what dad likes 'Lockdown activity' – different pre-covid? Pleasure from undertaking tasks together
4 5	Shared activity, a vital ingredient of relationships L74-75, P4 Going 'big' as a family L77-78, P4	Lisa: Ehm, it's really good coz...I feel like it gives us something to talk about together, and... it's havin the same interests, it's givin us like...somethin else, to do, it's quite a good...thing to do [laughs] 00:05:10 **Jen: What... coz that's like, like building a dark room is like no small thing** Lisa: [laughs] no...	Shared experiences help us to connect throughout our life – Relationships require shared experience and connection *Laugh – aware of magnitude of the task they chose* Do they do 'small' tasks in this family? Question about what is 'meaningful' task in this family?
6 7	Stuck in a rut, not doing anything – threat to sense of self L82-84, P4 The drive to fill time together L84-86, P4	**Jen: That's like...what was like to...what kinda got you goin building a dark room at the start of Covid an...what's that meant to you just to have that during COVID?** 00:05:25 Lisa: I think because we didn't have like, much...to do, coz can't go out anywhere or go to restaurants or...do anythin we thought like, it'd be fun to do somethin at home together because we were both kind of...in a rut an...had nothin else [Jen: yea...] to do an it was good because we'd get like the old like wood from the back garden and stuff like that an like...make a space in the shed where we could do it together an it gave us...it took a lot of time so it was....it was a big thing durin the start of lockdown to do together.	Couldn't leave the house, felt stuck inside – imprisoned? *Metaphor – rut – Felt dull and unproductive* – threat to self? What happens when we become dull? Is it dangerous? Building filled our time together – what happens if time is not filled?

8	Repetition, separation, inertia L90-92, P5	**Jen: Yea...and you were sort of talkin about the start of lockdown an it bein a bit like a rut [Lisa: yea..}, was was that like, to suddenly being in the start of lockdown?** Lisa: I think because we had to do the same things everyday...an it... was just like in the house, an I would sit in my room upstairs or they'd be downstairs an you just...you couldn't be bothered doin anythin so...makin the use of the time an doin something together	Repetitive days with everyday tasks too effortful – lose motivation Everyone moved away from one another, separate spaces – isolation, loss of connection Important to participate in shared activity Internal standards do not allow for wasting time?
9	Being alone felt empty L 97-100 P5	**Jen: So was it like, at the start then that you's were all a bit more separate?** Lisa: Yea **Jen: What was that bein kinda...** Lisa: I think...ehm at the start we, we thought this would be good alone time...maybe catch up on a TV show, like on your own, do whatever you wanted, but...after a while it got like really repetitive an you had nothin to look forward to. So doin that with my dad gave me a lot to like look forward to an, spend my time productively [laughs].	Imagined vs reality of being alone different – Shift in experience across time Being on own felt hopeless
10	Inactivity as a character flaw? L99-100 P5		Doing something productive with dad felt good *Laughs at own expense – at idea she had to stop wasting time-* Negative judgement about being unproductive as useless, meaning you are bad?
11	Fantasy vs reality of paused life: Emotional shift L108-111, P5	**Jen: An what were the feelings that would go along with that then? That feeling of repetitiveness...and there's nothin to do and...** 00:07:32 Lisa: I think just, the repetitiveness of it, it was just the saaame thiiing, all the time, or...because it was COVID nothin new was comin out, so it was just...it start to, all that excitement started to dim down a bit an it wasn't like, oh this new TV shows out an we can watch it together, it was more like...oh that's it now like, you've done what you wanted to do, there needs to be something else we can do as a family together.	*Extension of saaaaame thiiing – emphasise experienced of stretched time, boredom* time became flat, difficult to tolerate *Metaphor - Dim down – things started feeling dull*
12	Family activity as protective during lockdown L111-112 P5		Finding something to do together Sense of needing family time as response to finding the repetition difficult
13	Isolation and boredom provoke big emotions/difficult to articulate L120-121 P6	**Jen: An what were the feelings that would go along with that then? That feeling of repetitiveness...and there's nothin to do and...** Lisa: It was just quite...like...it got quite lonely and a bit like...I don't know how to explain it like...boring and...just like urghhhh [big breath and shoulders up and down as though exasperated]	*Repetition – like – trouble articulating, moving in towards loneliness then further away – too vulnerable? Desire to distance from these feelings?* Being on own feels lonely/boring -isolation, threatens self-worth? Sense of purpose? *Urghh, big breath/shoulders move – feeling difficult to articulate and feels physically uncomfortable?* – difficult to articulate thoughts when feelings are big? Emotions?

			Communicating to me difficult?
14	Shared activity as response to shared feelings L123-124 P6	**Jen: Yeaaaa** Lisa: [inaudible]...And I think everyone was feeling the same so somethin that...we could do together just...kinda helped with that	Shared feelings regarding boredom and loneliness - Doing together as coping strategy for shared feelings
14.5 15	Caring for the interviewee 'Doing' to feel useful L130-132 P6	**Jen: What was that, if you put that into words, what does that feel like, how do you experience it?** 00:08:55 Lisa Kinda like...I don't know, doin something kinda gives you a lift off your shoulders and... it just stops you like thinkin your wasting time on doin something that felt a bit useless like...actually doin something productive an feelin like 'oh I've accomplished something... together...which is...quite good	Changing direction of interview as interpreting interviewees difficulty with previous thinking Thoughts and feelings not easily accessed? *Metaphor – a lift off of shoulders – productive activity improves emotional burden triggered by not using time in perceived productive manner* *Metaphor – wasting time-* worry about inactivity meaning one is useless? Doing helps address negative thoughts about 'wasting time' Sense of achievement brings about positive mood and feelings about self
16 17	Concept of 'outside' changed? L144 P7 Loss of activity & connection: Unmet needs in Covid world L144-148 P7	**Jen: And thinking about, so kinda, your hobbies and relationships outside of the family, what was that, can you tell me a bit about them over the last year or so?** 00:09:54 Lisa: Ehm, well I used to do...dancing outside, like before COVID and obviously the restrictions stopped that, so I couldn't do that. I know my mum liked goin out with her like sister and goin like shopping an stuff and... she really relied on that as well and same with my dad. He has like friends that do photography with him and they meet every week. And I know that, was quite a big thing for him, and not havin that was ehm...I feel like we all felt like, a bit lost without the usual things that we rely on.	*Slip of tongue? – Dancing outside -concept of outside is anywhere not in the house?*Covid changes sense of different spaces? Felt lost without needed activity and social connection Activity and social connection supports well-being, mood, positive sense of self: lost sense of self without? These qualities are needed for mental illness population?

Appendix 2.7 Thematic Map



Based on version 4 of analysis – 14/3/22

Research Question: How do children and young people make sense of their lived experiences of living with a parent with a mental health difficulty during the COVID-19 pandemic.

Appendix 2.8 Example of subordinate theme (with transcript evidence)

From Superordinate theme: *'… if you're already like this [shows angled hand] a winds gonna knock you further'*

	Lisa	Alex	Gem	Emily
1.1 **'…some people doze off and stuff but it's different with my mum… it's so weird to explain'** (Gem, P26, L618-619)	Lisa: Ehm...because he has bipolar disorder I know that there is times where he is extremely low or...and like... there's nothin that you can do to make him feel better an I know that there's times that he's really high an that...it makes it, everyday varies or... every couple of months varies sometimes he's like 'let's do this let's do that let's do all this' because its very, like... Ehm...I don't know how to describe it, very...[Jen: take your time] ehm... (P14, L316-321) Lisa: I think it would be like, starting things off. Like we'd start loads of different things, have loads of things going on like we'll, [pace quicker] we'll paint, we'll paint the fence, we'll do this, we'll draw, we'll cook this we'll, and it's loads of these different things all the time …' (P14, L325-331) Lisa…but we never... you never fully finish them or you never resolve it and then it just...I dunno it's quite...quick sometimes, it can be...like quite snappy, and then the next day it's like no I'm not doin that I can't be bothered or… It's quite like opposites, polar opposites yea…'(P14, L327-331)	P3, L44-51 – Past trauma at the forefront of everyday life Alex: Er yea its fine...uhm my mum was in the kitchen we were in the livingroom my dad walked into the kitchen...actually before that uhm, my dad had grabbed my mum by the throat [Jen: right], as a joke [Jen: Uhuh] and my mum was like...[inaudible, it had been an accident], and then she'd bent over, in her pyjamas she'd bent over - in her pyjamas - to fill up the washing machine [Jen: Mmm], and he like...smacked her [Jen: riggght ok] ehm...(P6, L126-129) Alex: where she was [Jen: Mhmm], and went over to the sink and he was washing his hands, so I kinda knew uhm...and then my mum sat on the couch and was like...a ghost (P7, L133-134) Alex: Ehm she got uhm...like diagnosed with like ehm...BPD uhm...a few years back...but she was, abused multiple times as a child...so it all kinda stems from there (P11, L220-221) Alex: Uhm well...sometimes my mum...it's not as bad now because uhm...her partner, Tom, he kinda...helps her to get out of bed, well he works really early so like ehm...he drives deliveries, so he gets up like 5 in the morning or 4 in the morning uhm...so...sheehm, she's up, so he's like content	Gem: Ehm...because it's my mum who's got like mental health issues, an is why we - [laughs] - when we get on each other's nerves it tends to, like...I say 'ends badly' it's not like throwing things at each other or anythin [Jen: Mhmm] we don't like- but like- it will be like shoutin at each other, or like one of us will just like absolutely lose it [Jen: Yep}, and it tends to be more like, we don't just do the like [in angry voice] 'oh I hate you' an like walk away mum and I don't fall out very often but when we do [Jen: Right] it's like [laughs] quite bad...ehm...but I think it's because we're so close like, an because we both sort of have a lot going on at the one time, when one of us loses it, it's like [laughs] the entire house knows about it [laughs] ehm...(P6, L125-129) Gem: I think, the way my mum's feelin just now is she-, coz my mum and I'll talk about it an it'll be like- I'll be like 'right, what's wrong [laughs]-like whats going on like, this isn't normal for you mother [laughs] you're not normally this stressed', and it's like... the way my mum's explained it recently is it's like my wee brother's just gone into 3rd year, so he's in his sort of like [moody teenager voice] 'Oh I don't care about anybody mehmehmeh-nehneh' phase [Jen: Mhmm], like he'll just like, anytime you like try to talk to him in school he'll be like 'shut up', an I'm like 'thank you...brother, very nice to see you as well [Jen laughs], ehm...so like my mum's like doesn't feel like she can do anything to like help him because like...he's just kind of like, he's just bored of second year …so my mum can't do anythin to help him coz my mum can't go 'ok, go to third year!' like	Emily: Eh…well before they said she had Bipolar…[Jen: right] but ehm…it was like earlier this year, she got diagnosed with Borderline Personality Disorder [Jen: Ok] and…I know she has severe depression and anxiety…(P3, L56-57) Emily: Yea, uhm…well they're kind of the same essentially so it wasn't really like a big [Jen: ok] change, but I guess it was just, it was something new to kind of, like research on [Jen: Yea] look at how it is different (P4, L61-62) Emily: Ehm…I know it usually comes from like…like trauma and PTSD [Jen: Right ok]…ehm so if they've went through, like a traumatic childhood or something it will…you know, they have a high chance of getting that mental illness (P4, L75-76) Emily: Ehm…no not really, it was just like a…oh, like that's how…some people have it and like that there's something so severe to… and it was something that kind of…you know, ruin their lives, or make it difficult for them (P4, L78-79) Emily: Ehm, I know she has like, ups and down days [Jen: Ok]…and I know that she's told me she's days where she feels like she's gonna snap or that she wants to argue (P10, L184-185) Emily: Ehm, it's a bit of both I think…sometimes when she does kind

		when he comes back from work uhm...whereas before ehm...she would probably just...well she slept on the couch uhm...and would sleep all day ehm... (P11, L225-227) Alex: She...I think she just couldn't be bothered going up to bed like...even though things happened on that couch, coz we had a corner suite and [Jen: Yea...], but now we have white couches...she would sleep in the corner of the corner suite, instead of...obviously going up to bed [Jen:Mhmm], and she would have Max up next to her [Jen: Ok...], and like she'd say that he was her emotional support dog [Jen: Mhmm] because he was there all the time uhm...but...she ehm...she would just not get up most of the time, unless my Gran came over [laughs] (P11, L229-232) Alex: …I don't really know...just kinda...confused I guess...it's not like, I knew why she was like that, I just kind of, wanted her to get up. (P12, L244). Alex: Uhm...it kinda made me feel bad because even like...I couldn't really do anything like even if I tried getting her up she'd just like, get angry **Jen: Would you try and get her up?** Alex: Yea, we would try and be like 'mum, can you get up and do this or mum can you take me like... here' uhm just to get her like up, but she would get really angry [Jen: Ok], not angry but...upset like, yea... 00:23:05 **Jen: What was that like for you seeing mum upset when you were trying to get her up?** Alex: I don't really know...just kinda...confused I guess...it's not like, I knew why she was like	[laughs] [Jen: Yeaaa]...coz obviously that's not how it works, an she's getting really stressed coz she can't help me [Jen: right], coz it's just studying and it's like, my mum can't, like, show up at school and be like 'I need everything' like...I think- I think just now my mum just feels a bit...she said useless, my mum's not useless but I know it's the way she feels sometimes- (P7-8, L153-164) Gem: … bipolar, it's similar to like that so whereas like, obviously like bipolar's such a drastic switch BPD I think- B-P-D from what I khnow I think it's sorta like my mum will be absolutely fine, and then one minor inconvenience will happen [Jen: Mhmm], and then like entire world might as well have just fell on the floor (P15, L347-349) Gem: Ehm, when I was little I used to go to a thing in my primary school call nurture house…because when I was in primary I used to be SO worried about my mum I wouldn't want to go to school, cos my mum was quite ill when I was llike little ehm…and I used to like get so panicked and constant- I'd be like 'is my mum ok'? Like I'd be I used to get reeeeally really worried about my mum…like as I got older like- I still get worried about my mum obviously like I feel like most people get worried about like, ehm…but like I can like text my mum and like am like -it's like obviously now I'm older I'm able to like…regulate like…how I'm feeling a lot better, but whereas when I was younger obviously I couldn't, because I would get – (P18, L412-416) Gem: It was…not, coz my mum ehm had really bad post-natal depression [Jen: Ok] when she had my little brother…it wasn't too bad with me but she had really bad post-natal depression when she had my brother…ehm…and my mum didn't work, for…quite a few years until my brother and were like…both like in school, by like quite a wee bit I think it was so like ehm…I just used to just I think when I was little like I don't really like - especially when I was little, I used to just not know…why I was worried about my mum I just was worried about my mum but I knew that I was, like	of…ehm…whats the word, when she like…snaps, I guess I could say [Jen: Mhmm] it's like ehm…I do kind of- I do get that kind of, kind of scared feeling of, the argument is gonna happen [Jen: Ok] but on her good days it's like, we're constantly talking like we're laughing like we'll watch a bit, TV show together or something, it's lik- (P11, L197-199) Emily: Ehm, usually after psychiatrist appointments she gets kind of…coz she has to talk a lot about her like…PTSD and stuff like that [Jen: right] so it kind of, it brings back like, old memories that she didn't want to [Jen: Ok]…like bring up **Jen: Ok, ok…and how do you guys deal with that when it comes up?** Emily: Ehm, she usually just doesn't want to talk, for a bit, she usually just kind of…she'll be in like her own. little. space in her room, and I'll just…like I'll make dinner or something for her, and I'll give it to her [Jen: ok] but then again I'll just leave it for her, like I'll just leave her [Jen: yea] if she doesn't want to talk about it **Jen: Yea…what is your understanding of why she doesn't want to talk at those times? 00:07:24** Emily: I think she just doesn't want to…regain old memories of like what happened when she was younger [Jen: Ok]…she just doesn't want to like, remember them, or think about them **Jen: And is there something helpful about not talking then?** Emily: Yea it's like she can kind of like forget about them…and she doesn't have to like go through them or…like remember them and…remember how bad it was (P28, L534-546) Emily: Ehm, she usually just doesn't want to talk, for a bit, she usually just

		that, I just kind of, wanted her to get up. (P11-12, L238-244) Alex: She gets like confined to the house uhm...and- or unless we're with her, and like she hates- any time we go to even just Tesco up the road like uhm...she hates it [Jen: yeaaa] and when she comes back she'll sleep for a bit [Jen: Ok], or she'll lie down, uhm because she's drained uhm...(P27, L607-608) Alex: if anything happened in the house and I wasn't here, I'd feel really bad. Like especially ehm... in times before when she's self-harmed uhm [quieter: attempted suicide], and I've been the one to find her [Jen: right] been the one to help her. So like, if I'm not here, I feel like, even if she's fine, [Jen: Mhmm] something'll change [Jen: Ok], but...if I'm over here and I'm not at my Gran's then I feel really bad because my Gran's...quite lonely even though she says she's fine on her own and my little sister stays with her but- (P25-26, L572-576)	that sorta [Jen: Ok] like way I was sorta like – and I couldn't even tell you like thinking back on it [Jen: Yea] as like I'm older – to be able to go 'oh I was worried about –' I was just worried about her [Jen: Worried] because I didn't know what would happen, ehm my mum…has said to me, coz mum and I like talk about like when I was younger when she was ill and stuff like [Jen: Mhmm], because we're really open like, with each other like, ehm…and like I don't entirely remember this I sort of vaguely remember something about it but apparently when my mum was little [laughs] I wouldn't have thought when my mum was little, when I was little…my mum…had self-harmed and I like, I think it was like the kitchen or something and I walked in to her and said to her, when I was like 4 or something, 'don't worry mummy I'll clean up the blood' (P18-19, L421-430) Gem: yes that was, because of my mum but that wasn't because of my mum it was because of my mum's illness (P19, L439-440) Gem: Like see sometimes the telly or stuff, and you'll just be like 'oh mum did you like, see that' and she'll go 'oh sorry, am not really watching it'…and you're kinda like [in high pitched voice] 'ok so what are you doing then, because you were looking at it!' like that sort of way of like- I know some people doze off and stuff but it's different with my mum…like it's like- it's so weird to explain…' (P26, L617-620): Gem: she just looks quite down every so often, I'm very good at realising …that my mum's…upset but is hiding it, ehm…she'll just like look like she's crying constantly but she isn't like really like crying every so often her eyes will quite literally just, like leak…' (P26, L606-608). Gem: I think its- I think its just kind of because my mum's always said, that even as a young child I'm very in tune with people [Jen: Ok] which is quite amusing because every so often like- my mum says I'm very in tune with people but I'm actually very in tune with my mum I'm not in tune with	kind of…she'll be in like her own. little. space in her room, and I'll just…like I'll make dinner or something for her, and I'll give it to her [Jen: ok] but then again I'll just leave it for her, like I'll just leave her [Jen: yea] if she doesn't want to talk about it **Jen: Yea…what is your understanding of why she doesn't want to talk at those times? 00:07:24** Emily: I think she just doesn't want to…regain old memories of like what happened when she was younger [Jen: Ok]…she just doesn't want to like, remember them, or think about them **Jen: And is there something helpful about not talking then?** Emily: Yea it's like she can kind of like forget about them…and she doesn't have to like go through them or…like remember them and…remember how bad it was (P28, L537-546)

			with like…people my own age ehm… (P26, L623-625)	

Appendix 2.9 MRP Proposal

Proposal can be viewed online at OSF

Link: https://osf.io/hj8aq/?view_only=3e96f69efe504ef89e109d7761dfc6a1