Portfolio Volume 1: Major Research Project

Children's conversations with their friends about living with a parent experiencing mental distress: An IPA Study

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July 2017

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

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Acknowledgements

First and foremost, I would like to thank all the families who allowed me into their lives and agreed to be a part of this study. I would particularly like to thank all of the young people who took the time to speak to me about their experiences. This project would not have been possible without their generosity. I hope that those that took part were able to gain something from talking about their experiences, and that this research will inform others and help to make a difference to other young people's lives who live with parent's that experience distress.

I would also like to thank my research supervisor, Dr Lizette Nolte. She has not only provided me with invaluable advice and support, but also put so much time and effort into the project. Whenever I was struggling, she always managed to reignite my passion with her genuine thoughtfulness and enthusiasm.

I would also like to thank my field supervisor, Dr Nick Barnes, who dedicated a lot of time in helping me plan the project and putting me in touch with a number of organisations. These provided an insight into the challenges that both families and services faced and helped with recruitment. There were many professionals from several different organisations that were invaluable, including Julia Overton, Ashleigh Serevena and Tina Mclean.

I would like to thank the support of those around me, including the wonderful Cohort 14, who were always willing to offer help and support. I would especially like to thank Annabel Head for her endless support at getting me through the NHS ethics process; James Randall-James for putting me in touch with other avenues of recruitment; Amy Lyons for her help guiding me through the analysis process; and Elizabeth Malpass for working with me until the end.

Finally, I would like to thank the support of my family and friends for their patience, endless support and encouragement through the last three years. I would like to thank my parents for providing me with inspiration and a desire to make a difference (as well as some wonderful proofreading assistance); and my partner Sam who has made me laugh when things were hard, stood by my side and always offered valuable advice and support.

Contents

Abstract

Background and Aims

Estimates suggest more than three million children and young people (CYP) live with a parent experiencing mental distress (PEMD). It is suggested that CYP are often left to make sense of the uncertain nature of mental distress on their own. Furthermore, the existence of stigma can silence CYP and their families, as they try and hide from the view of others. CYP have voiced their desire for support. However, there are few services available to them in the UK, despite developments in policy highlighting the need for support. As CYP grow up, greater emphasis gets placed on relationships with friends. Therefore, CYP's peer group may provide a valuable source of support. This research aims to explore how CYP living with a PEMD gaining support from their friends.

Methodology

This research used a qualitative design to explore CYP's lived experiences. A purposive sample of six CYP who were living with a PEMD were recruited. CYP were invited to take part in semi-structured interviews, which were then transcribed.

Analysis and Findings

The interviews were analysed using Interpretative Phenomenological Analysis (IPA). The analysis revealed three superordinate themes: 'Fitting the puzzle together', 'Finding the experience of talking risky', and 'Coping with the up and down rollercoaster'.

The findings support research recognising the importance of understanding mental distress, but CYP's accounts in this study provide further insight into the intricacies of what is meant by understanding. Furthermore, the research brings to light the challenges that CYP face when trying to build trusting relationships, in order to confide in their friends about their parent's experience of mental distress. Clinical implications, including recommendations for possible interventions are discussed and suggestions for future research are made.

Chapter 1: Introduction

1.1 Overview

The current study uses a qualitative design to explore children and young people's (CYP) conversations with their friends about their parents' experience of mental distress. This chapter aims to introduce the reader to the epistemological position and background of the researcher, and familiarise the reader to the use of language in this project.

The current context of this study is then considered, to illustrate the importance of conducting research in this area. By doing so, research highlighting the current risks to this group of CYP, in addition to factors that promote resilience is examined. A critique of this view is introduced, which considers CYP as active agents in their lives, highlighting the need to focus research on how they make sense of their experience. Whilst considering how having a PEMD may change the CYP's lives, developmental and systemic theory are considered, in addition to the literature around adolescent relationships and stigma. Current research exploring both parent's and CYP's experiences is presented, which highlights the importance of peer relationships as a source of support. The interaction between both parents and their children is examined, using a systemic model, which highlights the relational patterns that may impact on both parties. Current research into possible interventions is explored, further highlighting how other children and young people can be a valuable support.

A systematic review will be presented in the next chapter to examine the current research about CYP's experience of talking to their friends about their parents' experience of mental distress. Therefore, the conclusions that inform the rationale and research questions will be presented there.

1.2 Language Use

This thesis will predominantly be written in the third person. However, in line with the researcher's epistemological position and belief that the CYP's reported experiences are co-constructed through their conversation with the researcher, the first person will be employed when the researcher wishes to convey their personal experiences or reflections (e.g. when describing the personal significance of the research, reflections on the recruitment process and

final reflections in the discussion). This will help to demonstrate the process of reflexivity and personal contributions of the researcher.

This project is interested in the experiences of CYP who live with a PEMD. Some of these CYP may be defined or define themselves as "young carers"; however, this term has come under criticism for devaluing the nature of the caring relationship and possibly implying burden (Molyneaux, Butchard, Simpson & Murray, 2011). Furthermore, the caring responsibilities of these CYP vary, depending on the socio-cultural environment in which they live. Therefore, this project employs the term children and young people (CYP).

There are many terms and definitions used to describe mental health conditions and individuals have different preferences for the language to describe such difficulties, including the use of diagnostic terms (Hayne, 2003). However, in a poll looking at service users' preferred terms, the National Service User Network (NSUN, 2015) found that the term "person with direct or lived experience of mental distress" was the most popular. In addition, this moves away from the constructs of "mental illness" which is associated with medical discourses and positions us to focus on the individual and treatment (Nolte, 2013). While these terms are in line with the researcher's preferred stance, all use of language in this field brings some aspects into view, while moving others to the periphery. Therefore, it is worth considering the potential implications of these choices. For example, it is worth noting that the use of this term 'mental distress' may imply that a PEMD may always be in a state of distress. However, there may be times when people experience mental health problems may not perceive themselves as distressed and therefore this term could be misleading. Furthermore, given that conventionally the term distress refers to an emotional experience of upset, it might be that this moves the focus away from other experiences related to parents' mental health concerns, e.g. parent's behaviour, other emotional experiences, etc., aspects that young people in this study might also find challenging. However, as this was the preferred term within the survey, the term "parent experiencing mental distress" is used within this project, which will be abbreviated to 'PEMD'. This term covers those that define themselves as having experienced "mental distress" and having received input from services to help them manage this distress. Therefore, it is used to cover a spectrum of experiences. For the purposes of this study, it is used to describe parents experiencing severe and enduring mental distress.

1.3 Position of the Researcher

1.3.1 Personal significance.

Finlay & Gough (2003) discuss how the subjectivity in research can be transformed into an opportunity through the process of reflexivity. This process of reflexivity can enable the researcher to critically appraise their own context and its impact on each aspect of the research process (Gough, 2003). Therefore, it is important to outline my own position in relation to this research and the reasons for which I was drawn to investigate this topic[1].

I define myself as a White British female from a middle-class background. I grew up with two working parents, one of whom experienced a physical health problem. At times, I felt aware of the stress my family was experiencing and this led me to feel protective towards my parents. I wonder whether these experiences indirectly impacted on my decision to explore this area. Despite my mother's concerns about how her health impacted on me, I feel her recognition of her emotional reactions and the encouragement she gave me to explore my feelings, helped me to develop skills in empathy and led me to view talking about my feelings as important. My relationships with my peers also performed a supportive function.

Whilst working with parents, I have noticed the comparisons they make which often led them to feel like they weren't "doing a good enough job". My view is that living with a family member experiencing mental distress provides another context to navigate, which can have both beneficial and more difficult consequences. However, at times I have wondered whether the more negative consequences originate from the position society puts these families into. Therefore, I have an interest in the role of stigma, the expectations families put on themselves and the supportive function that family members and friends can provide for each other. Furthermore, working with adolescents in an inpatient setting often led me to hear CYP ask, "what am I going to tell my friends" in fear of being subject to ridicule. Therefore, I wonder whether CYP struggle to share any personal experience of mental distress with others.

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[1] First person is employed here to provide an insight into the researcher's reflections & experiences

1.3.2 Epistemological position.

Post-modern approaches have given particular consideration to assumptions about knowledge (Gergen, 2001). Our understanding of what constitutes reality (ontology) and the meaning of knowledge (epistemology) is key to how we position ourselves in relation to research (Darlaston Jones, 2007). Willig (2001) highlights the necessity of outlining the objectives of our research and consider how this contributes to our understanding, thus emphasising the importance of specifying the epistemological assumptions of the researcher. There are many ways in which authors describe theoretical typologies (Harper, 2011). Lincoln, Lynham & Guba (2011) describe five paradigms including positivist, post-positivist, critical theory, constructivism & participatory/co-operative. These positions are seen to be informed by the epistemological, ontological and methodological approach of the researcher; the aims of the research; the consideration given to quality criteria; and the values, voice and training of the researcher.

In considering my own position[2], I reflect on my journey through training. This has taken me from a position of viewing reality and truth as something that is achievable, leading me to have a need for certainty. This was partly shaped by the positivist leanings of my undergraduate degree. However, in training to be a clinical psychologist, I have begun to question the existence of one reality. Class discussions, reflecting upon my own values and beliefs and my clinical experience have contributed to this shift. Whilst, providing therapeutic input to a complex case load, I have struggled to apply theory in a rigid way, and have learnt the importance of flexibility whilst considering the individual in front of me. Furthermore, the ideas of community psychology (e.g. Orford, 2008) and narrative approaches (see White & Epston, 1990) have been hugely influential in helping me to recognise the importance of context around the client, and the role of language in constructing knowledge.

Considering Lincoln et al's (2011) paradigms, I feel drawn to critical theory, which postulates that reality is shaped over time by social, political, economic and cultural factors, which then develops into a perceived reality. This seems comparable to Speed's (1991) idea of co-constructivism which describes a position in which a reality exists, but is constructed by the

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[2] The first person is employed here to provide an insight into the researcher's reflections and experiences.

ideas that people have about it based on what they experience. This approach postulates that we can advance our knowledge, but denies the existence of a single 'truth'. Therefore, within this research, I aim to advance our knowledge of how CYP living with a PEMD ascribe meaning to the interactions they have with their peer group. I believe that different elements of the CYP's lives will be highlighted through the questions that are asked and the language that is used, therefore the stories that are heard are a co-creation between the researchers and the CYP being interviewed. It is important to take a reflexive position and acknowledge my position as a researcher.

1.4 The Context of Research and Policy

The epistemological position described above acknowledges the importance of the context in which families live. Therefore, it is important to consider the historical and current political climate which has shaped the direction of this research.

Key policy developments within the 20th century led to greater recognition of children's rights and emphasised the protection of children. For example, The UN Convention on the Rights of the Child and subsequent publication of the Children's Act (1989) recognised the importance of a child's safety and acknowledged their right to express their views on decisions that affect them. The increased recognition of their needs and acknowledgement of children as individuals led to an increased interest from social researchers, who placed a greater emphasis on CYP's involvement in research (Balen et al.2006). However, research into CYP's experiences of living with a PEMD were largely ignored until the 21st Century (Mordoch & Hall, 2002).

The needs of children were given further priority, following high profile cases in which children were harmed at the hand of their carers (e.g. the case of Victoria Climbié reported on in the Laming report (House of Commons Health Committee, 2003). For example, a green paper "Every Child Matters" (2003) was published, which highlighted the failings of services working together to ensure the protection of children and outlined a new framework for service integration. This paper, along with the Care Act (2014) also acknowledged the existence of CYP who provided care for their parents and the impact that this may have had on them. These shifts resulted in more awareness of CYP who cared for a PEMD and made them more visible to services. Research has also highlighted the need for family-focused approaches leading to several initiatives and interventions designed to provide support for these families.

There has also been a shift in the conceptualisation and focus of research into parent's experience of mental distress. Medical research, dominating the mid 20th century, viewed mental distress in terms of physical illness and disability and focused on the negative consequences of 'mental illness' and the deficits in parenting skills (Aldridge & Becker, 1999). However, there was a shift towards a social understanding in the 1980s, which recognised the impact of environmental factors such as social support and appropriate resources and focused on the need to design interventions to support individuals and families (Aldridge & Becker, 1999). Much of the current literature still outlines the possible risks to CYP who live with a PEMD. However, the shift towards a social understanding, a move to increase CYP's involvement in research and an increasing awareness of the importance of involving CYP in their parents' care, has led to a focus on research examining CYP's views and experiences.

Despite the existence of these initiatives and interventions these families still face many barriers to seeking support and the result of this can be that many go unseen by services and members of the community (Loshak, 2013). Reasons for this include families trying to conceal their difficulties from others through fear of ridicule, a concern that children would be put in care and by services still not being configured in a way that promotes partnership working and recognition of family approaches (Loshak, 2013).

1.5 Prevalence, Risk and Resilience

1.5.1. Prevalence.

Documenting the prevalence of CYP living with PEMD can be difficult because families often do not disclose their situation for the reasons stated above. However, initial estimates suggest about three million CYP live with a parent with a mental health problem, physical illness or disability (Aldridge & Becker, 2003) and it has been suggested that around a third of these live with a PEMD (Cooklin, 2010). However, the basis of these estimates comes from studies carried out at the turn of the century and current estimates remain unknown.

1.5.2 Risk.

As discussed earlier, much of the earlier research into CYP living with a PEMD painted a negative picture of 'mental illness' (Aldridge & Becker, 2003). It has been suggested that the negative findings were partly due to methodological weaknesses (e.g. conclusions were drawn from second hand evidence) and research was heavily influenced by biological determinism,

which minimised the impact of social factors (Aldridge and Becker, 2003). Following the move towards a social understanding of mental distress, studies started to incorporate the effect of social context. For example, Rutter & Quinton (1984) demonstrated that two thirds of CYP of PEMD showed transient or persistent problems in childhood. However, they noted that these families were prone to several family stressors and psychosocial risk factors (e.g. single parenthood, parental separation & divorce, marital discord, social care involvement). Therefore, the authors concluded that psychosocial disadvantage accounted for the differences in psychological functioning.

Studies examining the risk to these children have highlighted the increased possibility of attachment difficulties and emotional and behavioural difficulties (Hall, 2004). In addition, when compared to their peers CYP living with a PEMD are more likely to have low self-esteem, struggle socially and have poor cognitive skills (Gladstone, Boydell, Seeman & McKeever, 2011). However, this focus on risk has failed to recognise the complexities of these CYP's lives (Bromley, Hadleigh & Roe, 2013). The difficulties that CYP face when living with a PEMD are often not a direct result of challenges of mental distress itself, but rather an interactional framework of risk factors during development (Hall, 2004). Biological vulnerabilities and contextual factors mediate this relationship. For example, the developmental stage of the child, the family context, and the burden associated with the stigma of mental health have been found to influence how CYP are impacted by their PEMD (Mordoch & Hall, 2002). The level of additional caring responsibilities that some CYP undertake has also been found to influence the wellbeing of the child (Cooklin, 2010). Furthermore, a lack of recognition of their caring role, and lack of support has been thought to have a negative impact on the CYP (Cooklin, 2013). Aldridge (2006) has highlighted the need to recognise CYP's contributions and emphasised the need to provide them with support.

Seeman & Göpfert (2004), drawing on a medical conceptualisation of psychological distress, explored the relationship between 'symptomology' and parenting ability and they found that certain 'symptoms' influence parenting more than others. For example, they considered how fluctuations in a person's mood and unpredictable behaviour may challenge the parent's ability to provide consistent care and this lack of consistency could put the child at risk. However, they also recognised the importance of context on parenting abilities. For example, hospitalizations could lead to separations and impact on the child's attachment. Furthermore, the stigma associated with mental health could result in the family's isolation and this may

change the opportunities children have to learn through social interaction. From a parent's perspective, the pressure of living up to the parenting role; the impact of stigma associated with mental distress on other's reactions; and the parent's own guilt can impact on the parent's ability to manage their mental distress (Nicholson, Sweeny & Geller, 1998).

1.5.3 Resilience.

However, despite this emphasis on risk, it has been recognised that not all CYP living with a PEMD are adversely affected (Mordoch & Hall, 2002). Children that are not seen to be affected are often viewed as resilient (Gladstone, Boydell & McKeever, 2006). Suggestions of factors that promote resilience include having their role recognised; being provided with information and support to gain an understanding of their parent's difficulties (Cooklin, 2010); and having social support from family, friends and professionals (Drost, van der Krieke, Sytema & Schippers, 2015). The chance to get away and focus on individual needs has also been found to be protective (Drost et al, 2015; Mordoch & Hall, 2008). Gladstone et al (2006) highlight the danger of focusing research on the risk to CYP and positioning those that cope as being resilient because this assumes they have no active contribution to their development. The authors postulate that children should be seen as competent social agents and they suggest research should be expanded to look at the contributions they make to their families and other social structures.

1.6 Theories of child development

CYP living with a PEMD do so in the context of their development. There has been some research that has suggested the developmental stage of a child influences their ability to manage living with a PEMD (Hall, 2004). In addition, some research suggests that CYP's understanding of mental distress has also been found to become more comprehensive with age (Wahl, 2002). Developmental theory can provide us with a framework to understand children's cognitive and social development. Although this perspective has received some criticism (e.g. Berk, 2008; Gladstone et al, 2006) it is important to consider how these theories can contribute to our understanding of how CYP make sense of and respond to their PEMD. Theories of development include Erickson's (1950) theory of psychosocial development; Piaget's cognitive-developmental theory (1971); Vygotsky's sociocultural theory (1978); and Bronfenbrenner's ecological systems theory (1979). For the purposes of this study, only those most relevant to the current research question will be discussed here.

Vygotsky's (1978) socio-cultural theory of development views learning as a social process and therefore acknowledges the culture of the person. The model proposes that cognitive development occurs in two stages. Firstly, learning occurs through social interaction and secondly, new knowledge is internalised into the individual's mental representations. Vygotsky's theory postulates that children can achieve more with guidance and have a 'zone of proximal development'. This 'zone' refers to an area that the child is cognitively developed, but requires social interaction to fully reach their learning potential. Parents, teachers and peers can 'scaffold' the learner to support the student's understanding. As the child starts to achieve more on their own the scaffolder can leave more for the child, until they can perform the task on their own. This theory emphasises the importance of language and conversations on the child's ability to learn and make sense of phenomena. Therefore, children's cognitive development may be hindered if their parents cannot provide this scaffolding. However, if CYP have other people with expertise, including other CYP, they may continue to develop appropriate skills. Furthermore, living with a PEMD and having open conversations about this experience may help CYP develop their understanding of mental distress. Professional support, conversations with their peers and media representations of mental health may also contribute to a child's learning (Wahl, 2002). Conversely, if the media portrays mental health in a negative light, CYP may only develop a partial understanding of what mental distress is and what causes this.

The impact of the CYP's context as a mediator in their ability to cope when living with a PEMD has been discussed. Therefore, ecological systems theory will be considered (Bronfenbrenner, 1979). The model outlines the reciprocal interactions between four contexts surrounding the CYP. These include the immediate context of the child (micro-level; e.g. family and peer groups); the relationships between members of the micro-systems (meso-system; e.g. the relationship between the parents & health services); systems that the individual has no direct contact with, but that interact with the micro-systems (exo-level; e.g. adult mental health services); and wider cultural systems in which the person lives (macro-level; e.g. cultural beliefs, societal norms etc.). This theory acknowledges the existence of the individual characteristics of the child (e.g. temperament, attachment style) and how this relates to the systems around the child. In addition, it recognises how the socio-political context can impact on the relationships between each layer of the system. This shift has led to more research and consideration of CYP's individual needs, which in turn has helped to design interventions to support the family.

1.7 Stigma & Blame

The impact that stigma has on both parents and family members that live with someone experiencing emotional distress, has been highlighted. Hinshaw (2004) provides a narrative account of his experience of growing up with a father who experienced mental distress. He acknowledges the silence and stigmatisation that surrounds mental distress and highlights attitudes towards those experiencing distress remain prejudiced. He also recognises the negative portrayal of people experiencing mental distress in the media, which results in many avoiding treatment. Furthermore, Corrigan & Miller (2004) highlight the way in which this stigma injures others associated with the person experiencing mental distress. They introduce the concept of "family stigma" which they define as "the prejudice and discrimination experienced by people because of their relationship…it is not a monolithic phenomenon' (p538). They raise several issues surrounding family stigma, including the discriminatory impact within social groups leading to the loss of friendships and a loss of relationships within faith communities. Furthermore, they report on findings that family members often view mental distress as something that should be kept secret and note that this can result in feelings of shame. This shame arises from ideas of blame and contamination. Reupert & Mayberry (2007) acknowledge that the way in which mental distress is constructed within society needs addressing to encourage understanding, respect and inclusion.

Many CYP have reported an awareness of stigma when discussing their experiences of living with a PEMD and described feeling unable to bring friends home (Fjone, Ytturhus & Almvik, 2009) or share their experience with others through fear of being bullied or rumours being spread (Alasuutari & Järvi, 2012; Baik & Bowers, 2005). This fear could result in them feeling reluctant to seek support from others outside the family, further instilling feelings of isolation.

1.8 The Developing Importance of Peer Relationships

The development of peer relationships has been seen as one of the most important processes for CYP (Brown & Larson, 2009). Belonging to a peer group that is perceived to be 'normal' and forming supportive relationships with others is associated with forming positive identities (Ragelienè, 2016). As CYP get older they tend to spend an increasing amount of time with their friends, develop social competencies such as making disclosures, and tend to place a growing emphasis on developing trust and intimacy (Steinberg & Morris, 2001). The experience of bullying or victimisation is seen to impact on the development of CYP's self-concept and may

lead to other difficulties, but having a close friendship is seen to be a protective factor (Steinberg & Morris, 2001).

Early research examining CYP's conversations with their peers highlights the increasing importance of adolescent relationships in providing emotional support. For example, the level to which CYP disclose intimate information to their peers increases, whereas the disclosures they make to adults decreases (Buhrmester & Furman, 1987). The research examining the topics of conversations is sparse, however some research has suggested that as CYP enter adolescence, age and gender related concerns are more freely discussed within their peer groups e.g. the opposite sex, seeking support and one's own qualities and attributes (Raffaelli & Duckett, 1989). These researchers also found that despite an increase in the level of interactions with their peers, the frequency of interactions with family members did not decrease, suggesting less of a move away from family but rather an expansion in conversations with peers. Conversations within the family were found to focus more on family issues, maintenance and leisure activities, with less focus on CYP's concerns (Raffaelli & Duckett, 1989). Little is known about the level to which CYP discuss family issues with their peers. Therefore, it maybe family issues may not be a topic for discussion in general. However, according to the literature examining the impact of having a PEMD, CYP prefer informal support networks, including peers as a source of emotional support (Wahl, Bruland, Bauer & Okan & Lenz, 2017).

In more recent years, there has been a wealth of research examining the impact of the internet on the quality of children's friendships. Research within the 90's generally found this increase led to a decrease in the quality of relationships with others (Kraut, Patterson, Lundmark, Kiesler, Mukopadhyay & Scherlis, 1998). However, more recent research has found the opposite, with internet use increasing social connectedness and disclosure (Valkenburg & Peter, 2009). The authors hypothesised that this trend is partly due to the internet use enhancing self-disclosure, due to the reduction in visual, auditory and contextual cues, which leads to young people feeling less concerned with how others perceive them (Valkenburg & Peter, 2009).

If we consider the importance of belonging to a 'normal' peer group on CYP's development, it stands to reason that the existence of stigma and comparisons that CYP make to others may impact on their developmental process. For example, research has suggested that living with a PEMD, can sometimes lead to CYP feeling different from their peer group (Bee, Beizins,

Calam, Pryjmachuk & Abel, 2013). CYP report fearing the reactions of CYP (Alasuutari & Järvi, 2012; Baik & Bowers, 2005; Murphy, Peters, Wilkes & Jackson, 2015a) and some have been subject to ridicule by their peers as a result of their PEMD (Kahl & Jungbauer, 2014). Therefore, CYP's ability to develop trusting relationships with others can be compromised, thus possibly impacting on their development.

1.9 Being a Parent and Experiencing Mental Distress

Parenting can be a challenging task but when experiencing mental distress, the role can, at times, become even more demanding, despite also potentially providing families with a positive focus (Nicholson et al., 1998). Dolman, Jones & Howard (2013) completed a meta-synthesis exploring mothers' experiences of parenting whilst experiencing mental distress. The findings demonstrated that mothers were concerned about the impact of stigma and this would prevent them from discussing their difficulties openly, preventing them from socialising. However, it is worth noting that in a survey of parent's discussions with their children about mental distress in general, 55% had never discussed the topic of mental distress with their children. Therefore, this lack of conversation may not be due to them fearing disclosing their experience of mental distress to their children, but rather societal norms about discussions on this topic (Time to Change, 2015). They often experienced self-stigma and saw themselves as 'bad' mothers. Many experienced guilt about the effects of their mental distress on their children and feared the loss of custody, with many reporting that they had lost custody. Mothers reported their concern for their children, particularly in relation to them having a genetic vulnerability or developmental difficulties due to the impact of their mental distress. Mothers were also worried about the possible impact of secondary stigma, with some expressing their CYP's experience of bullying as a result of their experience of mental distress. Less is known about fathers who experience mental distress (Reupert & Maybery, 2009).

1.10 Exploring CYP's Accounts of living with a PEMD

In recent years, there has been a growing emphasis on examining CYP's accounts of living with a PEMD (including Aldridge & Becker, 2003; Focht-Birkerts & Beardslee, 2000; Fudge & Mason, 2004; Garley, Gallop, Johnston & Pipitone, 1997; Grant, Repper & Nolan, 2008; Grové, Reupert & Maybery, 2016; Manu & Stein, 2010; Östman, 2008; Mordoch & Hall, 2008; Stallard, Norman, Huline-Dickens, Salter & Cribb, 2004; Tabak et al, 2016; Van Parys & Rober, 2013). This research has highlighted some of the day-to-day challenges that this group

face, in addition to the positive factors that they experience. Riebschleger (2004) found that children experienced both good and bad days when living with their parents. 'Good days' included days where their parents were functioning well and were engaging in more positive interactions with them. Comparatively, 'bad days' were characterised by times when their parents were more withdrawn or were seen to be more reactive. Mordoch & Hall (2008) discussed the ways in which young people reportedly coped with these changes. CYP spoke about the importance of finding a rhythm in their daily life by trying to adapt to fluctuations in their parent's mood. In addition, they attempted 'maintaining a frame', which referred to the child's ability to maintain a healthy distance from their parent by ensuring they continued to live their lives and give themselves opportunities to get away.

Literature reviews have been conducted which highlight that CYP report both positive and negative aspects of their experience (e.g. Dam & Hall, 2016; Drost et al., 2015; Gladstone et al., 2011). Dam & Hall's (2016) meta-synthesis highlighted the tensions CYP experienced. For example, they described CYP's reported love and care for their parent, in addition to their experience of being overwhelmed by feelings of worry due to the unpredictability of their PEMD. Furthermore, they reported that CYP preferred to keep their PEMD a secret to avoid the possibility of negative reactions of others. However, CYP spoke of talking as a way of coping and found comfort in talking to someone who had experienced something similar.

Gladstone et al.'s (2011) review of CYP's accounts of living with a PEMD, found there was considerable variability in CYP's experiences. The review emphasised the importance of the CYP's relationship with their PEMD. It also highlighted some adverse effects of living with a PEMD, including the CYP's worry about their parent's safety and potential separation; their experiences of self-blame; feelings of confusion and uncertainty due to lack of explanation; and fears of others' reactions. They found that CYP spoke about different ways of coping, including independent strategies (e.g. reading) and more communal ways of coping (e.g. team sports, talking to friends etc).

Drost et al (2015) conducted a systematic review examining CYP's reported strengths and resources. They highlighted their ability to problem solve and adapt to situations that occurred. Having the support of family, friends and mental health services were reported as positive coping mechanisms. However, the review highlighted the challenges to seeking this support e.g. not wanting to bother people with their problems and hoping that professionals offer support. Furthermore, the existing barriers to accessing support from services were apparent.

For example, services are often commissioned for certain age groups and therefore workers do not necessarily have the skills and training to work with families (Reupert & Mayberry, 2007).

1.11 Towards a Systemic Understanding of PEMD

One important component of systemic theory is that problems are seen as relational and each member of a system influences the other and thus relationships are circular in nature (Dallos & Draper, 2010). Therefore, if a parent is worried about the stigma associated with their mental distress, they may choose to hide it in an attempt to protect their children. Subsequently, their children may feel they can't ask questions, in case of upsetting or drawing attention to their PEMD. Through the consideration of the research examining families where a parent experiences mental distress, it seems that mental distress impacts on more than just the individual. Van Parys and Rober (2013) highlight the reciprocal nature of these difficulties. For example, parents' fear talking to their children about their experiences of mental distress and this may prevent CYP from asking questions (Nolte & Wren, 2016). This lack of conversation within the family may also communicate that mental distress is not something that can be talked about with others.

Murphy, Peters, Wilkes & Jackson (2014) proposed a dynamic cycle of familial mental distress that considers how CYP, parents and wider contexts around the family contribute to the maintenance of mental health within the family (see figure 1). This model not only recognises how a parent's experience of their mental distress may impact on the child, but also acknowledges that the child's reactions to their condition can have adverse effects on their parent's experience of mental distress. For example, parent's masking of symptoms, and reluctance to seek help may influence their children's understanding of mental distress. Equalling, if CYP distance themselves from their parents in an attempt to minimise the impact of their parent's difficulties, their parents may become disenfranchised, increasing their level of stress. This highlights the importance of recognising the need for services to work together to consider the needs of both parties.

1.11 Seeking Support and Interventions

The need for support for CYP and their families has been widely documented (e.g. Aldridge & Becker, 2003). Interventions have been designed including those providing CYP with psychoeducation (e.g. Grové, Reupert & Maybery, 2015a). Peer support interventions have also been effective at increasing knowledge, teaching CYP ways to manage their feelings,

connecting with others and reducing isolation, and giving CYP the chance to meet other young people in similar situations to themselves (e.g. Foster, Lewis & McCloughen, 2014). In the UK, an intervention has been designed which aims to provide psycho-education, increase communication within the family and offer CYP and their families a chance to meet others in a similar situation has been developed (Cooklin, Bishop, Francis, Fagin & Asen (2011). There have been differences in the research in terms of the kind of support that CYP prefer. For example, Maybery, Ling, Szakacs & Reupert (2005), found that children's siblings and existing peer group were preferred to external support, whereas, other studies have highlighted the preference of speaking to a professional in a confidential setting or to anonymous online support (Grové et al., 2016). Grové et al (2016) acknowledge that there isn't a model that fits each individual.
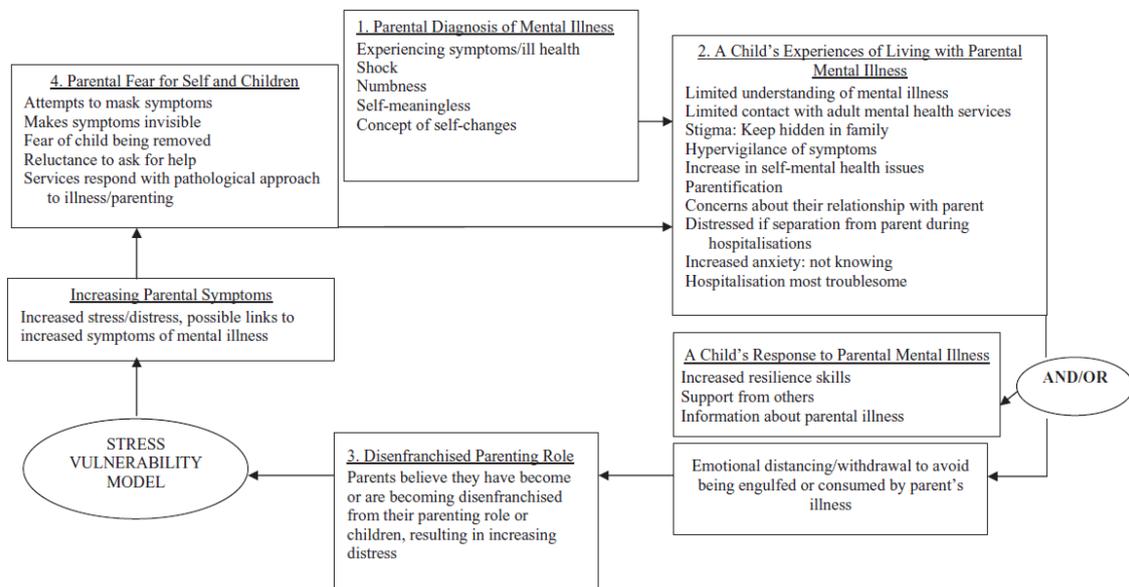
Figure 1. A Dynamic Cycle of Familial Mental Illness (Murphy, Peters, Wilkes & Jackson, 2014, p 949)

1.12 Conclusion

This chapter aimed to introduce the reader to the current context of research into parental mental health and consider this in terms of theory and reports from CYP and their parents. The research has considered the importance of support, but highlighted the challenges in accessing this. It seems that talking to trusted others is one way that CYP cope with their experience. However, there has been no research directly looking at CYP's experiences of speaking to others about living with their PEMD. Nevertheless, there have been a number of studies that

have highlighted its importance. The next chapter goes on to present a systematic review of findings in relation to CYP's conversations with their peers about their PEMD, to provide further understanding in this area.

Chapter 2: Systematic Literature Review

2.1 Overview

This chapter presents the findings from a systematic literature review, which was part of a meta-synthesis. The full meta-synthesis could not be presented within the main body of this document, as it is beyond the scope if this project, but it is included in appendix A. While there is now a significant amount of research exploring CYP's experiences of living with a PEMD, there are no studies that directly examine CYP's experiences of talking with their friends about their parent's experience of mental distress. Therefore, a systematic search of the literature was conducted to provide further insight into this question. The search revealed 19 papers that met the inclusion/exclusion criteria. The included studies are evaluated using Elliot, Fischer & Rennie (1999) quality appraisal. Finally, the results of the review are presented in the following themes: Putting the puzzle together and knowing how to talk about it; keeping the secret; finding someone to trust and escaping home life. A summary of the findings is presented which informs the chosen research question.

2.2 Systematic Search

Relevant terms were explored with an expert in the field and by examining the titles and keywords of published papers. The search of the literature was undertaken using Scopus, PubMed, and Psychinfo. Initially, it was conducted using keywords but this resulted in over 4000 papers, many of which were related to CYP's experiences of mental distress, physical health and disabilities, despite the exclusion of terms associated with these conditions. In their review, Gladstone et al (2011) highlighted the challenges of performing a structured search on this topic as database indexes do not distinguish between CYP's experience of mental distress and PEMD. Therefore, it was decided to complete a title search. This narrowed the search but provided more relevant literature to the field. It has also been suggested that including citation and reference searches increase the likelihood of retrieving all relevant studies (Papaioannou, Sutton, Carroll, Booth & Wong, 2009). Therefore, these methods were incorporated.

Search terms were divided into four blocks (see table 1) and were truncated (e.g. parent* = parent, parenting; child* = children, childhood). It was decided the term "adult children" and

"young adult" would be included as at times these provide valuable retrospective details of the process growing up, providing an insight into how children's relationships change over time.

Table 1.

Systematic search terms

Parent	Mental Distress	Child	Life experience
parent*	"mental distress"	child*	qualitative
family	"mental health"	adolescen*	experienc*
mother	"mental illness"	"young carer"	"quality of life"
father	"mental disorder"	"children of parents with a mental disorder"	"life experience"
mum	"psychiatric disorder"	"young adult"	"daily life"
dad	"psychiatric disability"	"young person"	coping
	depression	"adult children"	understand*
	bipolar		talking
	schizo*		support
	"personality disorder"		conversations
	anxiety		
	"obsessive-compulsive disorder"		
	"post-traumatic stress disorder"		

Following the search, 573 papers were found, following the removal of duplicates. Papers were initially screened by title and abstract and included or excluded based on the criteria provided below (see table 2). Initially, non-peer reviewed articles, including unpublished theses were excluded, including Aldridge & Becker (2003) research into young carers. Full text articles (n = 42) were then reviewed and assessed in more detail and further papers were excluded[3].

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[3] See figure 2 for a flow chart describing the inclusion of studies

Table 2.

Inclusion and exclusion criteria

Inclusion criteria	Exclusions Criteria
Focuses on the perspectives of CYP's living with a PEMD	Includes parental or professional perspectives only
Contains substantial reference to CYPs experience of talking about PEMD to their friends	Does not distinguish between multiple viewpoints
Involves accounts of adult children that lived with their parent before the age of 18.	Study focuses on evaluation of intervention
Published in English	Non-peer reviewed articles, reviews, dissertations & personal accounts
	Study uses quantitative or mixed methods design

As this review was primarily interested in CYP's experiences of talking about PEMD, studies examining CYP living with a PEMD exclusively (e.g. parental disability) were excluded (n = 2; Reupert, Goodyear & Maybery, 2012; Thomas et al, 2003). Intervention studies were excluded, unless they examined CYP more general experiences (n = 7; Foster et al., 2014; Grant et al., 2008; Grové, Reupert & Maybery, 2015a, 2015b, 2016; Pihkala, Sandlund & Cederstrom, 2012; Wolpert et al. 2015). Studies including mixed methods were assessed to determine if they had a substantial qualitative component. However, two further studies were omitted due to having a brief section dedicated to CYP's reports about their experience (n=2; Maybery et al 2005; Handley, Farrell, Josephs, Hanke & Hazelton, 2001). Furthermore, studies which included the perspectives of CYP, parents and professionals were only included when CYP's experiences could be distinguished from others. Therefore, two further studies were excluded (N = 2; Aldridge, 2006; Tabak et al., 2016). Another study examined both parents' and CYP's responses, but only gathered parents' views of the impact their difficulties had on their children's peer relationships (Stallard et al., 20004), so was excluded. One study explored adult children's experiences, and few references were made to when they were younger (Oskouie, Zeighami & Joolaee, 2011).

Figure 2: *Flow chart demonstrating inclusion of studies*

A further eight studies were excluded as they did not make a substantial reference to children's experience of peer support when living with a parent with mental health difficulties. Often these studies concentrated on the one area of children's experience e.g. children's perceptions of their parent's depression (Kaimal & Beardslee, 2010); parenting qualities (Venkataraman, 2011); the meaning for family life (Hedman Ahlstrom, Skarsater & Danielson, 2011); ways in which families can foster emotional relational resilience in children (Focht-Birkerts & Beardslee, 2000); experience of psychiatric services (Knutsson-Meddin, Edlund & Ramlint, 2007); recommendations for support (Fudge & Mason, 2004). Finally, two studies looked at the impact of living with a parent with mental health difficulties on their current adult lives

(Manu & Stein, 2010; Drost & Schippers, 2015). Following this process, 19 studies were included in the systematic review[4].

2.3 Evaluating the research

All of the studies included in this systematic review provide qualitative accounts of children's experiences of living with a parent with mental health difficulties. Elliot, Fischer and Rennie's quality appraisal criteria were used as it was designed for the evaluation of qualitative research from the perspective of clinical psychologists (see Barker, Pistrang & Elliot, 2002). This appraisal considers criteria of evaluation that should be common to both quantitative and qualitative research, in addition to more specific criteria for evaluating research (provided below).

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. General vs Specific
7. Resonating with readers

General principles of evaluating research are considered first (e.g. explicit scientific content & method; appropriate method; respect for participants; specification of method; appropriate discussion; presentation; contribution of knowledge), followed by the criteria listed above[5].

Each study provided a detailed rationale for exploring CYP's experiences of living with a PEMD. 15 studies chose to solely use individual interviews, which are appropriate for many qualitative analysis methods and may also allow for the generation of more unique ideas (Heary & Hennessy, 2006). However, one study used a focus group in addition to interviews (Riebschleger, 2004). It has been found that focus groups may allow for greater elaboration of ideas (Heary & Hennessy, 2006). In addition to interview data, Pölkki, Ervast & Huupponen,

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[4] A summary of the studies included in the systematic review is provided in Appendix B

[5] An extract of the completed quality appraisal is provided in appendix C

2004) analysed essays that were submitted as part of a writing competition which provided rich accounts which were not influenced by a researcher and could be triangulated with findings from the interviews, adding credibility. Van Parys & Rober (2013) utilised family interviews for ethical reasons. Although this may have helped the CYP feel comfortable, they may have struggled to express any difficulties with living with their parent.

One of the main criticisms of the research in this area is the representativeness of the samples. Participants were often recruited via intervention groups, adult mental health services or by self-selecting through responding to advertisements. As discussed earlier, many CYP living with a PEMD remain "invisible" to services and often fearful of talking to professionals, due to fear of being taken into care, or through lack of recognition of mental health difficulties. Therefore, the invisible population's voice may remain unheard and unrepresented in the research. The sample sizes reported vary greatly in the studies. For example, Meadus and Johnson (2000) used a very small sample (n=3), although the participants were interviewed twice. The phenomenological analysis adopted in this study is recommended for use with smaller samples as it allows the researcher to elicit the richness of an individual's experience (Smith, Flowers & Larkin, 2009). The authors noted the challenges of accessing CYP that live with a PEMD and attributed this to having to seek consent through a number of different parties e.g. parents. In addition, they noted that many families avoid seeking support for their children due to fear of stigmatisation. This further highlights the challenges families face with seeking support from others. However, the small sample size does limit our ability to generalise experiences that these CYP may have experienced.

The studies varied in their choice of analysis which gave a different focus to the different pieces of research. On the whole, the methodology chosen was in line with the research question. However, there were a few examples where it seemed that this lacked consistency. For example, the aim of grounded theory is to inductively consider young people's experience and from this develop a model using an iterative process (Charmaz, 2014). However, Baik & Bowers (2005) & Riebschleger (2004) presented themes, without illustrating the relationships between these themes. Other studies failed to describe the method for analysing the data, which led to questions about the validity of these methods (e.g. Somers, 2007).

I will now consider the qualitative criteria for assessing the quality of the research. Within qualitative research, it is acknowledged that the researcher is trying to make sense of the phenomena through various lenses (Elliot et al., 1999). Therefore, it is important for the

researcher to acknowledge their own perspective within the research. Having said this, only a handful of studies within this review made their position explicit (Alasuutari & Järvi, 2012; Fjone et al., 2009; Foster, 2010; Meadus & Johnson, 2000; Mordoch & Hall, 2008; Tronsden, 2012), but few of these studies provide evidence of their reflexivity. Alasuutari and Järvi (2012) reflect on how their position as a researcher may have influenced the responses of the children and provide extracts of conversation between interviewer and interviewee. However, none of the researchers give a description of who they are and the relationship that they have with the topic and this leaves the reader guessing as to how they shaped the research process.

Studies varied in the description that they provided about their participants. Some included minimal information e.g. number of young people and their age range (e.g. Valiakalayil, Paulson & Tibbo, 2004). However, others provided a rich description of the families included in the study which included their age, gender functioning, details of their parent's mental health & their family composition (e.g. Mordoch & Hall, 2008). Many of the studies did not describe the family composition, which is relevant to the topic area as it provides an understanding of how much contact the CYP had with their parent experiencing mental distress, their support network within the family and the type of symptoms their parent may present. Each of the papers grounded their themes with quotations from their participants. However, some studies used few examples within the text, making it more difficult to put the reader in the shoes of the child and assess the researcher's interpretation of the findings.

The use of credibility checks to ensure the reliability and validity of the findings can align the research to more positivist perspectives and is seen as an important criterion to evaluate the quality of the studies (e.g. Elliot et al, 1999). Nearly half of the studies did not report on their use of credibility checks (9/19). The most common reported method for providing credibility checks was to have more than one person analyse the transcripts (Backer, Murphy, Fox, Ulph & Calam 2016; Bee et al, 2013; Kahl & Jungbauer, 2014; Meadus & Johnson, 2000; Riebscheleger, 2004; Valiakalayil et al., 2004). Other methods for providing credibility checks included presenting data at specialist research groups (Baik & Bowers, 2005); discussing within the research team (Mordoch & Hall, 2008; Mordoch, 2010); or through the use of member checks (Foster, 2010). The lack of credibility checks apparent in these studies may imply that the findings may be subject to bias and therefore not be replicable. However, the understanding of bias is now sometimes seen in relation to the researcher's theoretical position e.g. not looking for a single truth (Roulston & Shelton, 2015). Nevertheless, there was a lack

of discussion about this in each of the studies. Nonetheless, these studies may still provide an insight through the eyes of the researcher about CYP experiences.

Many of the studies look at the broad range of parents' experiences of distress and include CYP from a range of backgrounds and family compositions. Therefore, they provide a general look at these children's lives which may be able to be applied more generally (Bee et al, 2013; Cogan, Ridell & Mayes, 2005; Fjone et al., 2009; Foster, 2010; Mordoch & Hall, 2008; Mordoch, 2010; Ostman, 2008; Pölkki et al., 2004; Riebschlegar, 2004; Trondsen, 2012). Although this provides a good sense of the general experience of these CYP, the findings may not be sensitive to the intricacies of how these difficulties may affect families. In comparison, Griffiths, Norris, Stallard & Matthews (2012) examine the impact of living with a parent who experience OCD. The CYP in this study reported the impact that rituals have on their liberty e.g. invading their personal space, being restricted by their parents' anxieties. The studies included in this review generally used quite open approaches to examine experiences, which allowed for both positive and negative experiences to be spoken about. However, Valiakalayil et al (2004) focused on the burden associated with having a parent with schizophrenia. This lens could have skewed the research and underestimated any positive aspects of the CYP's experience.

The researchers' approach in each of the studies led to each resonating in a different way. For example, Cogan et al (2005) used Huberman & Miles interactional analysis to compare CYP who lived with a PEMD and those without a personal experience. This provided an insight into how CYP's knowledge and understanding differed and how this may impact on children's conversations with others. This approach focused less on the depth and richness of CYP's descriptions which made it more difficult to imagine what their lived experiences were. Whereas, Mordoch & Hall (2008) provided a rich account of the dilemmas and variability in the CYP's lives, which provided a rich sense of their lived experience.

2.4 Summary of reviewed literature

The findings from the meta-synthesis four main themes were identified. These included: Putting the puzzle together and knowing how to talk about it; keeping the secret; finding someone to trust; and escaping home life.

2.4.1 Putting the puzzle together and knowing how to talk about it.

Many of the studies indicated that CYP often had a limited understanding of their parent's experience of mental distress (Alasuutari & Järvi, 2012; Backer et al, 2016; Baik & Bowers, 2005; Bee et al., 2013; Cogan et al, 2005; Foster, 2010; Meadus & Johnson, 2000; Mordoch & Hall, 2008; Mordoch, 2010; Östman, 2008; Riebschleger, 2004; Van Parys & Rober, 2013). This had a bearing on whether CYP were able to talk to others as they had to go through a process of realising that something was different before disclosing to others (Baik & Bowers, 2005; Fjone et al., 2009). Finding a common language to talk about it was influenced by CYP's desire for normality (Fjone et al., 2009).

There seemed to be a large variation in CYP's level of understanding and this seemed to depend on age and the level to which families discussed it (Backer et al, 2016; Foster, 2010; Fjone et al., 2009; Valiakalayil et al., 2004). Some CYP did not realise that their parents experienced mental distress until after they moved out of the family home (e.g. Backer et al, 2016; Baik & Bowers, 2005; Foster, 2010; Fjone et al., 2009). CYP reported a process of piecing together information over time to understand what was going on with their parent (Mordoch, 2010; Riebschleger, 2004). This could be through making comparisons to friends' families (Riebschleger, 2004); and inadvertently coming across information through hearing conversations, or finding information from the media (Mordoch & Hall, 2008). Some CYP recalled having conversations with their parents (Backer et al, 2016; Fjone et al., 2009) although many of these children reported not being able to remember much about these discussions (Backer et al, 2016). However, there was recognition that it was a topic that wasn't often discussed and this could leave children feeling worried but also gave the impression that mental distress was it was not seen as important (Mordoch, 2010), or that it was something they weren't allowed to know (Van Parys & Rober, 2013).

CYP's lack of knowledge about mental distress and how this impacted on the parent, left them trying and make sense of the changes that they noticed in their parents' behaviour (e.g. Backer et al, 2016; Mordoch & Hall, 2008; Mordoch, 2010) and often left them feeling worried, leaving them to picture the worst-case scenario (Meadus & Johnson, 2000; Mordoch & Hall, 2008; Mordoch, 2010). In addition, it could lead CYP to misattribute changes in their parent's presentation as personal characteristics of their parent, which could impact on their relationship (e.g. Alasuutari & Järvi, 2012; Foster, 2010; Valiakalayil et al., 2004). Other CYP reported that they blamed themselves, and at times stated that their parent would blame them for changes in

their mood (Baik & Bowers, 2005; Kahl & Jungbauer, 2014; Östman, 2008; Riebschleger, 2004). The shame associated with feeling to blame prevented some young people from talking about their experience with others, through fear of being judged as a 'bad child' (e.g. Baik & Bowers, 2005).

CYP went through a process of realisation where they came to understand their parent experienced mental distress, and this process allowed them to verbalise their experience (Baik & Bowers, 2005; Fjone et al., 2009). The process of realising that something was different about their home life, compared to other families and their realisation that this difference was due to their parent's experience of mental distress, increased with age (Baik & Bowers, 2005; Foster, 2010; Fjone et al., 2009).

The language that CYP used to describe their parent's experience of mental distress varied (Alasuutari & Järvi, 2012; Cogan et al, 2005). CYP of a variety of ages were able to use and recognise professional or medical language (Alasuutari & Järvi, 2012). However, CYP demonstrated a preference for more normalised language such as "problem" or "stressed" (Cogan et al, 2005) and it was unclear how much they understood more medical terms as they often showed some hesitation when using them (Alasuutari & Järvi, 2012). CYP often described mental health problems in relation to the impact the condition had on both their parents and their own lives. This may suggest that CYP have less fear of talking about their parent's behaviour if it is not associated with the stigma associated with more medicalised terms.

2.4.2 Keeping their parent's mental distress private

Many of the studies highlighted how CYP of all ages seemed extremely aware of stigma associated with mental health and spoke about how this prevented them from talking about their experience (Alasuutari & Järvi, 2012, Backer et al, 2016; Baik & Bowers, 2005; Cogan et al, 2005; Foster, 2010; Meadus & Johnson, 2000; Mordoch & Hall; 2008; Mordoch, 2010; Östman, 2008; Pölkki et al., 2004; Riebschleger, 2004; Somers, 2007; Valiakalayil et al., 2004). The existence of stigma was found in the language of CYP with no experience of mental distress, who would use more negative terms e.g. "crazy", "dangerous", "erratic". These more negative terms were influenced by their non-affected parent's use of language and media representations (Cogan et al, 2005). Even when CYP did not realise their parent's changes in behaviour were due to their experience of distress, they were able to perceive that their parent

was acting differently and this resulted in feelings of shame and embarrassment. Furthermore, CYP's ability to come to terms with living with a parent experiencing mental distress was influenced by CYP's feelings of stigma (Fjone et al., 2009). Furthermore, stigma also led CYP to minimise their parent's difficulties or highlight how much their parent had improved (Alasuutari & Järvi, 2012).

CYP's feelings of difference left them feeling uncomfortable, lonely and isolated and navigating friendships could sometimes lead them to struggle as they tried to fit in with their social world (Foster, 2010; Mordoch & Hall, 2008). This need to fit in sometimes led them to hide their experiences from others (Foster, 2010; Mordoch & Hall, 2008; Valiakalayil et al., 2004). Furthermore, some CYP also expressed a fear of placing too much burden on their friends (Kahl & Jungbauer, 2014). In addition, parents also expressed a desire to keep their experiences within the family, as they were also concerned about stigma and at times were reluctant to share their experience of distress with relatives (Griffiths et al, 2012; Mordoch & Hall, 2008; Pölkki et al., 2004; Riebschleger, 2004). On occasion, CYP reported their parents had asked them to lie to their friends as they were concerned about being viewed as "failing" (Pölkki et al., 2004). These factors also left CYP feeling protective of their parent and aware of others' judgements leading them to view their parent's experience of mental distress as a family secret (Cogan et al, 2005; Griffiths et al, 2012 Pölkki et al., 2004; Riebschleger, 2004; Somers, 2007). It seems likely that families' fear of stigma increased their isolation and reinforced the view that talking about mental distress is something that should be avoided.

In order to keep this secret, CYP made excuses for their parents' behaviours in order to avoid being judged negatively by others (Baik & Bowers, 2005; Fjone et al., 2009) and they often reported fears of being teased (Riebscheleger, 2004). When CYP did experience their friends observing their parents behaving in strange ways, they reported feeling ashamed. This often resulted in them not inviting their friends over again in the future, increasing their feelings of isolation (Cogan et al, 2005; Fjone et al., 2009; 2012; Somers, 2007). Some CYP reported experiences of being teased or bullied due to their parent's experience of mental distress (Kahl & Jungbauer, 2014; Mordoch, 2010). However, other CYP recognised that sometimes it was their own perception that led to feelings of being ostracised by others and acknowledged they hadn't been bullied (Foster, 2010). Others reported that they did not feel that their parent's experience of distress as something to be ashamed of, and they reported talking about it freely.

Although these CYP still recognised the existence of stigma related to mental distress (Meadus & Johnson, 2000).

2.4.3 Finding someone to trust.

Finding someone to trust was reported to be crucial when deciding who whether or not to talk about living with a PEMD (Ostman, 2008; Mordoch & Hall, 2008). CYP described using their discretion to determine who to share with, as they were often aware of the risk of people gossiping and there were concerns of rumours being spread around the school (Mordoch & Hall, 2008). However, CYP spoke about being able to confide in "best friends" or boyfriends (Valakalail, 2004). These friends were described as being empathetic, understanding and provided a safe space for CYP to discuss their experiences (Baik & Bowers, 2005; Mordoch & Hall, 2008). Disclosing to close friends allowed the CYP to anticipate the other person's reactions, providing a greater sense of safety (Baik & Bower, 2005; Van Parys & Rober, 2013). However, despite finding a friend that they could trust, young people still expressed a reluctance to share everything with them, and spoke of withholding information from them (Meadus & Johnson, 2000; Trondsen, 2012). In addition, younger children whose lives were more likely to centre around home life, were more likely to share information with family members, rather than friends (Mordoch & Hall, 2008).

CYP felt emotionally and functionally separate from their peers due to their experience of living with a PEMD (Bee et al, 2013). This led CYP to feel as though other children might not understand their experiences (Mordoch & Hall, 2008, Fjone et al., 2009). CYP found themselves drawn towards those that they perceived to have a similar lived experience (Fjone et al., 2009). Being able to speak with others that understood would allow CYP to open up about their situation. This gave them a sense that they were not alone (Griffiths et al, 2012; Mordoch, 2010). CYP spoke about the benefit of finding out that they were not the only one living with a PEMD (Mordoch, 2010).

2.4.4 Escaping home life.

CYP described the need to create a safe distance from their parents, in order to preserve their relationship and help them to maintain their sense of self. Many of these studies highlighted the importance of having friends (Backer et al, 2016; Bee, et al, 2013; Foster, 2010; Fjone et al., 2009; Kahl & Jungbauer, 2014; Mordoch & Hall, 2008; Trondsen, 2012; Van Parys & Rober, 2013). CYP reported benefit from just spending time with their friends, and recognised

that they did not always need to confide in them. They reported benefit from having a good time and restoring humour (Trondsen, 2012). These experiences provided a form of distraction (Bee et al, 2013), helped release tension (Van Parys & Rober, 2013) and provided CYP with a sense of normality (Fjone et al., 2009). By getting away from their parents and living their own lives, CYP continued to develop socially (Mordoch & Hall, 2008).

However, the age of the CYP impacted on their opportunity to spend time outside of the family home. For example, Mordoch & Hall (2008) reported that older children had more opportunity to spend time with their friends, engage in different activities and spend time socialising. At times, older children acknowledged they tried to avoid spending time at home, to reduce exposure to their parent's experience of mental distress (Fjone et al., 2009). However, this ran the risk if impacting on the parent-child relationship (Mordoch & Hall, 2008).

2.5 Summary of review

This review has highlighted the dilemma that CYP living with a PEMD face. This group report struggling to make sense of their parent's distress, feeling isolated and experiencing stigma regarding their parent's experience of mental distress. It seems this experience may leave them to feel cautious about seeking support from others, including their friends. In addition, many young people remain unseen by services and some prefer not to talk to professionals. Furthermore, CYP have highlighted the need to educate others about mental distress in order to reduce stigma associated with it. However, despite these findings, no research has directly examined how CYP living with a parent experiencing mental distress use their peer networks for support. The few studies that explore the processes that CYP go through to disclose information about their home life, come from retrospective accounts. Therefore, this study seeks to examine this gap in the research by utilising a qualitative design to investigate CYP's experiences of seeking support from their peers about living with parents who experience mental distress. It is hoped that by doing so, we can gain further insight into sources of support for young people with the aim of informing clinical practice and interventions.

2.6 Aims of the Research and Research Questions.

The aim of this research is therefore to examine CYP's experience of seeking support from their friends, regarding their experience of living with a PEMD. This will be explored through the following research question:

How do CYP living with a parent experiencing mental distress experience and make sense of gaining support from their friends?

Chapter 3: Methodology

3.1 Overview

This chapter details the rationale for the chosen research methodology. It considers the value of qualitative research design and introduces the reader to the chosen analysis, Interpretive Phenomenological Analysis (IPA). Further consideration is given to the strengths and weaknesses of this approach, and how this relates to the researcher's epistemological position. As discussed earlier, the importance of demonstrating reflexivity within the research is addressed and the method for how this is maintained is discussed. An explanation of the research method is presented, providing an overview of the ethical considerations, participants, procedures and analysis. Finally, an account of the measures taken to ensure the quality of the research is presented.

3.2 Methodology

3.2.1 Qualitative research.

Qualitative research attempts to make sense of the subject experiences of a phenomenon. It is concerned with questions that establish the meaning people attribute to their experience and seeks to determine what this experience is like or how people manage certain situations (Willig, 2013). It allows the researcher to collect in-depth accounts which can offer explanations and shed light on the processes involved in the patterns that occur (Barbour, 2000). In addition, the broad nature of the data can leave space to uncover unintended findings, and be used for hypothesis generation (Barbour, 2000). In relation to research examining CYP's accounts of living with a PEMD, the context surrounding the child has been found to be important in how the CYP make sense of and cope with their situation. Therefore, a qualitative account can explore the range of factors that may impact on the young person, and how these interact (Gladstone et al, 2011). Furthermore, given the lack of research exploring CYP's experiences of talking about their experience of living with a PEMD, a qualitative approach not only allows for in-depth exploration and hypothesis generation, but also provides the researcher with the opportunity to witness how they talk about it within the interview process.

3.2.2 My Epistemological Position.

I have outlined my ontological and epistemological assumptions in the previous chapter. These have contributed to my decisions regarding the methodology and are further discussed here. Co-constructionism implies that a reality exists, but different aspects of this reality are highlighted according to ideas held about it both by individuals and society. It acknowledges that we can't know absolute truths, but we can advance our knowledge on a given phenomenon (Speed, 1991). By studying CYP's own constructions about their experience of living with a PEMD, we can advance our knowledge about their own reality. Therefore, the importance of how these individuals make sense of their reality within the contexts that they live in is of great significance. This implies an approach that examines the meaning these individuals ascribe to their reality would be appropriate.

Applied to an interaction between researcher and interviewee, this approach implies that their interactions will be shaped both by the accounts provided by the interviewee, but also by the ideas that the interviewer brings to the conversation. Therefore, researcher reflexivity is required to determine the contribution of the researcher to the findings. Further information on how reflexivity is maintained throughout the research process is provided below.

3.2.3 Interpretive Phenomenological Analysis (IPA).

Several methods for analysing qualitative data exist, but IPA was deemed most appropriate for this study (e.g. Smith, 1996; Smith et al., 2009). The fundamental underpinnings of this approach and the reasoning behind choosing this method are provided below.

This approach was developed within the field of health psychology in an attempt to examine the lived experiences of individuals using a systematic method. It is concerned with three theoretical assumptions: It is phenomenological, hermeneutic and idiographic. Phenomenology is based on the ideas of the philosophers Husserl, Heidegger, Merleau-Ponty & Sartre. Their work highlighted how individuals develop knowledge of their own experience by "bracketing off" taken for granted knowledge to focus on their perceptual experiences. These ideas were developed to acknowledge the contexts in which people live and therefore how specific lived experiences can lead people to attribute certain meanings to events (Smith et al., 2009). Therefore, IPA is concerned with giving voice to these individual experiences (Larkin, Watts & Clifton, 2006) and recognises that people's perceptions develop from an interaction between language, cognition and affect (Smith & Osborn, 2008).

This relationship leads us to consider the second assumption - hermeneutics, the theory of interpretation. This idea stems from the work of Heidegger, who spoke from a realist position, yet highlighted the influence of social, cultural and theoretical contexts on the way in which we make sense of our experiences. A hermeneutic cycle (Smith, 2007) is activated, whereby the individual makes sense of their own experiences and provides an individual perspective through talking about this experience as a number of parts, which make up a whole at a number of levels. This forms a dynamic and circular relationship between the part and the whole (Smith, 2007). The researcher also lives within a number of contexts which influence their interpretation, and are therefore participating in a double hermeneutic process (Smith et al, 2009). It is acknowledged that it is difficult to remove the researcher's influence on the interpretation. However, this approach requires the researcher to take a reflexive position.

Finally, the approach is idiographic, meaning it is interested in the specific rather than making general claims. This enables the researcher to look in depth at the intricacies of a person's experience, in addition to allowing the researcher to understand how a phenomenon is understood from a particular perspective in a particular context (Smith et al, 2009). Therefore, the approach utilises small, situated and purposively selected samples in order to increase our understanding of a phenomenon (Smith et al, 2009).

3.2.4 The rationale for choosing IPA.

When reflecting on the most appropriate approach for this research, Grounded Theory (GT) was initially considered. This method is similar to IPA in that it uses an inductive approach. However, GT takes a broader view of the topic and seeks to develop a conceptual understanding or theory of a phenomena, based on larger sample sizes (Smith et al, 2009). The research question originally designed using this approach was concerned with the social processes that are involved when a young person decides whether or not to seek support from their friend. Therefore, the interview schedule that was developed took a broader approach to examine children's understanding and experience of their parent's experience of mental distress and how this impacted on their decision of whether or not to seek support from their peers. A number of interviews were carried out with this method in mind. However, following the initial interviews the data was inspected and pointed towards CYP's lived experience of talking to their peers. Therefore, it was felt that an approach with an idiographic focus would allow for the exploration of the complexities of CYP lived experience. In addition, due to the challenges in recruitment which are discussed further below, it was thought that theoretical sampling

would be difficult to achieve (Charmaz, 2008). A decision was then made to change the focus of the research to look at how CYP who live with a PEMD experience and make sense of gaining support from their friends, using IPA, and the focus in the interviews were slightly adjusted for the later interviews, although the areas of exploration was judged to still be relevant.

As discussed above, IPA allows for in-depth consideration of how the contexts surrounding the CYP impact on how they make sense of their situation. This approach is also in line with the researcher's epistemological position, which highlights the importance of context on the development of knowledge. Therefore, it was felt IPA would enable in-depth analysis of different perspectives, which was thought to be an important first step in advancing our knowledge of this issue.

3.2.5 Evaluating Interpretive Phenomenological Analysis.

There are many strengths to this approach. For example, IPA's focus on individual experiences invites healthcare professionals to listen to the perspective of the service users (Biggerstaff & Thompson, 2008). It provides a clear framework of the analytic process, which can be applied flexibly and be helpful in making it accessible to the novice qualitative researcher (Larkin et al, 2006). In addition, the openness and service user led perspective provides a space to express alternative viewpoints about strength and quality of life (Reid, Flowers & Larkin, 2005). This is particularly important for looking at parental mental health, as much of the literature is focused on risks and deficits (Gladstone et al, 2006).

Despite these strengths, IPA has received some criticism and it is recognised that this method is difficult to do well, due to the high demands it places on the researcher (Larkin et al, 2006). One author described the process of completing IPA as "drowning in a deep bowl of spaghetti" (p6) and noted the challenges of moving from the idiographic nature of the data to more general themes (Wagstaff et al, 2014). This may have implications for the need for smaller sample sizes (Smith et al, 2009).

Despite clear guidelines being developed (Smith et al, 2009), IPA has also been criticised for the lack of clarity about the level of interpretation and reflexivity required (Larkin et al, 2013). Due to these limitations, the need for ongoing research supervision is highlighted (Biggerstaff & Thompson, 2008). Finally, Willig (2013) emphasised that the method requires participants to describe their experience in some depth, which can be challenging for some. Smith &

Osbourn (2008) discuss the role the researcher has in eliciting the participants' experiences by providing space, open questions and "nudges" or "prompts" to facilitate this process.

3.3 Reflexivity

The role of researcher reflexivity has been highlighted. This is particularly relevant in IPA, due to the phenomenological and hermeneutic stance of this approach (Finlay, 2003; Smith et al, 2009). Reflexivity is relevant throughout the research process and challenges the researcher to consciously consider the ideology, culture and political position of those that are studied, as well as themselves (Hertz, 1997). From the beginning of the research process it is important to identify and 'bracket' these preconceptions truly enter the world of those we interview. This is hard to achieve and therefore all we can do is seek to be explicit about this process (Finlay, 2003). Reinharz (1997) describes a variety of selves that we bring to the research process: research-based selves (e.g. being a researcher, good listener); brought selves (e.g. being a daughter, a psychologist); and finally, situationally created selves (e.g. being a temporary member). Furthermore, the position of the researcher within the relationship (e.g. shares/ does not share experience; moves from insider to outsider) may impact on how the interviewee understands them. Attempts were made to address these aspects by using reflexivity during the research process (Berger, 2015).

I have engaged with clinicians working with families, PEMD and CYP navigating these complex family lives[6]. I have met people from a range of cultural, ethnic, socioeconomic backgrounds from two distinctly different geographic settings (a diverse inner London borough and the county of Bedfordshire). I have noticed differences in the relationships these families have with services, the support networks available to them and their ability to talk openly about their experiences to another professional. I have previously outlined my background, and I see myself more as an outsider within this research process. However, at times I noticed myself identifying with aspects of what participants were talking about, placing me more in an insider position. I believe this experience allowed me to empathise with the families within my research.

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[6] First person is employed to reflect researchers own experiences

By engaging in self-reflexivity, I was able to recognise how my position was influenced by the multiple lenses I hold. I have attempted to notice how these have shaped my experience through the use of a reflective diary[7] and sought supervision to help me identify my blind spots. For example, I noticed that at times I experience feelings of protectiveness towards my parent when she worries about the influence of her health on our upbringing. I identified with the CYP's tendency to talk about the more positive aspects of their parents whilst struggling to describe the more negative aspects of care. This at times led me to hesitate within my questioning and avoid asking some of the more difficult questions. Discussions with my supervisor helped me to address this in future interviews. In addition, I discussed analysis of my data with my primary supervisor and within an IPA peer support group in order to help provide me with a number of different perspectives and remain reflective about any potential biases or blind spots which I may have.

3.4 Design

3.4.1 Involving CYP in research.

This project sought the views of CYP to help understand their accounts of living with a PEMD. Hearing their perspective was important because they have a unique view on how this influences their everyday life (Gladstone et al., 2006).

There have been some concerns raised about involving CYP in research processes. In a review of the literature, issues relating to gaining and obtaining access to CYP (e.g. the engagement and appreciation of the role of gatekeepers within the research process); ethical considerations (e.g. seeking consent from parents, children and young people); and data collection procedures (e.g. the challenges that CYP display in expressing their thoughts and emotions in words) were discussed (Huang, O'Connor, Ke & Lee, 2016). This highlighted the potential danger of causing CYP to experience discomfort and anxiety when answering questions about their experiences. It also emphasised the potential benefit of CYP sharing their experiences and suggested that the process may help CYP to find appropriate assistance. Furthermore, CYP's involvement in research was seen to benefit other CYP that live in similar circumstances to

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[7] Extracts of my reflective diary are included in appendix D

those interviewed. Due to the potential cause for distress, special consideration was given to ethical procedures in the design of the research.

3.4.2 Service User Consultation.

The importance of involving services users in health and social care research has been recognised nationally (National Health and Medical Research Council, 2002) and research has highlighted the benefits (Staley, Kabir & Szmukler, 2013). However, ethical dilemmas and practical challenges can make this difficult (Smith, Monaghan & Broad, 2002).

Due to the importance of involving service users within the research, I had initially planned to consult their families about my research, e.g. to review my information sheets and research questions. I approached the University of Hertfordshire Doctorate in Clinical Psychology Service User and Carer Committee, Young Carers in Herts and clinicians from the mental health teams involved in my project and spoke to families about providing their expertise in this project, but no families came forward.

From the early stages of the project, I was fortunate to attend a training session based on young carers, consulted with clinicians working with families and attended carers groups to consider the issues family members faced. Professionals working with these families spoke about the challenges in accessing this group of people both for support and for research purposes. As described earlier, this group of people can remain "invisible" to services, partly due to services' lack of expertise in this area, but also because of fears children would be taken into care. Professionals working with CYP were able to highlight the influence of culture on family life and how this may feed into the view of children's roles within the family. The CYP involved in the training emphasised the importance of being heard and recognised by services, and therefore their involvement in the research seemed paramount. Finally, it was clear from my interaction with carers groups that CYP had different levels of understanding about their parent's experience of mental distress and the level of which this was discussed within the family varied. This influenced the language I used within the interview process, and in the conversations I had with families when asking for consent. When parents had not disclosed their experience of mental distress to their CYP, these young people were not approached. Therefore, it was important to approach parents initially to talk about the project.

3.5 Ethical Considerations

3.5.1 Process of Ethical Approval.

Ethical approval for this study was granted by the Oxford A NHS Research Committee (Protocol number: LMS/PGR/NHS/02347). Further permissions were sought for changes in the research protocol and for the addition of a research recruitment site[8]. In addition, following the advice from NHS ethics, further permission was sought from non-NHS participating organisations[9]. The research procedures were in compliance with the British Psychological Society (BPS) Code of Human Research Ethics (BPS, 2011). Particular ethical issues regarding the involvement of CYP in research were considered in this process. These included obtaining informed consent, confidentiality issues, avoidance of causing distress and disclosures of harm (Hill, 1997). Further details of how these issues were addressed are provided below.

3.5.2 Informed consent.

When conducting research with CYP under 16, it is generally recommended to seek consent from their parent/carer, in addition to seeking the CYP assent/consent (Huang et al, 2016). As the research involved talking about their parents' experience of mental distress, it was felt parents' consent should also be sought, regardless of the age of the CYP. Information sheets were provided to parents and CYP by the family's key worker which outlined the purpose and procedures of the study, and the confidentiality procedures. These emphasised that their involvement with Kidstime (further details of the recruitment site is given below) would not be affected by their participation, and they would have the right to withdraw at any time. After information was provided they were given two weeks to think about the project and discuss their involvement together. This ensured that participants and their families were fully informed of the implications of participating in the study. Informed consent was sought from both the CYP and their parent or carer who had capacity. The Information about the study was reiterated verbally prior to being asked to provide written consent.[10]

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[8] This process was confusing and challenging based on the transition to HRA, a reflection on this process is given in appendix D

[9] Relevant documentation to confirm ethical approval are presented in appendix E - I

[10] Example information sheets are provided in appendix J and consent forms are provided in appendix K

3.5.3 Confidentiality.

A clear confidentiality policy was provided on the information sheets and given verbally to families, prior to obtaining consent. This emphasised that material from the interviews would not be shared with anyone unless there was concern for the safety of somebody. In order to ensure the confidentiality of families, data was stored safely and securely in line with the Data Protection Act (1998). Encrypted digital audio recorders were used and all audio files were stored securely and deleted on completion of the study. Consent forms, containing personally identifiable information were stored separately in client files on local authority or NHS premises. Furthermore, all identifiable information was removed from transcripts and pseudonyms were used, to ensure anonymity.

3.5.4 Protection from harm.

Children could potentially become distressed when discussing difficult life events, such as living with a PEMD (Huang et al, 2016). Therefore, considerations were made to minimise any potential distress. Due to the challenges in organising a consultation with CYP, their parents and professionals, discussions with stakeholders, described above were used to inform the procedures of the study. A potential risk was identified regarding the level to which the parents' experience of mental distress was discussed within the families. This informed the inclusion and exclusion criteria and the choice of recruitment site (discussed below). Finally, a conversation with parents was had before approaching CYP to establish whether they had explicitly talked about their experience with their children and the language they used.

CYP were given the opportunity to look at the interview schedule before it commenced to ensure they were happy with the questions. However, it was acknowledged that these were not an exhaustive list. It was emphasised that they did not have to answer anything that they were uncomfortable with. All but one participant was happy to be asked questions in the areas that were listed. One interviewee reported that they didn't understand some of the questions, and was therefore worried about them. It was agreed that we would try and ask the questions in different ways, but that the interviewee could decline to answer any questions that were uncomfortable during the interview.

As a trainee clinical psychologist, I also had experience of working with CYP who experienced distress and I ensured I was sensitive to the needs of the CYP during the interview process. I ensured I checked with them if I noticed signs of distress and I offered them the opportunity to

take a break. In addition, I enquired about the participants' wellbeing after the interview and offered a debrief form which provided the details of possible support services[11]. In addition, all the CYP within the study were engaged with services which provided further protection for the CYP, and their key workers could be contacted if any concerns were raised.

3.6 Participants

3.6.1 Recruitment Site.

The Kidstime Foundation is a third sector organisation that provides an intervention designed to provide support for families where a PEMD (Cooklin, 2011). This is usually run collaboratively by a number of different organisations including NHS, local authority and third sector service providers. The intervention consists of psycho-educational workshops aimed at providing both parents and children with separate spaces to learn and talk about mental distress. Following these sessions, CYP and their parents are given a space to talk together about their separate conversations, providing a forum to facilitate joint discussion. The workshops aim to provide information about mental distress to increase knowledge and understanding and reduce confusion, help parents talk about their mental health and treatment and encourage young children to engage in age appropriate pleasurable activities. Wolpert et al (2015) explored families' qualitative experiences of participating in Kidstime. Children reported benefits from sharing their stories with other families as they felt this reduced their feelings of isolation, and their fears of experiencing mental distress.

The criteria for families to be referred to this service are that one or both parents experience enduring mental distress and have had contact (currently or previously) with mental health services. These families have been deemed to have experience of enduring mental distress by professionals and themselves and therefore, the researcher was not making a judgement on this. In addition, recruiting from this service also enabled the researcher to involve the whole family in the process of recruitment and gaining consent.

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[11] A copy of the debrief sheet is provided in appendix L

3.6.2 Sampling Strategy.

In accordance with the recommendations about sampling for an IPA study (Smith et al, 2009), a purposive sampling approach was used, to ensure participants matched the criteria of the study. A homogeneous sample is recommended for IPA, although it is recognised that the extent of this homogeneity varies due to practical and interpretive reasons (Smith et al, 2009). Developmental theories often refer to the final stage of childhood development, from age 12 – 18 (Erickson, 1950; Piaget, 1969). However, due to the variation in life experiences of this group, the CYP's development and their parent's different experiences of mental distress were considered during the analysis stage.

Participants were primarily recruited from Kidstime projects running across London and the South East of England. Unfortunately, two of the Kidstime projects that were initially considered were unable to support recruitment. Therefore, the local adult mental health services involved in the running of Kidstime were also invited to participate.

Staff from the participating organisations were asked to approach parents affected by mental distress in the first instance, to provide them with the information about the research. Parents were asked to indicate whether they would be happy to be contacted by the researcher, to provide them with further details about the study. If parents and CYP provided their consent to be contacted or approached at the Kidstime workshops, the researcher made themselves available to provide further details about the study and answer any questions that they had.

Families were given a further two weeks to consider taking part. Following this period, they were contacted to arrange a time to gain written consent and arrange an interview, at a location of the CYPs choosing.

3.6.3 Inclusion and exclusion criteria.

In order to participate in this study, CYP were required to be between 12 and 18 years and to currently be living with at least one PEMD, with difficulties which are chronic and enduring in nature. Furthermore, CYP involved needed to have a basic understanding that their parents experienced mental distress, to ensure nothing was revealed during the interview process. Suitability was established through discussions with the CYP's parents during the consent process. Participants were excluded if they were non-English speakers, due to the constraints on resources (e.g. translators) and the qualitative nature of the study.

Finally, participants were excluded if they experienced mental distress themselves, due to the risk that the research process itself might lead to distress.

3.6.4 Personal reflections on recruitment challenges.

Previous studies have often highlighted the many challenges in recruiting CYP for research in this area (e.g. Cogan et al, 2005; Kennan, Fives & Canavan, 2012; Meadus & Johnson, 2000; Thomas et al, 2003). These researchers discussed the challenges in working with gatekeepers to access the target population, as well as the challenges in the ethical processes, including getting consent from parents. It was recognised that many professionals had difficulty identifying CYP, demonstrating a lack of awareness about this "invisible" population (Thomas et al, 2003). Despite engaging a Kidstime project and adult mental health services across three London boroughs, initial recruitment proved very challenging. Clinicians were often uneasy about how families would feel about being approached. Furthermore, several CYP in the age group I required had disengaged from the Kidstime group and therefore, forming initial relationships with them was difficult. Parents sometimes reported feeling concerned about whether the interview process would distress their child.

3.6.5 The Sample.

Smaller sample sizes are advised when using IPA, to allow for the depth of analysis of individual accounts (Smith et al, 2009). It was acknowledged that this requires interviewees to be able to express themselves, something that young children may find difficult to do (Huang et al, 2016). Therefore, it was decided that a sample of 6 – 8 participants would be sought to allow for more in-depth review.

In order to retain confidentiality, a summary of the participants is provided below. However, due to recruitment through Kidstime projects, details of each individual are not provided to avoid participants from being identified. A total of 6 CYP aged 12 – 18 participated in the study (Mean = 14; standard deviation = 2.45). Three of the participants were female, three were male. Five of the participants were White British, another participant was White European. All of the children lived with their PEMD. However, the composition of these families varied. Two of the CYP lived with both biological parents; three lived in single parent households and another lived with his mother and step-father. All of the CYP lived with at least one sibling. All of the CYP's PEMD were mothers. Two parents had a diagnosis of 'bipolar disorder', two were diagnosed with chronic depression; one parent had a diagnosis of Obsessive Compulsive

Disorder (OCD) and borderline personality disorder, and another had a diagnosis of Premenstrual Dysphoric Disorder.

Table 3.

Participant information[12]

Pseudonym	Age Bracket	Affected parent
Charlie	12-15	Mother
Andie	12-15	Mother
Sam	12-15	Mother
George	12-15	Mother
Alex	16-18	Mother
Jo	16-18	Mother

3.6.6 Contextualising the sample.

All the children that participated in the study were recruited through the Kidstime projects. This brings with it a particular context, in which the CYP have engaged in discussions about their parents' experience of mental distress, and therefore they may have more of an understanding about what this means and have more experience of talking about it with other CYP, than CYP who are not accessing such support.

CYP were recruited from a Kidstime workshop based in the London borough of Haringey; with a population of over 265, 000 and a fifth of this made up of young people under the age of 20 (Haringey Council, 2015). The borough is the 5th most ethnically diverse area in the country. Estimates suggest that the largest ethnic groups are White British (34.7%), White Other (23%), Black African (9%) and Black Caribbean (7.1%) (Haringey Council, 2015). In addition, it is the 30th most deprived area in England (Haringey Council, 2015). There were challenges in recruiting from this site, partly due to adolescents not engaging in the Kidstime project. Also, both clinicians and parents were hesitant about getting involved. Out of the eight families that

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[12] Only brief information is presented in the table, to maintain the anonymity of the participants

were identified and approached about the project, two parents did not give permission to be contacted about the research; three young people declined to take part and two agreed to participate and one CYP was unable to meet for the interview.

Two further Kidstime projects were added as a recruitment site later into the project as they had a group designed specifically for adolescents. These projects were based in Bedfordshire, a county in the south east of England; with a population of 157, 840 covering 476km, it provided a different context to the London borough. This county is less diverse than the London borough (71.5% of the population are White British) and has lower levels of deprivation (Bedfordshire Council, 2011). Out of the eight families approached at Kidstime, one parent declined and two CYP decided not to take part.

3.7 Interviews

Jonathan Smith describes the research interview as "a conversation with a purpose… informed by the research question…which permits the participants to tell their own stories in their own words" (Smith et al, 2009, p.57). A semi-structured interview schedule[13] was developed to guide this process. These questions aimed to move the participant from a more general account to more detailed specific examples and allow for self-disclosure (Smith et al, 2009). The schedule was designed by examining the relevant literature, through conversations with the research team and by reflecting on the feedback provided during consultations with professionals and families. Broad and open-ended questions were designed to allow the participants to provide a description of their experience but prompts were used to encourage CYP to elaborate e.g. "can you tell me more about that"; and "can you give me an example of…". However, CYP struggled with some of the open-ended questions and therefore the researcher introduced some more specific questions to elicit their experiences.

The participants chose convenient locations for the interview. Two participants chose to be interviewed at their home, two participants chose to be interviewed at school and the remaining participants chose to be interviewed in a community location (e.g. at a children's centre). Before each interview, personal information was collected from the parent and the interviewee e.g. their age, ethnicity, family composition and the parent's diagnosis. The interviews lasted

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[13] An example of an interview schedule is provided in appendix M

between 31 and 52 minutes and were recorded using a digital audio recorder. The recordings were later transcribed and anonymised. Following the interviews, reflective journal entries were used to reflect initial thoughts and any factors that impacted on the interview process[14].

3.8 Data Analysis

The IPA data analysis was informed by the steps outlined by Smith and his colleagues (2009). The anonymised transcripts were formatted so that there was a column to the right, for initial noting, and a column to the left to note down any emerging themes[15].

3.8.1 Individual case analysis.

Due to the idiographic focus of IPA, interviews are initially analysed individually, with emergent themes and patterns across themes identified. When analysing each interview, the first step involved immersing oneself in the data, through reading and re-reading the transcript. Whilst doing so, initial thoughts and observations about the transcript were noted. Following this, the transcript is examined to identify how the interviewee describes, understands and makes sense of their experience, by noting descriptive, linguistic and conceptual comments. Descriptive comments are used to describe the content of the interview and examine key phrases or explanations within the script. Linguistic comments aim to explore how the content and meaning are presented by the interviewee. The analyst may focus on aspects of language such as pronoun use, repetition, pauses, tone and fluency. Finally, conceptual comments allow the analyst to be more interpretive and reflective (Smith et al, 2009).

The next stage involved capturing the essence of the interview by condensing the comments above into emergent themes and exploring the connections that exist between these ideas. The challenge the researcher faces is to reduce the volume of these comments whilst maintaining the complexity of the individual's experience (Smith et al, 2009). In doing so the researcher aims to connect the patterns between their initial comments to establish the essence of the participant's experience. The hermeneutic cycle is activated as the researcher focuses on chunks of the text, whilst bringing them together at the end. The emergent themes are then

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[14] Extracts from my reflective diary are included in appendix D

[15] An extract from one of the interviews is available in appendix N

clustered in order to represent overarching themes in the participant's description of their experience. Using abstraction techniques, related themes are grouped together and renamed to establish super-ordinate themes. Polarization and contextualisation techniques were also used to identify differences between themes and attend to the developmental and cultural aspects of their account (Smith et al, 2009)[16].

3.8.2 Identifying patterns between cases.

Once each interview was analysed, the themes generated by each participant were examined to identify patterns that existed between them. Overarching themes were created by examining the connections across participant accounts and identifying the most compelling themes. This resulted in the relabelling of some categories. These themes were then represented in a table, which informed the results section of this study[17].

3.9 Assessing the Quality of Qualitative Research

As established earlier, traditional methods for evaluating quantitative research are not applicable to qualitative designs (Barker, Pistrang & Elliot, 2002; Yardly, 2008). However, it is acknowledged that steps should be taken to assess the validity, e.g. an evaluation of how the study has been conducted & the extent to which the findings provide a useful insight (Yardly, 2008). A number of criteria have been developed to evaluate qualitative research (Elliot et al, 1999; Yardly, 2000, 2008). Yardley's (2000, 2008) criteria have been applied to this study as they are commonly cited by IPA researchers (e.g. Smith et al, 2009). These criteria include issues relating to the sensitivity to context; commitment and rigour; coherence and transparency; and impact and importance. The ways in which the research addressed these elements are addressed further below.

3.9.1 Sensitivity to context.

This criterion is concerned with the extent to which new ideas emerge, whilst considering the possible interactions between context and time (Yardly, 2008). In order to ensure research is

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[16] A detailed audit trail demonstrating the stages of analysis for one participant is provided in appendix O. In addition, the superordinate and subordinate themes for each participant are provided.

[17] An example of how these themes developed across participants is provided in appendix O

sensitive to context, attention should be given to the current theoretical thinking within the relevant areas of research, in addition to the consideration of context and perspectives of the participants (Yardly, 2008). This standard was addressed by ensuring an extensive and systematic search of the literature was conducted, in addition, to a wider examination of psychological theory (see chapter 1). This review highlighted some of the dilemmas that families face, in addition to views of CYP who live with parents experiencing mental distress with a focus on their experience of talking. However, it highlighted a gap in knowledge which led to the development of the current study's focus. This focus not only contributed to the development of questions of interest but also helped contextualise some of the findings. In addition, details of the family context were collected (e.g. family composition & parental diagnosis), in order to help situate the sample. In addition, the researcher attended the Kidstime workshops as part of the research process, which allowed them to gain some knowledge of the interventions offered to these families.

A semi-structured interview schedule was developed to provide a guideline of open-ended questions that offered the opportunity for participants to describe their experiences, which allowed for exploration of individual perspectives. This included a question which invited CYP to offer any additional information that had not been covered by the interview questions. The researchers use of a reflective diary allowed for consideration to be given to the influence of the researcher on the process and highlighted the influence of contextual factors on the interview process (e.g. rapport, power dynamics & interruptions). Furthermore, due to the differences in the difficulties experienced by the parent and the range of ages, consideration was given to developmental stage of the child and their experience of mental distress.

3.9.2 Commitment and rigour.

Four criteria which help to ensure commitment and rigour have been suggested: thorough data collection; depth/breadth of analysis; methodological competence; and in-depth engagement with the topic (Yardley, 2000; 2008). Due to challenges in recruitment, there were limitations in the homogeneity of the sample. However, the recruitment phase was extended to allow for thorough data selection and more interviews were scheduled to ensure the thickness of data. In addition, attendance of teaching in IPA, extensive reading on IPA and close supervision with a researcher who was knowledgeable about IPA allowed for the development of competence in this model. Furthermore, independent analysis of an interview transcript was undertaken by the research supervisor, which allowed for further discussion and agreement of emergent

themes. Finally, findings were discussed within a peer IPA support group of three trainee psychologists who fed back on their views of my themes. Substantial time was given to ensure in-depth engagement with the topic of interest. This included attendance at training events and engagement with the Kidstime project; substantial time spent examining the literature and considerable time spent both reviewing and analysing the transcripts.

3.9.3 Coherence and transparency.

The coherence of the study refers to the fluency of the research e.g. the fit between the theoretical approach and basis of the research, the research question and the chosen design and analysis used (Yardley, 2008). The introduction and systematic review presented in the previous chapter provide an overview of why this research is being undertaken and highlight the need to explore this area of research from the perspective of the child. Furthermore, the research aims to explore CYP's lived experience and therefore the choice of a qualitative approach is appropriate.

Transparency of the research is concerned with the extent to which the reader can follow what was done and why (Yardley, 2008). Detailed descriptions of the methodology are provided throughout, along with the rationale behind these decisions. Personal reflections are offered[18], highlighting the ways in which the researcher engaged in a reflexive process. Furthermore, examples of each stage of the research process are provided in the appendices. Finally, the themes generated are demonstrated using verbatim quotes, which allows for the reader to enter the world of the participant (phenomenological stance).

3.9.4 Impact and importance.

Consideration was given to the usefulness of this research in relation to the impact and importance of the findings. It was clear from the previous research presented that this population often remain invisible and weaknesses in service structures can exacerbate this problem (Loshak, 2013). Very little research has examined how these CYP utilised their support networks within the community. However, CYP have emphasised the importance of

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[18] Extracts of my reflective diary are included in appendix D

support in helping them cope with living with a PEMD. Therefore, it is important to consider in what way their peers can provide this, and the barriers that prevent them from doing so. The research may contribute to the possibility of designing interventions that can reduce these barriers or highlight areas for extra support services.

Chapter 4: Results

4.1 Overview:

This chapter presents the findings of an Interpretive Phenomenological Analysis of six interviews which were conducted with CYP who live with a PEMD. The analysis focused on examining the conversations these CYP had with their friends about their lived experiences.

Three super-ordinate themes emerged from the analysis (see table 4). These themes should be viewed as one possible interpretation of these accounts, and as a co-construction between the interviewer and the participants. The results aim to provide an insight into CYP's experience of having conversations and bring these idiographic accounts to life. From the process, it was clear that their experience and beliefs about talking were closely linked to the context in which they lived and therefore there was some variability in how they related to each of these themes. Furthermore, the process of conducting the interviews themselves provided an insight into the challenges of talking about their PEMD. These aspects will be explored further in the discussion[19].

The results are presented below with a summary of each overarching theme, broken down into further subordinate themes (see table 4). Following the summary, a more detailed account of each subordinate theme is given and participant quotes are used to demonstrate how CYP's experiences have been understood. Some of the quotes used have been edited for clarity.[20]

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[19] The researcher's reflections are provided in appendix D

[20] … indicates some words have been removed for readability; words in [] indicate a word has been added to help contextualise the comments made.

Table 4.

Superordinate and Subordinate Themes

Superordinate theme	Subordinate theme
Fitting the puzzle together	Trying to develop an understanding of mental distress
	Making sense of 'normal' and 'not normal'
	Gaining the confidence to explain the terms
	Becoming aware of stigma
Finding the experience of talking risky	Fearing the consequences of telling others
	Struggling to find someone to trust
	Being cautious about what is shared
Coping with the up and down rollercoaster	Coping in isolation vs connecting with others
	Changing the subject and seeking normality

4.2 Fitting the puzzle together

4.2.1 Overview.

"I just think like, what I can see and what I can hear and what I can like feel. I like guess that's how it is…like try to put it altogether to make one big thing to explain it." (Charlie)

This super-ordinate theme reflects the ongoing process of how the participants were making sense of their parent's experience of mental distress, which impacted on both whether they would talk to friends and what they would say. As part of '*Fitting the puzzle together',* four subordinate themes were identified, namely 'Trying to develop an understanding of mental distress'; 'making sense of 'normal' and 'not normal''; 'gaining the confidence to explain the terms'; and 'becoming aware of stigma'. These are described in more detail below.

4.2.2 Trying to develop an understanding of mental distress.

This theme reflects the gradual and ongoing process of CYP's journey of gaining an understanding of their parents' experience of mental distress. Despite CYP's understanding varying across interviews, they were all seemingly still trying to make sense of their experiences. During the research interviews, younger CYP seemed hesitant when asked questions about their understanding of mental distress. Sometimes it was unclear whether this was due to finding it difficult to describe what they meant, an uncertainty about whether their understanding of terms was correct, or a fear of saying the wrong thing.

Younger participants seemed to make sense of mental distress by drawing on their knowledges of physical ill health and disability. George simply stated "I don't know" when asked about the difference. The following extract shows Charlie's confusion over the causes of their mother's 'highs and lows':

> *Charlie: "[Mum]has like highs and lows and highs blood pressure…*
>
> *Interviewer: so when you say high and low do you mean her mood is high and low or is that more kind of her physical health?*
>
> *Charlie: …I don't know. Because once her blood pressure was like really low and she couldn't go anywhere and she had to go into hospital."*

Older participants seemed more able to distinguish their parent's experience of distress and describe a person suffering 'mentally',

> *"It just means that… people are suffering mentally and they find it hard, like harder than every day to day people." (Alex)*

In the quote below, Jo appeared able to distinguish their mother's physical illness, described as *"something's wrong with her nerves"* from her experience of having *"something else mentally"*. However, despite this distinction, Jo seemingly did not distinguish between their experience of these difficulties, as they were told that their mother sometimes found it "*hard to do things.*" Despite this awareness and being older, Jo still reported a struggle to understand what these difficulties meant:

"Well, I don't really [understand]. I haven't read anything to say that she has anything. I've just heard it from her. She said "I've got this…I can't do this…I find it hard to do this". I don't really fully understand it really. All I know is it's something with her nerves and that's it. But she's always going on about something else mentally and I don't understand that either." (Jo)

All participants described an experience of learning about their PEMD over time. By being vigilant and noticing what was going on around them, they appeared to start putting the puzzle of their parent's experience of mental distress together. These experiences are illustrated in more detail below.

All CYP found it difficult to articulate their experience of finding out about having a PEMD, with many showing hesitation and uncertainty when asked. Charlie spoke of recalling their[21] mother having a conversation with them about mental distress, whereas at other points in the interview, Charlie, was unsure whether an explicit conversation was had. However, it was clear that they found it difficult to recall the details of this conversation:

"I think I just like gradually realised and she like told me… I don't know…. I don't know what age I was when she told me, I don't even think she told me… I think I just realised and then like she told me. I don't know" (Charlie)

Sam reported difficulty recalling how they found out that their PEMD, but described noticing more and more over time, suggesting their awareness had grown gradually over time.

"I don't even remember…It was erm, like a few years ago that I started noticing a bit more and more." (Sam)

All of the CYP spoke about having little awareness of their PEMD, when they were younger, but there was a variation in when CYP started to notice their parents were experiencing mental distress. This varied, from early to late adolescence. Andie describes moving from a position of not knowing what was happening, to a place of better understanding:

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[21] No gender specific pronouns have been used to preserve the anonymity of the young person interviewed

"I think [my understanding] was better than then because... I didn't really know what was happening. But now, I know that it's just like, certain people." (Andie)

Jo spoke about not realising until the age of 15 or 16, despite having noticed changes in their parent's behaviour when they were younger, suggesting the difficulties were around earlier:

"Well, I didn't really notice that she was unwell when I was younger...I only really noticed when she was like, when I was like maybe 15 or 16, I'm not sure. Then she...got diagnosed...not very long ago, so that just clarified it. Because nobody knew what it was. My mum had it a few years." (Jo)

Here we see Jo trying to make sense of what they observed together with what they were told. This seemed to be a common experience of other CYP who were interviewed.

Despite developing more of an awareness of their PEMD, CYP often reported not fully understanding what led to the changes they observed in their parent's behaviour. Lack of explanation or clarity appeared to leave some young people feeling confused. For example, Andie spoke about noticing their mother shouting a lot, but reported feeling confused about this experience:

"I didn't really understand why she was shouting...I just thought she was stressed and I would just let her shout....I just, just was confused really." (Andie)

One of the ways CYP seemed to develop an understanding of their parents' experience of mental distress was through observing changes in their emotional state and behaviour. For example, George described their mother as being *"moody and tired",* Charlie noticed their mother *"couldn't always be happy",* Andie spoke about their mother seeming "always stressed". Sam also noticed their mother "cleaned a lot" and Andie noticed *"my mum always got shouting".* Other CYP noticed the differences between their parent and other people and highlighted their parents' difficulties with everyday things. For example, Alex noticed the challenges their mother faced day to day:

"I think she finds sort of like, the normal things like, the every day to day people do, like getting up and stuff a lot trickier than other people." (Alex)

Similarly, Jo noticed their mother slept more than usual, and they felt this may be her way of coping with her experiences of distress.

> *"She'll get exhausted very easily…she'll get up, she'll take [my sibling] to school, she'll do a bit of housework… If she's really not feeling well she'll probably go back to sleep again. I think that's maybe her way of like escaping how she's feeling at the time." (Jo)*

It was clear from these descriptions that CYP learnt a lot about their parents' experiences of mental distress through what they observed in their parent. In addition to observing changes, CYP spoke about noticing things around them. For example, Sam spoke about noticing a letter on the fridge which informed them about their parent's diagnosis; however, they were left to make sense of what this meant.

Charlie spoke about finding out more from hearing some of their mother's conversations after noting that people rarely spoke to them directly about what was happening. Charlie's experience of overhearing sensitive conversations was not described as a purposeful act, suggesting that conversations were happening around them. However, Charlie seemed to have an awareness that these conversations may not have been meant for them, and therefore should not be shared with others:

> *"I'm not the person who goes up to like her and like hides behind bushes whilst she talks about people, talks to people about it. I'm not like, I do hear some of her conversations. But I'm not saying like I'm going to blurt some of it out and say it" (Charlie)*

Although Charlie, stated they didn't 'hide behind bushes' this was a powerful image which seemed to demonstrate the lengths CYP went to in order to find out what was going on.

Charlie, highlighted their awareness of the severity of their mother's difficulty when discussing what they would or wouldn't tell others. This illustrates how distressing some information that they are exposed to can be.

> *"if I said that oh, my mum was going to kill herself because she has like mental illness."*

These accounts demonstrate how much CYP can pick up from what is going on around them, yet the lack of conversation seems to imply a sensitivity about talking about these issues openly within the family.

All of the CYP involved in the study were recruited via Kidstime, a support service which provides information and support to families where a PEMD. Therefore, CYP had a supportive space to speak with professionals, from which they said they benefitted. CYP expressed the benefit of this space. This support not only provided CYP with information about mental distress but also gave them the opportunity to talk to experienced staff, open up conversations with family members within a safe environment but also give them a space to have their questions answered. For example, Andie spoke about the positive experience of being able to develop a better understanding through attending Kidstime:

> *"[Kidstime] just like a lovely place there…if you have any questions they will answer it…But if, but if, without that, it would just be quite hard."*

Although for the most part, CYP said they benefitted from being given information, the two older participants, expressed drawbacks from knowing too much.

Alex reported feeling unsure about whether more information would be helpful. In the following extract Alex describes their fears about finding out more:

> *"The bad thing is [someone talking to me about] it might make me a bit more upset but the good thing they might make me realise more and give me more understanding of it."*

In summary, most of the participants described the experience of fitting the pieces of the puzzle together as a gradual process, that developed over time. CYP expressed some uncertainty in being able to identify how they found out about it. Instead, they spoke about different experiences that they had that increased their sense of understanding, including observations of their parents, conversations that they had, things they overheard or things they saw on documentation. Understanding seemed to be influenced by their age and their experience of talking to others, either inside or outside the home. Most of the participants reported benefit from an increased understanding, but others seemed more hesitant, as the experience of finding out more could feel quite distressing.

4.2.3 Making sense of 'normal' and 'not normal'.

This subordinate theme illustrates the ways in which CYP made sense of what they saw as 'normal' or 'not normal' aspects of mental distress. On the one hand, CYP described their

understanding of the ways in which people experiencing mental distress acted differently to others, at times. Yet, on the other hand, they spoke about the 'normality' of the problems their parents faced. Furthermore, they described their parents' characteristics primarily as parents, rather than as people with mental health problems. In addition, they were able to recognise their parents' own personal qualities as parents rather than people experiencing distress. It appeared as though the CYP's sense of the difference between 'normal' and 'not normal' seemed arbitrary.

Many of the CYP in the study described feeling as if their parent's experience of mental distress was not a 'normal' part of life. For example, Charlie conceptualised their parent's mental distress as outside of normality:

> *"Mental health means that like (3s) people with mental health aren't normal."* *(Charlie)*

Charlie goes on to describe their own experience of living with a parent experiencing mental distress:

> *"It's not really that hard, it's like…it's a bit weird." (Charlie)*

Similarly, Alex describes experiencing their mother as different from other people:

> *"she's not normal if you know what I mean. She's different to other people. She suffers with things." (Alex)*

It is interesting to note that Alex states clearly that their mother is 'not normal'; however, in terms of describing what that means, there appears to be much less detail and certainty. Andie described how they used to feel their parent's difficulties were 'normal', but how they came to see their parent as different to others, by seeing their mother's anger as an expression of her mental distress. However, this process seemed to result in some conflict, as Andie wrestled with the idea of their parent's experience being 'normal but not normal':

> *"I thought every parent would shout you know, because it's really hard work being a parent. So I just literally thought that's normal but then…it isn't, it is but then it's not. Cos not everyone has it like that." (Andie)*

Andie describes the common experience of mental health problems but appeared unsure about when these experiences become "proper". It is unclear whether knowing where the line between it being an experience that everyone shares and it becoming "proper" is.

> *"Cos everyone has like mental health but it's not really like proper until, I don't even really know." (Andie)*

Similarly, Sam emphasised the 'normal' nature of the experience of mental distress, mentioning that everybody experienced problems, and many people experienced mental distress:

> *"Because everybody cleans and everybody's like exhausted. So her mood's just the same. Just diagnosed with something" (Sam)*

In concluding that everybody cleans to some extent, Sam describes their mother's diagnosis as something that appears less relevant. Sam goes on to differentiate their mother's experience from other types of mental distress. This distances their mother from those whose experience they describe as 'bad':

> *"everybody has problems and it's normal like. Lots of people have like mental health and some mental health can be good mental health, some mental health can be bad mental...Bad mental health would be like really bad, they really need to go to the hospital or something. I think my mum has the good mental health, I know she does." (Sam)*

Sam appears slightly tentative about saying their mother has what they conceptualise as the *"good"* or *"bad"* mental health at first, but goes on to emphasise this is something they know.

In addition, to normalising their parents' mental distress, CYP were keen to emphasise other aspects of their parent, rather than focusing on their mental health difficulty. For example, Charlie described their mum's unique qualities:

> *"yeah because even though she has bipolar and a lot of other mums have bipolar and all that. She's herself... She isn't like everyone else. She has her own view, she has her own perceptions" (Charlie)*

Charlie seems to try and distinguish between their mother's 'bipolar' and how they imagine others who 'have bipolar' to be, whilst acknowledging their mother is unique and more than her diagnosis.

Similarly, it seems important for Jo to distinguish between someone who might be 'crazy' and their own parent who is described as 'not well'.

> *"Cos like, I don't want people to say "oh, your mum's mental, she's crazy" or something like that. Because she's not, she's just not well." (Jo)*

This distinction has implications for talking or keeping silent with their friends, which will be returned to later.

In summary, it appears that CYP struggle to work out for themselves what 'normal' or 'not normal' means. Most young people felt their parents were within what they saw was 'normal', whilst also experiencing them as 'different'. It seemed at points this distinction still caused CYP some confusion, but the process of normalisation seemed to have a reassuring quality. However, the perception of difference seemed to cause CYP some discomfort, as they feared how this would be perceived by others. However, despite this dilemma, the young people used normalising concepts to explain their understanding of mental distress, and tended to focus on their parent's attributes rather than their mental distress.

4.2.4 Gaining the confidence to explain the terms.

This subordinate theme reflects CYP's struggle to translate the meaning of more diagnostic or professional terms into their lived experience. When asked to explain the meaning of terms such as "mental health problems" or their parents' diagnosis, most CYP (especially those that were younger) struggled to put these concepts into words. This seemed to lead them to feel less confident about what they understood and how to talk about it. When it came to explain changes they noticed in their parents, their talking seemed to become more fluid and they were able to describe their experience using everyday language, and this allowed them to feel a bit more confident about providing a bit more depth to their answers. In general, when it came to talk about their parents' experience of mental distress with others, they spoke of rarely using these terms, and when they did they felt unsure what others understood of them. At times, their lack

of understanding of the terms led to feelings of uncertainty that prevented them from speaking to others about it.

 Many young people had heard terms such as "mental illness", "mental health issues" or just "mental health", which they seemed to use to communicate an experience of mental distress. Sam, however, stated *"I don't really use terms like that"*. Furthermore, some young people stated they used one term, and later switched to other terms, perhaps suggesting they were repeating phrases they had heard from others. For example, Charlie spoke about preferring the term *"mental health"* but later used the term *"mental illness" and "mental health issues"* when discussing their parent's difficulties.

In the following extract, Charlie tries to put the term "mental health" into their own words, but despite grasping some of the concepts they find it difficult to explain what they want to say:

> *"Mental health means that like (3s) people with mental health aren't normal. They have like disabilities with er specific things and erm (4s) I don't know how I would explain it but that's all I can say" (Charlie)*

Similarly, CYP often seemed aware of the diagnoses their parents had been given and named these within the interview process, either through being asked or by bringing it up themselves. However, when asked what the diagnosis meant, CYP would often provide explanations that had been given to them by others, yet they still reported feeling unsure about the meaning. This is demonstrated by the following extract from the interview with George:

> *Interviewer: Does your mum have a diagnosis?*
>
> *George: I think she's got Bipolar*
>
> *Interviewer: Bipolar, ok. So what does Bipolar mean to you?*
>
> *George: I don't know*
>
> *Interviewer: How did you find out that she's got Bipolar?*
>
> *George: I think she told me it's like ups and downs.*

However, when George was asked directly about what they noticed about their mother's ups and downs, they were able to give a description of what they noticed. For example, George described their mum's highs as *"When she's all happy and excited"* and her lows as *"When*

she's moody". So George seemed unable to relate these observations to the term 'bipolar', without being prompted.

Alex seemed confused by the question asking them to explain the meaning of their mother's diagnosis, and this led to some hesitation in their response. However, they were able to find ways of describing their experience of how this impacted on their mother:

> *"Well, depression erm (wry laugh). I don't know, she just finds it hard to like, deal with her emotions" (Alex)*

One way of viewing this confusion is that the word "depression" is used frequently in everyday language to reflect a mood state, so it may be more of an accepted term and one which is seen to reflect the lived experience within itself.

Despite Sam stating that they didn't use more medicalised terms, they were able to recall their parent's diagnosis but struggled to identify what the abbreviation stood for. Instead, they translated this into how they understood their parent's actions:

> *"I only know OCD (pause). It's obsessive (pause) cleaning disorder and it means that they clean a lot" (Sam)*

In addition to professional terms not feeling meaningful for the CYP, the participants described avoiding these terms outside the house. For example, when Jo was asked whether they used any terms like "mental health problems" they noted that their mother used them to explain the reasons why she found certain things difficult. However, they noted that outside of these contexts the terms didn't get used:

> *"Well in the home… she's always saying "Oh, with this mental illness I can't do this" …. Not really outside, it's not really mentioned so much"(Jo)*

Furthermore, Sam spoke about not wanting to use terms when they didn't understand, leaving them to avoid using diagnostic language when speaking to others:

> *"Cos I don't know what BPD means and stuff like that so I wouldn't want to like talk about that because I wouldn't know what it means and stuff" (Sam)*

Furthermore, CYP spoke about how the process of talking to other people their age enabled them to build their confidence about talking about their parents' experience of mental distress.

This was mostly through starting to speak to other young people with a shared experience at Kidstime. Through doing so, the young people seemed more hopeful about the possibility of being able to open up to their school friends:

> *"It makes me more confident to talk about it…so one day I can talk about it more, about mental health to like my best friend" (Sam)*

In contrast, Charlie spoke about how they would tell their friends about their parent's experience of mental distress, using professional terms. However, they seemed uncertain about what their friends understood by this:

> *"…I think she knows that mum has mental health issues and like all that" (Charlie)*

In contrast, Andie spoke about the usefulness of being able to give their parent's mental health difficulty a name in order to understand it:

> *"[A professional would] draw like a erm a body and of like mental health is like, labelling like the brain and stuff, what like stress and like how it's caused and stuff. And then, I think that's when I first knew what it was really about." (Andie)*

Whilst CYP tried to make sense of these terms, some CYP seemed to notice the negative connotations that seemed to be associated with these terms.

In the following extract, Jo distances their mother's experience of mental distress from the word "mental" which they associate with more unusual presentations. This may illustrate how they construct the word mental, based on the widely held societal beliefs:

> *"In my view, somebody that's not very aware or conscious of what's going on and my mum is aware and conscious of what's going on. Cos you see it like in films there's people that are just like staring and don't know what's going on. That for me is like mental." (Jo)*

This theme explores CYP's experiences of the use of more medicalised and diagnostic terms to explain their parents' experience of distress. Despite these terms having some practical use for the young people in the study, it seemed as though the use of these terms did not facilitate their understanding and left them with feelings of confusion. There seemed to be a mismatch

between being told the terms and knowing how these translated into both their own and their parents' experiences. Knowing these terms but not understanding them fully could potentially inhibit conversation with others. This is considered later.

4.2.5 Becoming aware of stigma.

As described above, CYP voiced their observations of the negative connotations that they sometimes saw being associated with mental distress. Although only one young person named this as stigma associated with mental distress, it seemed CYP started to develop a sense of this from a young age. This seemed apparent in how they felt others would react to mental distress, amplified by media messages further informed this view. Furthermore, some CYP voiced a sense of their parent's fear of stigmatisation.

During the interviews, CYP voiced their frustration and discomfort at the language used to describe their mental distress. This included associations with the word 'mental'. For example, Alex described feeling how the word 'mental' was associated with being 'unstable':

> *Alex: "I think it's the word 'mental'. It sort of, it comes across to like people that doesn't have mental health issues. It might come across to them, oh are they literally mental sort of thing.*
>
> *Interviewer: And what do you think that word 'mental' kind of evokes in people?*
>
> *Alex: Crazy, sort of, completely unstable."*

Later Alex describes one reason why others may think all people with mental health difficulties are "crazy". Alex concludes that this image may be valid for people who have more severe experiences of mental distress. Alex might feel worried that others would associate these images with their parent:

> *"I think it's when you see some people being put into asylums and stuff like that. Sort of being sectioned. But I don't think they realise that's sort of the severity, like the most severe cases." (Alex)*

Andie seemed to voice a sense of frustration at the media's way of depicting "mental asylums" and considered how this may skew people's views of others:

> *"in like programmes they go to mental asylums. They probably think that's why they're crazy because they have to go there but it's not really true or whatever" (Andie)*

Similarly, Jo came across as a little uncertain about what the media was trying to depict through the characters that seemingly experienced mental distress:

> *"...there's a film where someone has an imaginary friend and it turns out it's just another part of himself ...There's another one called "me myself and Irene"...And that's split personality disorder. I think that's mental, I'm pretty sure that is." (Jo)*

In addition to the way a person experiences mental distress is portrayed in television, Andie also pointed to the inaccurate accounts of people experiencing mental distress in newspapers and magazines:

> *"newspapers they just write about rubbish really and then people think that's true but it's not." (Andie)*

In contrast, Alex described the positive attempts by the media to represent the experience of mental distress in a good way, and in turn help to build awareness and reduce stigmatising attitudes:

> *"I think the media does sort of represent it in a good way because you see those documentaries of teenagers with mental health, adults with mental health and it sort of tells their story of it. So I think that will help people understand more" (Alex)*

Regardless of the reason for the development of stigmatising attitudes, CYP expressed an awareness of how stigma can impact on how others respond. For example, Alex spoke about their mother's embarrassment of letting others know about her mental distress, due to the stigma held in society:

> *"Because she probably doesn't want people to know. Probably because...she might be embarrassed about it but it might also be the fact that there's a stigma attached" (Alex)*

In summary, CYP seemed to express an awareness of the existence of stigma related to the experience of mental distress and this appeared to make them feel worried that negative images

of mental distress would be associated with their parent. Generally, CYP seemed aware of, but uncomfortable with, the portrayal of mental distress in the media, although there was some recognition of positive attempts to build awareness. Their perceptions of how the media wrongly portrayed mental distress, appeared to result in uncertainty and frustration. It seemed as though CYP experienced their parents as something differing from stigmatizing images portrayed, but felt worried that others would not be able to make this distinction.

4.3 Finding the experience of talking risky

4.3.1 Overview.

"some people…they'll say it to someone else and they might make fun of it and I'll get upset a bit, so I would prefer to keep it to myself and stuff…They'll just start laughing…repeating it…just getting rude about it and just going on with it for like weeks and weeks, so I just don't say it." (Sam)

This superordinate theme attempts to illustrate CYP's experiences of the challenges they faced when they considered sharing their experiences with other people, including their peers, family members and professionals. 'Finding the experience of talking risky' incorporates the themes 'fearing the consequences of telling others'; 'struggling to find someone to trust' and 'being cautious about what is shared'. These are described in more detail below.

4.3.2 Fearing the consequences of telling others.

CYP often described their preference not to tell other people about their parents' experience of mental distress. When questioned about the reasons behind this, it seemed there was an inherent fear of the consequences of sharing. This fear sometimes led them to worry about how other people of their age would react, and this was linked to their understanding of stigma associated with mental distress. CYP described worrying about both the personal consequences and consequences on others from generalised negative reactions. This included a concern for their parent, but also a concern for their friends. Furthermore, some participants worried about the consequences of professionals finding out and the "mayhem" that this may cause. This seemed to be linked to a fear of being taken into care, or a fear of the consequences for their family. Participants seemed to voice a lack of agency when it came to the reactions of both professionals and friends, and this led to an uncomfortable uncertainty about the consequences of letting others in.

Every young person interviewed voiced their fears of their peer group finding out about their parent's experience of mental distress. Charlie felt something bad might happen if other people found out:

> *"Cos sometimes I just think that if I say something that I shouldn't have I'll get like something bad for it." (Charlie)*

Three of the young people spoke about their fear that CYP would tell others and they worried about it being spread around the school:

> *"I really don't really tell people a lot because they will spread it. Or like they could like muddle up my words or whatever" (Andie)*

Every participant was concerned that other people might make fun of them or say unkind things about their parents. The thought of other young people being mean or making fun of their parent led CYP to worry about the impact this would have on their own emotions.

Andie described an experience of others making fun of them about their parent's mental health difficulties; there was a sense that they had been subject to, or observed young people being horrible:

> *"people are just so childish, they just make an excuse to … just make you down and then, it doesn't always work but and then, they'll just think, they just try and try again and they'll just say stuff about your parents. And then that's what makes you really like angry or sad. And it's not really nice because if they had that they wouldn't really want people doing that to them." (Andie)*

Both Andie and Alex expressed a worry that people's comments would be harder to brush off if they were about their parent:

> *"I think [talking] would upset me, I wouldn't be able to brush it off because it was to do with my mum" (Alex)*

Andie also voiced a concern that if people found out, they would no longer want to be their friend:

> *"I don't really want them to get uncomfortable and then not be my friend." (Andie)*

Charlie worried that others finding out would lead them to question them about their mother, and feared not knowing how to respond:

> *"I would feel like [peers] would come up to me and like say "oh is this true, oh is this true?" I don't know how I would respond to that." (Charlie)*

Furthermore, Charlie spoke about others finding out as though it was one of the worst things that could happen:

> *"[if people found out] I would feel like really sad, scared and like worried…like confused. It would be like unreal, like situation that has actually become reality." (Charlie)*

In addition to fearing the possible emotional consequences of others being mean to them, they also expressed a fear of upsetting their parent by telling others. This is illustrated by the following extract of the interview with Alex:

> *Interviewer:…you mentioned earlier that your mum might be worried about what people might say or think. Do you think that impacts on what you think you can say about it?*
>
> *Alex: Yeah, because I don't really want to go behind my mum's back and start telling people.*
>
> *Interviewer: …how do you think it would leave your mum feeling.*
>
> *Alex: She'll feel upset and disappointed because it's something that's personal to her.*

However, despite this fear, some CYP voiced their appreciation that their parent would probably be supportive if they chose to speak to other people about their parent's experience of mental distress. However, this seemed to be on condition that they were a trustworthy person:

> *"I'm not sure [how mum would react], one time I told my best friend but her dad had it... But [she] was a really good friend and [mum] knew the mum and dad. Like she talked to them and stuff… I think she thought it would be good that I could talk to someone and not like bottle it up…" (Andie)*

In addition to their fear of the impact on themselves and their parent, they also feared how telling their friend could place an undue burden on their friends. For some this was a fear of making their friends feel uncomfortable or upset:

> " I don't really want to bring it up with [my friends] because they might feel uncomfortable." (Alex)

Charlie had a more positive view of telling their friends. However, they showed concern over the burden that they may place on them. Especially because it was important that their friends kept their secrets to avoid professionals finding out. This seemed to be due to their previous experiences of the involvement of social care. They felt this left a large burden on their friends, as some of the things that they told them were hard secrets to keep.

> "Like if it was like very serious and like that she couldn't cope keeping it and like not saying anything about it" (Charlie)

This fear of professionals finding out was bigger than Charlie's fear of other people spreading rumours or making fun of them. Charlie was less aware of the stigma linked to mental distress, but their experience had highlighted the safeguarding role that professionals, including teachers, played and how this impacted on their family. Therefore, they feared the *"mayhem"* that would result if their secrets got out:

> "I would get like support and mum would like get a phone call and like all that and like all the mayhem. I would like have to like go into care because she gets so upset." (Charlie)

Within this process, Charlie acknowledged that even their good friends might have to break their trust in some situations and gave a sense that they had little power in preventing this from happening. Charlie's lack of agency in what would happen next led them to fear telling people what they wanted to:

> "even best of friends are going to sometimes betray you. But I mean that's life, like you can't stop it from happening" (Charlie)

This fear also went beyond their fear of telling peers, as Charlie also felt extremely cautious around what they told adults. This seemed to be demonstrated within the interview process. On

a number of occasions, Charlie used the phrase *"blah blah blah"* to fill in the details of what they might say to people they trusted:

"I just go "blah" like "blah blah blah". Like, like whatever the situation is." (Charlie)

On other occasions, Charlie would hint at something but would then struggle to put it into words:

> *"there are reasons but sometimes you can't really explain it, you can't really like say. Like, yeah" (Charlie)*

It seemed as though some of Charlie's tentativeness was linked to not knowing how to say something. At times, they appeared very cautious about what they were saying and it seemed to be linked to their fear of what might happen if I found out what they were thinking.

Similarly, George struggled to make eye contact during some of the interview and answered "I don't know" to many of the questions. However, at times George also started to say something and then stopped:

> *Interviewer:…Do you think your mum's moody is different to other people's moody or do you think it's the same?*
>
> *George: I think it's…[3s]. I don't know*
>
> *Interviewer: You looked like you were just about to say something, what were you just about to say?*
>
> *George: Yeah I forgot about it*

In summary, all of the CYP interviewed voiced their fear of the consequences of talking to others. This included the consequences to them (e.g. people making fun of them or not wanting to be friends); the consequences to their parent (they might get upset); the consequences for their friends (e.g. the burden of having to keep the secret); and finally the possible consequences from professionals of being taken into care. It seemed that this fear went beyond speaking to other CYP, and it seemed apparent that they found talking risky even in the interview process.

4.3.3 Struggling to find someone to trust.

The CYP's experience of working out who to trust is reflected in this theme. For some, trusting peers, even close peers, was something that felt too difficult. However, they often reported a desire to trust others. Others spoke about trusting their 'best' friends and confiding in them to some extent. The reciprocity of trust was a determinant of whether CYP could allow themselves to build trusting relationships. Telling their friends about their PEMD fully depended on developing a trusting relationship and this took time. When it came to trusting others, CYP seemed more likely to trust people who were likely to understand through having a shared experience of living with a PEMD. If they perceived someone as having a similar experience they seemed more confident that the person would understand. Conversely, they often perceived their peer group as one which lacked understanding, due to their lack of awareness of people's experience of mental distress.

All of the CYP brought up trust in relation to talking to their peers about their parent's experience of mental distress. George spoke about how they wouldn't confide in anybody about their mum's experience of mental distress, due to a lack of trust:

> *Interviewer: Would it be something that if someone kept it secret…?*
>
> *George: I wouldn't trust anybody*
>
> *Interviewer: You wouldn't trust anybody? And what stops you from trusting people?*
>
> *George: It's just [3s] …it's me, I don't really trust a lot of people*

Andie spoke about the struggle with trust, as they were keen to find a way to trust their friends but felt unable to do so. At times Andie spoke about how they '*should*' trust their friends, as they often share things with Andie. Andie reflected on the possible benefits of being able to trust others:

> *"Because they tell me stuff, and obviously they trust me, so I should trust them. But sometimes I feel like "should I trust them?" … I just really wanted to talk to people and then I didn't really trust them…" (Andie)*

Struggling to trust seemed to be common among the CYP, with many stating they would only trust a 'best' or 'very close' friend.

"I've only ever shared it with my best friend, who I've been best friends with for about 4-5 years so… I only told her about a year ago so it wasn't sort of straight away." (Alex)

Time did seem to be an important factor when CYP were deciding whether it was possible to develop a trusting relationship:

"I need to know someone a bit longer than, I don't know, a couple of months, before I let them in. So, I want to know them, I want to make sure they're alright." (Jo)

Developing a sense of trust and knowing their friends were empathetic and understanding, would reduce CYP's fears of others reacting negatively:

"I guess I don't think she'll sort of say "oh, your mum's crazy" or stuff like that. I know that she won't say anything like that and she can possibly understand"(Alex)

CYP also spoke about being able to trust other CYP who had similar experiences to them e.g. living with a PEMD. They perceived people with this shared experience as more understanding and therefore less likely to make fun of them. Therefore, participants often found CYP that attended Kidstime a source of support:

"Cos, the people at Kidstime, they understand it more. They won't take it as a joke, if you know what I mean, some people at school will take it as a joke" (Sam)

"Me as well, like with talking, with my friends [at Kidstime] I can say it, because I would know that they all know what I'm going through." (Andie)

Jo also spoke about close friends that had a similar experience:

"Well, he's basically the same as me but cos his mum's not well and his dad's never there, it's exactly the same as me, so I guess that's one similarity and that's maybe why we always tell each other what's going on..." (Jo)

However, even though people tended to confide in those they knew would understand, some were surprised by how understanding other people could be. Andie described how helpful a new friend was, when they opened up :

"….a couple of years ago I got a new friend….I just told her and she really helped me, even though…her parents…didn't….[have] mental health. But she still got me through, like when I was low about my mum, she always helped me, even though she didn't know what was really happening, but she did help a lot." (Andie)

Despite developing trusting relationships with their peers, some of the CYP still felt unable to trust their peers and tended to turn to trusted adults. For example, when CYP had another parent, grandparent, or sibling that they felt close to, they often chose to speak to them:

"I think with my dad because he'll know me and stuff and he can kind of try and cheer me up or help me" (Alex)

Other CYP spoke about being able to confide in professionals, such as teachers or mental health professionals at Kidstime. However, this depended on the context of these relationships and building a trusting relationship determined if they confided in others. For Charlie, the experience of being put into care meant they found it difficult to trust professionals:

Charlie: sometimes I find it hard to talk to teachers. Like if they're not in my surroundings…

Interviewer:…what is it about teachers that are difficult

Charlie: Just like the way they speak, like sometimes they can be a bit harsh when they speak, like harsh tones.

In summary, building trusting relationships seemed a difficult task for the CYP in this study. Knowing someone for a long time or meeting people who understood what they were going through seemed to help CYP build trusting relationships. Despite CYP expressing a struggle to trust others, it seemed a positive experience when they could do so. Sometimes they could not build trusting relationships with their peers but were able to develop a trusting relationship with an adult. However, the CYP's context seemed important in influencing their decision.

4.3.4 Being cautious about what is shared.

This theme relates to CYPs perceptions of the sensitivity of talking about their parent's experience of mental distress. CYP seemed very aware that they were talking about their parents' difficulties and therefore that it was not their place to do so. Participants often perceived family affairs were personal and should therefore be kept private. Even if they had

informed their friends about their parents' experience of mental distress, they were often likely to avoid talking about their experience openly. When they did talk to others about their parents' experience of mental distress they were careful about what they shared.

All of the CYP spoke about having a PEMD as something that was private or personal and therefore they believed it shouldn't really be shared with others, outside the family home. They were keen to emphasise their own agency in the decision to talk about their parent's experience of mental distress:

> *"I think it's just like more of my personal life that I don't have to show to anyone else. I don't have to say yeah, if I don't want to." (Charlie)*

However, it seemed that some CYP seemed to imply this decision was influenced by their concern that their parent would prefer them not to talk about it:

> *"To be honest I wouldn't say it in general cos, I just don't like, I prefer to like keep it personal like. Cos my mum, my mum might not want me to like tell, what she has and stuff. For myself, I prefer to like keep it personal." (Sam)*

Similarly, Charlie spoke about their awareness of their mother not wanting them to speak completely openly. However, Charlie felt their mother held a positive view of Charlie's being supported by friends. It seemed that there may have been an unwritten rule as to what could be shared:

> *"I don't think she would like me to blurt out random things." (Charlie)*

Alex seemed to hold a belief that family matters shouldn't be shared outside the home:

> *"I just don't feel like people should know what goes on like between me and my family" (Alex)*

Similarly, Andie spoke about having a preference for not telling others matters to do with themselves:

> *"I just, sometimes I don't really want to tell people about my own things" (Andie)*

Jo felt private matters were private because they had possible consequences, possibly linking to the idea that talking was risky:

Interviewer: I'm just wondering what makes something private. How do you make the decision to think that's a private thing?

Jo: Well [5s] it's something that could [1s] have consequences I would say, something that's private

It was clear that CYP carefully considered what they were sharing with other people. Alex described telling their best friend about living with PEMD, as a way of keeping her informed. However, there was a sense that this did not serve a supportive function due to her preference to keep things private:

Interviewer: Is it something that you talk to about with her a lot?

Alex: Yeah it's out there just don't really talk about it.

Interviewer: and would it be something that it would be useful again to talk about?

Alex: I don't really think it needs to be talked about further

Later Alex goes on to describe how this process took some of the pressure off as they did not feel the need to explain their parents' behaviour:

"I think it did help telling her because it took the pressure of like if she was to come round and my mum was down or upset then she'd understand why"(Alex)

Similarly, even if CYP confide in their friends for more supportive means, it seemed that they were unable to speak openly about everything they experienced, and would only share what they deemed appropriate:

Interviewer: Do you share everything with them or do you just share bits of information

Charlie: Like two or three quarters of it. But not like everything.

Sam spoke about only sharing aspects of their mother's difficulty, which they felt their friend understood. They did not go into other aspects of their mother's experience of mental distress:

"I prefer to like keeping that more to myself and... The cleaning I just tell my best friend and stuff but because his mum likes cleaning a lot too" (Sam)

Furthermore, four of the CYP reported that they only offered information about their parent's mental health difficulties if other people asked them what was wrong. It was at such times as this that they considered sharing some of the information.

> *"Normally if it was something that was really sort of getting to me I'd be upset and they'd see that and then they'd ask what's wrong." (Alex)*

This theme highlights the cautious way in which young people interact with their peers, even when they are able to develop trusting relationships. The participants all viewed their parents' mental health difficulties as private matters, be it for different reasons. Even when they were able to open up to their friends they were often careful about what information they shared, and often only offered it if their friends noticed there was something wrong.

4.4 Coping with the up and down rollercoaster

4.4.1 Overview.

This theme relates to CYP's ability to find ways to cope with the emotional toll of living with a PEMD, which for some involved talking with their friends while for others it did not. When they were unable to talk, they were left to cope independently which felt like an ongoing struggle. However, by taking the risk and opening-up they were able to find some relief and connection with others. In addition, just spending time with friends seemed to provide CYP with some relief. The theme incorporates two subthemes: 'coping in isolation vs finding someone to trust' and 'changing the subject and seeking normality'. These experiences are described in more detail below.

4.4.2 Coping in isolation vs connecting with others

This subordinate theme reflects the dilemma that CYP were often faced with, considering their struggle to open up to people. When CYP were unable to trust there was a sense of them feeling alone in their experience. During the interviews, it felt as if CYP were left to struggle with the impact of their parent's experience of mental distress internally. At times, they spoke of needing to distance themselves from others in order to cope with their sense of feeling overwhelmed, seeming to maintain their sense of isolation. In addition, CYP found it difficult to talk openly to their parents about their mental distress, as they spoke about their fear of upsetting them. This sometimes left them worrying about how their parent was feeling. As well

as the emotional toll of coping in isolation, some CYP highlighted the strain of being left to figure out the more practical side of things independently, which could at times take its toll. However, CYP also spoke about the benefits of being able to open up to others, and when they could, it reduced their sense of isolation.

During the interview process, CYP spoke about the emotional toll of living with a PEMD. They often described struggling with feelings of sadness and anger. In the context of discussing what support would be helpful, Charlie described their emotional experience:

> "...try and like feel like everything's normal...the way life should be...I've been up
> and down a roller coaster." (Charlie)"

In addition to managing their own feelings, CYP spoke about their concern for their parents, with many noting that they did not want things to deteriorate for their parents again:

> "I was like sad about it and I didn't want mum to get more ill...I didn't want her to
> leave again. You know, I didn't really want her to like shout or get stressed." (Alex)

However, as described earlier, CYP spoke about finding it difficult to speak to others about having a PEMD. This left them coping alone with their own thoughts and feelings. Charlie described the consequences of not being able to confide in others:

> "Like at the minute, sometimes I feel like quite sad. I feel like I can't really say
> what I'm thinking..." (Charlie)

Similarly, Andie described choosing not to talk to people and choosing to cope on their own. However, they speculated that should they be able to trust someone, their feelings would no longer be bottled up:

> "Well, sometimes I don't really want to talk about it, I just like talk to myself about
> it... I just, sit out on my own. But then I think it is good because then it won't be
> just bottled up, then you will feel lower than you are. It's just good if you can trust
> someone" (Andie)

Three CYP spoke about their need to take themselves away from people when they were feeling overwhelmed. For example, Charlie spoke about needing space to calm down when feeling very overwhelmed with emotion:

"I would want to talk about it but then again I would like to like just switch conversation if I just were like really sad…. that just like gives me time to like calm down and then like, like start being upset and like start going off on one and like start being angry and that." (Charlie)

Most of the CYP interviewed sought the closeness of their parent and family and showed a desire to look after them and try and make things better. One young person spoke about how looking after their mother helped them to cope:

Interviewer: Is there anything else that you can do to help you cope?

Alex: Not really

Interviewer: …what do you do when you're at home?

Alex: I'm with my mum, trying to talk to her.

Interviewer: …it sounds like one way of coping might be to talk to your mum. How does that help with your mum?

Alex: Erm, well if I can kind of cheer her up it can make me feel happy

It seemed this experience of connection provided Alex with some comfort.

In contrast, Jo spoke about spending more time with friends in order to distance them self from life at home and prevent arguments within their family:

"That's why I'm not really at home very often. I mean I've been staying at my friends for a little while. I do come home every so often. But, I'm just at my mates a lot of the time now." (Jo)

Despite feeling disconnected with others, Jo was able to find comfort in spending time with friends.

Each of the participants spoke about how they did not feel able to talk about their parent's experience of mental distress within the home. This was usually due to a fear of whether they would make their parent uncomfortable and an assumption that their parent wouldn't want to talk about it. However, this led to them being left to wonder how their parent was. When asked whether they spoke about their mother's experience of mental distress with their

mothers, three young people acknowledged that it wasn't talked about at home. Two CYP spoke about their reluctance to bring it up. For example, Andie described their worry about causing their mother to feel uncomfortable.

> *"Cos… I don't really want to bring it up to my mum…cos I'll think she'll feel like uncomfortable…because I would anyway…I just thought she'll feel uncomfortable... But she would talk, but I just feel really, I don't really want to talk about it to her." (Andie)*

In contrast, another interviewee spoke about not wanting to ask questions about their mother's mental distress, as their mother often confided in them which was sometimes a struggle to hear:

> *It's not nice to hear it everyday. I mean, she'll just tell me the same thing over and over again. And, I don't really like to hear it too much because it's not a nice thing. I mean, if it dramatically changed, then that would be cool. But I'd want to know. But it's just the same thing. (Jo)*

Not being able to talk about it, or ask questions seemed to leave CYP feeling uncertain. Therefore, when they were given the opportunity to meet other families at Kidstime is seemed to offer some sense of relief and connection. Five of the young people interviewed spoke about the benefit of this space. In allowing themselves to connect, they expressed relief of knowing they were not the only one, helping them feel less isolated:

> *"That not just my mum has it. Other people suffer as well. So it's kind of good to know that there's other children as well that are living with a parent or carer with mental health… It makes me feel, not sort of good but sort of…knowing that it's not just me going through it, knowing that I've got other people to help." (Alex)*

CYP's family context impacted on their feelings of loneliness and for single parent families, this was exacerbated by often having less support. This was highlighted by Charlie who spoke about the consequences of their mother's hospitalisation, and how there was no one left to care for them when their parent was unwell:

> *"… because mum doesn't really live with any other guardian or parent…There's like no one else to look after us so it's like kind of an issue for us to go places without getting split up or put in where we don't know people." (Charlie)*

One young person expressed the loss of not having a parent to look up to and help them meet their goals. This left them navigating the transition to adulthood independently:

> *"...sometimes it is hard to like do things... It's hard to have a parent that's not quite ...with it so much....I don't really have anybody in my family I look up to...my friend he just asks...[his family member]... if he could help him go somewhere or do something with him. I find it quite hard to do that with my mum cos we'd either both forget or she just won't be feeling very well and I'd miss out on the opportunity so." (Jo)*

Conversely, despite the risky nature of confiding in others, when CYP were able to talk to a trusted friend, there was a sense of relief. Charlie described the power of a hug and some reassurance:

> *"I normally talk to my friends and they like normally give me a hug and like, and like say don't cry, "I'm here for you" (Charlie)*

Later, they described the loss they would feel if they were unable to use their friends for support:

> *"I would feel like really sad, like I would always be like alone and I wouldn't be able to like talk." (Charlie)*

Andie acknowledged the benefits of talking to people, despite finding it particularly difficult to form trusting relationships. Andie described the possibility of others providing emotional support and advice:

> *"Like you can say what you, like what you're feeling and they won't tell and go on and like, you know like, they won't judge you, they will understand and they'll give you a good answer and if they can't, and then you can just talk about it."(Andie)*

However, despite being able to identify the benefits of talking to others as a means of realising some of their emotional experience talking still felt challenging.

One young person acknowledged the limitations of talking, which seemed particularly powerful:

"[talking] doesn't help, it doesn't do anything really. Cos it's not going to change the situation, I'm just telling someone the situation I'm in. So like, it doesn't really change anything."(Jo)

Finally, two CYP were able to recognise the function of talking as a way of tackling stigma. Here Alex talks about the need to raise awareness through talking:

Interviewer: What do you think in general, the benefits are of talking about it?

Alex: It will raise the awareness more to get people not to listen to stigma.

Interviewer: And how do you think talking about it would do that?

Alex: It would make people more understanding about it by sharing your view on it.

Interviewer: If you shared your view, how would that help someone's understanding do you think, what would it allow?

Alex; Because they've heard someone's experience of living with someone with mental health issues. And not just hearing about it from newspaper and TV.

This may serve the function of reducing isolation for this group. However, they did not necessarily feel they were the ones to do so. Instead, they recognised how celebrities, or people in the public eye, could start to talk about their experiences of distress:

"I think someone like a celebrity who has it or whatever, should like make a video…I think more people should do that, cos there's different mental health issues…like people who watch her think "oh well, I'll talk now" because they're probably scared too. But then with people telling what they're going through is probably make them feel they can talk now." (Andie)

This theme recognises how much young people cope with PEMD independently. It seems as though young people's fear of letting others in means that they are left coping with their situation on their own. Whilst they did not feel that they were always in need of support, they often talk about taking themselves off to deal with their own internal state on their own. Their worries about upsetting their parents, and their desire to look after their parent may prevent them from seeking support for their own needs. Furthermore, they may not always get the

practical support that they need as they grow into adults. When they are able to talk to their peer group, they talked about the sense of connection and relief that they got from this. There seemed to be a tension between coping in isolation or connecting to people that they trust.

4.4.3 Changing the subject and seeking normality

Young people spoke about enjoying a number of activities outside the home, both with their family and with their peers. Engaging in everyday activities was one way in which they coped with their difficulties. Young people spoke about the importance of joking with their friends, engaging in normal teenage activities e.g. gaming and going out with friends.

A number of the young people spoke about how much they enjoyed engaging in the normal life activities of a teenager, without having to speak about their parent's experience of mental distress. Young people spoke about enjoying 'gaming', watching movies or socialising with their friends.

For example, Charlie spoke about getting away from life at home and going into town with their friend:

> *"sometimes we go up to town and I …that might be like for us to get away normally at the weekend, on Saturday" (Charlie)*

Another young person spoke about engaging in 'general' activities and seeing their friends regularly as a way of coping with life at home, and they preferred this to talking about their difficulties:

> *"We use each other as, as like friends who like have fun and banter and er, like gaming with each other and just doing stuff in general from like calling each other and stuff, like seeing each other a lot." (Sam)*

Similarly, Jo spoke about preferring to take their mind off life at home and just spend time doing things that they enjoy and living their life, although they still described the benefit of being able to talk:

> *"It's good to do a bit of both but I think I'm more, sort of, prefer to just sort of get my mind off it and carry on doing whatever it is I'm doing." (Jo)*

It was clear that young people valued the support from their friends in more ways than just talking about their parent's distress. Having respite from home and being able to engage in normal activities was something that was valued highly. For some they preferred to use their friends to move away from their experience at home.

Chapter 5: Discussion

5.1 Overview

This chapter aims to discuss the findings in relation to the research question and wider literature. As the exploratory and inductive approach of IPA allows for the discovery of new ideas (Smith et al. 2009), new literature is introduced to explain some of these developments. Following the discussion of the results, the clinical implications of the findings are considered and the methodological issues are reviewed. Suggestions for future research are also presented. Final reflections of the researcher are provided in order to evaluate their contribution to the research. Finally, conclusions are drawn based on the researcher's interpretation of the analysis.

5.2 Discussion of Research Findings

The research question which this study aimed to consider was:

"How do CYP living with a PEMD make sense of gaining support from their friends?"

The superordinate themes that were co-constructed are discussed below. Consideration is also given to the context of these CYP's lives in influencing their experiences of talking to their friends.

5.2.1 Fitting it altogether

The results of this study imply that CYP interviewed described gradually building an understanding of their PEMD. This supports previous findings (e.g. Baik & Bowers, 2005; Fjone et al., 2009; Griffiths et al, 2012; Meadus & Johnson, 2000; Mordoch, 2010; Trondsen, 2012). Mordoch (2010) described this process as "fitting the pieces together". However, this study elaborates on the complexities of this experience. CYP described learning about their PEMD from what they observed around them and seemed perceptive to changes in their parent's behaviour and emotions. Totsuka (2013) conceptualized this process as experiential learning. The information CYP gained was not always deliberately shared with them, but rather included things that the parents may have considered private. This may indicate that PEMD might not always be aware of CYP's search for understanding. Hedman Ahlström, Skärsäter & Danielson (2011), similarly found, CYP often unintentionally heard conversations which

left them building an awareness of their parents' suicidal ideation. Within this study, information CYP observed was sometimes left without context or explanation, which was described as the source of uncertainty and discomfort. Handley et al (2001) found the uncertainty associated with not knowing led CYP to worry more about their parent's safety, feel to blame for their difficulties and fear experiencing mental distress themselves.

CYP interviewed generally felt that their PEMD was not discussed openly, both within and outside the home, which left them to come to an understanding through this process of experiential learning. This indicated that CYP might often be trying to make sense of complex information by themselves. However, CYP did talk about some incidents of their parent telling them about their experience of mental distress, in addition to getting information through the Kidstime support group and receiving information from other CYP with a shared understanding. Vygotsky's sociocultural theory of development (1978) highlights the importance of social support in scaffolding CYP's learning. Having conversations with CYP about PEMD may be understood as a way of scaffolding CYP's understanding of PEMD. The combination of learning through experience and from being given information provides further support for the findings of Totsuka (2013). Totsuka discussed how information could either validate or contradict their experiential understanding and highlighted the discomfort created from contradictions. Within this study, it seemed as though such moments of contradiction led young people to experience a level of uncertainty and discomfort.

CYP seemed to differ in their level of understanding of their PEMD, with older CYP tending to have a greater understanding which had developed over time. Younger CYP often seemed to feel uncertain about their understanding and were keen to seek further information. Backer et al (2016) likewise found that CYP often showed a basic awareness, which increased with age. Younger CYP may therefore be particularly vulnerable to the discomfort of living with uncertainty and confusion, which indicates they may be in particular need of support to help them make sense of their experience. In contrast to findings suggesting that providing CYP with more information could reduce the distress associated with not knowing, the two older CYP in this study spoke about not wanting more information. Their lack of desire for more information appeared to be due to a fear that more information would cause more discomfort. This is similar to the work of Ferguson (2011), who found that some CYP in her study did not want more information and actively avoided seeking out further information. This challenges the widely held assumption in parental mental health literature that more information is always

helpful (Mordoch, 2010) and invites a more nuanced consideration of providing information to CYP living with PEMD, which will be returned to later.

However, it did seem that CYP's understanding of having a PEMD influenced their tendency to talk to their peers about this experience. Within this study, CYP spoke about not being aware that their parent's behaviour was due to their experience of mental distress and attributed their mother's mental distress to their individual characteristics. Therefore, it seemed that developing an understanding may have been an initial step in their ability to discuss their parent's experience of distress with their peers, or at least recognise that they were talking about this, rather than their experience of their parent being angry or stressed.

In addition to being able to explain and understand their PEMD, this study developed the concept of understanding to include CYPs sense of how their PEMD fitted in with their conceptions of 'normality', their experience of using different terminology and how this impacted on their confidence of knowing how to talk about it, in addition to their developing awareness of stigma.   CYP appeared to recognise how their parent's behaviour differed from social norms, yet they demonstrated attempts to normalise their PEMD. This process is similar to one described by Secker, Armstrong & Hill (1999). In their study, CYP with no experience of living with PEMD drew distinctions between what they perceived as 'normal' or 'abnormal', based on social norms of acceptable behaviour. They perceived a description of depression and behaviour that challenged as being within the realms of normality because it was something that they could relate to. However, more unusual presentations e.g. a description of someone with a diagnosis of schizophrenia were deemed 'not normal'. This is similar to how CYP within this study made sense of psychological distress. Yet, significantly, in this study, it was noted that CYP appeared to work hard to distance themselves from what they viewed as "bad mental health". The process of making sense of what was happening for their parent, but also a negotiation of how this experience fitted in the realms of 'normality' may contribute to their own identity formation; therefore viewing their PEMD as 'normal', may seek to reduce the discomfort of the stigma associated with mental health concerns in society.

This study also highlighted the potential impact of CYP's experience of more medicalised language, which appeared to lead to further confusion in some CYP living with PEMD. CYP were left to learn a new and professional language that they sometimes struggled to translate into meaning. This is similar to the findings of Alasuutari & Järvi (2012) who found that CYP's use of the professional vocabulary often hindered conversation during the interviews. It seemed

using this language appeared difficult because of their sense of the stigmatising nature of the terms. CYP interviewed in this study seemed to underestimate their own understanding of their parent's experience of mental distress due to their struggle to understand and use 'correctly' the professional terms used by others. Cogan et al (2005) reported that CYP preferred using everyday terms to describe their PEMD e.g. "stressed", "depressed". However, others drew on illness discourses e.g. "unwell" or "sick", demonstrating a more medicalised understanding of PEMD. It seemed CYP often knew what the diagnosis given to their parents were, but they had little understanding of what they meant. However, for some CYP in the study, being given a label for their parents' experience of mental distress and knowing that it was 'an illness' offered some clarity. This is similar to the findings of Pihkala et al (2012) who found that CYP found relief from knowing their parents had 'an illness'.

As described above, CYP within the interviews showed some awareness that terms associated with mental distress had some negative connotations associated with them. CYP spoke about their associations with the word "mental" but also spoke about how other people might view their PEMD as "crazy". This seemed to be linked to their understanding of how mental distress is portrayed in society, particularly by the media. This view is supported by Cogan et al (2005) who demonstrated that CYP with little experience or knowledge of mental distress, often used language conveying more negative views about mental distress e.g. "not right", "dangerous" and "out of control". Media representations have consistently been found to portray mental distress in a negative light, often linking it to violence and aggression and this can lead to people having poorer knowledge of mental distress (Kimmerle & Cress, 2013). Corrigan & Miller (2004) highlight how stigma not only impacts on the person affected by mental distress, but also on their family members and they describe how this can lead to feelings of shame and a sense of 'contamination' in those associated with the family member.

Linking this back to the focus of this research, the findings of this study seem to support the idea that the development of understanding appears to influence CYP's ability to build the confidence to talk to others about their PEMD. This is similar to Baik & Bowers' (2005) findings which suggest CYP went through an initial stage of 'self-disclosure', a process by which they came to learn about their parent's mental distress, before opening up to others. Furthermore, Ali, Ahlström, Krevers & Skärsäter (2012) found that young people felt unable to tell others about PEMD, if they didn't feel they understood themselves.

5.2.2 Talking feels risky

Throughout the interview process, it seemed to the researcher that CYP found talking about their PEMD difficult. The researcher interpreted this experience as a struggle to determine what they could share without getting themselves or their parent 'into trouble'. Despite efforts to build a rapport with the CYP within the interviews, it was felt that CYP wrestled with how to answer each question, providing a glimpse of how hard this topic was to talk about. This is similar to findings from Pölkki et al. (2004) and Van Parys & Rober (2013) who found CYP struggled to speak about their experiences and noted their use of hesitations and restless non-verbal communication. In a study evaluating CYP's experiences of assessment and support, it was clear that trust was something that was important within their relationship with professionals, and this was something that built up over time, rather than a single meeting with a professional (Grant et al., 2008).

As drawn out by the systematic review presented in chapter two, fear of others' reactions could prevent CYP from opening up and seeking support from their friends. In support of these findings, CYP in this study expressed hesitation in talking openly to their friends about their PEMD. This fear of disclosing their PEMD is highlighted in a number of studies (Alasuutari & Järvi, 2012; Baik & Bowers, 2005; Bromley, 2008; Cogan et al, 2005; Fjone et al., 2009; Griffiths et al, 2012; Kahl & Jungbauer, 2014; Mordoch & Hall, 2008; Murphy et al., 2015a; Oskouie et al, 2011; Riebschleger, 2004; Somers, 2007; Trondsen, 2012; Valiakalayil et al., 2004). The fear of others' reactions, was linked to CYP's awareness of the stigma associated with mental distress. For example, CYP spoke about the fear that other children would be mean, make fun of them or spread inaccurate rumours. Fjone, Ytturhus & Almvik (2009) found CYP's embarrassment and shame associated with their parents' behaviour led them to "cover-up" their PEMD. Alasuutari & Järvi (2012) also reported CYP's fear of other people finding out, due to the shame and embarrassment associated with the stigma of having a PEMD. This is in line with research suggesting that stigma not only impacts on the individual experiencing mental distress, but also influences family members (Corrigan & Miller, 2004).

This fear not only led them to feel concerned about how it would impact on themselves, but they also seemed concerned about the impact that telling friends might have on their parent. In contrast to some previous research which has indicated that parents have told their children not to tell others about their experience of mental distress (e.g. Mordoch & Hall, 2008), the findings from this study indicated that CYP felt their parent would be supportive of them talking to

others. However, it seemed that despite this sense, CYP still felt hesitant about talking to others, in case it upset their parents and there was a sense of protectiveness towards their parents. Nolte & Wren (2016) found a strong protective element to parents' decisions regarding what they shared with their children. Van Parys & Rober (2013) similarly found that both CYP and their parents displayed these dynamics of protection of one another, which would both prevent them from informing the other of their difficult emotions, but also would prevent CYP disclosing their PEMD in case it upset their parents. Thus, this study supports research pointing towards how mutual protectiveness could discourage more open talking about PEMD, both within and outside the family. Furthermore, some CYP within this study also described protectiveness towards friends as a factor that impacted on their experiences of talking about PEMD, in that they seemed to worry about burdening their friends. This is similar to the findings of Kahl & Jungbauer (2014) who similarly found CYP expressed fear of placing too much burden on their friends by talking about their experiences.

When CYP made the decision to talk with their friends about their PEMD, it seemed imperative that they had built a trusting relationship with someone. CYP spoke about their close friends as though they were the exception, suggesting either a lived experience of the unkind nature of others or people breaking their trust. Murphy, Peters, Wilkes & Jackson (2015b) discuss the impact of cultural beliefs about trust and mistrust and relate this to how concepts such as stranger danger feed into the idea that others can't be trusted. Furthermore, it seemed this led CYP in this study to struggle to build trusting relationships with other people their age. Grant and colleagues (2008) found that CYP who lived with parents experiencing mental distress were left struggling to trust others. Part of this mistrust came from adverse experiences e.g. bullying at school or rejection from their peer group, and this often led the CYP in their study to withdraw from friendships and 'bottle up' their feelings. Similarly, Murphy et al (2015b) highlighted the challenges CYP living with PEMD face when it comes to developing trusting relationships, both as a result of their experience with their parents and their experience of how other people respond in stigmatizing ways. They highlighted how this experience may limit CYP's ability to seek support from others, including their friendships due to the potential high risk of disclosure.

Some CYP within this study felt unable to trust their peer group at all and this led to an avoidance of talking to others about their experiences. However, those that reported being able to trust a close friend spoke about developing this trust over time with people that showed

qualities of empathy and understanding. The reciprocity of trust was highlighted, as CYP described being more likely to trust others that confided in them. However, CYP sometimes reported feeling as if they "should" trust others because others had trusted them, but despite this developing this trust felt too difficult. CYP also spoke of feeling more able to trust someone with similar experiences to them, e.g. experiences of living with PEMD. This is similar to findings presented in the systematic review, which described how CYP sought out CYP who they perceived to be similar to them (Fjone et al., 2009). This was reported to help CYP to open up about their situation (Griffiths et al, 2012; Grové et al, 2015b; Mordoch, 2010), which was also described by some CYP in this study.

Despite some CYP being able to develop trusting relationships, many CYP expressed their beliefs about PEMD being private to the family, and therefore they were cautious about what they shared with others. This was similar to findings outlined in the systematic review (Cogan et al, 2005; Griffiths et al, 2012; Pölkki et al., 2004; Riebschleger, 2004; Somers, 2007.) The findings of the systematic review seemed to point to feelings of fear and embarrassment related to their PEMD, as a result of stigma. However, within the accounts of CYP in this study, although this was a factor, it also appeared that feelings of protection towards the parents and feelings that it was not their business to share with others, impacted on this decision.

When it was too difficult to build a trusting relationship with friends, CYP sought to find someone else they deemed trustworthy e.g. another family member or professional. This is similar to the findings that CYP often confide in other family members or professionals (e.g. Backer et al, 2016). It is worth noting that not all CYP felt that they had someone else to talk to and also had difficulty trusting professionals, meaning that some CYP in this study felt they had no one to talk to about their experiences of living with PEMD. This also demonstrates the importance of the context around the child, which will be discussed further below.

5.2.3 Finding ways to cope with the emotional rollercoaster

The CYP within this study described the emotional toll of living with a PEMD, despite at times reporting that it 'wasn't too hard', or was something they were 'used to'. This was constructed by the researcher as a way to try and minimise the impact of living with a PEMD, due to their contradictory reports of experiencing a range of emotions that sometimes felt uncontrollable. CYP have often described their experience of living with a PEMD as a rollercoaster, with many ups and downs (e.g. Foster, 2010). Riebschleger (2004) described how CYP's emotional

reactions to their parents' experience of 'bad days' resulted in them finding ways to cope with it. This could involve trying to ignore what was happening or trying to change their behaviour accordingly to try and help their parents. This is similar to Mordoch & Hall's (2008) findings that CYP put their effort into "finding a rhythm" by monitoring fluctuations in their parents' mood and adapting their behaviour in the hope to minimise the effects they had on their PEMD. One way that CYP seemed to monitor and adapt their behaviour, was to cope with their own emotional reactions independently, in a bid not to burden their parents. However, this experience seemed to lead to a sense of isolation. Previous findings have indicated that these feelings of isolation resulted from a sense that they are different or separate to their peers (Bee et al, 2013; Foster, 2010; Mordoch & Hall, 2008; Valiakalayil et al., 2004). However, the findings of this study also suggest their inability to share their experiences lead them to cope with their difficult emotions on their own, as they do not feel able to seek support. Research on social isolation has suggested that this can lead to poor outcomes in children. For example, Hall-Lande, Eisenberg, Christenson & Neumark-Sztainer, 2007) found that social isolation in adolescence led to low self-esteem and an increased risk of depressive symptoms.

There seemed to be a tension between feeling left to struggle with these feelings independently and taking the risk and finding someone to trust and confide in. CYP seemed to report beliefs that talking or sharing their feelings could prevent the experience of 'bottling up' feelings. However, sometimes this was discussed in relation to their parents not 'bottling things up' rather than themselves, suggesting that this was also a reaction to a prevalent discourse in society that talking is helpful. This is similar to the findings of Bromley (2008) who found that CYP seemed aware of a cultural expectation to talk, which was incongruent with CYP's desire. Having said that, some CYP reported an experience of finding relief through sharing. Not only did this prevent them from 'bottling up' their feelings, but it also allowed them to validate their experiences and seek advice from others in a similar situation. Mordoch & Hall (2008) reported that CYP helped "maintain the frame" by talking to others. Although they acknowledged that doing so was a possible risk, for those that were able to do so, it helped to validate the CYP's experiences and also helped reduce their sense of isolation. Furthermore, talking to others was also seen as a functional strategy, which enabled them to keep their friends informed, to avoid having to provide further information and to communicate to their friends when they needed support.

Finally, CYP were able to recognise that talking openly could serve a function of reducing the stigma associated with mental distress. They seemed to conclude that silence and inaccurate portrayal of mental distress in the media could perpetuate the stigma relating to mental distress. Similarly to these CYP, Hinshaw's (2004) personal reflections on stigma have highlighted how public narratives about mental distress may help to counter the silence and stigmatisation that surrounds mental distress.

In addition to the dilemma of whether to use individual or supportive networks as a way of coping, another finding of the study was that CYP also found engaging in everyday adolescent activities with their peer group was helpful at reducing their stress. This experience supports the findings of the systematic review that sometimes CYP need to escape their situation at home. For example, CYP within this study discussed the benefit of spending time with their friends, and acknowledged that sometimes this was more helpful than confiding in them. Bromley et al (2013) conclude that talking about their PEMD may not always be helpful as avoiding the subject and focusing on other everyday interests can be helpful at times, in addition to providing CYP with a sense of normality (Fjone et al., 2009).

5.2.4 The wider social context and children's experience of talking

In addition to the themes that are discussed above, the research highlighted the importance of contextual factors in CYP's conversations with their friends about their PEMD. Within the introduction, Brofenbrenner's ecological systems theory was presented to outline the multiple contexts in which CYP live, and this seems relevant to the variability in some of the CYP's accounts. Firstly, the people which make up the microsystem varied significantly between families. Some CYP lived in single parent families whereas others had other close family relationships in which they could confide, which included siblings, a well parent or an extended family member. In addition, the socioeconomic status of the CYP and their family also seemed to impact of their sense of struggle. Although financial hardship was not explicitly discussed, this was mentioned in relation to some of the struggles that CYP faced e.g. their ability to go away with their friends and engage in certain activities.

Thinking at a mesosystem level, the relationships between the people in their microsystem impacted on the CYP's ability to confide in them. For example, some CYP reported wide age ranges between themselves and their sibling and therefore despite not being alone within their

family, they did not feel able to confide in them. When the relationships were positive, CYP often spoke about preferring to open-up to their family members as they had a better understanding of their experiences. It also appeared that when there had been a breakdown in relationship with services (e.g. through social care involvement) CYP were less trusting of other professionals, reducing their ability to seek support from services. These fears have been thought to impact on why these CYP often remain invisible to services (Loshak, 2013).

CYP did not express their thoughts about the exo-level systems, but the families involved in this study were recruited from an intervention study, indicating involvement in mental health services or other organisations, and due to the nature of interventions, the CYP themselves were involved in the interventions too; however, this might not be the case for the majority of other CYP living with PEMD. This will be discussed further in the strengths and limitations and the clinical implications.

Finally, it seemed that CYP were aware of the stigma that surrounded mental distress, which seemed to have a big impact on both them and their families, in line with Corrigan & Miller's (2004) concept of stigma contamination. In addition to the effects of this referred to earlier, a further impact seemed to be that it altered CYP in this study's help-seeking behaviour. Although there has been a move towards addressing the stigma attached to mental distress, and despite a number of national and local campaigns (e.g. Time to Change, 2008), stigma in society persists and significantly impacts on the lives of those experiencing psychological distress and their loved ones and their ability to gain support.

5.3 Clinical Implications

The findings of this study point towards some potentially useful clinical implications which will be discussed below.

This research points towards the very challenging experiences CYP may have, including the significant struggles they have to find a way to understand what is happening with their parents and finally and the obstacles they experience in relation to accessing support. However, despite this not being a new message from research, there continues to be a risk that this population will be overlooked (Loshak, 2013). Despite awareness being brought to this area (Falcov, 1998; Aldridge & Becker, 2006; Every Child Matters, 2003; Carers Act, 2014) this does not appear to have meaningfully influenced service structure, and the needs of family members still go unaddressed. Thus, once again this research points towards the urgent need to consider the

wider family where a parent is experiencing psychological distress. Service restructure to ensure collaborative practice across adult and child mental health and social care is needed. Despite the development of interventions such as Kidstime (Cooklin, 2006) which aim to keep both the parent and child in mind, access to these services are limited and depend on whether it is available in the area. Therefore, there needs to be a clear assessment of the needs of the family, when they identify within services, in addition to access to interventions to provide support for family members. In addition, due to the complexities of PEMD and the challenges of opening conversations with these families about their needs of support, it would be helpful for clinicians (particularly those working in adult mental health and social care) to receive further training on the impact of PEMD (Power, Cuff, Jewll, McIlwaine, O'Neill & U'Rem, 2015).

Secondly, the findings again highlight the power of stigma and how this can have adverse effects on CYP living with PEMD, in addition to providing a barrier to seeking support. This again highlights the importance of clinical psychologists seeing their wider role in raising awareness and understanding of psychological distress and challenging stigma. Anti-stigma campaigns in schools may help demystify mental distress and therefore reduce the stigma attached, potentially allowing CYP living with PEMD to be more confident about seeking support from peers. Educational programmes in schools have been found to be helpful at reducing stigma in relation to schizophrenia (e.g. Pinfold, Stuart, Thornicroft, & Arboleda-Flórez, J., 2005).

Thirdly, turning more to the therapeutic context, the findings from this study, alongside previous research, seem to indicate that both CYP and their parents can be very protective towards each other. This can prevent them from talking about these difficulties, both within and outside the home, and thus may impact on their levels of distress (see Murphy et al, 2014). This, coupled with the stigma around PEMD, as highlighted in the current study, can compound this silence. Therefore, family interventions aimed at addressing the complexities in this relationship dyads, e.g. actively addressing (often unvoiced) experiences of loyalty, protectiveness, guilt, worry, between CYP and their parents are indicated. Family Interventions that have been found to produce positive effects include the Beardslee Family Intervention (Focht & Beardslee, 1996) or family and narrative work (Daniel & Wren, 2005).

Fourthly, CYP within this study highlighted the complexities of building an understanding of their parent's difficulties. CYP seemed to develop a lot of this knowledge through what they

observed and through conversations they overheard. However, sometimes they were unable to make sense of what this meant. Furthermore, there seemed to be a disconnect between how professionals and CYP spoke about mental distress. More medicalised language appeared to lead them to underestimate their understanding which seemed to cause them to feel under confident at talking about their parent's experience of mental distress. Ensuring interventions are designed from a child-centred point of view, drawing on CYP's own descriptions and concepts, may help them make sense of information and enable them to develop a coherent and integrated understanding.

Finally, the novel findings of this study relate to CYP's experiences of considering talking with peers about PEMD. CYP highlighted how difficult it was for them to develop trusting relationships with peers that would enable them to open-up and gain social support relating to their experiences of living with PEMD, which left them feeling isolated from others. Sometimes their perceived lack of understanding of their parent's difficulties and the professional language, and their fear of the stigma associated with mental distress, in addition to experiencing negative reactions from their peer group regarding their parent's distress, acted as a barrier to seeking this support. However, despite this, the findings also suggest that CYP benefit from meeting and/or discussing their experience with CYP their age, especially those who share similar experiences to them when able, as they perceive these young people to be more understanding. In addition, the research highlighted the benefit of spending time with their peer group and engaging in everyday social activities. Therefore, peer interventions that allow CYP a space to build supportive peer relationships with people they may perceive to be more understanding may provide them with a more positive experience of talking about their parent's experience of mental distress. This may help increase their confidence about talking and asking questions about mental distress and reduce their worry about being perceived negatively by other children. In addition, talking with peers may facilitate a conversation that is more CYP friendly, allowing them to have conversations in the language that makes sense to their day to day lives.

There are currently no peer interventions available in the UK, although the Kidstime Workshops involve an element of engaging with peers who share an experience. However, this is not the workshop's primary focus. Furthermore, CYP attending the Kidstime workshops can vary greatly in age and this may hinder the development of building close trusting relationships and ability to have conversations that are age appropriate. However, despite this not being the primary focus the CYP reported benefit from connecting with other CYP their age, with a

shared experience. In addition, given the protectiveness young people described in relation to their parent, it might be useful to consider group interventions for CYP independent of their parent, where they might feel freer to talk. Peer interventions programmes that implemented in Australia have been found to have a positive impact on increasing hope in these CYP e.g. the 'ON FIRE' programme (Foster, McPhee, Fethney & McCloughen, 2016). This programme incorporates fun days and social outings to facilitate relationship development, in addition to peer support groups to facilitate conversations about their experience of living with a PEMD. This may be a good model to develop and evaluate within this country.

Furthermore, the fact that some young people in this study were not able to trust anyone enough to talk about their PEMD related experiences highlight that some CYP are very isolated, with potentially significant implications for their wellbeing. Therefore, CYP may benefit from confidential online support, in which both their and their parent's anonymity is maintained. Such interventions specifically focused on PEMD are also not currently available in the United Kingdom, but have been developed elsewhere and the effectiveness of these is currently being investigated, with some positive results (Drost & Schippers, 2015).

It is worth noting that some studies examining the role of professional support have highlighted that not all CYP report finding benefit from this (e.g. Kahl & Jungbauer, 2014). The findings from the current study suggest some CYP reported that they did not want more information about their parent's experience of mental distress as they were worried that this would upset them. Furthermore, their experience of talking about their parent's difficulties led them to worry about saying the wrong thing. Therefore, offering a standard intervention, may cause harm to some CYP. Grové et al (2016) suggested that CYP and their families may have different preferences in the appropriate support, if they feel support is needed. This suggests that ensuring a proper assessment process is offered exploring the parent and CYP's goals from attending an intervention, will help to inform this process. Furthermore, developing a number of different interventions aimed at addressing these different needs may be required. For example, if family communication is something that the system wants to work with, a family intervention may need to be considered; alternatively, if CYP want to meet with other people who have a similar experience, a peer intervention may be implied.

In summary, this study highlights the importance of services going beyond the person with mental health problems to focus on the wider family, particularly children. We need to talk with the children, develop our understanding of their experiences and the obstacles to gaining

the support they need, and be responsive in addressing these. In particular, developmentally CYP may benefit most from peer support (as opposed to professional support), and facilitating such support where possible should be a priority.

5.4 Future Research

In recent years, there has been an increasing focus on qualitative research designed to explore CYP's experience of living with a parent experiencing mental distress.

The clinical implications mentioned above, highlight the challenges that clinicians have when faced with this group of young people. Research into clinicians' views, beliefs and experiences of working with the wider family, may highlight ways in which to equip practitioners better in maintaining a family focus. Furthermore, there was recognition that services designed to support families living with PEMD, and reduce their experience of distressed are important. There have been several different approaches that have been developed in different countries e.g. Kidstime in the UK (Cooklin et al, 2011); peer support programs (e.g. Foster, McPhee, Fethney & McCloughen, 2016) and online support groups (Drost & Schippers, 2015). It would be useful to complete a randomised control trial (RCT) to examine the effectiveness of these approaches at reducing CYP's distress.

Furthermore, as CYP are becoming more reliant on the internet as a source of information, especially given how difficult they find talking with others directly as highlighted in this study, it would be helpful to examine what information is available to CYP online and consider their experience of using it. For example, do they find the language accessible and how do they interpret the information? Is there information that they are accessing that is potentially unhelpful or even distressing?

Finally, it may be useful to examine the effects of de-stigmatising initiatives in schools to see whether they are useful at increasing awareness and understanding. It would be useful to complete a qualitative study of CYP's views of these campaigns and how they impact on their understanding and thinking about mental distress.

5.5 Methodological Considerations

This study used an IPA approach to analyse CYP's experiences, which is congruent with the research question. According to Smith et al. (2009) IPA allows for the detailed analysis of

individual experience. Due to the idiographic nature of this approach, in addition to the researcher's epistemological position, it is not possible to generalise these findings to all CYP living with a PEMD. However, these findings seek to enrich our understanding of the chosen topic.

When completing IPA, Smith et al. (2009) recommends small sample sizes in order to allow for an in-depth interpretation of each client. The sample size of this study was smaller than planned, due to the significant challenges in recruitment, but this allowed for detailed coding of those that participated and was in line with the recommendations for an IPA study. Smith et al. (2009) also highlights the need to ensure that interviews use open-ended and should encourage the participant to talk about the topic in-depth. Despite an interview schedule being developed to allow for this style of questioning, some of the CYP within this study struggled to answer the open questions and at times closed questions offering them different options to think about were used. This may have led to some interview offering quite "thin" descriptions, making the rich data collection required quite difficult. However, as the interview question was based on CYP's experience of talking, their struggle to answer the questions provided interesting information in itself. Smith et al's (2009) more recent guidance allows you to interpret a number of different factors through the use of exploratory comments. These include descriptive (e.g. content), linguistic (use of language) and conceptual (interpretive and abstract). This approach allowed the researcher to really explore the CYP's struggles and provided rich interpretations which informed the analysis.

Participants were recruited from Kidstime, an intervention designed to offer CYP and their families a space to develop their understanding, increase their communication and offer a space for them to connect with other CYP with similar experiences. Recruiting from Kidstime allowed for a link between the researcher, PEMD, CYP and professionals involved in the care, which allowed for an ethical recruitment process that both parents and CYP could feel involved in the decision-making process, and had a chance to meet the researcher. However, recruiting families via this intervention could have led to the sample only reflecting the experiences of CYP who were being provided with support that others may not have had. Despite attempts to address this by also recruiting from adult mental health services, challenges in the recruitment process did not allow for this to happen. In addition, the PEMD recognised the impact of their difficulties on their CYP, and were willing to talk about their experiences within a group. This could lead these CYP to have more experience of talking, which could change their view about

talking to others. However, despite being interviewed from this group, it seemed that CYP involved still spoke about their lack of understanding and fear of talking with others. It is interesting to note that, despite recruitment from what arguably is a more supportive context than available to many CYP, these young people still had significant struggles in talking about PEMD and seeking support from peers, raising the question whether these things might be even more challenging for CYP not experiencing such support.

Despite this not being the intention of the study, only CYP with mothers experiencing psychological distress came forward for this study. The absence of fathers in PEMD research has often been highlighted and the importance of including fathers is clear. It is a limitation of this study that no CYP described experiences related to a father experiencing mental distress and this should be considered in the interpretation of the data.

In order to ensure the quality of the research, I used the criteria developed by Yardley (2008). The details of how I met these criteria are described in chapter 3, and presented in a table in Appendix P.

5.6 Final Reflections

The importance of reflexivity of the researcher has previously been highlighted (Finlay & Gough, 2003). Throughout this thesis, I have provided reflections of my own experience to provide a glimpse of how I recognised my own personal biases. The process of keeping a reflective journal and having regular supervision helped me consider how these views and beliefs influenced the co-creation of stories between me and the participants.

From the beginning of the research process, I became concerned that even the process of asking the question about PEMD, made the assumption that this impacted on their children's conversations. I became aware of how this led me to become quite hesitant at approaching the parents and thus impacted on the initial stages of recruitment. However, through conversations with my supervisor and recognition of my protective feelings towards parents, I was able to reconsider the position, and recognise how parents themselves were keen to ensure their CYP had a space to get support, as they were aware of the challenges that they both faced in terms of talking.

My initial design of the information sheets and research questions was also influential in shaping participants' stories and the language that they used. The initial information sheets

used the term "mental health problems" which may have influenced the CYP's use of language as many began the process by talking about "mental health". However, as I came to realise that it didn't feel that CYP used these terms in everyday conversation, I changed the interview schedule to think with them about what led them to attend Kidstime. This demonstrated that CYP did not volunteer these terms, and often did not mention them unless asked directly. This highlighted how the researcher's use of language could shape the stories being told.

When I came to analyse the interviews, I became more aware of just how tentative many of the young people were within the interviews, often answering "I don't know" or by starting to say something and then backtracking. I felt this provided a real experience of how difficult it was for these young people to talk about their parent's experience of mental distress with others. Sometimes I found it hard to determine if this was due to a real struggle to explain what they meant, but most of the time it felt as though the young people were very cautious about saying the wrong thing and mostly they seemed very protective of their parent. My own struggle to find a way of asking my questions in sensitive ways was reflected in the way I checked in with young people and changed my course of questioning throughout the interview process.

The process of reflexivity made me reflect on my own position, by considering the social GGRRAAACCCEEESS (Burnham 2008). My position as a white, middle-class therapist, currently in higher education may have led CYP to position me as an expert who they had to impress or get things right. Furthermore, my own experiences that drew me to this project were of the assumption that talking was helpful. However, I had to challenge this view as CYP expressed their feelings of risk. When CYP spoke about the positive qualities of talking to others I had to think about how this was influenced by my research question and discourses around the helpfulness of talking.

Finally, I feel it important to reflect on how each interview left me feeling, as I left each one feeling as if the CYP needed more support, yet knowing that they did not meet the criteria for services. I feel strongly that this group need to be considered as an important priority in policy and service development.

5.7 Conclusions

This study aimed to gain a rich understanding of the conversations CYP have with their friends about living with PEMD and how they make sense of this. Through completing this study, it is hoped that I have provided some sense of the dilemmas CYP face when seeking support from

their friends, in order to address the lack of research directly examining this question. Within this study,

CYP seemed to illustrate the complexities of making sense of their PEMD and how this could sometimes act as a barrier in having conversations with others, including professionals. However, what seemed very powerful was the fear that CYP had in opening-up to people, especially their friends, and the struggle they felt in developing trusting relationships with their peer group. This seemed to be partly due to the stigmatising views held in society, but also their sense of protection of their parent. It seemed CYP faced a dilemma of whether to avoid telling others and cope with their own experiences on their own, or take the risk and find someone to trust to whom they could open-up. It seemed having a shared understanding with another young person with similar experiences could make this process easier. Despite the challenges in talking, CYP still seemed able to find friendships a supportive escape from life at home.

Considering these CYP's experiences within this research has potentially provided a more detailed understanding of why seeking support for this group is difficult. For example, the complexities of making sense of PEMD, and how much CYP pick up, without being told, in their efforts to make sense of their parent's difficulties, with this information often being decontextualized and confusing. In addition, the study highlighted how perceived understanding can impact on CYP's confidence of talking about it with others, especially due to the stigmatising nature of medical language. Additionally, this study has highlighted that it is not only the stigma that prevents CYP confiding in others, but also a sense of loyalty and protection of their parent, which may lead them to minimise the impact of PEMD on their wellbeing. Finally, this study has supported previous findings that having some time out to pursue enjoyable activities is an important coping mechanism.

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Appendix A: Meta-synthesis

2.1 Overview

This chapter presents the findings from a meta-synthesis. While there is now a significant amount of research exploring CYP's experiences of living with a PEMD, there are no studies that directly examine CYP's experiences of talking with their friends about their parent's experience of mental distress. Therefore, a meta-synthesis of the findings of the qualitative literature examining CYP's experience of living with a PEMD was conducted to provide further insight into this question. The search revealed 19 papers that met the inclusion/exclusion criteria. Sandelowski & Barroso's (2007) steps to conducting a meta-synthesis were followed and a thematic analysis of the findings from these studies was conducted. The results of the review are presented in the following themes: Putting the puzzle together and knowing how to talk about it; keeping the secret; finding someone to trust and escaping home life. A discussion around these findings is presented which informs the chosen research question.

2.2 Aim of current review

Findings pertaining to the experience of CYP living with a PEMD are presented in the previous chapter. These findings highlight the importance of friendships as a source of support. However, CYP have also emphasised the challenges of disclosing information and finding someone to trust (e.g. Baik & Bowers, 2005). To date, there has been no research specifically focusing on CYP's experience of support they receive from their friends, despite this issue being raised in a number of different studies. Therefore, the aim of this review of literature is to describe what is currently known about CYP's experience of seeking support from people their age, when they live with a parent experiencing mental distress.

2.3 Method

2.3.1 Design

It was thought a meta-synthesis of qualitative research findings would be useful, given the relatively small amount of literature exploring CYP's lived experiences, the variety of methods used to analyse these accounts and the lack of research regarding community support systems. This method provides an opportunity to interpret and integrate existing findings to explain a phenomenon (Sandelowski & Barroso, 2007). Although there has been a debate in the literature regarding whether qualitative research can be synthesised (Barnett-Page & Thomas, 2009), the importance of developing a method for integrating and summarising the current thinking in a

certain area of research has been acknowledged. In doing so, the following steps have been recommended when conducting a metasynthesis: "conceiving the qualitative research synthesis"; "searching for and retrieving qualitative research reports"; "appraising reports of qualitative reports" "classifying the findings in qualitative reports" and "synthesising qualitative research findings" (Sandelowski & Barroso, 2007). For the purpose of this review, I used this method to synthesize findings relating to CYP's experience of utilising their friends in a supportive way. This method of synthesizing information is in line with my epistemological position, which acknowledges the role of the researcher in co-creating meaning with the participants and therefore my synthesis aims to give another interpretation of these findings (Ludvigsen, Hall, Meyer, Fegran, Aagaard & Uhrenfeldt, 2016).

2.3.2 Searching and retrieving the literature

Sandelowski & Barroso (2003) emphasised the need for a comprehensive search to identify all relevant research, to ensure the validity of the metasynthesis. The authors emphasize the need to identify and define the topic area, population and methodology you wish to consider and the relevant timing of the research before conducting a search of the literature. The topic identified was to examine CYP's conversations with their friends about living with a PEMD. This topic requires two aspects to be defined: 'parent' includes anybody that a child has lived with that has parental responsibility; PEMD is defined by someone who has a ICD-10 diagnosis or has received support from mental health services. The population was defined as children who live or have lived with a PEMD before their 18th birthday.

Relevant terms were explored with an expert in the field and by examining the titles and keywords of previous literature reviews and published papers. Furthermore, the search of the literature was undertaken using Scopus, PubMed, and Psychinfo. Initially a search was conducted using key words but this resulted in over 4000 papers, many of which were related to CYP's experiences of mental distress, physical health conditions and developmental disabilities, despite exclusion of several terms associated with these conditions. In addition, few of the relevant studies within the literature were found (<15). In their review, Gladstone et al (2011) highlighted the challenges of performing a structured search on this topic as database indexes do not distinguish between CYP's experience of mental distress and experiences of living with PEMD. Furthermore, attempting to limit the studies by "qualitative research" resulted in many relevant studies being omitted. Therefore, it was decided to complete a title search. This narrowed the search but provided more relevant literature to the field. It has also been suggested that including citation and reference searches increase the likelihood of

retrieving all relevant studies (Papaioannou, Sutton, Carroll, Booth & Wong, 2009). Therefore, these methods were also incorporated.

Search terms were divided into four blocks, due to the number of different combinations of terms used in the literature (see table 1). Relevant search terms were truncated (e.g. parent* = parent, parental, parenting; child* = children, childhood). It was decided the term "adult children" and "young adult" would be included as at times these provide valuable retrospective details of the process growing up, providing an insight into how children's relationships change over time.

Following the search, 573 papers were found, following the removal of duplicates. Papers were initially screened by title and abstract and included or excluded based on the criteria provided below (see table 2). Initially, non-peer reviewed articles, including unpublished theses were excluded, including Aldridge & Becker's (2003) research into young carers. Full text articles (n = 42) were then reviewed and assessed in more detail and further papers were excluded[22]. Sandelowski & Barroso (2006) suggest that articles should not be excluded by quality, so despite differences in quality, all papers with a substantial reference to talking with friends were included. Mixed methods papers were excluded at this stage, as they did not provide detailed accounts of people's experiences.

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[22] See figure 2 for a flow chart describing the inclusion of studies

Table 1.

Systematic search terms

Parent	Mental Distress	Child	Life experience
parent*	"mental distress"	child*	qualitative
family	"mental health"	adolescen*	experienc*
mother	"mental illness"	"young carer"	"quality of life"
father	"mental disorder"	"children of parents with a mental disorder"	"life experience"
mum	"psychiatric disorder"	"young adult"	"daily life"
dad	"psychiatric disability"	"young person"	coping
	depression	"adult children"	understand*
	bipolar		talking
	schizo*		support
	"personality disorder"		conversations
	anxiety		
	"obsessive-compulsive disorder"		
	"post-traumatic stress disorder"		

Table 2.

Inclusion and exclusion criteria

Inclusion criteria	Exclusions Criteria
Study focuses on the perspectives of CYP's living with a PEMD	Study includes parental or professional perspectives only
Study must contain substantial reference to CYPs experience of talking about PEMD to their friends	Study does not distinguish between multiple view points
Studies involving adult children's' experiences, must include those that lived with their parent before the age of 18.	Study focuses on evaluation of intervention
Studies must be published in English	Non-peer reviewed articles, reviews, dissertations & personal accounts
	Study uses quantitative or mixed methods design

As this review was primarily interested in CYP's experiences of talking about PEMD, studies examining CYP living with a PEMD exclusively (e.g. parental disability) were excluded (n = 2; Reupert, Goodyear & Maybery, 2012; Thomas et al, 2003). Intervention studies were excluded, unless they examined CYP's more general experiences (n = 7; Foster et al., 2014;

Grant et al., 2008; Grové, Reupert & Maybery, 2015a, 2015b, 2016; Pihkala, Sandlund & Cederstrom, 2012; Wolpert et al. 2015). Studies including mixed methods were assessed to determine if they had a substantial qualitative component. However, two further studies were omitted due to having a brief section dedicated to CYP's reports about their experience (n=2; Maybery et al 2005; Handley, Farrell, Josephs, Hanke & Hazelton, 2001). Furthermore, studies which included the perspectives of CYP, parents and professionals were only included when CYP's experiences could be distinguished from others. Therefore, two further studies were excluded (N = 2; Aldridge, 2006; Tabak et al., 2016). Another study examined both parents' and CYP's responses, but only gathered parents' views of the impact their difficulties had on their children's peer relationships (Stallard et al., 20004), so was excluded. One study explored adult children's experiences, and few references were made to when they were younger (Oskouie, Zeighami & Joolaee, 2011).

A further eight studies were excluded as they did not make a substantial reference to children's experience of peer support when living with a parent with mental health difficulties. Often these studies concentrated on one area of children's experience e.g. children's perceptions of their parent's depression (Kaimal & Beardslee, 2010); parenting qualities (Venkataraman, 2011); the meaning for family life (Hedman Ahlstrom, Skarsater & Danielson, 2011); ways in which families can foster emotional relational resilience in children (Focht-Birkerts & Beardslee, 2000); experience of psychiatric services (Knutsson-Meddin, Edlund & Ramlint, 2007); recommendations for support (Fudge & Mason, 2004). Finally, two studies looked at the impact of living with a parent with mental health difficulties on their current adult lives (Manu & Stein, 2010; Drost & Schippers, 2015). Following this process, 19 studies were included in the meta-synthesis[23].

2.3.3 Appraising and classifying the findings.

Sandelwoski et al (1997) suggest that research should not be excluded based on quality. The danger being that important findings will be excluded based on surface level mistakes. However, appraisal of the literature is necessary to assess the quality of the conclusions drawn. All of the studies included in this meta-synthesis provide qualitative accounts of children's experiences of living with a parent with mental health difficulties. Elliot, Fischer and Rennie's

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[23] A summary of the studies included in the meta-synthesis review is provided in Appendix B

quality appraisal criteria were used as it was designed for the evaluation of qualitative research from the perspective of clinical psychologists (see Barker, Pistrang & Elliot, 2002). This appraisal considers criteria of evaluation that should be common to both quantitative and qualitative research, in addition to more specific criteria for evaluating research (provided below).

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. General vs Specific
7. Resonating with readers

General principles of evaluating research are considered first (e.g. explicit scientific content & method; appropriate method; respect for participants; specification of method; appropriate discussion; presentation; contribution of knowledge), followed by the criteria listed above[24].

Each study provided a detailed rationale for exploring CYP's experiences of living with a PEMD. 15 studies chose to solely use individual interviews, which are appropriate for many qualitative analysis methods and may also allow for the generation of more unique ideas (Heary & Hennessy, 2006). However, one study used a focus group in addition to interviews (Riebschleger, 2004). It has been found that focus groups may allow for greater elaboration of ideas (Heary & Hennessy, 2006). In addition to interview data, Pölkki, Ervast & Huupponen, 2004) analysed essays that were submitted as part of a writing competition which provided rich accounts which were not influenced by a researcher and could be triangulated with findings from the interviews, adding credibility. Van Parys & Rober (2013) utilised family interviews for ethical reasons. Although this may have helped the CYP feel comfortable, they may have struggled to express any difficulties with living with their parent.

One of the main criticisms of the research in this area is the representativeness of the samples. Participants were often recruited via intervention groups, adult mental health services or by self-selecting through responding to advertisements. As discussed earlier, many CYP living

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[24] An extract of the completed quality appraisal is provided in appendix C

with a PEMD remain "invisible" to services and often fearful of talking to professionals, due to fear of being taken into care, or through lack of recognition of mental health difficulties. Therefore, the invisible population's voice may remain unheard and unrepresented in the research. The sample sizes reported vary greatly in the studies. For example, Meadus and Johnson (2000) used a very small sample (n=3), although the participants were interviewed twice. The phenomenological analysis adopted in this study is recommended for use with smaller samples as it allows the researcher to elicit the richness of an individual's experience (Smith, Flowers & Larkin, 2009). The authors noted the challenges of accessing CYP that live with a PEMD and attributed this to having to seek consent through a number of different parties e.g. parents. In addition, they noted that many families avoid seeking support for their children due to fear of stigmatisation. This further highlights the challenges families face with seeking support from others. However, the small sample size does limit our ability to generalise experiences that these CYP may have reported.

The studies varied in their choice of analysis which gave a different focus to the different pieces of research. On the whole, the methodology chosen was in line with the research question. However, there were a few examples where it seemed that this lacked consistency. For example, the aim of grounded theory is to inductively consider young people's experience and from this develop a model using an iterative process (Charmaz, 2014). However, Baik & Bowers (2005) & Riebschleger (2004) presented themes, without illustrating the relationships between these themes. Other studies failed to describe the method for analysing the data, which led to questions about the validity of these methods (e.g. Somers, 2007).

The qualitative criteria pertaining to standards of qualitative research will now be considered. Within qualitative research, it is acknowledged that the researcher is trying to make sense of the phenomena through various lenses (Elliot et al., 1999). Therefore, it is important for the researcher to acknowledge their own perspective within the research. Having said this, only a handful of studies within this review made their position explicit (Alasuutari & Järvi, 2012; Fjone et al., 2009; Foster, 2010; Meadus & Johnson, 2000; Mordoch & Hall, 2008; Tronsden, 2012), but few of these studies provide evidence of their reflexivity. Alasuutari and Järvi (2012) reflect on how their position as a researcher may have influenced the responses of the children and provide extracts of conversation between interviewer and interviewee. However, none of the researchers give a description of who they are and the relationship that they have with the topic and this leaves the reader guessing as to how they shaped the research process.

Studies varied in the description that they provided about their participants. Some included minimal information e.g. number of young people and their age range (e.g. Valiakalayil, Paulson & Tibbo, 2004). However, others provided a rich description of the families included in the study which included their age, gender, emotional and cognitive functioning, details of their parent's mental health & their family composition (e.g. Mordoch & Hall, 2008). Many of the studies did not describe the family composition, which is relevant to the topic area as it provides an understanding of how much contact the CYP had with their parent experiencing mental distress, their support network within the family and the type of symptoms their parent may present. Each of the papers grounded their themes with quotations from their participants. However, some studies used few examples within the text, making it more difficult to put the reader in the shoes of the child and assess the researcher's interpretation of the findings.

The use of credibility checks to ensure the reliability and validity of the findings can align the research to more positivist perspectives and is seen as an important criterion to evaluate the quality of the studies (e.g. Elliot et al, 1999). Nearly half of the studies did not report on their use of credibility checks (9/19). The most common reported method for providing credibility checks was to have more than one person analyse the transcripts (Backer, Murphy, Fox, Ulph & Calam 2016; Bee et al, 2013; Kahl & Jungbauer, 2014; Meadus & Johnson, 2000; Riebscheleger, 2004; Valiakalayil et al., 2004). Other methods for providing credibility checks included presenting data at specialist research groups (Baik & Bowers, 2005); discussing within the research team (Mordoch & Hall, 2008; Mordoch, 2010); or through the use of member checks (Foster, 2010). The lack of credibility checks apparent in these studies may imply that the findings may be subject to bias and therefore not be replicable. However, the understanding of bias is now sometimes seen in relation to the researcher's theoretical position e.g. not looking for a single truth (Roulston & Shelton, 2015). Nevertheless, there was a lack of discussion about this in each of the studies. Nonetheless, these studies may still provide an insight through the eyes of the researcher about CYP's experiences.

Many of the studies look at the broad range of parents' experiences of distress and include CYP from a range of backgrounds and family compositions. Therefore, they provide a general look at these children's lives which may be able to be applied more generally (Bee et al, 2013; Cogan, Ridell & Mayes, 2005; Fjone et al., 2009; Foster, 2010; Mordoch & Hall, 2008; Mordoch, 2010; Ostman, 2008; Pölkki et al., 2004; Riebschlegar, 2004; Trondsen, 2012). Although this provides a good sense of the general experience of these CYP, the findings may not be sensitive to the intricacies of how these difficulties may affect families. In comparison,

Griffiths, Norris, Stallard & Matthews (2012) examine the impact of living with a parent who experience OCD. The CYP in this study reported the impact that rituals have on their liberty e.g. invading their personal space, being restricted by their parents' anxieties. The studies included in this review generally used quite open approaches to examine experiences, which allowed for both positive and negative experiences to be spoken about. However, Valiakalayil et al (2004) focused on the burden associated with having a parent with schizophrenia. This lens could have skewed the research and underestimated any positive aspects of the CYP's experience.

The researchers' approach in each of the studies led to each resonating in a different way. For example, Cogan et al (2005) used Huberman & Miles's interactional analysis to compare CYP who lived with a PEMD and those without a personal experience. This provided an insight into how CYP's knowledge and understanding differed and how this may impact on children's conversations with others. This approach focused less on the depth and richness of CYP's descriptions which made it more difficult to imagine what their lived experiences were. Whereas, Mordoch & Hall (2008) provided a rich account of the dilemmas and variability in the CYP's lives, which provided a rich sense of their lived experience.

2.3.4 Data Analysis

For the purpose of this review, a thematic analysis was used based on Braun and Clarke's (2006) guidelines on completing a thematic analysis. The selected papers were read several times to get to know the data. The finding from each study were then extracted and tabulated, following the separation of first order (participant's own interpretations of their experiences) and second order (author's interpretations of participants' responses) constructs. These constructs were examined and initial codes were generated, to sum up the essence of a segment of text. These codes were then sorted into themes. Once these themes were generated, they were reviewed and refined and checked against the findings of each study to ensure they were valid constructs.

2.4 Meta-synthesis of findings:

Four main themes emerged from the meta-synthesis of the findings. These included: Putting the puzzle together and knowing how to talk about it; keeping the secret; finding someone to trust; and escaping home life.

2.4.1 Putting the puzzle together and knowing how to talk about it.

Many of the studies indicated that CYP often had a limited understanding of their parent's experience of mental distress (Alasuutari & Järvi, 2012; Backer et al, 2016; Baik & Bowers, 2005; Bee et al., 2013; Cogan et al, 2005; Foster, 2010; Griffiths et al, 2012; Meadus & Johnson, 2000; Mordoch & Hall, 2008; Mordoch, 2010; Östman, 2008; Pölkki et al., 2004; Riebschleger, 2004; Valiakalayil, 2004; Van Parys & Rober, 2013). They were often able to describe their parent's difficulties in basic terms (Alasuutari & Järvi, 2012; Backer et al, 2016), but this did not always lead to a comprehensive understanding of the difficulties or what led their parents to experience these changes (Backer et al, 2016). This lack of understanding had a bearing on whether CYP were able to talk to others, including their friends, about their parent's experience of distress and their own experiences related to this. CYP had to go through a process of realising that something was different and find a way to conceptualise this difference, before being able to disclose to others (Baik & Bowers, 2005; Fjone et al., 2009). Finding a common language to talk about it was influenced by CYP's desire for normality (Fjone et al., 2009).

There seemed to be a large variation in researchers' reports about CYP's level and type of understanding, but there seemed to be a consensus that this varied with age and the level to which families discussed it (Backer et al, 2016; Foster, 2010; Fjone et al., 2009; Valiakalayil et al., 2004). For example, Valiakalayil and colleagues found young people's understanding ranged from *"…a chemical imbalance in the brain… to a nervous breakdown".* (Valiakalayil et al., 2004, p531). Backer et al's (2016) interpretation of CYP's accounts suggested that children as young as 6 were able to recognise changes in their parent's behaviour and emotional state. However, they were less aware of the reasons for these changes. For example, a 6 year old child stated *"because she just cries for no reason, I don't know, she just told that to me once"* (Backer et al, 2016, p6). Other research supported the notion that older children began to notice differences in their parent, but were left not knowing how to make sense of these until they were older:

> *"I knew from a fairly early age that there was something definitely weird about her and that she wasn't sort of quite right, but…we didn't know that she had schizophrenia. Nobody sort of said to us 'your mother has a mental illness'. I didn't find that out until I was 15 and that was by accident" (Foster, 2010, p3145)"*

Some CYP did not realise that their parents experienced mental distress until after they moved out of the family home (e.g. Baik & Bowers, 2005; Foster, 2010; Fjone et al., 2009).

> *"I don't know how old I was . . . it was . . . I guess I knew, but it was after the age of 18 that I started, or perhaps it was not before 20 that I started to think it over." (Fjone et al, 2009, p467)*

CYP reported a process of piecing together information over time to understand what was going on with their parent (Griffiths et al, 2012, Mordoch, 2010; Riebschleger, 2004). This could be through making comparisons to others (Riebschleger, 2004):

> *"For quite a while I knew (Dad) had a problem, but I just didn't know about it (psychiatric disability). I didn't know if it was normal or not normal, but I knew it was different." (Riebscheleger, 2004, p 28)*

Others inadvertently came across information through hearing conversations, or finding information from the media (Mordoch 2010):

> *"I could hear the phone. I could also hear their talking even when they hang up. I just sit here...I don't really want to hear but it is part of my home. See eavesdropping is picking up the phone and listening. It's not that." (Mordoch 2010, p 21).*

Some CYP recalled having conversations with their parents (Backer et al, 2016; Riebschleger, 2004; Fjone et al., 2009), although many of these children reported not being able to remember much about these discussions (Backer et al, 2016; Van Parys & Rober, 2013). For example, in one conversation, a seven year old described forgetting what she was told about her parent's experience of mental distress:

> *P: Err she's told me a tiny bit about it but I've forgotten.*
>
> *Int: Aah right can you tell me a bit more about that?*
>
> *P: Mmm I've forgotten most I've forgotten nearly all of it, I can't remember any anything else about it. (Backer et al, 2016, p7)*

However, there was recognition that it was a topic that wasn't often discussed and this could leave children feeling worried, but also gave the impression that mental distress was not seen as important (Mordoch, 2010):

> *"I'm not thinking that it is (MI) not important. It just seems like it's not important if people don't talk about it, learn about it, or know about it" (Mordoch, 2010, p21).*

Alternatively, it was interpreted that CYP felt that having a PEMD was something they weren't allowed to know (Van Parys & Rober, 2013):

''What I want to know is—if I'm allowed to know—what happened to you [father]?'' (Van Parys & Rober, 2013 p5)

CYP's lack of knowledge about mental distress and how this impacted on the parent, left them trying and make sense of the changes that they noticed in their parents' behaviour (e.g. Backer et al, 2016; Mordoch & Hall, 2008; Mordoch, 2010) and often left them feeling worried, leaving them to picture the worst-case scenario (Meadus & Johnson, 2000; Mordoch & Hall, 2008; Mordoch, 2010).

> *"I didn't know my father was sick until I was about 10. We didn't know what was wrong with him right because he hadn't been diagnosed or anything. So it was kinda like watching him and going, there's somethings seriously wrong with this guy and you know, like what is he going to do."*
>
> *(Meadus & Johnson, 2000, p 387)*

In addition, it could lead CYP to misattribute changes in their parent's presentation as personal characteristics of their parent, which could impact on their relationship (e.g. Alasuutari & Järvi, 2012; Foster, 2010; Valiakalayil et al., 2004). For example, Valiakalayil and colleagues found CYP's attributions of their parent's difficulties impacted on their reaction to it. They noted that:

> *"sleeping during the day or not cleaning the house is interpreted as "laziness"or lack of interest. Because of this causal attribution, some of the children believe it is in their parent's control to "pull it together" or "snap out of it".*
>
> *(Valiakalayil et al, 2004, p531)*

Other CYP reported that they blamed themselves, and at times stated that their parent would blame them for changes in their mood (Baik & Bowers, 2005; Kahl & Jungbauer, 2014; Östman, 2008; Riebschleger, 2004). For example, one adult child reflected on their experience of growing up with a mother who was depressed, and how this led her to believe she was a bad person:

> *"I did not know when I was growing up my mother was depressed... As a child I didn't think that was her problem. I thought that was my fault that I made her sad and unhappy, and I felt like I'm a bad person because I was making her feel sad. She never told me that wasn't my fault and she did blame me for making her sad."*
> *(Baik & Bowers, 2005, p3)*

The shame associated with feeling to blame prevented some young people from talking about their experience with others, through fear of being judged as a 'bad child' (e.g. Baik & Bowers, 2005).

> *"The average person doesn't understand what it was like because they haven't lived through it… They don't know what it's about and they think "oh, my God, you are a bad daughter…There is something radically wrong with you. Why are you talking about your mother in such a negative tone?" It's something that they really don't understand." (Baik & Bowers, 2005, p5)*

CYP went through a process of realisation where they came to understand their parent experienced mental distress, and this process allowed them to verbalise their experience (Baik & Bowers, 2005; Fjone et al., 2009). The process of realising that something was different about their home life, compared to other families and their realisation that this difference was due to their parent's experience of mental distress, increased with age (Baik & Bowers, 2005; Foster, 2010; Fjone et al., 2009).

> *"It started when I was about 12, but I did not understand much of it. I think I started to understand a bit more at the age of 14–15, about what was happening with mom. I started to investigate, and started to understand what was happening."*
>
> *(Fjone et al., 2009, p466)*

The language that CYP used to describe their parent's experience of mental distress varied (Alasuutari & Järvi, 2012; Cogan et al, 2005). CYP of a variety of ages were able to use and recognise professional or medical language (Alasuutari & Järvi, 2012). However, CYP demonstrated a preference for more normalised language such as *"problem"* or *"stressed"* (Cogan et al, 2005) and it was unclear how much they understood more medical terms as they often showed some hesitation when using them (Alasuutari & Järvi, 2012).

For example, Alasuutari and Järvi's (2012) interpretation of CYP's discourse suggests that professional vocabulary does not serve a function to help CYP understand their parent's difficulties:

> *"Often the children's difficulties and insecurity show that the professional vocabulary does not function as a resource for them to make sense of parental disorder. It seems that the children have difficulties in connecting the vocabulary to their everyday experiences." (Alasuutari & Järvi, 2012, p139)*

CYP often described mental health problems in relation to the impact the condition had on both their parents and their own lives. This may suggest that CYP have less fear of talking about their parent's behaviour if it is not associated with the stigma associated with more medicalised terms.

Despite most of the studies highlighting the important of CYP developing an understanding of their parent's experience of mental distress, two studies highlighted CYP's fears of being given more information:

> *"Some children described fear of receiving knowledge about the mental illness as it might aggravate their feelings rather than improve their situation."*
>
> *(Kahl & Jungbauer, 2014, p190)*

One study highlighted the importance of acceptance of having a PEMD in helping them talk about it:

> *"It has been an important step for me to get as far as this. To talk about it"*
>
> *(Fjone et al, 2006, p468).*

In this first theme, (title), it is clear that understanding of PEMD could have a significant impact on CYP's ability to talk about their experiences with others, including their friends. The reviewed research showed much uncertainty and confusion in relation to PEMD and reported a slow and gradual development of understanding, with young people at times describing only feeling they understood what was going on later in their teens or in early adulthood. Furthermore, a number of factors seem to add to this lack of clarity of what was going on and how to talk about it. These included that PEMD was unimportant, was a secret that they were not to know about or was their fault. Also, the medicalised language did not fit for many young people as it was removed from their lived experience, thus making it difficult for them to find the language to express their experiences.

2.4.2 Keeping their parent's mental distress private

Many of the studies highlighted how CYP of all ages seemed extremely aware of the stigma associated with mental distress (Alasuutari & Järvi, 2012, Backer et al, 2016; Baik & Bowers, 2005; Cogan et al, 2005; Fjone et al, 2009; Foster, 2010; Meadus & Johnson, 2000; Mordoch & Hall; 2008; Mordoch, 2010; Östman, 2008; Pölkki et al., 2004; Riebschleger, 2004; Somers, 2007; Valiakalayil et al., 2004).

> *"People are afraid of person's with a mental illness". (Östman, 2008, p357)*

> *"I think it [psychiatric disability] is something that other people think bad about…lots of people get teased" (Riebschleger, 2004, p28)*

The existence of stigma was found in the language of CYP with no experience of mental distress, who would use more negative terms e.g. *"crazy", "dangerous", "erratic"*. These more negative terms were influenced by their non-affected parent's use of language and media representations (Cogan et al, 2005).

> *"I remember one time when my mum said to me that this man down our street was crazy, like, he lived at the end of our street, but I hadn't to go near him cos he was mental"*
>
> *(Cogan et al, 2005, p55).*

Even when CYP did not realise their parent's changes in behaviour were due to their experience of distress, they were able to perceive that their parent was acting differently and this resulted in feelings of shame and embarrassment (Alasuutari & Järvi, 2012, Baik & Bowers, 2005; Fjone et al, 2009).

In some of the studies, CYP's awareness of stigma and subsequent feelings of embarrassment, could stop them from telling others about their parent's distress. This is illustrated in the following interview segment from Alasuutari & Järvi, 2012:

> *I: What if your classmates had found out about this [intervention group] when you thought that they wouldn't really understand (.)….what would have followed of it*
>
> *E: Well it would have like I would have like (. . .) of course felt a little ashamed*
>
> *I: Mm*
>
> *E: then but (.) it ((theword)) would have certainly got around and it would have been quite bad (.) like thing (Alasuutari & Järvi, 2012, p 143)*

Furthermore, CYP's ability to come to terms with living with a parent experiencing mental distress and talk to others about it was influenced by their awareness of stigma (Fjone et al., 2009).

> *"I did not want to be identified with mom's illness, I admit that's the situation… The shame comes from structures in society and from those mechanisms that come into force, even if you are (cognitively) not ashamed yourself."*
>
> *(Fjone et al, 2009, p466)*

Stigma also appeared to lead CYP to minimise their parent's difficulties or highlight how much their parent had improved (Alasuutari & Järvi, 2012). CYP's feelings of difference left them feeling uncomfortable, lonely and isolated and navigating friendships could sometimes lead them to struggle as they tried to fit in with their social world (Fjone et al, 2009; Foster, 2010; Mordoch & Hall, 2008). This need to fit in sometimes led them to hide their experiences from others (Fjone et al, 2009; Foster, 2010; Mordoch & Hall, 2008; Valiakalayil et al., 2004).

> *"pressures of fitting in with peer groups at this particular age have led many subjects to keep their parent's illness a secret from friends and new acquaintances. At a time when peer support and interaction is crucially important, some of the adolescents feel compelled to keep a major part of their lives hidden."*
>
> *(Valiakalayil et al, 2004, p532)*

Furthermore, some CYP also expressed a fear of placing too much burden on their friends (Kahl & Jungbauer, 2014; Trondsen, 2012).

> *"In general, I feel like I'm bothering people when I begin talking about my problems or what's wrong. I have a sort of feeling like it's not a good enough reason to be sad, even though other people say it is." (Trondsen, 2012, p181)*

In addition, parents also expressed a desire to keep their experiences within the family, as they were also concerned about stigma and at times were reluctant to share their experience of distress (Griffiths et al, 2012; Mordoch & Hall, 2008; Pölkki et al., 2004; Riebschleger, 2004).

> *"My parents tell me to keep it hush-hush." (Mordoch & Hall, 2008, p1134)*

One study documented how some CYP reported their parents had asked them to lie to their friends as they were concerned about being viewed as *"failing"* (Pölkki et al., 2004). For example, one parent asked her child to tell others that her father was on a business trip rather than in hospital. These factors also left CYP feeling protective of their parent and aware of others' judgements leading them to view their parent's experience of mental distress as a family secret (Cogan et al, 2005; Griffiths et al, 2012 Pölkki et al., 2004; Riebschleger, 2004; Somers, 2007).

> *"Keep it in the house, if people outside knew you would get a bad name."*
>
> *(Somers, 2007, p1326)*

It seems likely that families' fear of stigma increased their isolation and reinforced the view that talking about mental distress is something that should be avoided.

In order to keep this secret, CYP made excuses for their parents' behaviours in order to avoid being judged negatively by others (Baik & Bowers, 2005; Fjone et al., 2009) and they often reported fears of being teased (Riebscheleger, 2004). When CYP did experience their friends observing their parents behaving in strange ways, they reported feeling ashamed. This often resulted in them not inviting their friends over again in the future, increasing their feelings of isolation (Cogan et al, 2005; Fjone et al., 2009; 2012; Somers, 2007).

> *"... the house is not clean ... I cannot bring my friends in and I am afraid she will*
> *go to the neighbours and talk funny." (Somers, 2007, p1327)*

Some CYP reported experiences of being teased or bullied due to their parent's experience of mental distress (Kahl & Jungbauer, 2014; Mordoch, 2010).

> *"Kids bothering you if they find out that your parents have a MI and they make fun*
> *of you, just laugh it off...so they know they're not getting to you...just let it go in*
> *one ear, out the other." (Mordoch, 2010, p23)*

However, other CYP recognised that sometimes it was their own perception that led to feelings of being ostracised by others and acknowledged they hadn't been bullied (Foster, 2010).

> *"I felt, not separated but singled out and that was only my perception...I didn't get*
> *any flack from school, so there was no substantiation of that...so it's not that I was*
> *bullied at school, there was no external stuff that was happening to me, it's just my*
> *perception". (Foster, 2010, p3146)*

However, a few young a few young people reported that they did not feel that their parent's experience of distress as something to be ashamed of, and they reported talking about it freely. Although these CYP still recognised the existence of stigma related to mental distress (Meadus & Johnson, 2000).

> *"I have no problem talking about my mother's illness, it's not something that I'm*
> *ashamed. Ah, I don't think it is something my mother should be ashamed. The only*
> *thing is other people's reactions." (Meadus & Johnson, 2000; p388)*

In this theme, "*keeping their parent's mental distress private*" young people reported that stigma had a significant impact on whether they would talk to others, including their friends, about their parent's mental health concerns. Sometimes this related to their own sense of shame, while at other times the received messages to keep it secret from their parent of family members. Even when they did not feel a sense of shame and felt they

could talk about their experiences openly, they were still aware that others might react negatively.

2.4.3 Finding someone to trust.

Finding someone to trust was reported to be crucial when deciding whether or not to talk about living with a PEMD (Ostman, 2008; Mordoch & Hall, 2008). CYP described using their discretion to determine who to share with, as they were often aware of the risk of people gossiping and there were concerns of rumours being spread around the school (Mordoch & Hall, 2008).

> *"I just told them he [father] has a mental illness. They're like, that's not good. They help me out though, my friends. If I'm feeling down, they already know. I can trust them and what's the big deal if they wanna go blab that to everyone, well, it is a big deal to me."*
>
> *(Mordoch & Hall, 2008, p1135)*

However, many CYP spoke about being able to confide in "best friends" or boyfriends (Baik & Bowers, 2005; Meadus & Hall, 2008; Mordoch & Hall, 2008; Valakalail, 2004; Van Parys & Rober, 2013).

> *"There were times I guess when I felt really you know, upset and frustrated, but I suppose I talked to other people about it. Oh, my boyfriend I guess. I don't know if I talked to Dad or anybody else." (Meadus & Johnson, 2000, p388)*

These friends were described as being empathetic, understanding and provided a safe space for CYP to discuss their experiences (Baik & Bowers, 2005; Mordoch & Hall, 2008). Disclosing to close friends allowed the CYP to anticipate the other person's reactions, providing a greater sense of safety (Baik & Bower, 2005; Van Parys & Rober, 2013).

> *"How they respond to the things that you say. You can tell by their voices, their looks on their face, and their responses to you in how they are going to react on what you are going to say." (Baik & Bowers, 2005, p5).*

However, despite finding a friend that they could trust, young people still expressed a reluctance to share everything with them, and spoke of withholding information from them (Meadus & Johnson, 2000; Trondsen, 2012).

> *"I try to be strong, but am often very sad, even though I don't show it to the rest of the family. Fortunately, I've got myself a good girlfriend who I can talk about it*

with, and I also have a good boyfriend who is very helpful. But it's still often very

difficult, and I notice that I keep a lot inside me." (Trondsen, 2012, p180)

In addition, younger children whose lives were more likely to centre around home life, were more likely to share information with family members, rather than friends (Mordoch & Hall, 2008).

"Younger children, whose families were their dominant point of reference, were more likely to share information with only family members: "Actually I don't tell my friends about it, because I don't share with people that are not family." (Mordoch & Hall, 2008, p1134)

CYP felt different from their peers due to their experience of living with a PEMD (Bee et al, 2013).

"Children described how they often felt emotionally and functionally separated from their peers, primarily due to the dissimilarities that they experienced in their home environments, levels of family responsibility and daily routines." (Bee et al, 2013, p5).

This led CYP to feel as though other children might not understand their experiences (Mordoch & Hall, 2008; Fjone, et al, 2009). CYP found themselves drawn towards those that they perceived to have a similar lived experience (Fjone et al., 2009):

"Me and my best friend, we are alike; we both stay with foster parents'

(Fjone et al, 2009, p468)

Being able to speak with others that understood would allow CYP to open up about their situation. This gave them a sense that they were not alone (Griffiths et al, 2012; Mordoch & Hall, 2008). CYP spoke about the benefit of finding out that they were not the only one living with a PEMD (Mordoch, 2008).

"We could actually talk about it 'cause we had something in common with the families: manic depression. So I guess we're not shy about it. We don't tell anybody [else]." (Mordoch & Hall, 2008, pp1135).

In this theme, *"finding someone to trust",* the reviewed papers reported on the importance for CYP of identifying someone they could trust. For some where there was open communication in their families, there was less of a need to talk to anyone outside the family. However, for many talking to a close friend or boyfriend/girlfriend was a great

source of support. Some CYP described the value of having a friend with similar experiences of living with PEMD.

2.4.4 Escaping home life.

CYP described the need to create a safe distance from their parents, in order to preserve their relationship and help them to maintain their sense of self, as described by this 17 year old young person:

> *''Social, creative, miscellaneous type things, so my good day would be doing anything like that, playing the piano, going out with my friends, helping other people out, that would be part of my day.'' (Bee et al, 2013)*

Many of these studies highlighted the importance of having friends (Backer et al, 2016; Bee, et al, 2013; Foster, 2010; Fjone et al., 2009; Kahl & Jungbauer, 2014; Mordoch & Hall, 2008; Trondsen, 2012; Van Parys & Rober, 2013). CYP reported benefit from just spending time with their friends, and recognised that they did not always need to confide in them about PEMD. They reported benefit from having a good time and restoring their sense of humour (Trondsen, 2012).

> *"Others said they chose to spend time with friends to get time out, whether the aim was to confide in someone about their difficulties, to get a feeling of being appreciated by someone, or to just have a pleasant time to restore their humor. One girl stated that she constantly had plans and was staying at home as little as possible during her parent's difficult periods." (Trondsen, 2012, p182)*

These experiences provided a form of distraction (Bee et al, 2013), helped release tension (Van Parys & Rober, 2013) and provided CYP with a sense of normality (Fjone et al., 2009). By getting away from their parents and living their own lives, CYP continued to develop socially (Mordoch & Hall, 2008).

However, the age of the CYP impacted on their opportunity to spend time outside of the family home. For example, Mordoch & Hall (2008) reported that older children had more opportunity to spend time with their friends, engage in different activities and spend time socialising. At times, older children acknowledged they tried to avoid spending time at home, to reduce exposure to their parent's experience of mental distress (Fjone et al., 2009; Mordoch & Hall, 2008). However, this ran the risk if impacting on the parent-child relationship (Mordoch & Hall, 2008).

"Go and play road hockey. You'll forget about it and it'll be alright. If I'm getting too frustrated here, I have to go see my buddies. Either I'll come back or I'll sleep over there." (Mordoch & Hall, 2008)

In this theme, *"escaping home life"*, it was described how CYP often reported the importance of having some time away from PEMD and just having a fun and relaxing time with friends, where they wanted to forget about the PEMD for a while, rather than talk about it. Particularly, at times when their parents were going through more difficult periods, older CYP often described the value of spending time with friends away from home, just doing everyday things.

2.5 Conclusion

The findings of this meta-synthesis suggest that CYP living with a PEMD can often feel isolated from their peer group, as they struggle to understand what is happening to them, and are then left to negotiate whether it is something that is appropriate to share with others. The four themes that are presented within this study highlight the dilemmas that young people face.

Developing an understanding seemed to be an important step in facilitating discussion. Understanding was seen as a developmental process, that impacted on how CYP made sense of living with a PEMD. Although coming to the realisation of having a PEMD was not often directly discussed within the context of talking to others about their PEMD, it seemed this served as an important context when considering CYP's choices about whether they were able to talk about their experiences to others or not. For example, Baik & Bowers' (2005) interviews with adult children, highlighted how self-disclosure was the first step in being able to talk about it to others. The majority of studies found that young people were poorly informed about their parent's experience of distress. It seemed that this was a topic that was not often discussed either at home, in schools or with friends. The majority of studies suggest that CYP seek more information. However, two studies made reference to CYP not wishing to talk, or be talked to about, their parent's experience of mental distress (Backer et al, 2016, Kahl & Jungbauer, 2014). Age seemed to be a factor in determining how much information CYP sought. With older CYP and young adults reporting a greater desire for knowledge. The differing approaches within these studies highlighted various aspects of understanding: the understanding of the terms used, attributions that CYP made when making sense of changes in their parent's behaviour and the way in which they developed this knowledge. Further examination of these factors may help to facilitate our understanding of how understanding of PEMD helps or hinders conversation and CYP's support seeking behaviours.

In addition to understanding acting as a barrier to talking about their experience, CYP within the studies included within this review often spoke of the shame and embarrassment of having a parent who was different from others. In order to protect themselves, CYP spoke about the need to cover up their parent's difficulties. At times, this seemed to be a personal decision, whereas other CYP seemed aware of their parent's desire to keep mental distress within the family. These ideas seem to support those presented in chapter one regarding the power of stigma and how this can have a wide-reaching effect (Corrigan & Miller, 2004). This belief that having a PEMD must be kept secret in order to protect themselves and their parent, can further isolate CYP. Exploring CYP's lived experiences of stigma relating to their parent, may help determine how CYP come to develop an awareness of stigma and how give a sense of how this impacts on them.

There seemed to be a sense in the studies presented that CYP benefitted from support. Studies identified that CYP had a number of different preferences to who they spoke to. Whereas some noted that their friends were a good source of support, others seemed to stress that they did not want their friends to know. One of the elements that seemed to underpin what was shared was the opportunity to develop a trusting relationship. However, it was unclear from the studies the processes that young people went through to develop this trust but also their lived experience of finding someone to trust. This raises the question of how it felt for CYP to know they had someone that understood them and they could open up to.

Even when CYP expressed fear about telling friends, a number of studies also referenced how having friends to engage in activities with could still have a positive impact. As suggested by Fjone and his colleagues (2009), being able to engage in everyday activities enabled young people to gain a sense of normality. Mordoch & Hall (2008) suggest that it served the function of being able to give CYP a bit of space, whereas other authors just spoke of the enjoyment CYP got out of spending time with their friends.

Despite these findings, data related specifically to peer relationships were thin throughout the review and no research has directly examined how CYP living with a parent experiencing mental distress use their peer networks for support. Given the importance of peer relationships for CYP, this is a limitation to current knowledge and understanding of families living with PEMD. It would be helpful to explore what meaning CYP attribute to having friends, and if and how they use their friends for support. Also, the few studies that explore the processes that CYP go through to disclose information about their home life, come from retrospective accounts. Therefore, this study seeks to examine this gap in the research by utilising a

qualitative design to investigate CYP's experiences of seeking support from their peers about living with parents who experience mental distress. It is hoped that by doing so, we can gain further insight into sources of support for young people with the aim of informing clinical practice and interventions.

2.6 Aims of the Research and Research Questions

The aim of this research is therefore to examine CYP's experience of seeking support from their friends, regarding their experience of living with a PEMD. This will be explored through the following research question:

How do CYP living with a parent experiencing mental distress experience and make sense of gaining support from their friends?

Appendix B: Description of studies included in the systematic review

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Alasuutari & Javi (2012). "My dad got Depression, or something": How do Children talk about parental mental disorder	Finland	To explore how children talk about mental distress	Participants were recruited from a peer group intervention. The sample included 10 children aged 8 – 12 yrs. In four families, the mothers were affected, in one both experienced distress, and in one the father was affected parent. Parents had diagnosis of depression or bipolar disorder.	CYP were asked to take part in individual interviews Discourse analysis was used to analyse the interviews	Three 'vocabularies' were used to describe how CYP talked about mental distress: **Professional** - This included the labelling of mental distress using terms like 'mental health' and diagnostic language. This language was not found to convey meaning for the CYP and appeared to provoke stigmatising images, causing some distress. **The empirical** – This was used to describe how PEMD impacts CYP's day to day e.g. parental mood, behaviour & patterns of interacting **Concern** – Thesis included descriptions of CYP's worries about stigma & the impact their parents condition had on their economic situation.	This is an original piece of research which looks at CYP's use of language. The authors described their epistemological position, which was consistent with their language and choice of methodology. Participants were interviewed following an intervention, therefore their language use may have been different to the general population. In addition, the research looks at parent's who experience depression, and therefore it may not be appropriate to generalise to other conditions. No credibility checks were described in the study.
Backer, Murphy, Fox, Ulph & Calam (2016) Young children's experiences of living with a parent with bipolar disorder: Understanding the child's perspective	UK	To explore CYP's experiences of living with a parent with bi-polar	Purposive sampling method was used to recruit 6 parents from a user-led organisation, using a research advert. Out of these families 10 children were recruited, ages: 4 – 10. Five of the affected parents were mothers, two were fathers. All had a diagnosis of bipolar disorder	Computer assisted semi-structured interviews which were designed for facilitating interviews with younger children. Verbatim transcripts were analysed using a thematic analysis	Four main themes emerged from the thematic analysis: **Perceptions of parents:** parent with bipolar – CYP were able to describe their parent's symptoms and used a variety of terms but some did not understand the causes of these 'well' parent – having a well parent was a protective factor. **Knowledge & awareness of BD:** communication about illness; description of illness **Managing family life:** emotional effects; sources of support **Living in a family with BD:** positive & negative family experiences	This study provides an account of young children's experiences. Thought has been into how to elicit these children's experiences. Credibility checks have been used to ensure consistency of the research findings. This study uses a relatively small sample size for thematic analysis which may limit the generalisability of the sample. However, provides a further insight into these young people's experiences.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Baik & Bowers (2005) Living with a mother with chronic depression: To tell or not to tell.	US	To explore children's experiences of growing up with a parent experiencing depression and their experiences of disclosure over time	5 Adult children Chronic Depression Ages: 26 – 50 who had lived with their mothers with depression until ages 15 – 20.	A qualitative design was used to explore retrospective accounts using grounded theory. Adult children were completed two in-depth interviews were used which lasted from 1½ - 2 hours on the first occasion and ½ hour on the second occasion.	A process in which three different types of disclosing was identified: **Self-disclosing as discovery** – This was the process by which CYP became aware their parents were different from other parents. **First disclosing** – This described the CYP's first experience of disclosing their parent's difficulties to people outside of the family. **Selective disclosing** – This involved CYP's decisions whether or not to disclose, based on their perception of the advantages and disadvantages of opening up.	This is an original study that uses an appropriate design to explore the process CYP go through when disclosing their parent's experience of distress. However, it is unclear whether theoretical sampling has been used, and the sample was small. Therefore, it is unclear with data saturation was met. The authors do not present a model but describe how the process develops. This study also only looks at one mental health presentation, depression. This condition may well be more accepted within society.
Bee, Berzins, Calam, Pryjmachuk & Abel (2013) Defining quality of life in children of parents with severe mental illness: A preliminary Stakeholder-Led Model	UK	To develop a model of quality of life for children living with a parent experiencing mental distress	Participants were recruited by advertisement or email. 19 participants were recruited in total. These included six CYP aged 13 – 18; 5 parents; 8 professionals Parents of children were diagnosed with bipolar, depression, or a personality disorder	A qualitative design was used. Children and parents participated in individual interviews (35 – 80mins), professionals took part in a focus group. A thematic analysis was used to analyse the data.	11 key meta-themes were identified through the analysis. These were then mapped onto an existing framework which was used to discuss the findings. These themes were as follows: **Children's emotional wellbeing** (this described the emotional impact of living with a PEMD) **Children's social wellbeing** (this included CYPs socio-emotional abilities, their relationship qualities & their activity engagement) **Children's ecomonic wellbeing:** resources were found to be important in ensuring wellbeing of CYP. **Children's family contexts and experiences:** This examined the impact of different symptoms, family functioning and relationships. **Children's self-esteem and self-actualisation:** children's self-esteem, coping and understanding about MH.	This study provided an insight into the similarities and differences between the perspectives of children, parents and professionals. However, the small number of participants in each group brings into question the generalisability of these findings. In addition, few quotes were used to demonstrate each person's perspectives. In addition, an existing framework was used to cluster themes, therefore this could have lost the detail of each person's accounts. Quality checks were used.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Cogan, Riddell & Mayes (2005) The understanding and experiences of children affected by parental mental health problems: a qualitative study	UK	This study aimed to compare the perspectives of CYP living with PEMD and those without this experience.	A purposive sample was used. CYP were recruited from adult mental health services. The final sample included 10 boys & 10 girls of depressed parents The comparison group included 10 boys and 10 girls of 'well' parents Children were aged between 12 & 17	A Qualitative design was used. Participants completed a 1:1 semi-structured interview. These lasted from 30 – 42 minutes. A qualitative content analysis was used using NUD*IST software.	The analysis revealed 6 major themes: **Alternative choice of language:** There was a difference in language between affected and non-affected groups. **Distinction from physical health problems:** CYP made distinctions from physical health conditions to help explain their understanding **Source of understanding:** Personal experiences media representations and views of other people helped CYP develop an understanding. **Reasons for MHPs:** Both groups were able to provide good understanding, but emphasised environmental factors. **Stigma of MHPs:** Stigma led to concealment of parent's difficulties. Comparative children held stigmatising views **Request for information:** Both groups, especially affected children identified the need for more information	This paper provided a unique insight into the difference between CYP living with a PEMD and those that don't. The paper used a relatively large sample to demonstrate these differences. However, the choice of analysis limited the depth to which the authors could describe the CYP's experience.
Fjone, Ytterhus & Almvik (2009) How children with parents suffering from mental health distress search for 'normality' and avoid stigma.	Norway	To explore the ways in which CYP present themselves to avoid stigma.	Participants were recruited via advertisements. 20 CYP aged 8 – 22 (18/22 were under 18) 5 boys 15 girls. Parents' were classed as experiencing "mental health distress". Mothers, fathers and step parents were included	A qualitative design was used to explore CYP's experiences. Individual semi-structured interviews were used, which lasted between 1-3 hours. Meaning condensation & categorization was used to analyse the data.	The analysis revealed three subthemes. **Realisation & feelings of being left out or ashamed:** CYP reported feelings of shame and embarrassment to parent's 'deviant behaviour'. At times, this led to CYP minimising chance of shame e.g. by not inviting friends over. CYP described the process of realising difference to being able to name the problem. **Impression management**: This explored the actions CYP used to blend in e.g. seek company of 'similar' friends, pursing normal activities, avoid exposure to parent. **Seeking solitude:** CYP could seek solitude in their bedrooms. CYP would use art as a form of expression, to help them cope.	This study provides an in-depth account of the experiences of CYP in relation to coping with the stigma attached to mental distress. There is not much detail given on the analysis which makes it difficult to determine how the themes were developed. In addition, the way the themes are structured is quite confusing. However, the paper has a relatively large sample and extensive interviews to explore the topic.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Foster (2010) 'you'd think this rollercoaster was never going to stop': experiences of adult children of parents with serious mental illness.	Australia	To explore what it was like to grow up with a PEMD & to identify the coping mechanisms used by CYP	10 adult children were recruited for the study via advertisements in print and radio media. 8 women & 2 men were recruited They had grown up with parents experiencing a number of difficulties including: Schizophrenia, bipolar disorder Severe Depression Schizoaffective disorder	An Interpretive qualitative approach was used. Participants competed narrative interviews. These were analysed using a thematic analysis	Four themes emerged from the analysis: **Being uncertain** – Participants described feelings of uncertainty throughout childhood and into adulthood. They often reported not quite understanding what was happening. **Struggling to connect** – Participants described their trouble to connect to family and friends. **Being responsible** – CYP described the responsibilities that they took on within their families **Seeking balance** – Participants reported a need to continue living their own lives, to provide a balance	This theme presented the experiences of adult children. The sample size was quite small for a thematic analysis, limiting the generalisability of the sample. The description of the analysis is unclear. It describes how the researcher's own written narrative was included, but little information is provided on how this was incorporated into the analysis. Participants checked the transcripts and added notes, increasing the depth of the research, providing some level of member checking. However, this did not involve looking at how their interviews were understood.
Griffiths, Norris, Stallard & Matthews (2012) Living with parents with obsessive-compulsive disorder: children's lives and experiences	UK	To explore CYP's experiences of living with parent with OCD	Participants were recruited through adult mental health services. 10 CYP aged 13 –19 years (5 girls & 5 boys) who were living with a parent with OCD (6 mothers, 1 father)	The study explored qualitative accounts of CYP using semi-structure interviews. A thematic analysis was used to analyse the results	Five themes emerged from the analysis: **Control and boundaries:** This theme described how their parent's OCD could sometimes crossed boundaries: e.g. they had to perform rituals with their parent **Doing what I can do to help:** CYP described taking on extra responsibilities and giving their parents care and reassurance **Telling: embarrassment & pride:** CYP described keeping their parent's difficulties secret from others. **Do I have OCD:** CYP spoke about their concerns of getting OCD **Getting the right help for me:** Participants spoke about the importance of receiving information, but also getting the correct support.	This provides a good insight into the specific difficulties of living with a parent experiencing OCD. The nature of CYP's involvement in their parent's rituals is a unique finding. The article is well structured and easy to follow, helping the reader make sense of the findings. The sample size is relatively small for a thematic analysis and therefore lacks generalisability. The themes were not described in great detail, with only a few quotes provided so it was difficult to really put yourself in the shoes of the participants.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Kahl & Jungbauer (2014) Challenges and coping strategies of children with parents affected by schizophrenia: Results from an in-depth study	Germany	To explore CYPs ways of coping when living with a PEMD	Participants were recruited as part of a larger study, via adult community & inpatient settings. 34 CYP aged 8 – 18 (19 girls, 15 boys), living with a parent affected by schizophrenia or schizoaffective disorder.	This study employed a qualitative design which utilised in-depth Interviews with CYP. The interviews lasted between 45 & 120 minutes. These were analysed using qualitative content analysis	The main category identified was "challenges of children". This consisted of three categories: **Household disruptions & complications:** Described challenges of life at home. **Issues with social interaction:** Described difficulties in relationships to their peers.. **Intrapersonal stress:** CYP described the emotional impact, which impacted on school. In addition, the analysis reported two types of coping: **Emotion-focused coping:** This included aggressive behaviour or distraction **Problem focused coping:** Made use of social support and trying to cope independently. Personal resources: **Personal resources:** Social support and professional support was helpful.	This provides an insight into CYP's ways of coping. The content analysis provides a sense of the different ways in which CYP coped. However, the analysis lacks depth and few quotes are used to give you a sense of CYP's lived experience. Inter-rater reliability checks were used to increase the credibility of the research.
Meadus & Johnson (2000) The experience of being an adolescent child of a parent who has a mood disorder	Canada	To explore adolescents' experiences of living with a parent with a mood disorder	Participants were recruited from adult inpatient service. The sample consisted of 3 female, 17 year old adolescents who lived with a parent with a mood disorder	This study used a qualitative design. Unstructured in-depth interviews were used. Each participant was interviewed twice. A phenomenological analysis explored the participants lived experiences.	Three themes were identified: **Unavailability of the ill parent:** CYP spoke about the disruption caused to their life by their PEMD. **Lack of knowledge and understanding:** The participants described their lack of knowledge and understanding about their PEMD which increased worry **Coming to terms:** This described the emotional toil oF growing up with a PEMD	This was one of the first studies to described CYP's experiences in depth. The analysis provided a detailed descriptions of the difficulties famileis faced. The small sample size makes it difficult to draw any conclusions. Two people rated the transcripts increasing the credibility of the analysis

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Mordoch (2010) How children understand parental mental illnesss "you don't get life insurance. What's life insurance"	Canada	To explore how CYP's understanding of mental distress.	Participants were recruited through adult mental health services. Theoretical sampling was used. 22 CYP Aged 6 – 16 14 boys 8 girls Parent's experiencing, depression, bipolar or schizophrenia were included. Most of the affected parents were mothers, three were fathers.	This study was a secondary analysis of the study below. Individual interviews were used and analysed using grounded theory	The analysis revealed one core variable: **fitting the pieces together.** This was made up of a number of processes which included: **Having part of the story:** CYP spoke about not being well informed and reported experiencing silence around PEMD **Kaleidoscopic parental behaviour:** This involved the diverse changes of parental behaviour **Finding out:** CYP spoke about the range of methods in which they fit the pieces together **Telling other children:** CYP should be told about mental distress in ways which 'aren't scary.	This study focuses on CYP's understating and documents how they learn about PEMD. This allows for rich exploration of one area. Participants experiences are highlighted by use of quotes. It is unclear whether the use of secondary data to explore a new research question allowed for data saturation to be reached. The sample was drawn from a relatively large sample. The age range within the sample is quite large and there is limited discussion of the differences between different CYP.
Mordoch & Hall (2008) Children's perceptions of living with a parent with a mental illness: finding a rhythm and maintaining the frame	Canada	To explore how CYP manage their experiences of living with a PEMD	Participants were recruited through adult mental health services. Theoretical sampling was used. 22 CYP Aged 6 – 16 14 boys 8 girls Parent's experiencing, depression, bipolar or schizophrenia were included. Most of the affected parents were mothers, three were fathers	This study used a qualitative design. Individual interviews were used and analysed using grounded theory	This study revealed the processes in which CYP went through to manage their experience. The main categories were: **Finding the rhythm:** This involved a process of monitoring and adjusting their behaviour in order to try and avoid upsetting their parent. **Maintaining the frame:** This is how CYP made sure they kept an equal balance between caring for their parent and caring for themselves. In order to maintain the frame, participants engaged in life activities, spoke to friends, and used individual coping mechanisms. When it wasn't possible CYP could "opt out" which would involve distancing themselves from their parent	This provides a detailed account of how CYP cope with their experience. It brings to life the challenges that this group face and how they manage their day to day. The authors recognised that theoretical sampling was hard to reach due to the difficulty recruiting. In addition, it may have been the people that agreed to participate were a biased sample. Research was reviewed by other members of the team, who challenged the analysts interpretation, therefore adding to the credibility of the research.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Östman (2008) Interviews with children of persons with a severe mental illness – Investigating their everyday sitiation	Sweden	To explore CYP's experience of living with mentally ill parents	Participants were recruited from an adult inpatient service 8 CYP aged 10 – 18, 5 girls & 3 boys. There parents either had a diagnosis of schizophrenia or affective disorder	The study utilised a qualitative design to explore CYP's experiences. Open-ended interviews were used and lasted from 60 – 90 minutes. A thematic analysis was used to elicit themes.	The themes conversation, love, maturity, fear, blame, loneliness, responsibility & associated stigma emerged: CYP reported that communication with trusted others was helpful at providing relief but noted this was difficult. They all expressed their love towards affected parents. They recognised a level of maturity that they had developed. They reported fear from lack of understanding of their parent's experience of distress. Children often blamed themselves for their parent's difficulties. They experienced loneliness through lack of communication and there being no time for activities. They spoke about increases in responsibility and a recognition of the stigma.	This study provides an overview of CYP's experiences. The categories are not explored in depth and few quotes are used, meaning it is hard to get a sense of the variation in experiences. No credibility checks were described suggesting that these themes may be impacted by the interpretations of the researcher. However, it provides an insight into the conversations that were had.
Pölkki, Ervast & Huupponen (2004) Coping and resilience of children of a mentally ill parent.	Finland	To explore CYP's experiences, needs, stress reactions, coping & resilience when living with a PEMD	Data was collected via 2 sources: Interviews with 6 children aged 9 – 11 Written transcripts from 17 female adolescents & adult children. The youngest was 15 years old and the oldest was described as being in late adulthood. Parental difficulties included: psychosis Depression and suicide	A qualitative design was employed. Thematic interviews lasting 25 – 75 minutes were used. Analysis of written accounts as part of a writing competition which asked "how life changed after a member of my family became mentally ill" A grounded theory analysis was used.	**CYPS experience:** Some CYP's parent experienced mental distress when they were older whereas others were born to PEMD. Experiences varied according to this experience. Discussed "unusual behaviour" and how this impacted on them e.g. losing security. Talked about feeling isolated from friends & relatives, socialising very little. **CYP responsibilities:** Older and younger children spoke about not being informed about their parent's mental health problem. Children spoke about a variety of emotions that their parent's mental health problem aroused in them. The children used both practical problem solving & emotional coping mechanisms. Informal support was available to them.	This study utilised original methods of data collection, allowing for the anonymity of the respondents. However, no details were provided of the analysis process so it was unclear whether theoretical sampling was used. A model was presented to describe how CYP experiencing living with their parent. However, it was unclear how these themes linked together. No details of credibility checks were used.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Riebscheleger (2004) Good days and bad days: The experiences of children of a parent with a psychiatric disability	US	To explore child's view of day to day life, when living with a parent with a mental illness	Participants were recruited from intervention programmes. 22 CYP aged 5 – 17 (11 boys, 11 girls) They were living with at least one parent with either: mood disorder schizophrenia or PTSD (12 mothers, 5 fathers, 5 both parents)	This was a secondary analysis of previous study. 9 CYP completed individual interviews 11 were interviewed as part of a focus group. The data was analysed using grounded theory	**Good days**: These described days when the parent was doing well which led to increased interactions, communications and ability for the parent to complete tasks. **Bad days:** These described when the parent wasn't doing so well resulting in the parent being less attentive or showed changes in mood **Descriptions of disability:** Descriptions varied depending on knowledge about MH. The CYP discussed fears about the consequences of MH and their awareness of others' reactions. **Perceptions of rehabilitation:** CYP described treatment in medical terms but had a lack of awareness if different treatments. CYP were aware of hospitalizations but showed a lack of understanding over what these were for.	This study provided further insight into the experiences of CYP living with a PEMD. A relatively large sample size was used to collect qualitative accounts. However, the fact that they were recruited from an intervention sample may have impacted on the results of the study. The study used grounded theory methodology. However, no model was developed, but it described the variations in experiences. It was unclear if theoretical sampling was used. It is unclear whether the research focused on processes, therefore this methodology may not have been the most appropriate.
Somers (2007) Schizophrenia: The impact of parental illness on children	Ireland	To explore the impact of living with a parent with schizophrenia, consider the impact of separations, obtain their view of support and consider CYP's experience of stigma	Participants were recruited via adult mental health services. The sample included 37 children (20 boys & 17 girls) In 26 families the mothers were affected, and 11 the fathers were affected. This was matched with a control sample	Semi-structured interviews were carried out with parents & children separately. Descriptive statistics were used to present the data.	**Invisible children:** Children were often not recognised by adult services **The child's lifestyle:** CYP living with a parent experiencing distress missed more school, had less family time. Friends were most common form of support. **The child's experience of MH:** CYP had a strong awareness of stigma & believed it should be kept hidden, expressing embarrassment. Struggled to trust others. **Awareness of symptoms:** children spoke about their reactions to their parents distress (sadness, anger, anxiety), burden of illness	This provides a unique insight into CYP who live with parents experiencing schizophrenia. The information presented provides an insight into differences between the 'sample' CYP and the control group. However, this does not provide rich description of their experiences.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Trondsen (2012) Living with a mentally ill parent: Exploring adolescents' experiences and perspectives	Norway	To explore adolescents' everyday life when living with a parent with mental health difficulties	Participants were recruited from an online support group. 16 adolescents were part of the online discussions, including 15 girls, 1 boy aged 15 - 18 At least one of their parents experienced serious mental health problems, including bipolar disorder, psychosis or suicide attempts	The study was an action-oriented study, in which the researcher participated in an online forum. An analysis of the content of online conversations was completed using an observational, interactive framework	Lack of Information and openness: CYP were often not given information about their parent's condition, yet they were aware of how it was impacting on family life Unpredictability & Stability: Parents mood and behaviour could fluctuate rapidly leading to feelings of uncertainty which impacted on their ability to manage. Loneliness: Feeling lonely, having to struggle with the challenges they faced. Noted it was hard to confide in others, or for others to understand. Loss and Sorrow: Adolescents described the loss of not living in a normal family Strategies for managing: these included taking responsibility, being on "emergency alert mode", taking time out (e.g. spending time with friends) & seeking professional support.	The design of this study was original and allowed the researcher to observe some intimate interactions within the online support group. It maybe that material was influenced by the context of the support, or by the researcher. Furthermore, no credibility checks were conducted.
Van Parys & Rober (2012) Trying to comfort a parent: A qualitative study of children dealing with parental depression	Belgium	To explore how CYP experience parental depression and their caregiving responsibilities	Participants were recruited via inpatient services. 14 CYP agreed to take part in the research (aged 7 – 14). 9 girls, 5 boys. Each had experience of living with a parent with depression (7 mothers, in the other cases it was the father.	A qualitative design was used to explore these CYP's experience. CYP were interviewed with their families. These interviews lasted between 60 – 70 minutes. The data was analysed using thematic analysis	The thematic analysis revealed 8 themes: **Sensitivity to parental distress** – CYP reported worrying for parent **Understanding what's going on with the parent** – CYP developed an understanding but many questions remained. **Experiencing distress**- CYP named worry, guilt and the fact they missed their parent **Experiencing no burden** – CYP reported their parent took good care of them **Finding support to release tension**- through engaging in activity, sharing worries **Talking in the family is rather difficult** – CYP did not ask for info from parent **Taking responsibility within the family** – CYP reported taking on extra responsibilities **Trying to comfort the parent** – CYP provided both verbal and non-verbal support	This provides an insight into CYP's experience of living with a parent with depression. The hospitalisation of the parent's in this study provided a certain context to the research question, and so some of the findings might not be applicable to other settings. The themes presented are done so quite briefly, with the exception of "trying to comfort the parent" which is analysed further. Few quotes are provided throughout the text so it is hard to assess the validity of the analysis. Use of family interviews may have prevented some CYP from being honest.

Authors & Date	Country	Aims of report	Participants	Method & Analysis	Findings	Strengths & Limitations
Valiakalayil , Paulson & Tibbo (2004) Burden in adolescent children of parents with schizophrenia	Canada	To explore the types of burden associated with having a parent with schizophrenia	Participants were recruited through an adult inpatient unit. 13 adolescents Ages 13 – 18 9 female, 4 male Identified through an adult inpatient unit Schizophrenia	A qualitative design was used. Individual semi-structured interviews with adolescents were carried out. No analysis was specified.	Attribution of parental disorder: most adolescents attributed their parent's illness to past behaviour e.g. drug & alcohol use, head injury, stress or a psychological problem. The attribution that CYP gave to their parent's illness Impacted on their response. Dealing with symptoms: the adolescents described the challenges of dealing with positive and negative symptoms. Changing roles: Participants had additional responsibilities resulting in a shift in roles. Coping: Talking to others, using solitary strategies which were not deemed as adequate. Positive aspects of the relationship: feeling closer to their parent, learning important lessons	This provided an insight into CYP's experience of living with a parent with schizophrenia. However, the focus on burden left the findings feel quite skewed. In addition, it was difficult to get a sense of what the participants described without examples provided.

Appendix C: Example of quality assessment of quality of included studies:

Author	Explicit scientific content & method	Appropriate method	Respect for participants	Specification of method	Appropriate discussion	Presentation	Contribution of knowledge
Alasuutari & Javi (2012).	Outlines risk & resilience literature Highlights lack of children's perspectives but gives brief details into some existing studies looking at understanding & language. Problem of language in relation to finding children's experiences	Uses qualitative interviews & conducts discourse analysis to address aim: to look at language children use when discussing parental mental health.	Yes, research approval given, consent procedures described, withdrawal right highlighted, methods ensuring confidentiality highlighted, use of counsellors, those known to family – not involved in interviews	Interviews & discourse analysis Provided a description of analytic process. Did not highlight detailed steps of analysis chosen e.g. states interviews were transcribed, re-read and relevant sections of text distinguished but no further steps of analysis.	Yes, summarises findings, highlights how it applies to practise. Improvements: further discussion of strengths and weaknesses and discussion on interviewer as co-constructor would be useful	Method section difficult to follow – it would be useful to break text up e.g. into participants, procedure, ethics & analysis.	Unique & original study exploring use of language – provides insight into understanding Useful in considering shared language and use of labels within mental health teams and how these contribute to the stigma associated with parental mental health. In addition to consideration of peer support as an intervention.
Backer et al (2016)	Sets out context – prevalence of bi-polar and percentage of parents Explores psychological risks. Recognition of lack of child view – recognition of current studies, problem with current studies e.g. mixed parental conditions & provides rationale for studying current phenomenon	Qualitative Computer assisted interview – provide rationale (e.g. found successful with young children) Researcher asks open questions and make reflections – discussion on how this may influence process.	Yes, detailed description of thought that went into the process. E.g. meeting with families to discuss the language that should be used, pilot interviews, consent procedures highlighted, withdrawal rights emphasised.	Yes: Description of method (computer assisted interviews), recruitment (purposive sampling) & pathways – advert & UK user led BD group) Analysis described: thematic analysis and the steps which were made	Yes, summarises purpose & findings. Recognises weaknesses of small sample and challenges in generalising Contrast between other studies that show poor understanding. Grounds findings in literature, offers explanation	Research clearly presented. Test split up into sections. Participant details provided in table. Table/ diagram of themes would have bene useful.	Provides useful insight into children's experience – highlighting positives, not just grounding in risks. Also adds to understanding of impact of specific condition. Provides insight into the amount that children understand and pick up and the need to provide children with a space to voice their concerns and to talk to other children.

Author	Owning perspective	Situating sample	Grounding in examples	Providing credibility checks	coherence	General vs specific	Resonating with readers
Alasuutari & Javi (2012).	Named "social constructivist" Takes view of researcher as co-construction – co-participant & what this means in terms of research. Language as a social practise or way of doing things. Provide role in research Interactional event Noting that this study looked at a discourse between professional and child. Although children's language and relationships were talked about, the construction between children might be different	Mostly: Provides details of context in which children were interviewed & who agreed and who did not. Describes mental health condition and family make-up & history of hospitalisations. Also where they came from. No description of gender or ethnicity.	Yes, examples given for each category: Transcript between Tomi & Interviewer about professional language. Examples include interviewer questions and conversational style – in line with constructionist approach Also extracts provide example of categories	No reference to these checks but makes suggestions tentatively and explains where they are coming from & grounds suggestions in research– in line with epistemological position.	Yes, outlines key components of findings which follow question of *how* children talk about things.	This is quite a specific piece of research and there is no discussion in relation to the generalisation of these findings and the limitations of this. For example, the children talk about peer support, following an intervention. Children that may have not been involved in this may construe things differently, plus there may be more awareness of issues following group. Futhermore most parents experienced a mood disorder.	The study gave a good account of how language can impact on the way in which a child makes sense of mental health. I felt the child's struggles through his use of medical terms, and need to feel knowledgeable. However, given the opportunity to put it back into their own language, the dialogue flowed a bit more. The research is written in a way that follows epistemological position. However, I get less of a sense of the interviewers own experience.

Author	Owning perspective	Situating sample	Grounding in examples	Providing credibility checks	coherence	General vs specific	Resonating with readers
Backer et al (2016)	Implied but not stated. Phrase "systematic & iterative" process	Good – looks at child & parent scores of functioning, hospitalization history, detailed description of participants including level of education, ethnicity etc etc	Yes, provides a number of relevant examples. However, more examples of quotes would have brought data alive more.	Yes; Consistency: two independent researchers given transcript excerpts Reflective journal & audit trail of decision making kept	Yes, follows a direction to explain children's experiences of living with a parent with bi-polar. Themes make sense and are explored in discussion	Acknowledges limited generalisability of sample but offers tentative suggestions about the meaning of research. Also looks at effects of specific disorder (bipolar)	Provides useful summary of children's experiences. Some categories could have been explored further but given the age of the sample and challenges in conducting interviews about complex topic provides good introduction. However, difficult to get a sense of the children and how they spoke about things as quotes were quite short.
Baik & Bowers	No, did not disclose their epistemological position or role of researcher explicitly. Described	Moderate description of experience of living with PMH e.g. age at which they lived, experience of hospitalisations, current mental health of sample. Gender but not ethnicity.	Yes. However, sometimes the examples were not given in "" making them hard to distinguish from the authors description	Stated that they periodically presented data to a grounded theory research group. However, Eliott & Lazenbett (2004) highlight that the process of credibility checks is not necessary due to the iterative process used within grounded theory methodology.	Yes, follows description and analysis. Answers aims. Provides story of how they disclose over time. Details differences in older and younger children. Looks at how categories link together as a process. Acknowledges how interview questions were refined & rationale	The study looks specifically at retrospective accounts of adults who had lived with a parent with chronic depression. Retrospective allows us to get a greater understanding of the journey of understanding & disclosing. Self selecting – therefore more likely to be able to talk?	Provides a useful introduction to the process of disclosure and the processes in which the young people go through to get to a point when they feel safe. Less of a sense of the researcher's experience.

Appendix D: Extracts from my reflective diary

23rd November – Reflection on recruitment process

I attended Kidstime today, as I had got permission from some of the parents to talk to them about my research. I found myself feeling quite paralysed when it came to approaching the parents and I wondered what this was about. I reflected on my fear that by studying the impact of their mental health difficulties, I was indeed implying that it was something that was a problem for their child and I wondered how that might feel. This position was partly influenced by the reading that I had been doing for my introduction that had suggested that parents feared the actions of professionals, in case they were viewed as bad parents and also research thinking about the child as an active agent, rather than someone 'at risk'. However, I also reflected on my own experience of being a daughter of someone with a health problem and recognised how protective I often felt towards my mother as I grew up when she apologised for getting angry or upset. At the time, I remember my mother as someone who worked hard and took us from one place to another and felt her frustration was a response of the situation, but it upset me to feel that it made her feel as if she wasn't doing a good job as a parent.

I also reflected on my relationship with the borough in which I was recruiting. Having previously worked in the service, I had been part of very tentative discussions about service change and development and it seemed people were very cautious and protective of the families they saw and I remember valuing how thoughtful the clinicians were. However, at times it did seem to lead to a feeling of being stuck. Similarly, it felt as though my discussions with my field supervisor at the beginning of this process had reflected the care and protection in the system. I also felt about the relationship between the families and services, and had a sense that there was sometimes a tension between those in power and the people that they served. I often felt many of the families I had been involved with had a sense of disempowerment due to a number of contextual things e.g. it's a very diverse borough with high amounts of inequality. This made me very aware of my position as a White, middle-class professional, studying for a doctorate.

Interestingly, when I plucked up the courage to speak to some of the parents, they were very forthcoming and spoke to me about how the experience might be good for their child, to give them a space to think about it. This made me think about why I chose to do this research in the first place – to ensure that families (including parents) were given enough support to help them. Interestingly a couple of the parents seemed hesitant about me talking to their children because they had a sense their children would not understand the concept, and therefore it would not be good for them to have a discussion about it, highlighting their protective role. This made me think about the sessions that I sat in on with the other (sometimes very young) young people, where I was taken a back my how much they understood. There was a session which I observed when the CYP were talking about what to do when their parent got sick (physical health) including how to ask for support from their family and from services. I wondered how families navigated this dilemma.

Reflection on applying for NHS ethical approval

When I first looked at the website, I was overwhelmed by the amount of information on it and it took me a while to work out what and how I had to do it. When I phoned them to clarify aspects, I tended to get told to "look on the website". The initial process seemed quite straightforward. I was seen quickly in front of a panel of people who asked me a number of questions that appeared relevant to ensuring the ethical procedures of my study. The process

of getting approval for this came quickly and with clear guidelines. However, this quickly descended into confusion, especially given my site was a collaboration between NHS, local authority and 3rd sector organisations. The HRA process seemed quite straight forward, despite the forms requested asking me about costings, with little information on how to fill them in. However, this took another 4 months to process. Then things became very confusing, as local R&D became involved. I applied for a minor amendment to add another Kidstime site (as advised) but was then told they couldn't add them, due to the local authority involvement. This resulted in endless emails flying backwards and forwards between myself, NRec, HRA and R&D. This was very confusing as I was unsure how to move this forward. I went from completing a minor amendment and a substantial amendment, both of which were approved by HRA, to then face the same problem with R&D. I have felt the process went from being a rigorous process to ensure participants were kept safe, to an onerous bureaucratic process that seemed to be more about ticking boxes than ensuring the participants were ok.

Reflection after 1st interview:

This was the first interview that I was doing. I felt a sense of anxiety but also excitement, I did not know what to expect or how the parents would respond to my arrival. Due to the delays in my recruitment, I felt quite relieved that I was going to be speaking to a young person about their experience and I wondered what I would learn.

I arrived at the house and it was full of activity. I was struck by how each of the sisters were sharing one room and I felt guilty that I needed to ask if we could have the space. However, I wondered how the eldest must feel, and how she was able to get space.

When I started asking her about the research, she still seemed a bit unclear about what it was about. I spent about 20minutes talking with her and thinking with her about her consent. I asked her what she understood by it and questioned her about her rights to withdraw, to make sure that she understood. I showed her the interview questions and was struck by how she was unsure about the ones that included talking to her friends. We had a bit of a chat about what made these questions difficult and she spoke about not knowing what she would say to them. We had a bit of a think about there being no right or wrong answer and that she could say she didn't know, but I was struck by a sense that she had to say the right thing, or impress me. We played with the recorder a bit, as I could sense her apprehension, to try and build the rapport (e.g. and saying "testing, testing" and playing it back).

During the interview process we were interrupted many times by the young persons sisters, and it became clear how supportive she was towards her sisters. I was struck by her maturity but also by her child like manner.

I was aware of both of our struggle to use the medical terms, and despite asking her questions about what she heard, it sometimes felt as if she was repeating things back (or repeating words she had heard). It did not seem to be a language that she was used to.

[The interviewee] struggled to answer open questions and was looking to me to see if it felt like enough (or whether she had said the right thing) so I found myself talking more than I had expected to, this was partly to maintain a rapport but also to provide her a little guidance. It seemed like there were things that she didn't want me to know and would use the term "blah blah blah" in the place of providing the essence to the question. I tried using different angles to elicit some of her experiences, but I found myself moving on from topics when it felt too difficult. I also checked in [the interviewee a number of times]. I was struck by how much information was elicited through reflecting on the process of the interview – talking was clearly hard.

Reflection after 3rd interview (extract)

I was excited about doing this interview [the interviewee] had seemed very enthusiastic about taking part and was slightly older so I felt that this would be an opportunity to get more in-depth data. However, the process did not reflect this. The [interviewee] responded to my questions in a very matter of fact way and I was missing the emotion to what she was saying, but again it felt as if talking about this subject was hard. I felt a strong sense of protection towards [the interviewees] mother, which triggered my fears of positioning her mother as a problem.

Despite having a sense that the [CYP] was holding back and not providing me with what I observed as their real experience, there seemed to be a lot of emotion in the room. I felt a sense of anxiety about talking about it, which I think reflected the anxiety they were feeling. At times, it felt like if I asked a question, I might unleash something that was too difficult for them to respond to, so I held back. I felt myself feeling frustrated at myself for not being able to put them at ease, or establish a better rapport and I noticed myself avoiding the prompts for more information. My questions became more closed, in an attempt to normalise their experience and emotions and give them permission to provide more information. Again, I found myself constantly checking in, and moving onto the next question when things felt too difficult.

Reflection after 5 interview (extract)

At the end of the interview, I observed how different the interview felt from previous ones. Although there was a lot of love, affection and care towards their parent, there seemed to be a sense of anger, frustration and loss of a 'normal childhood'. I felt myself wanting to rescue the CYP, and provide them with the support they were asking for. It felt like there had been a role reversal in their relationship, with [the interviewee] taking the role and caring for their mother. However, it felt as if part of the frustration was directed towards me, a professional who had not provided them with the support they needed. A professional that had left them to get on with things and make their own way through life.

Analysis reflection (extract)

I had now completed three interviews and transcribed the data. I looked at the transcript and wondered how I was meant to do an IPA analysis on them. After writing my method section and recalling all of the times I had spoken about the idiographic and phenomenological nature of IPA. I felt a bit disheartened at this stage. It felt like there was no way I would be able to write 10,000 words on my results. Although there seemed to be clear comparisons between the interviews, what I seemed to be lacking was the depth, or the "what does that mean". However, as I started the analysis process, and completed the initial noting, I was able to elicit an amazing amount of detail from looking at the language they were using and the process that was unfolding between me and the young person. I found myself taking over a week just to get to the end of this stage of the process.

At times, I wondered about whether I was straying too far from the words of the young people, but I reminded myself of the 'interpretive' nature of IPA, and actually found many of the interpretations I were making were then summed up beautifully by the words of the participant.

The analysis also brought the emotions of the CYP to life and I was left feeling quite sad about the challenges in talking this group felt. I wondered how they could get the support they needed but also imagined them 'getting on with it'. This reignited some of my passion for the project, which had been fading through the challenges of recruitment. It felt as if this was something that needed to be heard and spoken about.

NHS
Health Research Authority

05 September 2016

Letter of HRA Approval

Study title:	**Children of parents with mental illness: A grounded theory study exploring young people's conversations with their peers.**

IRAS project ID:	**202951**
Protocol number:	**LMS/PGR/NHS/02347**
REC reference:	**16/SC/0298**
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 noted in this letter.

Participation of NHS Organisations in England
The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical 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 and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices
The HRA Approval letter contains the following appendices:
- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval
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.

In addition to the guidance in the above, please note the following:
- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope
HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback
The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training
We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **202951**. Please quote this on all correspondence.

Yours sincerely

Senior Assessor

Appendix F: Confirmation of Sponsorship from the University of Hertfordshire

University of Hertfordshire UH

27 September 2016

Re: **UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:**
RESEARCH STUDY TITLE: Children of parents with mental illness: A grounded theory study exploring young people's conversations with their peers
NAME OF CHIEF INVESTIGATOR
NAME OF INVESTIGATOR (Student)
UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER:
LMS/PGR/NHS/02347

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. It is also essential that evidence of NHS Trust Management Permissions (formerly known as R&D Approval) is sent as soon as they are received.

Permission to seek changes as outlined above should be requested from myself before submission to an HRA (NHS) Research Ethics Committee (REC) and notification to the relevant University of Hertfordshire Ethics Committee with Delegated Authority (ECDA), and I must also be notified of the outcome. It is also essential that evidence of any further relevant NHS management permissions (formerly known as R&D approval) is provided as it is received. Please do this via email to

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

Appendix G: Ethical Approval - Confirmation of Minor Amendment

From: AMENDMENTS, hra (HEALTH RESEARCH AUTHORITY) ████████████
Sent: 11 January 2017 12:55
To: Nolte, Lizette
Cc: Oliver, Sarah; Senior, John; NOCLOR, Contact (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST)
Subject: RE: IRAS ID: 202951; REC ref no: 16/SC/0298, Nolte-Oliver, Minor Am 1 - Category B amendment

Dear Dr Lizette Nolte,

IRAS Project ID:	202951
Short Study Title:	Exploring young people's conversations about parental mental health
Date complete amendment submission received:	10/01/2017
Amendment No./ Sponsor Ref:	NSA #1 - Addition of Kidstime Intervention Bedfordshire site to study
Amendment Date:	21/12/2016
Amendment Type:	**Non-substantial**

Thank you for submitting the above referenced amendment. In line with the UK Process for Handling UK Study Amendments I can confirm that this amendment has been categorised as:

- **Category B** - An amendment that has implications for, or affects, SPECIFIC participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England that are affected by this amendment.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales that are affected by this amendment, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the four conditions below, you will be able to implement the amendment at affected participating NHS organisations in England **35 days after you notify them of the amendment**. A template email to notify participating NHS organisations in England is provided here.

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion where applicable, (for participating organisations in England, please see 'Confirmation of Assessment Arrangements' below). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England that are affected by this amendment, plus to local research teams at any affected participating NHS organisations in Northern Ireland, Scotland or Wales*.

- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.
- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.
- For amendments adding new sites, you may not commence research activities at site until the nation specific processes to allow this are concluded, e.g. NHS Permission in Northern Ireland, Scotland or Wales and Confirmation of capacity and capability in England (if this amendment adds new sites in England, the HRA will shortly provide further information on expectations relating to their formal confirmation of capacity and capability).

Note: you may only implement changes described in the amendment notice or letter.

If you receive required regulatory approvals (for participating organisations in England, please see 'Confirmation of Assessment Arrangements' below) after the 35 days have passed you may then immediately implement this amendment at all existing participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study. As above, the 35 days does not apply to opening new sites and nation specific processes should be followed.

For existing participating organisations, there is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35 day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.

Participating NHS Organisations in England – Confirmation of Assessment Arrangements

<u>Further to the details above, I can confirm that no HRA assessment of this amendment is needed.</u>

- If this study has HRA Approval, this amendment may be implemented at participating NHS organisations in England once the conditions detailed in the categorisation section above have been met
- If this study is a pre-HRA Approval study, this amendment may be implemented at participating NHS organisations in England that have NHS Permission, once the conditions detailed in the categorisation section above have been met. For participating NHS organisations in England that do not have NHS Permission, these sites should be covered by HRA Approval before the amendment is implemented at them, please see below;
- If this study is awaiting HRA Approval, I have passed your amendment to my colleague in the assessment team and you should receive separate notification that the study has received HRA Approval, incorporating approval for this amendment.

Please do not hesitate to contact me if you require further information.

Kind regards

Alka Bhayani
HRA Approvals - Amendments Coordinator

Would you like to receive the latest updates on HRA work? Sign up here

For more information on the HRA Approval process Click here

The HRA is keen to know your views on the service you received – our short feedback form is available **here**

Appendix H: Email confirmation from non-NHS sites

██████████████████████████████████ ██████

Wed 22/03/2017 11:09

To: ██████████████████████

Cc: ███
████████████████████████

That sounds great and I have spoken to the team who are aware of what you will be doing.
Hope all goes well.

██████████

Parenting Team Manager

PLEASE NOTE MY MOBILE NUMBER HAS CHANGED

Child Poverty and Early Intervention
Our Pledge in Operations is to;
• Put children and families first in everything we do.
• Work as 'one team' close to our communities and partners.
• Be great corporate parents to children in care and care leavers.
• Provide a well managed service and give great public value to the people of Central Bedfordshire.
██
Direct Dial ██████████████████████████████

From: ████████████████████████
Sent: 22 March 2017 10:58
To: ██████████
Cc: ██████████
Subject: Re ████████████████████████

Dear J███

Thank you for your help with this and for confirming that you are happy for me to
recruitment from the two Kidstime workshops which are run in Bedfordshire.

As discussed this would involve members from your team approaching families to ask
whether they are happy for me to approach them about the research. If they are happy for me
to speak with them about the project, I will then approach them and provide them with further
information at the Kidstime interventions. I will arrange the interviews at a location that is
convenient to them.
Many thanks,
Sarah

From: ███████████████████████████████████████
Sent: 21 March 2017 08:38
To: Oliver, Sarah
Subject: RE: ████████████████████████

Hi
That Is all ok to go ahead.
██████████
Parenting Team Manager

Appendix I: Ethical Approval - Confirmation of Substantial Amendment

NHS
Health Research Authority
South Central - Oxford A Research Ethics Committee

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented   at NHS sites in England until the outcome of the HRA assessment has been confirmed.

Dear Dr Nolte #
The above amendment was reviewed by the Sub-Committee in correspondence.

Study title:	**Children of parents with mental illness: A grounded theory study exploring young people's conversations with their peers.**

REC reference:	**16/SC/0298**
Protocol number:	**LMS/PGR/NHS/02347**
Amendment number:	**Substantial amendment 1 22.03.17**
Amendment date:	**22 March 2017**
IRAS project ID:	**202951**

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.
Recommendations

1. The Sub-Committee note that in the young person's PIS the researcher is interchangeably referred to in the third person (Sarah) and first person (I) and this should be amended for consistency.

2. As parents are no longer included the adult PIS wording should be amended to ask them to agree for their child to take part, not to take part themselves.

Approved documents
 The documents reviewed and approved at the meeting were:

Notice of Substantial Amendment (non-CTIMP) [AmendmentForm_snapshot.pdf]	Substantial amendment 1 22.03.17	22 March 2017

Participant consent form [4_Parental_Consent_YP v4 22.03.17.docx]	4	22 March 2017
Participant consent form [11_Consent+_YP_12-15 v3_22.03.17.docx]	3	22 March 2017
Participant consent form [3_Consent+_YP 16 to 18_v4 22.03.17.docx]	4	22 March 2017
Participant information sheet (PIS) [1_Information_Sheet_info_for_parents_YP_Participation v4 22.03.17.docx]	4	22 March 2017
Participant information sheet (PIS) [10_Information_Sheet_info_for_YP_12-15 v2.docx]	2	22 March 2017
Participant information sheet (PIS) [2_Information_Sheet_info_for_YP_16+to+18 v4 22.03.17.docx]	4	22 March 2017
Research protocol or project proposal [Research Protocol v3.docx]	3	22 March 2017

Membership of the Committee
The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations
Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

16/SC/0298:	Please quote this number on all correspondence

Yours sincerely

████████████
████████████████████

Enclosures: *List of names and professions of members who took part in the review*

From: ████████████████████████████████████
Sent: 25 May 2017 14:51
To: ████████████████████████
Cc: ████████████
Subject: IRAS 202951. Confirmation of REC Validation and Categorisation of Amendment

Dear Dr Nolte,

IRAS Project ID:	**202951**
REC Reference:	**16/SC/0298**
Short Study Title:	**Exploring young people's conversations about parent's mental health**
Date complete amendment submission received:	**25 May 2017**
Amendment No./ Sponsor Ref:	**Substantial amendment 1 22.03.17**
Amendment Date:	**22 March 2017**
Amendment Type:	**Substantial**

Thank you for submitting the above referenced amendment. I am pleased to confirm that this amendment has been submitted to the REC for ethical review. Please find attached a copy of the validation letter.

Categorisation of Amendment

In line with the UK Process for Handling UK Study Amendments I can confirm that this amendment has been categorised as:

- **Category A -** An amendment that has implications for, or affects, ALL participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices **and** local research teams at your participating NHS organisations in England.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

Subject to the three conditions below, you will be able to implement the amendment at your participating NHS organisations in England **35 days after you notify them of the amendment.** A template email to notify participating NHS organisations in England is provided here.

- You may not implement this amendment until and unless you receive all required regulatory approvals, including REC favourable opinion, (for participating organisations in England, this includes receiving confirmation of HRA Approval for the amendment). You should provide regulatory approvals to the research management support offices and local research teams at your participating NHS organisations in England, plus to local research teams at any participating NHS organisations in Northern Ireland, Scotland or Wales*.
- You may not implement this amendment at any participating NHS organisations which inform you within the 35 day period that they require additional time to consider the amendment, until they notify you that the considerations have been satisfactorily completed.
- You may not implement this amendment at any participating NHS organisation that informs you that it is no longer able to undertake this study.

Note: you may only implement changes described in the amendment notice or letter.

If you receive required regulatory approvals (for participating organisations in England, this includes confirmation that the amendment has been granted HRA Approval) after the 35 days have passed, you may then immediately implement this amendment at all participating NHS organisations that have not requested additional review time, or are no longer able to undertake this study.

There is no need for you to receive a letter of confirmation from the participating organisation that the amendment can be implemented, as the intended date of implementation is communicated through the above process. However, you may be able to implement this amendment ahead of the 35 day deadline, if all necessary regulatory approvals are in place and the participating organisation has confirmed that the amendment may be implemented ahead of the 35 day date.

* Where the study involves NHS organisations in Northern Ireland, Scotland or Wales, the HRA will forward regulatory approvals to the relevant national coordinating function to distribute to their research management support offices.

Please do not hesitate to contact me if you require further information.

Kind regards

Health Research Authority

HRA, Ground Floor, Skipton House, 80 London Road, London, SE1 6LH

E:

<u>**Consent to participate in a research project**</u>
<u>**Information Sheet for Parents**</u>

Children's conversations with their friends about living with parents experiencing mental distress: An IPA study

Why have I been given this information sheet?

Your son/daughter has been invited to take part in a piece of research being conducted by Sarah Oliver, Trainee Clinical Psychologist.

Before you decide whether you are happy for them to take part in the research, it is important that you understand why this research is being conducted and what will be asked of your son/daughter, should he/she decide to take part in the research.

Please take your time to read the information below carefully. This aims to answer any questions that you may have about the research. However, if you have any further questions or if you are unclear on any information on this form, please feel free to contact the researcher - details are given at the end of this document.

What is the research about?

The overall aim of this study is to talk with young people, who are living with a parent that experiences mental distress. The research will focus on young people's beliefs and experiences of talking with their friends about mental distress, particularly living with their parent who experiences distress.

Young people's views and opinions will be used to determine whether there are any common experiences that young people have. This could help organisations think about ways of supporting young people and to consider other avenues of support which are available for young people.

What does your son/daughter have to do?

If you agree to take part in this research, you and your son/daughter would meet with Sarah Oliver, Trainee Clinical Psychologist. During the first meeting, Sarah Oliver would speak to you both about the research and make sure that you understood the information provided to you. You would then have the opportunity to ask any questions before both you and your son/daughter are asked to sign a consent form that shows that you are willing to participate.

Sarah Oliver will then arrange a convenient time and place to meet with your son/daughter individually on one occasion for an interview which will last up to an hour. The interview aims to hear about their experiences of talking about mental distress with their peers. The questions that are asked are guided by the experiences that they talk about. If you and your son/daughter decide to take part, they may be asked about their ideas about talking to their friends about mental health, how they talk about it and how and when they are able to share their experience of living with a parent experiencing mental distress.

What are the benefits of taking part?

We cannot promise the study will provide immediate help to young people, but the information we get from this study will help us to think about ways we can support young people and their families that are affected by mental distress. With this we can try to improve the services in the future.

What are the possible disadvantages of taking part?

There are no dangers involved in taking part, although it is possible that your son/daughter could get upset if they were talking about something they had found difficult. They will be able to take a break at any time in the interview or decide to finish the interview. If they do find talking about some difficult things, the researcher can provide information on people that can provide them with further support.

Do I have to take part?

No. It is entirely up to you and your son/daughter to decide if you want to take part. Sarah Oliver will describe the study and go through this information sheet. If both of you agree to take part, both of you will then be asked to sign a consent form. Your son/daughter will be given the same information before being asked to sign a consent form.

If either you or your son/daughter change their mind about taking part, they can withdraw at any stage, without giving a reasons. This will not affect your involvement with the Kidstime Foundation or mental health services in any way.

Are the interviews and focus groups kept private?

Each interview will be with Sarah Oliver and take up to an hour. The interviews will be recorded on a video or audio recorder, depending on what your son/daughter prefers. This ensures that Sarah can remember what has been talked about. Sarah Oliver is the only person who will listen to the recording and she will delete it at the end of the study. The transcript will be anonymous, which means any names that your son/daughter used will be removed so that the interview can't be traced back to them or family, including their own name and the name of their friends, family or professionals that they see. Sarah Oliver will keep the consent forms separate from the transcripts to ensure that your details are kept secret. Any personal information will be stored safely either on password-protected computers or in locked cabinets.

Finally, anything your son/daughter tells us will be treated in confidence unless Sarah Oliver is concerned about their/your safety or the safety of someone else. In this case Sarah would tell you and your son/daughter that she will have to discuss her concerns with another professional to ensure that your son/daughter are kept safe.

What will happen to the results of the study?

When the study is completed Sarah Oliver will write up the findings as an academic theses that will be submitted as part of the requirements of her course. In addition, she will disseminate the key findings to The Kidstime Foundation and write up an article for publication in a journal.

These publications might use quotes from the interviews, but Sarah Oliver will ensure the quotes will not identify you or your son/daughter and she will use codes and pseudonyms to ensure your privacy. If your son/daughter says something during the interview that they don't want to be used, they can ask for it to be removed from the transcript.

Who has reviewed this study?

This study has been approved by the Oxford A NHS Research Committee (Protocol number: LMS/PGR/NHS/02347). It has also been approved by the University of Hertfordshire Ethics Committee.

Contact information

If you have any questions or concerns regarding this study you can contact the researcher (Sarah Oliver) who will do her best to answer your queries. Alternatively you can contact the research supervisor, Lizette Nolte. Contact details are provided below.

Principal researcher: Research Supervisor

██████████████████████████████████   ████████████████████
████████████████████████   ██████ ██████████
██████████████████████   ████████

Email: ██████████████████████████████████████

If you are unhappy and wish to complain formally, <mark>you can contact your Key Worker from Kidstime on</mark> ██████████. If you would like further independent advice, you can contact the local Independent ████████████████████████████████████

Consent to participate in a research project
Information Sheet for young people 16 – 18yrs

Children's conversations with their friends about living with parents experiencing mental distress: An IPA study

Why have I been given this information sheet?

You have been invited to take part in a piece of research being conducted by Sarah Oliver, Trainee Clinical Psychologist.

Before you decide whether you would like to take part in the study it is important that you understand why this research is being conducted and what will be asked of you, if you decide to take part in the research.

Please take your time to read the information below carefully. This aims to answer any questions that you may have about the research. However, if you have any questions or if you are unclear on any information on this form, please feel free to contact the researcher - details are given at the end of this document.

What is the research about?

The overall aim of this study is to talk with young people, who are living with a parent that experiences mental distress. The research will focus on young people's beliefs and experiences of talking with their friends about mental health and particularly living with their parent who experiences distress.

Young people's views and opinions will be used to determine whether there are any common experiences that young people have. This could help organisations think about ways of supporting young people and to consider other avenues of support which are available for young people.

What do I have to do?

If you agree to take part in this research, you and your parent(s) would meet with Sarah Oliver, Trainee Clinical Psychologist. During the first meeting, Sarah Oliver would speak to you about the research and make sure that you understood the information provided to you. You would then have the opportunity to ask any questions before being asked to sign a consent form that shows that you are willing to participate. Sarah Oliver will then arrange a convenient time and place to meet with you individually on one occasion, to hear about your experiences of talking about mental distress with your peers. The questions asked will be guided by the experiences that you talk about. If you decide to take part, you may be asked about your ideas about talking to your friends about mental distress, how they talk about it and how and when you are able to share your experience of living with a parent who experiences mental distress.

What are the benefits of taking part?
We cannot promise the study will provide immediate help to young people, but the information we get from this study will help us to think about ways we can support young people living with a parent who experiences mental distress. With this we can try to improve the services in the future.

What are the possible disadvantages of taking part?

There are no dangers involved in taking part, although it is possible that you could get upset if you were talking about something you had found difficult. You can take a break at any time in the interview or decide to finish the interview. If you do find yourself talking about some difficult things, I can provide information on people that can provide you with support.

Do I have to take part?

No. It is entirely your choice to take part. Sarah Oliver will describe the study and go through this information sheet. If you agree to take part, she will then ask you to sign a consent form. In addition, she will ask your parent or carer if they are happy for you to take part in this investigation. They will be given the same information as you and asked to sign a consent form.
If either you or your parent change your mind about taking part, you can withdraw at any stage, without giving a reasons. This will not affect your involvement with the Kidstime Foundation in any way.

Are the interviews and focus groups kept private?

Each interview will be with Sarah Oliver and take up to an hour. Sarah will record it on a video or audio recorder, depending on what you prefer, to help her remember what has been talked about. Sarah is the only person who will listen to the recording and she will delete it once the research is finished. The transcript will be anonymous, which means any names that are used will be removed so that the interview can't be traced back to you. This includes your name and the names of friends, family or professionals that you see,. The consent forms will be kept separate from the transcripts to ensure that your details are kept secret. Any personal information will be stored safely either on password-protected computers or in locked cabinets.
Finally, anything you tell Sarah will be treated in confidence unless she is concerned about your safety or the safety of someone else. In this case she would tell you that she has to discuss her concerns with your family and possibly another professional to ensure that you are kept safe.

What will happen to the results of the study?

When the study is completed Sarah will write up the findings as an academic thesis that will be submitted as part of the requirements of my course. In addition, she will disseminate the key findings to The Kidstime Foundation and write up an article for publication in a journal.
These publications might use quotes from our interviews, but Sarah Oliver will ensure the quotes will not identify you and she will use codes and pseudonyms to ensure your privacy. If you say something during the interview that you don't want to be used, you can ask Sarah to remove this from the transcript.

Who has reviewed this study?

This study has been approved by the Oxford A NHS Research Committee (Protocol number: LMS/PGR/NHS/02347). It has also been approved by the University of Hertfordshire Ethics Committee.

Contact information

If you have any questions or concerns regarding this study you can contact the researcher (Sarah Oliver) who will do her best to answer your queries. Alternatively, you can contact the research supervisor, Lizette Nolte. Contact details are provided below.

Email: ███

If you are unhappy and wish to complain formally, you or your parent can contact your Key Worker from Kidstime on █████████████. If you would like further independent advice, you can contact the local Independent ██

Information Sheet for young people age 12 – 15yrs

My name is Sarah Oliver and I am a Clinical Psychology trainee at the University of Hertfordshire. I would like to invite you to take part in a research project. The research is about young people's experiences of living with a parent who experiences mental distress. Through this research I hope to learn more about whether young people speak to their friends about what it is like living with a parent who experiences mental distress. This may help make services better at supporting young people's needs and help families who want support.

What does you have to do?

Taking part in the project involves being interviewed (for approximately an hour) so I can learn about your experience.

When you meet me, I will ask you some questions about your experiences of talking about mental distress with your friends at school. I will also ask you about things that help you or stop you talking about your experience.

Before you decide if you want to join in it's important to understand why the research is being done and what it will involve for you.

Do I have to take part?

It is entirely up to you and your family to decide if you want to take part. If you do want to take part, I will ask you to sign a form (called a consent form) to show you understand everything about the research. Your parents will also be asked to sign another consent form. If either you or your parent change your mind about taking part, you can say you don't want to do it at any time, without having to tell me why. This will not change how you are treated at Kidstime at all.

You do not have to take part, it is up to you. If you do want to take part, you will be asked to sign a form giving your consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide not to take part or to stop, this will not affect the care you or your family receive.

What are the advantages of taking part?

We cannot promise the study will help you but the information we get might help us support young people and their families when a parent experiences mental distress in the future.

What are the possible disadvantages of taking part?

In the conversation with Sarah, it might be that you could feel upset if you were talking about something you had found difficult. However, if you felt upset you could take a break at any time or decide to finish the conversation. If you do find yourself talking about some difficult things, I can help you find someone to support you.

Are the interviews and focus groups kept private?

The interview will be recorded on a video or audio recorder, depending on what you prefer. This helps me remember what you have talked about. I am the only person who will listen to the recording and I will delete it once I have typed up the conversation we have into a transcript. The transcript will not have your name on it, or any names that you mention during our conversation. All your details will be kept secret at all times.

Finally, anything you tell us will be kept secret unless we are worried about your safety or the safety of someone else. In this case we will tell you that we have to discuss these worries with your family and possibly another professional to ensure that you are kept safe.

What will happen to the results of the study?

When the study is completed I will write up a report called an academic thesis. This will be submitted as part of my coursework. In addition, I will let the Kidstime Foundation know what we found out from talking to you and other young people. I will also write up the research article which may be published in a journal. These reports & articles might use quotes from our conversations, but I will ensure the quotes will not identify you and your name will not be used. If you say something during the interview that you don't want to be used, you can ask I to remove it from the transcript.

Who has reviewed this study?

When somebody plans to do some research, some professionals in a research committee agree that it will not harm anybody. This study has been approved by the Oxford A NHS Research Committee and the University of Hertfordshire (protocol number: LMS/PGR/NHS/0237).

Contact information

If you have any questions about this research you can contact me (Sarah) and I will do my best to answer your questions. You can also contact the research supervisor, Lizette Nolte. Our telephone numbers and email addresses are shown below:

If you are unhappy and wish to complain about anything, you can contact your Keyworker at Kidstime. If you would like further independent advice, you or your parent can contact the local Independent Complaints and Advocacy Service (ICAS) on ▮▮▮▮▮▮▮▮ Thanks for taking time to read this.

I hope you will consider taking part

University of
Hertfordshire UH

Consent Form

Title of research: Children's conversations with their friends about living with parents
experiencing mental distress: An IPA study

I, the parent/carer, agree with the following statements (please tick the box if you agree)

☐ I confirm that I have read and understood the information sheet provided

☐ I understand what my son/daughter's participation in the project involves. Any
questions that I have had have been answered to my satisfaction

☐ I understand my son/daughter can withdraw at any time without giving reasons and
that they will not be penalised for withdrawing nor will they be questioned on why
they have withdrawn.

☐ I understand that they can decline to answer any questions that they are not
comfortable with.

☐ I understand that any information obtained will be kept confidential, unless the
researcher is concerned for my son/daughter's safety. When concerns are raised these
will be discussed with me.

☐ I understand that the interviews will be recorded using audio or video recording
equipment and that these recordings will be destroyed once the interviews have been
transcribed.

☐ I agree that research data gathered for the study may be published and if this occurs
precautions will be taken to protect my family's anonymity.

☐ Contact information has been provided should I wish to seek further information from
the investigator at any time for purposes of clarification.

Parent/carer name:
Parent/carer signature:
Date:
Researcher's name:
Researcher's signature:
Date:

Consent Form

Children's conversations with their friends about living with parents experiencing mental distress: An IPA study

I, the participant, agree with the following statements (please tick the box if you agree)

☐ I confirm that I have read and understood the information sheet provided

☐ I understand what my participation in the project involves. Any questions that I have had have been answered to my satisfaction

☐ I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.

☐ I understand that I can decline to answer any questions that I am not comfortable with.

☐ I understand that any information obtained will be kept confidential, unless the researcher is concerned for my safety. When concerns are raised these will be discussed with me.

☐ I understand that the interviews will be recorded using audio or video recording equipment and that these recordings will be destroyed once the interviews have been transcribed.

☐ I agree that research data gathered for the study may be published and if this occurs precautions will be taken to protect my anonymity.

☐ Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.

Participant's name:
Participant's signature:
Date:
Researcher's name:
Researcher's signature:
Date:

Consent Form
12 – 15 year olds

Title of research: Children's conversations with their friends about living with parents experiencing mental distress: An IPA study

I agree with the statements written below (please tick the box if you agree)

☐ I have read the information about the research and I understand it

☐ I know what I will be asked to do and Sarah has answered my questions.

☐ I know I can change my mind at any time and not take part. I don't have to give a reason for this and I will not be told off or questioned on why I have changed my mind.

☐ I know that I can say I don't want to answer the questions that are asked

☐ I know that what I say will be kept secret, unless Sarah is worried about my safety. If she is worried she will talk to me about it first and then talk to my family and a professional.

☐ I know that the interviews will be recorded and these recordings will be deleted once they have been written down.

☐ I agree that this research will be written up and available for others to see. However, my name will not be given so that no one knows who I am

☐ Sarah has given me and my family a telephone number for herself and another researcher. I can use this number if I want to speak to someone about the research.

Name: ……………………………………

Signature:………………………………..

Date:…………………………………………

Researcher's name:……………………….

Researcher's signature:…………………..

Date:………………………………………..
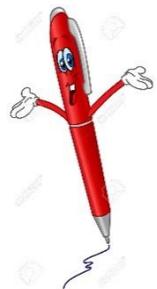
Appendix L: Participant Debriefing Information

<div align="center"><u>**Debriefing information:**</u></div>

Thank you for your generosity in giving your time to take part in this research project. Hopefully this research will help us better understand young people's experience of living with a parent with experiencing mental distress and the support that they do/don't receive from their friends. This will hopefully expand our thinking so we can help provide support for young people who are in a similar situation.

Previous research findings have implied that friends can provide a useful source of support to young people living with a parent with mental health difficulties. However, it is acknowledged that sometimes talking can be hard in practise. There is still a limited understanding about what helps or hinders young people's conversations about parental mental distress, and this is what is being investigated.

The information that you have provided will be kept confidential and the recordings will be destroyed after the interviews have been transcribed and analysed.
If you wish to withdraw your involvement in the research, you can do so at any time.

If participation in this research caused you any distress, please discuss this with a representative from the Kidstime Foundation.

However, if you would like further support, please find below the details of some resources and organisations that may be useful:
ChildLine:
This is a free and confidential telephone counselling service for young people
Freephone: 0800 1111
Website: www.childline.org.uk

Get Connected:
This is a free confidential telephone and email helpline to provide support and advice to young people.
Freephone: 0808 808 4994
Website: www.getconnected.org.uk

Samaritans:
This is a confidential helpline for anyone experiencing any emotional distress
Freephone: 08457 90 90 90
Website: www.samaritans.org

If you have any further questions, or would be interested in being informed in the outcome of this study, then please contact me by email (s.oliver3@herts.ac.uk)
If you have any complaints about the study, please contact Lizette Nolte by email (l.nolte@herts.ac.uk)

Thank you again for your participation and support.

Appendix M: Interview schedule

Interview Framework

Young people

1. Can you tell me what the term 'mental health difficulties' or 'mental illness' means to you?
   Prompts: Which term do you feel most comfortable with? Do you remember when you first learned about mental health problems? Has your understanding of what it means changed over time?
   Can you tell me what you mean by...?. / How did you feel when you first heard….?

2. What is your experiencing of living with someone with a mental health difficulty [insert favoured term/ participants language]?
   Prompts: What are the good things about it? What are the challenges? What does that mean you about you/ your mum/ life at home etc? Can you give me an example of that?

3. Who talks to you about your parent's mental health difficulty?
   Prompts: What is it like when they do/ don't talk to you?

4. Who do you talk to about living with a parent with mental health difficulties?
   Prompts: what it is about that person that allows you to talk?

5. How does it come up in conversation?
   Prompts: Who brings it up? How is it brought up? How does it feel when it is brought up?
   Can you tell me what you mean by...?. / How did you feel when you….?/ can you give me an example of...

6. What makes you decide to talk about your experience of living with a parent with mental health difficulties with people outside of the home?
   Prompts: Can you tell me what you mean by...?. / How did you feel when you….?/ can you give me an example of...

7. When does talking about living with a parent with a mental health difficulty go well?
   Prompts: Can you tell me what you mean by...?. / How did you feel when talking goes well.?/ can you give me an example of a time when talking went well?

8. When does talking about living with a parent with a mental health difficulty not go well?
   Can you tell me what you mean by...?. / How did you feel when talking does not go well.?/ can you give me an example of a time when talking didn't go well?

9. How do you think people who do not have personal experience of mental health problems (either for themselves or someone close to them) understand or think about mental health difficulties?
   Prompts: What does that meant about talking?

10. What do you notice about how mental health problems come up in the media, e.g. on television, in films, magazines or on social media?
    How does this feel for you/ your parent/ your friends?

11. How has Kidstime shaped your understanding of living with a parent with mental health difficulties?

12. What is your experience of talking about living with someone with a mental health problem at the Kidstime Foundation?

13. Has talking at the Kidstime foundation, altered your view about talking to people outside the home about your experiences of living with someone with a mental health difficulty?

Appendix N removed to maintain anonymity

Appendix O: Audit Trail for Analysis

Example of how themes were clustered together for Andie
1. **Feeling relieved by making sense of mental distress**
   - Feeling uncertain about something unknown
     - o Feeling confused about the unknown
       - ▪ Not knowing what mental health was
       - ▪ Feeling confused
       - ▪ Thinking this was the norm, then realising it wasn't
       - ▪ Not knowing what was happening
       - ▪ The Chaos of hospitalisation
     - o Making sense of changes in mum
       - ▪ My mum was normally happy and calm
       - ▪ She would shout and I didn't know why
       - ▪ Small things got blown up
       - ▪ She gets stressed
       - ▪ She's still mum
       - ▪ Making sense of the past
     - o Feeling grown up from gaining knowledge
       - ▪ Having the information now I'm grown up
         - • Being able to give it a name
       - ▪ Gaining knowledge from seeking support:
         - • Being taught about the brain and mental health
         - • Having the opportunity to ask and gain clarity
       - ▪ The abstract nature of mental health:
         - • it's not something you can see
         - • It's an individual experience - I don't have it so I don't know
   - Coming to terms and developing hope
     - o Recognising experience of mental distress is common
       - ▪ Lots of people have it
     - o The relief of knowing there's support out there
       - ▪ Knowing she'll be ok
       - ▪ Mum's a rock
       - ▪ Wanting others to know they it'll be ok
         - • Don't let it affect your life
         - • They're going to be ok
     - o Building a strong family connection

Coping with painful experiences
   - Worrying about each other
     - o Worrying about and protecting mum
       - ▪ Not wanting her to become ill again
       - ▪ Not wanting mum to become stressed
       - ▪ Not wanting to make her uncomfortable by asking questions
       - ▪ Remaining empathetic and understanding
     - o Pulling together as a family
       - ▪ We care for each other
       - ▪ We'll talk together if we need to
   - The pain of hospitalisations
     - o Emotional impact of losing connection with mum
       - ▪ I didn't know where she was
       - ▪ Crying all the time
       - ▪ Seeking physical closeness
     - o Family ruptures
       - ▪ Feeling betrayed by people who should care
       - ▪ Losing connection with each other
     - o Loss of agency
       - ▪ Not being allowed to talk to mum
       - ▪ Not knowing where mum was
   - Feeling alone
     - o Feeling like I'm the only one
     - o Sitting with it on my own
     - o Finding it hard to trust people

2. **Talking feels too risky**
   a. Keeping the secret
      o It's personal
         i. Not wanting them to know what they don't need to
         ii. Normal' people won't understand
         iii. Reliance on others to notice – I don't bring it up
      o The elephant in the room
         i. It wasn't talked about it when I was younger
         ii. It's still hard to talk openly
         iii. Feeling uncertain of what each other are thinking
         iv. Trying to put a positive spin on difficult things
   b. Fearing the reactions of others
      a. Talking about it might make people uncomfortable
      b. They might not want to be my friend
      c. It gives people another excuse to be mean
      d. Mistrusting of others
         i. People blow things up
         ii. They might muddle my words
         iii. People are childish
      e. The emotional toil of others reactions
         i. Feeling angry and sad
         ii. Feeling judged and picked on
   c. Facing the stigma of mental health
      a. Facing people's views about mental health
         i. Crazy and weird people in the asylum
         ii. It's just a joke
         iii. It's not something you can see
      b. The media's misrepresentation of people with mental health
         i. They just make up rubbish
         ii. Media stories impact on people's views
         iii. They have a responsibility to provide an accurate portrayal

3. **Taking the risk and opening up**
   a. Talking to people you know you can trust
         i. Finding support from teachers
         ii. Talking to nan
            • Not being messed around
            • She'll keep my confidence
            • She understands
            • We're really close
   b. Talking to people that understand what it's like
         i. My friends dad has it, I can talk to her
         ii. Talking to people at Kidstime
            ▪ It helped build my confidence
            ▪ Developing a positive view of talking
            ▪ What's said at Kidstime stays at Kidstime
   c. When we've taken the leap, it's been helpful
         i. Mum finds talking to helpful
            ▪ She no longer bottles things up
         ii. Talking to people when I really needed it
            ▪ The perceptiveness of friends led them to notice my sadness
            ▪ Feeling surprised by friends help and understanding
            ▪ Developing trust over time
            ▪ Wanting to trust, but finding it hard
         iii. The relief of making connections and no longer feeling alone
            ▪ Knowing they understand and I'm not the only one
            ▪ People know what I'm going through
            ▪ Reciprocity in support
            ▪ Prevents bottling it up

Audit trail – Example quotes from Andie's themes:

| Superordinate theme	Subordinate theme	Example quotes
Feeling relieved by making sense of mental distress	Feeling uncertain about something unknown	"Well I, cos I was young we didn't really know. …I didn't really know what it was called until like I was like grown up when we were getting more with Kidstime like and stuff. That's really what I know what it was called, mental health. Not really, I didn't really know what it was called." "I thought it was all about shouting cos my mum always got shouting like when she was stressed and stuff. And I literally thought that was only my parent but when I went to Kidstime it was not really just my parent." "I didn't really understand why she was shouting but then, you know, I just thought she was stressed and I would just let her shout and then I would just, sometimes I just, just was confused really."
	Coming to terms and developing hope	"I was like more relieved, not relieved but I knew that it wasn't just my mum so she can get help, because other people have it so they know and they can like talk about it. But if it, like, without other people, she would just, like wouldn 't of like talk in like, it would just be like bottled up." "I just don't think you should really worry. You shouldn't be scared because they're going to be alright so don't let them ruin your, like, you know, your life."
Coping with painful experiences	Worrying about each other	"I didn't really want her to erm, do that again or be sad or stressed or like unhappy. I wanted her to be happy and like calm be like my mum" "I think we're all stronger now because, of like, we're just like all stronger because we don't want no one to be like, we don't want my mum to be stressed. And we just, really close now"
	The pain of hospitalisations	I really didn't like it [mum in hospital]. I was like crying all the time. And we talked to her on the phone. And I slept with my dad. I was really like vulnerable and I didn't know what was happening. "Apparently my Auntie made her go into hospi, like where she was…because she thought that she couldn't… look after her children…she wouldn't hurt us anyway…my nan's really upset with my auntie and my auntie and my mum don't talk anymore…my auntie was so mean to her she really, was vile"
	Feeling alone	"Well, sometimes I don't really want to talk about it, I just like talk to myself about it. If I don't really trust no one. I just, sit out on my own." "And I just really wanted to talk to people and then I didn't really trust them, or I just didn't want to talk about it at the time"

Superordinate theme	Subordinate theme	Example quotes
Talking feels too risky	Keeping the secret	"I won't like talk about other people what they go through. I'll talk about me and say it to like my nan, like what I'm, not what other people said. Because it's not really nice telling what they've said or what they're going through" "Cos I'll think she'll feel like uncomfortable or whatever, because I would anyway. Because I just, don't know, I'm not sure, I just thought she'll feel uncomfortable.. But she would talk, but I just feel really, I don't really want to talk about it to her."
	Fearing the reactions of others	"And I really don't really tell people a lot because they will spread it. Or like they could like muddle up my words or whatever." "I don't really want them to get uncomfortable and then not be my friend." " It's like, cos, I get judged sometimes like whatever. Like, people just pick on you, or whatever. But I really don't listen. But what, when it's in my family, then that's when I will listen and I'll get really angry." "Just general judgement, people really don't understand. They're just childish about just like really life. They've not really gone through it so they don't understand"
	Facing the stigma	"I'm not sure like but in like programmes they go to mental asylums. They probably think that's why their crazy because they have to go there but it's not really true or whatever. "and like newspapers they just write about rubbish really and then people think that's true but it's not. Cos like, everyone can have it, even celebrities."
Taking the risk and opening up	Talking to people you know you can trust	Like she'll [nan] just give me an answer, like straight away. She won't just, like mess around. She will literally tell me. And...I trust her "I was really worried about my mum. So I always talked to teachers about it and they always helped me. And also, like I talk to my nan, my mums mum, about it….I talk to her mostly because I trust her.
	Talking to people that understand what it's like	I talked to one friend about it when it first happened but her dad had it as well. So she helped me cos I didn't really know what was happening and she really helped me.
	When we've taken the leap, it's been helpful	"a couple of years ago I got a new friend…because sometimes I was low because I was thinking about my mum …And I just told her and she really helped me, even though her parents wasn't like, had mental health. But she still got me through, like when I was low about my mum, she always helped me, even though she didn't know what was really happening, but she did help a lot."

Superordinate & subthemes for each participant

Charlie	Sam	Alex	Andie	Jo	George
Putting the puzzle together • Building a narrative of what I see, hear & feel • Trying to differentiate weird from normal • Struggling to explain what's happening **Being left to cope independently** • Taking responsibility for keeping it altogether • Finding it difficult to stay in control • Portraying a normal life rather than the rollercoaster **Learning if it's safe to trust** • Fearing mayem from telling others • Testing the water, to learn who to trust • Finding comfort in talking to friends • Being cautious not to blurt things out	**Making sense of Mum** • The developing nature of understanding of PEMD • Finding the language to talk about it • Everybody has problems **Keeping the secret** • It's my choice not to tell • We don't really talk about it at home • Stigma and the portrayal of mental distress • The fear of people finding out • The isolating nature of other's lack of understanding **Finding ways to feel supported** • The importance of having fun • Finding ways to talk about parental mental distress	**Making sense of mental distress** • Making sense of mum's mental health • The trials and tribulations of caring about my parent • Developing as an individual **Negotiating the stigma of mental health** • The nature of stigma • Uncertainty about the origins of stigma • The impact of stigma • Finding ways to tackle stigma **Deciding whether to talk** • Fearing opening pandora's box • Ensuring the safety of making a disclosure • Finding the confidence to talk about it • Recognising the benefits of talking	**Feeling relieved by making sense of mental distress** • Feeling uncertain about something unknown • Coming to terms and developing hope **Coping with painful experiences** • Worrying about each other • The pain of hospitalisations • Feeling alone **Talking feels too risky** • Keeping the secret • Fearing the reaction of others • Facing the stigma **Taking the risk and opening up** • Talking to people you know you can trust • Talking to people that understand • When we've taken the leap it's been helpful	**Making sense of the situation** • Developing a sense of the strange situation • Differentiating mum from 'mental' people • Taking on the parenting role • Moving to a place of acceptance **Feeling hopeless about home life** • Doing lots of listening and not much talking • Feeling frustrated by being misunderstood in the home • Feeling powerless in knowing how to help • Being left to sort it out alone **Wanting a different life** • Having a sense of something missing • Finding a means to escape • Talking as a form of connection • Talking serves a function • It's private, it has consequences • Changing the subject to take my mind off life at home	**Making sense of mum's mental health** • Feeling unsure about understanding • Noticing but normalising difference • Knowing the terms but struggling to explain the meaning **It's not really talked about** • It's not spoken about day to day • Friends don't talk about family issues **Mum's mental distress is a sensitive subject** • Not wanting to say something wrong • Trusting no one • Wanting to play games

Example Clustering Maps:
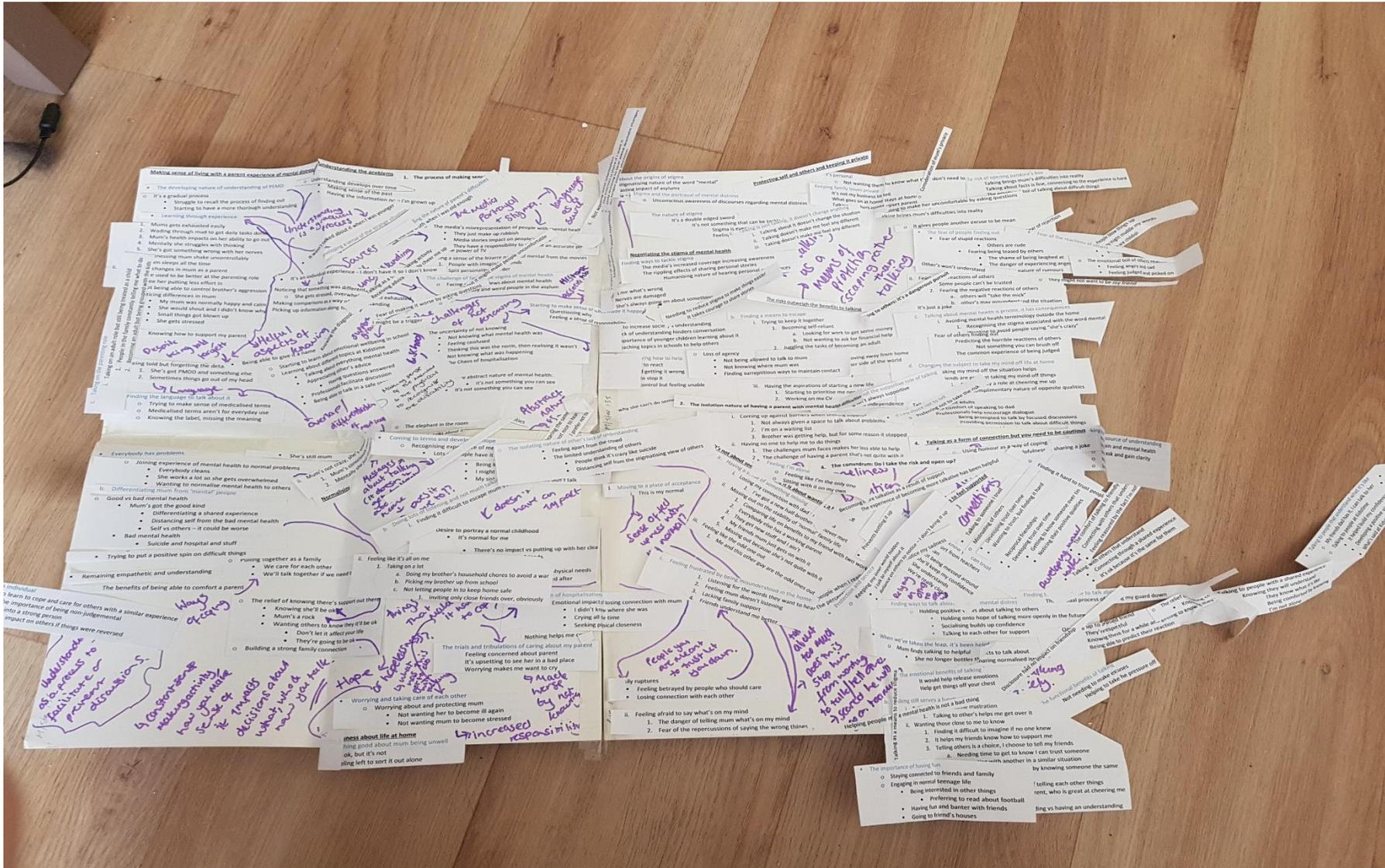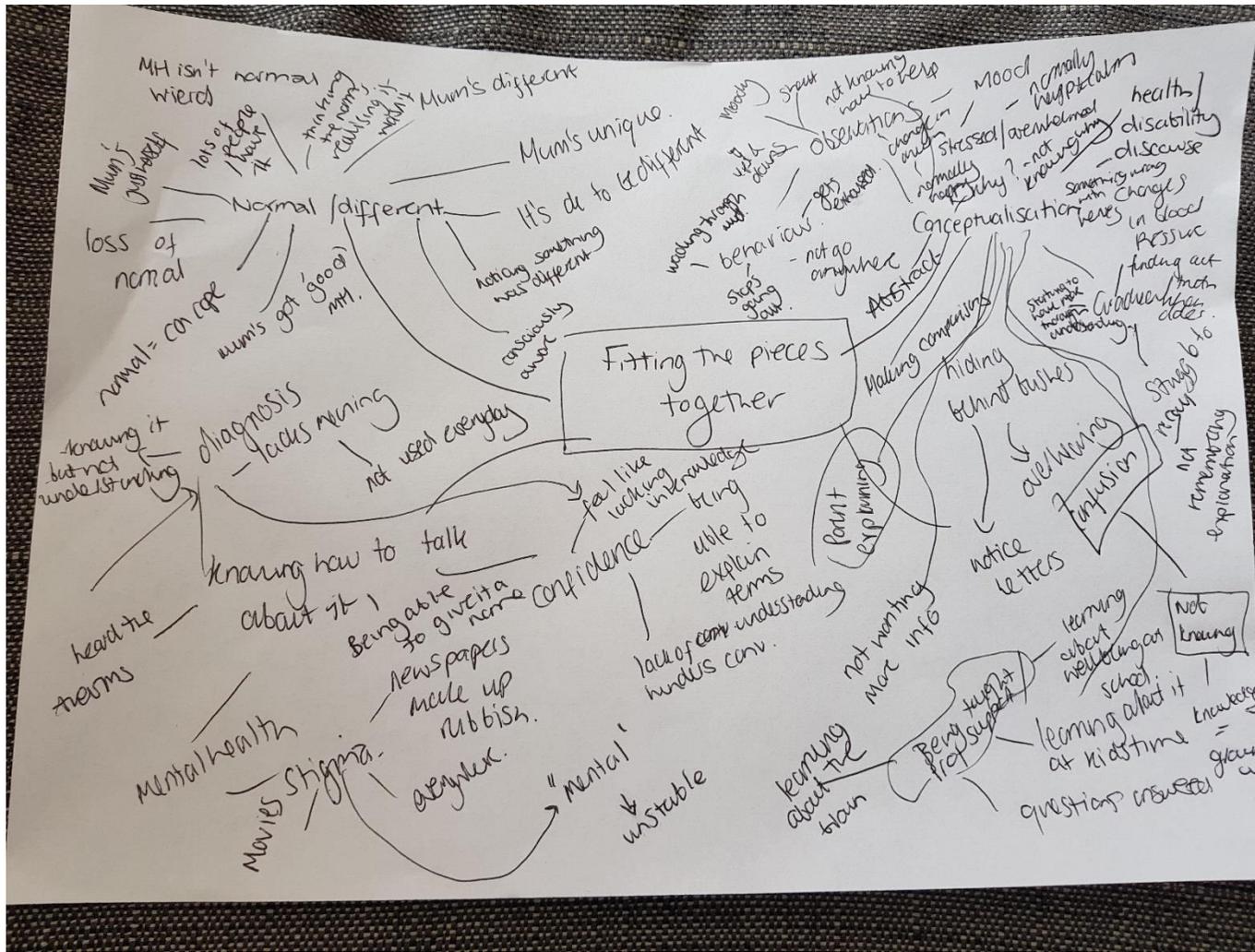
Master & Superordinate Themes & Quotes
Superordinate theme: Fitting the puzzle together

Subordinate theme	Participant quotes[25]
Trying to make sense of mental distress	"No, I think she just gradually like, I think I just like gradually realised and she like told me… I don't know…. I don't know what age I was when she told me, I don't even think she told me… I think I just realised and then like she told me. I don't know" "I just think like, what I can see and what I can hear and what I can like feel. I like guess that's how it is and like, like try to put it altogether to make one big thing to explain it." C:"Mum has like highs and lows and highs blood pressure.. I: so when you say high and low do you mena her mood is high and low or is that more kind of her physical health? C:.. I don't know. Because once her blood pressure was like really low and she couldn't go anywhere and she had to go into hospital…" "I think I'd seen [her diagnosis] like on a letter or something on the fridge or something like that. I've seen it somewhere." "I notice she gets stressed out and she's erm overwhelmed and she's erm she's exhausted." "I don't even remember…it was erm, like a few years ago that I started noticing more and more" "It wasn't until she started going to [a support service] that I knew. Sort of fully understood it. Because when I was younger she might have had it but I wouldn't have understood." "It just means that…people are suffering mentally and they find it hard, like harder than every day to day people" "Noticing things. Like, I noticed she was more down on some days and stuff like that." "I thought it was all about shouting cos my mum always got shouting like when she was stressed and stuff. And I literally thought that was only my parent but when I went to Kidstime it was not really just my parent." "I think [my understanding] was better than then because I knew, I didn't really know what... I didn't really know what was happening. But now, I know that it's just like, certain people like can like." "she'll get exhausted very easily. Like, she'll get up, she'll take [my brother] to school, she'll to a bit of housework, maybe go to the shop. And then she'll come in and then she'll fall asleep... If she's really not feeling well she'll probably go back to sleep again. I think that's maybe her way of like escaping how she's feeling at the time. I don't know if she's genuinely tired or not." I: And do you see her being up and down? G: Sometimes I: And what does up look like? G: When she's all happy and excited I: Yeah? And how about down? G: When she's moody

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[25] Colour key: **Charlie, Sam, Alex, Andie, Jo, George**

Subordinate theme	Participant quotes
Making sense of 'normal' and 'not normal'	"yeah because even though she has Bi-polar and a lot of other mums have Bi-polar and all that. She's herself… She isn't like everyone else. She has her own view, she has her own perceptions" "everybody has problems so it's just normal for me. "Because everybody cleans and everybody like exhausted. So her moods just the same. Just diagnosed with something" "some mental health can be good mental health, some mental health can be bad mental health or like. Bad mental health would be like really bad, they really need to go to the hospital or something. I think my mum has the good mental health, I know she does…It's not like dramatic and stuff. Like, it's just like mostly cleaning and stuff so. It's not really good (stumbles) mental health. Like some mental health can be like suicidal that they need to go to hospital." "she's not normal if you know what I mean. She's different to other people. She suffers with things." "Well, she like, she was always stressed and like, any little thing she would like shout, but she didn't really mean it you know, so it's just not like her fault. And after she realised what she did she always said sorry. And I, I really didn't know what was happening, I thought everyone, every parent would shout you know, because it's really hard work being a parent. So I just literally thought that's normal but then, when we went there it isn't, it is but then it's not. Cos not everyone has it like that." "Cos everyone has like mental health but it's not really like proper until, I don't even really know." "Cos like, everyone can have it, even celebrities." I: Do you ever notice your mum being unwell, or not ok, or not her usual self? G: No I: How would you describe your mum G: Just herself I: What do you mean by that, what's her usual self? G: Mostly moody [smiles] and tired "In my view, somebody that's not very aware or conscious of what's going on and my mum is aware and conscious of what's going on. Cos you see it like in films there's people that are just like starring and don't know what's going on. That for me is like mental. They're not aware and it's sad really."

Subordinate theme	Participant quotes
Gaining the confidence to explain the terms	"Mental health means that like (3s) people with mental health aren't normal. They have like disabilities with er specific things and erm (4s) I don't know how I would explain it but that's all I can say. "Cos I don't know what [the diagnosis] means and stuff like that so I wouldn't want to like talk about that because I wouldn't know what it means and stuff." "I only know OCD. It's obsessive cleaning disorder and it means that they clean a lot" "It makes me more confident to talk about it …so one say I can talk about it more about mental health to like my best friend" "Well depression erm (wry laugh). I don't know, she just finds it hard to like, deal with her emotions" "basically the way she thinks, I'm pretty sure. Or how the brain actually works. [2s] It's called [diagnosis]…I don't really know exactly what it is. [2s] I think there's another one she's got but I can't really remember the name." "In my view, somebody that's not very aware or conscious of what's going on and my mum is aware and conscious of what's going on. Cos you see it like in films there's people that are just like staring and don't know what's going on. That for me is mental." "I: Does your mum have a diagnosis G: I think she's got bipolar I: Bipolar, ok so what does Bipolar meant to you? G: I don't know
Becoming aware of stigma	"some people might treat people with mental health with a little less respect or just think that they are not normal so they can't treat them exactly the same." "I think it's when you see some people being put into asylums and stuff like that. Sort of being sectioned. But I don't think they realise that's sort of the severity, like the most severe cases." "if the stigma weren't there she'd want to talk about it a lot more." "in like programmes they go to mental asylums. They probably think that's why their crazy because they have to go there but it's not really true or whatever" "newspapers they just write about rubbish really and then people think that's true but it's not." "…there's a film where someone has an imaginary friend and it turns out it's just another part of himself …There's another one called "me myself and Irene"... And that's split personality disorder. I think that's mental, I'm pretty sure that is." I:How do you think they talk about it [mental health]? G: Like them being crazy I: Ok. So what, do you think. So the term crazy, what does that bring to mind? G: I don't know

2. Superordinate theme: Finding the experience of talking risky

Subordinate theme	Participant quotes
Fearing the consequences of telling others	"sometimes I just think that if I say something that I shouldn't have I'll get like something bad for it." "I would feel like [peers] would come up to me and like say "oh is this true, oh is this true?". I don't know how I would respond to that." "[if people found out] I would feel like really sad, scared and like worried…like confused. It would be like unreal, like situation that has actually become reality." "I would get like support and mum would like get a phone call and like all that and like all the mayhem. I would like have to like go into care because she gets so upset." "some people like might just like, they'll say it to someone else and they might make fun of it and I'll get upset a bit, so I would prefer to keep it to myself and stuff…They'll just start laughing it erm, repeating it. And erm, just getting rude about it and just going on with it for like weeks and weeks, so I just don't say it." I think [talking] would upset me, I wouldn't be able to brush it off because it was to do with my mum "I think [friends] would be not confused and stuff but not really understanding about it… using the stigma probably that's attached to it…[they'd] probably be horrible or disrespectful. "[parent] probably doesn't want people to know…because she might be embarrassed about it but it might also be the fact that there's a stigma attached" Alex: Yeah, because I don't really want to go behind my mum's back and start telling people." I: So if you were the kind of person that sort of shared lots of things with other people, how do you think it would leave your mum feeling. Alex: She'll feel upset and disappointed because it's something that's personal to her. "I really don't really tell people a lot because they will spread it. Or like they could like muddle up my words or whatever" "it's just like at this school, every little thing they just make it so big. They just say horrible things., like, I don't know they'll just take the micky out of you really" "people are just so childish, they just make an excuse to … just make you down and then, it doesn't always work but and then, they'll just think, they just try and try again and they'll just say stuff about your parents. And then that's what makes you really like angry or sad. And it's not really nice because if they had that they wouldn't really want people doing that to them." If I told a random person that my mum's got a disability and I've never met them, and I don't know what they're like. They could take the piss or, they could, I don't know. I guess I'm just worried about people taking the mick really….cos like, I don't want people to say "oh, your mum's mental, she's crazy" or something like that. Because she's not, she's just not well."

Subordinate theme	Participant quotes
Struggling to find someone to trust	"I tell mostly just [my best friend] but like I have some like really really great friends and like if they like see me upset they will say and ask but they won't say anything. Unless there's like really great friends that I like, and that, they won't say but that's the only occasions." like other people are going to be like mean. Other people are going to betray you, and other people… even best of friends are going to sometimes betray you. But I mean that's life, like you can't stop it from happening. I would just talk about it with my best friends but not my, not a lot of friends like. Cos, the people at Kidstime, they understand it more. They won't talk it as a joke, if you know what I mean, some people at school will take it as a joke. "I've only ever shared it my best friend, who I've been best friends with for about 4-5 years so. I only told her about a year ago so it wasn't sort of straight away." "I guess I don't think she'll sort of say "oh, your mum's crazy" or stuff like that. .I know that she wont say anything like that and she can possibly understand" I think the children coming [to Kidstime] are a bit more understanding. Because they've had sort of experience. "I just really wanted to talk to people and then I didn't really trust them, or I just didn't want to talk about it at the time, so I'd just like talk to the teachers." Well, in my middle school, because I was really worried about my mum. So I always talked to teachers about it and they always helped me. And also, like I talk to my nan, my mums mum, about it. And she, just like, I talk to her mostly because I trust her.. **"I only have two main friends that come in the house cos obviously they're close friends. I don't let anybody else in really cos you can't trust some people…. They know that my mum's not very well… It's just me being, just making sure that the house is safe really. [1s] I only have certain people in it.** **I need to know someone a bit longer than, I don't know, a couple of months, before I let them in. So, I want to know them, I want to make sure they're alright.** **Well, he's basically the same as me but cos his mum's not well and his dad's never there, it's exactly the same as me, so I guess that's one similarity and that's maybe why we always tell each other what's going on. I don't really know why…I've known him for like ten years.** **G: I wouldn't trust anybody** **I: what stops you from trusting people?** **G: It's just [3s] …it's me, I don't really trust a lot of people**

Subordinate theme	Participant quotes
Being cautious about what is shared	"I think it's just like more of my personal life that I don't have to show to anyone else. I don't have to say yeah, if I don't want to." "I don't think she would like me to blurt out random things." To be honest I wouldn't say it in general cos, I just don't like, I prefer to like keep it personal like. I prefer to like keeping that more to myself….the cleaning I just tell my best friend because his mum likes cleaning a lot too" "My mum, my mum might not want me to like tell, what she has and stuff." ""I just don't feel like people should know what goes on like between me and my family." Normally, if was something that was really osrt of getting to me I'd be upset and they'd see that and then they'd ask what's wrong" I just, sometimes I don't really want to tell people about my own things "It's just private really [2s] I only let certain people know about it."

3. Superordinate theme: coping with the up and down rollercoaster

Subordinate theme	Participant quotes
Coping in isolation vs connecting with others	"sometimes I feel like quite sad. I feel like I can't really say what I'm thinking and like what I really, like I don't know how to put it." "There's like no one else to look after us so it's like kind of an issue for us to go places without getting split up or put in where we don't know people." "They just normally see me sad and go "what's the matter? What's the matter? I know you're upset?" and I just go "blah" like "blah blah blah". Like, like whatever the situation is." To be honest, I don't even know if they understand it. Because they probably have without mental health. It's different for people who have parents that have mental health. Alex:It upsets me to see her when she's down or upset or in a really bad place. I: And what do you do when you feel like that? Alex: Normally cry (nervous laugh) Normally if was something that was really sort of getting to me I'd be upset and they'd see that and then they'd ask what's wrong. Well, sometimes I don't really want to talk about it, I just like talk to myself about it. If I don't really trust no one. I just, sit out on my own.. Well with my mum being how she is, sometimes it is hard to like do things... It's hard to have a parent that's not quite [1s] I'd say, not quite with it so much….I don't really have anybody in my family I look up to…my friend he just asks…[his family member]… if he could help him go somewhere or do something with him. I find it quite hard to do that with my mum cos we'd either both forget or she just won't be feeling very well and I'd miss out on the opportunity so. I: So do you prefer not to say anything so you don't say something that mum wouldn't want to say? L: mmmm I: Ok. So does that mean that sometimes you're left with thoughts in your head that you want to say to somebody but you can't say because you don't want to….? L: Yeah I: yeah, ok. [2s] what does it feel to think, I kind of want to say something but you don't feel you can? L: Weird

Subordinate theme	Participant quotes
Changing the subject and seeking normality	"I would want to talk about it but then again I would like to like just switch conversation if I just were like really sad…. that just like gives me time to like calm down and then like, like start being upset and like start going off on one and like start being angry and that." sometimes we go up to town and I …that might be like for us to get away normally at the weekend, on Saturday "to be honest we have like a joke like that are mums like clean… we like shout at our mums when they're cleaning like "get out the room while we're playing" "We use each other as, as like friends who like have fun and banter and er, like gaming with each other and just doing stuff in general from like calling each other and stuff, like seeing each other a lot." Erm, we'll put something online, like a film I haven't watched yet, something that's quite new …I don't know really. He's just good at doing it….Yeah taking my mind off things is my, it's better for me rather than talking about it…It's good to do a bit of both but I think I'm more, sort of, prefer to just sort of get my mind off it and carry on doing whatever it is I'm doing.

Appendix P: Quality appraisal of current study

Criteria (Yardley, 2008)	Evidence for meeting criteria
Sensitivity to context: Consideration to the context of existing literature in the development of the research question	As stated in the method, an extensive literature review was carried out, which highlighted a gap in the evidence based. This highlighted the need for the current study.
Sensitivity to context: Attention paid to context surrounding the participants which may influence their ability to freely express themselves	CYP were asked to give their consent/assent to take part and chose a venue that they felt comfortable with. There was still a power dynamic between the researcher, who was a professional in the area of mental distress and therefore this may have made them feel like they had to say the right thing, in addition to not say the wrong thing. To prevent this from happening, the interviewer spent some time speaking to the participants before the interview began and played games during the interview. They were reassured about confidentiality and this was maintained throughout the research process. As CYP were also given the chance to look at the research questions before the interview began. As it proved difficult for the CYP to talk about their experience, the researcher kept a reflective diary throughout the process which helped highlight the impact of these contexts on the CYP. These points are considered within the analysis and discussion.

Criteria (Yardley, 2008)	Evidence for meeting criteria
Commitment & Rigour: This involves the consideration of thorough data collection; depth/breadth of analysis; methodological competence; and in-depth engagement with the topic	Due to the fact CYP were recruited via an intervention programme, they may not have been representative of other CYP. However, despite their involvement in this programme, they still expressed a struggle to understand and a fear of talking, which suggests the findings may be even more pronounced for other groups. The sample was relatively homogenous, with most CYP aged 12-15. The differences between younger and older participants were considered within the analysis. CYP found talking difficult but the process of the interview elicited rich information. A detailed analysis was completed to gain an insight into the dilemmas faced by CYP. To ensure methodological competence, close supervision was provided throughout the study. In addition, one of the transcripts was independently analysed and agreement was reached regarding the themes. Furthermore, peer supervision was sought throughout the analysis process. However, although member checking is advised, it was not possible to do this within the confines of the project.
Coherence This refers to the fluency of the research e.g. the fit between the theoretical approach and basis of the research, the research question and the chosen design and analysis used	The chosen methodology allowed exploration of CYP's experience of talking to their peers. Due to the struggles for some CYP to discuss their difficulties it was difficult to elicit in-depth accounts but the process of the conversation between interviewer and interviewee provided insight into the research question. The epistemological position of the researcher was considered throughout the project, and it was acknowledged that the results provide further accounts to help inform our thinking.

Criteria (Yardley, 2008)	Evidence for meeting criteria
Transparency The research and analysis process are transparent for the reader	The thesis has documented the stages, and challenges throughout the research process, in an attempt to be transparent. In addition, a detailed account of how the analysis was carried out is available in the method section, and examples of how the interviews were coded are available throughout. Weaknesses of the research are described within the discussion, with thought given to how this may influence the findings.
Impact and importance: the usefulness of this research in relation to the impact and importance of the findings.	This study explored an area that has not currently been researched. Furthermore, the research built on existing knowledge regarding the processes CYP go through when developing an understanding. The research suggests that careful consideration should be given when thinking about how to inform CYP. Furthermore, this research highlights how difficult it is for this group to get support. This has many implications in regard to the design of interventions. Thought has been given to the clinical implications of these findings, in addition to possible directions for future research.

Appendix Q: Dissemination of research project to participating organisations

RESEARCH PROJECT

Young people's conversations with their friends about living with parents experiencing mental distress: An IPA study

What was the research about?

This research aimed to find out whether children and young people had conversations with their peers about their experience of living with their parent experiencing mental distress.

Why was this research carried out?

Previous research has indicated that children and young people living with a parent experiencing mental distress can at times find it difficult. However, young people have spoken about the importance of having someone to speak to. Sometimes young people spoke about sharing their difficulties with their friends. However, no research has examined this directly.

Who took part in the research?

Six young people who attended a Kidstime workshop in London and the South East took part in the project. Their ages ranged from 12 – 18 years of age and included three boys and three girls. The length of time they had attended the project varied from 1 month to two years.

What were the young people asked to do?

Young people were asked to take part in an interview that lasted up to an hour. In the interview, they were asked questions like "What brought you along to the Kidstime Workshops"; "What is your experience of living with your parent who experiences mental distress?"; "What do you share with your friends?"

What did the young people say?

Young people's answers were summarised by the following themes:

Fitting the puzzle together

"What I can see and what I can hear and what I can like feel… [I] try to put it altogether to make one big thing to explain it."

Young people described a process of gradually fitting the pieces of the puzzle together to develop an understanding. They described learning about their parent's experience of mental distress through having conversations with their parents and professionals, noticing changes in their parent and overhearing conversations. Developing an understanding seemed to be the initial step in their ability to consider how to talk about their experiences with others.

Most young people felt their parents were within what they saw was 'normal', whilst also experiencing them as 'different'. It seemed at points this distinction still caused CYP some confusion, but the process of normalisation seemed to have a reassuring quality. However, the perception of difference seemed to cause CYP some discomfort, as they feared how this would be perceived by others.

"I thought every parent would shout…because it's really hard work being a parent. I … thought that's normal but…it is but then it's not."

The young people spoke about their understanding and experience of using more medicalised terms for mental health. There seemed to be a mismatch between being told the terms and knowing how these translated into both their own and their parents' experiences. Knowing these terms but not understanding them fully could potentially inhibit conversation with others.

"Cos I don't know what BPD means and stuff like that so I wouldn't want to like talk about that because I wouldn't know what it means and stuff"

"I think it's when you see some people being put into asylums and stuff like that. But I don't think they realise that's sort of the severity, like the most severe cases."

Young people seemed aware of the stigma related to the experience of mental seemed uncomfortable with the portrayal of mental distress in the media, although there was some recognition of positive attempts to build awareness. Young people experienced their parents as something differing from stigmatizing images portrayed, but felt worried that others would not be able to make this distinction.

Finding the experience of talking risky

"I really don't really tell people a lot because they will spread it. Or like they could like muddle up my words or whatever"

All young people feared the consequences of talking to others due to the possible impact on them (e.g. people making fun of them or not wanting to be friends); the possible consequences for their parent (they might get upset); or their friends (e.g. the burden of having to keep the secret); and finally, the possible consequences from professionals finding out e.g. being taken into care.

Building trusting relationships seemed a difficult task for young people. Knowing someone for a long time or meeting people who understood what they were going through seemed to help CYP build trusting relationships. Sometimes they could not build trusting relationships with their peers, but were able to develop a trusting relationship with an adult.

"It's just [3s] ...it's me, I don't really trust a lot of people"

"I just don't feel like people should know what goes on like between me and my family"

Young people were cautious when interacting with their peers. Their parent's experience of mental distress was seen as private matters. Even when they were able to open up to their friends they were often careful about what information they shared, and often only offered it if their friends noticed there was something wrong.

Coping with the up and down rollercoaster

Young people spoke about the challenges they faced when living with a parent experiencing mental distress. However, their fear of letting others in often led to them coping with their situation on their own. Whilst they did not feel that they were always in need of support, they often talk about taking themselves off to deal with their own internal state on their own. Their desire to protect their parent possibly prevented them from seeking their own support. When they are able to talk to their peer group, they talked about the sense of connection and relief that they got from this.

"Like at the minute, sometimes I feel like quite sad. I feel like I can't really say what I'm thinking..."

We use each other as friends who like have fun and banter, like gaming...and just doing stuff in general"

Young people valued the support from their friends in more ways than just talking about their parent's distress. Having respite from home and being able to engage in normal activities was something that was valued highly.

Implications:

The findings of this study implied children and young people would benefit from further support. The following suggestions have been put forward in terms of supporting this group:

- Families effected by mental distress benefit from collaborative practice across adult and child mental health and social care.
- Stigma may act as a barrier to young people seeking support. Therefore, programmes aimed at reducing stigma within schools could demystify mental distress and reduce the consequences of talking.
- Both young people and their parents can be protective towards each other, which can prevent them from talking about these difficulties. Therefore, facilitating conversations between family members could help encourage more open dialogue, which may help young people to build a more coherent understanding of their parent's difficulties.
- Peer interventions may be helpful at helping build connections for young people and provide a support network. Given the protectiveness young people described in relation to their parent, it might be useful to consider group interventions for CYP independent of their parent, where they might feel free to talk. For example, anonymous online support forums.
- Young people may benefit from accessing social activities with their peer group. Therefore, offering support to families to access activities and provide young people with a space away from home might be beneficial.

What did the young people say about the Kidstime Workshops?

The aim of this project wasn't to directly ask questions about their experience of attending Kidstime. However, many of the young people mentioned it as a source of support. Young people spoke about the following benefits of attending Kidstime:

- **Meeting other families where a parent experienced mental distress.**
  Young people spoke about the benefit of meeting others and realising they were not the only one with a parent experiencing mental distress. They also found support and friendships within the group and felt more able to talk to them, as they would understand what they were going through.

  > "It's also, good to talk about [at Kidstime] cos the other kids have, their mums have mental health so...people at Kidstime, they understand it more. They won't talk it as a joke"

- **Having a place to learn about mental distress**
  Young people described learning about different topics about mental health as a useful way of helping them to understand mental distress. They also spoke about finding it helpful to have a place to ask questions.

- **Having a space to have fun and socialise**

  > "It's just like a lovely place there. And if you have any questions they will answer it. Everyone's really nice. Without that it would just be quite hard."

  The young people in the study described Kidstime as a fun place and spoke about enjoying the different activities they had on offer. This is supported by the research findings that sometimes young people find benefit from not talking about it, but through engaging in everyday activities with people their age.