Portfolio Volume 1: Major Research Project

Talking and making meaning about parental mental health problems: the role of children's family caregivers

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June 2018

Word Count: 32,898

Submitted to the University of Hertfordshire in partial fulfilment of the requirements of the degree of Doctor of Clinical Psychology

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Acknowledgements

To all the caregivers who took part in this study, thank you. I am so grateful for the openness, honesty and emotion with which you shared your stories and experiences. Thank you for placing your trust in me to represent the things we talked about and to help them benefit others. I will continue to work towards these ends.

To my top-notch supervisory team, Dr Lizette Nolte and Dr Cassie Bromley, thank you for your wisdom, support and reliability. Lizette, thank you for providing such an encouraging environment and helping me flourish. Cassie, thank you for stepping into my supervisory team and being so generous with your time and advice. To Dr Nina Memarnia, thank you for helping me set sail. Also thank you to Dr Helen Ellis-Caird, for supporting me through my training journey.

To the many, many people who have supported this project in children's social care, third sector organisations, carers groups, the NHS and online: thank you, this wouldn't have happened without you.

To my friends, thank you for the out-of-the-blue messages, encouragement and for keeping me laughing. Particularly to Lauren, your support has been instrumental. To Cohort 15, you have been wonderfully containing and entertaining, and I appreciate you all.

To my parents, who are consistent guides, friends and mentors. Thank you for many things, but in this case especially for your unfailing love, support and interest in my work. To Payam, thank you for being so accommodating of this process, and understanding what it involves. I am so grateful for your unbreakable willingness to listen, help me keep perspective and eat cheese with me at the end of a long evening's work.

Abstract

When parents with severe and enduring mental health problems (MHP) are less able to meet their children's needs, other family members often help with childcare. Research with children and parents with MHP has pointed to the vital role family caregivers play in helping children make meaning and communicate about their parents' MHP. The caregiver's perspective on this, however, is barely known. The purpose of this study was to examine how children's family caregivers contribute to children's meaning-making about parental MHP. In-depth interviews were conducted with 19 adults living in England and Wales who supported at least one related child aged 4-17 who had a parent with MHP. A substantive theory was developed using constructivist Grounded Theory. It was found that participants engaged in a core social process of *providing protection in uncertainty*, through which they sought to protect the child, the parent, the self, and the wider family. In making meaning and communicating with children, participants were concerned with *shaping the interactional space*, *communicating through the developmental process*, and *engendering a sense of safety*. Participants appeared to position themselves to the childcare role by assessing the child's needs, the parent's needs and their own needs. This was conceptualised as *developing a caregiver identity,* and seen to shape their contributions to children's meaning-making. A large amount of communication was found to occur nonverbally, and seemingly without caregiver intent or awareness. The findings support the agenda for family-focused provision of mental health and social care. Clinical recommendations are made for better psychoeducation for caregivers and their inclusion in interventions with children and parents with MHP.

1. Introduction and Literature Review

This research is a grounded theory (GT) in the topic area of parental mental health. It focuses on the adult family caregivers of children who have a parent with a severe and enduring mental health problem (MHP). Parents provide children with the practical and emotional care they need but MHP can challenge this. In families affected by parental mental health problems (PMHP), relatives often help with childcare. This study examined how children's family caregivers contributed to children's understanding about their parent's MHP.

I begin this chapter by positioning myself to the research, and orient the reader to terminology used in the report. A broad introduction to PMHP is provided, including the current United Kingdom (UK) legislative climate for affected families and caregivers. I go on to outline the relevance of understanding and communication in families affected by PMHP from children's and parents' perspectives. Subsequently, the literature pertaining to the meaning-making and communication experiences of adults who have a family member with a severe and enduring MHP is systematically reviewed. This highlights the knowledge gap this study addresses, leading to the research objectives.

1.1. Positioning the Researcher

Family, childhood and mental health are topics that affect everyone, tapping into our early experiences, relationships and self-concept. My interest in this topic has been influenced by experiences in my family of origin. I begin by explaining my relationship to the research, followed by my philosophical approach.

1.1.1. My relationship to the topic.

Until I was sixteen my mum was a carer for my Granny, who had a slow-progressing dementia. I remember her how monthly visits to my grandparents punctuated our lives.

Anxiety, sadness and tiredness often came up around these visits. I saw that caring was often unpredictable and required selflessness; I made efforts to support my mum. A family narrative of looking after each other and talking about things helped me make sense of the situation. Still, we all felt the impact of her caring role. One person needing a lot of emotional energy can mean others have to compromise, be patient, and figure out when it's okay to ask for more. Our family were supported occasionally by a local dementia carers' charity; my mum became a trustee after Granny died, wanting to return the support to others.

As an adult I have recognised that I too engaged in a caring role as a child because of my family situation, even though I wasn't asked to. I believe this has had a lasting impact on my tendency to adopt a caregiver position and has sometimes required me to work more on self-care. Likewise, children in families affected by PMHP or other health and social challenges develop ways to understand their family's situation, whether it is talked about or not, and their experiences often continue to impact them in adulthood. My interest in how families understand shared experiences and the process of family caregiving are shaped by my experiences as a child, adult, aspiring psychologist, and hopefully one day, parent. I am interested in community psychology approaches which value the significant contributions people make at family and community levels.

Engaging with an emotive topic using GT required me to go on a journey. I have often felt moved, in awe and hopeful when hearing participants' stories yet have also felt sadness, frustration and worry. At times, these have come simultaneously, seemingly reflecting the complex emotional experiences of people who support children affected by PMHP. Self-reflexivity and supervision have been essential. I endeavour to be transparent about these processes throughout this report, and embrace my role and responsibility in what and how I write. Approaching this research within a qualitative paradigm, I acknowledge my potential bias and nearness to the topic, and my intention that this piece of work contributes meaningfully to understanding about this group of caregivers. One means of doing this is first person dialogue, which I use intentionally to bring my voice across.

1.1.2. Philosophical approach to the research.

Learning about social constructionism (Burr, 2015; Gergen, 2001) as a Masters student was pivotal for me. Initially, the impact appeared to be on my academic development. However, as time passed, I realised that the conceptual shift required to explore constructionism had evoked something much greater, opening new ways of approaching meaning and knowledge. Concerned with how and why individuals construct meaning about the world and themselves within it, social constructionism emphasises the centrality of interaction and questions the nature of 'truth' (Crotty, 1998). Clinically I find this a useful position for relinquishing an 'expert' stance and embracing ambiguity (Anderson & Goolishian, 1992).

Simultaneously, contesting the legitimacy of the physical world and questioning lived experience is not always helpful or therapeutic in clinical settings (Smail, 2005). This is also pertinent to the modern fiscal and socio-political context, which shapes the 'real' and felt human experience of society and influence and how psychology operates within it. Letourneau and Allen (1999) posit that the human mind may only be able to partially glimpse the nature of an independent world, yet the results of its causal forces may be apparent, whether physical or social. As Smail (2004) conjectures, "It is not people's intentions, decisions, beliefs and wishes that count, but the ways in which people, via their interests, are and have been caught up in the swirling currents of power in the world around them."

I am therefore interested in understanding how individuals make sense of the combination of psychological and physical embodied experience and the constructed interaction and culture that occur beyond them. This is more closely aligned with a critical realist ontology (Parker, 1999), from which I approach this work.

1.2. Language, Terminology and Key Concepts

It is necessary to clarify terms and language use before proceeding. I take a stance of linguistic relativism: that the language we use influences what and how we think. This is pertinent to mental health, where the growing voice of people with lived experience contributes to rapid evolution in terminology. Variability in language use in the parental mental health literature also makes it necessary and is typical of a developing concept.

Authors' experiences of MHP, the mental health discourses of the societies they live in, and their professional and academic experiences can be seen to structure their language use. I am unavoidably affected by such factors and therefore aim for transparency. I acknowledge that the terms I use might not be chosen by others, not even by all participants in this study.

1.2.1. Mental health problems.

Within the literature, frequently used terms for mental and emotional challenges are: 'mental illness', 'mental ill health', 'mental health problems', and 'mental health difficulties'. Psychiatric diagnoses defined in diagnostic manuals (American Psychological Association, 2013; World Health Organization [WHO], 2016) are also commonly used, including 'bipolar disorder', 'schizophrenia', 'psychosis', 'major depressive disorder' and 'personality disorder'. These terms appear in most peer-reviewed journal articles, books and reports by professional and third-sector organisations[1], and also in writings by people with lived experience.

Alongside this, an increasing body of literature favours terms that emphasise the person and disconnect from the stigma of diagnostic labels (Timimi, 2014), including: ‘lived experience’, ‘mental wellbeing’, ‘survivor’, ‘person with mental health challenges’ and ‘service user’. These choices separate from or reject the medical-model understanding of psychological distress as ‘illness’ (Crossley, 2004).

I agree with Focht and Beardslee (1996) that it is important to address the tensions between the modernist view that psychiatric disorders exist as ‘real’ entities and the postmodern stance, which privileges multiple interpretative frameworks of ‘truth’. Furthermore, greater consensus on terminology would support the development of shared concepts and research dissemination in this topic area. This, my epistemological stance and the research objectives have guided my language choices.

This study aimed to engage with a heterogeneous sample of family caregivers across society. It was expected that many families would be in contact with health and social care services but others would not, whether by choice or circumstance. Some might not align with dominant UK medical-model health discourses. In all cases, it was important to use language that was familiar and relevant to different participant groups[2].

Consequently, the terms *mental health problems* and *parental mental health problems* are used. My intention is to be clear about the nature of the challenges but without the assumption of ‘illness’ rather than ‘distress’. *Severe and enduring* is used to signal difficulties with a broad-reaching and long-term impact (as compared with ‘mild’ or ‘moderate’), as per the widely-

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[1] For example, bodies such as the British Psychological Society (BPS) and organisations like MIND and Re-think.

[2] These language choices affected promotional material for the study and recruitment methods. This will be discussed further in Chapter 2.

used National Service Framework terminology for differentiating MHP severity (BPS, 2002).

Where other terms are used, it is because other authors' work is being discussed. In line with a person-centred approach, participants' preferred terms were used during interviews and in the Results and Discussion.

1.2.2. Children's family caregivers.

How to refer to relatives who support children due to PMHP emerged early on as a challenge. In some cases they also care for the parent, but not always. Due to the dearth of work with these individuals the literature provides no clear term, even less a selection to choose from. References to 'supporting family members' and 'the family' exist, while some studies specifically discuss 'partners and other relatives' (Reupert & Maybery, 2007), 'other carers' (Nolte & Wren, 2016), and 'current supportive relationships' (Rogsoch, Mowbray, & Bogat, 1992).

'Alternative caregiver' or 'other caregiver' was considered initially, but feedback from peer and service user consultation suggested that 'alternative/other' minimised the usual co-parenting role of many participants. Consequently, after further consultation, the term *children's family caregivers* was selected.

1.3. Parental Mental Health Problems: The Impact on Families

1.3.1. Prevalence.

Estimates suggest that between 1:4 and 1:6 adults in the UK will experience a MHP[3] in their lifetime (Royal College of Psychiatrists (RCP), 2017; McManus, Bebbington, Jenkins, & Brugha, 2016). More than half are parents: approximately 68% of women and

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[3] Specified as depression, generalised anxiety disorder (GAD), panic disorder, phobias, obsessive-compulsive disorder (OCD), and bipolar disorder (BD).

57% of men (RCP, 2017). UK prevalence of severe and enduring MHPs[4] among adults was estimated at 0.7% (1 in 100-200) in 2014, with the highest rates in those aged 35-44 (McManus et al, 2016). Around a third of these adults live with children, with higher incidence in single-parent households (Mental Health Foundation, 2010). Overall, PMHP is thought to affect approximately 2.5 million UK children (Tunnard, 2004).

The burden of PMHP for families is evidenced as significant. Approximately 13-15% of the UK carer population support someone with a severe MHP, although estimates rise above 25% when co-occurrence of mental and physical health problems is included (Carers Trust, 2017; NHS, 2010). An estimated 50,000-200,000 children are young carers due to PMHP and many support younger siblings (Mental Health Foundation, 2010).

McManus and colleagues (2016) note that published statistics are likely underestimated, particularly due to mixed data collection and reporting methods, and exclusion of certain diagnoses[5]. Under-reporting is substantial in BME communities where MHP may be conceptualised differently or highly stigmatised (McManus et al, 2016).

1.3.2. Children's outcomes.

There is now an established base of large-scale quantitative research conducted primarily in Europe, the USA and Australia that evidences the increased risk of psychosocial difficulties among children with a parent with severe and enduring MHP. Compared to their unaffected peers, these children are consistently found to be more likely to develop attachment difficulties (Fonagy, Steele, Steele, Moran, & Higgitt, 2001), internalising and externalising problems (Dean, Stevens, Mortensen, Murray, Walsh, & Pedersen, 2010; Van Loon, Van de Ven, Van Doesum, Witteman, & Hosman, 2014),

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[4] Specified as schizophrenia, schizoaffective disorder and affective psychosis (but not including psychosis associated with dementia.)

[5] Particularly personality disorder

and psychological problems (Meltzer, Gatward, Goodman, & Ford, 2000). They may be up to five times more likely to access mental health services (Plass-Christl, et al., 2017).

Poorer outcomes for children correlate with a more conflicted, less cohesive and less communicative family environment (Plass-Christl, et al., 2017; Van Loon et al, 2014). This implicates the family context beyond the parent-child relationship. The social deficits associated with growing up around PMHP appear to contribute to intergenerational transmission of psychological difficulties via global attachment styles, learned adjustment and coping patterns, and social challenges (Foster, 2015). Reduced emotional responsiveness in parents is associated with poorer mentalising in children and over-identification with parent mood states, increasing their risk of relationship difficulties and poor self-concept (Sharp & Fonagy, 2008). A mounting body of research with adult children of parents with PMHP documents intimacy difficulties, anxiety and depression and caregiving burden into adulthood (Foster, 2010; Knutsson-Medin, Edlund, & Ramklint, 2007).

Importantly, however, not all children experience poor outcomes (Walsh, 2009). Positive mediating factors are associated with better parent-child interaction and family communication. These include parental emotional availability and nurturance (Elgar, Mills, McGrath, Waschbusch, & Brownridge, 2007), encouraging self-disclosure in children (Van Loon et al, 2015) and cohesiveness among extended family (Barber & Buehler, 1996). Many children with a parent with MHP go on to become adults with high resilience and adaptive coping skills (Polkki, Ervast, & Huuponen, 2004). These protective characteristics have been related to having caring responsibilities and independence at a younger age and effective professional intervention (Foster, O'Brien, & McAllister, 2004).

Qualitative enquiry from children’s and parent’s perspectives during the last decade has started to unpick what underlies these complex outcomes. Parents want to reduce the negative impact on their children and are orientated to the practical and emotional pressures upon them (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). However, when parents evaluate their child's mental health in the same way they do their own, or family relationships are 'enmeshed', the child's needs can be minimised or unseen (Ackerson, 2003; Stallard et al, 2004). Some parents report difficulty relating emotionally to their children, but are uncertain how to address this at home or with professionals (Wang & Goldschmidt, 1994). This demonstrated the relevance of mental health education for families, children's needs being differentiated from their parents' needs and the potential benefit of other supportive adults being involved.

Qualitative findings have also highlighted positives, with parents and children describing good relationships and appreciating fun times together (Meadus & Johnson, 2000; Mordoch & Hall, 2008) and parents taking pride in parenting (Ackerson, 2003). Children often express love and worry about their parent, and try to reduce parental suffering by doing housework and supporting their siblings (Trondsen, 2012; van Parys & Rober, 2012). When child distress remains low, this responsibility-taking is associated with higher resilience and emotional literacy outcomes (Power, et al., 2016).

Open dialogue about PMHP has been associated with better psychological outcomes for all family members (Yamamoto & Keogh, 2018). Nonetheless, children frequently conceal PMHP to protect the parent or avoid stigma and shame. Children who are told to stay silent can feel they have nobody, which may increase reliance on less helpful coping strategies (Yamamoto & Keogh, 2018).

1.3.3. Childcare implications for relatives.

Increased emphasis on community care since deinstitutionalisation means that the responsibility for supporting a family member with MHP falls increasingly on relatives, including providing childcare (Magliano, Mcdaid, Kirkwood, & Berzins, 2007). Mental health service closures and bed reductions over the past ten years have intensified pressures on relatives, coupled with poor rebalancing through investment in community resources (Thornicroft & Tansella, 2013). When a parent is less emotionally or physically available for mental health reasons, children often become dependent upon their immediate or extended family members (Nicholson, Sweeney, & Geller, 1998).

Childcare in the PMHP context is known to take many forms: the other parent may shoulder more parenting and housekeeping duties than usual; an aunt living nearby may help with the school run; grandparents may take parental responsibility under a Kinship Care or Special Guardianship Order (SGO); and many other scenarios (Reupert & Maybery, 2007). Crucially, children's family caregivers contribute to the consistency of their emotional care, attachment relationships, and practical needs (Davey & Lynch, 2016; Fischer & Gerster, 2005; Reupert & Maybery, 2016). Relatives may facilitate and protect the parent-child relationship, for example, taking children to visit the parent in hospital (Cunningham, Oyebode, & Vostanis, 2000; Marrs, Cossar, & Wroblewska, 2014). Informal family support with childcare has been associated with less frequent parent mental health crisis, parents retaining custody of children (Ackerson, 2003; Rudder, Riebschleger, & Anderson, 2014) and better psychological outcomes for children (Winokur, Holtan, & Batchelder, 2014). Relationships with relatives have been found to protect children's psychological health by fostering resilience and promoting meaning-making about PMHP (Reupert & Maybery, 2007). Many parents report being aware that relationships with other caregivers can permit children to narrate, express emotions and develop understanding about the MHP in a context where they feel less burdened and protective (Nolte & Wren, 2016). Children themselves have talked about the helpfulness of relatives and family friends in managing the effects of PMHP, particularly by gaining emotional support (Handley, Farrell, Josephs, Hanke, & Hazelton, 2001; Mordoch & Hall, 2008).

It is important to note, however, that family caregiving responsibilities – whether for parents, children or both – are associated with significant burden for relatives themselves. The shock of a mental health diagnosis can result in fear and confusion (Outram, et al., 2015). Subsequently, caregivers frequently experience psychosocial challenges and reductions in quality of life, including disruption of leisure activities and career, increased isolation, emotional distress, parenting stress, financial burden, grief and burnout (Ostman, 2007; Rudder, Riebschleger, & Anderson, 2014; Gallagher & Mechanic, 1996). Many describe fluctuating loss of hope for the future (Rose, 1983) and stigma from peers, professionals and strangers (Bruland, Lenz, & Wahl, 2017). Adjusting to role change and loss can be a unique challenge especially for custodial grandparents (Ziminski, 2007). Possibly unsurprisingly, parenting stress can be worse for older custodial grandparents (Conway, Jones, & Speakes-Lewis, 2011; Seeman, 2009). Custodial grandmothers can be particularly vulnerable to experiencing low mood, especially when there are child behavioural difficulties (Goodman & Silverstein, 2006).

Lack of professional support is a common barrier to addressing these challenges, and providing childcare informally often means caregivers' needs go unrecognised (Afzelius, Plantin, & Ostman, 2018). This literature documenting caregiver burden has been criticised, however, for its often-negative bias: many caregivers also describe an enjoyable sense of purpose and a desire to support their family (Hayslip & Kaminski, 2005). Furthermore, differences in wellbeing outcomes among different ethnic populations indicate the relevance of cultural expectations about caregiving upon perceived burden (Goodman & Silverstein, 2006).

Therefore, research with parents with MHP and their children has highlighted the vital role of relatives who support them, including their seemingly substantial and often unrecognised needs (Chatzidamianos, Lobban, & Jones, 2015; Stallard et al, 2004). There are increasing calls for research to develop better understanding of how family caregivers shape the family environment (Nolte & Wren, 2016; Reupert & Maybery, 2016; Saunders, 2009). As will be discussed in the following overview of UK health and social care policy, families, researchers, clinicians and policymakers alike endorse the inclusion of children's family caregivers in family-focused interventions (Beardslee, Gladstone, & Forbes, 2007; Reupert, et al., 2016; Yamamoto & Keogh, 2018; Yates & Lina, 2017).

1.4. UK Health and Social Care Context of Informal Family Caregiving

1.4.1. The 'whole family' approach.

Increasing awareness of the impact of PMHP on children and relatives has been reflected in UK policy during the last decade. A key strategy of the national agenda to integrate Health and Social Care (Department of Health, 2013)[6] is to shift the focus from the person with MHP to the family. From this perspective, family bonds are seen as social capital and children's and relatives' needs are incorporated.

The *Families at Risk* review (Cabinet Office, 2007; 2008) highlighted the potentially dramatic impact for children of parental circumstances, including PMHP. The trend toward individualised interventions for adults was recognised, as were the multiple disadvantages (e.g. financial hardship, social isolation), which affected families often face (Office of National Statistics, 2006). The review identified that services often had little or no impact in the longer term and did little to mitigate the environmental factors increasing risk for children. The *Reaching Out: Think Family* report (Cabinet Office, 2008)

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[6] Although this policy relates specifically to England, health and social care integration is a key policy objective for the devolved governments of all UK countries. Northern Ireland has had integrated services since 1973, while Scotland and Wales introduced integrated structures in 2004 and 2009 respectively.

and *No Health Without Mental Health* agenda (Department of Health, 2011) both asserted the need for strengths-based family approaches to reduce intergenerational transmission of MHP and recommended the inclusion of caregiving relatives in interventions. Being excluded from health settings due to confidentiality was a frustration frequently reported by relatives.

Beyond various stand-alone tools and theoretical family therapy orientations, however, there continues to be limited elaboration of what constitutes a 'whole family approach' in practical terms. Many adult mental health services continue to see parents with MHP individually, virtually ignoring parenting; this problem is not new (Fraiberg, 1978). Psychologically distressed children are usually referred and treated separately. Current challenges include detraction from collaborative practice due to funding deficits, reserving multi-disciplinary approaches for 'complex' cases, and failures of social policy to accommodate modern family structures (Clarke, Hughes, & Morris, 2009). Indeed, the national agenda for integrated care recently reported no overall improvement in psychosocial outcomes, only local successes (National Audit Office, 2017). Going forward, recommendations still focus on supporting collective family needs and involving relatives (The King's Fund, 2016).

The BPS (2015) called on the education sector to include these systemic psychological considerations in school-improvement agendas too. In 2017, the Health and Education Select Committees advocated a 'whole school' strategy to promote children's mental health. While parental input and family responsibility were strongly emphasised, however, neither the impact of PMHP nor the childcare roles of other relatives were mentioned.

1.4.2. Carer legislation.

In 2008, the 10-year Carers Strategy, *Carers at the heart of 21st century families and communities* (Department of Health), addressed the increasing burden on family caregivers due to demands on public services. Identified priorities for carers were annual health checks and better psychological support. Carers Strategy updates also attended to caregivers' parenting and work statuses (Department of Health: 2010, 2014).

Patterns of deteriorating mental and physical health are seen uniformly in unpaid carers across all economic levels, increasing with weekly hours of caregiving (Adcock, et al., 2017). A common challenge is finding time for respite and self-care, and many are unaware that legislation exists to support them (Adcock, et al., 2017). The Care Act 2014 placed responsibility on local authorities to identify individuals requiring assessment. The specific needs of old-age carers, young carers and dementia carers are increasingly well defined but less has been done to target mental health caregivers. Recommendations would most usefully take into account the commonality of multi-generational caring responsibilities among this population, which frequently includes the adult relative with MHP, dependent children and elderly parents.

Third sector and community provision for unpaid carers is considerable, both nationally and locally. Again, the focus is often on family carers of elderly relatives and people with dementia. Among mental health charities, mutual support groups for family caregivers are becoming more common, as are young carers organisations. Overall, however, provision for mental health caregivers continues to lag behind, including for those with childcare responsibilities.

Regarding childcare arrangements, UK legislation (e.g. *Family and Friends Care: Statutory Guidance for Local Authorities*, 2011) upholds the position in the Children's Act 1989 that kinship care is preferable to non-kin fostering where possible. It recognises informal and formal kinship fostering under Care Orders, Residence Orders and Special Guardianship Orders (SGOs). Kinship carers may have access to local authority services and financial provision but both seem subject to a 'postcode lottery' (Farmer & Moyes, 2006;

Grandparents Plus, 2013). Loss of professional support can be a significant challenge when guardianship arrangements are formalised (Farmer & Moyes, 2008).

Despite these provisions, a central issue for informal family caregivers is whether they identify, or have been identified, as carers (Cowling, Seeman, & Gopfert, 2010). For example, a father whose spouse has MHP may shoulder the childcare and support his partner, but identify simply as 'dad' rather than 'carer'. Therefore, although interest in children's family caregivers is growing, they remain largely 'hidden'.

1.5. The Relevance of Making Meaning and Communicating about PMHP.

As already highlighted, PMHP can significantly impact children's psychosocial wellbeing. Informal relationships with family caregivers have been found to be protective for children, as have opportunities to talk and make meaning about their parent's MHP. As Focht and Beardslee (1996) clarify, 'meaning-making' in this sense does not preclude acknowledging a potential biological aspect to MHP. It goes beyond diagnostic descriptions, however, to a deeper level of interpretation where families consider the effects of MHP-related emotions and behaviours and develop insight into their own interpretations.

Before going on to systematically and critically examine how family caregivers make meaning and communicate about MHP, it is important to briefly consider the perspectives of children and parents themselves.

1.5.1. The impact for children.

At a systemic level, family communication has been evidenced as the most influential factor in shared adaptation and coping with PMHP (Jonker & Greeff, 2009). Talk can benefit relationships and improve children's conceptualisation of parental difficulties by providing terminology and encouraging future communication (Focht-Bickerts & Beardslee, 2000; Beardslee & Podorefsky, 1988). Mental health literacy (i.e. knowledge) helps children to interpret and predict parental behaviour, which improves their coping (Pikhala, Sandlund, & Cederstrom, 2011) and healthy 'self' and 'other' identification (Cooklin, 2013; Focht & Beardslee, 1996). As Cooklin (2013, p.235) summarises, "an important goal of explaining to the child about the parent's illness is to help the child view the parent from 'outside'."

A few studies report that a large minority of children do not want more information and not all parents feel it would be appropriate (Stallard et al, 2004). Stallard and colleagues (2004) suggest that openness is especially beneficial in these situations, to assist with assessing children's perceptions and avoiding overburdening them. There is a need for further research to examine when and why sharing might not be helpful. Nevertheless, the majority of studies report that most children, parents, relatives and professionals want children to know more about PMHP and see value in talking (Dam & Hall, 2016).

Despite this wish, uncertainty about how, what and when to talk to children about 'the elephant in the room' is a common theme (Reupert, Cuff, & Maybery, 2015). For parents, issues centre on the age-appropriateness and timing of information, fear of initiating dialogue, and protecting children's innocence (Pikhala & Johansson, 2008; Yamamoto & Keogh, 2018). Desire to shelter children from the 'realities' of mental health, even when parents believe knowledge will benefit them, can significantly inhibit talking (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). Additionally, deciding what to share and what to keep private can cause confusion (Focht & Beardslee, 1996). Consequently, children miss opportunities to put their experiences into words.

Nolte and Wren (2016) reported a slightly different perspective, finding that parents with MHP sometimes refrained from talk because they assumed children already understood because of what they had witnessed at home. However, as the authors warn, seeing does not necessarily mean understanding. Indeed, children up to mid-childhood often describe PMHP via behavioural description rather than in more sophisticated relational or emotional terms: "One girl said, 'What I see as mental illness is that you don't get all your facts straight and you are slow at most things you do'." (Riebschleger, 2004).

For children, having unexplained thoughts and feelings about PMHP can contribute to fear of 'catching' the MHP or of their parent dying (Mordoch, 2010). They may blame themselves for unusual parental behaviour or hospitalisation (Mordoch & Hall, 2008). As this shows, children tend to make meaning via their internal reactions and may attribute meaning to parenting behaviours rather than to the MHP (Riebschleger, 2004). Better mental health literacy is thought to guard against this by promoting children's ability to narrate a coherent account of their experiences (Main, Kaplan, & Cassidy, 1985). At times of crisis, children often seek reassurance and meaning from the parent or other caregivers (Maybery, Ling, Szakacs, & Reupert, 2005; van Parys & Rober, 2012). Parent-child talk about 'normal life' during hospitalisations appears to promote closeness, with humour supporting intimacy (Nolte & Wren, 2016). However, children's willingness to ask direct questions can impact whether caregivers initiate mental health talk, and vice versa (van Parys & Rober, 2012).

1.5.2. Supporting family meaning-making processes.

It is thought that family talk about PMHP often happens sporadically, interspersed through daily conversations (Nolte & Wren, 2016), which fits with children's descriptions of learning about it gradually over a long time (Riebschleger, 2004). Particularly in the absence of intervention, conversations tend to be child-led and focus on the questions they have thought to ask (Reupert, Cuff, & Maybery, 2015). It is widely reported, however, that families would value more support with talking to children about mental health, including advice about timing, terminology and age-appropriateness (Ackerson, 2003; Jones, Pietila, Joronen, Simpson, Gray, & Kaunonen, 2016).

This has been recognised and a growing number of studies evidence that promoting communication about PMHP in families is possible and effective. Approaches include in-person, online and written psychoeducational approaches (Cooper & Reupert, 2017; Grove, Melrose, Reupert, Maybery, & Morgan, 2015; Fadden & Heelis, 2011; Sherman, 2006), peer support programmes for children (Foster, McPhee, Fethney, & McCloughen, 2016; Gladstone, McKeever, Seeman, & Boydell, 2014; Hargreaves, Bond, O'Brien, Forer, & Davies, 2008) and family-focused interventions (Beardslee, Gladstone, Wright, & Forbes, 2007; Margolis & Fernandes, 2017; Wolpert, Hoffman, Martin, Fagin, & Cookin, 2015; Yates & Lina, 2017). Most interventions target parents and children, although some address family system and subsystem interaction (Biebel, Nicholson, & Wolf, 2016). Meta-analytic evidence suggests that this joint intervention is most effective (Thanhauser, Lemmer, de Girolamo, & Christiansen, 2017). Intervention evaluations consistently find that children report less worry after knowing more about MHP and relief at being able to talk (Pikhala, Sandlund, & Cederstrom, 2011). Parents report feeling motivated and supported by having their parenting role recognised and incorporated into their treatment (Mowbray, Oyserman, Bybee, & MacFarlane, 2002; Wang & Goldschmidt, 1996). Parents have also reported increased marital strength, mental health knowledge and family communication (Beardslee, Gladstone, Wright, & Cooper, 2003)

As discussed, however, limitations in family-focused adult mental healthcare mean provision of such interventions is the exception rather than the norm. Cultures of austerity and individualism appear to significantly impede systemic approaches due to chronic under-resourcing; the number of clinicians with sufficient skills to intervene presents an organisational barrier (Maybery & Reupert, 2006). For caregivers, the reality of supporting family life often means working and interventions in the daytime cannot be attended. Family relationship breakdowns may further hinder attendance. In cases of parental hospitalisation, staff play a key role in guiding discussions with children, although families report that this does not always happen (O'Brien, Anand, Brady, & Gillies, 2011). Consequently, there are often significant constraints to professional support, and the responsibility of communicating with children falls to the family.

Nolte and Wren (2016) found that parents often wanted or expected others to provide information to their children, especially when they felt less able to communicate for mental health reasons. However, the authors found a surprising lack of curiosity from parents about what children were told or whether communication actually happened. It might be that parents assume such talk occurs and is led by relatives. Children’s family caregivers are more likely to engage in mental health talk with children when PMHP renders the parent less available (Rudder et al, 2014), with explanations sought more by children at these times (Cunningham, Oyebode, & Vostanis, 2000; Tabak, et al., 2016). Caregivers’ roles in shaping children’s experiences of PMHP and supporting communication are clearly important, yet there is a striking dearth of research or intervention with this group beyond the recommendation of their inclusion in family-focused approaches. A lack of clarity about the role of children’s family caregivers in family dynamics and communication may underlie this.

1.6. Systematic Literature Review

1.6.1. Overview.

The research discussed has highlighted the significant burden, social and economic costs and health risks that PMHP pose to children and relatives. Simultaneously, families often report positive relationship factors and many children become resilient adults. Nonetheless, what emerges from research into child and parent perspectives is that children’s worry about PMHP is often under-recognised, and their desire to make meaning may be hampered by various barriers to communication. Professional intervention is effective when it is available and engaged in, but questions remain about how consistently this occurs in practice.

Although the literature addresses the psychosocial effects and practical burdens for relatives involved in caring for the parent and/or child, it does not unpack how they make sense of PMHP nor the influence this may have on the family. Consequently, a systematic review of peer-reviewed primary research was conducted to examine existing knowledge about adult relatives’ meaning-making and communication experiences regarding their family member’s MHP.

1.6.2. Search strategy.

The search initially aimed to find papers about the meaning-making and communication experiences of the adult relatives of *parents with MHPs*. Due to low numbers, however, this was extended to the adult relatives of *any adult with a MHP*. As searches progressed, the search terms were refined as shown in Table 1 and Table 2.

Table 1: Key search terms used in initial searches

AND	NOT
"parent* mental health problem" OR "parent* mental health difficult*" OR "parent* mental ill*" OR "parent* mental well*" OR “parent with mental health” OR “parent with mental ill*”	autism OR ADHD OR ADD OR “attention deficit disorder” OR "learning disability" OR "intellectual disability" OR “developmental disabilit*” OR cancer OR “multiple sclerosis” OR diabet*
Child* OR famil* OR care* OR relative	

Table 2: Key search terms used in follow-up searches

AND	NOT
"relative with mental health" OR "relative with mental ill*" OR "relative with schiz*" OR "relative with bipolar" OR "family member with mental health" OR "family member with mental ill*" OR "family member with schiz*" OR "family member with bipolar"	autism OR ADHD OR ADD OR "attention deficit disorder" OR "learning disability" OR "intellectual disability" OR "developmental disabilit*" OR cancer OR "multiple sclerosis" OR diabet*
meaning OR understand* OR communicat* OR talk* OR experienc* OR impact	
Child* OR famil* OR care* OR relative	

Searches were conducted of the SCOPUS, Pubmed, Psychnet, Social Care Institute for Excellence, CINAHL+ and Cochrane databases. No publication date limits were applied. Subsequent consultation with topic experts and reviews of key papers' reference lists and key journals led to consideration of additional articles. Relevant articles were identified through a staged process of reviewing abstracts and full texts according to inclusion and exclusion criteria (Table 3). See Figure 1 for a flow chart of the process.

Table 3: Inclusion and exclusion criteria for systematic literature review

Inclusion criteria	Exclusion criteria
Focuses on adult relatives of someone with a severe and enduring mental health problem (also an adult).	Research only with children or parents with PMHP themselves.
Gathers information about relatives' meaning-making or understanding about the mental health problem and/or their family communication experiences.	Retrospective focus on adult children's childhood experiences or their adult adjustment.
Article available in English.	Intervention evaluations or epidemiological research.
	Research exclusively with non-relatives or professionals (including friends, volunteers, befrienders and support workers).
	Not primary research; not peer-reviewed.

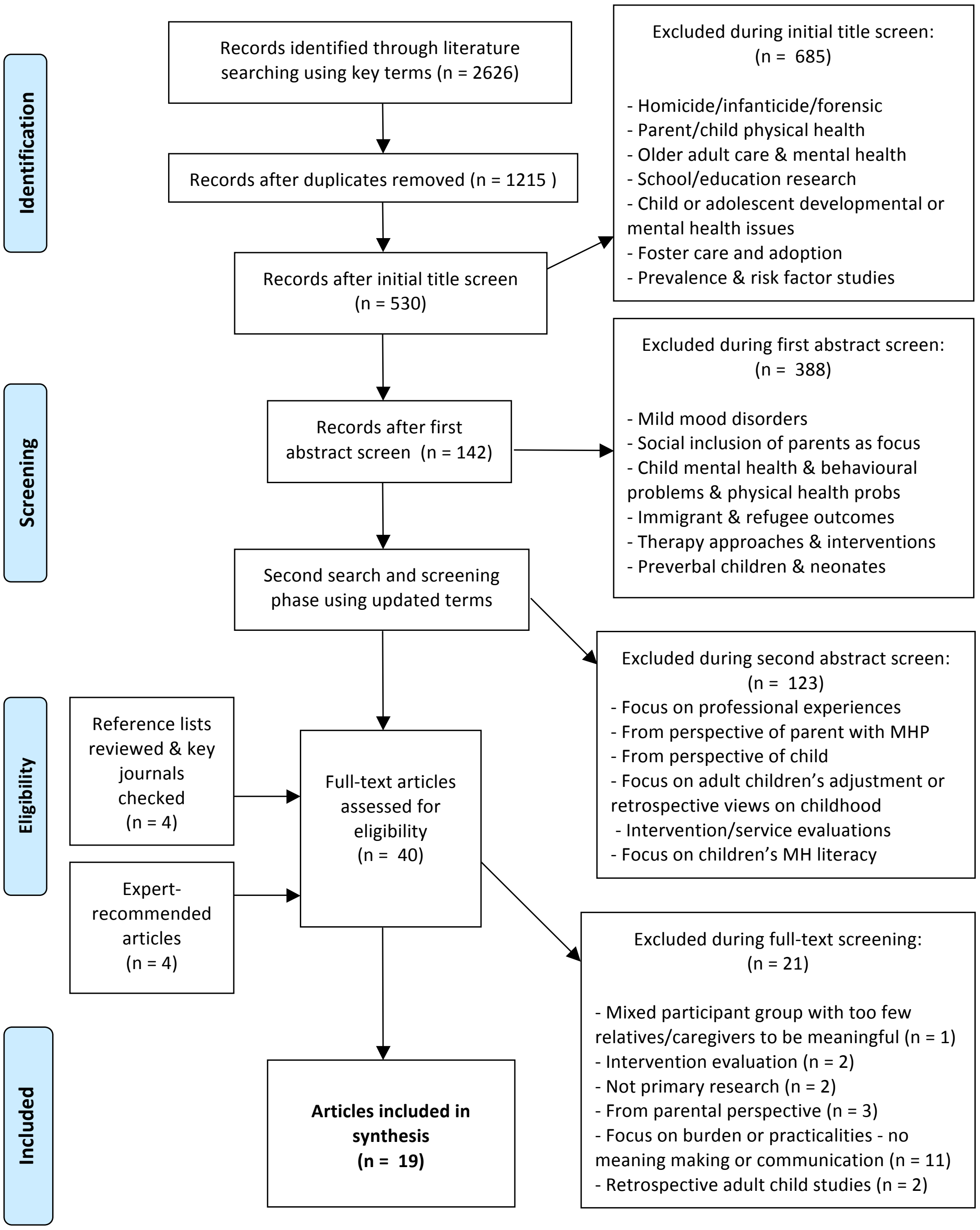

Figure 1: Flow diagram of systematic literature search process

1.6.3. Systematic review method.

The review aimed to critically evaluate and integrate the findings of relevant peer-reviewed studies. The intention was to establish what is already known, seek relationships between concepts and identify contradictions, to allow formulation of an overarching conceptualisation of the topic area to inform this study (Cooper, Hedges, & Valentine, 2009).

The process described by Siddaway et al (in press) was followed. Articles were carefully read with particular attention to the method and results. An article-by-article summary can be found in Appendix B. Recurring themes were noted and compared across papers. These shared findings were integrated into categories for discussion and checked back against the papers to ensure a representative synthesis. Contrasting and inconsistent findings are reported alongside the main themes below.

1.6.4. Summary of reviewed literature.

Nineteen articles were reviewed for their aims, findings, implications and quality. Quantitative, qualitative and mixed methods studies were assessed but the final set comprised qualitative papers only. This is understood as a result of the focus on meaning-making and communication.

The studies were conducted in 11 countries, most commonly Australia and the USA. Sample sizes ranged between 6 and 50 caregivers. Participants' relationships to the person with MHP varied but were most commonly parents, followed by spouses and siblings. The majority of participants were female. Due to awareness of a gender imbalance, two studies recruited male caregivers only.

Many participants cared for their relative with MHP, although not exclusively, and many also had caring responsibilities for other family members, including children. A number of studies did not provide detail about this, focusing instead on 'family member' experiences. Authors' own terms for caregivers and mental health are used throughout the review to capture the variation.

Table 4: Design characteristics of studies included in the systematic review

Design element	Option	Number of studies
Analysis method	IPA	5
	Grounded theory	5
	Thematic analysis	5
	Narrative	1
	Immersion/crystallisation analysis	1
	Not stated (coding and categorising procedures described)	3
Temporal design	Cross-sectional	19
	Longitudinal	1
Country conducted in	Australia	5
	USA	4
	UK	2
	Sweden	2
	Belgium	1
	Japan	1
	Jamaica	1
	Norway	1
	Canada	1
	The Netherlands	1
	India	1
Caregiver type(s)	Mixed (Including: spouses, parents, siblings, adult children and cousins)	12
	Spouses only	3*
	Parents only	1
	Male caregivers only	2*
	Female caregivers only	1
	Not stated/unclear	2
Sample size	Range	6 – 50
	Mean	16.7
	Median	14.5
Studies where the relative with MHP was a parent	All relatives were parents	1
	Some relatives were parents	15
	Not stated/unclear	4

* Mizuno, Iwasaki Sakai (2011) is represented twice here as their sample included husbands only.

1.6.5. Quality assessment.

Tracey's (2010) 'Big-Tent' framework was used to help evaluate study quality. The varying epistemological and ontological underpinnings of different qualitative methods *and* quality assessment frameworks present a challenge to using universal criteria (Lincoln & Guba, 1985). Nonetheless, such frameworks are invaluable tools for assessing research formally and consistently against shared values. Tracey's (2010) eight criteria orient the assessor towards 'common markers of goodness' across qualitative approaches in a way that allows for paradigmatic differences: this broad structure provides the 'big tent' framework (Denzin, 2008). The extent that studies met the criteria is represented graphically in Table 5 and verbally in Appendix A. Study strengths and limitations are discussed as part of the systematic review findings with a comparative quality summary provided later in the chapter.

I will now present and compare the findings of the reviewed studies. The research covers four broad topic areas for relatives: (1) making meaning about the MHP and affected individual; (2) conceptualising the self in the presence of the MHP; (3) meaning-making processes underlying relatives' wellbeing outcomes; and (4) relatives' perspectives on family communication about the MHP. The review findings are synthesised into an integrated evaluation towards the end of the chapter.

Table 5: Comparative summary table showing the extent that papers included in the systematic review met Tracey's (2010) 'big-tent' quality assessment criteria.

PAPER	1. WORTHY TOPIC	2. RICH RIGOUR	3. SINCERITY	4. CREDIBILITY	5. RESONANCE	6. SIGNIFICANT CONTRIBUTION	7. ETHICS	8. MEANINGFUL COHERENCE
Ballal & Navaneetham (2018)	✓✓	✓	✓✓	✓	✓✓	✓✓	✓	✓✓
Endrawes et al. (2007)	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓
Fraser & Warr (2009)	✓✓	✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓
Jonsson et al. (2011)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Karnieli-Miller et al. (2013)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓	✓✓
Karp & Tanarugsachock (2000)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Lawn & McMahon (2014)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Maenhout et al. (2014)	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Mizuno et al. (2011)	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Pusey-Murray & Miller (2013)	✓✓	✓	X	✓	✓	✓✓	✓	✓
Rose (1998)	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓	✓✓
Rose et al. (2002)	✓✓	✓✓	✓	✓	✓✓	✓✓	X	✓✓
Rusner, et al. (2012)	✓✓	✓✓	✓	✓	✓✓	✓✓	✓✓	✓✓
Stern et al. (1999)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
Tranvag & Kristoffersen (2008)	✓✓	✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Veltman et al. (2002)	✓✓	✓	✓	✓✓	✓✓	✓	✓	✓✓
Van der Sanden et al. (2015)	✓✓	✓✓	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Wynaden (2007)	✓✓	✓✓	✓	✓	✓✓	✓✓	✓	✓✓
Yeung et al. (2017)	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓

Key: ✓✓ = Criteria well met ✓ = Criteria partially met X = Criteria not met

1.6.6. Systematic review findings.

1.6.6.1. Making meaning about the MHP and affected individual.

Six studies explored how relatives made sense of the MHP. They linked meaning frameworks with caregiving practices to varying extents. None directly addressed how relatives' conceptualisations impacted family members other than the person with MHP, although some pointed to these issues indirectly.

Jonsson, Skarsater, Wijk and Danielson (2011) conducted a thematic content analysis (TCA) with 17 relatives with a family member with bipolar disorder (BD). The people with BD determined sample selection, which is an ethical strength but potentially contributed to an imbalanced sample of mainly females and mothers. The researchers reported that understanding the MHP required participants to engage in constant interpretation of their family member's presentation. Letting the 'abnormal become normal' (p.32) and finding an acceptable explanation were highlighted as crucial stages for relatives in settling their own doubts and finding ways to explain to non-relatives. Participants were careful about how and to whom they talked, despite relief after doing so. The authors recommended that professionals support knowledge development as being able to discuss the MHP may strengthen relatives' social networks.

Examining meaning-making in depth, Stern, Doolan, Staples, Szmukler and Eisler (1999) conducted a narrative analysis of seven carers' stories. Considering Tracey's (2010) criteria, this study is rigorously and sincerely reported. The authors acknowledged researcher subjectivity, accounting for their influence in the hermeneutic circle. Stern and colleagues (1999) identified two dominant narratives. In 'restitution and reparation', initial experiences of disruption due to the MHP were followed by reconstructive processes that yielded meaning and positioning of the MHP in the carer's life. In 'chaotic and frozen' narratives, however, MHP experiences remained incoherent and carers spoke repetitively and confusingly. The authors emphasised the importance of supporting carers to find a ‘platform’ to structure their understanding, scaffold action and increase coping. They posited that high expressed emotion might hinder narrative reconstruction, highlighting this for future research. It could be hypothesised that carers’ narratives are shaped by other family members’ views, and opportunities to share experiences verbally; however, this is not discussed. Again, they had a majority female sample, but discussed this as a likely gender bias in caregiving rather than a sampling issue.

Similarly to Stern and colleagues, Rose’s (1998) rigorously reported grounded theory (GT) of caregiver meaning-making highlighted how meanings can develop into a guiding framework. Member checks of the model lent credibility to the findings. Rose (1998) reported a central theme of ‘essence of person’. Caregivers maintained connectedness with the person rather than the ‘illness’, which helped them process distressing behaviours and provided terms for communicating with others. This framework appeared to guide caregiver self-concept and decision-making, including when to talk or offer support. How it affected interaction with other family members, however, was not addressed. Rose (1998) notes that caregivers seek control and sense in the unpredictability of MHP; again, she emphasised the role of professionals in promoting these processes.

Three studies explored relatives’ meaning-making about the MHP in particular cultural contexts. All highlighted the impact of socio-political factors, biomedical perspectives and religiosity on individual-level mental health beliefs, and consequent instability in relatives’ meaning frameworks. As Yeung, Irvine, Ng and Tsang (2017) stated, “[relatives] alternated between the professional and the folk sector, or applied both Western traditions and traditional healing simultaneously” (p.596). This has implications for applying ‘western’ healthcare practices across cultures without sensitivity.

Two studies focused on migrants, specifically Egyptian families in Australia (Endrawes, O'Brien, & Wilkes, 2007) and Chinese families in England (Yeung et al., 2017). Endrawes and colleagues (2007) conducted an Interpretative Phenomenological Analysis (IPA) with seven relatives to explore caregiver experience; in places, their findings addressed meaning-making. Interviews were conducted in participants' mother tongue, Arabic, and translated into English, the limitations of which are discussed. The authors associated caregiver meaning-making with religious traditions and family obligations, noting the influence of "…obligation to maintain family ties…" (p.437). Nonetheless, within-family stigma and variation in mental health understanding was reported by participants: "even my elder son, when he gets angry, he would tell me 'it's in the genes Mum'" (p.436). First- and second-generation immigrant status influenced these differences, with older relatives more sceptical of medication and hospitalisation. The authors noted that a lack of shared meaning could be silencing and that language barriers hindered knowledge-gathering.

Yeung and colleagues (2017) interviewed five male and five female relatives in their preferred language, Cantonese or English, conducting a thematic analysis. The authors describe steps taken to address bias and assumptions. Similarly to Endrawes et al (2007), the authors concluded that cultural stigma hampered meaning-making due to beliefs that MHP should not be discussed outside the family. Males in particular took a long time to label their wives' unusual behaviours in mental health terms, using personality attributions instead. It is not discussed how this was addressed with the couples' children.

Finally, Pusey-Murray and Miller (2013) conducted focus groups with eight female caregivers in Jamaica, exploring perceptions of caring and medication non-compliance. They reported simultaneous use of medical and spiritual interventions by relatives. Uncertainty about the causes of MHP and the expense of psychiatric intervention were posited as reasons why both approaches continued to be used. Caregivers were described as "somewhat confused about what mental illness is" (p.116). Descriptions like "brain not functioning well" and "excess talking" were reminiscent of Stern et al's (1999) 'chaotic and frozen' narratives, indicating a lack of mental health literacy. Participants unanimously described medication as the means to control MHP. The authors' recommendations are political: establishment of a Disabilities Act in Jamaica to promote legislation about MHP. A small sample and poorly described aims and method weaken this study, but its findings are coherently discussed. The paucity of research into mental health caregiving in Jamaica makes this an important contribution.

1.6.6.2. Contextual social and emotional factors underlying relatives' meaning-making

Five studies reported on social and emotional processes that affected relatives' ability to make meaning and communicate their experiences and shaped their wellbeing outcomes. Van der Sanden, Bos, Stutterheim, Pryor and Kok (2015) looked at stigma-by-association of 23 relatives, attending particularly to gender, relationship to the person with MHP and cohabitation. Stigma-by-association was experienced most acutely by females, parents and spouses[7], and those cohabiting with their family member. When these caregiver types felt more blamed and more responsible for their family member's MHP, they reported greater stigma-by-association. Many participants described stigma from non-relatives, professionals and sometimes their families. Participants reported increased social isolation and silence about mental health due to stigma-by-association, and avoided contexts where it might come up. It was unclear whether this also led them to talk less with family members at home. The authors concluded that stigma-by-association challenged relatives' conceptualisations of the MHP, leading to negative patterns of

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[7] As compared to siblings and children.

relating to self and to others. They noted recruitment from support groups as a limitation as attendees often have poorer experiences of statutory services and family support, potentially skewing the findings.

Two studies examined the relationship between relatives' emotional processes and meaning-making. Karp and Tanarugsachock (2000) conducted a GT study with 50 participants, aiming to examine interrelations between caregiver emotional experiences and perception of the person with MHP. The sample over-represented white people and women, although the rigorous reporting enables consideration of the data by a wide range of audiences to whom the findings may apply. An unfolding caregiver emotional journey and corresponding development in the caregiver-relative relationship was evidenced, from 'pre-diagnosis' and 'diagnosis', to 'realisation of permanence' and 'acceptance'. The authors emphasised the historical caregiver-relative relationship as fundamental for understanding a caregiver's presenting emotional state and meaning-making, because past events shaped participants' interpretations of the MHP. This points to complex factors making up a relative's emotional position at any given time.

Taking a different angle, Veltman, Cameron and Stewart (2002) looked at caregiver experience with an emphasis on positive emotion. Again, the authors reported a mostly-female sample of 20 caregivers. Their acknowledgement of the potential for researcher bias lends credibility to the report. Although participants reported well-known caregiver burdens, the focus on positives yielded a less-heard narrative replete with love, pride and gratification. Caregivers described how these feelings gave meaning to their 'unconventional' lives, with the personal gains of 'finding value' and 'growing through pain'. Positive emotions were associated with relationship growth and improvements in family communication, suggesting them as important for communicating with children. Examining process would have enhanced the contribution of these resonant findings, particularly given the emphasis on family relations. While the authors appear to have followed a GT-type process of iterative constant comparison, they stopped short of the theory development that could elucidate these mechanisms.

Drawing together aspects of the social and the emotional, Tranvag and Kristoffersen's (2008) IPA study with six spouses and two cohabitants presented a model of cumulative adjustment incorporating 14 distinct adjustment experiences, such as 'fear and the incomprehensible', 'self-doubt' and 'dawning acceptance'. Mastering each new stage was described as contingent on progression at the previous stage. Perceived high burden was associated with later burdensome experiences, while good experiences were associated with more good experiences. Drawing on gestaltism, the authors theorised that spouses progressed through stages of disruption/imbalance and incomplete meaning (associated with self-doubt and familial conflict), to equilibrium and complete gestalts (associated with gaining insight and appreciation of togetherness). Mental health education, emotional awareness and family talk are suggested as vital components for achieving wholeness of meaning at each stage. Consequently, the authors call for intervenions that address these needs. The findings are strengthened by the two-interview process undertaken to permit model-checking, although there are limits to reporting a cumulative process via cross-sectional design as the authors have done.

Rose, Mallinson and Walton-Moss (2002), investigated contextual factors that affect families' responses to the MHP. Their longitudinal design was a more rigorous method for examining cumulative process than Tranvag and Kristofferson's (2008) cross-sectional approach. Rose and colleagues initially interviewed 29 relatives from 17 white, African-American and hispanic families in the USA. Twelve families completed two more interviews each over the next two years, although it is not reported how many participants this represented nor the demographic change. Rose and colleagues (2002) reported a basic social problem for relatives of 'living with ambiguity', which they responded to by 'pursuing normalcy'. The extent of their grief and anger was linked to whether they could update their view of 'normal' to account for the MHP, or pursued an approach of helping the person with MHP conform to social ideals of 'normalcy' and 'happiness'. In addition to pursuit of normalcy, the authors reported that participants' age-based expectations and pre-MHP knowledge of their family member impacted their meaning-making processes. These factors were seen to shape family interactions, particularly conflict and the desire to maintain stability. How these communication processes played out, however, was not explored in depth.

1.6.6.3. Conceptualising the self in the presence of the MHP

Five studies focused specifically on relative/caregiver identity. Two papers presented grounded theories focusing on different relationship types. Wynaden (2007) interviewed 27 family caregivers, mostly females and parents. She reported a substantive theory with two key psychosocial processes: 'being consumed' by the MHP and 'seeking balance'. Her findings describe a pattern also reported by other authors, where disruption of meaning due to the MHP is followed by seeking equilibrium. Again, accepting the ongoing presence and effects of the MHP was associated with resolving grief and loss. Exploring the processes underlying relatives' establishment of a caregiver identity, Wynaden (2007) described denial, assertiveness, present-moment focus and emphasising positives. Participants described learning "tricks of the trade" (p.385): acquiring mental health knowledge and refining their communication strategies were important for developing mastery and a caregiver identity. Again, education to promote relatives' self-concept development is recommended clinically.

Lawn and McMahon's (2014) GT with 28 spouse carers reported a central theme of 'a real and genuine relationship', capturing how the spousal bond was valued above caregiving. Supporting Rose (1998), participants were found to act due to spousal commitment, protecting their relationship through narratives of loyalty and love. For most, the term 'carer' was uncomfortable. This was tied to primary self-conceptualisation as a spouse: "You have to value who you are, not as what you do" (p.261). Of the 21 participants with children, many described feeling like both mother and father, shouldering the emotional side of parenting and balancing care of their spouse and offspring. Nonetheless, most expected their partner to co-parent whenever possible. Several parents reported that their children had also experienced MHP, although none expressed concern about them growing up around it. Understanding this more would be beneficial, although no analysis is provided. It is possible that the emphasis on the person (not the MHP) is a transferable value that shapes the parent-child relationship. This may have implications for how parenting couples label MHP-related emotions and behaviours at home and how children understand what they witness. The researcher reflects on potential bias due to lived experience as a spousal carer, lending transparency to the discussion. However, the homogenous sample is a limitation, making it important to explore these findings with ethnicially diverse groups and same-sex couples.

Mizuno, Iwasaki and Sakai (2011) also explored spouse experiences with 12 husbands of women with schizophrenia in Japan: nine couples had children. This TCA is positioned within the Japanese context: the authors highlighted how shared values about children binding a marriage and husbands protecting wives dominated participant discourse. Substantial quotations are provided, demonstrating the themes discussed. Like Lawn and McMahon (2014), the study found that some husbands felt they did both parenting roles and nurtured the child-mother relationship, evidencing cross-cultural similarities. Some talked to the child about MHP whereas others decided not to; how fathers made these decisions was not described. 'Excessive' attachment in children, seemingly comparable with attachment ‘disorder’ or ‘disturbance’ (Reupert, Maybery, & Kowalenko, 2013), is cited as a common challenge of maternal schizophrenia. The results implicate the important mediating role these fathers play in protecting children’s attachment. Generalisation of these findings to non-stable marriages and non-traditional family structures may not be appropriate, including cross-culturally.

Fraser and Warr (2009) also studied the experiences of males. Five fathers and five spouses in rural Australia were interviewed about their caregiving roles. A ‘partnering’ versus ‘parenting’ dichotomy across the groups indicated the guiding influence of their relationship to the person with MHP. Like Lawn and McMahon’s (2014) participants, spouses reported dissonance when trying to be husband and carer. Spouses tended to be reactive caregivers, focused on reducing housework and childcare burdens. There was no evaluation of how the MHP was addressed with the children. Fathers, however, were more proactive and focused on illness management. They had a stronger narrative of ‘limitless responsibility’. Fraser and Warr (2009) appeared to use TA, but the lacking description of their analysis method means its methodological rigour cannot be comprehensively evaluated. Nevertheless, they provide thoughtful consideration of the limitations, and the topic is worthy and timely. As service-led research, this study’s findings directly impacted clinical practice in the region. There are clear implications here for tailoring support differently for spouses and fathers. Changes in gender norms mean that men increasingly take on caring roles, yet these experiences may still conflict with dominant discourses about masculinity.

The final study exploring relatives’ self-concept in the presence of MHP considered the experiential meaning of being related to someone with BD (Rusner, Carlsson, Brunt, & Nystrom, 2012). Twelve adults of mixed relationships (including four co-parents) described their paradoxical experiences of being needed and rejected. In particular, relatives intensified the relationship with their family member to support them and counter isolation, but often became socially isolated themselves in doing so. Like Wyndaden's paper (2007) there was a theme of relatives developing mastery over internal conflicts (e.g. desire to protect) and external challenges (e.g. stigma), which required them to maintain a personal identity and assimilate the MHP into it. Many relatives took responsibility for their family member's stress at the expense of their own emotional wellbeing. To further this research, the authors suggested exploring what eases relatives' experiences and cross-cultural replication. Participants' 'essential meanings' (p.207) are captured richly using IPA; exploring how interpersonal processes influence relatives' experiences would, however, enhance the clinical implications.

1.6.6.4. Relatives' perspectives on family communication about mental health

Finally, three recently published papers reported on family communication from the relatives' perspective. Karnieli-Miller et al's (2013) immersion/crystallisation analysis was conducted as part of a larger stigma-reduction study. Using focus groups, they explored 14 relatives' management of stigma during social encounters with other adults. The findings described the importance relatives placed on decisions about when, how much and what to communicate about the MHP; this was termed 'the art of selective disclosure'. Family social rules and history were key determinants of disclosure, as were relatives' beliefs about what the person with MHP wanted to be shared. Encounter-by-encounter, relatives described weighing up the pros and cons of preserving emotional energy versus educating others. These communication choices are discussed by the authors as 'mapping onto' caregiver experience processes, moving from internalisation of blame through to empowerment and advocacy. This corresponds with the cumulative model of caregiver experience proposed by Tranvag and Kristoffersen (2008). While

Karnieli-Miller et al's (2013) findings largely relate to communication outside the family, similar processes are probably relevant to within-family communication. Indeed, some participants reported that conversations occurred with extended family members who thought differently about the MHP. Given that extended family often provide practical or emotional support, especially to children, these findings about selective disclosures and silencing factors (e.g. emotional exhaustion) are pertinent.

Maenhout, Rober and Greeff (2014) conducted an IPA study of spouse interaction in families where one partner has depression. There were six participants, and five couples had children. The severity of MHP is unclear from the sample description and potentially would not be deemed 'severe and enduring', but this study's content was considered relevant enough to consider. It must also be noted that this report is very light on data. Two communication styles were reported: talkative couples (many conversations, easy communication) and taciturn couples (silence dominates, talking difficult). Increased communication was linked with spouses having greater mental health literacy, which increased their empathy and led them to feel more valued. Participants described the challenges of picking the 'right' moment to talk but found dialogue helpful. Furthermore, talking was seen to strengthen family resilience: "Yes, I think if we did not talk about [the depression], things would have been worse" (p.6). This evidences the widely-cited clinical need to promote mental health talk in families. One participant, however, reported avoiding talk in front of the children. Across the participant group, spouses minimised MHP talk if their partner felt silence was protective. Unfortunately, the authors provide no evaluation of the findings related to talking with children, limiting the conclusions that can be drawn. Given children's wishes to know more, this finding suggests a potential avenue for targeting communication interventions and it would be helpful to understand more about spouses' decisions to hold back from talk.

Finally, a recent IPA exploration by Ballal and Navaneetham (2018) explored 'well' parents' experiences of talking to children about their other parent's MHP. Conducted in India, a gender-balanced sample of ten 'well' parents participated. The findings emphasised that participants limited children's exposure to PMHP, were selective about having conversations and regulated children's other information sources to reduce the possibility of incorrect details and stigma. Participants aimed to reassure their children, although there was also evidence of 'parentification'. Similarly to Maenhout et al (2014), participants described instances where initiating mental health talk was percieved as helpful. However, whether this continued over time and involved the parent with MHP was not described[8]. It appears that the use of IPA in this study did not enable process-related analysis. From the data provided, parents with MHP in this study do not appear to be involved in discussions with children. If not, this is in line with Nolte and Wren's (2016) finding that parents with MHP often leave others to address the topic with their child. Overall, this study elicidates a number of dilemmas that 'well' parents face when communicating with children, and suggests they shoulder the burden of this. Where children have little other information and emotional resource and parents wish to minimise talk, however, this may be a barrier to children conceptualising PMHP in ways that are helpful for them. Investigation of 'well' parent-child communication in other cultural contexts is necessary to explore universality of these findings.

1.6.7. Comparative quality summary.

A common feature of these studies was the high proportion of female participants. Sampling bias may play a role in this: perhaps women are more willing to take part in research or attend the support groups often used for recruitment. It is known, however, that more women undertake informal caregiving, lending credence to Stern et al's (1999)

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[8] They state that a further paper describing 'well' parents' evaluations of the risks and benefits of such communication is due to be published.

suggestion that imbalanced samples are representative of family caregiver populations. If this is true, research with females may be more accurately generalised. Still, this leaves the relatively fewer male carers less well understood, with clinical implications unable to target the unique challenges they face. The studies conducted specifically with male relatives are especially valuable for understanding how their needs differ. Studies with participants of mixed genders and relationships to the person with MHP often carry greater weight due to higher sample sizes (Karp & Tanarugsachock, 2000; Lawn & McMahon, 2014; Rose et al., 2002; Veltman et al., 2002; van der Sanden et al., 2015). However, they provide less detail about idiosyncratic differences between these relative types.

Three studies described their analysis methods poorly (Fraser & Warr, 2009; Pusey-Murray & Miller, 2013; Veltman et al., 2002). This means it cannot be evaluated whether other aspects of their method (e.g. sampling, triangulation) were implemented approriately, and fit the philosophical underpinnings of the approach. Indeed, statements of research epistemology and the researchers' relationships to the topics were rare. This rendered bias harder to evaluate, which can raise questions particularly when findings are strongly positioned. Lawn and McMahon (2014) were the only authors to provide both.

Another issue across the papers was evidence of procedural and relational ethics, with only five studies addressing this comprehensively. The two studies that gave the most space to ethical considerations were both conducted with Asian populations (Mizuno et al, 2011; Yeung et al, 2017). This may be associated with the significant stigma reported within Asian culture, and reflect authors' sensitivity in the research context.

Several studies provided consistently rigorous methodological reporting with thick, rich data that 'showed' the reader the findings and did not just 'tell' (Tracey, 2010): Jonsson et al (2011); Karnieli-Miller et al (2013); Karp and Tanarugsachock (2000); Lawn and McMahon (2014); Mizuno et al (2011); Rose (1998); Stern et al (1999); van der Sanden (2015); and Yeung et al (2017). Wynaden (2007) and Rose et al (2002) both lacked raw data in the form of quotations, though. It appears likely that journal word counts were a limiting factor. As both authors presented grounded theories of substantial complexity, trustworthiness was gained instead through rich descriptions of categories and processes.

1.6.8. Evaluation of review findings.

The literature review demonstrated the profound practical, emotional and social impact of being a relative of an adult with a severe and enduring MHP. Many studies replicated findings about caregiver burden, stigma and shame, financial difficulties and isolation, evidencing the universality of these experiences. There was variation in how these challenges were manifested, depending on relatives' gender, culture, relationship to the person with MHP, cohabitation and access to education and support. Many relatives were involved in caring for the person with MHP, although the impact existed even when they were not. Being able to conceptualise and communicate about the MHP, understand the affected family member and understand the self in the presence of the MHP were found to be beneficial for relatives and those they cared for. Many participants had children under 18, which is consistent with the statistics on the high number of children affected by a parent having MHP (Mental Health Foundation, 2010), yet they were often barely mentioned in the evaluations and implications. This suggests that the literature mirrors the reported splits between adult mental health care, child and family services and caregiver support.

Cycles of identity disruption and rebuilding were reported. Finding ways to 'scaffold' understanding about the MHP and position the self in relation to it was highlighted as a vital process. This was associated with developing a sense of mastery and renewed self-concept that incorporated the MHP. Where barriers prevented meaning-making and disruption continued, relatives experienced poorer emotional wellbeing, greater difficulty caring for themselves and others, and less opportunity to talk. The prevalence of family relationship challenges was evident, with frequent references to conflict, violence and a desire to maintain calm. Across countries, cultures and ethnicities, the authors of these papers spoke with one voice about the clinical need for earlier, family-focused education and interventions that include relatives and recognise their pivotal roles in family welfare.

Meaningful understanding and communication were often associated with improvements in family relationships and relatives' quality of life. Nonetheless, there were indications that relatives sometimes purposefully held back from speaking or acting as a strategy to manage uncertainty, avoid distress and preserve stability. Numerous studies referred briefly to the costs and benefits of family communication. The objective of many studies to explore 'experience', however, appears to have contributed to many descriptive reports and fewer examinations of underlying process. Only three studies addressed communication from the relative's perspective, and only two with a family focus (Ballal & Navaneetham, 2018; Maenhout et al, 2014). Both indicated the conflicted relationship relatives have with family MHP talk, including talk with children. This indicates that complex decision-making underlies relatives' choices to talk or stay silent in a given moment. Ballal and Navaneetham's (2018) deeper exploration of parents' experiences of talking with children raised important themes of selective disclosure and regulating information flow. Taking the perspective that meaning creation occurs between people, and in conjunction with what is known about the impact on children of growing up with a parent with severe and enduring MHP, it would be helpful to understand how and why children's caregivers make particular communication choices and the understandings that inform them.

1.7. Rationale and aims.

Despite the number of children known to live in families where a parent has a severe and enduring MHP, there has been little attempt to investigate if and how they are included in meaning-making and communication. The potential benefit of hearing from children's family caregivers on this topic has been widely noted, as have the clinical implications for all family members. This is consistent with the need for more family-centric enquiry into PMHP and improving outcomes for future generations.

The present study intends to address this gap. By generating phenomenological data from the perspective of children's family caregivers, the objective is to address the following research questions:

a) *How do children's family caregivers make sense of parental mental health problems?*
b) *How do caregivers give an account of their communication with children about parental mental health problems and what influences this?*

2. Method

This chapter details the study's method and methodological considerations. The design and the rationale for constructivist Grounded Theory (GT) methodology and interviews are discussed in accordance with my philosophical stance. Associated theoretical assumptions and issues of quality are discussed throughout the chapter. Service user consultation and the ethical considerations are addressed before the sample and recruitment process are described. Finally, the GT analysis process is described.

2.1. Methodology

2.1.1. Qualitative approach.

Qualitative approaches allow researchers to capture subjective human experiences and explore psychosocial processes in context with little pre-existing knowledge (Harper & Thompson, 2012). Analysing verbal accounts enables exploration of participants' meaning-making and constructions (Willig, 2017). When theory-testing, cause-and-effect comparisons and generalisability are research objectives and quantitative methods may be more appropriate (Cresswell, 2008). However, they limit the extent that subjective experiences can be recorded and evaluated.

Social psychological research has been criticised for imposing positivist assumptions on social contexts, limiting data accuracy by altering the environment under study (Humphreys & Rappaport, 1994). This speaks to the importance of aligning a study's aims, method and epistemological assumptions. Qualitative methods allow insights to be generated inductively from the data without applying existing frameworks or generating variables (Corbin, Strauss, & Strauss, 2014). Therefore they can generate new concepts and hypotheses for further investigation (Creswell, 1994). This is currently necessary to understand more about how family caregivers contribute to children's meaning-making about PMHP. Consequently, qualitative methodology was chosen.

2.1.2. Constructivist Grounded Theory: considerations and justification.

GT focuses on systematically building theory in a bottom-up fashion. It allows the discovery – or construction (Charmaz, 2014) – of explanatory substantive theory about social processes, which should be recognisable to those who experience them (Hutchinson, Johnston, & Breckon, 2012). Theory is 'grounded' in the data and speaks to the "analytic sense" (Charmaz, 2014, p.3) made about participants' accounts.

Since Glaser and Strauss (1967) first defined GT in *'The Discovery of Grounded Theory: strategies for qualitative research',* significant developments have led to various authors publishing distinct methods, including a well-described split between Glaser and Strauss (Urquhart, 2013). Differences between GT methods centre on coding processes and the accommodation of different epistemologies (Hutchinson, Johnston, & Breckon, 2012). Nonetheless, the core methodological components endure: theoretical sensitivity, constant comparison, and developing meaning from 'slices' of data (Urquhart, 2013).

Along with other qualitative methods, GT is argued to have a paradigmatic flexibility that makes it appropriate in various epistemological and ontological contexts (Klein & Myers, 1999; Levers, 2013). Urquhart and Fernandes (2006) describe it as orthogonal to both the researcher's epistemology and the type of data. Charmaz (2014, p.9) defines it as "like a container into which different content can be poured", applicable in positivist and interpretivist paradigms alike. It follows that researchers should clarify their philosophical stance and choice of GT approach and then evaluate how they apply it.

Glaser (2005) declared his original GT as epistemologically neutral. Others, however, have suggested that it aligns more closely with positivism, Straussian methods with interpretivist pragmatism, and Charmaz' approach with a relativist position where subjectivity and social existence are considered inseparable (Annells, 1996; Breckenridge, Jones, & Nicol, 2012, Evans, 2013)[9]. Charmaz (2014) views both Glaserian and Straussian methods as fundamentally positivist, warning that coding strategies in the Straussian form can 'force' data into analytic frameworks. Others note similarities between constructivist and Straussian methods due to shared emphasis on language and interpretation (Evans, 2013). Arguably, the pragmatism of Straussian GT could inhabit either an objective or subjective ontology. A clear difference between constructivist GT and other approaches, however, is the credence given to the role of the co-constructive researcher and is a primary reason for its use here.

Here, GT was appropriate for researching the as-yet-undescribed social phenomena of how family caregivers share meaning with children about PMHP. I set out to use it in pursuit of substantive theory about meaning-making and experience (the 'what'), but to go beyond the descriptive level to examine underlying processes (the 'how' and 'why'; Charmaz, 2014). Critical realism and GT share a focus on the interconnections between evidence, theory and application, within a framework of fallibalism. This makes them compatible, especially for psychosocial research like this where the end-goals are practical yet emancipatory (Oliver, 2011).

Charmaz (2014) posits that constructivist GT supports critical positions as well as 'hard' constructionism. Her postmodern position coheres with the 'critical' aspect of critical realism, describing 'layers of reality', inter-subjectivity, and the interpretative role of the researcher. Annels (1997) describes Glaserian GT as ontologically critical realist. While I agree with the notion of a reality independent of the human mind, the objective Glaserian view of 'impartial' researchers who collect data representing 'reality' is less congruent with my understanding that social reality is co-constructed *between* individuals.

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[9] Other coding strategies and GT guidelines have been put forward, but further comparison and discussion is not possible within the scope of this report. For further discussion see: e.g. Evans, 2013; Howard-Payne, 2015; Levers, 2013.

Later Straussian methods (e.g. 1990) address this issue, but offer the researcher less methodological flexibility than Charmaz (Urquhart, 2013). I agree with Bryant (2009) that constructivist GT deals more effectively with potential bias than other forms of GT by explicitly addressing the researcher's co-constructive role in interviews and analysis.

While arguments can be levied at the alignment between constructivist GT and a critical realist position, overall I believe they are sufficiently compatible for this research. I have taken Urquhart & Fernandez' (2006) advice for executing GT in a critical realist paradigm, implementing inter-coder reliability checks, triangulation procedures, and transparency about the substantive nature of theory (Yin, 2009).

2.1.3. Consideration of other methods.

Other qualitative methods were considered, most notably the collection of naturally occurring data, Interpretative Phenomenological Analysis (IPA) and Thematic Analysis (TA).

Collecting naturally occurring observational data would have provided a means of witnessing caregiver-child interactions directly (Silverman, 2006), for example using ethnography (Geertz, 1983). However, existing evidence that child-caregiver interactions occur sporadically, unpredictably and briefly meant that field work with multiple families would require a time commitment unmanageable for this particular project, and without the guarantee of observing enough high-quality data. Furthermore, important practical challenges were anticipated in relation to children not necessarily living with the caregiver. The parent might not need much support with childcare at the time of data collection, or interactions might happen outside the observed environment (e.g. during car journeys).

Phenomenological approaches like IPA aim to illuminate the details of personal lived experiences with a focus on meaning-making (Smith, Flowers, & Larkin, 2009), and were therefore also relevant to the research objectives. IPA would have been a powerful tool to explore the complexity, emotionality and ambiguity of caregivers' experiences of childcare. However, it would not have supported the analysis of social and communication processes within the caregiver-child-parent system or the development of theory: as such it would have fundamentally altered the research question.

Finally, TA was considered as a potentially suitable approach. Braun and Clarke (2009, p.6) describe TA as a method for "…identifying, analysing and reporting patterns (themes) within data…" and epistemologically flexible. Consequently, its suitability lay in the coding and analysis of data to address experience-focused research questions and compatibility with a critical realist position. Overall, while these characteristics made TA appropriate here, it was considered that the greater emphasis GT places on identifying social processes more closely addressed the research questions. TA supports both inductive and deductive coding, therefore permitting existing knowledge to be tested and guide enquiry while new information is identified from raw data. The benefits of using deductive coding, however, would have been minimal due to the lack of existing research with children's family caregivers. This was therefore not considered a potential hindrance to the quality of analysis.

2.2. Design

2.2.1. Service user consultation.

User contributions to research tend to improve its relevance and impact (Wykes & Trivedi, 2002), with involvement varying from conducting research to collaborating, participating, and consulting (Wilson, Fothergill, & Rees, 2010). Particularly in psychology and medicine where research is ultimately useful for the end-user, consultation can support the deconstruction of unchallenged professional 'experteeism' (Shippee, et al., 2015).

Tokenism and researcher inexperience are obstacles to realising the benefits of service-user contributions (Wallcraft, Rose, Reid, & Sweeney, 2003). Further, the wariness of professionals associated with psychiatric survivor/user perspectives can understandably deter participation (Seebohm et al, 2013). This was a serious consideration here, partly due to my belief in the value of community psychology perspectives, but also because I aimed to recruit from outside statutory services.

I learned the value and challenges of user involvement when conducting research in a user-led organisation for adults with severe and enduring MHPs (Gammage & Foster, 2017). This project highlighted the importance of social capital[10] as a community resource. This led me to reflect on how researchers can support this in the form of 'research-focused social capital'. In the case of this previous project, 'research-focused social capital' appeared at different levels: (1) for service-user consultants and participants, via involvement in design, participation and reflective processes; (2) for the group, via evaluation of the findings to review existing leadership processes and using them in future funding proposals; and (3) for me, via personal growth and achieving career targets.

I returned to this group to discuss the challenges and opportunities of the current project. I also consulted with a member of the University of Hertfordshire's Service User and Carer Committee. In both cases, I received feedback about the research objectives and recruitment processes. This led to refinement of the recruitment plan. It also placed emphasis on caregiver experience rather than meaning-making alone, which shaped the interview schedule and my understanding of participants. This appropriate suggestion reminded me of the importance of replicating existing knowledge, and the ongoing crisis this presents within psychology (Maxwell, Lau, & Howard, 2015).

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[10] Defined by Crossley (2006) as community networking and a shared responsibility that supports social functioning.

A pilot interview was conducted with a grandmother who helped care for her grandchild because of PMHP. This participant received the same ethical treatment as all others. Feedback led to improvements to the interview schedule and study documents. The balance between caregiver experience and meaning-making was refined: as caregiver experience was integral throughout, I decided to move more quickly into asking about meaning-making but addressing experience topics as they arose. Personally, piloting enabled me to start engaging more in reflective processes about interviewing, GT, and PMHP as a topic.

2.2.2. Quality assessment.

Tracey's (2010) framework has been used to assess the quality of this study. To evaluate the application of GT specifically, Hutchinson, Johnston and Breckon's (2012) assessment criteria have also been applied. This framework is intended to address concerns about researchers applying GT inadequately and 'cherry picking' techniques. Like Tracey's (2010) criteria it addresses shared characteristics and goals of GT types: it is therefore appropriate for use with constructivist GT and a critical realist stance. Tables assessing this study against these criteria are provided in Appendix X.

The COREQ 32-item checklist (Tong, Sainsbury, & Craig, 2007) was used to ensure reporting quality (Appendix X). This tool was developed to address inconsistent reporting in qualitative research and is suitable with interview-based data collection.

2.2.3. Qualitative Interviews.

As discussed earlier, psychological research has suffered from positivist controls being imposed on social contexts where subjective experiences are reduced to numerical variables (Alvesson & Skoldberg, 2002). Qualitative interviews, however, permit the collection of phenomenological data about individual perspectives without the loss of context.

Nonetheless, critiques have been levied at the assumptions that participant accounts provide either a "…'mirror reflection' of the reality that exists in the social world" or "authentic accounts of subjective experience" (Miller & Glassner, 2016, p.52). Epistemologically, both stances assume the existence of a social 'truth'. I agree with Sanders' (1995) proposal to "…[be] skeptical about the bases of truth claims while carefully examining the grounds upon which these claims are founded". This is in line with a critical realist stance, suggesting that interviews provide access to social worlds but through researcher-participant inter-subjectivity. Consistently with Charmaz, (2014), the interviews are seen as symbolic interactions where points of view and experiences may be explored (Miller & Glassner, 2016).

From this position, individual interviews were considered appropriate for collecting phenomenological data and addressing the research objectives in a constructivist GT framework.

2.3. Participants

2.3.1. Recruitment plan

Recruitment in the area of parental mental health is known to be challenging (Cunningham, Oyebode, & Vostanis, 2000), particularly of male participants (Nolte & Wren, 2016). Consequently, a recruitment strategy comprising multiple pathways was developed (Table 6). This supported sample heterogeneity, in line with GT methodology, and reaching caregivers who were not service users or did not identify as carers.

Each pathway often comprised multiple recruitment methods. For example, several charities emailed the study details to members, hosted the poster (Appendix H) on their websites, tweeted about it, and invited me to present to staff and/or service-user groups.

Internet recruitment was advantageous for reaching people who access online communities more than physical communities for reasons including disability and travel constraints. However, 9% of UK adults and 22% of disabled UK adults do not use the internet (Office for National Statistics, 2017) and each platform has limited users, so there were restrictions to the populations reached.

Table 6: Summary table of the recruitment pathways and the methods that each pathway comprised.

Pathway type	Example organisation/group	Recruitment methods
Children's Social Care	- Regional children's social care teams - Family fostering and kinship care teams	- Staff informed about study by researcher during presentations at meetings. - Staff approach potential participants and refer to the researcher if interested.
Charities and third sector organisations (local and national)	- Mental health charities - Carers charities - Drug and alcohol charities	- Staff and members informed about study by the researcher during presentations at meetings. - Study information circulated online via mailing lists, Twitter or website.
User-led community groups (local)	- Mental health mutual support groups - Community service user involvement and consultation organistions	- Staff and members informed about the study by the researcher during presentation at meetings. - Study information circulated online via mailing lists, Twitter or website. - Posters and flyers displayed in group premises.
Internet-based recruitment	- Twitter - Mental health forums - Parenting forums	- Study promoted via researcher's Twitter and study website. - Posters and information posted on forums/groups.
NHS	- Local Child and Adolescent Mental Health Services (CAMHS) - Service user involvement networks	- Staff informed about the study by researcher during presentation at meetings. - Staff approach potential participants and refer to researcher if interested. - Circulation of study

	information via service-user involvement networks.

2.3.2. Sampling strategy

Early on, purposive sampling (Patton, 2002) was used. The aim was to sample a cross-section of children's family caregivers diverse in age and gender, child age and gender, PMHP, culture and ethnicity. Snowball sampling became possible around interview five, once links had been made with teams and individuals via the methods described in Table 6. Opportunity played a role in early sampling due to low participant numbers. Recruitment challenges are discussed in Section 2.3.5.

Later, theoretical sampling was used to pursue theory (Charmaz, 2014). To expand and test the categories identified through analysis (Glaser & Strauss, 1967), males, siblings and under-40s were actively sought. Theoretical sampling also involved adapting the interview schedule (see 2.5.1). As Charmaz (2014) advises, I used these sampling strategies mindfully so that theoretical sensitivity did not quash my receptiveness to novel concepts during later interviews.

Sample size in GT is guided by theoretical saturation rather than by a pre-determined number. Theoretical saturation is defined as when no new concepts, relationships or dimensions are identified through analysis (Mason, 2010). Notably, however, research objectives, data quality, sample homogeneity, ethics approval processes, researcher experience and philosophical stance also affect this (Bowen, 2008; Glaser & Holton, 2007; Thomson, 2011). Further, constructivist GT means alternative conceptualisations are always possible. Charmaz (2014) argues that data quality and depth of analysis are key to saturation, enabling smaller samples to yield sound findings. However, she warns researchers to continually critique the theoretical adequacy of categories.

In total, 19 participants took part in 18 interviews. Evidence of theoretical saturation began to be identified around interview 12 and was judged to have occurred around interview 15. Saturation is a judgement, not an event (Wiener, 2007). Consequently, the 'theoretical sufficiency' (Dey, 1999, p.257) of categories was considered throughout conceptual development. The final two interviews were used to discuss the developing theory and further elaborate the categories, providing a means of triangulation (for the impact, see 2.6.5).

2.3.3. Inclusion and exclusion criteria

Participants were required to meet the following criteria:

- Parent/caregiver of a child aged 4–17 who had a parent with a MHP.
- Aged 18+.
- Willing to take part in an individual interview.
- Did not have a severe and enduring MHP.

The focus on meaning-making meant a sufficient level of child language skills was necessary. Families were included when at least one child was older than 4 and did not have a developmental disorder or language acquisition problem.

It was expected that participants might experience mild low mood and anxiety[11]. These are considered normal experiences, particularly in caring populations, and are unlikely to significantly affect childcare or communication. Use of interpreters was planned with caregivers who did not speak English as a first language, but this did not arise.

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[11] The subjectivity inherent in this description is acknowledged. 'Mild' is used here to distinguish from 'severe and enduring', as per the terms set out in the National Service Framework (BPS, 2002).

2.3.4. Summary of participants

Sample demographics are summarised in Table 7. Of the 19 participants recruited over a period of twelve months, seven were male and 12 female with an age range of 24 to 69 (average=49, median=48). All were white British except two who were also Caucasian and had immigrated to the UK over ten years ago. The white British participants were majority English; three were from other UK countries[12]. All participants lived in England and Wales.

Table 7: Summary table of participant demographic information

Name (Pseudonym)	Age	Gender	Relationship to child(ren)	Number of children cared for due to PMHP	Occupation
Liz	67	F	Grandmother	2	Full-time grandmother
Jon	45	M	Stepfather/ Father	1	Full-time carer / unemployed
Marcus	44	M	Father	2	Part-time manager; Dad; Carer
Connor	34	M	Father	1	Full-time clerk; Dad
Alice	24	F	Sister	2	Full-time student; support worker
Lucinda	42	F	Aunt	2	Full-time clerk
Christopher	48	M	Father	1	Full-time professional
Tash	42	F	Mother	1	Full-time carer; part-time clerk
Emilia	30	F	Stepmother/ Mother	4	Full-time professional
Marilyn	56	F	Grandmother	3	Carer
Rosie	62	F	Grandmother	3	Retired clerk
Kimberley	42	F	Mother	2	Homemaker; carer
Allen	69	M	Step-grandfather	3	Retired professional

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[12] The countries of origin of the three non-British participants are not stated for confidentiality reasons.

Judy	67	F	Grandmother	3	Retired professional
Darcy	49	F	Mother	2	Full-time carer; volunteer
Sally	49	F	Mother	1	Support worker
Lorraine	58	F	Grandmother	1	Carer
Pete	60	M	Father	1	Full-time self-employed business owner
George	41	M	Father	2	Carer

Participants varied in socio-economic, occupational and employment status. Eight spouses, three ex-spouses, six grandparents (five with SGOs), one aunt and one sister participated. Seven identified as carers as part or all of their occupation. Another eight currently provided care to the parent with MHP, but were not all the same people who identified as carers. Thirteen participants had supported the parent longer than the child[13]. Length of time in a childcare role ranged from 4 to 20 years (i.e. the age of the eldest child). Between them, the participants looked after a total of 33 children (Table 8). There were surprisingly more male than female children[14]. It was also notable that the parents with MHP were majority female (n=13) and that all grandparents looked after the child of a mother with MHP.

Table 8: Demographic information of children cared for by participants

Child gender		**Child Age**	
Female	11	Average	11.7
Male	22	Median	12
		Mode	14

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[13] Three kinship carers had supported the parent (their child) on and off for between 30 and 40 years.

[14] No reason was identified for this, although one could hypothesise about male child behaviour being more challenging to parent with MHP, greater concern about the wellbeing of male children leading to more caregiver intervention, or a bias in local services. However, it may be coincidence. This does not appear to be a pattern in the literature.

	Range	4 to 20

The sample was limited in ethnic diversity, caregiver gender balance and caregiver age. Attempts were made to address this, with most success in recruiting more males. These issues are discussed in the Limitations (4.4.2).

2.3.5. Recruitment challenges

Low participant numbers were a challenge during the first six months of recruitment, so efforts were made to reduce the number of steps required to reach potential participants. Calls for participation by email required repetition to elicit responses: understandably, staff were busy and caregivers might not check emails frequently. Developing relationships with champions for the study was important for addressing this. These individuals were often managers, but not exclusively. For example, a social worker that had recruited a participant received feedback from them that the interview had been rewarding. She spontaneously described this when I next attended her team's meeting, which encouraged her colleagues to refer. This stimulated me to look for champions at all organisational levels.

Other challenges occurred once participants had registered interest. Several did not meet the inclusion criteria because of child age and having moderate-severe MHP. Some adult children and parents with MHP also contacted me hoping to participate. Explaining inclusion on the grounds of research design often felt over-complicated and rejecting, despite being appropriate, and I found it hard saying 'no'. I did not want to discourage future research participation. I reflected on how I often rely on body language and expression, but could not convey these by phone or email.

The pressures on caregivers quickly became apparent, impacting the interview and analysis timeline (Table 9). Several people postponed or rescheduled due to parental relapse, childcare needs and work. Numerous participants told me the research was important and how rarely their views were asked. A small number were wary about confidentiality, citing tension in the relationship with the parent. Several, however, said they would have waived anonymity to improve things if they had had to.

Table 9: Details about individuals not recruited and delayed participation.

Pathway	Declined straight away	Showed interest then changed mind	Interested but ineligible	Asked for extra time to decide due to circumstances		Interviews postponed/ reorganised due to circumstances
				Participated	Declined	
Social Care	3	3	1	1	2	3
Third sector	1		1	2		1
Internet		2	2			
NHS		1				

2.4. Ethical Considerations

2.4.1. Ethical approval

The University of Hertfordshire Health and Human Sciences Ethics Committee granted ethical approval covering recruitment via Children's Social Care, third sector organisations and online (Appendix C). Approval to recruit from NHS services was granted by the Health Research Authority following favourable opinion from the East of England Research Ethics Committee (Appendix E & Appendix F). A confidentiality agreement was in place with the transcription service (Appendix G). Participants and their data were treated strict in accordance with the BPS Code of Ethics and Conduct (2009).

2.4.2. Study design.

In line with the literature, the study design originally incorporated adult family friends who helped care for children as well as relatives. However, during ethical approval it was requested that I change this due to concern about participants discussing a non-relative's mental health. Several participants raised the importance of friends, and two explicitly asked if their friends could be interviewed. Consequently, this remains an area of significance and is highlighted as a future research consideration (4.5.2).

The recruitment pathways enabled participant identification via affected parents and children. This raised the issue of how the parent or child might feel about the interview, and whether their consent ought to be required. This was discussed during the NHS ethics process (Appendix D). It was agreed that caregivers reserved the right to participate regarding their own experiences without others' approval. As a safeguard, I actively steered away from caregivers' judgements of the parental difficulties during interviews. As an integral part of caregivers' experiences and something they wanted to talk about, however, this was admittedly challenging at times.

2.4.3. Informed consent.

Either the referrer or I provided a Participant Information Sheet (Appendix I) to potential participants. They were encouraged to discuss participation with family and friends and given a minimum of 24 hours to consider it. I fully explained the study during telephone screening and again at the beginning of each interview, prior to informed consent procedures. Consent to audio record was provided for all but one interview, where I made typed notes instead. Informed consent is an ongoing process and I invited questions at any time, including after participation. Each participant was invited to read the consent form (Appendix J) and ask questions before signing it.

2.4.4. Participant confidentiality and wellbeing.

I invited participants to talk openly about their experiences of looking after children because of the PMHP. Developing trust and openness is valuable in research interviews, but disclosure can be associated with vulnerability (Sullivan, et al., 2012). It was possible that reflecting on these experiences could cause some emotional distress. Consequently, I reminded participants to share only what they felt comfortable with and that they could choose to not answer questions or stop the interview. I tried to be aware of participants' emotional states and be flexible in my interview style to prioritise their needs. Each interview concluded with debriefing, when I asked about their experience of the interview, addressed any concerns, and reminded them of their right to withdraw. A written debrief sheet was provided (Appendix K). Nobody withdrew following participation.

During several interviews, participants became emotionally affected or cried. The emotional strain associated with PMHP was apparent, as many explicitly said. Three participants took short breaks and continued afterwards. I asked if they would like to stop but all opted to continue, describing emotional upheaval as part of their experience and important to express. One participant contacted me afterwards to ask my thoughts about an issue raised during the interview. After a brief supportive conversation, I explained that I was unable to offer therapeutic help and signposted to relevant services.

Prior to informed consent it was explained to participants that confidentiality would only be broken if I was concerned about their safety or that of someone else. Appropriate pathways were identified for safeguarding advice and onward referral in case interviews raised concerns about participant mental health, parental mental health or child wellbeing. 'Closing the care loop' was a significant consideration during the NHS ethical approval process (Appendix D). No such concerns were identified or acted upon throughout the study.

2.4.5. Data storage.

Identifiable data gathered included names, contact details, demographic information and audio recordings or notes. All information collected on paper was made electronic following interviews and the physical copies shredded. Audio recordings were deleted from the dictaphone after downloading. All data was stored on a password-protected computer drive in password-protected files that were only accessible by me. All identifiable data was removed during transcription. Identifiable and anonymised data were kept separately, assigned with unique identifiers that only I could decode.

All participants consented to secure storage of their names and contact details until the dissemination stage so that the findings of the research could be shared with them. They also all consented to storage of anonymised transcripts for up to five years for secondary analysis.

2.5. Data collection

2.5.1. Interview guide and style.

The intensive interviewing[15] style was used to facilitate in-depth exploration of lived experience via interviewer-participant connection. This approach encourages consideration of what the researcher brings to the interaction in terms of personal characteristics, questioning style and motives (Charmaz, 2014).

In line with this, I attempted to remain mindful of how my status as a white British, female research student and trainee psychologist in my late 20s might have influenced not only how different participants perceived me, but also my interactional style, use of language and appearance. Furthermore, the local context of the interview setting (e.g. the location and room of the interview) and broader social and societal contexts (e.g. including meanings associated with the NHS, social care, parenting and mental health) are recognised as potentially affecting the accounts produced. Inevitably, I will have been aware of some these factors and my impact on interviews, but not all. To name my

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[15] As defined by Charmaz (2014, p.57-58): 'During the interview, the participant talks; the interviewer encourages, listens and learns. … Because the interviewer seeks to understand the research participant's language, meanings and actions, emotions and body language, intensive interviewing is a useful method for interpretative inquiry.'

characteristics and encourage open dialogue with participants, at the start of each interview I introduced myself as a Trainee Clinical Psychologist and student researcher and described my motivation to conduct the research and its background. Self-reflexive and supervisory practices were used throughout data collection and analysis to consider what I brought to the interaction process with participants and their data.

The initial interview guide was developed in collaboration with supervisors, service-user consultants and the pilot interview. Charmaz (2014) refers to 'points of departure' for entering the research topic, including guiding interests (e.g. communication about PMHP), 'sensitising concepts' that spark thinking (e.g. who talks about PMHP), and discipline-related perspectives (e.g. intergenerational transmission risks). Consequently, broad 'sensitising' questions were used enabling data to 'flow' while pointing to topics of interest (Charmaz, 2014). I used follow-up and probe questions (Rubin & Rubin, 2012) to encourage elaboration.

I scaffolded flexibility in the conversation by telling participants that I hoped to cover certain topics but that we could see where the conversation went. I asked their permission to move things on or to slow down at times. I found that this also gave me permission to listen and respond more adaptably. After listening back to recordings, I started leaving longer gaps before asking follow-up questions and introduced 'softening' prefixes (Rosenblatt, 1995).

In line with GT method, the analysis processes and pursuit of theory led me to amend the interview guide. For example, it became apparent through initial coding that caregivers spoke to issues about their identity as a caregiver, integrating this with childcare decisions. Consequently, I added questions about these concepts alongside the original questions. As such, ideas generated by participants 'in process' during interviews (Charmaz, 2014) enabled exploration with subsequent participants and shaped the theoretical plausibility of the findings. Although the interviews became more structured as they progressed, I made efforts to remain flexible and listen for new information. During interviews 17 and 18, the developing theory was used as a basis for discussion to expand the categories and seek contradictory evidence. Overall, this supported the notion of 'protection' as the Core Social Process, and informed the relabeling and amalgamation of several categories and sub-categories. Evolution of the interview guide can be seen in Appendix M, Appendix N and Appendix O.

2.5.2. Interview procedure

Interview locations were guided by participant preferences. Eleven interviews were conducted in participants' homes, two at the participant's workplace, one at a community group's premises, three on University premises and one via Skype. Lone worker procedures were followed for all in-person interviews. Slight loss of nonverbal cues made the Skype interview different from the others. However, the live video with good sound and video quality, concurrent audio recording and the interviewee being in a confidential space in her home at the time enhanced its compatibility. Importantly, the use of Skype enabled inclusion despite significant geographical distance.

Each interview began with the informed consent procedures before demographic information (Appendix L) was collected and the interview itself began. A few interviews ended at a pre-set time because participants had other commitments but most continued until we felt that most topics had been covered. I explained that interviews would likely last around 60 minutes, but frequently found that participants had more to say than could fit into this time. They lasted between 48 and 92 minutes (average=73). Many participants spontaneously offered to be interviewed again if needed and reported finding the experience interesting. The interview closed with debriefing and thanking participants for their time.

2.6. Data Analysis

The data was analysed using Charmaz' (2014) guidelines for constructivist GT. Analysis begins from the first interview. Re-listening, transcribing and re-reading facilitate immersion in the data and initial consideration of meanings. Subsequently, coding begins the process of describing and defining identified processes. Iterative information-gathering and constant comparison inform further sampling and data collection.

2.6.1. Memoing and reflective processes.

Memos, a reflective diary and process-based supervision were used throughout the research process. The reflective diary largely contained my experiences of interviews whereas memoing centred on developing analytical ideas, although there was some overlap.

I wrote reflective diary entries after interviews and transcription, detailing comparisons and arising ideas. This also provided self-debriefing when the content had been emotionally challenging (Appendix U). I often sought supervision after interviews to discuss my reflections.

Memoing, a way to interactively "converse with yourself" (Charmaz, 2014, p.162), is considered crucial in GT for writing about and analysing conceptual ideas throughout analysis, and increasing their abstraction. Memoing helped me to verbalise and organise my ideas; this supported constant comparison and documented the analytical journey (Appendix V). After beginning coding, I began including more reflective writing in my memos. At moments of stuckness, writing and re-reading memos helped me to move forward. The following description of the analysis process contains further details about memoing.

2.6.2. Transcription.

All recordings were transcribed verbatim with attention to conservation of inflection, punctuation, silence and nonverbal sounds. To ensure confidentiality, linguistic forms revealing regional accents were standardised (Boyatzis, 1998). I transcribed the first eight interviews myself. Due to time limitations, the remaining transcription was professionally outsourced. Transcripts were stored and analysed using qualitative analysis software NVivo v.11 (Appendix P).

2.6.3. Initial coding.

Initial coding was conducted line-by-line, using gerunds to capture process and codes reflecting participants' perspectives. Initial line-by-line coding is intended to deconstruct the data into fragments that can be categorised for their 'analytic import', while giving freedom from the concreteness associated with whole sentences and paragraphs (Charmaz, 2014). The process of analytic naming aims to make implicit meanings visible. Secondary coding of four interviews by three other researchers[16] supported the credibility of my initial codes. After coding six interviews, 550 initial codes had been developed and few new ones were being generated.

I noticed that some codes represented a higher level of abstraction, and some appeared more linked to my ideas than participants' words. Charmaz (2014) suggests that such occurrences can represent as-yet-unconscious meanings. To explore this, I interspersed memoing with coding.

An example of initial coding is available in Appendix Q.

2.6.4. Focused coding.

Focused coding required condensing and refining the theoretical direction of the analysis by sorting the initial codes. Some codes were collated where the same concept

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[16] Two supervisors and one peer Trainee Clinical Psychologist.

had been labelled slightly differently. Those making greater analytical contributions were elevated to focused codes. I began to identify key conceptual ideas and processes at this stage and wrote many memos to capture arising ideas about the data alongside ideas for new interview questions and self-reflections. Questions provided by Charmaz (2014)[17] and Urquhart (2013)[18] were valuable for constant comparison and increasing the conceptual abstraction of focused codes. I returned repeatedly to the research question to keep these objectives central to the analysis.

This iterative process, which often did not feel as clear as it may sound, continued as more interviews were conducted, transcribed and coded. As described, interview questions were added and theoretical sampling was used to test analytical ideas. The focused codes were applied to six more interviews to test them against new data, and further refined. This process continued with all interviews, until all data had been reviewed and coded. From around interview 15, no novel concepts were identified and the focused codes appeared comprehensive and well-represented by quotations. Through discussion with supervisors, it was agreed that they appeared theoretically sufficient (Dey, 1999).

I discussed the focused codes, identified categories and sub-categories regularly in supervision which promoted my sensitivity to theory. Examples of focused coding are available in Appendix Q and Appendix R, with an example of abstraction from coded text to category in Appendix S.

2.6.5. Theoretical coding.

Focused codes conceptualise the ‘empirical substance’ of the area of research; theoretical codes conceptualise how focused codes relate to one another (Glaser, 1978). I

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[17] E.g. ‘Which of these codes best account for the data?’ and ‘Are these codes interchangeable indicators of something else?’

[18] E.g. ‘Is this focused code in fact a relationship?’ and ‘Is this focused code truly representative or can it be honed?’

began creating tentative conceptual categories to see how the focused codes might fit together theoretically, clustering and re-clustering them on paper. I also explored these groupings and key conceptual ideas through diagramming (Appendix T). Spradley's (1979) semantic relationships[19] were useful for exploring the relationships and hierarchies between concepts.

Different theoretical models were developed using the focused codes. I reviewed these alongside transcripts to explore how well they accounted for the data. Seeing how negative cases[20] contrasted with major conceptual patterns was particularly useful for elevating the theory. Through these processes, the models were adapted and amalgamated, with forays back to rename and reorganise some focused codes, until a model had been developed that appeared to best account for and explain the majority of the data.

As before, I used memoing and supervision throughout theoretical coding, particularly to guard against 'forcing' the data into pre-existing or preferred theoretical concepts. Not having conducted the systematic literature review at this stage, in line with GT methodology, likely helped. During theoretical coding I reviewed and expanded earlier memos, moving to higher levels of abstraction and linking in quotations. Examples in Appendix V demonstrate how this process contributed to identification of the Core Social Process (CSP), *providing protection in uncertainty*.

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[19] Used by applying statements such as the following to the relationships between codes or concepts: 'Is a kind of…', 'Is a way to…', 'Is a reason for…' and 'Is a result of…'.

[20] Defined by Charmaz (2014) as cases that contrast sharply with the major patterns seen across the majority of the data, and which are important for critically examining the GT being described.

3. Results

This chapter presents a substantive grounded theory of how children's family caregivers[21] accounted for their contributions to children's meaning-making about their parent's MHP. The findings are subject to the co-constructive and interpretative nature of constructivist GT, and the additional layer of hermeneutic and experience-based intersubjectivity brought by the reader (Bryant, 2009; Charmaz, 2014). The model will be introduced as a whole before the categories that comprise it are described individually, with rich data in the form of participants' words[22] to credibly evidence the findings (Tracey, 2010).

3.1. Summary of the Theory: Providing Protection in Uncertainty.

The overall sense gained from the interviews was that caregivers' contributions to children's meaning-making were informed by a central premise of providing protection in a context of uncertainty (Figure 2). This was conceptualised as a core social process (CSP) of *providing protection in uncertainty*. In contributing to children's meaning-making, all caregivers described engaging in protective processes in relation to the child, parent, family and themselves. It was understood that they experienced a pervasive context of unpredictability associated with the PMHP. How caregivers responded to uncertainty about the short, medium and longer-term shaped how they appeared to share meaning with children about the PMHP, everyday life and the future, as did cues from children themselves. These were understood as evolving and relational processes.

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[21] For brevity, 'caregivers' will be used throughout this chapter.

[22] For notes on the presentation of quotations in this chapter, see Appendix P.

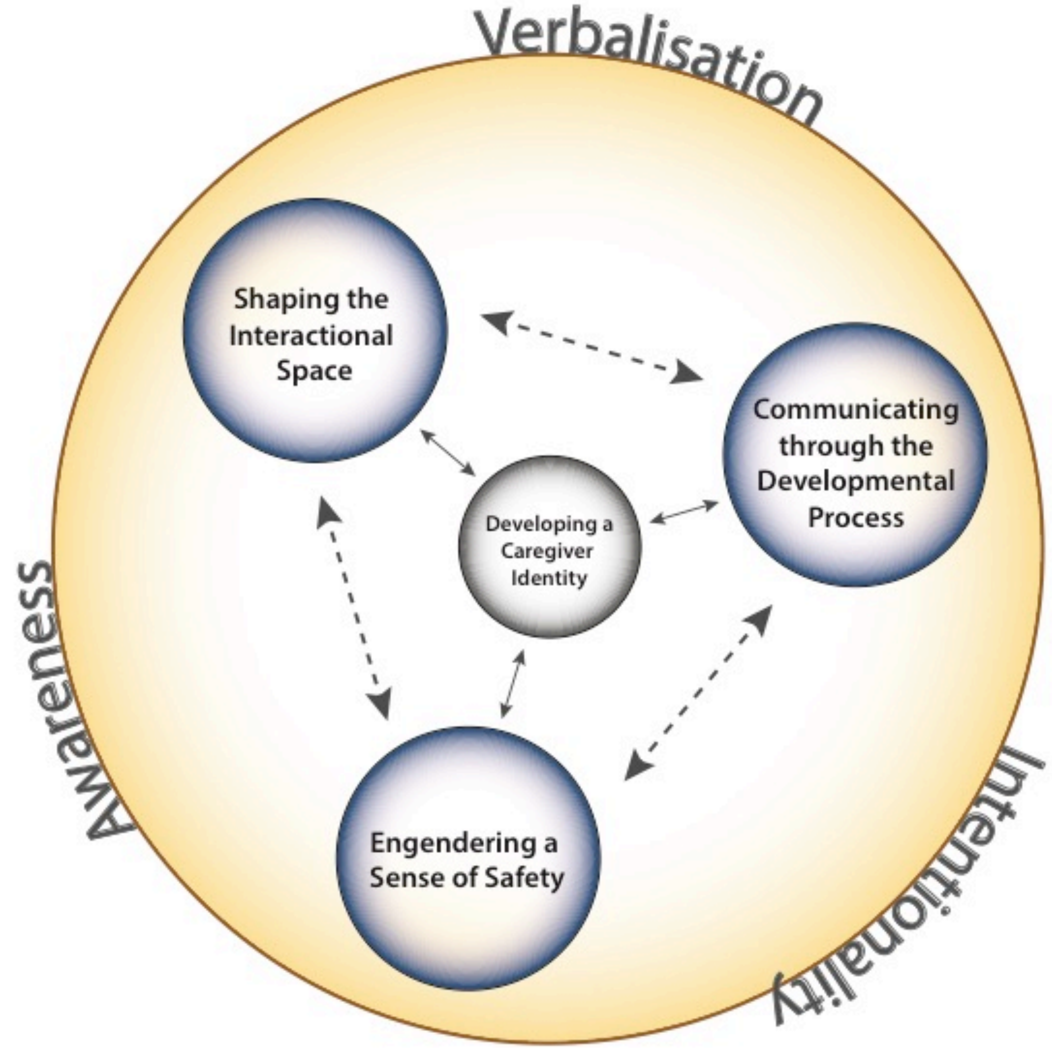

Figure 2: Diagrammatic representation showing the relationships between the Core Social Process (CSP) of 'providing protection in uncertainty', the main categories and the Key Social Positioning (KSP) of 'developing a caregiver identity'. The subcategories and caregivers' strategies and orientations are subsumed within each of these main categories and can be seen in Figure 3.

Meaning-making between caregivers and children was seen to occur with varying levels of verbalisation, intentionality and awareness, which have been conceptualised as three multidimensional continua: verbal-nonverbal (i.e. whether meaning was conveyed through speech, intonation, silence or action); intentional-unintentional (i.e. whether caregivers appeared to have meant to convey meaning or not); and conscious-unconscious (i.e. whether caregivers appeared to recognise that they had communicated). It was understood that caregivers moved to different positions along these continua in different interactions. These continua will be referred to throughout the Results to draw out how they appeared to structure and influence meaning-making.

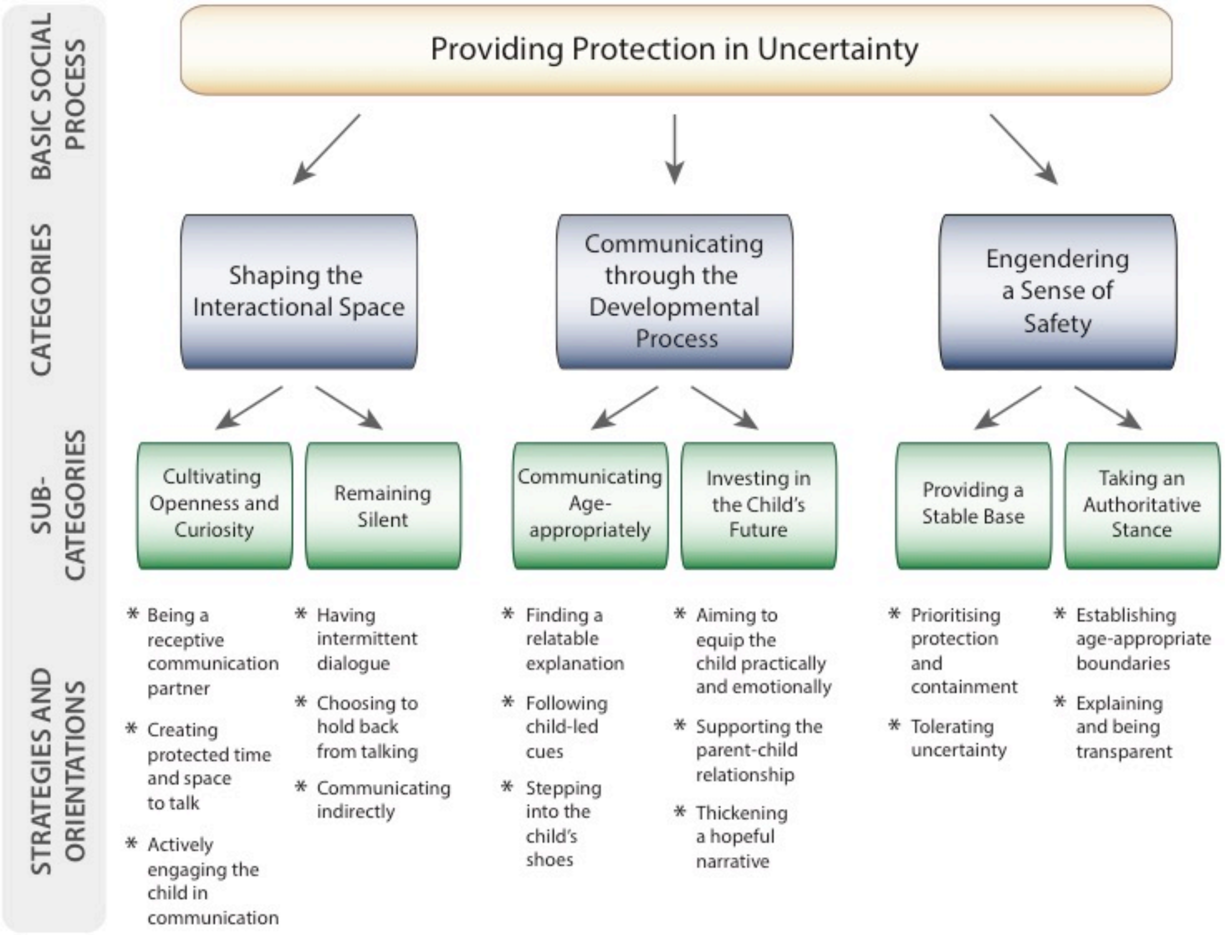

Figure 3: Hierarchical and linear presentation of the Core Social Process (CSP), categories, subcategories, and caregivers' strategies and orientations. The interactive relationships between all categories (as shown in Figure 2), subcategories, strategies and orientations should be kept in mind. For clarity, however, these relationships are not all represented here.

Three conceptual categories were identified that comprised the CSP of *providing protection in uncertainty* (Figure 3): (1) *shaping the interactional space*; (2) *communicating through the developmental process*; and (3) *engendering a sense of safety*. These categories will be presented separately for clarity, but it should be borne in mind that they represent interrelating processes. Linkages between them will be drawn through the chapter, with brief synopses at the end of each category and a full synthesis of the findings at the start of the Discussion.

Caregivers were found to position themselves in the childcare role according to their assessment of the child's needs, the parent with MHP and their life experiences. This was conceptualised as a key social positioning (KSP) called *developing a caregiver identity*. This appeared integral to how the processes of providing protection manifested for different caregivers; the two were understood to iteratively influence one another.

Before presenting the categories and sub-categories in detail, I will elaborate the KSP. In order to further unpack the reciprocal influences identified between caregiver identity and providing protection, I will refer back to this social positioning throughout the chapter.

3.1.1. Key social positioning: Developing a caregiver identity.

The KSP, *developing a caregiver identity*, captures the variation in caregivers' contributions as a function of how they perceived themselves within the PMHP and childcare context: in other words, their caregiver identity. Caregiver identity was understood to provide a reference point for meaning-making and communication choices with children.

Caregivers appeared to assess children's needs to develop an understanding of their cognitive capacity, emotional resilience and how the PMHP impacted them. This understanding seemed central in how their caregiver identity developed:

> Lily-May[23] was being exposed to the conflict that was being created because of it, and I didn't know how to get out of the conflict because just being in the house was a conflict in the end. And I thought I've got to do something to change, cause she's [parent with MHP] not gonna change. ***(Steve)***

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[23] All the cared-for children and other people who participants talked about have been assigned pseudonyms. A reference table is provided in Appendix W.

How caregivers understood the parent with MHP also shaped caregiver identity. This included the manifestation of their MHP, perceived childcare capacity and risk level. Caregivers appeared to monitor fluctuations in the parent's state, either directly or via others' reports:

> How I say life is with Shane now, is that most of the time it's okay, but I-I'm always constantly worried that he can have a relapse. I'm worried it- I don't think he's going through a relapse at the moment, but he didn't sleep the other night. He hasn't slept for a couple of nights. ***(Sally)***

The findings indicated that, together, these assessments of the parent and child informed the caregiver's understanding of the childcare needs, and the extent and nature of their role:

> To then just find that I was the team by default, because of nobody's fault, and the pressure of just having to get the stuff done without somebody there to help, guide, bounce anything off. So it kind of all became my responsibility, and (…) it's pressurised and it's almost crushing, you know. I learned to become a jack-of-all-trades really, really fast. ***(Kimberley)***

Caregivers also seemed to draw on other life experiences to inform their identity, particularly historical family relationships, lived mental health experience, and past parenting experiences including their own childhood parental model:

> With me, I've experienced stuff myself. I came out of a very bad relationship. ***(Emilia)***
>
> My mum suffers from fibromyalgia, and actually it's relatively similar in terms of fluctuation. ***(Tash)***

The impact for caregivers was evident, with perceived emotional burden, role change, stigma, social isolation and financial challenges appearing to differentially influence their self-concept. Therefore, caregiver identity was understood to develop in line with personal, interpersonal and contextual factors, and to guide the variation in responses to children and beliefs about their needs. This will be discussed in the presentation of the categories and sub-categories.

The factors contributing to caregiver identity were understood to be shaped by relationships between people and, as such, were non-linear, evolving and dynamic. This was particularly apparent in caregivers' descriptions of how they had adapted and changed:

> Your life will change. Because it does change, you've gotta be prepared to accept that change. ***(Liz)***
>
> I can't really pinpoint anything that changed, I just think (...) I don't know if maybe just my understanding changed? ***(Alice)***

Caregiver positioning was conceptualised as simultaneously influencing, and being influenced by, engagement with *providing protection in uncertainty*. For example, a child's comment could precipitate the caregiver re-assessing their cognitive and emotional capacity. This update in the caregiver's understanding of the child's needs could provoke a shift in caregiver identity and caregiving practices:

> I always wanted to hide this from Bethanie that her mum was unwell, I always wanted to hide that, so she doesn't have to deal with it. But do- you know, it comes to a time when you can't hide it anymore, you know? Bethanie knows that her mum gets unwell. ***(Connor)***

Consequently, the KSP of *developing a caregiver identity* was understood to significiantly impact caregiver-children meaning-making. As will be elaborated below, these communications were seen to occur along the continua of verbal-nonverbal, intentional-unintentional and conscious-unconscious.

3.2. Category 1: Shaping the Interactional Space

The ways caregivers contributed to *shaping the interactional space* with children was seen to influence if, how and when meaning was shared about PMHP. This category is comprised of two sub-categories: *cultivating openness and curiosity* and *remaining silent*. Caregivers appeared to place varying levels of value upon shared understanding and belief in talk as protective, which was understood to guide orientation towards interactional approach or retreat.

3.2.1. Subcategory: Cultivating openness and curiosity.

3.2.1.1. Being a receptive communication partner.

Most caregivers described the belief that communicating about PMHP-related experiences would benefit children's emotional wellbeing, drawing on a societal view that it is better to "not just bottle it all up" ***(Liz)***. Even when not talking often, caregivers descriptions suggested that they aimed to be receptive communication partners for children:

> If they're worried about anything, yeah they can talk to us about anything… And try and get them to open up about it, because if they open up then it helps them, because it's not inside them and it's not sort of like, laying inside them. Until they're in their (…) I dunno, until they're an adult and then all of a sudden it'll explode.
> ***(Rosie)***

Some caregivers, like Connor, described explicitly expressing this position to the child. Others, like Allen and Judy, seeemed to communicate it by adopting a state of monitoring and responding as opportunities arose:

> I encourage her to be really open yeah so she doesn't have to hide anything.
> ***(Connor)***
>
> ***Allen:*** We're in the background supporting him. He knows we are here. And we don't force ourselves upon him.
> ***Judy:*** We have e-mail communication with him.

The belief that communicating could help the child appeared connected with caregivers' own positive experiences of talking, including feeling unburdened and understanding PMHP better: "That's what's helped me through it all" ***(Jon)***. This appeared to inform a receptive attitude towards children:

> ***Emilia:*** I was sort of happy upset in a sense.
> ***Interviewer:*** Yeah. It sounds very emotional.
> ***Emilia:*** Yeah, yeah and- and relief because, um, Elias [son] knew bits.
>
> It feels good with them because I feel close to them. ***(Lucinda)***

Caregivers often indicated their understanding, however, that PMHP could be a distressing topic. Linked to children's readiness, caregivers appeared to weigh up the pros and cons of how to approach communication:

> He wants to stay on the computer, and obviously that's going to cause anxiety if you start pushing and pushing. ***(Darcy)***
>
> Don't rush in and be sort of like (…) try and be gentle and understanding as to what they've been through. And then sort of like try and coax them out of (…) so they can then tell you what experiences they've had, so that you can then try and understand it. ***(Rosie)***

Resultantly, several caregivers seemed to position communication as something that could happen in time:

> So, it was horrendous at the end. So, I don't [talk] straight away with Alanna. I leave it. And then we had a chat later on. And this is what I love about it is the fact that we do talk. We do communicate 'cause that's how it's always been. ***(Marilyn)***

Caregivers of younger children often described the expectation that communication might increase months or years into the future, and planned to remain open to it:

> She's five, she's literally sometimes you can be there going "Cami, Cami, Cami, Cami"… Having a long conversation about anything like "Daddy's brain sometimes-" she just goes "Yeah (...) Spongebob". She's just not at that place, and I don't think it's going to be until she's around eight or so when her brain develops slightly more, that (...) she'll start to have questions I would think. ***(Tash)***
>
> As she get's older, if Amber asks me questions, I will answer them as honestly and as age-appropriate as I feel she can deal with. ***(Lorraine)***

This raised the question of how caregivers can adapt to children's developing needs. This will be considered later, particularly in *communicating through the developmental process*.

3.2.1.2. Creating protected time and space to talk.

Creating a time, place or space for talking was identified as a strategy described by many caregivers. Their intention often appeared to be faciliation of honest dialogue, rather than discussing PMHP specifically. Some caregivers described actively creating this time, for example at dinner:

> For years we've always sat down at the dinner table and chatted, because that's how you air your problems out. ***(Jon)***

Others said they had noticed the child talking at a certain time and protected it:

> Bethanie likes to speak, and it might be because she wants to stay up a little bit later, but she likes to speak before she goes to bed at night after she's read her book to me, she will then want to speak. ***(Connor)***

As Connor went on to describe, this provided a chance to understand her inner world:

> And sometimes they're just like kids' things and you can say "Oh stop being silly it's just fine", but sometimes it's concerning. Sometimes she'll say things to me that are concerning, and I'll be like "Oh this child, this is damaging". ***(Connor)***

Creating space and time to communicate appeared to scaffold and boundary challenging topics. A shared – but seemingly unspoken – understanding that PMHP could be discussed at these times appeared to be protective for both caregiver and child. Marcus described the importance of an 'ending' to talk:

> It's mostly when we're walking outside. You've got space. Nobody else is gonna bother you. You know there's an end, because you're gonna arrive… I've always enjoyed conversations walking because it does feel (...) it feels somewhat freer. You're not gonna see an email appear on the screen 'cause you're walking along, you know, all the- all the distractions. ***(Marcus)***

His description of minimising distractions implied that daily tasks could be barriers to talk, or a means of avoidance. This appeared relevant for caregivers who saw value in talk but struggled to create space for it:

> Um, but that is a problem - but it's not communicated. [laughs]… I said "Let's have a family meeting" yesterday. I mean, Derek said that ages ago as well, but it never happens. So we could all sit down and discuss things… but it doesn't happen. ***(Darcy)***
>
> That's the other thing you see, having a private converstaion is quite difficult in this house! [laughs] Because there's- you don't get a lot of privacy. ***(Liz)***

3.2.1.3. Actively engaging the child in communication.

Many caregivers appeared to proactively cultivate openness by engaging children in conversations about PMHP. This often seemed to occur in response to difficult PMHP experiences, the child's distress, or family life cycle transitions:

> But I couldn't just say to Alanna, "Yes you can have contact with your mum but it's got to be this, this and this and this" without giving her any reasons because she's fifteen… So, it was really, really difficult and I just said to her, I said, "Right. Let's sit down and let's have a talk about this." (***Marilyn***)
>
> Erm… but if it's possible to sort of, you know, a little bit after the event, after it's calmed down to say, 'Oh why do you think that happened then?'. Give her the space to have a conversation, if she wants to. (***Steve***)

Successfully engaging children appeared to allow caregivers to share understanding about PMHP while gaining insight into children's experiences. The extent of conversations, however, was not always clear from the interviews. Additionally, some caregivers indicated that they felt the child did not always engage:

> ***Interviewer***: Do you talk with him about his own mother's mental health?
> ***Judy***: Try to.
> ***Interviewer***: You try to?
> ***Judy***: Try to.
> ***Interviewer***: What's that like?
> ***Judy***: He doesn't- he doesn't really want to know, does he.
>
> Her mum would go up and lock herself in her bedrooom, you know that's her- that was her safety mechanism, locking herself away, but that's not really

> helpful. My daughter now seems to be following the same trait, she spends all her time in her bedroom. ***(Pete)***

Some caregivers described trying to understand children's silence, considering the impact of PMHP on their behaviour. Alice described engaging her brother when he was upset, seemingly trying to protect him from sadness and strengthen his resilience:

> When I said about mum, if she's snapped at him and then he's been upset and I'll go upstairs and mull it over, try and tell him he's not stupid and stuff like that, he'll say things then. ***(Alice)***

This appeared to have helped him open up over time, indicating active engagement as an effective strategy for emotional processing and containment. Additionally, it seemed to have positioned Alice as an attachment figure for her brother:

> He used to be quite closed. Erm but in the past like couple of months or so he's opened up really, he's much more loving. Erm, yeah, I'd say we are quite close. ***(Alice)***

3.2.2. Subcategory: Remaining silent.

3.2.2.1. Having intermittent dialogue.

Despite the value that caregivers were understood to place on helping children make meaning about the PMHP, many explained that communication about it was intermittent or rare. This appeared linked with the ebb and flow of talk in family life, the proximity of the parent with MHP, avoiding "heavy" conversations ***(Judy)***, and the child's developmental stage.

Some caregivers described talking with the child about the PMHP less over time. Reasons for this often centred on the costs of talking outweighing the benefits:

> We used to, we don't now because, um (…) we just go round in circles really. So, we don't really talk about it. I suppose it's selfish really, we don't talk about their names because (…) unless they see Amber, they don't phone us or anything. ***(Lorraine)***

> Um (…) it- it [sighs] (…) it used to. They used to talk about it. But they don't talk about it so much now. They used to talk about, um, I remember when we first had them. ***(Rosie)***

In contrast, others described talking more over time. Caregivers linked this to different things, including having developed closer relationships and the PMHP improving:

> More often now than before. When we were in crisis when it was, I dunno, you- you basically just had to live in the crisis. Erm, but we're beginning to do that and in a lot more erm (...) objective way? ***(Marcus)***

> [It's] Newer, because if I tried to say something it would be (...) I'm only Carla's boyfriend. But I've been with Carla four years now you know, so, I'm not just a boyfriend. … I'm here for the long haul. ***(Jon)***

This indicated the flexibility that caregivers employed in their approaches to communication. It appeared that breaks in PMHP talk could be perceived as protective for emotional wellbeing and family relationships. Alice felt that "it's not necessary to talk about it all the time", a sentiment echoed by Lorraine:

> People think you need to grieve and talk about it but I don't always need to talk about it. ***(Lorraine)***

Intermittent dialogue therefore also appeared to support caregivers' needs for space and silence, indicating how their emotional state could affect meaning-making occurred with children. During quieter phases, caregivers described that children would sometimes unexpectedly raise the topic during everyday activities:

> I was drying her hair and she's on her phone like they all are on Instagram or whatever, and she said … "They should have my life". "Yeah, what?", So she said, "Oh whatever the child's name was, erm (...) 'Oh' she said, 'She's off to cut herself because she's fed up with her life". She said, "She should have had my life". [Pause] So, that's a referral- she knows it was crap for want of a better word. ***(Liz)***
>
> He's sitting on the toilet and he went- what was his words? Um (…) "Am I going to live here now Nanny?" I went, "Yes, darling." Like he's on the toilet, okay! [laugher] ***(Marilyn)***

> I'd be cooking tea or something and he'd come into the kitchen and talk about something that was, sort of, more significant and you know (…) whether he might go and see mum or not and how he was feeling about it. ***(Judy)***

Although a surprise in the moment, caregivers described seizing such opportunities to address the child's concerns. Again, they appeared to value the insight into the child's cognitive and emotional state.

A few caregivers described an absence of dialogue, with meanings about PMHP rarely shared verbally. Fear of distressing the children seemed to present a barrier to talk:

> ***Kimberley***: We have never known how to say, you know, "Daddy's unwell." How do you tell a six-year-old? Um, without them stressing that Daddy is gonna die?
> ***Interviewer***: Um, what- what do you do?
> ***Kimberley***: Uh, we just haven't told them. I don't know how you would tell a child that their father has bipolar.

Darcy also expressed difficulties discussing it directly. Instead, she focused on encouraging healthy lifestyle habits that would support her son's mental health:

> But yeah, but we don't talk about mental health much in the family. But I do say to Sebastian that it's important to relax and get proper sleep and eat properly. ***(Darcy)***

She described why silence had become a key factor in maintaining relationships and managing stress:

> But yes, so like with social we've always had them come in and try and set boundaries and that, but it never really happens and it just seems to make us all more argumentative. And more anxious and worked up. ***(Darcy)***

To address this, Kimberley and Darcy both felt they would value professional support:

> Yeah, like I've always felt it'd be good to have a communication course. Like, how best to communicate with people and with mental health. ***(Darcy)***
>
> I think a lot of parents would like to know how to talk mental health with their children without scaring them. Because the bipolar scares me. ***(Kimberley)***

3.2.2.2. Choosing to hold back from talking.

At times, caregivers referred to holding back from talking about PMHP with children. This often appeared linked to controlling the flow of information to protect the child, the parent or the self.

Several caregivers focused on physical safety, giving children minimal verbal detail. This appeared to draw on the societal views that "too much detail" ***(Tash)*** or not giving information in child-friendly ways "could do a lot of harm" ***(Steve)***, and that caregivers ought to protect children:

> I'd like to say to him 'If you have memories of mummy come to me', but I don't want to broach that subject and say 'What are your memories?' ***(Lucinda)***
>
> If she pushes and asks more then (...) I have to tell her as little as I think she could just accept, because I don't think she needs to- I don't know perhaps I'm (...) [sighs] being over-protective, perhaps I'm a bit out of touch. Probably a lot out of touch. Erm, but I think, be a child for a bit longer. ***(Liz)***

This filtering of information often appeared appropriate, especially with younger children, although seemed to continue as children got older. As Liz's quotation demonstrates, some caregivers appeared to question their choices as they spoke during interviews. It is possible that the interview process led caregivers to critique their views more than usual.

Particularly where caregivers seemed to want to protect the parent, holding back appeared to be a way to limit what children could tell others about the PMHP. This could help minimise criticism from outside and support the parent-child relationship:

> When we told the boys why- because they knew he was off work, but they didn't know why. … Just to keep the peace of her then not coming back or (...) Jackson was afraid that she would stop him seeing them. Because she could come up with some sort of thing that he's violent or aggressive, which he isn't. ***(Emilia)***

At times, however, caregivers described having to tolerate others (e.g. professionals, the parent with MHP) telling the child things they had tried to shield them from:

> Some of her erm (...) conversations she had with them were ones that I wasn't really comfortable with. … It meant that sometimes that she could actually be really hurtful without (...) without realising. ***(Marcus)***

At times, though, holding back from talk may have meant that underlying anger, resentment and sadness were harder for caregivers – and perhaps children – to express:

> ***Liz***: And at seven she said she wasn't coming. Now they've wasted all day. [pause] You don't do that to children.
> ***Interviewer***: Do you- did you talk about that with them at the time? How do you- how do you go about it?
> ***Liz***: Well I just- well I just say 'Ohh mummy got held up'. What can I say? I don't know what- she said she'd gone for an interview. But she says so many things.

Pete lamented needing to talk about PMHP, describing silence as a safeguard against negative talk:

> It's hard to talk to her about her mother in a positive way. To be honest I'd rather not talk if I can, about that. If I keep talking negative about her mother which I have done … maybe I shouldn't have. So I try not to, I think. ***(Pete)***

3.2.2.3. Communicating indirectly

All caregivers described nonverbal and indirect meaning-making with children through their presence and actions. Caregivers appeared to vary in their awareness and intentionality in nonverbal communication.

Some caregivers described writing to overcome barriers to talking, or to convey meaning effectively. Written communication appeared a way to confer protection to the writer, whether the child:

> So she didn't tell me, she wrote me a note. Yeah she would tell me, but not by actually speaking. So she had- in her head, she hadn't betrayed Mummy because she didn't actually say it. ***(Liz)***

the caregiver:

> If she wants to know the real reasons, like the nitty-gritty if you like of why she was taken away from her parents, I've kept every single bit of paperwork. And if I need to, if would she- she needs to- to see it for herself, I'll give it all to her and she can read it. ***(Lorraine)***

or the parent:

> I suppose there could be an element of him [dad with MHP] being able to write (...) write to her when she's old enough to understand it. So that he can express that he's scared of this, that and the other, so she can (...) she can probably understand it a bit better, and might be able to say "Okay Dad, I get that, okay. ***(Tash)***

Several caregivers indicated the expectation that children would learn about PMHP by observing parent-caregiver interactions and witnessing everyday scenes:

> I would assume that there's going to be an element from Cami where she has taken on a lot of stuff by osmosis anyway, so for her a lot of things are gonna be normal, and she's not really gonna think too much of them I suppose. In the same way as somebody who grew up with somebody with epilepsy, say. ***(Tash)***

In other cases, it was less clear whether the caregiver considered what the child understood from what they observed. Challenging circumstances appeared to move the focus onto managing practicalities rather than making meanings:

> I think, "Okay, I have- this is what's happening, what's the best thing to do?" ***(Emilia)***
>
> I said "Lily-May, put another pillow there behind her" and I tried to prop her up [mother with MHP], like that, but she fell over. She sort of fell off the side and started crying, so I gave her a hug, and she said "Go away! And just leave me alone." … I said "Right. I'll be leaving in the next half hour, if you think, if you're ill, tell me, otherwise we're going" I thought, I'm not ruining Lily-May's day out, she's gonna have a day out, I've had enough. ***(Steve)***

It remained unclear how Steve thought Lily-May understood this situation. This indicated that attending to children's understanding might be less possible during crises, although not that caregivers are unaware of nonverbal communication. Steve later described the power of indirect communication within the parent-child interaction:

> It's got to the point now where her mother doesn't even need to say much. You know, she can convey all she wants in body language and, turns of phrase. ***(Steve)***

Returning to these topics with children at a later, safer time may be critical for helping them process what they observed.

Some caregivers described communicating care to children through touch and presence, rather than words:

> He knows I'm there, we have cuddles. ***(Lucinda)***
>
> I contacted my work and said I need to take some time away. Because I needed to really focus on the fact that I'd got a wife in hospital and children who needed somebody who was gonna take care of them. Erm, the last thing they needed was me answering the telephone in the middle of lunch. ***(Marcus)***

Marcus' comment indicates the value placed upon togetherness. Some caregivers described children seeking physical nearness and rejecting independence, suggesting they felt secure when close to the caregiver:

> He sat down, sort of, beside- this close to me. ***(Judy)***
>
> She's got a- a key to come in from school, she only goes to school the other end of the road, erm (…) never ever uses it. Because somebody would have to be here. ***(Liz)***

At times, caregivers described observing children supporting the parent or managing their siblings:

> But Cami is now very (...) er, she's seen it, it doesn't upset her. She goes to him and she goes "It's alright Daddy". She just sits with him and says things, 'cause she must have heard me say it so many times, "Breathe (...) two (...)". ***(Tash)***

> He tries to manage his little brother… Elias steps in, Joshua steps in. It's like a little cue to the other two, "Just keep it down. Go into separate rooms." Or something like that. ***(Emilia)***

All children in these last six examples were under ten. Through indirect communication, it seemed that caregivers saw that children had learned from them about caring in the PMHP context.

In summary, this category demonstrates how caregivers' beliefs about the value of communication and perspective of their role in helping children understand the PMHP interacted with their decisions about *cultivating openness and curiosity* or *remaining silent* at different times. Although talk was a reported aim of many caregivers, it appeared that the emotional strains they managed for themselves and for children could sometimes make silence a necessary option. At times it seemed that unspoken rules were conveyed as a result, which children learned. Nonetheless, whether now or in the future, caregivers appeared hopeful about engaging with children about PMHP, with the hope of meeting their emotional needs.

3.3. Category 2: Communicating through the Developmental Process

Throughout the interviews, caregivers talked about sharing meaning according to children's age, developmental level (*communicating age-appropriately*), and future needs (*investing in the child's future*). This was conceptualised as *communicating through the developmental process.* Caregivers' decisions were understood as intimately tied to their caregiver identity, particularly their child development perspectives. Addressing the child's current needs and the caregiver-child relationship while simultaneously establishing protective mechanisms for the future appeared to present a unique challenge.

3.3.1. Subcategory: Communicating age-appropriately

3.3.1.1. Finding a relatable explanation.

All caregivers described how they sought a relatable explanation of PMHP to use with children. Most described using an 'illness' framework. Illness seemed to be considered understandable due to children's experiences of physical illness. Many caregivers chose this terminology to try and facilitate conversation and promote hope:

> I would be like erm (...) "Do you know how you get like tummy-ache and your tummy's not well, you got a bad leg and your leg's not well?… Mummy's mind is unwell at the moment". ***(Connor)***
>
> Children know that you go to hospital to get mended. And so, "Mummy's ill, she's in hospital, she'll come back better." ***(Marcus)***
>
> I don't think he would understand what mental ill- you know, not being well to him is having a headache or (...) you've got a cold, that's not well. I have to let it just sit with that. If he accepts that, that's all he needs to know surely, I don't need to go into details. ***(Liz)***

Several caregivers indicated this was an oversimplification but appropriate and sufficient for the child's developmental level. Others described it as the parent's terminology:

> It's her word… So, she says, "Well, I'm ill, you know, I can't. I just can't, I'm ill." ***(Judy)***
>
> She kind of explained it in the way that I'd explain it to my brother now. So she'll say "I'm having a bad day, I don't feel very well up here". ***(Alice)***

While aiming for children to understand, caregivers talked about minimising the information given. Children appearing satisfied seemed an important marker of having achieved 'age-appropriateness' ("He was quite happy with that" – ***Marilyn***). Caregivers also described that they 'softened' explanations, especially with younger children. This was understood as a protective strategy that decentralised from medical terminology:

> I will say things like, "Today, Daddy is tired" or, "Daddy didn't sleep last night, be gentle with Daddy." Or "Today, Daddy is battling." Um, or,

> "Daddy is stressed." I don't know how much a six-year-old can actually take in. Although we underestimate children, we also don't want to scare them. ***(Kimberley)***

Particularly as children got older, however, caregivers said they sought more detailed explanations. Caring for children of different ages appreared to present a challenge, as did deciding whether getting older consituted a reason for disclosure:

> ***Marilyn***: With Alanna it is okay because of Alanna's age. But with the boys, they're not capable yet are they.
>
> I don't think there's any age is the right age to be able to talk about that. ***(Pete)***
>
> He's 17, he still doesn't know everything. It's on like a need-to-know basis… She is talked to a little bit more, but still she doesn't know the ins and outs. And that's just because the two of them are separate, you know? ***(George)***

Emilia, the only participant to describe faciliating parent-child talk about PMHP, explained that professional advice had enabled relatable conversations that deepened the children's understanding:

> So he [dad with MHP] explained what PTSD is, in sort of child friendly ways. He said that he's experienced some bad things, his head's not been able to process them… So they now, sort of, you know, tongue-in-cheek go "Oh Dad's like!" [laughs]. Which was a very positive turn because everybody was like "Ooh". I was half in tears. ***(Emilia)***

The flexibility and depth of caregivers' explanations appeared to reflect how they understood PMHP themselves, and their relationship with the parent. Some said they honoured the parent's decisions about what to share:

> They're mainly hers [mum with MHP], but some of the thought process that she's having, I would have agreed with that anyway. ***(George)***

Several caregivers seemed to use a biological explanation, whereas others felt this jeapordised children's mental health:

> It turns out that it's hereditary or genetic. ***(Lucinda)***

> I think it is in the gene pool. ***(George)***
>
> That's really, really unhelpful! Because you're basically saying to the- to this girl, "You're likely to get your mum's illness". (***Marcus)***

Whether caregivers attributed parental behaviour to mental health or personality appeared to impact their explanations to children. Using mental health attributions, externalisation of the MHP became possible:

> "At the moment Mummy's got an illness which means that she cannot do these things. So, I'm really sorry, Mummy can't come see you today, her illness is in the way and it's really annoying. That's annoying, of course it is, but it's not her." (***Marcus***)

With personality attributions, the 'illness' framework seemed to help caregivers excuse parental behaviour whilst protecting the child's view of them:

> Say they were going for tea tomorrow and she rings tonight and says she can't have them, sometimes she does and says it's not convenient. Erm, I can't say that to them. I say "Mummy's not well". (***Liz***)

Although subtle, these conceptualisations appeared to carry considerably different meanings in what was communicated to children. Furthermore, during interviews, caregivers' beliefs about the parent were communicated by what was unsaid and expressed via intonation, timing and context. These nonverbal processes were understood as likely to occur in conversations with children too.

3.3.1.2. Following child-led cues.

Many caregivers described attending to children's communications to guide age-appropriate engagement about PMHP. This process often appeared observational rather than conversational, regardless of the child's age.

Caregivers described children showing awareness about the parent's behaviour:

> Bethanie started to notice that her mum speaks differently, that she laughs differently. So that was a sign for me, like (...) Bethanie's starting to understand her mum's mental health. ***(Connor)***
>
> I see- when Vikki's inappropriate, I do see Alanna's eyes roll as if like, "Oh really?" So she is recognizing mum's inappropriate behaviour. ***(Marilyn)***

Monitoring the child's communications and distress over time appeared to facilitate understanding of their current needs:

> She's quite happy to see her parents. But at the moment, she's not showing any signs of being upset coming away from her parents either. So, whether that's just- at the moment that's how life is, I don't know. ***(Lorraine)***
>
> Like if it happened yesterday she won't tell me until a week or two, 'cause she's- she'll say "Daddy I'm scared to tell you". She will tell me eventually and I will say to her like, "You know truth always comes out regardless, you cannot ever ever hide from the truth… But Daddy's here for you, if you want to tell me you can tell me anything you like". ***(Connor)***

Child-led cues could be used to inform responses to children's needs, including giving reassurance, encouraging communication and considering practicalities like contact. Consequently, while *holding back from talking* was understood to protect child and caregiver from feeling overwhelmed for periods of time, *following child-led cues* seemed to guide when to break the silence with age-appropriate support:

> 'Cos he's still young it's not necessary to talk about it all the time and be like "Mum's got bipolar". Erm, but when it's relevant and when it's necessary, so when (...) when mum is having a bad day and she's said something that would have upset him, that's when I'll kind of seize the opportunity and say then, you know, "She doesn't always mean what she says sometimes, emotions get the better of her". ***(Alice)***

Notably, not all caregivers appeared to consider whether the child thought about PMHP during periods of silence, possibly leading to fewer invitations for emotional support. This may reflect caregivers sometimes needing to 'switch off' from PMHP, or being less attuned to children's unverbalised experiences.

3.3.1.3. Stepping into the child's shoes.

Stepping into the child's shoes seemed to provide a perspective-taking technique for caregivers to anticipate children's meaning-making needs in line with their developmental stage. Several caregivers reflected on children's emotional experiences:

> Alanna (…) see, it breaks my heart, has gone straight up to her Mum and stood there. Not a word said between them. And it hurts, and it upsets and that's how I feel. So how on earth does that child feel? ***(Marilyn)***

Perspective-taking appeared to enable communication to be adapted and pre-planned to protect the child emotionally. Some caregivers metaphorically stepped into the child's shoes, stating during interviews what the child thought and felt:

> Obviously he's [son] a bit protective of me as well because, you know- and (...) I wouldn't say he's afraid of him [parent with MHP], but he's just afraid how (...) how, you know, "What am I gonna do? Can I do something about this?" ***(Emilia)***

This was striking because caregivers sometimes appeared to assume the child's experience. However, these views may have been informed by countless small, scattered, verbal and nonverbal communications over time. Perspective-taking was conceptualised as a way that caregivers could fill in unknown aspects of children's understanding:

> ***Interviewer***: So it sounds like there are some things maybe that you- you don't start doing with them because you don't want to send those signals?
> ***Marcus:*** That don't want those signals. They want to know that Mummy's still coming back.
> ***Interviewer:*** Okay. Have they said that to you in as many words?
> ***Marcus:*** No.

> They're little boys, you know, they'll just worry. And "Daddy is sick, so when is Daddy going to get better?" - "Daddy is not going to get better." - "Is Daddy going to die?" You know, I can see these questions coming now. ***(Kimberley)***

This appeared to help caregivers reassure themselves and assess caregiving strategies. Kimberley anticipated her children's distress if she were to increase talk about PMHP, so did not. Liz considered her grandaughter's experience of boundaries:

> Well, because part of her still wants to be a little girl as well. She does, you know she doesn't want to, erm (...) she doesn't want to be too grown up yet. ***(Liz)***

Consequently, caregivers were seen to make sense of what the child needed from them. Again, it is possible they used perspective-taking to answer a previously unconsidered interview question. Alice, among others, commented on this:

> I think now just talking through it I've kind of like made links to things that I wouldn't of before. ***(Alice)***

3.3.2. Subcategory: Investing in the child's future

3.3.2.1. Aiming to equip the child practically and emotionally.

By promoting emotional resilience, independence and views of 'normality', caregivers appeared to aim to equip children for the future. This led to intentionally and unintentionally sharing understandings about managing emotions, life opportunities and help-seeking.

Several caregivers described boosting children's resilience through activities, praise and self-reflection:

> They've, at school, they've encouraged her to come to the university to do some courses. Because with one parent, if they're not well, it's, it's a bit of a stigma. … Because people pick up on it. ***(Sally)***
>
> I don't think it's gonna help her to think she's at risk… It's more a focus on who are you and what are you actually experiencing. ***(Marcus)***

In doing so, it was understood that they explicitly shared reflections with children about the significant impact of PMHP upon them:

> I've said so many times that she's remarkably well adjusted. Remarkably grounded, for what she's been through. ***(Liz)***

Caregivers indicated an understanding that motional maturity could protect children's wellbeing outcomes:

> And like when we were watching that programme I said "It's important to talk about your feelings and how you feel. That's what they're doing, 'cause it helps". And now he will kind of say "I feel angry". And that's fine, you can feel angry. ***(Alice)***
>
> What I really want her to do is develop her critical thinking skills, so that she can work stuff out for herself, and I think she is slightly working stuff out for herself. It's gonna take a long time. ***(Steve)***

This was linked with an understanding that children were at risk of developing MHP, and the PMHP environment as a trigger. Caregivers described choosing parenting and communication styles to guard against this:

> Yeah, and erm, that style of parenting in theory is supposed to give more resilience. Er, in theory then if you do develop any mental health problems you'll have more resilience to be able to see yourself through them. ***(Tash)***
>
> So Bethanie shares the same blood as her mum, so there's always the thought that maybe Bethanie could get ill some day if she doesn't make the right life choices. This is why I'm so strict on education because (...) that's my only hope for her to get out of this, basically. ***(Connor)***

In comparison, others normalised parenting and MHP:

> I think what it has done is helped him [dad with MHP] to- to feel more normal. You know, married with kids like everybody else. Um, it also, I think, has made him have to up his game. ***(Kimberley)***
>
> But I think there's a big picture, so when he's older he would understand that, yeah, everybody (...) nobody's protected from mental health and it happens. ***(Emilia)***

These differing messages about the potential impact of PMHP pointed to caregivers' positionings to health problems, the parent, and experiences of accessing help, and could be expected to shape the meanings promoted to children.

3.3.2.2. Supporting the parent-child relationship.

Many caregivers appeared to invest in the child’s future by nurturing the parent-child relationship. This was described by caregivers who reported both good and poor relationships with the parent with MHP.

Several caregivers described refraining from negative comments about the parent:

> I never [pause] talk about her mother in a negative way. Erm (…) I think if I start criticising her mother in front of her that’s just gonna, create (…) more conflict for her. ***(Steve)***
>
> I try to be a positive influence in her life, I don't slate her mum, yeah, I don't swear. … And then (...) so what happens is her mum breaks Bethanie and then I have to fix it, like so she'll- she'll break something and I have to pick up the pieces. ***(Connor)***

An empathic narrative was promoted by sharing understandings about PMHP and preferable caregiving. Notably, the quotations below are from spouses:

> I'd say, “Dad's going a bit- through one of his funny turns.” Yeah. “He needs to get help. He needs a bit of rest. He needs some support.” ***(Sally)***
>
> Yeah, "Daddy's having (...) Daddy's brain is making him think that there's something- that A, B or C. So he's- he's upset. It's okay, he's just gonna cry now. Erm, and we'll be here, we'll look after him". ***(Tash)***
>
> I make sure all the time that we're never angry at Mummy. That's really important. We're never upset with her, we're never disappointed. ***(Marcus)***

Some children and parents relied on caregivers to facilitate contact, whereas others lived together. In both cases, caregivers described inviting the parent into parenting and encouraging parent-child interaction:

> Even now when she's in hospital I'll call them and be like “Bethanie's asking about her mum because she hasn't spoken to her mum in three weeks or whatever, is it okay for Bethanie to speak to her mum?” ***(Connor)***
>
> I don't really know what her parents talk to her about when they have contact. We usually end up going to the same place. Um, it's an indoor play area. I never leave them- leave the building while she has contact. I'm always there. ***(Lorraine)***

In doing so, caregivers appeared to communicate an understanding about the parent being irreplaceable to the child. As Lorraine's description demonstrates, however, less positive messages also seemed to be communicated nonverbally at times. Caregiver presence during contact was sometimes court-mandated and may have supported children's sense of security, but appeared to convey meaning about parental risk level. These conflicting verbal and nonverbal messages about the parent could be seen as potentially confusing for children. It could also be speculated that children might feel rejected, angry or sad if their parent did not take up opportunities to talk or spend time with them:

> I've tried to tell her mother that. I sort of said in that first year, "You should ring her [daughter] every day. You should ring her every day to see how she is". She doesn't ring her for months. ***(Pete)***

Maintaining positive relationships with the parent was frequently reported as challenging, especially by kinship fosterers. Caregivers of younger children, like Rosie, often didn't push contact and minimised talk with children. Contrastingly, caregivers of older children, like Marilyn, described mediating the parent-child relationship:

> [sighs] It's really weird. It's like when she talks to me, um she'll phone me up and she'll talk to me and then (…) she won't ask to talk to the boys. She'll ask how the boys are but she won't ask to talk to them. ***(Rosie)***
>
> We had a meeting on Friday to discuss the contact. Um, and I said to Alanna, "I'm gonna have a meeting with your mum today. This is what I've written down". We've had that meeting before. And, you know, there's no change to it. "Are you happy to see your mum once a month?" ***(Marilyn)***

Via caregiver mediation, it seemed that messages were implicitly and explicitly communicated about the parent's childcare capacity. Liz described feeling compelled to step into the parent-child interaction:

> I went to pick her up and she came out with these stiletto shoes and I said, "Give them back to your mum". She said "Oh no they're mine", she said "I

> bought them I thought they'd be alright for dance". I said "Oh no", I- I- probably shouldn't have said it, and I said "She does street dance not pole dancing". [pause] She was ten years old. ***(Liz)***

Caregivers' frustrations and concens were conveyed during interviews via their words, tone, and description of parental behaviour. It seemed probable that, at times, similar messages were conveyed to children.

3.3.2.3. Thickening a hopeful narrative.

The interviews contained many hopeful and future-focused comments, and descriptions of caregivers sharing these with children. This was understood to strengthen optimism and closeness, promoting child and caregiver resilience in an unpredicatable context.

Many described closer relationships as a result of the PMHP:

> I think they've [mother with MHP and daughter] become closer as well, they've got a better bond with each other as well, through it all. ***(Jon)***
>
> Having us both in the house all the time has, I think, been really helpful in a lot of ways. Erm, there's always somebody here when she [daughter] comes home. You know, there's always somebody here. There's not a lot of absent parenting. ***(Tash)***

Alice, a sibling caregiver, said she valued this relationship but considered its downsides:

> So yeah, like I said I think it's a positive and a negative really because it's good because he's close to me and he wants to come to me with things, but then he (...) he should just go to Mum with them. ***(Alice)***

Several caregivers actively used a strengths-based perspective of the PMHP, labelling improvements in the parent's mental health in ways that felt hopeful. This seemed to indicate the positive atmosphere they worked to convey:

> We all try and keep her [parent with MHP] positive as well you know. … And that is good 'cause we don't want to moan and (...) bleedin' moan all the time. We want it happy. ***(Jon)***

Lucinda, however, described a disingenuous side to this:

> Even though I know outside of there they're not good. I feel like I'm almost putting on a front, playing a game, painting everything as rosy and laughing about funny memories but we're all still hurting. ***(Lucinda)***

This indicated how positivity and laughter with children might serve a protective function for all involved, but might sometimes come with an emotional cost to the caregiver. Many caregivers laughed and joked during interviews, introducing lightness to serious topics:

> ***Marilyn***: And, you know, to be responsible on your own for three children that have suffered (…) abuse and stuff like that, you know, it's scary. … I know what- but I just need to hear it from other people. So I'll then make a phone call.
> ***Interviewer***: Who do you call?
> ***Marilyn***: Um, Ghostbusters most of the time. [laughs] Sorry, humour has to come into it.

This was understood as an adaptive coping strategy. Whether it could at times also hinder sharing sadness and anger, however, was unclear.

Marcus described sharing memories of the parent before PMHP as a means of retaining hope:

> We went back home and we looked through photographs and we pulled out pictures of Mummy when- when she used to take him to things. … I don't want him to deny the reality of what he's experiencing, but I do want him to still hold onto hope. ***(Marcus)***

Here, Marcus indicates that accepting the current reality was seemingly equated with losing hope, emphasising the importance of being future-focused. Making plans that included the parent appeared to be a strategy to move towards the hoped-for future, and acting towards those plans immediately grounded positivity in the present:

> “But we're looking forward- we're looking forward to the time when she's better because then she can spend time with you. And shall we plan what we're going to do?” And then we're in (...) in the hopeful part. “And instead that means- the good news is we can spend the time together, and we can do- you know you said you wanted to do a jigsaw puzzle? Let's get it out and see what we can do.” ***(Marcus)***

Throughout the interviews, the emotionality and meaningfulness of supporting the child came across strongly. Caregivers’ narratives were imbued with hope:

> How they've- and how they've progressed and everything. And I suppose that's all you can do really. It makes me feel happy. I'm gonna cry now. ***(Rosie)***
>
> She said, “You won't be able to cope with the stress of your husband and the kids.” Well, I did it anyway and, um, I will not want to send my kids back. They are beautiful and the best thing I've ever done. But it just comes with a price. Looking back would I do it again? Yes. ***(Kimberley)***

This category was characterised by caregivers’ efforts to provide appropriate, meaningful and useful information to children, in relation to their current age and the hoped-for future. How they implemented protective aims and strategies often appeared guided by social understandings about protection and parenting. Caregivers’ wishes to give satisfactory explanations and be optimistic also seemed to play a role. Caregivers generally appeared to make conscious choices about what they told children, although it seemed hard at times completely to hold back messages about frustration or concern about the parent with MHP. It appeared likely that these meanings were sometimes conveyed by what was left unsaid; however, it cannot be assumed that silence precluded children understanding.

3.4. Category 3: Engendering a Sense of Safety

All caregivers described *engendering a sense of safety* by establishing a predictable and boundaried environment with children, and parenting in an authoritative and transparent manner. These findings spoke to how caregivers’ understandings about PMHP and their other life experience affected their approach to childcare. Caregivers assumed protective positions which were sometimes in contrast to the parent with MHP. Through their actions, meanings about the parent and the child's safety often appeared to be shared. As such, much meaning-making about safety appeared to occur nonverbally. These orientations and strategies were conceptualised in the subcategories *providing a stable base* and *taking an authoritative stance*.

3.4.1. Subcategory: Providing a stable base.

3.4.1.1. Prioritising protection and containment.

Several caregivers described a sense that the child *"…needed someone. To fight their corner, to keep them safe"* ***(Liz)***. By taking safeguarding action and minimising exposure to potentially upsetting scenes, caregivers appeared to inadvertently make meanings with children about their safety and the PMHP:

> I went round there one night with Ella and basically, got refused to go into the house to see my grandchildren by him. So I then phoned the police and then they got involved and everything and that's when I then took them. ***(Rosie)***
>
> Yes we'll probably have to keep him away from the children for a minute, so he'll come upstairs or go into his office, because he's got an office downstairs. ***(Tash)***

As Tash went on to explain, this could be challenging when also caring for the parent. Distraction and appearing composed were described as containment strategies:

> And he was in some kind of medieval battle, running away from people on horses and stuff. You know, it's just like, oof. I suppose it's like someone being on an acid trip. And at those points you have to kind of go "Right okay, well the children are safe. They're watching TV", you have to try and keep it as normal as possible. ***(Tash)***

Caregivers seemed to discuss protective strategies more with older children, which indicated more shared understanding about PMHP:

> I had to explain to them that they wouldn't be going any more, she just accepts it erm (...) because she saw her mother fighting and she knew what had gone on, and she knows what her mother's like basically. ***(Liz)***

They also described prioritising schooling, socialising and routines, which signalled to children the importance of consistency:

> School is like the stability in Bethanie's life because she knows she turns up at nine, she leaves at three, she turns up at nine, she leaves at three, yeah? No matter what's happening at home, the school are consistent. ***(Connor)***
>
> He normally does the school run because it gives him (…) what do you call it? A routine. It gives him something that he has to get up, have breakfast, get dressed, and out of the house. ***(Kimberley)***

As Kimberley described, routine could also help the parent and support parent-child interaction.

Despite the importance caregivers placed on *prioritising protection and containment* for children, it was often associated with role loss or confusion. Distress associated with role confusion appeared to vary with caregiver identity. Grandparents described it particularly keenly:

> They've stolen my right to be a real proper Nanna to her. I can't spoil her. ***(Rosie)***
>
> Well I suppose the last year I have been the parent, although I have been acting parent for three years. Erm (...) he [grandson] sometimes forgets himself and says “Mum” but I say “No, Nan”. ***(Liz)***

As Liz’s quote indicates, these blurred lines appeared to impact children, especially younger ones.

3.4.1.2. Tolerating uncertainty.

Providing a stable base required caregivers to tolerate the unpredictability of PMHP. The emotional work this required was indicated by their words but also the fluctuating emotional tone of most interviews. *Tolerating uncertainty* was understood as vital for meeting children’s needs and managing the demands on caregiver identity.

Caregivers described the "very emotional rollercoaster" ***(Liz)*** of their experience, including anger, sadness, loss, self-doubt and loneliness. They described controlling their emotions for the child's or parent's benefit:

> And then you also have that little (…) in your mind. "Uh, have I done the right thing? Have I done the right thing?" So I don't- I don't know. It's very difficult. You know, I'm worried sick about the contact. ***(Marilyn)***
>
> If I'm experiencing Camille wanting my attention, Katerina starts crying and then Javi has psychosis, I might be a little bit more fraught than I would want to be. So I'm like "Arrghhh", whereas I wish I could be more "I got this, I've got this, I can deal with this". ***(Tash)***

Linked to *holding back from talking*, holding back emotions appeared to protect the child's experience of the caregiver as containing and predictable. Containing their emotions appeared to help caregivers feel in control. George linked feelings of powerlessness with his understanding of the causes of MHP:

> Cause it's all in the mind as well, you're powerless as well. Because there's nothing you can to do make it better. You know, you're in that protective state, but you still can't protect them. ***(George)***

Caregivers regularly named uncertainty about their childcare decisions, especially female participants:

> Whether it's the best way, I don't know, but that's what we have done. ***(Judy)***
>
> I don't know if I'm doing the right thing or the wrong thing, but I don't know what to say. What do I do? ***(Lucinda)***
>
> Like I said I'm very conflicted. It's not my problem, but it is as well. ***(Alice)***

It appeared that these feelings were not shared directly with children, buffering their sense of safety.

Whether caregivers lived with children or not, they reported fluctuating childcare needs and being 'on call' in case of PMHP crisis. They appeared to tolerate these uncertainties via a flexible attitude and steady environment:

> Everything's put on hold, you can't deal with your own stuff at that time. But (...) once that person has recovered, then you will be able to go through your moment and then recover, you know? ***(Connor)***
>
> I'd be like "Hello?" [clicking fingers] and um, he [dad with MHP] is not in the room. And how do you explain that to all them? So I used to go, "All right, let's go"... I will take him out and then I'll send him upstairs and then I'll finish off the game with them or something like that. ***(Emilia)***

Defocusing from the future and uncontrollable contexts also seemed to help some caregivers achieve flexibility. Several caregivers referred to acceptance and "living in the moment" ***(Marcus)***. It was understood that they tried to share these messages with children through daily discourse, although not necessarily in relation to PMHP:

> It's about an acceptance really. I'm not a religious person, but I like the, um, prayer of tranquility… changing those things that you are able to change, and accepting those things which are beyond your control, and developing the wisdom to know the difference. ***(Judy)***
>
> ***Pete***: Maybe the way I say it to her doesn't help.
> ***Interviewer***: What do you think that you say- how you say it that doesn't help?
> ***Pete***: Well just abrupt, exactly what I'm saying to you now: "Forget about the past, look forward, look ahead. Enjoy- let's do stuff together."… Timing is key in some of this stuff.

As Pete indicated, sharing these messages so they could be understood by the child could feel challenging.

Contrastingly, some caregivers recounted providing children with a sense of certainty about the parent's future wellbeing, especially male participants:

> Millie will say to me "I don't want my mum not well" and I'll say "Look, your mum ain't going in one of those places again, I'm not letting it happen". ***(Jon)***
>
> Daddy just fixes it like if there is something wrong with me, her, family, she wants something from the toy shop, like anything at all yeah, Daddy will fix it. ***(Connor)***

Caregivers' accounts indicated that certainty reassured children and caregivers alike. Caregivers' stories represented certainty as a functional response at challenging moments.

It raised the question, however, of whether children ever held back worries to contain the caregiver.

3.4.2. Subcategory: Taking an authoritative stance.

3.4.2.1. Establishing age-appropriate boundaries.

Caregivers appeared to prioritise authoritative and supportive parenting. Most provided a significant amount of childcare and needed to establish age-appropriate boundaries with the child. Some caregivers described negotiating these boundaries. This demonstrated respect towards children and for some, was part of setting up a life together:

> She wanted a bikini this summer but we settled on a sort of bra- bra-type top and shorts rather than the white stringy thing that she'd picked out. [laughs]… I don't think it's appropriate for a twelve-year-old. ***(Liz)***

Caregivers described scenarios that many parents would recognise, especially with teenagers. Additionally, however, caregivers described repairing and re-negotiating boundaries that the parent with MHP had not upheld.

> Yeah, it was very, um, very firm and very- like 'this is how it's going to be'. 'Cause they didn't have that before. It was all airy-fairy. There was no structure, there was no discipline, there was nothing. And I am not like that. ***(Marilyn)***

At times, caregivers noticed children responding to this variability in parenting messages:

> She has to know the two things are true and has to be able to cope with two things opposing being true at the same time in order to erm, meet the needs of both of her parents. ***(Steve)***
>
> I try not to let them get away with it. But, because my husband battles with it [MHP], there's no backup. … He is determined to get there. Oh, the boys run circles around him, it frustrates him. And occasionally, I go in and say "Do you want me to just take over?" and he goes "Yes please." [laughs] ***(Kimberley)***

Like Kimberley, several caregivers co-parented or shared parental responsibility with the parent with MHP. Many tried to establish boundaries without undermining them, seemingly protecting the parent-child relationship while conveying to the child that both caregivers held authority. Some assessed how the PMHP might impact their co-parent's perspective:

> So her process was "Oh they're crying, something must be up". Whereas I'm "No, you don't get that and then have a tantrum". ***(George)***

Parenting couples negotiating boundaries together is understood as a normal process. However, some caregivers described breaking with collaboration due to concern about their co-parent's choices, or 'losing' them to the PMHP:

> But that was really hard because I didn't like being in a position that I had to make (...) what it felt to me like a very very important decision, without being able to have that really long and deep conversation. ***(Marcus)***

One-sided parenting and undermining the parent with MHP could be a source of discomfort. However, caregivers described acting on protective instincts, prioritising children's wellbeing. This sometimes included boundarying parent-child contact:

> It was considered that as our oldest turns to a teenager it is not very helpful for her to be in an environment where those kinds of conversations happen. … She would say, erm (...) things like, she would say "Look at this, look what I've got on my hand. It's- I've drawn red lines because it's better than cutting myself'. ***(Marcus)***
>
> I just said to Alanna, "You can't do that. If you want to have Facetime and communication with your mum, I'm afraid you've got to do that in your bedroom." The boys can see (…) and I'm very protective. ***(Marilyn)***

As Marilyn's comment shows, some caregivers appeared to manage an age gap between children by encouraging older children to take responsibility for younger siblings.

3.4.2.2. Explaining and being transparent.

Many caregivers aimed to be transparent and provide explanations to children. This was understood to fit with the authoritative stance that most had adopted.

In line with *being a receptive communication partner* and *finding a relatable explanation*, caregivers described being transparent with the children especially as they got older. Some related this to children's questions about PMHP:

> After he's calmed down, I will sit and talk to him and say, "You do know that you can't simply- you can't live with Mummy until you're 18. And then you can then decide whether to or not." He goes, "Okay." ***(Rosie)***
>
> I feel that Joshua can have a little bit more responsibility and I think because of that he comes back to me when he's got questions because he thinks from me he would get a more open answer. I mean, I'm more transparent with him. ***(Emilia)***

For others, it was a response to implementing parenting boundaries. Nonetheless, this still appeared intimately tied to meaning-making about PMHP: caregivers described often giving explanations after setting new rules that they felt contradicted children's expectations:

> ***Allen***: But we'd said through from day one, "Okay, we will not shout at you."
> ***Judy***: Yeah there was shouting, her shouting.
> ***Allen***: Um, and we never did.
>
> She would get cross, would get angry with them (…) and then there'd be no love afterwards… The art is- I feel personally, is to get that child and just say, "Look, the reason I got cross with you was because so-and-so" and then have a cuddle and whatever. ***(Marilyn)***

By explaining their thinking, caregivers attempted to promote children's ability to understand and evaluate their process. This was understood as likely to protect the child-caregiver relationship and enhance children's mentalising. Even when explaining meant that unstated negative meanings about the parent with MHP were conveyed, caregivers were seen to prioritise the child's wellbeing and the caregiving relationship.

In this category, caregivers described how their wish to provide protection informed the physical and parenting environment they tried to create, and the meanings that were likely shared as a result. Much communication in this category was understood to occur nonverbally, via actions. Beliefs about containment and boundary-setting often appeared so central to caregivers' values and identities that they were carried out without much conscious consideration; the most protective course of action seemed to be automatically taken. Many of these boundaries and actions appeared to support caregivers' wishes to be age-appropriate communicators and shape a safe interactional space, whether intentionally or not. For example, explaining decisions supported the notion that difficult topics could be discussed, and was likely to help children to develop emotionally.

4. Discussion

In this final chapter I will return to the research objectives to synthesise the findings. I will then explore them in relation to existing literature and psychological theory, considering their novel contributions and clinical implications. The reader will be invited to evaluate the findings alongside the study's strengths and limitations. I will offer recommendations for future research before a concluding reflection and summary.

4.1. Synthesis of Findings

Previous research had examined how family caregivers experience and make meaning about a family member's severe and enduring MHP, and a handful of studies had considered the nature of family communication about mental health. Where family caregivers supported children, however, these issues had been given little consideration, and underlying processes had not been studied. Research with parents with MHP and their children had pointed to the importance of other supportive relatives in their lives, but not directly sought their views. By addressing the third member of the child-parent-caregiver triad, this study progresses the aim of integrating knowledge about family caregiving in the context of PMHP, offering robust initial insights.

A substantive grounded theory of how children's family caregivers make meaning and communicate with children about PMHP was generated, addressing the following questions:

c) *How do children's family caregivers make sense of parental mental health problems?*

d) *How do caregivers give an account of their communication with children about parental mental health problems and what influences this?*

4.1.1. How do children's family caregivers make sense of the PMHP?

The sense caregivers[24] made about PMHP was understood as integral to how they influenced children's understanding, informing the 'what', 'how' and 'when' of meaning-making. Caregivers' accounts indicated that they ongoingly assessed parental presentation and childcare capacity, and associated child wellbeing. The sense they made appeared closely linked to whether they attributed parental presentations to personality or mental health. These factors subsequently shaped the messages that appeared to be conveyed to children, whether verbally or nonverbally, intentionally or unintentionally, and consciously or unconsciously.

Caregivers who attributed parental behaviour to 'personality' appeared to experience more anger, particularly when the parent let the child down. When using a mental health framework, caregivers more commonly expressed sadness and forgiveness. A key difference between these meaning-making patterns seemed to be the caregiver's beliefs about the parent's control over their actions and emotions, and therefore over their engagement with children. In both cases, caregivers described working hard to manage their emotions, protect their relationship with the child and provide a containing environment. Caregivers were seen to shift between these meaning-making frameworks. It appeared, however, that spouses and caregivers who cohabited with the parent tended towards mental health attributions, while kinship caregivers and non-cohabitants tended towards personality attributions. Crucially, cause and effect in these patterns could not be differentiated. The emotional tone of parent-caregiver relationships might guide caregivers' attributions, rather than the other way around. Experiences with health and social care services, and associated feelings of being involved or dismissed, also appeared important in caregiver conceptualisations of PMHP.

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[24] Again, for brevity, 'caregivers' will be used to indicate 'children's family caregivers' throughout this chapter.

Vitally, caregivers were understood to segue between making sense of PMHP themselves and sharing this with children according to their caregiver identity. Caregiver identity appeared to be founded on the caregiver's subjective understanding of the child, the parent, and their own life experiences. It was seen to inform their understanding of the child's needs and their role in meeting them. Caregiver identity development was associated with significant role change, and likely with confusion for some children. All caregivers appeared to constantly re-evaluate their position, which was understood as a function of ever-changing needs due to child development and family life cycle stages.

4.1.2. How do caregivers communicate with children about the PMHP, and what influences this?

Within this dynamic context, the findings suggested that caregivers contributed to children's meaning-making via processes of *shaping the interactional space*, *communicating through the developmental process*, and *engendering a sense of safety*. These interrelated processes represented how caregivers engaged in *providing protection in uncertainty* to the child, the parent with MHP, themselves, and the family. Again, meaning-making with children appeared to manifest with varying levels of verbalisation, intent and awareness. The commonality of seemingly nonverbal, unintentional and/or unconscious communication was understood to reflect the complex practical and emotional context associated with PMHP, which caregivers were attempting to navigate.

Caregivers described facilitating conversation or silence about PMHP at different times, regulating information flow according to their perception of the child's age-related protection needs. Most caregivers aimed to provide the minimum that children would accept and used 'illness' as an explanatory framework. When children stopped asking questions, caregivers seemed to perceive that age-appropriateness had been achieved. Despite protecting children from overwhelming detail, caregivers described trying to make information relatable, seeing genuine understanding as beneficial. Attentiveness to child-led cues was the norm, as was willingness to communicate about PMHP. Creating boundaried times and spaces for communication appeared to be a containing strategy that facilitated talk.

Protecting the parent and the self also appeared important motives in whether PMHP discourse was invited or inhibited. This was understood as a way to cope with strong emotions and uncertainty. Nevertheless, absence of verbal communication would not necessarily prevent the flow of meaning to children. Safeguarding actions or disagreement about parenting decisions could implicitly emphasise the differences between caregivers and parents to children, as could caregiver emotional responses to the parent. At times, caregivers appeared to use nonverbal messages to strengthen their relationship with the child and protect their position as caregiver.

It came across strongly that caregivers cherished the children – and often the parents – they supported, and wanted to ease their journeys. Messages of hope, love, and encouraging education and self-care pervaded caregivers' accounts. They communicated these messages in different ways, but importance was universally placed on building children's resilience and planning for the future.

4.2. Relationships to Literature and Psychological Theory

The findings will now be discussed in relation to the literature and psychological theory, drawing on critical and social psychology perspectives. The discussion is structured around two of the identified key concepts related to making meaning with children: caregiver identity and age-appropriate protection. Relationships to the conceptual categories of *shaping the interactional space*, co*mmunicating through the developmental process* and *engendering a sense of safety* are drawn throughout.

4.2.1. Caregiver identity in relation to meaning-making with children.

Widely-reported findings of family caregiver burden, stigma and disruption of lifestyle were replicated here (Ostman, 2007; Rudder et al, 2014; van der Voort et al, 2009). As Wynaden (2007) reported, caregivers described taking responsibility for children's needs at the expense of their own, often using present-moment focus, humour and positivity to cope. The upheaval associated with role loss/change, especially for custodial grandparents (Ziminski, 2007), was replicated. The tendency of spouse/cohabiting caregivers in particular to promote personhood of the parent with MHP was also replicated (Lawn & McMahon, 2014). There were numerous indications of the known impact of PMHP upon children's emotional development, behaviour and attachment patterns (Fonagy et al, 2001; Dean et al, 2010), particularly in association with conflicted family environments (Plass-Christl, et al., 2017). Caregivers' descriptions of improvements in children's wellbeing over time endorsed the benefits of informal support from relatives (Winokur, Holtan, & Batchelder, 2014), including via meaning-making about PMHP (Reupert & Maybery, 2007).

The finding of an evolving caregiver identity was consistent with previous studies that report how understanding of the relative with MHP integrates into caregiver self-concept (Rusner et al, 2012; Wynaden, 2007). Here, it is additionally suggested that knowledge of the child and the parent-child-caregiver relationships are also continuously assimilated, with positioning to childcare, parenting beliefs and communication skills mediating how meaning-making occurs in actuality. This is consistent with Stern and colleagues' (1999) suggestion that caregiver identity development occurs via 'scaffolding' with MHP knowledge. It follows that children's knowledge, especially that of younger children with fewer social resources, is shaped by the content and extent of caregivers' 'scaffolding'. Caregivers were seen to use communication with children as a protective strategy, whether talking, holding back, or both. Many appeared to hope to reduce children's risk of developing MHP, whether by providing knowledge or protecting from perceived causes. Regardless of strategy, caregivers' attempts to be receptive communication partners indicated their attunement to young people's preference for informal relationships with adults where they can ask questions (Cooklin, 2009; van Parys & Rober, 2012).

The notion of caregiver identity as a social positioning bears similarity to Positioning Theory (Harré, 2012). This provides a method of description and analysis for how discourse is used by people to position themselves and others, whether at the level of individuals and dyads, groups and institutions, or societies and cultures (Moghaddam & Harré, 2010). As the concept of a 'key social positioning' is used here to describe how caregivers appeared to conceptualise and enact their caring role in accordance with their individual childcare, mental health and societal contexts, so Positioning Theory suggests that these understandings and actions may arise according to 'forces' that influence caregivers' positioning from interaction to interaction. These 'forces' include assumptions versus rejections of particular 'storylines', shared moral expectations versus personal characteristics, implicit versus intentional positioning and placement of the self and the other (van Langehove & Harré, 1999). In Positioning Theory terms, it could therefore be understood that caregivers' discourses and social acts were the manifestation of internalised social and personal rules about family, childcare and mental health, via which caregivers positioned themselves but also children and their parents through their meanings and communications. This provides an explanatory context to caregiver meaning-making and communication appearing to be variably conscious, intentional and verbal/nonverbal. Furthermore, it allows for the changeable and potentially conflicting meanings that caregivers sometimes appeared to hold, as the positioning of each social act can be understood to take place within its own context-based 'storyline' (e.g. that a child needs to be rescued from the parent, but the parent also needs to be saved from the mental health problem).

Epistemologically, Positioning Theorists purport that despite the human tendency to use a Newtonian-Euclidian space/time framework for understanding social interactions, an alternative 'persons/act' framework where speech acts are the 'substance' of social reality and acts are located in and between people may be more appropriate (van Langehove & Harré, 1999). The social past, present and future can be seen as located within the people who enact them and as fundamentally intertwined and not clearly time-delineated. Tranvag and Kristofferson's (2008) model of caregiver identity being cumulatively built on the substance of past social interactions and meanings and shaping the nature of future ones is, for example, concordant with this perspective. This social constructionist perspective (Slocum & van Lagenhove, 2004) also appears useful for examining the evolution of caregiver identity here, particularly regarding the seemingly continual updating of caregiver positioning as a result of progression in children's cognitive capacity and maturity. Given the significant economic, political and institutional influences (and associated power dynamics) that were also understood through the analysis to be impacting caregivers, children and families, the relevance of ontological realism is also highlighted. For example, caregivers' variably positive, negative and neutral experiences of statutory services appeared to impact their trust and engagement with health and social care structures, and seemed likely communicated to children through preferred conceptualisations of mental health problems and modelled relationships to help.

Caregivers' accounts indicated that they often conveyed nonverbal messages to children from an alternative/'other' position to the parental presentation, often just by being themselves or establishing parenting boundaries. This demonstrated how Cooklin's (2013) notion of helping children gain an 'outside' or meta-perspective on the parental difficulties might be achieved. Generalising the differences between groups, however, the efforts by spouses/cohabitants to normalise parenting with MHP appeared to minimise the messages to children about differences between themselves and the PMHP, reducing this meta-perspective. Protectively, these caregivers described trying to promote messages of empathy toward the parent, to nurture child-parent relationships. Among kinship/non-cohabiting caregivers, more negative affect and conflicting messages[25] about the parent had potential to confuse children, increasing stigmatising 'us' and 'them' conceptualisations (Goffman, 1963). Contradictory parenting messages about MHP have been reported elsewhere, and are understood as largely unconscious embodiments of social taboos (Mueller, Callanan, & Greenwood, 2014). Parent-child relationships appeared weaker in the kinship/non-cohabiting group, linked with lower-empathy messages from caregivers and less parent-child contact. Custody loss likely impacted this, as did social stigma towards women with MHP[26], who are more likely to be branded as incompetent mothers (Corrigan & Miller, 2004).

This highlighted a dilemma for caregivers, where disputing social ideologies[27] of 'normality' in favour of tolerance may jeopardise children's development of healthy 'self' and 'other' distinctions between themselves and the PMHP, yet excessive distinctions may contribute to stigma towards the parent. If children do experience MHP later (moreso, become a parent with MHP), there is increased risk of self-stigma (Watson, Corrigan, Larson, & Sells, 2007). Children's awareness of in- and out-group desirability during early

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[25] E.g. An empathetic verbal message alongside a nonverbal message about high parental risk level, or a verbal criticism of the parent alongside the more positive nonverbal communication conveyed by supporting contact.

[26] All children in the sample in kinship care were affected by maternal PMHP.

[27] Ideology is used here in the Marxist sense, indicating that some socially held notions and ideas sustain unjust social relations that benefit some people and not others via practices that are biased in the favour of those with power.

childhood (Corrigan & Watson, 2007) and the psychological partitioning of mental and physical health during mid-childhood (Fox, Buchanan-Barrow, & Barrett, 2010) render them sensitive to stigmatising concepts. Consequently, how conflicting messages dovetail with a child's developmental stage is paramount. It is suggested that these meaning-making processes are largely unrecognised by caregivers, who act on the best available knowledge of what children need whilst managing considerable personal emotional burden.

Indeed, caregivers were seen to engage in significant emotional self-management. This was connected with purposefully expressing or holding back inner experiences when talking with children. Gross and Barrett's (2011) model of emotional regulation emphasises dual-processes of emotion management: (1) appraisal of an internal or external cue (antecedant) leading to an emotional experience; and (2), trying to up- or down-regulate it (response). Caregivers could be understood as using antecedant-oriented emotional regulation by habitually seeking or avoiding exposure to the PMHP via parental contact or talk with the child, alongside response-oriented emotional regulation to emphasise or hide their internal reactions from children. Hochschild's (1979) concept of 'emotion work' also positions caregivers' attempts to inhibit or promote talk as 'secondary acts' to change their emotional experiences. Largely described in relation to organisational contexts, 'emotion work' theorises that individuals act to pursue shared social goals.

The goal of caregiver emotional regulation may therefore be pursuit of the most valued 'ideal affect' (Tsai, Knutson, & Fung, 2006) for the self and the child. The regularity with which caregivers 'stepped into the child's shoes' demonstrated their attempts to understand children's emotional states. In the UK context of culturally individualist tendencies, 'ideal affect' is suggested as most associated with pleasure-seeking and disconnection from discomfort (Vastfjall, Garling, & Kleiner, 2001). The value caregivers placed on guarding against emotional pain and promoting positivity is consistent with this. From the ‘emotion work’ perspective, caregivers’ hopeful narratives may sometimes be surface-level deflections from unpleasant emotions, to support everyday coping. At other times, however, they may represent deep-acting regulations of children’s PMHP appraisals and emotional habits in line with social expectations (von Scheve, 2012). Caregivers appeared to use both strategies but at different times, indicating the multiple ‘levels’ of meaning and protection that they attempt to address.

From a sociological perspective, then, caregivers’ responses to PMHP and meaning-making with children were seen to tie in with internalised social norms about emotional expression. Via self-regulation, caregivers modelled social rules about what ‘ought’ or ‘ought not’ be expected, felt and expressed about PMHP, and provided mechanisms to follow these rules[28]. From a symbolic interactionist stance, these representative meaning-making processes can be understood as a channel for communcation with children, who naturally seek social rules. In the PMHP context, the wish to avoid stigma-related shame may further heighten this attentiveness (Chandra & Minkovitz, 2007). These processes are understood as two-way: as caregivers updated their identity according to changes in child development and PMHP presentation, there were developments in their preferred social rules (Reynolds, 2003).

Perhaps congruently with caregivers’ seemingly conscious and unconscious attempts to remain flexible in an uncertain context, many expressed contradictory approaches to communicating with children. Their accounts reflected self-doubt and powerlessness, yet also conviction and firmness. From a Role Theory perspective, these fluctuations can be seen to arise from stress due to role change (Davis, Gillis, Deshefy-Longhi, Chestnett, &

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[28] For example, talking or not talking, or embracing or rejecting uncertainty.

Molloy, 2011). For children, this is suggested to challenge the development of a cohesive self-concept and the mentalizing abilities that support interpersonal behaviour, particularly differentiating cognition from affect and separating self and other (Bateman & Fonagy, 2012). Therefore, although some caregivers expressed concern about burdening children emotionally, sharing conflicting experiences may help children develop mentalising abilities. When verbal dialogue with children was rare, caregivers may not have been able to convey conflicting feelings of this complexity. It could be surmised that this might increase children's misunderstandings about PMHP (Maybery et al, 2005) and inhibit reflective functions that protect against psychosocial difficulties. Again, the importance of establishing child-caregiver dialogue for children's outcomes is emphasised.

4.2.2. Providing age-appropriate protection

Caregivers repeatedly referenced age-appropriateness as the cornerstone of meaning-making, communicating and protecting. The same concerns have been reported by parents with MHP, to protect children from inappropriate details and reduce their psychosocial burden (Mueller et al, 2014; Pikhala & Johansson, 2008). Children themselves generally want more information about PMHP and benefit from receiving it (Handley et al, 2001; Ostman, 2008). This indicates that other caregiving adults are aligned with the parental perspective on protection, and suggests the impact of adult-held social understanding about children's resilience and innocence on children's realities. The number of caregivers who reported surprise at children breaking periods of silence about PMHP with questions emphasises this view. It signifies that caregivers were not always aware of children's experiential learning in the absence of talk, in accordance with their developmental 'zone of proximal development' (Vygotsky, 1978).

Caregivers' descriptions of attending to child-led cues indicated close monitoring of child development. Their knowledge largely appeared based on lay perspectives, which fits with the reported dearth of access to support. As described, many caregivers held back from talk, and observed that children did not always ask questions. It remained unclear from caregivers' accounts whether children's silence might be because they were satisfied by their understanding of PMHP, or if they sometimes remained silent to fulfil a learned protective role towards caregivers (van Parys & Rober, 2012). As others have speculated, caregiver tendencies to hold back are likely copied by children (Nolte & Wren, 2016). On the other hand, caregivers' attentiveness to children's nonverbal cues[29] could provide a means of overcoming this. Greater awareness of mediators of PMHP can help move children's understanding on from basic illness/medical conceptualisations as they get older, which is helpful in the longer-term (Fox, Buchanan-Barrow, & Barrett, 2007). Children's ability to assimilate new understanding follows development in their abstract thinking. It may therefore be better to base information-giving on conceptual skills rather than age, and to give more details rather than fewer. The question, then, may be caregivers' willingness and confidence to verbalise first.

Caregivers described softening and controlling explanations given to children, which Ballal and Navaneetham (2018) also reported. Reasons for this were identified here: repecting parental wishes and confidentiality; protecting children from fright; and letting them 'be children' without the burden of understanding for a little longer. Pervasive uncertainty about what might damage children and caregivers' wishes to protect their own emotional coping were also present. In studies of caregiver-child communication about parental physical illness, unhelpful but well-intentioned limitations have also been reported (Patterson, McDonald, White, Walczak, & Butow, 2017). Limited communications are linked to a vicious cycle where caregivers understand little about children's experiences, increasingly make assumptions, and see children as indifferent or

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[29] For example, responding to parental behaviour by rolling their eyes or staying quiet.

unaware (Christ & Christ, 2006). This demonstrates how protective action can paradoxically promote psychosocial difficulties for children, possibly perpetuating silence and non-mentalising states.

The strong theme of protection here fits within the historically recent view of children as biologically and psychologically distinct from adults, requiring protection and valued for the meaning they bring to parents' lives (Cunningham, 1991; Zelizer, 1994). Discourses of parenting as a public health concern (Dermott & Pomati, 2015) and approaches like 'attachment parenting' and 'intensive mothering' (Hays, 1996) can be understood to amplify cultural ideologies where 'good' parenting involves parental devotion and child-centredness, often through adolescence and into early adulthood (Johnston & Swanson, 2006). As discussed earlier, this can be amplified for parents with MHP, who are more likely to be labelled 'bad' parents (Corrigan & Miller, 2004). Contamination by PMHP, akin to an infectious process, is a commonly described social representation (Jones et al, 1984), and children themselves describe this fear (Koschade & Lynd-Stevenson, 2011).

While understood as often unintentional, these social narratives about protection and PMHP may go some way to explaining caregivers' attentiveness to age-appropriateness and shielding children. The focus on reducing exposure to PMHP indicates how meanings may perpetuate in families, reducing caregiver belief in child resilience and perhaps increasing children's distress when they do witness parental difficulties. Additionally, caregivers may experience pressure to 'correct' the failures of the parent with MHP and guard themselves against externally and internally located stigma. Conforming to society's 'normalising gaze' (Foucault, 1978) on parenting practices may feel protective for self and child. Simultaneously, messages linking 'fitting in' with happiness may be conveyed to children. It could be conjectured that this response is stronger when the law has been involved (e.g. for care orders), and contribute to caregivers separating more from the parent.

The greater acceptance by spouse/cohabiting caregivers of children's exposure to PMHP may represent an amended view of 'good' parenting related to reduced mental health stigma in these families. A minority of caregivers in this group rejected cultural sterotypes about MHP and parenting, aiming to increase children's awareness of this 'false consciousness' (Fox, Prillenltensky, & Austin, 2009). For others, insight into PMHP appeared linked to reduced hope of achieving idealised 'good' parenting. This could be compared to the 'insight paradox' described among people with schizophrenia, where greater understanding about the condition is widely believed to be helpful and a clinical aim, but is associated with reduced hope and increased depression (Lysaker, Roe, & Yanos, 2007).

Caregivers' emphasis on protection somewhat contrasts, however, with child development narratives that focus on children's independence and autonomy. Within these perspectives, caregivers are positioned as faciliators of adult social skills (Woodhead, 2006). This has been critiqued as a 'western' social construction steeped in individualism and not necessarily transferable cross-culturally (Carr & May, 2000; Kagitcibasi, 2005). Nonetheless, in the UK and other 'western' countries, the view of children as reciprocal social actors with rights to participation, not just protection, is a growing argument in theoretical and legal perspectives on childhood (UNICEF, 2014). From a Vygotskyan standpoint, culturally dominant values about autonomy become instrinsic to children's actual developmental process and expectations (Kolb, 2014). Consequently, in a context where children's voices are respected from an increasingly early age – intensified by independent internet use by mid-childhood – it may be that they are increasingly sensitised to over-protectiveness and not feeling heard. This perspective endorses involving children in PMHP dialogue rather than shielding them (Grove et al, 2015; Pikhala et al, 2011). It also indicates the value in caregivers exploring where beliefs about age-appropriateness come from, and the meaning-making needs of children in today's context.

4.3. Clinical Implications

4.3.1. Broader implications.

Caregivers' attempts at *providing protection in uncertainty* constituted complex interlinking processes of meaning-making and communication, where the characteristics of caregiver, child, parent, family, PMHP and society were all seen as influential. It is understood that families' needs vary considerably, and therefore too will the clinical implications. Person-centredness and family-centredness are consequently both key clinical implications. There is a need for support that meets caregivers 'where they are' emotionally, practically, culturally and linguistically.

The findings demonstrated that as children, caregivers and parents age and change, so do their requirements for meaning-making. Consequently, all clinical implications are offered with the recognition that there may not always be a clinical 'need', and that health and social care professionals and institutions are not necessarily useful to caregivers, nor perceived so by them. The findings highlighted the importance of communities, friendships, family relationships and engagement in activities and work to caregivers and the children, and that sustaining these resources is vital. Consequently, these implications extend beyond the 'clinical' in the medicalised sense, and are also located within community and social approaches, including online.

Despite this, there is a need to consider the genuine risks that PMHP can pose to children, and that legal systems taking responsibility for their safety is sometimes appropriate. Not all affected children experience neglect or abuse, but a considerable number do. In these cases, living separately to the parent with MHP or having little or no contact can sometimes represent the 'least worst' option for protecting all parties. Decision-making about these issues is often not clear-cut and stresses the interplay between medical and moral epistemologies (Foucault, 1973; Pollock, 1993). Here, ethical, moral and cultural complexities were evidenced by caregivers' fluctuating positions of certainty and uncertainty, tussles between safeguarding and 'letting go', and wishes to protect parents, children and themselves. Services and clinicians face similar dilemmas, albeit from different positions.

This study evidenced, however, that caregivers often shoulder the responsibility for supporting children, taking great care at personal cost, and with little or no external support. The value added to society by these hidden caregivers renders family caregiving a collective issue, not an individual one. There is a clear requirement for policymakers, clinicians and third sector workers to address caregivers' needs beyond the starting point of positive regard, and for funding bodies to provide the economic means for this to happen. With influence from the individual client through to the political arena, Clinical Psychologists are among those positioned to drive this agenda.

4.3.2. Specific clinical implications.

4.3.2.1. Psychoeducation and communication skills.

The findings indicated that caregivers want and would benefit from psychoeducation about MHP, managing the burdens of caregiving, talking to children about PMHP, and awareness of nonverbal communication. 'Scaffolding' caregivers' mental health knowledge will likely benefit family communication and reduce reliance on social perceptions (Stern et al, 1999). Certainly, mental health remains a challenging topic, but with more knowledge comes a language to use, a reduction in stigma and greater empathy (Maenhout et al, 2014). Increasing children's mental health literacy is associated with greater resilience and help-seeking from trusted adults (Riebschleger, Grove, Cavanaugh, & Costello, 2017). Positioning caregivers to share this understanding promotes the two-way communication that is known to benefit children (Cooklin, 2006) in the environment where they want it (Bilsborough, 2004). Caregivers will likely benefit from hearing more about children's preferences for understanding, and how talk about PMHP is more likely to help their long-term psychosocial outcomes than damage them. Discussing the protective role and intentions that caregivers have in their relationship with children is suggested as a potential jumping-off point, along with normalising the challenges of talking about PMHP, being age-appropriate, and encouraging creativity in finding relatable explanations.

Several caregivers explicitly said that they would engage if education and support were available. Many were motivated to access this online, read books and leaflets and attend groups including peer support; the implications do not only point to professional therapeutic intervention. The pressures of balancing work, other dependents and finding self-care time mean that flexibility in provision is critical. Only offering clinic-based groups during office hours leaves many unsupported and frustrated and may discourage future help-seeking. Grove and colleagues (2015) reported that when parents and children watched and discussed a DVD about mental health in families, knowledge improved for both parties and caregivers 'joined in' to make meanings with children. As the authors suggest, video has broad application across clinical and non-clinical environments.

Increasing caregivers' resilience through self-reflection may help reduce their need to hold back from PMHP talk with children due to overwhelming emotions and uncertainty. Psychoeducation would provide caregivers an opportunity to explore biases, assumptions and stereotypes about MHP, where these come from, and to consider linguistic choices appropriate to their family values. This could be seen as fitting within an Acceptance and

Commitment Therapy framework (e.g. Hayes & Smith, 2005). Likewise, mindfulness-based approaches have been associated with improved decision-making, meta-cognition and self-regulation (Friese & Hofmann, 2016; Shapiro, Jazaieri, & Goldin, 2012), including for carers of people with severe and enduring MHP (Moorhead, 2012). Conceptualising thoughts and emotions as passing events may help caregivers manage their emotional responses and reduce reliance on silence as a coping strategy. Evidence of child-parent similarities in metacognitive capacities suggests that children might experience a secondary benefit through caregiver modelling (Esbjorn, Normann, Lonfeldt, Tolstrup, & Reinholdt-Dunne, 2016). Additionally, Mindfulness exercises, ACT metaphors and exploring family values would provide facilitatory activities that caregivers could do with children. Again, these approaches are both accessible outside specialist health services, including online, via books and charities.

4.3.2.2. Implementing the family-focused agenda inclusively and sensitively.

The results suggested that for many caregivers, improving the parent-child relationship was an investment in the child's future. It also appeared that closer parent-caregiver relationships facilitated the same for children. This seems concordant with the UK health and social care agenda to provide family-focused approaches that meaningfully include caregivers (Cabinet Office, 2008; Department of Health, 2011).

The findings support the provision of systemic therapeutic interventions such as Beardslee's Family Intervention (Focht & Beardslee, 1996; Pikhala et al, 2011) to increase family communciation. Elevating less conscious beliefs and emotions that may be shared between family members, and drawing out nonverbal dynamics, are suggested as important aims (Focht-Bickerts & Beardslee, 2000). Considering caregivers' descriptions of 'picking up the pieces' and wanting practical tools, perhaps most important for them will be a sense of gaining skills to maintain meaning-making with children beyond the therapy room.

Proponents of narrative therapies have offered approaches that faciliatate 'storying' of family and caregiving narratives, where previously-stifled or 'weak' storylines can be shared (Kis-Sines, et al., 2008). Particularly relevant is the concept of 'double stories', where narratives of difficulties and seriousness but also strength and love can be heard simultaneously (White, 2006). This provides a way to hear the hope and humour that pervaded caregivers' accounts in a context of family togetherness and counters the problem-saturated nature of many clinical approaches (White & Epston, 1990). Where it is possible to work with the parent-child-caregiver relational triangle, therapetuic intervention might allow relational difficulties to be voiced more safely.

For marginalised communities including BEM families and refugees, narrative trauma approaches have focused on 'relational stories of security', silent witnessing of trauma and sharing meaningful nonverbal communication (De Haene, Rousseau, Kevers, Deruddere, & Rober, 2018). Where caregeivers and children who have experienced traumas in PMHP contexts, and for doubly marginalised families[30], this emphasis on processing the unsaid may be highly beneficial. Similarly, the importance that several caregivers placed on written communication is worth consideration by clinicians as an alternative means of child-caregiver or child-parent interaction. This also points to reflective/journal writing as a tool for emotional processing for children and caregivers.

As Daniel and Wren (2005) discuss, the aim of narrative approaches to draw out and deconstruct underlying values encourages clinicians to question our personal and therapeutic assumptions. Given the potentially stigmatising societal perspectives on 'good' parenting, it is important that Clinical Psychologists and our clinical colleagues continue

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[30] For example, families from marginalised or minority ethnic communities who are also affected by PMHP.

to enagage in robust self-reflection when working with families affected by PMHP. In line with the family-focused agenda, clinicians have a responsibility for involving caregivers and not shying away from challenging intra-family dynamics that underlie many nonverbal communications with children (Thompson, Bender, Lantry, & Flynn, 2007).

There is also, however, a need for pragmatism about availability of therapetic interventions in the current healthcare climate. As social care focuses less on parental distress, more on the child, and often includes family caregivers, they may be well-positioned to connect the needs of all family members and address children's needs early. The Hackney 'Reclaiming Social Work' initative has aimed to provide this by increasing reflective practice, risk-sharing, time with families and capacity to respond. This has been supported by employing Clinical Psychologists to facilitate a more therapeutic environment in clinical work and within staff groups. Although implementing the model has led to significant service upheaval in some regions, there is evidence of more collaborative therapeutic work with families and positive feedback from families and staff (Forrester, et al., 2013; Mugweni, Gammage, Bevington, Akister, & Wilkinson, In preparation).

Finally, some caregivers in this study reported having accessed peer support, usually via local authority provisions for kinship carers. Social care and peer support may both provide protection-focused and non-medicalising resources for caregivers. As the literature review highlighted, third sector provision for mental health caregivers is lacking. Stressing this unmet need through research publication will support the agenda to improve this. Across the statutory and charitable sectors, peer-led support, with its educational benefits, should be a priority.

4.4. Methodological Considerations.

Inherent in my philosophical stance to this study is the acknowledgement that research processes are bound by time and context; this constitutes both a strength and a limitation. My interpretation of the findings is supported by triangulation processes, but other constructions would be possible. My influence throughout the research was unavoidable and essential but is recognised. In pursuit of rigour, I have comprehensively applied reporting guidelines (Tong, Sainsbury, & Craig, 2007) and assessed this study using two quality frameworks (Hutchinson et al, 2012; Tracey, 2010; all provided in Appendix X).

4.4.1. Strengths.

Building on previous research, this study is the first to examine how caregivers contribute to children's meaning-making about their parent's MHP, attending to underlying processes. The research objectives enabled new insights to be made from the caregiver's perspective, while strengthening what was known from research with children and parents with MHP and providing an alternative angle. Information for policy-writers considering caregivers' needs has been offered, as have informed clinical recommendations.

A key strength is the robust implementation of GT methodology (Charmaz, 2014), including rich description of data collection and analysis processes and abundant presentation of data. The trustworthiness of the findings was strengthened by achieving theoretically sufficient categories, which attested to an adequate sample size and triangulation procedures. Honouring ethical practices, including caregivers' rights to participation, supported the quality of the data.

Finally, sample diversity adds resonance to the findings, with heterogeneity in caregiver age, occupation, relationship to child/parent, education level and socio-economic status. Diverse recruitment pathways meant that caregivers were engaged via social care, the NHS, third sector groups and online, broadening the range of perspectives. Sample heterogenetity is an aim of GT, and broadens the transferability of the findings within similar groups and the UK population.

4.4.2. Limitations.

Sample characteristics also constitute a limitation, however, as most participants were English, all were caucasian and younger caregivers were under-represented. Comparisons between some sample sub-groups (e.g. age, recruitment pathway) was therefore not possible. Attempts were made to recruit from culturally and religiously diverse groups. Difficulties with this may relate to cultural variation in understanding and response to PMHP, barriers to support that people from ethnic minority backgrounds experience and the research timescale. Caregivers of other races and cultures may have different experiences to those described here. Like most studies in the systematic review, there were also more females than males. Following Stern and colleagues (1999), I suggest this is probably representative of children's family caregivers in the UK, and makes male caregivers' experiences important to understand.

A further limitation is that the design did not include the views of children or parents with MHP. It would be informative to hear these family members' views on what caregivers described to further draw out the relational dynamics. In line with this, observation of child-caregiver interaction was not possible.

4.5. Directions for Future Research.

4.5.1. Cross-family perspectives.

Research has addressed the perspectives of children, parents with MHP and now caregivers. There is an agenda to replicate the findings reported here and future research allowing the views of different family members to be heard together would be valuable.

Not only would this go some way to address the biases inherent in individual interviews, but family interaction would to an extent be observable.

4.5.2. Diverse families.

Conducting this research with communities not represented here, particularly immigrants, refugees and caregivers whose first language is not English would be helpful for understanding how the concept of providing protection in uncertainty varies in families affected by PMHP across society. This would support clinical implications to address the needs of families from other cultural backgrounds more appropriately.

Additionally, this study pointed to differences between younger and older caregivers, but sample sizes across age groups were not large enough to draw comparisons. Further research could provide insight into how age and associated factors, including prior parenting experience, may influence caregiver coping.

Because of ethical concerns, this study was unable to include family friends who support children. Nonetheless, several participants described help from friends and this remains an area for future consideration.

4.5.3. Role change.

This study found that children's family caregivers can experience profound role change which can be associated with role confusion and grief. While this has also been reported elsewhere, especially in the kinship care literature, it would be helpful for future research to further examine factors that ease or challenge these role transitions.

4.5.4. Interventions research.

The findings indicated how therapeutic interventions could be tailored to caregivers' needs, providing mental health knowledge, child development education, communication skills and emotion management skills. Development and evaluation of psychoeducation packages would be a helpful and practical next step. It would likely be beneficial to deliver psychoeducation in person in social care settings, via stepped care NHS services or through charities supporting families (e.g. Kidstime, MIND, NSPCC). Computerised and printed resources are also recommended to help caregivers access support despite other pressures. The scope for statutory services and carer organisations to co-produce guidelines with caregivers should be prioritised.

4.6. Final Self-Reflection.

As I described when introducing myself and my postion to this research, engaging with this topic using GT required me to go on a personal, professional and often emotional journey. Representing what I found by writing this thesis is a significant waymarker in the course of this project. As this stage nears completion and what may follow has become more prominent in my thinking, I have contemplated my experience of talking with caregivers, what this project meant to them and how they have shaped it and me.

On an individual level, I see that I have grown as a clinician as well as a researcher through this process. Something I believe will stay with me is several caregivers' reflections on their experiences of services. They described how significantly the ongoing reforms and austere times have impacted their families. Simultaneously, professionals who have connected in a genuine, human manner despite this context of 'not enough' had made meaningful – if small – differences to them. This led me to consider how simple and honest connection with others helps us hold onto the self during turbulent journeys: I believe this is also what caregivers aim to give children. Rather than representing something profound, this seems like something many of us relate to, in one way or another.

On a broader level, this project continues rather than ends. I have embraced my role in the collection and interpretation of caregivers' stories, and so too shall embrace my role in passing these messages on to wider audiences where they will hopefully be of use to other people, particularly families, professionals, organisations and communities.

4.7. Concluding Comments.

By exploring the accounts of 19 children's family caregivers, this research has contributed a substantive theory about how they contribute to children's meaning-making about their parent's MHP. Existing knowledge about caregiver experiences been built upon and child-caregiver communication processes have been elaborated for the first time.

Caregivers spoke about their aim to protect children and other family members despite a context of pervasive uncertainty due to the nature of severe and enduring PMHP. Most did so with hopefulness and humour, although the emotional burden considerably impacted how meaning-making occurred with children. Although caregiver tendencies to talk or hold back from communication varied, the intention to maximise children's wellbeing outcomes by providing age-appropriate nurturance and support was universal. The incidence of nonverbal communication was evidenced as high, with potentially confusing outcomes for children in some situations. The results point to the need for this devoted and under-recognised group of caregivers to be better supported, particularly with developing mental health and child development knowledge and with communication skills.

These findings support the family-focused agenda and have relevance for policy and clinical practice with children's caregivers and families. Many participants told me that improvement and change was their hope and primary motivation for taking part, so that others' lives might be improved. Further research will help to promote this legacy, in a way that is attuned to the diverse contexts and experiences of families today.

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6. Appendices

Section 1: Systematic Literature Review

Appendix A. Textual Quality Assessment of Reviewed Studies

PAPER	NOTES
Ballal & Navaneetham (2018)	• Limited discussion about Ethics of all kinds. • Credibility (and Rigour) are somewhat impeded by the quotations often being very short excerpts. Overall more data could have been presented and this would be helpful to really get the themes. The analysis method was also not well described. • Overall, the method is well presented, and its limitations discussed well – this brings Sincerity. The same is true of acknowledgement of the Indian cultural context. • The study is worthy and provides a meaningful contribution that is resonant for the reader and clearly situated within other literature.
Endrawes et al. (2007)	• Worthy: looking at CALD population in western country. • Sincerity: Interviews were translated, and there is acknowledgement of associated meaning loss/challenge. • Rigour: Age, gender and relationship of participants is only given in results – could have been clearer.
Fraser & Warr (2009)	• Very worthy topic and meaningful, and significant. Clear goals and application, and future directions. • Mostly a well described method. There is some self-reflexivity/positioning of the researcher, which is a credit to the study. Good Ethical considerations. • However, poor elaboration of the analysis method, no evidence of cross-checking/coding or triangulation, and no clear method stated, limit the rigour and credibility. • Good discussion of limitations, including that the insights are cross-sectional rather than longitudinal, and carer experiences fluctuate.
Jonsson et al. (2011)	• Rigour and sincerity well met. Good description of method, including Ethics. Good number of quotations of sufficient length to met Credibility requirements. • Worthy and meaningfully coherent: well set in the literature and makes sense but is interesting. However, it’s not that different to other papers on this topic. It more replicates than takes things further. It evidences these issues for Bipolar specifically.
Karnieli-Miller et al. (2013)	• Clear description of Sincerity and Credibility, and of Rich Rigour through description of analysis processes, especially triangulation and identification of bias. Good level of quotes. • Good clear adherence to stated model: stress-appraisal-coping model. • Description of Ethical procedures is lacking beyond stating approval.
Karp & Tanarugsachock (2000)	• Worthy, meaningful and significant: This study meets all of these criteria. It is timely and clearly situated, and the report is coherent and detailed. There is generalizability from these findings to other caregiver groups (or one suspects), giving is Resonance. • Excellent Rigour and sincerity in description of method and researcher positioning. Slight weakness in lack of self-reflexivity re. bias and assumptions (i.e. what brought them there). • Credibility is high due to long and many pieces of data in write-up.
Lawn & McMahon (2014)	• Overall, excellent reporting. All of the quality components are present and thickly described. • Sincerity: One of the only papers to explain the position of the researchers, and where the study arose from, including clinical and lived experience. Epistemological

	stance given, and biases owned.
Maenhout et al. (2014)	• Sincerity: Method is described well, but there is no reflexivity at all, and no statement of epistemology. • Credibility: There is only one quotation given per theme, and more would improve the credibility. However, those given match the analysis well. • Overall this meets the criteria well, especially given the short word count of this report and the amount of detail they get into it.
Mizuno et al. (2011)	• Overall, this paper is very well reported. It is well situated in Japanese culture and context, with comparisons with western norms. It also discusses the findings based on the Japanese context so they have local meaning and recommendations. • Ethics: excellent description with much more detail than other studies. • Rigour and sincerity are upheld by excellent description of procedure and analysis method. Plenty of quotes of varying lengths. • Researcher position not really described, but no less than most other papers.
Pusey-Murray & Miller (2013)	• Rigour, Sincerity and Credibility are all limited by the lack of clarity about the method and analysis reporting. There is no researcher self-reflexivity, transparency about assumptions and biases even though the reader may guess some, and there is no discussion of study limitations and strengths. • Lack of clarity regarding aims means its coherence is limited. • However, this is a worthy topic in its relevance to Jamaican culture and does provide a significant contribution given the paucity of research in this country on this topic, and the evident need.
Rose (1998)	• Rigour, sincerity and credibility are all afforded by the methods description and transparency. Data were checked with participants and results are described with sufficient quotes. a few more would strengthen it slightly. • Highly resonant – findings are related and clearly link to other research and models, but they bring it on a step making this a significant contribution. Minimal ethics discussion, and could have been more description of researcher position.
Rose et al. (2002)	• A worthy topic that is clearly explained as novel, different but not too different and well linked to literature. It is meaningfully coherent and the model explained well. The move from narrow processes (e.g. burden, sigma, EE) to broader processes underlying carers' coping goals is useful. • It is let down in a number of ways. There is no ethical detail at all. Quotations are very short (word limit?) and not that many. There is no self-reflexivity, researcher positioning or transparency about shortcomings and strengths at all. • Data collection and analysis methods are well described on a practical and GT level though.
Rusner, et al. (2012)	• Ethics: has a section, attended to sufficiently well. • Worthy, significant and meaningfully coherent: it makes sense and is shown to fill a relevant gap, providing a new and interesting angle. • Improvement would be more quotes to increase credibility, but there were enough to get it. Limitations are discussed although small sample not mentioned. Also, no researcher reflexivity.
Stern et al. (1999)	• This is a high quality paper. Rich rigour and sincerity: excellent description of method and hermeneutic circle incorporating researcher. Worthy and clear aims. • The limitations and shortcomings in terms of sample and method are both discussed. • Topic has resonance and significant - linked to future research and interventions.
Tranvag & Kristoffersen (2008)	• The study is relatively coherent, but few things are not clarified that well – why they had certain inclusion criteria, and how this study is different to the literature (cited) that already exists. • The write-up is a bit repetitive and the discussion is more like the results in places – using this detail with more quotes in the findings section would improve credibility. However, it's worthy and resonant in terms of clinical implications.

	• Rich Rigour: Excellent description of method. • Sincerity: No researcher reflexivity but transparent.
Veltman et al. (2002)	• Worthy topic, with relevance, coherence and a meaningful contribution for practice (positive focused-interventions). However, could have gone further in elaboration of process/connections, especially in discussion, and this weakened it too. It's clear as a reader that this would be possible. • Rich rigour and sincerity limited by failure to choose a specific qualitative method. Elaboration of method given, but seriously weakened by this and lack of philosophical position and no researcher self-reflexivity except potential for bias. • Ethics very limited description.
Van der Sanden et al. (2015)	• Rigour/Sincerity: Excellent method description – more detail that most papers give. • No self-reflexivity at all in terms of researcher positioning. • Overall excellent reporting. Lots of data, good description of method and weaknesses, flows well.
Wynaden (2007)	• Good description of GT process and there is mention of philosophical stance and aims. • Credibility is limited by hardly using any quotes. However, this is likely due to word count limits, and the model is very well explained and a figure provided. The Resonance and Meaningful Coherence of the research enhance its credibility. • Sincerity: No discussion of strengths & weaknesses, no self-reflexivity but good transparency.
Yeung, Irvine, Ng & Tsang (2017)	• This is a very well written report – the only one to say that they followed quality reporting guidelines. Rigorous reporting of method, Worthy and Significant for topic area, Ethics addressed, Resonance is evident and novel concept explored. • Good description of researcher reflexivity and steps to address bias and cross-cultural knowledge. • The main critique is that more quotations would have better supported the themes, but those provided are sufficient.

Appendix B. Table of Reviewed Studies: Full Summaries

TITLE & LOCATION	DESIGN	SAMPLE	KEY FINDINGS & IMPLICATIONS	EVALUATION
Ballal & Navaneetham (2018) Talking to children about parental mental illness: The experiences of well parents India (urban) This study is all about talking to children.	Qualitative: IPA Semi-structured interviews explored experiences of talking to children, perceived risks and benefits, challenges, and others' roles. Another paper will report on the risks and benefits part – this study presents how well parents manage dilemmas (i.e. by talking or concealing)	10 well parents whose spouses had severe MI, and were inpatients in the recruiting facility. 5 mothers, 5 fathers. All involved in care and treatment. All at least one child aged 5-18 (13/19 children were teenagers).	- Themes provide insight into how well parents try to regulate children's' understanding and responses to PMI by avoiding or selecting certain topics (although lack of process/'why'). - Themes relating to limiting children's exposure: 'distancing children from PMI', 'avoiding conversations about the illness'. Separating from distressed parent may help, but helping child maintain parental relationship is also needed, and open communication helps. - Themes relating to well parent sensitivity and responsiveness: 'giving and receiving emotional support' and 'providing explanations of the illness'. Parent anxiety and uncertainty can shape this. Parentification is evidenced, as reported elsewhere. - 'Providing explanations' theme: they actually described incidences of the parent explaining opening up communication from the child – but they don't explore this further. - Themes showing apprehension about info: 'regulating other sources of information'. Ill parent doesn't seem to be involved in these discussions (fits with Nolte and Wren). May be helpful to encourage child to share selectively. - Themes similar to other papers come up: fear of stigma and what others think about PMI, others not understanding (including family), age-appropriateness of information.	- Shows the parenting challenges that well parents face, and useful for MH professionals. Possibly shows split between ill and well parents in communication – implicated intervention need. Greater need to help well parents, who hold the carer burden. - The themes are interesting and fit with other findings, but they don't go into WHY well parents might avoid/approach talk. Lack of process. - Caregiver thoughts and emotional responses to what children say back to them are also often not really explored. - Only looks at families where the parent is currently an inpatient – acute/crisis. Also, only in India – cultural context – they acknowledge this and the impact it may have on parent-child talk. - Small sample due to IPA. - Future directions: more

				populations and family set-ups, eg. Both parents unwell.
Endrawes, O'Brien & Wilkes (2007) Egyptian families caring for a relative with mental illness: a hermeneutic study Australia Doesn't explicitly discuss communication – focused on cultural aspects/comparison. Addresses meaning-making.	Qualitative: Hermeneutic IPA using depth interviews. Conducted in Arabic and translated. Specifically looking at experiences of CALD Egyptian families in Australia.	7 Egyptian caregivers (born in Egypt, living in Aus) of a relative with severe mental illness. Most relatives are PMHP: Spouse – 3 Parent - 1 Sibling – 2 Adult child - 1	- Why did it happen? How do I care for loved ones? What has it done to me? What has it done to us? How do I survive? - Similar outcomes to other cultural groups, but culturally sensitive and relevant support/intervention needed. - Families continued caring despite isolation, lack of support, powerlessness, stigma and shame. Discussion of within-family stigma and negative impact on family relationships. - Shock of diagnosis, emotional impact, protection and lack of information themes were comparable to non-CALD research, but worse due to language barrier. - Caregiving and meaning making linked closely to cultural and religious influences. God mentioned a lot; strong family obligations clear; other family members mentioned frequently, including strong family tensions.	- Hard to access sample, possibly due to reticence to participate. Other research should look into why. - Lack of religious diversity is a limitation – mainly Christian not Islamic. - Translation and non-English research by Egyptian researcher is a strength. - Future directions: comparing experiences of Egyptians in Egypt and Australia would be useful.
Fraser & Warr (2009) Challenging roles: Insights into issues for men caring for family members with mental illness Rural Australia Focused on male carers' understanding of MHP and meaning making about role. No discussion of family	Qualitative: 'coded for content and themes' Assume TA, but not explicitly stated. Semi-structured interviews.	10 men: 5 fathers, 5 spouses (all were fathers and some had children with the care recipient). Various MH diagnoses.	- Relationship between men & recipient influenced how men understand and practice care. Shows how they made meaning about their roles. (parenting vs partnering differences). Both showed strong sense of duty and rewards of role – feared that noting positives would make them seem inhibiting of recovery. - Fathers = more consistent, proactive and focused on management of illness. Sense of limitless responsibility. Valued services. Enjoyed spending time with children. - Husbands = reactive, less involved with clinical care, and responded more to situations as they arose – husband vs carer dissonance. Tried to create low-stress environments and reduce stressors on spouse by doing housework, meds and childcare. - Reduced social support and estrangement from friends due to stigma or staying silent.	- Anglo-Australian rural participants – homogenous. But, this was also part of the design so mainly just reduces generalizability. Has direct meaning for the MH service how conducted the research. - Some ppts may not have identified as carers. - Men increasingly in caring roles due to shifting gender roles. May contradict dominant ideals and ideas of masculinity. Husband vs father difference is important for future research and

communication.				services/ support.
Jonsson, Skarsater, Wijk & Danielson (2011) Experience of living with a family member with bipolar disorder Sweden Mostly about carer developing MH conceptualisation. Very brief mention of reducing communication but talk being a relief. No exploration of family communication.	Qualitative: Content analysis Interviews Aim: to elucidate what it means for family members to live with an adult person who has BD, re. their views of the condition of the person affected and the future.	17 relatives – parents (10), spouses (5) and adult children (2). Had to be a significant influential person to unwell person (not carer necessarily). BD DSM diagnosed. 15/17 cohabiting with relative.	- Results are presented in the domains of views of the person and views of the future, so essentially the questions they asked. - Themes under view of person: facing change alone, making sense/finding an acceptable explanation for the illness (major concern), maintaining normality (and powerlessness at not being able to), coping with outsiders' lack of understanding – leading to being careful about talking. Being able to talk was a relief and made things easier. - Themes under view of future: bearing the burden of responsibility, worry and uncertainty, building hope for the future by belief in improvement, not always worrying, needing to adapt. - They say it's similar to van der Voort (2009) spouse study in terms of responsibility, loneliness and sense-making findings. - Shame and stigma described by ppts, which undermines other social support. - Hope and building a personal space are described as important for family members to cope, including social support.	- People with BD determined the recruitment, and an imbalance in relationships to them (many mothers, no siblings). Could have been broader. - More female than male family members were selected. - But, the service users were given choice, and that's potentially empowering. - Suggests that family members should be considered by professionals, helped with understanding the condition (i.e. education) and used to strengthen the family social network. - More research into family members' experiences needed. - Replicates findings for general mental health studies with a specific population. Not totally new, but helps bolster what's seen elsewhere.
Karnieli-Miller, et al. (2013) Family members of persons living with a serious mental illness: experiences and efforts to cope with stigma	Qualitative: Immersion/crystallisation analysis. Part of larger stigma-reduction study & program. Focus groups, exploring family	14 first-degree relatives. All lived with and cared for person with schizophrenia or bipolar (12 parents, 2 adult children).	- Participants experienced rejection, blame and avoidance by others. They used flexible coping strategies depending on resources, motivation and their relative's willingness to disclose. - Theme of the 'art of selective disclosure' is discussed: who, when, what, and how much to tell people outside the family, based on what they learn from their family and historical experiences. It's linked with protecting the relative, personal boundaries, and preserving emotional	- Participants often weighed up the pros and cons of talking vs secrecy. Whether they talked to extended family members is unclear – this would have been useful. - Findings related to family stages model of: 'catastrophe', 'learning to cope', and

Conneticut, USA Family communication and issues related to it are explored within stigma framework	relationships, and perceiving and managing stigma. Analysed using a stress-appraisal-coping framework.		energy for more important things. They knew other family members sometimes felt differently to them. - Empathic understanding developed over time. Then, people who stigmatised could be seen compassionately due to their lack of knowledge.	'moving into advocacy'. - Limited men, ethnic diversity, family relationship diversity, and high numbers of peer volunteers (bias/keen). Suggest intervention via prep for stigma and planning coping, including selective disclosure.
Karp & Tanarugsachock (2000) Mental illness, caregiving and emotion management. USA Caregiver meaning making discussed in relation to their emotional journey and interpretation of relative.	Qualitative: Grounded Theory. Aim: To explain and account for the different emotions that arise as family members engage over time in interpretations of what they owe their relative with emotional troubles.	50 caregivers to spouse, parent, child or sibling. Mixed serious MHPs. Parents – 18 Spouses – 13 Children - 10 Siblings – 9	- 4 interpretative junctures in the evolving caregiver-patient relationship are identified that influence the ebb and flow of emotions: pre-diagnosis – anomie, chaos; diagnosis – hope, compassion; realisation of permanency – anger, resentment; acceptance – decreased involvement without guilt. - Framed in sociological understanding of emotions: reciprocity & exchange, but taking it a step further to why these commitments arise, via emotions. MHPs mean people don't inhabit the same phenomenological world and threaten 'concrete routines of daily life and the symbolic order on which such routines are premised'. - Caregivers must engage in arduous interpretive efforts to make sense of their obligations and feelings. There is a pattern to the way caregiver emotions unfold over time: the link between the emotional illness and caregiver's emotions, in a historical dimension. Current emotions should be understood in their historical context, as the past often comes with us into the present.	- Sample limits: White people (48) and women (35) are overrepresented. - No particular method limitation given. - Strength is interviews arising from extensive ethnographic work, and good sample size. - Future directions: research that understands that emotions in groups, settings or organisations have distinctive histories.
Lawn & McMahon (2014) The importance of relationship in understanding the experiences of spouse	Qualitative: Grounded theory. Open-ended semi-structured interviews.	28 spouse carers (19 women). 21 reported having children and were asked specifically about experiences related to this.	- Central theme: "a real and genuine relationship". 6 interrelated subthemes. Findings indicate the uniqueness of caring for a spouse with SMI compared to other caring roles, primarily because spouse carers strive for a relationship and accommodate SMI to protect this. This leads to surreal lives marked by emotional pressure and isolation.	- Further research suggested to explore longitudinally, to see why some spouses stay whereas others leave, and what's different. - Suggest research offers fresh insights into why QoL can

mental health carers. Australia GT of carer broader experience; specific section on childrearing. A couple of hints at carer responsibility for communication environment.	Aim: to explore the experience of being a spouse MH carer and develop a theoretical understanding.	Severe mental illnesses – varied.	- 'Carer' was not a comfortable term for ppts: husbands, wives and partners first. Also, their partner was a person first, MH came second. Loyalty and love were central narratives. Many felt the MH made them a stronger couple. - Subthemes: Striving for the relationship, Expectations, responsibility & navigating, isolation, getting needs met, implications for children, a different experience to adult children's carers. - Results indicate carers perceiving themselves as responsible for mediating the interaction and communication environment, and for nurturing family relationships. - Carers' actions driven by genuine commitment to relationship rather than playing role of 'carer'. - Gender played an important role in how experiences were expressed and support was sought. Isolation: Carers often struggled for emotional support from in and out of the family. Men especially affected due to smaller social networks. - Specific section (subtheme) on experiences with childrearing. Focuses on caregiver perspective of children – communication is implicit in some sentences. Expectations that partner would parent too. Felt that children just got on with it. No concerns about children growing up around MH, but many reported to have MHPs later.	remain despite SMI – nurturing positive parts of relationship bringing couple closer. - Sample limits: homogenous group due to snowballing/ Australians only. Chinese caregivers have stronger tendency for longer commitment, for example. Heterosexuals only, and fewer men. Tried to maximise variation in SMI, location, age, etc. - Method limits: single interviews, only with carer, bias to analysis due to lived experience of researcher.
Maenhout, Rober & Greeff (2014) Communication between spouses as a resilience factors in families in which a parent has depression:	Qualitative: IPA. Semi-structured interviews. Questions related to the nature of spousal communication	6 participants whose spouses were diagnosed with depressive disorder. 5 couples had children.	- Two groups were found: talkative couples (many conversations; easy) and taciturn couples (talking difficult; silence dominant). Most saw talking as vital to their relationship. - Insight into MHP facilitated communication, which improved knowledge, empathy, and feeling valued. - Talking was avoided in front of children – associated with protection, maintaining normality and spouse feeling	- Symptom severity of depression unclear from description – may include mild. - No evaluation of the avoidance of talking around children is provided in the Discussion – this would have

a condensed report. Belgium Focuses on spouse communication	during and about the depression.		shame. - Participants experienced blame, guilt and anger from spouse, but also observed and felt emotional relief through talking and felt it developed family resilience. - Needing to pick the right moment to talk was important – when this occurred varied.	been beneficial. - Implications for couples-focused interventions to strengthen family resilience.
Mizuno, Iwasaki & Sakai (2011) Spouses with schizophrenia: an analysis of the husbands' descriptions of their experiences Japan Focuses on husband meaning-making and burden, but meaningfully draws in child/family factors and communication	Qualitative: Content analysis. Semi-structured interviews. Aim: To describe spouse caregiving experiences (which are under-reported) and generate a reference for nursing approaches.	12 husbands of women with schizophrenia, recruited from outpatient facilities. 9 couples had children.	- Located research clearly in Japanese context: considerable institutionalisation and hospitalisation associated with stigma in society; families increasingly as carers. Links back to this in discussion – e.g. marriages didn't fail because of short hospitalisations that are intended to reduce weakened intimacy. Also, children are seen as binding relationships. - 6 major themes reported: identification and acceptance of disease, past and present experience with wives, roles and burdens of husbands, marital relationships, social resources, participation in community, perspectives on future. - Mostly it is about making sense and carer burden, there isn't really anything on communication – it's just inherent in the data. Aspects of making sense of role change. - Children are mentioned several times: Some mention of children making comments about parental behaviour within findings about husband making sense and learning about MHP. Children mentioned as helping carry chore burden. Consideration of child-wife relationships, wanting to nurture good feeling to mother, when they decide to talk, and how they feel towards the children. - Lack of opportunity to talk to others – family and social networks lacking. Similar to other cultures. This is seen to impact husband's coping and wife's illness.	- Discussion is very culturally linked, for example seeing improvements in MHP as a result of being married, and children keeping the family together. Some men didn't know about MHP before marriage. - Discussion about children developing 'extreme' attachment and MHPs. - The concept of 'reasonable acceptance' of the MHP meaning it can be managed but without excessive anxiety. - Evaluated in terms of needing to consider individual family members' experiences rather than the family as a whole (the traditional way). - Accept limits of not being able to generalise to non-stable marriages or long-term hospitalisation.
Pusey-Murray & Miller (2013) 'I need help':	Qualitative: No specific method named, but process of 'open,	8 caregivers. All female and over 50. Convenience	4 themes described: Caregiver perceptions of MI; perceptions of how MI can be controlled; why patents found it difficult to take medication; caregiver coping skills.	- The actual aims of the study are slightly unclear, with multiple aims stated at different points in the article,

caregivers' experiences of caring for their relatives with mental illness in Jamaica Jamaica Cross-cultural – relating to caregiver meaning making about MI. No communication aspects really. Nothing related to children.	axial and selective coding' described. 2 focus groups of 4 caregivers each, using semi-structured questions. Unclear aims: To explore perceptions of caregivers about caring for relatives. To explore possible solutions to reducing non-adherence to medication. To what extent are caregivers knowledgeable about MI?	sample from a larger research project examining medication non-compliance in PWMI at public clinics.	- Mostly, the findings pertained to practical aspects of the caregiving role and elements of caregiver burden and coping strategies. The first two themes are short but have some relevant aspects of meaning making about MI. - Caregiver perceptions of MI are cited as: 'brain not functioning well, confused about everything, disorientated, something wrong with them, hearing voices, excess talking, and depression'. Caregivers said to be "somewhat confused" about what MI is. - Control of MI: Unanimously stated medication is only option for control. This underpinned caregiver experiences. Related to burden with lack of resources impacting on providing /administering medication - source of not feeling able to cope. Perceptions of side-effects (e.g. drowsiness, violence) led to withholding medication. - Some attended the bush doctor for treating spiritual matters, indicating both understandings – holding both meanings? Cheaper than medical doctor.	but it does address meaning making. - It is possible that knowing they were in a study related to medication and being people attending clinic meant medication focus was more likely. - Lack of resources and professional help may contribute to uncertainty about how to control MI and what its causes are. - Education and resources needed to educate caregivers and support their caring roles better, including a Disabilities Act. - No future research directions suggested, only policy/government/practice changes.
Rose (1998) Gaining control: family members relate to persons with SMI USA Focused on making meaning about MHP and caregiver	Qualitative: Grounded Theory (Glaser & Strauss). Open interview with sensitising questions regarding experience and making sense of caregiving.	15 family members (8 women) of people with SMI recruited from psychiatric units. Spouses – 5 Parents – 4 Siblings – 4 Adult children - 2	- Central theme of "essence of person" – caregivers needed to talk about personality of patient as framework for understanding illness, and communicate the 'essence' to others. Essential to caregiver's own identity. Caregivers varied in their sense of effectiveness. They described meanings changing over time. - Three interconnected themes identified relating to the meaning of caregiving: (1) Finding the essence of the person obscured by illness – finding and staying connected to the person; redefining done where necessary. Processing distressing behaviours	- Lack of patient perspective that may have illuminated shared meanings and how it developed through interaction. - Future directions: observation of carer-relative interactions. Longitudinal designs. - Differences in meaning based on ethnicity,

identity, and how this impacts care provided	Aims: to examine ways in which meanings are formulated for caregiving experiences and how they are adjusted and reformulated over time, from a caregiver perspective.		and live with them by comparing 'then' and 'now', and internal dialogue about illness severity and permanence. Relationship to relative and presence of offspring impacted this process. (2) Finding a place for self in influencing the illness – influencing relative through words, actions and presence. Understanding self as carer and family member, including power to influence. Making life routine, reducing illness behaviours to maintain calm/reason. Words & actions could 'make it better not worse' – choosing words carefully & being calm. Using relationship to help control illness: by doing, or by holding back to prevent relapse. (3) Helping the relative move forward – attempts to gain a sense of control over the uncontrollable; linked to hope for future, goal setting, and deciding when to step in/back. Parents committed to doing whatever. Spouses considered relative's responsibility more. Desire for normality. Deciding when to step back linked to retaining sense of self. Differed across relative types.	relationship to relative and time in caring role: this needs exploring further. - The strength of caregivers to try and gain control in unpredictable situations should be considered by professionals carefully as a critical factor for long-term coping.
Rose, Mallinson & Walton-Moss (2002) A grounded theory of families responding to mental illness USA Elucidates meaning making processes behind carer coping processes. No communication or mention of children explicitly.	Qualitative: Longitudinal Grounded theory (Strauss and Corbin) over 2 years. Semi-structured interviews focused on storytelling. Aims: In-depth investigation of contextual factors that affect families'	29 participants from 17 families interviewed at T1, and 12 families participated at T2 and T3. Contact once a week with relative. Parents = 13 Spouses = 4 Adult siblings = 8 Adult children = 4 19 females (T1) SMI diagnoses – relative = 2	- Focuses on emergence of normalcy as a coping process, and how families strive for this by being goal-oriented and helping their relative to be normal. - Central concern (basic social problem - description): living with the ambiguity of mental illness. The basic psychosocial process (explaining variation) of pursuing normalcy included: confronting ambiguity, seeking to control it, seeing possibility for future. - Pertinent themes include making sense of relative, considering responsibility, re-defining relationships and re-affirming hope. Loss and impact on family relationships are important considerations. There is also mention of maintaining stability in chaos.	- Slightly more ethnically diverse sample but still weighted: white (19), African American (8), hispanic (2). - Another limitation of this study is the complete lack of discussion of its limitations! Also researcher position or self-reflexivity. - Future directions: identifying how health professionals can assist with finding normalcy. Focusing on complexity & diversity of experience, including family strengths, not narrow concepts like stigma or

	understanding of the illness and their responses to it.	hospitalisations and been in treatment for 2 years. Currently both hospitalised and community.		burden or EE.
Rusner, Carlsson, Brunt & Nystrom (2012) The paradox of being both needed and rejected: the existential meaning of being closely related to a person with bipolar disorder. Sweden Focuses on carer identity and sense making, with insights into communication with relative/others, but not with children or as main focus.	Qualitative: Explorative lifeworld phenomenological analysis (Dahlberg at al, 2008). Open-ended interviews. Focus on meaning and experience. Aim: To elucidate the existential meaning of being closely related to a person with BD.	12 adults closely related to adult with BD and been a psychiatric inpatient. Spouse – 5 Sibling – 2 Parent – 4 Adult child – 1 4 spouses had children with the person.	- Reveals paradoxical and existential finding of relatives being needed and rejected, whilst overshadowed by changeable nature of BD. - Themes: struggling for survival, having to compensate, and being both one step ahead and one step behind. - Concept of the 'bipolar world' - loss of normal life. There is discussion about how to hold onto personal identity within the caring process, and the internal conflicts about this. Having to explain, but not necessarily defend, to others. - Protection misjudged as being controlling. Need to be in control, be a 'mainstay' – one step ahead. Need to follow sudden changes, being 'on tenterhooks' – one step behind. - Exclusion from intimacy – communication environment shuts down – 'he's like a mussel'. One ppt talks about living in 'two completely different worlds' in relation to this. - Adult children have to take responsibility young, and deliberate miscommunications/not explaining occurs for protection. - Relatives compensate for lack of understanding from others. Leads to intensifying efforts to strengthen system of relationships. Illness 'spills' onto relatives and reduces social time and support (i.e. stigma). - Paradox of reducing relative's inner stress at cost of own emotional world.	- Recommend professionals to change attitudes and structures to help relatives participate more in care and treatment. Holistic view. - Future direction: studying intensified confusion due to cultural differences. Is it to do with MI itself or societal values being exceeded? What makes relatives' lives easier? - Reflects on within-family cross-cultural meanings that shape MHP perceptions: wanting to be with family in Sweden = manic symptom, in Asia = important for relationships. - Doesn't discuss how relatives understand the communication processes or where these come from – just reports on the experience. - Limits: all partners had stayed in relationships. Excluding minors reduces generalizability. - Strength in phenomenological method

				and ‘essential meaning’.
Stern, Doolan & Staples (1999) Disruption and reconstruction: Narrative insights into the experience of family members caring for a relative diagnosed with SMI England, UK Clearly located in meaning making and associated with nature of communication although not really in terms of family.	Qualitative: Narrative, using adapted life story analysis, aiming to extract a plot-line, attending to what and how things were said. Semi-structured interviews using Relative Influence Questioning (White, 1988) to explore influence of problem on them, and vice versa. Aims: to explore the relationship between disruption, narrative reconstruction and coping in the accounts of relatives of PWMI.	7 participants of people with SMI. Mothers – 5 Parental couple – 1 Wife – 1 (4 married, 1 widowed, 2 separated).	(1) Restitution & reparation narratives – experience takes on meaning and occupies space in carer’s life. Stories began with disruption. Reconstruction helped by finding platform or scaffold to rebuild on. Change and continuing life-project meaning had to both be incorporated. Sense of a moral quest for meaning, finding life worth living despite it all. (2) Chaotic & frozen narratives: illness remains a series of random events. Above pattern of construing was lacking or germinal. Carers repetitive/loose in storytelling, with a persistent theme. Illness remains mystifying/nonsensical. - Effects of coping on these narratives were explored: gender biases/assumptions came out (e.g. women more emotional and caring but feel more guilty; beliefs about control/mastery). Coping related to belief systems (e.g. self-care vs in negative spiral; locus of control). - Issues related to passage of time – fear of future, but living as if without future was anxiety-provoking. Other well-reported issues around stigma, social embarrassment, strong emotions, lack of support, ambivalence re care. - Belief in PWMI as sensitive and vulnerable. Taking responsibility re medication and future. - Feeling uncertain re expectations and lacking guidelines. Difficulty distinguishing illness and person and circumstances from each other.	- Majority white ppts (6) women caring for men – narratives homogenous. Gender themes testify to impact on women, who are more often carers, though. - Sample randomly chosen from project on a relatives counselling intervention -ppts well resourced? - Interaction between narrator and listener is acknowledged. - Life story approach limited by transcription and researcher subjectivity. - May be important for carers to shape meaning of illness experience as discussed in family consultation as they are central to coping and problem solving. Interventions can help carers find a ‘platform’. - EE may reduce possibility of narrative reconstruction – criticism making it hard. Future research to explore impact of narrative change on EE (?mediators).
Tranvag & Kristoffersen (2008) Experience of being the	Qualitative: IPA. Open-ended interviews.	6 spouses & 2 cohabitants (4 female). 6 couples had children together. 2	- 3 major aspects of findings: cumulative process containing up to 14 experiences; pre-understanding affected perception of subsequent experiences; pre-understanding affected how they mastered new challenges. - Perceived meaning of previous challenges affected future	- Only included when relatives have been admitted twice – why? - They wanted to look at experience longitudinally, and

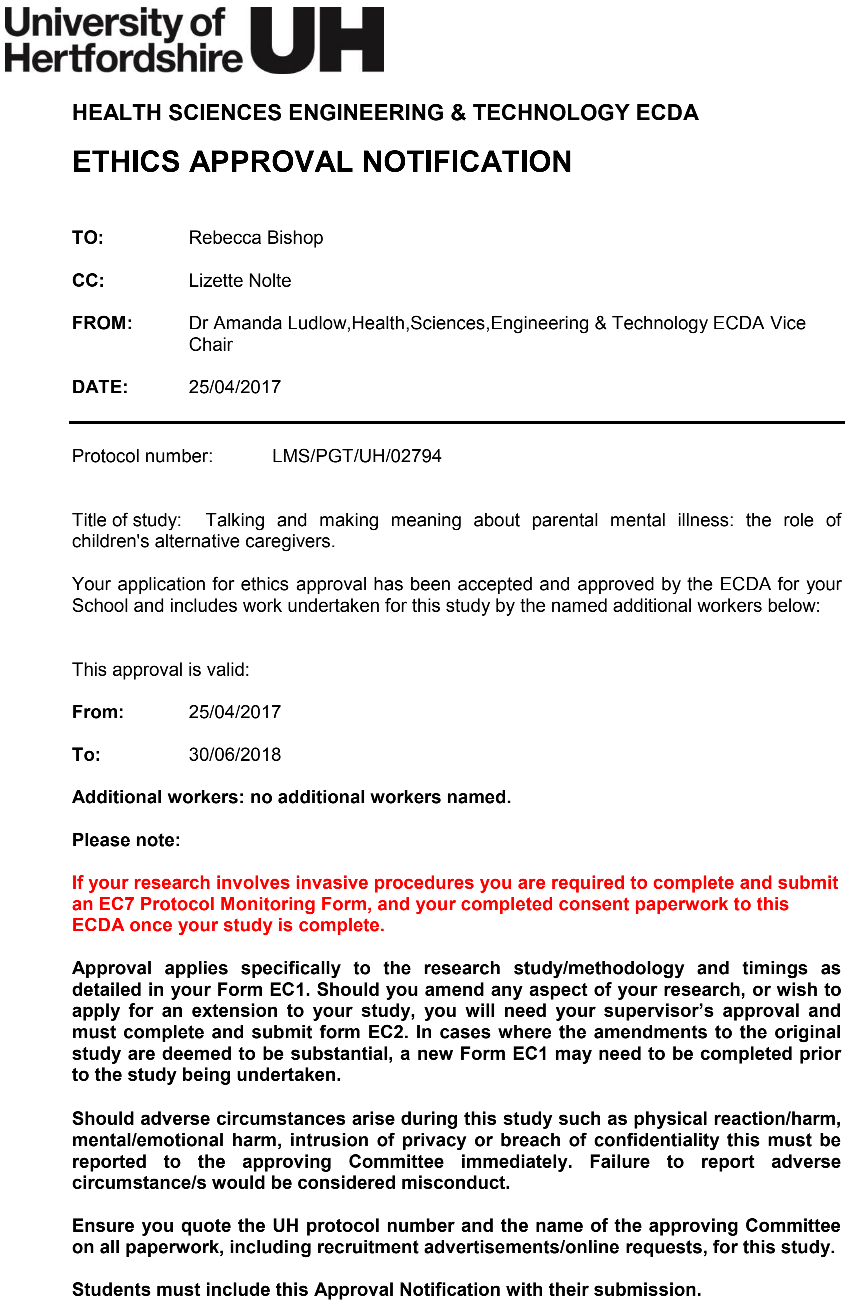
spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time. Norway Phenomenological spouse meaning making and adjustment focus; minor communication info. No mention of children.	Aim: to identify and describe spouses/cohabitants experiences of living with a partner with BD over time.	interviews per person, to discuss initial findings. Recruited via psychiatric hospitals; at least 2 inpatient stays. Breadth of experience sought.	ability to cope with new ones. - Discusses theoretically in relation to gestalt therapy, where inner imbalance is seen as inability to find whole meaning in experience. - There is some info about communication: being accused and shouted at (negative communication), losing social network. - Burden of chaos left spouses vulnerable to negative communication. Self-doubt due to not attributing spouse accusations to MH. - Previous friendliness was lost, leading to a new, incomplete gestalt. Dialogue and cooperation lost. MH education helps this. - Similar themes to other studies: loss, stigma, uncertainty, powerlessness, hope, strong emotions, own health problems, acceptance.	achieve this with a cross-sectional sample rather than over time – design could be faulted. - Strength in analysis and interview approach (2-interview process good). - Claim that researcher bias can be filtered out by method – questionable. - Future directions: Developing education to help spouses no matter their stage of the process. Universal family needs/ different relatives should be better understood as many interventions ineffective.
Veltman, Cameron & Stewart (2002) The experience of providing care to relatives with chronic mental illness. Canada Focused on carer meaning making, with strong relevance to communication.	Qualitative: No specific method stated. Description of iterative process, constant comparison, and theoretical saturation. Definitely a thematic analysis, not a process-based analysis. Semi-structured interviews. Aim: To gain	20 family caregivers (17 women). Parents – 13 Spouses – 5 Adult children – 1 Siblings – 1 Diagnoses all SMI. 8 caregivers treated for depression at some time after onset of relative's illness.	- Themes: stigma, systems issues, life lessons, and love and caring. Common negative impacts of caregiving as seen elsewhere. Beneficial effects: love, pride, and gratification. Most believed they were stronger, patient, appreciative, caring and less judgemental. - Stigma silencing, including within family – 'you keep it to yourself', 'people don't talk about it'. Linked to PWMI as well as carer. Lack of family communication including ignoring/withholding details. Being unable to talk linked to MI ignorance and carer burden. - Stigma theme helps carer make meaning about MI, society, and themselves in relation to those things (values). Also seen in idea of 'unconventional living' in life lessons learned theme – cherishing, finding value, growing through pain. - Love and caring theme associated in part with improvements in communication with PWMI, and	- Unique perspective on positive outcomes. Counters the often problem-saturated and negative accounts in the literature with positive aspects of caring too. - Health professionals should help families identify rewards and positives, and improve systemic supports. - Bias possible due to self-selection of participants from support groups – most keen/greatest distress/best resourced. - Lack of sample heterogeneity – gender and recruitment

	knowledge of the meaning that caregivers derive from their situation, including the positive aspects of caregiving.		relationship growth. Unfortunately, no analysis of why this process may have occurred. - Love and caring also provided meaning to their lives – learning about MI 'helped me grow as a human being' – positive frame. Also, getting to spend time with relative even though this may not be norm/expected. Making sense of self in relation to mental illness (although again, not really discussed in this way).	sources. - Researcher bias acknowledged. - Lack of process-oriented discussion and interrelation between themes – there seemed to be plenty as a reader but it wasn't mentioned.
Van der Sanden, Bos, Stutterheim, Pryor & Kok (2015) Stigma by association among family members of people with a mental illness: a qualitative analysis The Netherlands Explores lack of communication and silencing among family, in relation to stigma.	Qualitative: Thematic content analysis. Semi-structured interviews. Aims: To comprehensively explore SBA experiences among immediate family members with attention to relationship, gender and cohabitation.	23 family members: spouses = 6 adult children = 4 siblings = 8 parents = 5	- Significant impact of stigma by association experienced from community and professionals, with people not understanding the complexity of MHP and being negative & discriminatory. - Manifestation of stigma was different for parents/spouses (blamed & held responsible), and siblings/children (stigma during teens, seen as different = shame. Less blame – not usually caregiver?). - Worse when they cohabited with unwell relative – greater shame/difference. Women more blamed - stigmatised as overprotective and exacerbating of MHP by professionals/family. - Themes of loss of other relationships, rejection, and avoidance so they didn't have to explain about the MHP. - Recommends tailored emotional support and education based on gender, relationship and age, and professionals being better trained. - Emphasises silencing and holding back.	- Application of qualitative method including triangulation and SU involvement are strengths. Good sample size. - Quality markers are mentioned, but are quant-type ones – low generalisability cited as limitation. - Recruitment mainly via support groups – may have meant participants had certain MH service experiences (i.e. worse). - No inter-rater reliability done – weakness. - Future research should consider relationship, co-residence and gender.
Wynaden (2007) The experience of caring for a person with a mental illness: A grounded theory study	Qualitative: Grounded Theory (Glaser & Strauss 1967). Symbolic interactionism/co	27 primary carers for relative. Severe and enduring diagnoses. 22 female, 5 male. 20 parents; 4 adult	- A: Being consumed: engrossed in experience of illness, identity threatened, life goals impacted, grief and loss, being overwhelmed. (1) Disruption to established lifestyle, (2) sustained threat to self-equilibrium. - 'Participants also felt guilty because the time they spent caring for the ill member impacted on the other children's development'.	- Clear and engaging presentation of a substantive theory. No quotes used really – word count? - No future directions for research suggested, but for intervention they suggest

Australia Focuses on carer identity and sense-making, but not communication	nstruction. Semi-structured depth interviews. 38 interviews with 27 carers (9 re-interviewed) No clear aim– GT broad approach? Seems to be to understand caring experience from carer perspective.	children. 5 more than one ill family member. Unknown how many relatives had children.	- B: Seeking balance: trying to neutralise experience/cope, find equilibrium and calm. (1) Trying to make sense of what was happening, (2) restoring self-identity, (3) reaching out to make a difference. - Use of denial to carry on with daily routines and present-moment attention. - Themes of staying positive and optimistic, and appreciating humour. Later, seeing positives of role. Learning 'tricks of the trade' (like insider knowledge). Developing assertive behaviour, esp with professionals. - Focuses strongly on carer experience.	better early education for relatives to increase understanding of MH and reduce stigma. - Also suggest monitoring of prodromal behaviours in 'at risk' people by professionals. - More need for relatives to be listened to and advised. - Limitations not discussed.
Yeung, Irvine, Ng & Tsang (2017) How people from Chinese backgrounds make sense of and respond to the experiences of mental distress: TA. England, UK Focuses on meaning making and impact on help seeking and family conceptualisations. No direct mention of children or communication.	Qualitative: TA. Depth interviews with open-ended questions. Conducted, transcribed and analysed bilingually. Aims: To examine how Chinese populations give meaning to experiences of mental distress and how meaning making impacts their journey through mental health care.	14 PWMI and 16 family members – seem to have been interviewed separately (34 interviews). Spouse – 8 Parent – 7 Cousin - 1	- Understanding of distress was not static but refined through the relative's journey, with western biomedical and alternative explanations evaluated and explored. - Recognising illness sometimes took several years – attributed to 'normal' behaviour, physical health, to 'women's problems' by men, or just confusing. Normalisation and rationalisation = delayed help seeking – only accessed when very serious. Difficult behaviour tolerated for a long time. - Cultural stigma and shame of MHPs (punishment for misdeeds of ancestors) leading to belief that it shouldn't be discussed outside family. More common among male carers – likely due to male head of household and shame. Families often refused interpreters. - Supernatural explanations considered at different points. Carers would travel abroad/far to seek out ritual healers.	- Recruited via voluntary organisations, and those not in contact wouldn't have been captured – especially those more affected by stigma. - Austerity has exacerbated health service inequality and limited outreach – may be getting worse. - Professionals to be aware of high stigma and cultural factors – don't disregard spiritual beliefs. Use transcultural workers. - Future directions: research to understand and tackle extreme stigma in Chinese societies so people can be helped.

Section 2: Ethics Documentation

Appendix C. University of Hertfordshire Ethical Approval Confirmation



University of Hertfordshire UH

HEALTH SCIENCES ENGINEERING & TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO: Rebecca Bishop

CC: Lizette Nolte

FROM: Dr Amanda Ludlow,Health,Sciences,Engineering & Technology ECDA Vice Chair

DATE: 25/04/2017

Protocol number: LMS/PGT/UH/02794

Title of study: Talking and making meaning about parental mental illness: the role of children's alternative caregivers.

Your application for ethics approval has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

This approval is valid:

From: 25/04/2017

To: 30/06/2018

Additional workers: no additional workers named.

Please note:

If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and your completed consent paperwork to this ECDA once your study is complete.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

Appendix D. NHS Ethics Process - Response Letter to Committee

Doctorate in Clinical Psychology
University of Hertfordshire
Health Research Building
College Lane Campus
Hatfield.
AL10 9AB

Cambridge Central Research Ethics Committee
Royal Standard Place
Nottingham
NG1 6FS

16th February 2018

Dear Dr D,

RE: **Study Title:** Talking and making meaning about parental mental health difficulties: the role of children's family caregivers
REC reference: 18/EE/0003
IRAS project ID: 234373

Thank you for the provisional response letter from you on behalf of the REC dated 26th January 2018. Further to this, detailed below are our responses and further information requested.

Amended documents

The following documents have been amended:

- Participant Information Sheet
- Advertisement Poster
- Study Protocol
- Consent form

The amended documents have been submitted via IRAS. The documents have been highlighted to show where the amendments have been made in line with the REC's recommendations.

Points requiring clarification

Clarification was requested by the REC with regard to the following points:

1. Consideration of whether inclusion of NHS patients in the study is likely to capture incidences of more severe mental health problems and detail on how this would be managed.

We are uncertain whether this query relates to whether the study captures a) parents who have severe mental health problems, or b) caregivers who have severe mental health problems. For completeness, we address both possibilities. (NB. What constitutes a 'severe and enduring' mental health problem for the purposes of the inclusion and exclusion criteria has also been raised as a point requiring clarification. The detail of this definition is therefore addressed separately in point 2).

- ***Regarding: a) parents who have severe mental health problems***

The study objective is to learn more about the experience and sense making about mental health problems of children's caregivers, in families where a parent has a severe and enduring mental health problem. Severity of the parent's mental health problem is therefore an inclusion criterion. Consequently, the study will capture incidences where a parent is an NHS patient and has a severe mental health problem. However, they will not themselves be the participants. As such, they are not recruited to participate in the study. Issues pertaining to the management of this for individual families are addressed further in points 5 and 6.

- ***Regarding: b) caregivers who have severe mental health problems***

An exclusion criterion for the study is the children's caregiver having a severe mental health problem. This is because existing research evidence suggests that communication and childcare behaviours are significantly affected by severe mental health problems, and to include caregivers who also had such difficulties would lead to a different research question than ours.

We note that existing research points towards the caregivers of children whose parent has a severe mental health problem not being at increased risk of severe mental health problems themselves. Rather, personal, relational and contextual factors determine the impact, rather than the parent's diagnosis. For example, NHS 'patients' having the support of say a psychiatrist or care coordinator, may relieve the caregiving burden rather than exacerbate it. Mild to moderate depression and anxiety are, however, evidenced as common experiences within this group and broader carer populations. As such, these do ***not*** constitute an exclusion criterion and are expected to be common experiences of our participants.

To address concerns about this issue, we will ensure a robust participant screening process. All potential participants will be explicitly asked if they have any diagnosed mental health problems and about their mental health service use. Should they have a severe and enduring mental health problem, they will not be recruited. Should the research team become aware at any subsequent point that a participant has a severe mental health problem, research processes with that individual would be halted in a respectful manner. Should there be an associated context of distress or risk concerns, the research team would follow the risk/safeguarding procedure laid out in the protocol (e.g. supporting the individual to access A&E, or raising safeguarding concerns with the referring NHS team). Any data already collected would not be included in the analysis.

At all stages, the research student will consult with Dr Nolte who is an experienced clinician and researcher, and Dr Bromley who is also an experienced clinician and a local NHS PI.

2. The categories detailed for inclusion and exclusion are too imprecise and need to be more clearly defined.

Our understanding is that greater definition of the first and final criteria (highlighted), pertaining to the definition of 'severe and enduring' mental health problems, are the ones to be addressed:

- ***Parent or family carer for a child/children with a parent with a severe and enduring mental health difficulty.***
- *Aged 18 or above.*
- *Help care for children, including at least one aged between 4 and 17, who do not have a developmental disorder or language acquisition problem.*
- ***Do not have a severe and enduring mental health problem themselves. However, it is anticipated that participants may have past or current mental health difficulties, particularly those associated with caring. Therefore, individuals who report mild mood and anxiety problems will be included.***

Our use of the terminology 'severe and enduring' is intentional, and in line with the language used by the Department for Health and within the National Service Framework. This terminology is used to classify the level of need and duration of different mental health problems seen in the general population.

The definition of 'severe and enduring' mental health problems includes: schizophrenia and schizoaffective disorders; bipolar disorder; eating disorders; personality disorders; major depressive disorder; and psychosis. Also included are comorbidities such as depression with psychotic features, or substance misuse. Definitions of what constitutes 'enduring' are a duration of either at least a year, or at least two years, depending on the source. This study is using the former definition of at least a year.

The above definition underpins 'severe and enduring' for the purposes of this study. This has been updated in the study protocol. In our recruitment from NHS services, we expect that all parents (whom our participants will be supporting with childcare) will have one or more of the diagnoses listed above. This is due to the diagnostic model used for mental health service provision.

As discussed in the REC review meeting, however, we acknowledge that not all NHS mental health patients or their families will accept, agree with, or find such diagnoses useful. This is why the terminology on the recruitment material has been kept intentionally vague (i.e. so as not to put off participants who do not want to associate with psychiatric terminology). It is also a way of ensuring that potential participants do not exclude themselves incorrectly (e.g. if a working or combined diagnosis has been given but is not listed on the poster). However, the mental health problem that the supported parent presents with will form part of the screening process. Where a parent has not received a diagnosis or used mental health services over time, the caregiver will not be invited to take part in the study.

We acknowledge that this involves taking what the caregiver says to be true, and that this involves an element of uncertainty and trust. As the parent will have been referred via an NHS service, however, it will be possible to corroborate information with the referring clinician if required. We believe it is relatively unlikely that a caregiver would put themselves forward for the project untruthfully, especially given that there is no financial incentive to participate.

If a caregiver were to report having been given one of the above diagnoses, they would not be invited to participate, as it would be deemed 'severe and enduring'. The study protocol has been amended to reflect these changes. For the reasons given above, the participant information sheet, consent form and poster have not.

Relevant references:

British Psychological Society (2002). The British Psychological Society Division of Clinical Psychology Briefing Paper No. 18: Clinical Psychology in Services for People with Severe and Enduring Mental Illness. Prepared by the Division of Clinical Psychology. ***Accessed online via the BPS website.***

National Institute for Health and Care Excellence (NICE) guidance for the mental health problems listed, for example:

NICE (2014). CG178: Psychosis and Schizophrenia in Adults: Treatment and management. NICE: London. ***Accessed online.***

3. It must also be considered what would happen should someone be identified as being clearly close to risk of self-harm, but not in danger of suicide; would they no longer be included in the study and how would that be handled?

Should a participant be identified as at risk of self-harm, the same management procedure would apply as for participants identified as at risk of suicide. The protocol has been amended to indicate that these procedures also apply for high self-harm risk:

"If the research student identifies immediate risk to the participant due to intent toward self-harm or suicide, the research student will call 999 from her mobile and the participant will be supported to attend A&E. Where risk is not immediate, participants will be advised to seek support from an appropriate source, which may include the referring clinician or relevant NHS structure (i.e. carers group they are a member of), a family member, a friend, a local or national third sector organisation (E.g. Samaritans, MIND). Any risk or safeguarding concerns identified with regards to the caregiver, parent or children will be reported back to the referring clinician as soon as possible to close the duty of care loop."

As identified by the committee, should this high level of distress arise, it would be considered by the research team that the participant was likely suffering from an undiagnosed or undisclosed severe mental health problem himself or herself. Consequently, it would no longer be possible to include them in the study as this is an exclusion criterion. This would be discussed with the participant at a time when they were no longer distressed or in crisis, in a sensitive manner and with the opportunity for them to ask questions. The research student would seek supervisory support from both supervisors in the management of such cases. As a final year Trainee Clinical Psychologist and with several years' experience working in mental health settings, the research student has experience of dealing with complex presentations and managing risk within NHS settings.

The study protocol has been amended to reflect these details.

4. Clearer information both on how the decision to involve the parent/caregiver in the study will be made…

As above, this will be done via the screening process and clarification of inclusion and exclusion criteria.

5. …and how it will be gauged whether the person with the mental health issue is content for the interview with their parent/caregiver to go ahead.

It is not a criterion of the study for the parent with a mental health problem to consent. It is considered that the experiences of children's caregivers are an important and unexplored research topic, and the research participation of this population should not be contingent on the parent with mental health difficulties giving consent for them to do so. If only caregivers are included where a parent consents, then we are very likely to exclude a large number of potential participants, including where there is a difficult relationship or where the parent has more substantial care needs. Therefore we are keen to keep both options open. As discussed at the REC meeting, we have been very diligent in keeping the focus on the experiences of the caregiver, and where they talk about the parent or child, to always bring it back to what the implications for thoughts, feelings and actions are for the participant as per the study's aims.

The research team believes that the needs of the family are paramount, and this is always prioritised. In cases where the parent expresses concern or discomfort with their family member participating, or the caregiver is concerned that the parent would be unhappy about them taking part, the research student discusses this fully with the caregiver to help them decide the most appropriate course of action for them and their family. In our recruitment through children's social care teams, potential participants have been encouraged to discuss the issue with the referring social worker and, if they feel it would be helpful, the parent. We have seen this to be a helpful suggestion and it has resulted in caregivers taking both options on board. Similarly, in NHS cases we can suggest the family discuss it further with the referring clinician, if appropriate, and where helpful or possible, with the parent.

The research student would seek supervisory support from both supervisors in the management of such cases. Dr Bromley will be available to support directly if required for cases within HPFT, where she works clinically. The protocol has been updated to detail this information.

6. Consideration must also be given to the possibility of the interview with parent/caregiver raising additional mental health issues in the affected individual. A decision tree to assist with this process is required to be put in place.

We acknowledge this as a potential risk, and thank the committee for raising the question. We believe that the steps outlined in point 5 will help to mitigate this risk. Nonetheless, we would like to address this concern to further reduce the risk. During debriefing, the research student will:

- Ask participants 'how do you anticipate the parent might experience your participation today?' Should their response indicate a concerning level of increased risk in the parent, the research student will close the loop by raising the concerns as soon as possible with the referring NHS clinician and local PI, who will have known about the research due to the recruitment process.
- Include a section in the debrief sheet suggesting the participant contact the person's care team/GP should they feel any concern about any potential impact of their taking part in the research on the parent.
- As per point 7, participants will be made aware that such concerns will be raised with the referring clinician and PI by the research student as part of the research team's duty of care (i.e. closing the loop).
- Seek supervisory support if she has any concerns, to discuss the most suitable course of action. Dr Bromley will be available to follow up concerns about patients within HPFT.

The study protocol and debrief sheet have been amended to reflect these changes. A decision tree has been provided to visually display this process.

7. Detail on how it will be ensured the duty of care loop will always be closed.

As stated in point 6, any risk or safeguarding concerns identified with regards to the caregiver, parent or children will be reported back to the referring clinician as soon as possible. This clinician will know that the caregiver has been involved in the research due to the recruitment procedures. The local PI will also be informed, should the issue require follow-up by the NHS trust involved as part of the parent/family's ongoing care from NHs mental health services.

The study protocol has been amended to reflect these changes.

8. Please include this information in an updated Protocol, and where appropriate, in the Participant Information Sheet.

As noted throughout the above points, the appropriate documents have been updated.

<u>Additional matters noted from your letter</u>

9. In private discussion the Committee noted the requirement for the IRAS ID to be added to the Participant Information Sheet and Consent Form, in line with the HRA Approval Initial Assessment Information.
The IRAS ID has been added to the PIS and Consent form as requested. It has also been added to the Debrief Sheet and poster.

10. In line with the HRA Approval Initial Assessment Information, the Committee observed in private discussion the requirement for clarity around future research studies and amendment to the Participant Information Sheet in line with this.

The PIS and consent form have been updated to clarify that anonymised transcripts will be stored for up to 5 years for the purposes of secondary analysis, with the participant's consent.

If you require any further information or clarification at all, please do not hesitate to contact us. We look forward to hearing from you soon.

Yours sincerely,

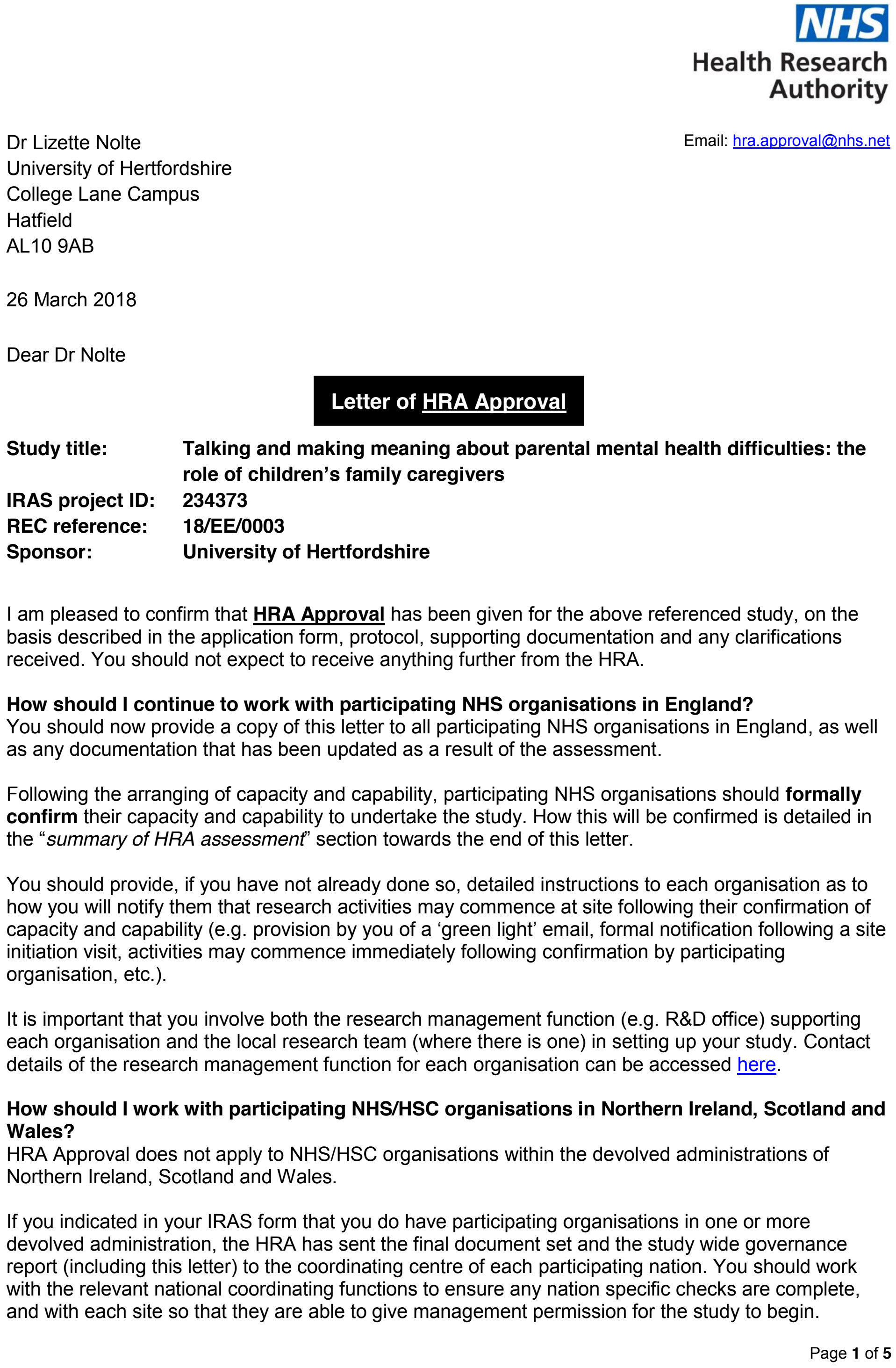
Dr Lizette Nolte
Chief Investigator
Clinical Lecturer

Rebecca Gammage
Research Student
Trainee Clinical Psychologist

CC:

- Dr Cassie Bromley, Clinical Psychologist & Field Supervisor
- Ms Ellie Hubbard, Research Office, University of Hertfordshire
- Thanusha Balakumar, Hertfordshire Partnership University NHS Foundation Trust

Appendix E. NHS Ethics Process: HRA Approval Confirmation



NHS
Health Research
Authority

Email: hra.approval@nhs.net

Dr Lizette Nolte
University of Hertfordshire
College Lane Campus
Hatfield
AL10 9AB

26 March 2018

Dear Dr Nolte

Letter of HRA Approval

Study title: **Talking and making meaning about parental mental health difficulties: the role of children's family caregivers**
IRAS project ID: **234373**
REC reference: **18/EE/0003**
Sponsor: **University of Hertfordshire**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further from the HRA.

How should I continue to work with participating NHS organisations in England?
You should now provide a copy of this letter to all participating NHS organisations in England, as well as any documentation that has been updated as a result of the assessment.

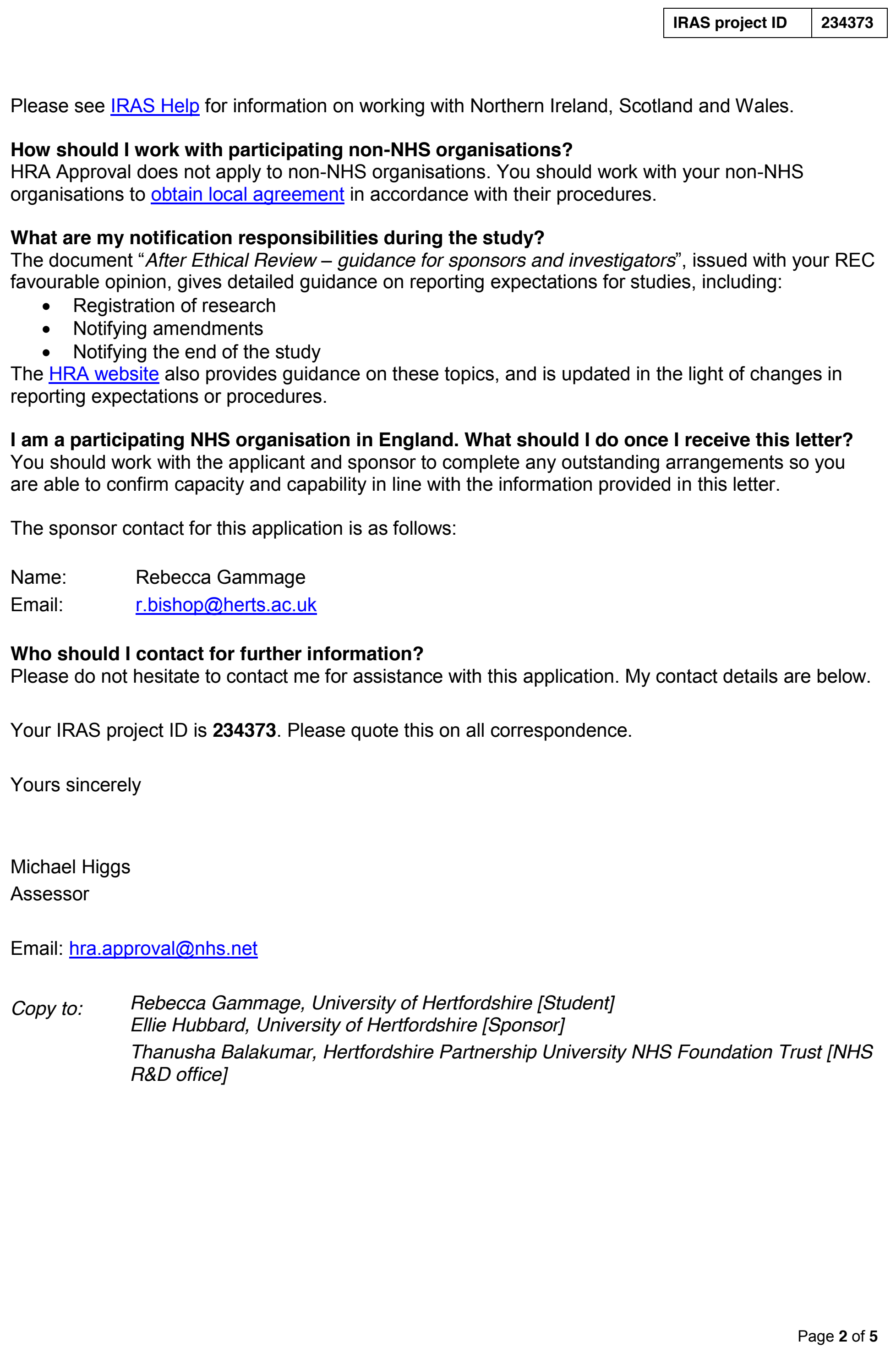
Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of HRA assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland, Scotland and Wales?
HRA Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland, Scotland and Wales.

If you indicated in your IRAS form that you do have participating organisations in one or more devolved administration, the HRA has sent the final document set and the study wide governance report (including this letter) to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.



Please see IRAS Help for information on working with Northern Ireland, Scotland and Wales.

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

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

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

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

I am a participating NHS organisation in England. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name:	Rebecca Gammage
Email:	r.bishop@herts.ac.uk

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

Your IRAS project ID is **234373**. Please quote this on all correspondence.

Yours sincerely

Michael Higgs
Assessor

Email: hra.approval@nhs.net

Copy to: *Rebecca Gammage, University of Hertfordshire [Student]*
Ellie Hubbard, University of Hertfordshire [Sponsor]
Thanusha Balakumar, Hertfordshire Partnership University NHS Foundation Trust [NHS R&D office]

Appendix F. NHS Ethics Process: UH Sponsorship Confirmation

University of Hertfordshire
Higher Education Corporation
Hatfield, Hertfordshire
AL10 9AB

Telephone +44 (0) 1707 284000
Fax +44 (0) 1707 284115
Website www.herts.ac.uk

Dr L Nolte & Ms R Bishop
Department of Psychology & Sport Sciences
School of Life & Medical Sciences

27 April 2018

Dear Dr Nolte and Ms Bishop

Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:
RESEARCH STUDY TITLE: Talking and making meaning about parental mental illness: the role of children's alternative caregivers
NAME OF CHIEF INVESTIGATOR (Supervisor): Dr Lizette Nolte
NAME OF INVESTIGATOR (Student): Ms Rebecca Bishop
UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER: LMS/PGT/NHS/02902

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements.

Permission to seek changes as outlined above should be requested from myself before submission to the Health Research Authority (HRA) NHS Research Ethics Committee (REC) and I must also be notified of the outcome. It is also essential that evidence of any further NHS Trust Management Permissions (formerly known as R&D Approval) is sent as soon as they are received. Copies of annual reports and the end of study report as submitted to the HRA also need to be provided. Please do this via email to research-sponsorship@herts.ac.uk

Please note that University Sponsorship of your study is invalidated if this process is not followed.

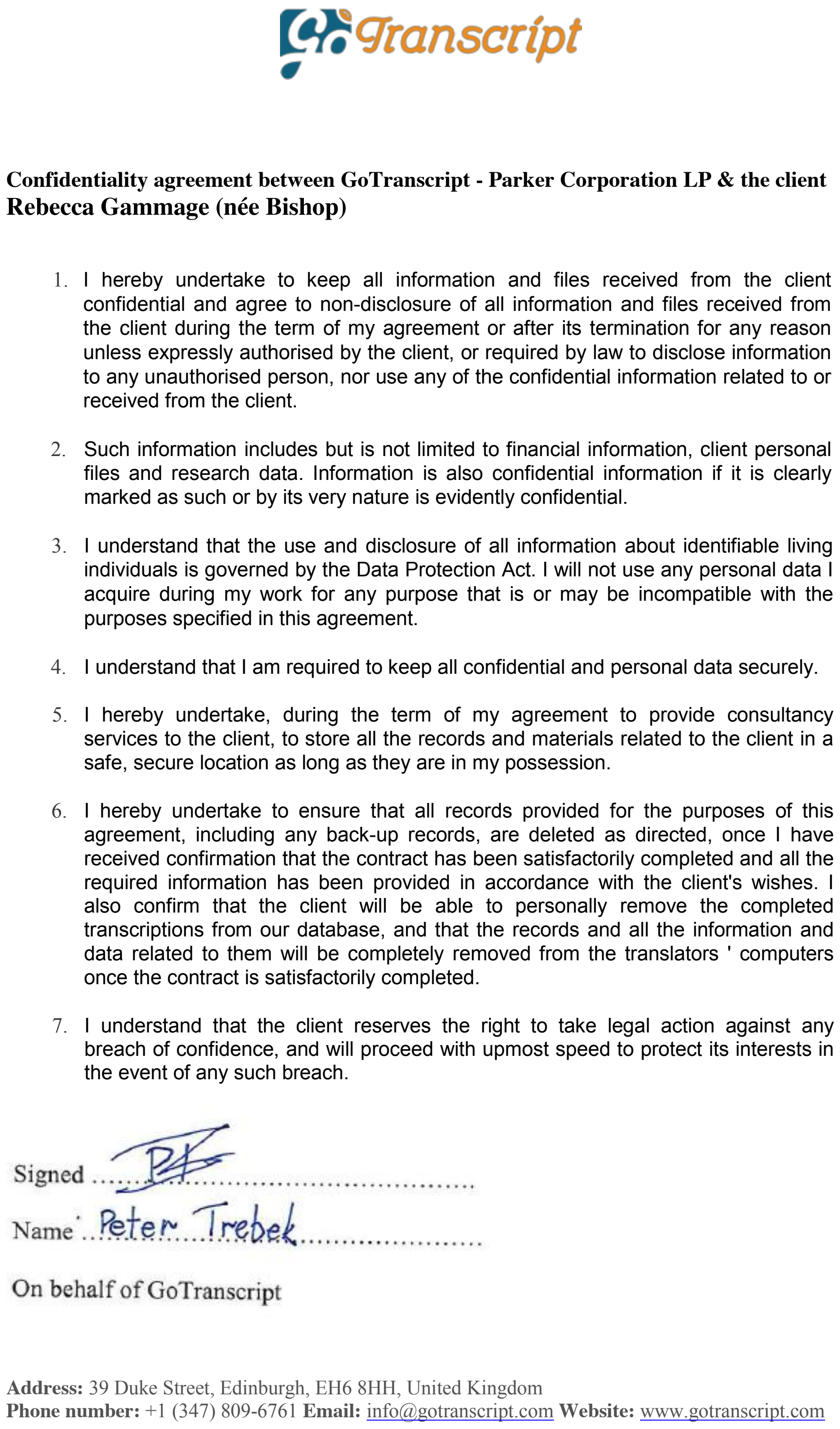
In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely

Professor J M Senior
Pro Vice-Chancellor (Research and Enterprise)

University of Hertfordshire Higher Education Corporation is an exempt charity

Appendix G. Confidentiality Agreement from Transcription Service



Confidentiality agreement between GoTranscript - Parker Corporation LP & the client
Rebecca Gammage (née Bishop)

1. I hereby undertake to keep all information and files received from the client confidential and agree to non-disclosure of all information and files received from the client during the term of my agreement or after its termination for any reason unless expressly authorised by the client, or required by law to disclose information to any unauthorised person, nor use any of the confidential information related to or received from the client.
2. Such information includes but is not limited to financial information, client personal files and research data. Information is also confidential information if it is clearly marked as such or by its very nature is evidently confidential.
3. I understand that the use and disclosure of all information about identifiable living individuals is governed by the Data Protection Act. I will not use any personal data I acquire during my work for any purpose that is or may be incompatible with the purposes specified in this agreement.
4. I understand that I am required to keep all confidential and personal data securely.
5. I hereby undertake, during the term of my agreement to provide consultancy services to the client, to store all the records and materials related to the client in a safe, secure location as long as they are in my possession.
6. I hereby undertake to ensure that all records provided for the purposes of this agreement, including any back-up records, are deleted as directed, once I have received confirmation that the contract has been satisfactorily completed and all the required information has been provided in accordance with the client's wishes. I also confirm that the client will be able to personally remove the completed transcriptions from our database, and that the records and all the information and data related to them will be completely removed from the translators ' computers once the contract is satisfactorily completed.
7. I understand that the client reserves the right to take legal action against any breach of confidence, and will proceed with upmost speed to protect its interests in the event of any such breach.

Signed ....

Name: Peter Trebek ....

On behalf of GoTranscript

Address: 39 Duke Street, Edinburgh, EH6 8HH, United Kingdom
Phone number: +1 (347) 809-6761 **Email:** info@gotranscript.com **Website:** www.gotranscript.com

Section 3: Recruitment and Interview Documentation

Appendix H. Advertisement Poster

Talking and making meaning about parental mental health difficulties: the role of children's family caregivers

A doctoral research study being run at the University of Hertfordshire

This project is looking into the experiences of parents/carers who help to look after a child or children in their family who have a parent with mental health difficulties. We are looking for participants to take part in interviews.

Who can take part?

You are eligible to participate if you meet the following description:

- You look after a child/children aged 4-17 with a parent with a mental health difficulty (this may or may not be 'officially' diagnosed)
- You are age 18+
- You are willing to take part in an interview with a researcher to talk about your experiences

Why are you doing this research?

This study aims to learn more about the experiences of parents/carers who look after a child or children in families where a parent has mental health difficulties. Family carers don't often get much attention despite being so important in families affected by parental mental health difficulties.

When a parent is less emotionally or physically available due to mental health reasons, other family members often step in more to help to look after their child/children. This might include the children's other parent, their parent's partner, grandparents, older siblings, aunts and uncles. These caregivers provide emotional and practical care for the children. They also sometimes help with housekeeping.

What will happen to me if I take part?

We are interested in hearing about your life, experiences and views. If you decide to take part you will participate in an interview, which will last around an hour. Interview locations are flexible depending on your needs, but can include a community location or your home. We can also do Skype interviews if needed.

If you are interested in taking part or would like further information, please get in touch at r.bishop@herts.ac.uk or using the details below.

r.bishop@herts.ac.uk | Tweet @beccajbg

www.childcaregiverstudy.co.uk

Appendix I. Participant Information Sheet

Participant Information Sheet

Talking and making meaning about parental mental health difficulties: the role of children's family caregivers

You are being invited to take part in a research study. Before you decide whether to take part it is important to understand why it is being done and what will be involved. Please take time to decide if you would like to participate. Ask any questions you like and discuss it with others if you wish.

What is the purpose of the study?

This study aims to learn more about the experiences of people who help look after a child/children in families where a parent has mental health difficulties. When a parent is less emotionally or physically available due to mental health reasons, children are often dependent upon other family members for care, including their other parent, their parent's partner, grandparents, older siblings, aunts and uncles.

These individuals may usually be involved in shared parenting (e.g. mothers, fathers, grandparents), may only become involved when needed for mental health reasons, or may have a role somewhere in between. They often provide emotional and practical care for children and sometimes help with housekeeping. Previous research has suggested that those who provide this type of support are important in families affected by parental mental health difficulties. We are interested in talking to these individuals to learn more about their lives, experiences and views.

Do I fit this description?

We are aware that those who help with childcare in the ways described above do not always identify specifically as 'caregivers' or 'carers', because that looking after the child/children is just a part of life. However, others do identify in this way, and some are legalised in kinship orders. Everyone's situation is different, and we are interested in a wide range of individuals' experiences and situations. Participants taking part in this study should be aged 18 or over.

We are ***not*** including individuals where the childcare is provided by someone outside the family or is more formalised, for example people who receive payment for childcare, health and social care professionals, or paid/unpaid support workers.

Do I have to take part?

No, taking part is voluntary. If you would prefer not to, then you do not have to give a reason why. If you decide to take part but change your mind later, you can withdraw from the study at any stage. Just let the researcher know by telephone or email.

What will happen to me if I take part in the study?

If you decide to take part you will participate in an interview, which will last around an hour. The interview will be informal. You will be asked some questions, but most people find that it feels like a conversation. It is completely your choice to decide what you are comfortable sharing. If you decide to take part in the research, a precise location can be confirmed, to fit with room availability and the time and place most convenient for you. This might be on NHS premises, in a community location or at the University of Hertfordshire.

What are the possible benefits of taking part?
It is expected that most people will find taking part interesting and thought provoking. By participating, you have the opportunity to reflect on your experiences and be listened to. More broadly, we anticipate that your participation will improve understanding about families affected by parental mental health difficulties.

What are the possible disadvantages or risks of taking part?
It is possible that thinking and talking about your experiences will bring up thoughts and feelings, some of which could be upsetting. You can let the researcher know if this happens and you may choose at any time not to answer questions if you do not wish to.

Whilst very unlikely, if you were to feel so distressed that you experienced thoughts of wanting to hurt yourself or end your life and you felt that you were going to act on these thoughts, Rebecca would support you to access A&E.

Will my participation be kept confidential?
Any information that is collected from you during the interview is confidential and only available to the research team. The only time that we might have to share information about you is if we learned information which meant that you or someone else was at risk of harm. Whilst uncommon, under these circumstances, if we did need to share the information, the purpose would be to help ensure the safety of you or others and we would always aim to explain to you who we will share information with and why.

The only time confidentiality would be broken is if the researcher was worried that you or someone else was at risk of harming themselves or someone else, based on the information that you give. In that case, the researcher might have to break your confidentiality to seek further help and support for individuals whom the researcher perceived had a risk inducing and/or receiving harm.

Personal details such as your name will be kept separately on a password-protected computer drive that only the immediate research team can access. With your consent, the interview will be audio recorded. This is to improve the accuracy of the information collected from the interview and means the quality of the study is as high as possible. The recording will be stored under a code name so it is anonymous, and destroyed after it has been transcribed. All data collected will be password protected and only accessible by the research team.

We may wish to re-use the data for ethically approved research in the future. With your consent, an anonymised written transcript of your interview will be stored electronically and password-protected for 5 years, after which it will be destroyed. It won't be possible to identify you from this transcript.

What will happen to the results of the study?
When the research has been completed, Rebecca will write up the findings as a part of her studies at university. The findings will also be written for publication in an academic journal. In this article, and in the work for the university, there may be quotes included from the interviews; however these will be carefully selected and anonymised to protect the identity of those who provided the quotes.

After the study, you will be able to request a summary of the findings by contacting the researcher. The results will be published in peer-reviewed journals, and the researcher's doctoral thesis. Your data will always be confidential and it will not be possible to identify you.

Will I get paid for taking part?
Participation is voluntary so you will not be paid or reimbursed for your travel costs.

Who has reviewed the study?
This study is being completed as part of Rebecca's doctoral training in clinical psychology at the University of Hertfordshire. The University of Hertfordshire have reviewed this project and are sponsors for the project to take place in the NHS. The project has been approved by the NHS ethics committee (Health Research Authority) and the University of Hertfordshire Health and Human Sciences Ethics Committee.

Researcher contact details

If you would like more information or to discuss any part of the study, please get in touch using the contact details below:

Researcher:	**Research Supervisor:**
Rebecca Bishop	Dr Lizette Nolte
Trainee Clinical Psychologist	Clinical Psychologist
(Contact details here)	(Contact details here)

Appendix J. Participant Consent Form

Participant Consent Form

Talking and making meaning about parental mental health difficulties: the role of children's family caregivers

NAME ____

CONTACT DETAILS (email, postal address or telephone number)

____
____
____
____

Please put your initials in the boxes

- I confirm that I have read and understood the information sheet for this study and been able to ask any questions I have had. ☐
- I understand that my participation is voluntary and I am free to change my mind and withdraw at any time, without having to give a reason why. I know that I have the right not to answer questions or to end the interview early. ☐
- I understand that I will be told about any major change to the aims or design of the study, and if this happens I will be asked to give my consent to participate again. ☐
- I understand that any recordings and written notes made by the researcher will be made anonymous to protect my confidentiality. I agree for anonymous quotes to be used in the write-up and any publications of the research. I understand that it will not be possible to identify me. ☐
- I agree to the interview being audio-recorded. ☐
- I understand that the transcript of my interview will be stored securely and anonymously for up to 5 years, and that only the researchers will have access to it. I understand that this is for the purposes of potential secondary analysis of the data. ☐
- I understand that I may be contacted again in the future in connection with this study, and I agree to this. ☐

____________________________ ____________________
SIGNATURE OF PARTICIPANT DATE

____________________________________ __________________
R BISHOP, TRAINEE CLINICAL PSYCHOLOGIST DATE
RESEARCH INVESTIGATOR SIGNATURE

Appendix K. Participant Debriefing Sheet

Debrief Sheet

Talking and making meaning about parental mental health difficulties: the role of children's family caregivers

Thank you for taking part in this study. We really appreciate you taking the time to help us.

The aim of the study is to further understand more about families where a parent has a mental health difficulty by learning about the experiences and perspectives of family members who help with childcare. Your interview will be compared with others to see if there are any similar themes or patterns. We hope that this information will help us to learn more about communication and the development of understanding in families affected by parental mental health difficulties.

Please be assured that the information that we have gathered will be kept anonymous and confidential within the limits already explained to you. You have the right to withdraw from the study at any time. You are entitled to have a research findings summary, and this will be made available upon your request to the researcher when the study is complete.

If taking part in this research has caused you to feel upset, you may wish to seek support to talk about this. You may choose to do this with a trusted family member or friend. Alternatively, the contact details of organisations who can provide support are provided below. Should you feel concerned about the mental health of the parent you support due to your participation in this interview, we recommend that you contact the mental health care team and/or GP.

Samaritans
The Samaritans provides support for people who are experiencing feelings of distress or despair.
08457 90 90 90
24 hours a day, 365 days a year
Minicom/textphone: 08457 90 91 92
Email: jo@samaritans.org
www.samaritans.org.uk

Mind Infoline
Leading mental health charity in England and Wales offering callers confidential help on a range of mental health issues.
Call 0300 123 3393 or text 86463
Weekdays 9am - 6pm
www.mind.org.uk

NHS Direct
NHS Direct delivers information and advice about health, day and night, direct to the public.
Telephone 111
www.nhsdirect.nhs.uk

Researcher contact details

If you would like any further information about the study, or you would like to know about the results of the study, please contact us on:

Rebecca Bishop (lead researcher) Trainee Clinical Psychologist	Lizette Nolte (supervisor) Clinical Psychologist

(contact details here)

Thank you for participating in this study

Appendix L. Demographic Information Sheet

Demographic Information

Talking and making meaning about parental mental health difficulties: the role of children's family caregivers

NAME: ______________________________

AGE: ______________________________

GENDER: ______________________________

ETHNICITY: ______________________________

OCCUPATION: ______________________________

____

RELATIONSHIP TO CHILD/CHILDREN: ______________________________

AGE AND GENDER OF CHILD/CHILDREN (e.g. age 4 & female, age 10 & male): ______________________________

____

____

DETAILS OF PARENTAL MENTAL HEALTH DIFFICULTIES (Please give a brief description of the difficulties as you understand them, to help us understand the type of families included in our study. This might include a diagnosis if you know that the person has been given one):

____

____

____

____

____

____

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Appendix M. Initial Interview Guide (Interviews 1 – 5)

Interview guide

(Prompt/follow-up questions below the open-ended questions may be used as appropriate)

- Tell me about your involvement with looking after the child/children. What's it like?
    - How much do you do? / What do you do?
    - What affects how much you do/what you do?
    - What's the impact of that?
    - What do you think its like for (parent)/child/children/family?

- Do you ever find yourself talking to the child/children about their parent/the mental health difficulty (use their terms)?
    - What's it like?
    - How do you think the children understand it?
    - What's it like when you're looking after the children when (parent) isn't there?

- Can you tell me about how those conversations come up, and how you decide what you're going to say?
    - How is it for (parent)?
    - Does the parents ever talk to them about it too?
    - Tell me about what helps you manage that / makes it difficult.

- Do you ever talk with anyone else about it? What's that like?

- What are the most positive things about the situation for you?

- What are the more difficult parts of the situation for you?

- Is there anything you would change about the way the family communicated about (parent's) experiences/difficulties? (use participant's terms)

- From your experiences, what advice would you give to someone in a similar position to you?

- Is there anything I haven't asked about, or that you feel is important to mention?

Appendix N. Updated Interview Guide (Interviews 6 – 10)

Interview schedule

- Can you tell me about your involvement with looking after the child/children. What's it like?
- Do you ever talk to the child/children about the mental health difficulty? What's it like?
- Do you ever talk with anyone else about it?
- How do you manage/cope with the situation?
- Do you feel your relationships with the children have changed? What's it like?
- What are the most positive/difficult things about the situation for you?
- Is there anything you would change about the way the family communicates?
- From your experiences, what advice would you give to someone in a similar position to you?
- That's the end of my questions. Do you feel there is anything important that I haven't asked about, or that you feel is important to mention?

Follow-ups/prompts:

Can you say any more about that?
What's that like?
Could you clarify what you mean?

Appendix O. Second Updated Interview Guide (Interviews 11 – 16)

Interview schedule

- What's it like for you looking after the child/children?
- Do you ever talk with them about the mental health difficulty? What's it like?
- Do you feel things have changed?
- How do you manage/cope?
- Is there anything you would change about how your family communicates about mental health?
- How do you that the caregiving situation has impacted on you? (i.e. identity/sense of self)
- What are the most positive/difficult things about the situation for you?
- If you and/or the child were to receive support, what would you find most helpful?
- That's the end of my questions. Do you feel there is anything important that I haven't asked about, or that you feel is important to mention?

Section 4: Data Analysis

Appendix P. Overview: Data Analysis Appendices and the use of NVivo

Notes on transcription style

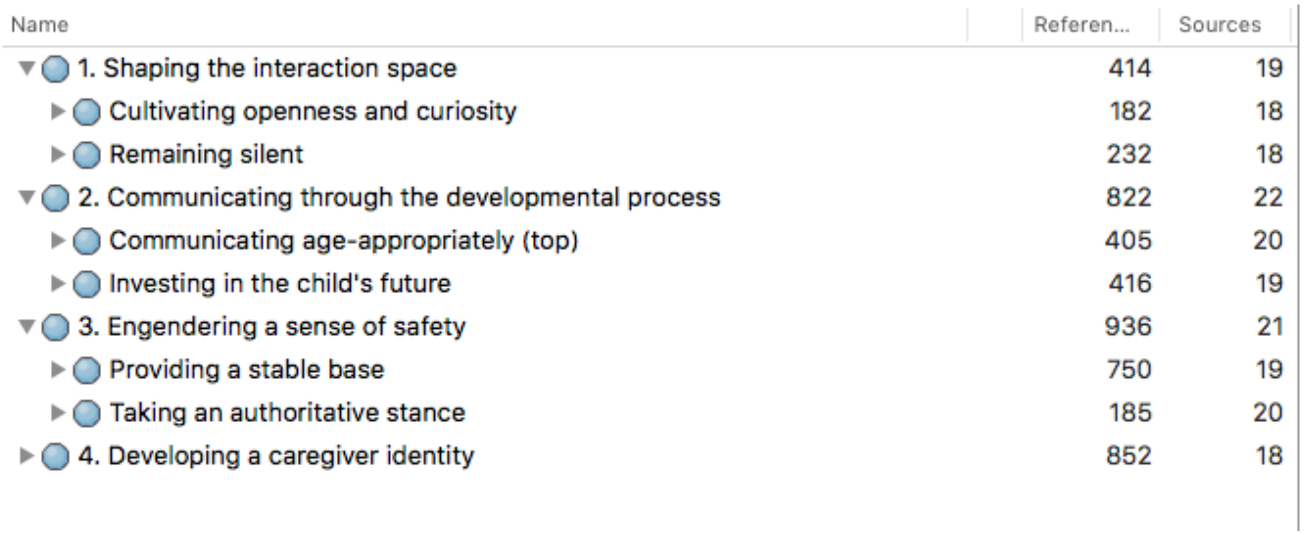
As stated in the Method, transcription was conducted with attention to retaining the participant's voice as much as possible. Efforts were made to preserve hesitation, repetition and intonation through the use of transcription conventions. Verbatim quotations are provided throughout the Results chapter. Some of them have been edited slightly for readability although, again, effort has been made to preserve inflection and meaning. In the Results chapter, the following conventions are used:

- Square brackets are used to insert nonverbal communication and explanatory information, e.g. [crying].
- Ellipsis is used where text has been removed to condense the material, e.g. '…'.
- Round brackets with ellipsis indicate a short pause during speech, e.g (…).
- A single dash attached to a word is used where a speaker interrupts the direction of their sentence, e.g. 'I was- she was going'.

Use of NVivo during analysis

On-screen in NVivo, the transcript is displayed on the left and the 'coding pane' appears on the right – this can be seen in the following extracts of transcripts with coding. Sections of text are highlighted and assigned codes, which are called 'nodes'. These nodes then appear in the coding pane so you can see what has been coded. I chose to have NVivo automatically assign the nodes different colours in the coding pane, so that I was able to differentiate them easily.

NVivo allows you to code as many pieces of text as you like under each node. This means all quotations are then grouped together for easy reference. You can create different 'levels' of node to represent the different levels of a model hierarchy (i.e. categories, subcategories, etc). The more abstract, high-level codes can become 'parent nodes', while the lower-level codes (i.e. initial codes) become 'child nodes' that can be collected underneath them. As you build and change your model, you can move the nodes around as much as you like while still retaining all the original coded material under each node heading. NVivo is a tool that moves with you as you build the analysis.

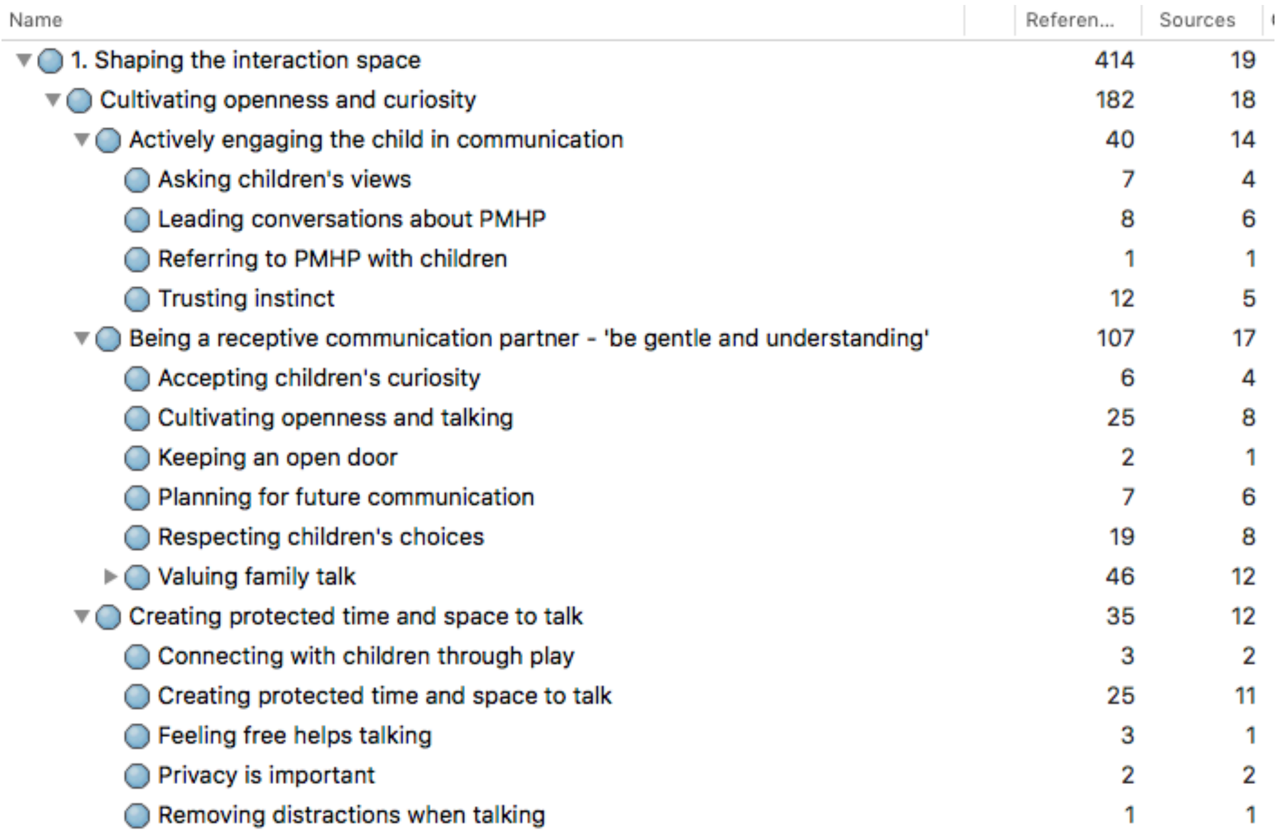


Name	Referen...	Sources
▼ 1. Shaping the interaction space	414	19
▶ Cultivating openness and curiosity	182	18
▶ Remaining silent	232	18
▼ 2. Communicating through the developmental process	822	22
▶ Communicating age-appropriately (top)	405	20
▶ Investing in the child's future	416	19
▼ 3. Engendering a sense of safety	936	21
▶ Providing a stable base	750	19
▶ Taking an authoritative stance	185	20
▶ 4. Developing a caregiver identity	852	18

Above, the categories and subcategories can be seen. The arrows to the left hand side show where these can be expanded or collapsed to show or hide the earlier initial and focused codes. ‘References’ shows the total number of quotations assigned under each category and subcategory (collated from the initial and focused codes) and ‘sources’ shows the number of data sources that contain the code, including both transcripts and memos.

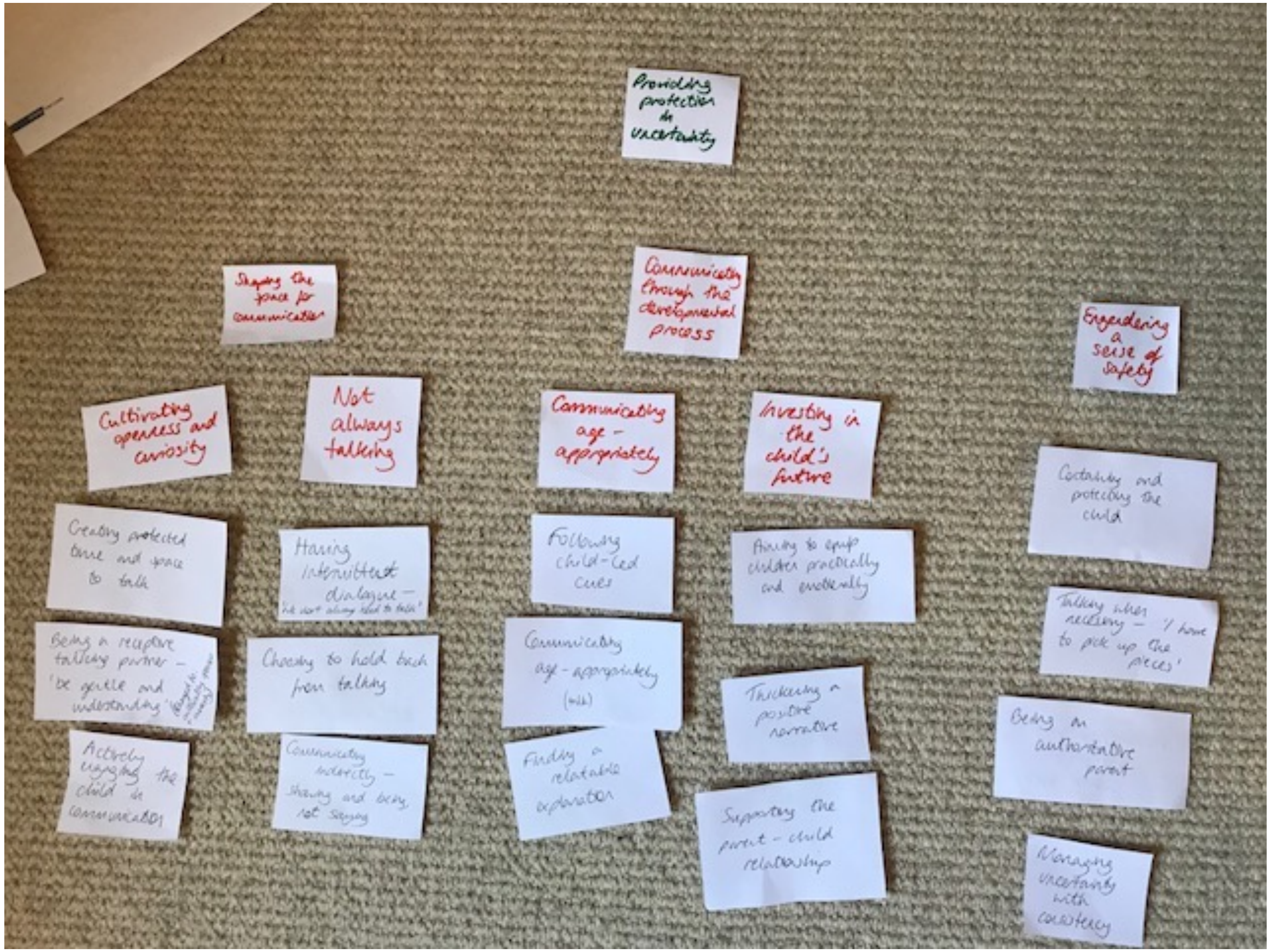
During initial coding, as described in the main report I ended up with 550 nodes. As I progressed from intial to focused coding, it enabled me to collect together lower-level nodes under higher-level labels – these were the focused codes. In many cases, the focused codes were initial codes that had been elevated due to their higher analytical level and abstraction. Sometimes, I created a new label for a focused code that better accounted for the intitial codes within it. I also removed some codes that weren’t relevant to the research questions – at times this process of ‘letting go’ was quite challenging,as I worried about losing data. I regularly discussed these decisions in supervision.

Below, the different levels of the hierarchy within the subcategory of category ‘Shaping the Interactional Space’ can be seen. The subcategory ‘Cultivating openness and curiosity’ is opened out, showing where the focused and intial codes have been grouped together.



Name	Referen...	Sources
▼ 1. Shaping the interaction space	414	19
▼ Cultivating openness and curiosity	182	18
▼ Actively engaging the child in communication	40	14
Asking children's views	7	4
Leading conversations about PMHP	8	6
Referring to PMHP with children	1	1
Trusting instinct	12	5
▼ Being a receptive communication partner - 'be gentle and understanding'	107	17
Accepting children's curiosity	6	4
Cultivating openness and talking	25	8
Keeping an open door	2	1
Planning for future communication	7	6
Respecting children's choices	19	8
▶ Valuing family talk	46	12
▼ Creating protected time and space to talk	35	12
Connecting with children through play	3	2
Creating protected time and space to talk	25	11
Feeling free helps talking	3	1
Privacy is important	2	2
Removing distractions when talking	1	1

of



At times during focused coding and for all of the theoretical coding stage, I came off the computer and worked on paper. This provided space from the data, helping me move to a higher level of abstraction using the focused codes, draw diagrams, and move concepts around in physical space. This can be seen in the image to the left, which shoes an earlier version the model, very similar to the final one.

I returned to NVivo once the theory had been built on paper, and organised the nodes so that they represented it. When I wrote up the Results section, I was then able to open nodes on NVivo and see the collated quotations together. I was able to refer constantly to the intial codes as well as the strategies and orientations, subcategories and categories, drawing on the relevant level of detail as I wrote.

Appendix Q. Transcript Extract showing Initial and Focused Coding

The following pages contain an extract from Marcus' interview, which shows both initial and focused coding. As described in Appendix R, the transcript extract is seen on the left and the codes are shown in the pane on the right.

This was one of the transcripts initially coded line-by-line, which were subsequently re-named and re-organised into focused codes. I returned to later on to this transcripts and checked through the focused codes to check that they still accounted well for the data. Therefore, line-by-line initial codes and longer chunks coded with focused codes can both be seen here. Line-by-line coding is evident from the short colour blocks on the right hand side. Focused codes tend to be visible from the longer colour blocks on the right hand side.

Subsequently, Appendix R shows an extract from Kimberley's interview, which was only coded with the focused codes. The difference can be seen because the colour blocks in the coding pane are overall longer than those in Marcus' interview. During the application of cosued codes, attention was still paid to novel concepts which were created as new codes where relevant.

(Transcripts removed following examination for confidentiality purposes)

Appendix R. Transcript Extract showing Focused Coding

As described above in Appendix Q, the following extract shows focused coding of Kimberley’s transcript.

(Transcripts removed following examination for confidentiality purposes)

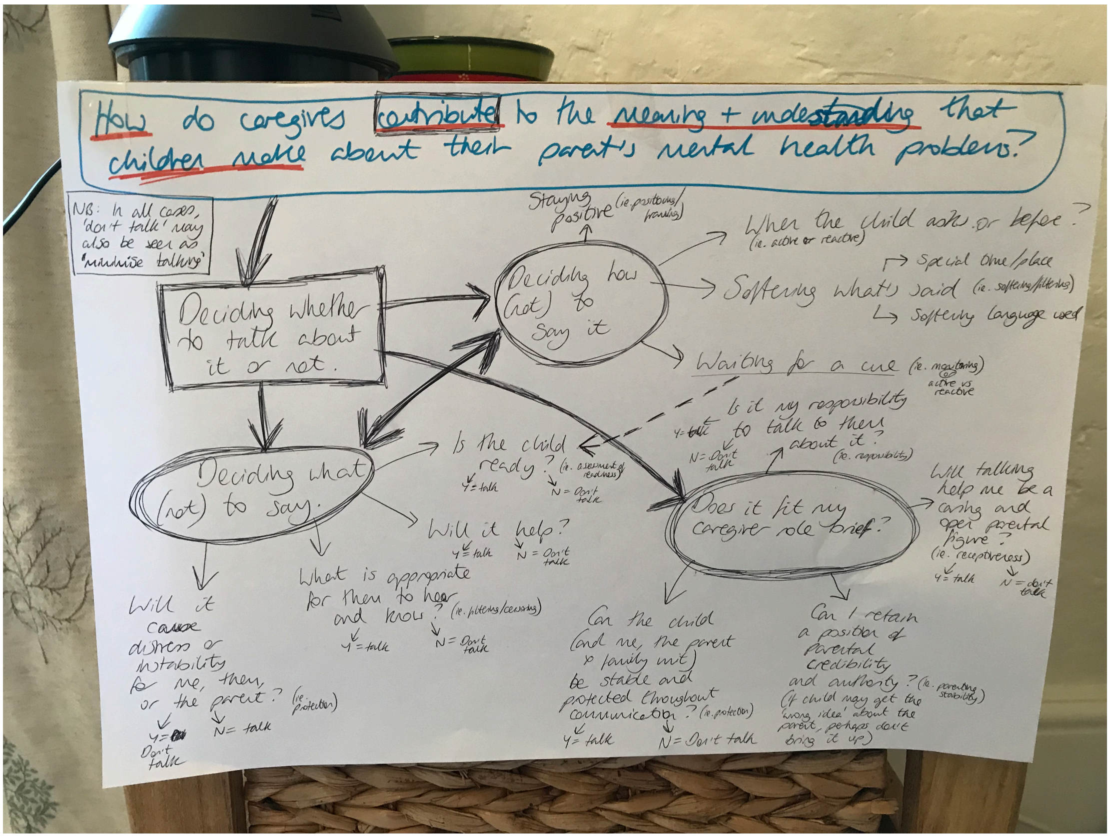
Appendix S. Examples of Progression from Initial Codes to Categories

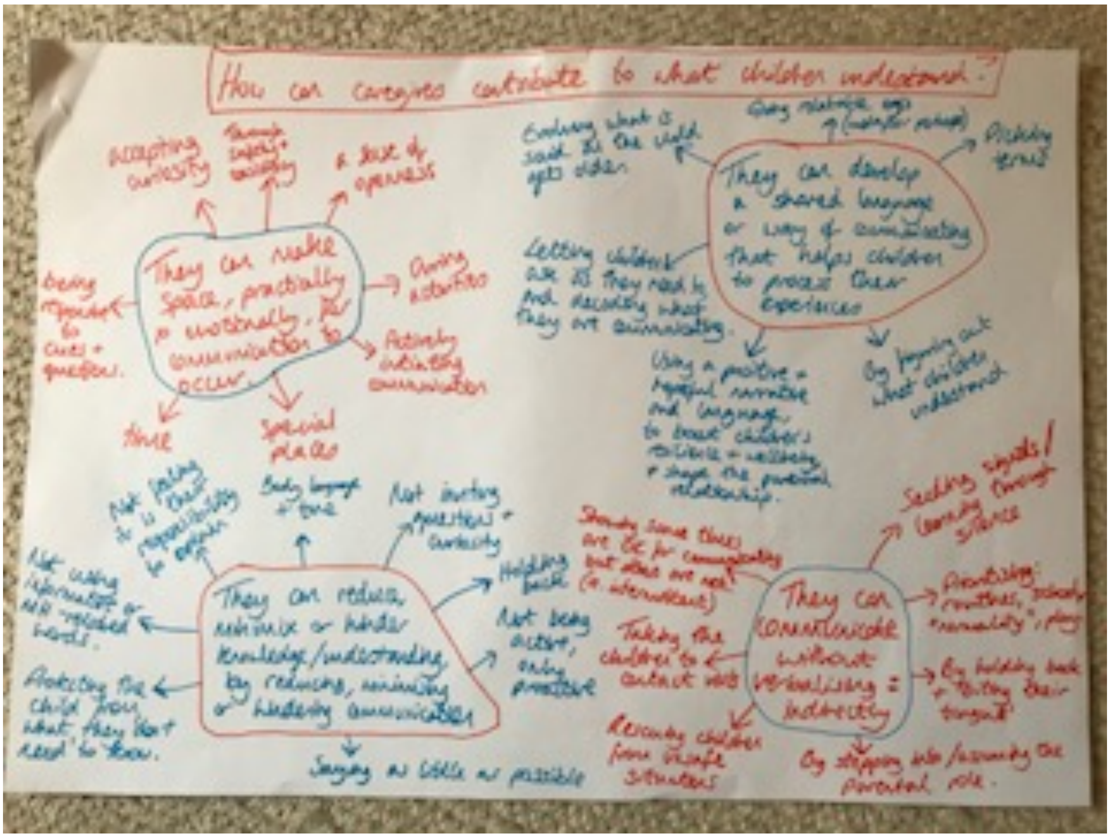
The example given here is for the subcategory ‘Communicating age-appropriately’.

Original Phrase	Initial Code	Focused Code	Strategy/Orientation	Subcategory	Category
No, no I'll only answer questions, I don't bring the subject up.	Not bringing the subject up	Responding to questions as they come up	Following child-led cues	Communicating age-appropriately	Communicating through the developmental process
We're in the background supporting him. He knows we are here. Um and we don't force ourselves upon him.	Not forcing talk on children				
I guess because I give him a little bit more than others and he-- I tell him that "Look, I'm telling this to you but don't tell the others" kind of thing. To manage that I do that with Finn as well. [laughs] Because like-like to a different degree.	Giving different children what they need	Being responsive to children’s needs			
We have never known how to say, you know, "Daddy's unwell." How do you tell a six year old? Um, without them stressing that Daddy is gonna die?	Being careful about language – ‘I will not accept…’	Needing better explanations for children	Finding a relatable explanation		
So it was, how much do I tell her? How much do- What do I do?	Questioning what to tell older children				

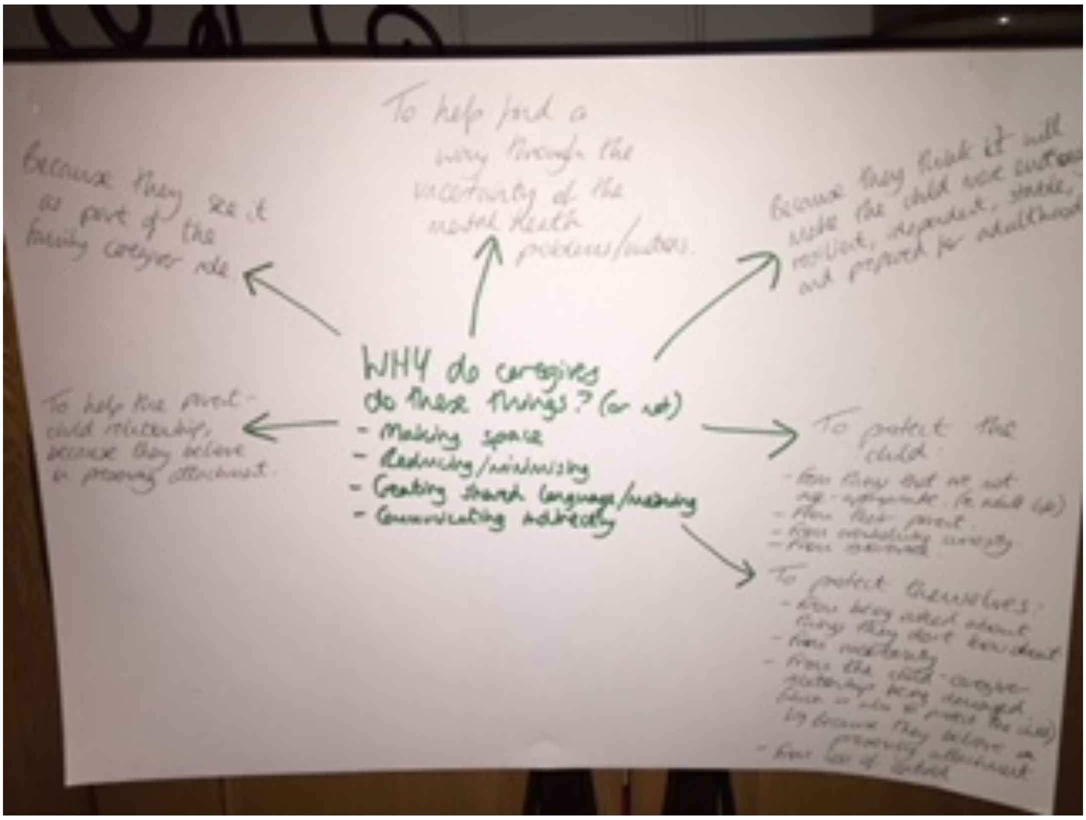
Appendix T. Examples of Diagramming for Theoretical Development

I used diagramming to explore the developing concept and my ideas, paticularly by asking questions of the findings. As can be seen in the two diagrams below, I kept the research questions central to my examination of the identified concepts. This assisted in making sense of the relationships and processes between different concepts.



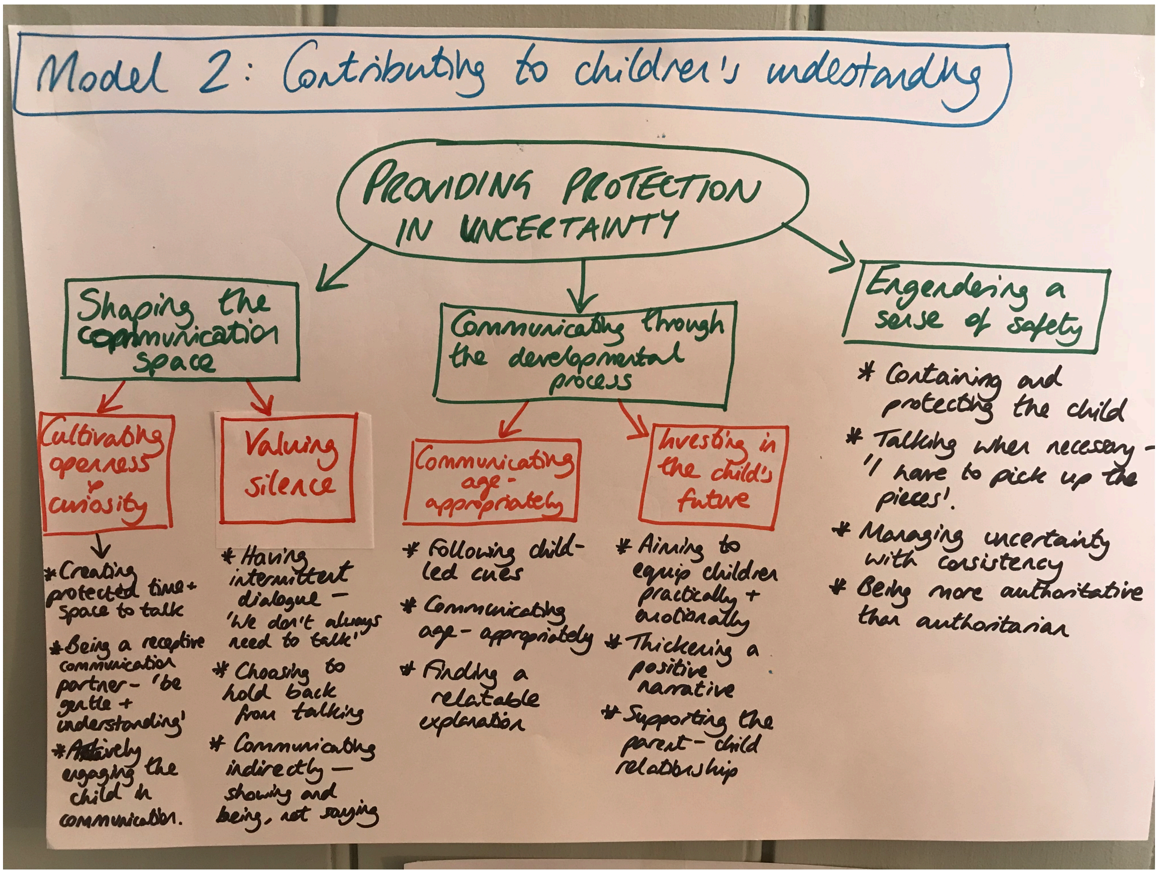


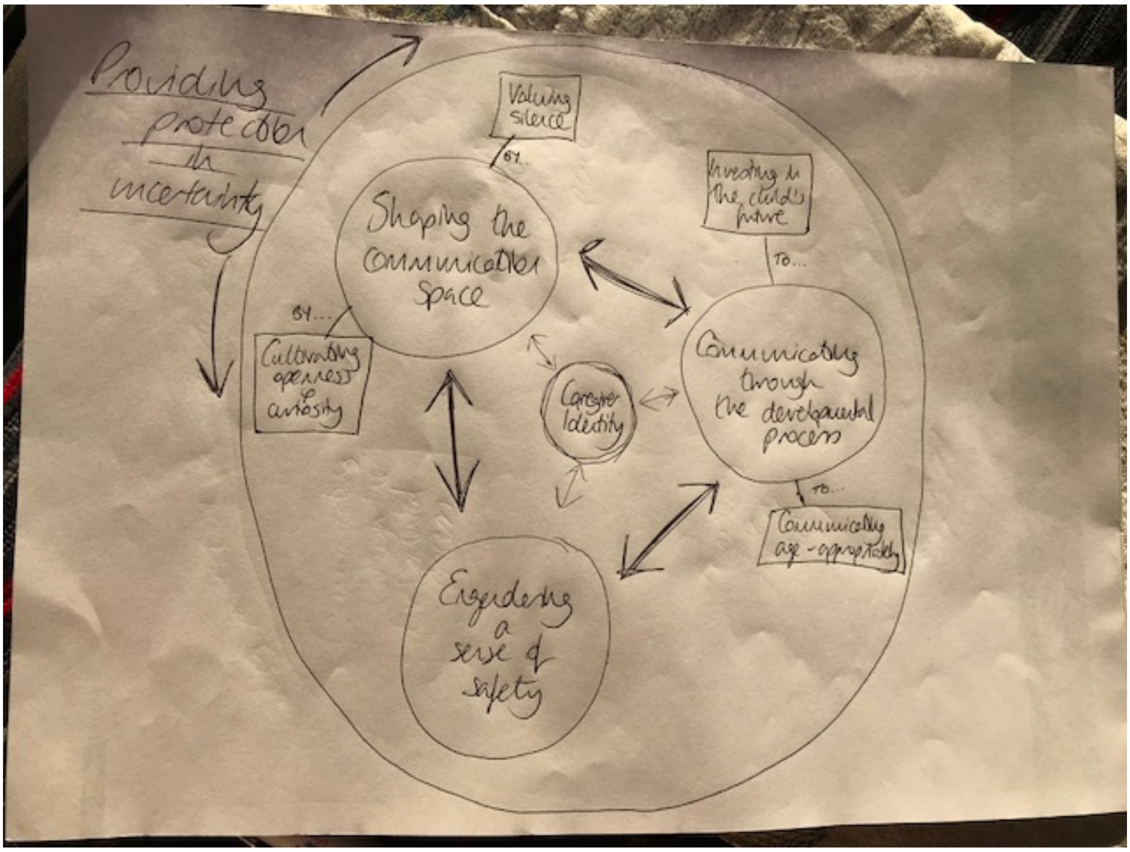
The diagram below was valuable for exploring the centrality of the concept of protection. I made repeated efforts to question this concept, which appeared to arise freuently, and to evaluate evidence for it including looking for contradiction and indications that it was not that important.



Here, I was exploring the concept of caregiver identity and the factors that appeared to contribute to it.

These two diagrams show earlier versions of the final model. These were both drawn before the final two interviews, where the theory was checked with participants, and small but important changes were subsequently made.





Appendix U. Extracts from Research Diary

Interview 1

I actually started! It's good to have the first proper interview out of the way. It went on for much longer than I'd expected – she had so much to say. There is evidently a need for these caregivers to have a chance to be heard. I felt really sad hearing some of the stories about the children before they went to live with her, I felt really tearful at a couple of points and when I got into the car afterwards I felt really emotional. So much respect for her taking them on when she was meant to be starting retirement and having a really different lifestyle. I wonder if others are going to be as emotionally complex. She commented on getting emotional and apologised for that. Some hesitance about getting emotional? Do emotions need to be suppressed to an extent?

Initial ideas….

- Loosening expectations around 'ideal' childcare to fit with what the unwell parent is able to offer.
- Changed role (grandparent to parent)
- Loss of 'fun' role (grandparent to parent)
- Reassuring the children – providing stability, getting them to school, keeping them safe.
- Frustration with social services. Quite a lot of this….

Transcribing interview 2

Competing interests between children. Older teenagers expected to look after their parents and be independent, possibly forgoing 'babying' or being cared for that adult/teenage children in other families may get when they return to the parental home after moving out. Here, new baby is the priority – parent can only manage one child at a time? Having to choose between children - which is the most needy or deserving of parent's time. Caregiver may help the parent decide about this.

Step-parent protective of parent and asks older child to manage their own distress at the situation in order to achieve this. How is that for the child? This may be different with biological and step parents, because there is something here about who's distress is the most important. Also, there is something about silencing the distress of the child.

Parents and children can become closer through the challenges of mental health.

Stories of caregivers' previous experiences of dealing with stress, including unhealthy coping styles. They have learned from these previous experiences and draw on what was helpful and what was not in their current caring relationship. Also, caregiver's previous experiences of mental health. He said that he hadn't got previous experiences and has learned a lot, but then also goes on to talk about a 'breakdown' in the past and his mum taking him to the mental health place. Is this to do with how bad it is? Having a diagnosis? For some reason they aren't in the same category in his understanding of mental health. But actually, these experiences mean that he understands unhelpful coping and what helps, and puts in boundaries/structure around these things to support the parent.

Tension between care available for mum and stepdad's new baby, and the needs of mum's adult daughter from previous relationship? He protects mum from her daughter to some extent. Appropriate or unfair? (What do my own biases say here? I think I feel sorry for the daughter).

Interview 3

Instant reflections… I feel like this Dad has to contain his own feelings as it's helpful for his children. Conversely to the previous interview, the children absolutely come first. However, in this case he is the biological father, and they are younger. Greater sense of sole responsibility. He talked a lot about loss of the family life he wants – daughter at boarding school, wife not totally his wife anymore. He wouldn't want it this way but he accepts his situation for the good of others. It's seen as better for the child that she's at boarding school because she's out of the way of the situation – it's like a form of protection but he, as a dad, kind of suffers for it.

There was definitely a sense that he is giving up a lot and putting his needs lower for others in order to cope. I wonder if there are gender differences around this… do fathers always do this, or is this a more maternal role? I feel like a lot of mothers would hold this narrative, even in non mental-health/carer situations? Possibly a greater adaptation for men? Like the previous interviewee, he also gave up working in order to do the caring role.

Another interesting study would be around adjustment to loss of 'lover' and 'equal partner' due to caring role. Has this been done already?

Transcribing Interview 3

Clinging to positive narrative – seems to be most helpful for him. This participant has thought really clearly about the message he wants to give to his children and what his role is in helping to promote that. It feels a bit different to other interview where we just didn't get to the same sort of conversation topics or questions, because the person hadn't verbalised it in the same way.

He externalises the illness naturally, separating it to his wife and helping his children to do this too. Mum herself is not blamed or the focus of anger/upset, only the illness can be. Use of 'the' to emphasise the externalisation (and explicit reference to narratives at times). This man is aware that he can choose to think about things a certain way, even if they have happened outside his control.

- Important quote: 'Just asking the question is enough'. Emphasises the importance of conversation being raised by others, having the opportunity to talk, breaking the silence.

- Idea of hospital being ineffectual and not wanting children to take that message on. Putting self into children's minds effectively to think about how they might perceive things: mind-mindedness kind of idea. In a way, this goes against some other things he's said because hospital doesn't seem to have been all that helpful for them, but perhaps its about retaining hope, or something else?

- Narratives about bipolar: 'unhelpful' for children. Stuckness/certainty narratives are unhelpful. He uses an individualised formulation type approach instead.

- Discussion about diagnosis: there is a theme here about how the caregiver manages if they don't like the illness label or diagnosis, or they don't agree. They have feelings about it, but there may not be a space for these. How do these feelings affect how they talk to the children? In his case, it's a greater use of symptom descriptors and general illness terms, rather than agreeing with the idea that its never going to go away/its genetic.

- 'I'm supposed to know the answers' – feeling lost, lack of information, poor understanding of MH terminology and timescales. Could be better provided for family caregivers.

- Recovery college ideas and desire for courses: This seems to have an obvious and direct meaning – he wanted more information for both himself and the children to save having to figure it out themselves over time. Services could be more supportive. However, this is also a bit at odds with his earlier statements that it appears that BPD is an unhelpful label, nobody really seems to know what it means, and that certainty isn't helpful. Is there a theme here? Wanting certainty and not wanting certainty. It would make things easier, but it also pigeon-holes you.

……………………………………………

Interview 6 - transcribing

As expected, data quality is compromised by not having audio recorded. I have lost a lot of the detail and can't remember all her tone of voice, etc.

Section about receiving support from other people: she says that people always think you need to talk, but that she doesn't always need to. I haven't really asked people about this. It will be important to explore this aspect of not talking.

Something like this can go on the question list: Do you find it helpful to talk to others about it? Are there times when you don't find it helpful? Why?

Difficulty making sense of the intergenerational or family commonality. She talks about her ex partner wondering why she knows so many people who have attempted or committed suicide. To me this feels very sad, and uncaring for someone to ask.

She talks very explicitly about how the caregiving role can be enabling rather than empowering, and take the need to take responsibility for the children away from the parent in a way that may be unhelpful for their mental health. I think that this has been alluded to more implicitly by other participants but not said in as many words. It seems this is because she actually lost her sister to suicide and has had to think more about the impact of her actions. Others have talked about the parent continuing to be/becoming more irresponsible and the need for them to look after the children on their behalf increasing.

"Because if you strip them of responsibilities, when someone makes that decision to take their own life it's in their darkest moment, and if they think 'Nobody needs me because someone else can do it', then it makes it easier."

She emphasises that people should be encouraged to support and to do it together, but not to disempower the parent and let them feel they are not needed.

……………………………………………

Interview 5

After a long drive to that interview, it was totally worth it. It felt so different to the others! It was really related to her age I think – partly probably because I was able to connect more with her because she's closer to my age than a lot of participants have been so far, but also because there's just something about life experience. She's taking on loads of responsibility – and blaming herself for doing so, which felt so sad – and I can't help but feel like this links to the fact that she's younger. It would be helpful to try and speak to other younger people, and also to siblings. This experience presumably ties in more closely with adult children's perspectives. I had such a sense of wanting to look after her, and there were definitely questions I'd have asked clinically that I didn't ask today. That reminder to myself to stay in the researcher role.

Transcribing interview 5

I am feeling sad listening to this interview. I think it's to do with how much she's crying partly, and feeling that sadness with her, but also because she's so young and blames herself so much. That is a common thread in this interview – that she's supporting the family but somehow it's her ***fault*** that she does so much. That her mum would manage without her. Listening, I feel like maybe they would manage, but maybe not, and it certainly wouldn't be as good a life for her siblings without her support. There is a guilt about enabling her mum's difficulties. She wants to move out but it presents a challenge because she won't be able to support as much.

Participant talks about thinking mum feels relieved when they talk about mental health. As the main caregiver/support, her mum talks to her most. She pulls out listening as an important factor. Later, at fifty five mins, she talks about her mum being open about it (ie talking) has meant she doesn't see her childhood as being bad. However, she cries during this section. I'm not sure if this is indication of mixed feelings, strong emotion related to reflecting…

She talks specifically about her mum not seeing the bipolar as a problem, but seeing it as part of her. This is positively connoted. I was struck by this because as psychologists we often work hard to separate the person from the difficulty, but this seems reframed somehow. Also other participants have spoken explicitly about separating the parent from the mental health problem as the best thing to do, so this is different.

Age appropriateness in talking to children is a theme – how much to say to them when. She seems to judge from personal experience of being a child too of when the time will be right. She brings it up when there are problems by the sound of it, not really at other times: when 'necessary'. She seems to be linking this talking with her brother showing emotional expression/naming anger when he feels it, and this being a good thing.

Advice for others: Self-care especially by doing little things to reduce responsibility on yourself; self-education about mental health.

She raises a really helpful point about the carers support that's available (to people who identify as carers) not often being what she needs – I imagine this is true for others, especially those who don't live with the unwell parent (e.g. respite care). Then, if there's a comorbid problem like MHP plus alcoholism, they get batted between services and family support isn't necessarily available, especially if the person is medicated and not in therapy. They wouldn't be offered FT.

……………………………………………

Interview 8
This one was via Skype, and that felt different but actually I don't feel like loads was lost because the sound and video were fine, and I feel like we developed a rapport. She had such a great sense of humour, I feel like it was a comfortable conversation and we laughed quite frequently. Is that something about me wanting it to be more light-hearted? Did that come from her? Is it okay? It' a relief to finally be getting a few more interviews in the diary now… I feel like that's going to be a game-changer from here on.

'But his mum won't talk to him about it'. – Talking about the father's family history of schizophrenia, and the lack of communication in previous generations as unhelpful. He went on to talk about their daughter being able to talk as a key to successful emotional growth, but concern that she's a bit introverted. She is working from the position that communication and emotional expression are inherently good. She goes on to explicitly say that it would be best for them to be able to open dialogue up between him and his daughter so she can understand his fears and this history of not communicating, even if he has to write it to say it.

Thinking about this afterwards, part of me feels a bit irritated because I feel like it's putting a lot on the daughter. It's as though the dad will make the effort to write things down, but the idealised response from the daughter is an incredibly mature, understanding and accepting one. Is this realistic? Is it fair to expect this? I wonder how the participant, as a woman, has expectations of her female child to respond to the PMHP. 'Should' she be as understanding and forgiving as the participant?

Re deciding when to have conversations: Take child's asking as the cue. That seems to be how 'appropriate to age' is judged. WHAT if they don't ask?? Then again, maybe it's the best way in a tricky situation?

Appendix V. Examples of Memos and Category Development

Memos are provided here with the intention of illustrating how memoing was used throughout the analysis process to support the construction of the GT model. Three memos are provided showing different aspects of the analysis process, written chronologically near the start, middle and end of analysis.

1. This shows a memo relating to an early concept called 'fighting for the kids', and how it developed as I added to it over a couple of weeks. The challenges I experienced in wanting to 'hold on' to ideas that felt important are evident here, particularly because the interviews contained so much detail about general caregiver experience, including coping and experiences of services, that did not always link directly to communication and meaning-making. 'Fighting for the kids' later informed the role of caregiver identity, and advocating for children as a means of protection. This memo also shows how I asked myself questions to inform the development of the interview schedule over time.

Fighing for the kids – 23rd Feb

Again, this is another code name that I could have called other things. It links with the caregiver's role being to protect the children, to stand up for their rights and safeguard them because they are vulnerable, but it is also related to fighting the system to get them. And in some cases not just fighting against a challenging and large legal system, but feeling like its a one to one, individual fight with people on the ground: social workers in particular, for those who have been through custody/social care arrangements.

Along with this, the codes related to having to form a strong opinion also seem to be connected to this idea. Having to develop a view, and then stand for that in order to be resilient for the kids.

Who fights for who? Stronger people fight for weaker people. We fight for people we love. We feel a responsibility to keep up the fight, and perhaps self doubt if we don't win or fight well. Sometimes I have noticed that in the sentences I code as a strong opinion, I often code something related to questioning or self-doubt just before or after. The person says something strongly and then questions themselves, or as the sentence goes along they become more certain.

What does this reflect about what caregivers have to do for children? How they prepare and steel themselves for keeping going?

5th March

I have been looking at this idea again today, and I'm feeling a bit like it doesn't directly link to how the caregiver talks and communicates with the child as much as some of the other codes. This feels like my main challenge at the moment - keeping focused on talk with the children. There is just so much else in the data and I'm going to have to let it go at some point. I'm trying to now, but it's hard. I don't want to lose something relevant.

However, I do feel this code is very relevant to how caregivers communicate with other people outside the family still. I also think it's very linked with how they make decisions, justify the action they take, and persist at it. There is a code category around taking responsiblity for the children and taking action, which is really associated with making a stand and holding your viewpoint. This is definitely something that caregivers have to do, because they have to make parenting choices and hold boundaries, with the parent, child and others. This hugely affects how they talk about things and how they communicate:

"I said well you, you know 'Until I think things have calmed down, mum is obviously not well again, until things have calmed down you won't be going'."

Normally he would just leave it up to me because, uh, they-- I think they kinda push him around a little bit more.

Perhaps there is a better name for this code/memo that I have not yet got to, because 'fighting for the kids' is fine, but I'm not sure all caregivers do fight, more those with kinship care experience.

2. **This is a memo written in the mid-stages of analysis in relation to ideas around a sense of movement or progression in caregivers' narratives, and the purpose this may have in their own coping and in communication with children. This went on to inform 'thickening a hopeful narrative' and 'finding a relatable explanation', and clearly shows links between these concepts.**

<u>Getting better, getting worse/Defocusing from uncertainty? – 26th March</u>

I was just coding and thinking about this idea of things being discussed as GOING SOMEWHERE. They are getting better, they are getting worse, they have been stable for a bit but probably they will get worse again at some point. There is the expectation of movement and change in the way the caregiver talks about the MHP.

For P3, this was connected with the medical model of illness. The parent has an illness, they go to hospital to get better because that's what we do when we are ill, the doctors will find a cure and then they will come home and be better. Again, that sense of movement... they go away, they come back, they aren't around, they are around.

She has got better, she's started a recovery process. The recovery process was erm (...) coincident with a reduction in her- her drugs, whether which one was cause and which was effect. It was also- but also because she was- been able to intermit on her study which relieved a huge amount of stress. Erm, and she's gradually reclaiming things. Erm, her current situation is she's not in hospital, which is good. She has- she celebrated sixty days yesterday of not being in hospital, which was excellent.

However, he talks about this no longer being a sufficient explanation once the parent has gone away and come back several times but aren't better yet. Earlier on, he talked about having learned to take things as they come, one day at a time. This is in a mindful kind of sense, but it seemed more associated with being a way of coping than with having found acceptance of the situation.

More like narrowing one's view to only think about near time is a way of coping with the uncertainty. Defocusing from uncertainty. Helping self and children by talking and thinking about today (including the parent as they are today) and only taking much time to really think back and ahead when totally necessary (i.e. when a child's question brings up strong emotions that that then need to be dealt with).

I think this should connect with the 'holding onto hope' code/theme. Perhaps knowing that things are always shifting allows hope to remain, because they could always go in a positive direction.

"I don't want him to deny the reality of what he's experiencing, but I do want him to still hold onto hope."

It's as though he's saying that accepting reality would mean accepting that there is no hope. Perhaps this also relates to the certainty with which some participants talk about the parent, the illness, and the child's wellbeing - they assert things to reassure the child that there will be hope and things will be okay. They 'know' and they 'won't let X happen'. They tak responsiblity. This provides containment, and seems to serve a function of them also reassuring themselves at the same time (e.g. P2).

P3 gives a beautiful demonstration of how this then segways back into hope, and into action. Action can be used to ground hope to the present moment - they do an activity together or make an immediate plan, which is linked to the future and incorporates the unwell parent, but can be put into practice without them now so that things can be good straight away (and good stuff happening is not just a magical yet potentially unreachable feature of the future).

P3: 'And shall we plan what we're going to do', and then we're on- then we're in (...) in the hopeful part. Or 'And instead that means- the good news is we can spend the time together, and we can do- you know you said you wanted to do a jigsaw puzzle? Let's get it out and see what we can do.' You know, or whatever it is. Or, he's very fortunate, he gets (...) it was his birthday last month and his godmother sent him a- a new game to play which is really complicated. So we can- we can get that out and try and understand some of the rules gradually, and you can do those things which (...) 'Look this is your game, this is what we're gonna do. Now, and won't it be brilliant because we can (...) you know, mummy wil be- mummy can see it when we've- when we've got it right.' And that's good, erm (...) but it has to always be erm (...) because (...) she doesn't want to be ill.

Coming back to this later on.... I am now coding some sections that still fit with these types of codes, but the conclusions are almost opposite. So, focusing on uncertainty to help variation be more tolerable, especially in relation to going in and out of hospital and coping with fluctating symptoms and general uncertainty. It annoys me because of everyone banging on at uni about sitting with uncertainty', but it seems to be a central theme here!

This is managed by caregivers by decentralising from specific illness terminology with children. So for example, talking about 'illness' rather than Bipolar. This is associated with keeping things lighter/less heavy/less serious, which is somehow seeming linked with 'more manageable'. I suspect it's also to do with what caregivers consider age-appropriate.

So maybe 'Decentralising' is somehow the common thread? From severity? From seriousness?

3. Memos from later in the analysis process where protection has been identified as important in caregivers' contributions to children's meaning-making and understanding, and I am refining and developing my thinking around this. Again, this memo details my reflections about 'letting go' of certain parts of the coding in order to hone in on the research question, and ordering ideas and concepts. This memo demonstrates how these ideas that were so hard to ignore led to me widening out the idea of protection beyond just the child, broadening the concept so that it better represented the data

Coding interview 12.

She talks about age-appropriate communication. Two important points that may be helpful for the results section:

1. Her own experiences of the MHP (i.e. that it's scary) shape her difficulty finding the right explanations for the children, and wanting to protect them.

Kimberley: Very, and I think a lot of parents would like to know how to talk mental health with their children without scaring them. Because the bipolar scares me. Um, when he 's on a high, he is obnoxious. Um, not very nice, unreasonable, um, doesn't sleep. We fight all the time. And people- and the boys (…) it would be nice to tell them, you know, "Well, that's a phase". I know it it's a phase, even though you know, occasionally I want to strangle him! Um, but (…) so, you know, you can just tell them, you know, "Life is up and down and you know Daddy is going through a manic phase at the present moment" or "Daddy (…)" But it's how to be sensitive and age-related. And talk about these things in a way that they would understand and not upset them.

This is interesting because she reels off a number of things she could say, but still feels she needs help working out what she would say. Is this to do with confidence? With helping her to know that she won't be damaging the children by saying these things? It would potentially be very helpful for this lady to hear that communicating and giving children language is actually protective for them, but perhaps this would require addressing her own fears about the scariness of the MHP - clinical implication?

2. She states that if the children were older it would be different in terms of communication - more could be said and, crucially, the expectations of them would be higher.

Kimberley: They're six for heaven's sake!

Interviewer: As much as six-year-old boys will.

Kimberley: They're six.

Interviewer: [laughs]

Kimberley: [chuckles] If they were 15, one would expect more. [whispering]. They're six. They love their daddy [chuckles]. Fortunately he has come to the point in his health where he is well enough to actually begin to regain the time that he has lost. Um, he's (…) if he had only- kind of when they were six or- if they were seven or eight, and he was still like he was when- when they were four, he would have lost. Um, but the boys are still in a position where he can build a relationship with them.

We didn't go into the expectations of what, but this is an interesting factor. Just thinking about the critical perspective on views of children, this is really interesting because it suggests that smaller children are seen as more vulnerable than older and requiring more protection, and that a spouse might have higher expectations of the child pulling their weight or caring for the parent when they're older (than, say, some of the grandparents I've spoken to - P16 is a good example)

Protecting children physically and emotionally

Today I feel that I am really mulling over what broader conceptual ideas all the focused codes might relate to. It feels hard! I feel like I have too many ideas that at the moment are too disparate, that I don't want to let go of, or that I can't decide what 'order' they might come in.

Reading back over my memos about 'Going on a Communication Journey', 'Controlling Information Flow' and 'Generating a Sense of Safety' has really highlighed a theme of protectiveness from the caregiver to the child. The focused code I am currently working with called 'Protecting the child and their innocence' is in regular use when I am coding the next set of interviews. This seems to form an aim/motivation/wish of many caregivers, but also an action. I wonder if it will need to expand out into more than one focused code or if it can stay all as one.

As an aim/wish, caregivers frequently indicate they they feel the children 'see' or 'know' too much due to their experiences with the unwell parent. This sometimes relates to MH crisis situations or the caregiver's view that the parent's parenting/behaviour/comments are inappropriate due to their PMHP. These feelings appear to arise for caregivers who have either a good relationship or a poorer relationships with the parent - although that shapes the emotional tone of their comments about the parent, it doesn't seem to affect their desire to protect the children.

When I think about my experiences in the interviews, this reminds me about asking the question "What are the most positive aspects of the sitation for you?" and how many interviewees would crumble into tears at this point, and talk about their relief at being able to provide the children with normality, stability and love. These things all speak to the desire to protect children's emotional and physical wellbeing. The tears, including from people who had told me during consent that they weren't much of a crier, felt in the moment like they signaled a deeply important aspect of the cargivers' experience.

That, despite the significant losses they suffer as a result of stepping into the parent role or 'losing' a co-parent/child/relative, the intense emotions (frustration, anger, sadness) that they experience and must tolerate in order to address the child's needs, and the stresses that necessitate shifts in worldview and lifestyle in order to cope, it is worth it because they have a higher order purpose and role: protector.

This reminds me of research about the efforts that people will go to, to save relatives depending on how near or far they are genetically. (i.e. mother more likely to give up life for child than aunt is).

Combined with the arising ideas from the analysis, this points to Protection being a very important concept.

An important thing that links the sense the caregiver makes of the PMHP and what they do with the children is the sense they make of the caregiving role. How they conceptualise what is needed of them. This is associated with thinking about themselves as a person, their own caregiving experiences (i.e. being a parent before; drawing on their own parental model), and how they are similar and different to their peers and professionals. It is also associated with what they understand the child to need from them, as this determines the type of caregiver they need to be. This is associated with significant role change, and often loss of certain roles. So for grandparents, this seems to mean dampening or pushing aside the grandparent role in order to be more like a parent. For parents, it seems to involve coming to terms with parenting alone, or being the primary caregiver.

Consequently, the caregiver is not just making sense of the PMHP: they are trying to figure out what they can communicate with the child and how to do this, based on the interaction between the nature of the PMHP and the child's personal characteristics. Therefore, for example, caregivers hold back from talking when they feel the child is not ready to hear certain information or they are too young. This seems to be a means of protecting them from information they are not yet ready for. They filter and censor the explanations they give, again based on age and on their evaluation of the child's emotional readiness and maturity.

The type of communication that caregivers subsequently use with children is, unsurprisingly, shaped by the meaning they have made about PMHP for themselves. This communication is both verbal and nonverbal, depending on the situation and the caregiver. The theme of protection links in because the communication between child and caregiver is shaped by their desire to protect the child.

Communicating through action - often inadvertently

The caregivers' desire to protect children is often actively communicated via their actions. Caregivers who feel that children have been exposed to things they shouldn't see, and who express concern about this, are also those who talk about physically removing the child from the PMHP context, or trying to remove the parent (whether that is moving to another room, reducing contact or fighting for custody). They may also be responding to the parent by caring for them. When this is ongoing, caregivers are largely responding with action rather than words, or with words to the parent rather than the child. Children might witness these events sometimes, although it is not always clear if they do from caregivers' descriptions - they are often more focused with asserting responsibility for protecting the child than considering what the child has noticed. It might also be that I've not asked, and they don't want to say if the child was present - this might be seen as them not protecting the child. This could addressed in future interviews. Children learn about PMHP (and the caregiver's interpretation of it) through observing the caregiver's responses, actions and emotional tone - this is a form of role modelling and is often inadvertent. Caregivers sometimes realise the child has picked up on things when they observe them doing them later (e.g. comforting the parent using copied phrases, or displaying caregiving behaviour to sibs).

Communicating with words

The caregiver's desire to protect children is often evident in the ways they choose to talk to children, when they talk, and how they create time and space for this to happen. I currently have a lot of thoughts about the how, why and when caregivers engage in talk with children, and what influences the way this happens.

Even when language/explanation choices are not necessarily conscious, they do seem linked to protecting the children. Caregiver choices to talk or not talk (and possibly 'show' even if they did not mean to) tend to be for the purpose of enhancing the child's wellbeing. If a child asks a question about something the parent has said or done (or not done) and the caregiver doesn't really want to answer so holds back in some way, they are not doing this because they can't be bothered to explain. They do it because they think the child isn't ready, or will be overwhelmed. If they give more information, they usually feel it will benefit the child to know, and they want to develop their resilience or teach them about 'how it could be done better' (and in so doing, help shape the child's relationship to health and illness, help increase attachment to the 'better' caregiver, or assist with focusing on education as a means to 'escape' the clutches of mental illness).

So... perhaps sometimes they are protecting themselves... Or protecting the parent, or the parent-child relationship, or their own status/relationship with the child.

<u>The desire to protect.</u>

Widening this out means it is more able to contribute meaning to caregivers' use of externalisation, which is less to protect the child and more to protect the parent, by separating them from the behaviour and MH symptoms. This also speaks to the codes that relate to supporting the parent-child relationship by retaining 'space' for the parent to step back in to when they can, not 'replacing' the parent (although associated with role confusion at times), and inviting the parent into parenting/PMHP conversations. These things all help nurture the parent-child relationship, and both individuals within it.

It also gives meaning to the processes around caregivers coming to understand themselves within the role and how they can become fixed in their views of what they 'have to do'. Protecting the children by taking action, protecting the sense of self within the caregiver role by acting on serious concerns (rather than turning a blind eye or living to regret it), protecting hope that things will get better, the future will be brighter, and if they just keep going now then it will all be worth it. So this preserves the ability to plug away at everyday life and keep a positive outlook (feeling lucky; holding on to hope; laughing together; joking during interviews; recognising recovery in the parent; praising and appreciating the child's qualities). Perhaps in interviews, protecting the self by following up firm statements with uncertain ones - guarding against me having a different view.

Appendix W. Table of Pseudonyms of Participants and their Family Members

Participant(s)	Participant's relationship to child(ren)	Relatives and relationships to participant
Alice	Sister	n/a - no relatives named in quotations
Allen & Judy	Grandparents	n/a - no relatives named in quotations
Connor	Father	**Bethanie** - Daughter
Darcy	Mother	**Sebastian** - Son **Derek** – Husband; dad with MHP
Emilia	Mother/Stepmother	**Elias** – Emilia & Jackson's son **Joshua** – Jackson's son/Emilia's stepson **Jackson** – Partner; dad with MHP
George	Father	n/a - no relatives named in quotations
Jon	Father /Stepfather	**Carla** – Partner; mum with MHP **Millie** – Carla's daughter
Kimberley	Mother	n/a - no relatives named in quotations
Liz	Grandmother	n/a - no relatives named in quotations
Lorraine	Grandmother	**Amber** - Grandaughter
Lucinda	Aunt	n/a - no relatives named in quotations
Marcus	Father	n/a - no relatives named in quotations
Marilyn	Grandmother	**Alanna** - Grandaughter **Vikki** – Daughter; mum with MHP
Pete	Father	n/a - no relatives named in quotations
Rosie	Grandmother	**Ella** – Daughter; sister of mum with MHP.
Sally	Mother	**Shane** – Husband
Steve	Father	**Lily-May** - Daughter
Tash	Mother	**Cami/Camille** – Elder daughter **Katerina** – Younger daughter **Javi** – Partner; dad with MHP

Section 5: Quality Assessment

Appendix X. Quality Assessment of Present Study

As noted in 2.2.2 of the Method, the quality assessment criteria provided by Tracey (2010) and Hutchinson, Johnston, & Breckon (2012) were applied to this study throughout the research process, and the writing of this report. The criteria are detailed in the left hand column, and evidence of how each one was met is provided in the right hand column. The COREQ checklist is provided with notes on where (and, where relevant, how) this study met each requirement.

Tracey's (2010) 'big-tent' criteria	Evidence of criteria being met
Worthy topic - Relevant, timely, significant, interesting. - Context is integrated into design (e.g. consultants; research responds to recent event) - May challenge assumptions or have element of surprise ("that's interesting" not "that's obvious".	- The literature review revealed that there was indeed a considerable gap in this area, making the project both relevant and timely. The recent paper by Ballal and Navaneetham (2018) evidences that other groups are currently interested in this topic too. - Several papers in the review indicated that there is clinical relevance to exploring this topic area further.
Rich rigour - Uses sufficient, appropriate and complex constructs, time in field, sample, context, data collection and analysis procedures. - Abundant descriptions and enough data. - Often evident in method section and through consistency of analysis.	- A period of 14 months was available in the field, which was deemed a good amount of time for collecting data. Although there were challenges to recruitment, having time to complete 18 interviews allowed for a sample with theoretical sufficiency. - While there were limits to the sample, it had a number of homogenous characteristics that broaden the relevance of the findings to the UK population. Further research is recommended to address the sample limitations. There were examples of individuals in the sample providing 'negative' evidence, and thus contradicting the model to make it more comprehensive and meaningful. - The GT method was applied rigorously and with attention to detail about its epistemological underpinnings, which are drawn out throughout the write-up. The analysis is evidenced thoroughly using examples in the appendices where possible. - I hope it is evident that the coding and memoing processes were applied consistently, from the richness of the

	method and results. - Care was taken to explain and evidence the points made in the Results, using as many illustrative quotes as word count would allow. At times, I would have like to use more, but this is a limitation of presenting a detailed theory.
Sincerity - Self-reflexivity about researcher biases, assumptions, values and inclinations. - Transparency about methods, challenges and shortcomings of the research. - Describes data collection and analysis procedures, and transcription.	- I have attempted to be as clear as possible through the report about my philosophical stance to the research and how this impacted various choices, including language. - I have also been transparent about my personal position to the topic, and included evidence about how I was affected and coped with the interview topic and personal aspects of meeting caregivers through the method and research diary extracts. I have attempted to show how and where I used supervision and reflection to address any potential bias, but also to show my unavoidable human-ness and emotionality, which I think are also a benefit in a topic area like this. I have used my own voice through first person narrative throughout the report to be as sincere and direct as possible. - The identified limitations and strengths have been discussed in the report, and I have tried to illuminate its weaknesses. - The data collection, analysis and transcription procedures were described in detail, and transcripts and coding examples have been provided to evidence the process and reported results.
Credibility - Thick description, concrete detail, and explication of non-textual knowledge. - Shows the reader, doesn't just tell. Plausible and trustworthy. - Triangulation or crystallisation techniques used, leading to multiple lenses, researchers, data types or methods contributing. - Multi-vocacity (multiple voices) and member reflections or checks for validation.	- Details and rationales for choices throughout the research process have been described within the report, and backed up where relevant with references. Figures have been labelled with detail to attempt to describe what they show. - That the results section is the most lengthy evidences my attempts to show the reader the data, not just tell them about it in the Discussion. I hope that it makes sense and has good readability, even thought it is a complex model to discuss and has many linkages.

	- Triangulation via secondary coding with multiple researchers was used to strengthen the credibility of the coding and analytic concepts. Theoretical sampling also allowed findings to be triangulated within the target participant group, bringing different lenses and multivocacity to the findings and making them more nuanced. - Checking the theory itself with two participants was evidence of the credibility of the findings, and that they found them personally meaningful and relevant.
Resonance The research impacts or moves the audience via: - Aesthetic, evocative representation: reader can make links and connections. - Naturalistic generalisations: readers have intuitive understanding of the findings. - Transferable findings: impact goes beyond researchers and research team.	- My understanding from talking to participants, supervisors, clinicians, my proof-readers and colleagues is that the findings make sense, are resonant and relevant beyond just my immediate research team. - I believe the clinical implications provide further evidence of this.
Significant contribution - May be given conceptually/theoretically, practically, morally, methodologically or heuristically. - Existing knowledge is extended or transformed.	- This study's objectives build on existing knowledge but moved into new territory, so I believe that existing knowledge has been both extended and transformed, especially in theoretical and practical ways. The details of the theory created here are not currently reported anywhere else in the literature to my knowledge. - A test of the significance of the contribution will be in my future dissemination and publication of this work, and its reception of that paper(s).
Ethics - Procedural ethics: human subjects treated ethically; accuracy; anti-fraud measures; confidentiality maintained. - Situational ethics (e.g. in interviews) and culturally-specific ethics (e.g. respectful) - Relational ethics: aware of impact on participants and treat them as people not subjects. - Exiting ethics: disseminations, study closure, avoiding issues for participants.	- Efforts were made throughout the process to treat caregivers and their families with utmost respect and to high ethical standards. This has been detailed in the report as much as possible. - The emotional nature of many interviews meant that relational ethics were highly relevant, and I feel my interpersonal skills and clinical style were helpful for this. - Dissemination to participants, organisations, groups and the wider academic and clinical worlds are planned via publication and talks. No known issues have arisen for participants so far due to

	their participation. All efforts towards anonymity will be maintained going forward.
Meaningful coherence The study: - Achieves what it purports to do/be about - Uses appropriate methods for its goals. - Meaningfully interconnects literature and the research questions with findings and interpretations. - The report flows and makes sense.	- I hope that this report has flowed and been thought provoking to read, and that it makes sense. I also hope that it has brought new insights as well as building on previously known information. - Summaries and signposting have been used throughout the report to improve its readability and help the reader gain as much meaning as possible from it. - Pictorial figures have been created to further elucidate the results as much as possible for the reader, and bring together the connections between the categories in a simpler way than the text can.

Hutchison Johnston & Breckon's (2018) Criteria for Grounded Theory	**Evidence of criteria being met**
Was grounded theory an appropriate methodology for this research? - Was a justification presented for adopting a grounded theory approach? If so what was it? - How was grounded theory defined? (e.g., as a research methodology or simply a data analysis tool?)	- Use of GT was justified in accordance with the epistemological stance to the research, with consideration of different GT approaches and why this one was chosen. - The justification was to do with enabling analysis of process, development of substantive theory, and collection of qualitative data for meeting the objectives. - It was intended for use as a full methodology.
Was sampling conducted in accordance with the tenets of grounded theory? - What evidence is there to suggest that sampling was conducted to facilitate theory generation? - How was the initial sample selected? On what grounds? - Did theoretical formulations guide some of the data collection, if so how? - Based on the answers to the above two questions did theoretical sampling occur? - Is there evidence of concurrent	- The sampling methods are detailed, including initial purposive sampling, snowballing and opportunity sampling, and later theoretical sampling. The grounds for a heterogeneous sample are given: implementation of GT method in addition to knowledge of the sampled population from the literature base. - Concurrent use of data collection and analysis are described in the method, with evidence in the adaptation of the interview schedule in accordance with refinement of analytic ideas, and model checking with two

involvement in data collection and analysis?	participants.
How were the initial concepts and categories developed? - What initial concepts and categories were presented? - What evidence is there to suggest that these concepts or categories were generated from the data itself and not from pre-conceived logically deduced hypotheses? - Do the initial categories cover a wide range of empirical observations, was the initial focus broad	- Development of initial concept and categories, how these were developed from focused codes and tested against the data is evidenced in the description of the method and the provision of relevant appendices showing work on NVivo and coding extracts. - The initial focus was broad, using line-by-line coding, which is provided as an appendix for evidence. The development of tighter analytical categories is evidenced in the memos provided.
How did theoretical development continue after the initial concept identification? - How did theory development advance during each step of data collection and analysis? - What major categories were presented? - What techniques were used to construct or develop these categories (e.g., axial or focused coding, systematic comparisons, questioning)? - What evidence is there to suggest that the constant comparison method was used? That is, were systematic comparisons made between observations and between categories? - What techniques were used to construct or develop these categories (coding, memo writing, comparisons, questioning, use of attributes, etc.)? - Are the categories theoretically dense? Are there clear links between individual categories and subcategories as well as between individual categories and the larger core category? Have the dimensions of categories and subcategories been explored?	- As above, theory development is evidenced through a set of pictures of earlier models, coding examples and memos. - Three final major categories are presented, each with two subcategories and one main social process that has been evidenced in the Results as relating to all categories. - Focused coding was used, with constant comparisons and asking questions of the analysis and data – examples of these questions and the authors who provided them are given in the main report. - The categories are all theoretically dense as evidenced by the multiple concepts, including contrasting cases, provided in the Results. - Links between the categories are pictorially shown in figures to help the reader understand the linkages. All subcategories and their component Strategies and Orientations have been described in detail with the use of quotations.

What was the end product of this research and how was it finally constructed? - How and why was the core category selected? On what grounds were the final analytical decisions made? - What evidence is there to suggest that the study achieved theoretical saturation? - What conclusions were drawn? - What evidence is there to suggest that the results offer new insight into the studied phenomenon?	- The final analytical decisions were made following discussion with further participants about the relevance of the core category and also with supervision. Exploration of the pertinence of the core category can be seen in the diagrams provided in the appendices. - Theoretical saturation, or sufficiency, was indicated at a number of stages through the analysis, with the analysis not moving to next stage until the previous stage was properly completed. The sample size of 19 is not so low as to be of concern about the claims to theoretical sufficiency. - The conclusions speak to the theoretical and clinical relevance of caregivers ‘providing protection in uncertainty’, with suggestions made specific to the UK context but with broader applicability, and consideration of their limitations. - These findings are discussed in relation to existing literature to show where they replicate and where they build on the topic.

No.	**Item**	**Guide questions /description**	**Where/how criteria is evidenced**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
2.	Credentials	What were the researcher's credentials?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
3.	Occupation	What was their occupation at the time of the study?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
4.	Gender	Was the researcher male or female?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
5.	Experience and training	What experience or training did the researcher have?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Relationships with gatekeepers and participants discussed through Section 2.3.

7.	Participant knowledge of the interviewer	What did the participants know about the researcher?	Discussed in Interview guide and style - section 2.5.1.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator?	Researcher positioning, characteristics and reflexivity provided in sections 1.1. and 2.5.
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study?	Grounded Theory. Discussed in section 2.1, including comparison with other methods and rationale for selection.
Participant selection			
10.	Sampling	How were participants selected?	Described in section 2.3.2.
11.	Method of approach	How were participants approached?	Described in section 2.3.1, 2.3.2 and 2.3.3. Challenges to recruitment discussed in 2.3.5.
12.	Sample size	How many participants were in the study?	Sample summarised in detail in 2.3.4.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Discussed in 2.3.5 along with recruitment challenges. Numbers of people who declined or dropped out are provided, along with reasons where known.
Setting			
14.	Setting of data collection	Where was the data collected?	See 2.5.2 for description.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	No. Description of individual interviews in 2.2.3 and 2.5.2.
16.	Description of sample	What are the important sample characteristics?	Sample summarised in detail in 2.3.4.
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes to both questions. Interview style described in 2.5.1. Pilot interview described in 2.2.1.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No. Developing theory discussed with subsequent participants. See section 2.5.1.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio – decribed and discussed in sections 2.4.3, 2.4.5 and 2.5.2.
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes, through reflective diary and memoing. Described in 2.6.1 and in the description of the coding processes. Appendices provided of reflective diary and memos.

21.	Duration	What was the duration of the interviews or focus group?	48 – 92 minutes. Described in section 2.5.2.
22.	Data saturation	Was data saturation discussed?	Yes – see section 2.3.2.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, as per methodology. Transcription was full verbatim and transcripts were reread multiple times enabling accuracy.
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Primary researcher, with 3 researchers secondary coding sample sections. Described in section 2.6.3.
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Description of coding process given in sections 2.6.3 – 2.6.5. Final focused coding framework (i.e. 'tree') can be see in Figure 3 (section 3.1). Examples provided in Appendices P to T.
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Derived from data. Described in sections 2.1.2. and 2.6.
27.	Software	What software, if applicable, was used to manage the data?	NVivo v.11. Described in section 2.6.2. Details provided in Appendix P.
28.	Participant checking	Did participants provide feedback on the findings?	Developing theory discussed with subsequent participants. See section 2.5.1.
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?	Yes – evidenced throughout Results (Chapter 3). Pseudonyms used.
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes – see chapters 3 and 4. Evidenced throughout discussion.
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes – see figures 2 and 3 and textual description in section 3.1.
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes – throughout Results (Chapter 3).