

**Portfolio 1: Major Research Project**

**Adult Sibling Stories of Parental Mental Distress**

**Wendy O'Neill**

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

June 2019

## **Acknowledgements**

I would like to thank my ever-growing family, without whom this journey would never have started or completed. Without their absolute unwavering support and encouragement when the doubts crept in, I have no idea how I would have got through it. Thank you from the bottom of my heart for all the support, love, and humour over the last ten years. I will do my best to repay your faith in me when I finally stop being a student!

I would like to thank the siblings who agreed to participate in the interviews. Each story touched me personally and I have so much respect for your generosity in sharing some of your experiences with me. I really wanted to portray your stories honestly and authentically. I hope that this study reflects your accounts and helps services become more family inclusive.

Pieter and Nic thank you for providing me with heaps of encouragement, feedback, and setting deadlines that I may have struggled to meet occasionally! I also valued the relaxed and humorous nature of our meetings and your thoughtful and considerate comments. Your availability towards final submission made the process so much less stressful. Thank you!

Lastly, my fellow trainees Kaan and Laura, your friendship has sustained me through some challenging and enjoyable times, with good times and friendships that will last much longer than the Doctorate. To Cohort '16, I wish you all the best in your future careers and no doubt the world of clinical psychology will be much richer having you all in it.

## Table of Contents

1. Abstract .....	9
2. Introduction.....	11
2.1.Chapter overview.....	11
2.2. Language and key terms .....	11
2.3. Position of the researcher .....	12
2.3.1. Personal position .....	13
2.3.2. Epistemological position.....	13
2.4. The context of the family and PEMD.....	14
2.4.1. Policy and research context.....	14
2.4.2. Prevalence .....	17
2.4.3. Family risks.....	18
2.5.Theoretical context of the family and PEMD.....	20
2.5.1. Family systems theory .....	20
2.5.2. Structural theory.....	22
2.5.3. Parent-child relationship.....	23
2.5.4. Sibling relationships.....	24
2.5.4.1.Siblings as a support.....	25
2.5.4.2.Developmental trajectory.....	28
2.6. Implications for practice.....	28
2.7.Systematic literature review .....	29

2.8.	Search method.....	31
2.9.	Evaluating the research .....	36
2.10.	Summary of the findings .....	37
2.11.	Overview of the studies .....	37
2.11.1.	Quality criteria specific to qualitative methods .....	39
2.12.	Data analysis and meta-synthesis.....	44
2.12.1.	Sense of responsibility .....	44
2.12.2.	Sibling support .....	47
2.13.	Clinical implications .....	49
2.14.	Conclusion .....	49
2.15.	Rationale for current project .....	50
2.16.	Aims of the research .....	51
3.	Method.....	52
3.1.	Overview.....	52
3.2.	Qualitative research .....	52
3.2.1.	The case for narrative inquiry .....	53
3.3.	Design .....	55
3.3.1.	Service-user consultation .....	55
3.4.	Procedure .....	57
3.4.1.	Recruitment of participants.....	57
3.4.2.	Collecting stories.....	59

3.4.3.	Interviewing sibling pairs.....	60
3.5.	Ethical considerations .....	61
3.5.1.	Explaining the research .....	62
3.5.2.	Consent and confidentiality .....	62
3.5.3.	Potential distress .....	63
3.6.	Analysis of the narratives.....	63
3.6.1.	Interview transcription .....	64
3.6.2.	Framework of the analysis .....	65
3.6.3.	The analytic process.....	66
3.7.	Attending to quality .....	67
3.7.1.	Credibility .....	67
3.7.2.	Pragmatic use .....	69
3.8.	Reflexivity.....	70
4.	Results .....	72
4.1.	Introduction .....	72
4.2.	Reflections on stories.....	72
4.3.	Introduction to the participants and global impressions .....	73
4.3.1.	Lana and Shelby.....	73
4.3.2.	Anna and Karen .....	76
4.3.3.	Aaron and Hannah .....	79
4.3.4.	Jane and Denise.....	81
4.4.	Emerging storylines .....	84

4.5.	Plot 1: The story of us .....	85
4.5.1.	Me in relation to you .....	86
4.5.2.	The Yin to my Yang.....	91
4.5.3.	Our mother and us .....	95
4.5.4.	Our father and us .....	99
4.5.5.	Being the parent .....	102
4.5.6.	Go your own way .....	106
4.6.	Plot 2: “That made us who we are if you know what I mean” .....	109
4.6.1.	This is me and this is us .....	109
4.6.2.	History will not repeat itself.....	113
5.	Discussion .....	117
5.1.	Overview .....	117
5.1.1.	Making meaning of the experience .....	117
5.1.2.	The sibling relationship.....	119
5.1.3.	Factors that contribute to a positive or negative sibling relationship .....	123
5.1.4.	Having conversations .....	124
5.2.	Implications for clinical practice .....	125
5.2.1.	Clinician level .....	126
5.2.2.	Systems level.....	127
5.2.3.	Societal level .....	128
5.3.	Methodological considerations .....	129
5.3.1.	Strengths.....	129
5.3.2.	Limitations .....	130

5.3.3.	Suggestions for future research.....	132
5.4.	Personal reflections.....	133
5.5.	Conclusion.....	135
6.	References.....	136
7.	Appendices.....	154
7.1.	Summary of literature review.....	154
7.2.	Evidence of correspondence with consultees.....	161
7.3.	Recruitment poster.....	162
7.4.	Recruitment email.....	163
7.5.	Participant information sheet.....	164
7.6.	Lone worker policy.....	167
7.7.	Consent form.....	174
7.8.	Debrief form.....	176
7.9.	Interview schedule.....	177
7.10.	Ethical approval.....	178
7.11.	Amended ethical approval.....	179
7.12.	Transcription service agreement.....	180
7.13.	Protocol for managing distress.....	181
7.14.	Example of initial impression of an interview.....	183
7.15.	Example of an analysed transcript.....	184
7.16.	Mind map of Aaron and Hannah’s analysis.....	204
7.17.	Reflective diary example.....	205

**PAGE LEFT INTENTIONALLY BLANK**



## **Chapter 1: Abstract**

There is a limited body of research that focuses on the experiences of families of people with mental distress. While there is research regarding children's experiences of parents with mental distress, there are few discourses about adults who have lived with a parent with mental distress. More specifically, there have been no studies which have looked at how adult siblings make sense of this experience together. Drawing on a family systems theory approach, the following study explored sibling stories of parental mental distress and the societal discourses that may have contributed to the adult siblings' sense making.

Employing a qualitative method, the study examined the accounts of four sibling pairs who were purposively recruited across England. Using narrative inquiry, the sibling pairs were interviewed at one time point, using a topic guide, which was developed to elicit narratives that were privileged and silenced. All interviews were audio-recorded, transcribed, and analysed within a narrative analytic framework combining several different approaches. These stories were then situated within the local and broader socio-cultural contexts.

The findings were presented through global impressions of the sibling narratives and then illustrated via a discussion of the similarities and differences across the collective storylines. The findings supported the identity construction of each sibling and the collective identities of the siblings in the context of parental experiences of mental distress. The findings suggested that there was a change in the siblings' meaning making from childhood to adulthood. The findings highlighted that the siblings felt they had shared similar life events with each other, but their understanding and involvement had been different as young people which had been influenced by the positions and roles they had taken in the family in response to the parental experiences of mental distress.

Factors that contributed to a positive or negative sibling relationship were acknowledged which included individual characteristics of the participants and communication styles. Communication was deemed an important factor in the context of parental experiences of mental distress. The findings were considered within the local and wider narratives, such as stigma related to mental distress, and within a family systems and structural theoretical approach. Implications for clinical practice were proposed at a clinician, systems, and societal level, with the strengths and limitations of the methodology, and directions for future research identified.

. . .

## **Chapter 2: Introduction**

### **2.1. Chapter overview**

The current study uses a qualitative design to explore adult sibling stories of parental mental distress. The chapter intends to describe the main themes written on sibling relationships and parental mental distress within the literature. It will also consider the current context of the study and the epistemological and personal position of the researcher. Key terms and the language adopted for the study will be identified, with the overarching aim of situating and contextualising the present study.

### **2.2. Language and key terms**

The study will predominantly be written in the third person. At times, the first person will be employed to emphasise and acknowledge the personal stance and reflections of the researcher. The first person will be used to maintain coherency with the study's epistemology and methodology which considers that research is co-constructed between the researcher and participant.

The language employed within the mental health field can be powerful and either challenge or perpetuate the stigma around mental health. There are many terms and diagnostic labels referenced by different professional groups, service users, the public, and media which can be helpful. Contrastingly, the language may also be pejorative and have negative connotations for consumers of services. Therefore, it is important to consider the language used when describing mental health which authenticates and represents the experience of these individuals. In a survey conducted by the *National Service User Network* (NSUN, 2015), the preferred language identified by the network to describe their experiences was a person with direct or lived experience of mental distress. Consequently, the study will use this term and

describe the study's participants as having parental experience of mental distress (PEMD) and use the phrase 'a parent with PEMD' when speaking directly about a parent.

While the term PEMD is preferable as it moves away from the medical model of diagnosis and labels, it foregrounds other language which is also important to consider. The term 'mental distress' may imply all experiences associated with mental health problems cause distress. Some experiences may cause distress; however, others may be viewed differently acknowledging the continuum of distress. Therefore, I believe that individual experiences should always be privileged over the collective. With respect to this study, the term may also convey a parent's emotional state as distressed which might mitigate other reported experiences of the sibling story by assuming a particular state of the parent. I will endeavor to pay attention to any harm or assumptions inferred by the use of the language.

Nonetheless, as this was the preferred term from the survey, it will be used throughout the study. The term encompasses siblings who define their parents as having 'mental distress', which they may understand through a diagnosis such as Anxiety, Depression, or Bipolar Disorder which caused a significant impairment at least once during the sibling lives.

## **2.3. Position of the researcher**

### **2.3.1. Personal relationship**

Reflexivity in qualitative research provides the researcher with a tool to create an awareness of what they are bringing to the research based on their previous experiences and interests, adding credibility and enabling the researcher to be aware of the co-construction of knowledge (Finlay, 2003). Therefore, it is an important component of the research process to consider both the personal perspective and epistemological position of the researcher.

I was interested in exploring sibling relationships in the context of PEMD as my family, in particular, my siblings have helped me cope and provided support through some challenging and difficult family events. I am one of four siblings and as a teenager, my family went through some turbulent times which changed the family dynamics and the roles each of us took. These challenges had a significant impact on my parents' well-being and on my siblings in different ways throughout the years.

Reflecting on these experiences as an adult and trainee clinical psychologist, I find myself thinking about my siblings and I, and how each of us made sense of the experience individually and as a collective. I am drawn to thinking about the conversations we shared with each other at the time and what remained silent. Similarly, there is a shared understanding as adults of what we experienced and the differences and impact of this on the family system and subsystems. These experiences have made me privilege the sibling relationship as a protective factor in family systems as it is often overlooked when working with families (Whiteman, McHale, & Soli, 2011). Combining this with my interest in families and PEMD, I wanted to invite siblings to share their stories and understand more about how they construct narratives about themselves and their relationship in the context of what can be a challenging and confusing time for families.

### **2.3.2. Epistemological position**

Epistemology is concerned with the type and form of knowledge and how knowledge is created, understood, and communicated (Scotland, 2012). Combined with ontological assumptions (i.e., what constitutes reality), there are a number of scientific paradigms representing different ontological and epistemological assumptions which underpin particular

research approaches.

It is important to consider how my position on knowledge creation influences the research. My epistemological position has been influenced by my training on the Clinical Psychology Doctorate. Having previously undertaken a Biochemistry degree, I came from a positivistic epistemological position, acknowledging that there is absolute knowledge about an objective reality. I have been invited to consider an alternative position, the social constructionist approach, which I have found challenging yet enlightening. I have developed a relationship with the approach which I draw on to conceptualise the experience of mental distress, recognising that there are multiple perspectives and the consideration of the context and relationships in which the distress arises. A socially constructed reality cannot be conceived as being independent of the observer and that reality is constructed through one's own understanding and knowledge of the world generated through social interactions with others (Gergen, 1999). Therefore, drawing on the social constructionist position, the researcher will approach the research with an emphasis on multiple perspectives and the co-construction of knowledge to illuminate sibling experiences of PEMD.

## **2.4. The context of the family and PEMD**

### **2.4.1. Policy and research context**

The epistemological position of this research considers the importance of the context in which families live and therefore, it is necessary to understand the historical, political, and research context that underpins the current research.

Historically, the dominant societal and political discourse surrounding individuals experiencing distress imposed a political and professional framework of diagnostic categories, whereby

support was framed as treatment or being detained and having one's rights restricted (Beresford, 2002). This view was supported by national policies with an emphasis on the risk and limitations of the individual experiencing distress (e.g. *The Mental Health Act, 1983*).

More recently, mental health policy has taken a more centralised position on the political agenda in response to the prevalence of mental distress among the population and the lack of resources available. In this regard, austerity measures and political uncertainty has meant there are longer wait times for mental health services and a focus on time-limited support, resulting in negative media and societal discourses around services (The Kings Fund, 2018). Most policy changes over the last twenty years have arisen in response to serious incidents such as inquiries from homicides and child deaths which have emphasised the needs and risks of children with PEMD (HM Government, 2018). Consequently, there has been a growing interest in identifying children at risk of abuse and the identification of support and protection for them. The *Children's Act (1989)*, a framework of care and protection for children, identified that the welfare of the child is a priority and children should be kept safe, if at risk of harm, with their views sought in an age appropriate manner. Under the Act (1989), the importance of involving children and families is acknowledged and it seeks to ensure that all phases of the assessment process are carried out in partnership with key family members.

Following on from this, *Every Child Matters* (Department for Education and Skills, 2003) and *Children and Young People's Plans* (Department for Education and Skills, 2005) identified an agenda for inter-agency working, acknowledging that families with PEMD would need further consideration across children and adult services, both at a service and policy level. This need would be assessed with the aim of gaining a better understanding of all aspects of the psychosocial impact of PEMD on children and other family members in order to offer better

assessments and intervention (Department for Education and Skills, 2003).

The Cross-Government *Mental Health Outcomes Strategy* (2011) aimed to ensure mental health awareness and treatment are given the same prominence as physical health, with children at the centre of this initiative (Cleaver, Unell, & Aldgate, 2011). The strategy also recognised that parents may require additional support to manage anxiety and depression during the early years of childhood (Cleaver et al., 2011). With this in mind, an attempt has been made to move towards family-based interventions and programmes, which was reflected in the *Think Family* paper (Social Care Institute for Excellence (SCIE), 2011) which recognised and promoted the importance of a whole-family approach with recommendations for practice.

Research within the mental distress literature initially has centred on a medical model of genetic vulnerability and the relationship of the parent with PEMD towards the child (Mattejat & Remschmidt, 2008). Research explored PEMD as being located within the family context and the individual themselves. However, there has been a shift in broadening these ideas to include social determinants of mental distress such as poverty, exclusion, and discrimination (Gatsou, Yates, Goodrich & Pearson, 2017). Additional evidence supports the relationship between PEMD and social factors, with mothers experiencing mental distress more likely to report severe financial difficulty, health problems, and child behavioural difficulties (Oyserman, Mowbray, Meares, & Firminger, 2010). The central themes within the PEMD research focuses on risk and resilience. However, there is a growing body of research that explores the experiences and needs of children of PEMD (Jonssen, Skarsater, Wijk, & Danielson, 2011; Martinsen, Martinsen, Weimand, Pedersen, & Norvoll, 2019).

Children with PEMD are at risk of developing mental distress and they are more likely to enter



the Social Care System (SCIE, 2011). This highlights the need for more family-based supports and interventions (SCIE, 2011). Despite this knowledge, there has been little change in the way services support these at-risk families, with adult and child mental health services segregated, and social services appearing to respond to families when they are in crisis. This can impact on families seeking and accepting support, with parents potentially feeling blamed and criticised in how they raise their children, making them wary of services (Falkov, 2011). Reasons for the reluctance to work with the whole family have included, professionals not feeling adequately skilled to support families and therefore not seeking to actively engage with all family members (Gatsou et al., 2017). Furthermore, in the presence of large caseloads and a lack of resources, it is difficult for professionals to evidence the effectiveness of working with families.

#### **2.4.2. Prevalence**

It is difficult to estimate the current number of children in the UK living with a parent with PEMD because the tools used to estimate figures and how mental distress is measured vary considerably. Furthermore, mental health services do not often consider the parenting role of the individual, information on children is not routinely collected, and the reluctance among parents to disclose their distress due to concerns from services over the welfare of their children, compounds the difficulty in accurate reporting of these figures (Tunnard, 2004). Nonetheless, figures suggest that one in four children will be at risk of having a parent with PEMD (Parker et al., 2008) and an estimated 10–15% of children live with a parent with PEMD (Falkov 2011). Additionally, around 15% of dual-parent families, and 28% of single-parent families have a parent with a diagnosed mental illness (Parker et al., 2008). However, in an earlier report, it was estimated that just under 4 % of parents with dependent children experience mental distress equating to around 1.7 million adults and 2.5 million children

(Stanley & Cox, 2008; Tunnard, 2004) highlighting the disparity in the reporting.

### **2.4.3. Family risks**

Families affected by PEMD are some of the most vulnerable in society and are at an increased risk of poverty, social isolation, and marital discord (Reupert & Maybery, 2007). Supported by the research mentioned earlier, children living with PEMD are at a greater risk of developing psychological distress, attachment difficulties, experience poor academic attainment, interpersonal difficulties, and behavioural and emotional problems (Foster, 2010; Reupert & Maybery, 2007). More specifically, it has been reported that two thirds of these children experience psychosocial or mental distress in adulthood (Foster, 2010). Given the high risk of developing significant difficulties in adulthood, it is important that we understand what contributes and protects against this, in order to mitigate the risks and optimise emotional and social wellbeing.

Parental mental health and child outcomes within the research have shown both positive and negative effects for children with PEMD. In particular, research has identified that the mother's mental health is important in the long-term mental health of the child (Fitzsimons, Goodman, Kelly, & Smith, 2017). This supports the dominant social discourse that mothers provide more of the parenting to the child and therefore, the impact of maternal PEMD is more significant. Children are at risk of poorer outcomes when they are exposed to the parental distress and the risks are compounded by associated factors such as poverty, unemployment, attachment difficulties, disruptions to parenting, and the individual factors of the child (Nolte & Wren, 2017). However, some children may be disposed to developing mental distress because of a difficult temperament, poor social and cognitive skills, or emotional difficulties which may have been present pre PEMD or as a result of living with PEMD (Reupert & Maybery, 2016).

With respect to parenting, mental distress may not play a role in the parenting of a child while other parents may require support, with parenting ability likely to be influenced by the severity of the difficulty and the length of time that the distress is present (Reupert & Maybery, 2016).

Research exploring the experiences of adult children of a parent with PEMD has also focussed on the risks associated, such as confusion and difficult relationships with the parent, isolation and a lack of support from outside the family unit (Murphy, Peters, Jackson, & Wilkes, 2011). Research has described the adult children's own mental distress, including their experiences with anxiety, depression, poor psychosocial functioning, and interpersonal and attachment difficulties (Mowbray & Mowbray, 2006; Sorenson et al., 2009; Stenager & Qin, 2008). It has been suggested that a lack of understanding and knowledge about a parent's mental distress contributes to feelings of fear and isolation from others (Foster, 2010; Van Parys & Rober, 2012). Foster (2010) explored adult children's experiences of PEMD and described how adults struggled in their relationships with their peers, family, friends, and parents. It was suggested that these relationships can be affected by feelings of stigma and shame around the mental distress. However, the studies of adults within this population are limited and explore experiences with a particular lens which may result in other perspectives being silenced.

#### **2.4.4. Protective factors**

While there are risks associated with living with PEMD, there are also factors that mitigate the adverse impact and provide a protective element. One such factor is an understanding of a parent's mental distress (Mordoch, 2010). Some research has indicated better outcomes for children who felt they understood the emotional responses and behaviours of the parent as this led to less uncertainty and distress (Mordoch, 2010). The absence of communication around PEMD can result in a child's misperception of the situation while attempting to balance the

reality of the experience of the distressed parent (Mordoch, 2010). In contrast, it has been suggested that where children are able to express themselves and their worries and reflect on how they are feeling, the adverse impact of PEMD is reduced (Falkov, 1999; Van Parys & Rober, 2012).

Positive relationships with family members and friends have been identified as important as they help children feel connected, normal, and provide them with a space to share their problems (Drost, van der Krieke, Sytema, & Schippers, 2016). Additionally, supportive and close relationships have been seen as helpful in reducing the risk of the negative effects of living with PEMD (Riebschleger, 1991). In a study by Reupert & Maybery (2007), participants reported developing a close relationship with the parent without mental distress which appeared to compensate for the reported lack of closeness with the parent with PEMD. However, this does not preclude a close relationship with the parent experiencing mental distress. Other children reported finding support from friends, grandparents, teachers, adult friends of the family, and neighbours (Reupert & Maybery, 2007). Where families feel less containing for the child, a child's ability to cope may depend on their ability to extend their boundaries of trust to other members of their network (McKie & Cunningham-Burley, 2005). Therefore, there is a relational aspect to the risk and protective factors for children living with PEMD and in the construction of the experience that requires further exploration.

## **2.5. Theoretical context of the family and PEMD**

### **2.5.1. Family systems theory**

Systemic approaches and subsequent therapies arose from Bateson's (1972) work drawing from Cybernetics (Wiener, 1948) and General Systems Theory (von Bertalanffy, 1968) in order to understand family systems, processes, and dysfunction (Carr, 2012). The general systems

theory proposes that the family is a system consisting of a set of individuals with relationships which are supported and maintained through communication (Beavin, Bavelas, & Segal, 1982). Family systems theory proposes that families are governed by a set of rules, with each person being seen as influencing the other and their responses in turn influence them, which influences the first person's responses (Dallos & Draper, 2010). Symptoms of distress are considered expressions of 'dysfunctional' family rules, roles, patterns, and beliefs. Relationships form as if there are implicit rules and these rules reflect how people relate to each other (Burnham, 1986). Therefore, the sibling relationship can be influenced by PEMD which may vary across time and place. In this regard, the role that each sibling takes may change and how they communicate with each other around this change will be influenced by the relationship with the parent with PEMD and vary at different times. Furthermore, according to family theories, conflict that is not overt is more difficult to resolve (Burnham, 1986). Therefore, if the parent with PEMD does not communicate with the child about their mental distress, this may stop the siblings from discussing the parent's mental distress, or the change in their relationship, perpetuating a silence around the topic which has been shown to be harmful for children of PEMD (Murphy et al., 2015b).

One of the key concepts within the theory is the idea of triads being the foundation of the human relationship (Dallos & Vetere, 2003). The idea states that when any two people interact, their interactions are influenced by their respective relationships with the same third person (Dallos & Vetere, 2003). For example, when considering the current study, the interactions between the siblings may be influenced by their relationship with the parent with distress, the other parent or any other siblings. The idea of the triad does not assign a negative or positive attribution to the relationship but considers that these triads can act in ways to stabilise or destabilise relationships (Dallos & Vetere, 2003). Furthermore, stability underlines the theory

whereby patterns are maintained and once established homeostasis compels the system to remain the same (Dallos & Draper, 2010). Therefore, even if family systems display unhelpful behavioural patterns, they will strive to maintain these patterns in order to ensure homeostasis.

A family systems approach also addresses the larger context in which the family exists, how sibling relationships develop, and how families adapt in response to internal and external circumstances. Within the framework, subsystems are at their optimum when there are flexible boundaries which allow for the influence of other subsystems (Whiteman et al., 2011). Dysfunction in families may arise when subsystems form which have rigid boundaries and when there are continuous changes in the norms, roles, and activities within the family system (Whiteman et al., 2011).

### **2.5.2. Structural theory**

Structural theory proposed that families consist of hierarchical structures with the parental subsystem being at the top of the hierarchy (Minuchin, 1974; Carr, 2012) and the overt and covert rules that are said to influence interpersonal choices and behaviours in the family (Dallos & Draper, 2010). Healthy families are assumed to have a structure that permits them to meet lifecycle demands categorised by clear intergenerational boundaries between the parent and child subsystems (Carr, 2012). These boundaries are not rigid, nor diffuse, and not enmeshed or disengaged, whereas problematic family organisational structures may limit the families' resources to meet the demands of lifecycle changes or unpredictable intrafamilial or extrafamilial stresses (Carr, 2012). These problematic family organisational structures may be characterised by subsystems that may be too close or over involved or too distant (Dallos & Draper, 2001). Given what has been spoken about in previous research regarding parental mental distress, it is worth hypothesising that families with experience of PEMD may have problematic organisational structures in so far as any member of the system may occupy

boundaries that could create dysfunction. Additionally, a rigid subsystem may be exhibited by the parent with PEMD and the siblings or with the other parent not experiencing mental distress and the siblings which may create dysfunction and disharmony within the system. However, other more helpful processes can also be evident in family subsystems. For example, siblings can form an alliance by sharing a common interest together or more covertly, a coalition, hiding a particular event from other members of the family (Burnham, 1986). Within the family system, particular relationships and subsystems exist in the context of mental distress which will be discussed below.

### **2.5.3. Parent-child relationship**

The parent-child relationship is constructed through roles, norms, individual practices, and social institutions and is considered one of the remaining social bonds that has permanence and duty attached to it (McKie & Cunningham-Burley, 2005). Furthermore, there are societal discourses around parenting and gender that draw on the idea of the mother as the primary caregiver and the working father which may influence the meaning making of the parent-child relationship. Thus, the parent-child relationship is influenced on many levels. One change that can disrupt the relationship is that of the parentified child (Byng-Hall, 2008), which describes a child as someone who assumes the emotional responsibility of the parent and may care for them and other members in the family (McKie & Cunningham-Burley, 2005). There are several theories that are drawn on to explain the impact of parentification on the child, including attachment theory (Bowlby, 1980), and Erikson's (1959) social developmental theory which considers how the child forms its' identity and relationships with others.

A sustained indefinite period of parentification can have a lasting negative effect on the child and later in adulthood (Earley & Cushway, 2002). As the child cares for a parent and other

family members such as siblings, they put others needs before their own, at the expense of their own development. This can result in difficulties in their future functioning and ability to form adult attachment relationships (Hooper, 2007). Role reversal and parental boundary problems have been found to predict controlling interpersonal styles and emotional and somatic problems in children (Earley & Cushway, 2002). Where the child adopts a role in providing for the physical needs of the family, feelings of accomplishment, and contribution are engendered in the child while simultaneously providing relief for the parent (Hooper, 2007). This can become harmful when the role is not recognised or lasts indefinitely (Hooper, 2007). Studies in the area are generally retrospective and rely on the use of self-report measures and student samples which reduces the heterogeneity of the findings and does not take account of multiple perspectives. Nonetheless, they have identified adults continuing to assume caretaking roles later on in life (Earley & Cushway, 2002) indicating that this role becomes a part of an individual's identity.

#### **2.5.4. Sibling relationships**

Most of what is understood about children's psychological development has arisen from the assumption that the experiences are grounded in a child's relationship with a parent, and their social and cultural context. In this regard, children growing up in homes with PEMD will make sense of their experience in the context of their individual developmental stage and the interactions within the family and wider systems. The sibling relationship is one such interaction which has been identified as being important within the literature (Reupert & Maybery, 2007). Given that 55% of families in the UK in 2015 reported having two or more dependent children (Office for National Statistics, 2015), it is an area of interest to explore. Sibling relationships are unique from other relationships as siblings will usually share life experiences, genetic similarities, and will remain in each other's lives usually in various forms



(Cicirelli, 1995). They involve varying degrees of closeness and investment, and can provide connection and support, mirrored experiences, validation, belonging, as well as distress and competition (Cicirelli, 1995). Sibling relationships can be a great source of meaning making and enjoyment, however, they can also be challenging at times (Griffiths & Sin, 2013). As such, the sibling relationship can be a major determinant of both identity formation and self-esteem (Cicirelli, 1995). Two major themes have been extrapolated from the literature on siblings to date.

#### **2.5.4.1. Siblings as a support**

Siblings within families that experience disadvantage have the potential to provide support to each other (Widmer & Weiss, 2000) and sibling support also has been shown to serve as a protective factor for young children in families experiencing difficulties, acting as a buffer from the negative effects (Jenkins & Smith, 1990).

In a study looking at children living with PEMD, many participants assumed protective and/or caring roles for siblings, often taking on the parental role (Reupert & Maybery, 2007). Parents have reported that they felt their mental distress strengthened the family relationships by bringing parents, children, and siblings closer together (Gladstone, Boydell, Seeman, & McKeever, 2011). Positive sibling relations acted as a protective factor from the impact of stressful life events on internalising problems (Gass, Jenkins, & Dunn, 2007). Given the proximity and shared life experiences of this relationship, and in the absence of a supportive parent or disharmony within the family, a sibling may turn to another sibling for support and potentially initiate a relational pattern where one sibling takes on a compensatory role or a parentified role. In a meta-synthesis, it was reported that some young people found they did not have a choice when it came to caring for a family member and there was a need for this

role to be acknowledged (Rose & Cohen, 2010).

Furthermore, a small number of studies have suggested that close sibling relationships minimise the impact of marital discord on adjustment (Deković & Buist, 2005; Jenkins & Smith, 1990; O'Connor, Hetherington, & Reiss, 1998). Some research suggests that sibling support can moderate the impact of an absent parent or peer support on an individuals' self-esteem, loneliness, and depression (East & Rook, 1992; Milevsky & Levitt, 2005). Therefore, positive sibling relationships are not only important influences on adjustment in general, but also serve to moderate the impact of negative parent, peer, and other experiences on young people's mental health (Feinberg, Solmeyer, & McHale 2012). Sibling support could also result in potentially negative consequences. In particular, siblings can engage in frequent conflicts and occasional violence (Waldinger, Valiant, & Orav, 2007). Studies have shown that conflict between siblings during middle childhood has been associated with greater anxiety and depression in adolescence (Waldinger, Vaillant, & Orav, 2007). Furthermore, it was identified that a poor relationship with siblings in childhood is a risk factor for depression in adulthood irrespective of the quality of parenting reported, citing the importance of the relationship (Waldinger et al., 2007).

It is evident that the family context is important in understanding the sibling relationship and this has been mostly explored in families with different family structures, including divorced families and stepfamilies (Hetherington & Clingempeel, 1992). The emotional consequences of family disharmony including marital discord, and satisfaction is linked to the quality of sibling relationship, with conflict more common in sibling relationships from disharmonious homes (Dunn, 1992). One finding is that sibling relationships influence, and are influenced by,

the conflict and ambivalence typically found in disrupted families. For example, conflict between parents tends to have a knock-on effect, increasing sibling hostility and emotional distance (Hetherington & Clingempeel, 1992; Hetherington, et al., 1999). Siblings often experience lower levels of mutual engagement following divorce and during the beginning stages of remarriage (McGuire & Shanahan, 2010). Hostility towards a sibling usually increases when a stepfamily is formed but declines as children get older and spend more time together (McGuire & Shanahan, 2010). In an early study, it was found that children from disrupted homes were more likely to develop aggressive and hostile relationships than those in the control group (Jenkins, 1992). However, it was also found that those who did develop supportive relationships could offer support and some protection against the psychological consequences from the stress (Jenkins, 1992). In particular, some siblings actually grew closer when presented with intense parental marital conflict, relying on each other for emotional support (Deater-Deckard, Dunn, & Lussier, 2002).

Furthermore, the few studies which have explored the impact of socioeconomic status (SES) on sibling relationships have reported that lower SES is associated with more negative relationships (Dunn, Slomkowski, & Beardsall, 1994), whereas other studies have identified a contrasting relationship (McHale, Whiteman, Kim, & Crouter, 2007; Updegraff & Obeidallah, 1999). However, no such research has been carried out on the sibling relationship in the context of PEMD and given the disparity and lack of research with the PEMD field, this is an area to explore further.

#### **2.5.4.2. Developmental trajectory of the relationship**

Sibling relationships fluctuate in intensity over the developmental life course and can at times be the most emotionally salient relationship in a child's development (Waldinger et al., 2007).

Siblings tend to become more independent of each other in late adolescence and young adulthood (Goetting, 1986; Widmer, 1999). Goetting (1986) described a model of the developmental tasks of siblings in different phases of the family life-cycle, proposing varying degrees of closeness and support depending on where the siblings are in their lives. Adolescents report lower levels of friendship, intimacy, and affection with their siblings than children and pre-adolescents (Buhrmester & Furman, 1990), and the frequency of shared activities decreases with age (Rafaelli & Larson, 1987; Widmer, 1999). In this sense, adolescence is a time in which sibling relationships decrease in importance and influence compared with other influences and sources of support. As previously mentioned, a potential harmful effect can result when siblings take on a caregiving role, resulting in sibling relationships becoming estranged (Reupert & Maybery, 2007). However, older children and those with additional resources reported how they were able to maintain their independence and manage the relationship with the parent whilst managing their needs with those of other family members (Gladstone et al., 2011).

Structural changes to the relationship have also been shown to change during middle childhood and adolescence (Buhrmester, 1992). As siblings' transition from adolescence into adulthood, they have a choice in maintaining their relationship and those relationships that do, become more like friendships (Whiteman et al., 2011). Studies have highlighted factors such as contact, help and support, and feelings of closeness and security as indicators of adult sibling attachment, and these behaviours are in turn related to psychological well-being and physical health in old age (Cicirelli, 1992, 1995).

## **2.6. Implications for practice**

Despite the evidence stated above and a recognition that a parent with PEMD may require

additional needs, the impact on the child will also depend on the child's developmental stage, and their ability to understand their family's situation and the strategies the family have adopted to cope with the challenges. Other factors that will influence the impact of PEMD is whether the parent is the primary caregiver and the severity and chronicity of the mental distress (Reupert & Maybery, 2016). These factors need to be considered when thinking about appropriate services and interventions for families.

With regards to mental health support, children recognised what helped them cope with PEMD. They felt that having professionals involved with care planning and medication for the parent was helpful. They also valued being recognised by the professional as having a significant role in the parent's distress day to day, being given the opportunity to understand their parent's difficulty and being included in their treatment (Drost et al., 2015). Some children however felt it was more helpful to be separate from their parent's distress. Therefore, services will need to consider each family individually yet, recognise the importance of involving all family members to help minimise the impact of having PEMD.

Finally, sibling relationships have been identified as potentially helpful and important relationships that are enduring and share many environmental commonalities which could contribute to the family resources in the context of PEMD.

## **2.7. Systematic literature review**

In the following section I will briefly consider some of the research on the families' experience of parental mental distress, before presenting a qualitative meta-synthesis on sibling experiences of PEMD. Research on PEMD has previously focused on the parent's perspective and then shifted towards the experience of the young person, with more studies now exploring

the experiences of adult children of PEMD (Bauer, Spiessi, & Helmbrecht, 2015). Studies in the area have generally tended to focus on the constructs of risk and resilience. These children are at a higher risk of developing behavioural, developmental, and emotional difficulties, compared to their same age peers (Reupert & Maybery, 2007). Children are perceived to be more at risk of developing their own psychological distress as they are affected by a high level of parentification and burden resulting from responsibilities (Earley & Cushway, 2002). Furthermore, studies have indicated that children are at risk of developing poor relationships (Rutter, 1993). However, studies have also focused on the resiliency of this population, noting the importance of supportive relationships, coping skills, positive relationships between parents, and higher socio-economic status. Resiliency comes from learning how to handle risk with appropriate support or coping skills (Riebschelger, Grové, Cavanaugh, & Costello, 2017). The concept of connectedness to others has also been shown to be a moderator of the effects of PEMD and siblings within families have the potential to provide support for each other (Widmer & Weiss, 2000).

While there is a body of research, from an adult retrospective and child perspective that examines the experience of children living with PEMD, no studies could be found that explore the sibling experiences of living with PEMD. It was considered a useful method to systematically compile and understand the literature in the area. The synthesis of literature in the PEMD field enables the researcher to collect and capture the salient themes within the field and to analyse and interpret the findings (Lachal, Revy-Levy, Orri, & Moro, 2017). A meta-synthesis also allows for identification of any gaps or omissions in a body of research (Siddaway, Wood, & Hedges, 2018). Given the absence of literature on sibling experiences of PEMD, the systematic review sought to understand what the reported experiences of siblings living with a parent with PEMD are from the literature and how these meanings have been

constructed. The researcher conducted the meta-synthesis according to the guidelines proposed by Sandelowski, Barroso, and Voils (2007) for qualitative research synthesis. Therefore, this section presents the findings from a qualitative synthesis which was undertaken to explore the research on sibling experiences of parental mental distress.

## **2.8. Search methods**

From a search of the literature, relevant search terms were identified and discussed with an expert in the field, who has written on PEMD, to determine their suitability for inclusion. Search terms were derived from the question ‘*What are the families experience of PEMD?*’. The aim was to capture all the literature concerning the families’ experience of mental distress so that any study findings that spoke to the sibling relationship or siblings could be extrapolated. Search terms were divided into four blocks, due to the number of different combinations of terms used in the literature (Table 1). Relevant search terms were truncated (e.g. parent\* = parent, parental, parenting; deal\* = dealing).

Table 1: Search terms

Parent	Mental Distress	Family	Experience
Parent*	“Mental Illness”	“family member”	“Lived Experience”
Mother	“Mental Health”	Mother	“Quality of Life”
Father	“Mental Distress”	Father	Deal*
Mum	“Mental Disorder”	Wife	Cope*
Dad	“Mental Ill health”	Husband	Living
Maternal	“Psychiatric Disorder”	Sister	
Paternal	Schizophrenia	Brother	
	“Schizoaffective Disorder”	Daughter	
	“Major Depression”	Son	
	“Bipolar Disorder”	Child	
	Anxiety	Sibling	
	“Personality Disorder”	Relative	
		Offspring	

Systematic searches were conducted in CINAHL, PubMed, PsychINFO, PsychArticles and Scopus. Studies were included if they 1) employed a qualitative approach, 2) were written in English, 3) explored first-person accounts of a child living with PEMD, 4) a retrospective account of a child’s experience and 5) published between 2000-2019. It was considered relevant to include both young people and adult accounts as the current study was interested both in the retrospective experience of being a sibling and young person and living with



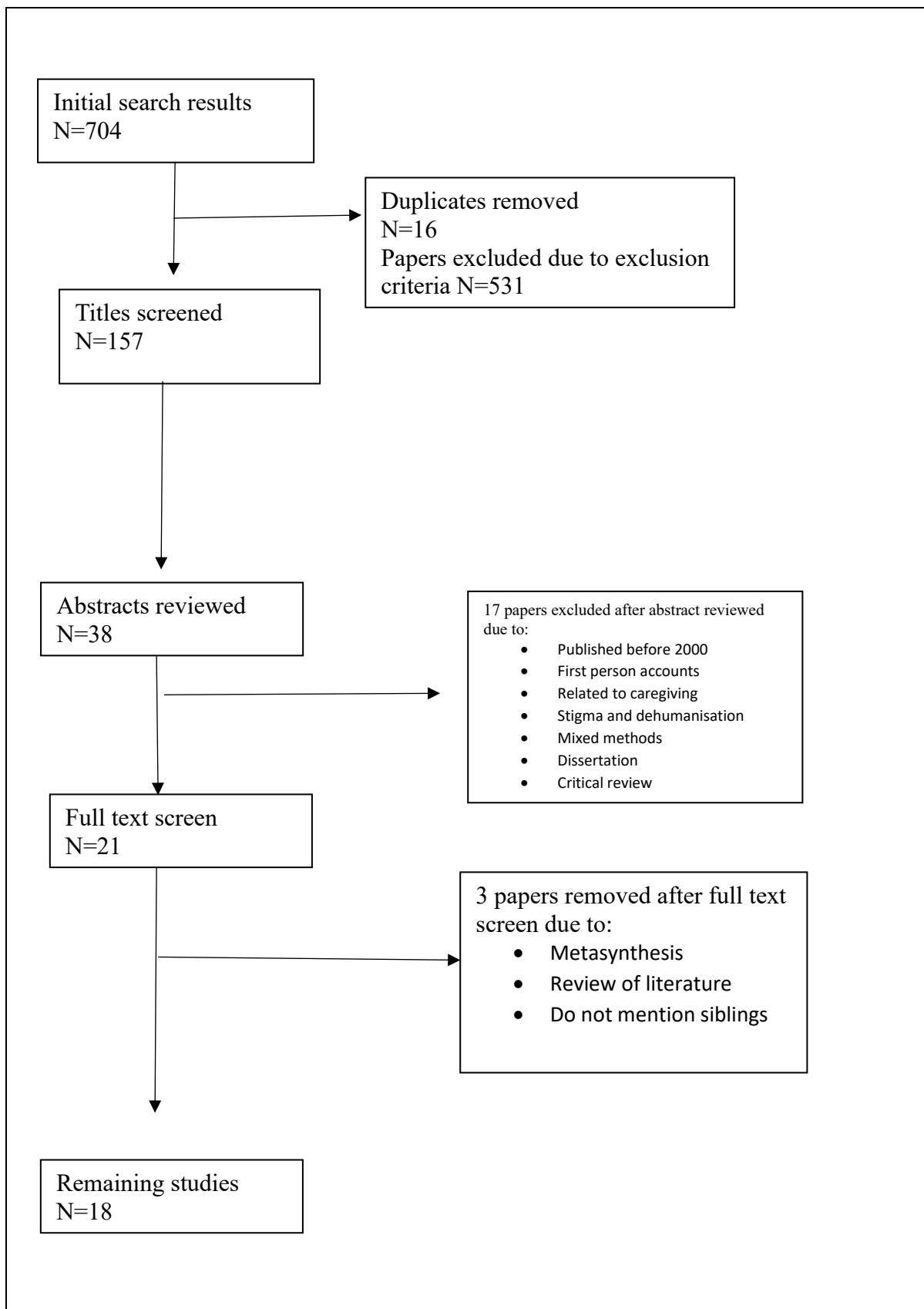
parental distress and in the meaning attributed over time. Earlier studies were excluded as it was considered that research in the area had progressed and the language and meaning making in which mental distress is discussed has changed over the last twenty years.

Studies were excluded if they 1) explored children's experiences from professionals' or parents' accounts or employed a quantitative methodology, 2) if the focus was on a particular construct, for example, stigma or resilience as these studies did not speak to the overall experience of living with PEMD and the relational aspects that were of interest in the review, 3) if they reported on an intervention and, 4) the focus was on the experience of being a carer.

Following the search, 157 papers were found. Papers were initially screened by title and abstract and eliminated on the basis of the criteria mentioned (Table 2). Figure 1 shows the search and retrieval flow.

Table 2: Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
English Language	Papers before 2000
Peer Reviewed	Intervention studies
Papers between 2000-2019	Focus on service or professional accounts
Adult retrospective accounts	Report by parents
Papers were included if they considered more than one construct e.g. coping & challenges	Papers excluded if they explored one construct e.g. burden
Young person's account	Quantitative studies
Report on siblings	



**Figure 1: Search and retrieval process**

## **2.9. Evaluating the research**

There is no consensus about the use of quality criteria that should be employed to appraise the quality of qualitative research (Lachal et al., 2017). Nonetheless for the purpose of this review, the papers selected were appraised using the guidelines specified by Elliot, Fischer, and Rennie (1999) as they provide appropriate and valid reviews of qualitative studies and encourage self-monitoring within research. The guidelines were conceptualised for appraising psychological research and hence the rationale for implementing them in the present review. The guidelines set out criteria shared by both qualitative and quantitative approaches and more specifically criteria pertinent to qualitative research outlined below (Elliott et al., 1999).

1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs specific research tasks
7. Resonating with readers

During the process of the review, the researcher reflected on their position and subjectivity of the appraisal. The categorical nature of the criteria made critiquing some of the studies difficult in concluding a definitive 'yes' or 'no'. Credibility in qualitative research is akin to validity in quantitative studies and is used as a measure of the validity of the data and findings in a move considered positivist in the qualitative realm (Elliott et al., 1999). There have been arguments on the use of credibility checks, however, given the breadth of research employing these methods, it offers a useful barometer to measure studies. Credibility checks can include a

number of methods such as member checking or employing multiple qualitative analysts. Therefore, to enhance the credibility and rigour of the review and reduce the subjective bias of the appraisal, 16.7 % of the papers were checked by the supervisory team to ensure consistency across the review and a 95% concordance was reached. Furthermore, the researcher employed a three-tiered rating system; ‘criteria met’, ‘partially met’, ‘and not met’ to reflect a more nuanced rating scale (Table 3).

## **2.10. Summary of the findings**

18 papers were included in the final review of the literature. These papers were based on fifteen studies, with three studies publishing more than one paper from the findings (Mordoch & Hall, 2008; Murphy et al., 2014; Van Parys, Smith, & Rober, 2014). These papers were included in the review as they spoke to different aspects of the experience of parental mental distress. All the studies employed a qualitative design and represented studies from nine different countries: UK (n=1); Belgium (n=2); Sweden (n=2); Canada (n=3); USA (n=2); South Africa (n=1); Australia (n=4); Spain (n=1); Germany (n=1); Faroe Islands (n=1). All the studies mentioned siblings (Appendix 1 for summary of the literature).

## **2.11. Overview of the studies**

Each study in the review set out their aims which included the exploration of children’s experience of mental distress or a retrospective account of the experience. One study’s focus was on the parenting narratives of adult children of PEMD (Murphy et al., 2015, 2016) and one study looked specifically at the coping strategies and challenges of PEMD (Kahl & Jungbauer, 2013). Nine papers considered the experience of PEMD retrospectively, while nine studies explored the child’s current understanding of PEMD. Most of the studies interviewed participants individually and one study employed individual interviews and a focus group

(Riebschlager, 2004). Another study invited children to take part in an interview and analysed children's essays as part of a writing competition (Pólkki, Ervast, & Huupponen 2004). One study invited participants to draw, employing a creative method of engaging young people while discussing a difficult topic (Mordoch, 2009). The qualitative methods employed in the review were appropriate for the studies undertaken and included grounded theory, IPA, and narrative inquiry.

According to Sandelowski (1995), there is a misconception about small sample sizes in qualitative research as there is a belief that a small sample size does not represent the phenomenon under study. The aim in qualitative research however is often not to offer representation beyond the research participants themselves. However, it has been argued that small sample sizes may not adequately represent the claims, and too large sizes may dilute the nature of an in-depth analysis (Sandelowski, 1995). A number of studies had very small sample sizes; N=3 (Petrowski & Stein, 2016) and N=5 (Kadish, 2015; Van Parys, Smith, & Rober, 2014). Sample sizes were varied which reduced the trustworthiness of the findings. Furthermore, samples were obtained conveniently through community-based treatment settings and from individuals accessing support. This is likely to minimise the representativeness of the findings as this population is likely to demonstrate more insight and be more transparent when discussing the distress with their children. Participants' mothers were overrepresented as the identified parent with mental distress, highlighting a gender disparity in the literature, and reinforcing potentially stigmatizing narratives around the mother role in society.

With regards to the studies that retrospectively spoke about PEMD, samples were predominantly female, with limited male representation. This may reflect the wider discourse

about men being less likely to talk openly about their feelings, be indicative of certain groups less likely to access services, resulting in a lack of representation in the studies (Woodall, Raine, South, & Warwick-Booth, 2010), or the gender expectation that parenting is the woman's role. Similarly, this area is regarded as being a difficult area to access and recruit families due to the stigma of PEMD and fear of criticism from services (Hinshaw, 2005). Qualitative research is reliant on self-report data and adult accounts may have been affected by memory retrieval and social desirability responding may have influenced credibility across studies.

The studies varied in the method of analysis and included content and narrative analysis; grounded theory; thematic analysis; autoethnography; and IPA. One study employed a thematic content analysis with a sample of N=5 (Kadish, 2015). The study may have benefited from a different analytic procedure such as IPA as thematic analysis normally requires larger sample numbers. A number of studies did not comment on the steps that were involved in the analysis which made it difficult to ascertain the trustworthiness of the findings. However, those studies that did comment on the analytical process brought the studies to light by displaying the information which increased the trustworthiness of the findings.

## **2.12. Quality criteria specific to qualitative methods**

Specific criteria for appraisal in qualitative studies will now be considered. The aim of qualitative research is to understand and represent the experiences of particular phenomena from the perspective of the individuals being studied however also considering that the researcher cannot set aside their own perspective completely (Elliott et al., 1999). Therefore, it is important that the researcher declares their theoretical and personal orientations to the subject matter. Surprisingly, only six of the papers (Foster, 2010; Griffiths, Norris, Stallard, & Matthews, 2012; Meadus & Johnson, 2000; Nieto-Rucian & Furness, 2018; Van Parys et al.,

2014; Van Parys et al., 2015) either met or partially met this criterium. Despite an acknowledgement of their position, there is limited evidence of reflexivity. Griffiths et al. (2012) acknowledged a critical realist perspective in considering the participants lived experience and their own personal perspective from previous literature employing reflexivity as a tool to minimise bias. However, the majority of the studies did not mention their orientation or personal position which resulted in the reader wondering how the research was informed and shaped. As an aside, Foster (2010) used her own lived experience of being an adult child of PEMD as an initial point for the research and included her own experience within the research. Nieto-Rucian and Furness (2018) demonstrated reflexivity in considering the impact that disclosing to participants about the principal researcher's mother who had schizophrenia had on the study.

The majority of the studies provided descriptive data about the participant, the parents' diagnosis, and the gender of the parent. However, the papers varied on the amount of information that was provided on the samples. For instance, McCormack, White, and Cuenca (2017) provided a significant amount of information about participants and the parent, including the history of living with the parent, and sibling information. However, no information was included about ethnicity or social class. Given that there is a link between socioeconomic status, marginalisation, and mental distress, this information is important in thinking about the participant's environment. Some of the papers (Meadus & Johnson, 2000; Van Parys et al., 2014; Van Parys et al., 2015) described the family context, including the number of siblings, which was of interest to the researcher as it also led to a consideration about the relationship with the sibling. A number of the studies also included sibling participants within the study (Dam et al., 2017; Griffiths et al., 2012; Kadish, 2015; Mordoch & Hall, 2008; Pólkki et al., 2004), which may have impacted on the representativeness of the experiences of



the participants.

All of the studies provided examples which illustrated the themes. However, how the data was used to highlight the themes differed across studies. For example, some studies utilised a chunk of text to highlight the themes (Dam et al., 2017; Foster, 2010; Nieto-Rucian & Furness, 2018; Pólkki et al., 2004; Riebschleger, 2004) while minimal data was extrapolated to support the findings in other studies (Ostman, 2008; Pólkki et al., 2004). The studies displaying stories felt more compelling to read and provided the studies with credibility and transparency.

Studies varied in the interpretation of the data and how the findings fitted together in a coherent manner. A number of studies displayed findings diagrammatically (Dam et al., 2017; Griffiths et al., 2012; Mordoch & Hall, 2008; Mordoch, 2008; Van Parys et al., 2014; Pólkki et al., 2004). Diagrams drew the reader to the findings initially, highlighting the salient narrative and interconnectedness of themes, before a more in-depth reading of the findings occurred. One study (Ostman, 2008) did not provide a coherent framework where the reader was able to make sense of the findings.

Three studies did not provide any evidence of credibility checks (Kadish, 2015; Ostman, 2008; Pólkki et al., 2004). Other papers reported limited information on credibility checks, alluding to a team of analysts, but not explicitly stating that the checks were carried out (Murphy et al., 2015). Another study reported that 10% of the data had been checked (Griffiths et al., 2012). Credibility checks for the other studies employed the co-author or a member of the research team to review the data. One paper used member checking as a method for credibility (Foster, 2010). There was also a lack of personal reflexivity which limited the credibility of the studies. The lack of transparency of credibility checks confers a subjective bias to the research which

was not referred to in the studies.

For this review, the researcher was interested in studies that spoke to the general experience of PEMD and therefore the majority of the papers used approaches which elicited both positive and negative aspects of PEMD. Two studies were more specific in their focus, for example living with OCD (Griffiths et al., 2012) and the recollections and reflections of women who were raised by mothers suffering with psychosis (Kadish, 2015). These accounts gave an in-depth perspective of the impact of disorder specific behaviours and the experience of the participants. The issue of transferability was managed well across the studies with the authors acknowledging the lack of generalisability of the findings to a wider population. On account of the small sample numbers and convenience sampling in the studies, generalisability was further reduced. Nonetheless similar themes, such as coping and feeling a sense of responsibility, were extrapolated across the young people's accounts of their experience living with PEMD.

The studies all resonated individually and differed in how this was conveyed. The studies that constructed metaphors from the themes brought a personal and reflective component to the analysis and evoked the participant's experience (Mordoch, 2008). Other studies touched me personally when describing children's every-day experiences and when their needs had not been met. For example, children described "feeling happy" when a parent "reads me a story," "watches TV with me," "helps me with my homework," and "plays a game with me and my brother" (Riebschleger, 2004).

Table 3: Summary of the qualitative research evaluation

Authors	Owning one's perspective	Situating the sample	Grounding in examples	Coherence	Providing quality checks	Accomplishing general v specific research tasks	Resonating with readers
McCormack, White & Cuenca (2017)	?	✓	✓	✓	✓	✓	✓
Kahl & Jungbauer (2013)	X	?	✓	✓	?	✓	✓
Dam, Joensen & Hall (2017)	X	?	✓	✓	✓	✓	✓
Foster (2010)	✓	?	✓	✓	✓	✓	✓
Griffiths, Norris, Stallard, & Matthews (2012)	✓	✓	✓	✓	?	✓	✓
Nieto-Rucian & Furness (2018)	✓	✓	✓	✓	✓	✓	✓
Mordoch & Hall (2008)	?	✓	✓	✓	✓	✓	✓
Mordoch (2009)	X	✓	✓	✓	✓	✓	✓
Murphy, Peters, Wilkes & Jackson (2015)	X	✓	✓	✓	✓	✓	✓
Murphy, Peters, Wilkes & Jackson (2016)	?	✓	✓	X	✓	✓	✓
Riebschleger (2004)	X	✓	✓	✓	✓	✓	✓
Van Parys, Bonnewyn, Hooghe, De Mol, & Rober (2015)	?	✓	✓	✓	✓	✓	✓
Kadish (2015)	?	✓	✓	✓	X	?	✓
Petrowski & Stein (2016)	✓	✓	✓	✓	?	✓	✓

	Owning one's perspective	Situating the sample	Grounding in examples	Coherence	Providing quality checks	Accomplishing general v specific research tasks	Resonating with readers
Van Parys, Smith & Rober (2014)	✓	✓	✓	✓	✓	✓	✓
Meadus & Johnson (2000)	?	?	✓	✓	✓	✓	✓
Ostman (2008)	X	?	✓	X	X	✓	✓
Pólkki, Ervast, & Hupponen (2004)	X	?	✓	✓	X	X	X

### 2.13. Data analysis and meta-synthesis

A thematic analysis was used based on Braun and Clarke's (2006) guidelines. After reading all the studies to obtain a big picture of the data, specific findings related to siblings and sibling experiences were extracted, aggregated, interpreted and synthesised into two main themes: 1) sense of responsibility and 2) support. First-order data represented quotes from the participants identified in the studies, and second-order constructs, interpretations of the data by the researchers, were also extracted. The constructs were examined, and initial codes were generated, to sum up a cluster of text. These codes were then sorted into themes. Once the themes were generated, they were reviewed and refined and checked against the findings of each study to ensure they were valid constructs.

#### 2.13.1. Sense of responsibility

Overall the studies spoke to the experience of PEMD. However, nine studies spoke about the sense of responsibility individuals felt having to take care of a sibling in the context of parental mental distress. There was a common theme that the older siblings felt a responsibility to care for the younger siblings (Dam et al., 2017; Kadish, 2015; Riebschleger, 2004).

*“When Mom gets sick, I’m responsible for (younger brother) so he doesn’t get in trouble...and that he heads right home.” (Riebschleger, 2004, p.24)*

Siblings held different responsibilities, and these varied across the studies. Some studies reported that siblings would take care of the sibling, and adopt a parental role (Griffiths et al., 2012; Meadus & Johnson, 2000; Petrowski & Stein, 2016). Responsibilities included helping their sibling with the practical aspects of their daily routines (Van Parys et al., 2014) and being responsible for the other siblings which had become so much part of one child’s identity they did not want the parent to come home.

*“I mean at this point I don't really want [father] around because whatever else there is to do, I've, for as long as he's been in hospital whenever, I've taken over for him and I can continue to do that like just kinda keeping the kids [younger siblings] in line.”(Meadus & Johnson, 2000, p.386)*

One study referred to this felt sense of responsibility as having its foundation in improving the situation that they found themselves in (Mordoch & Hall, 2008).

Siblings also acknowledged that they felt a sense of responsibility in protecting their sibling by withholding information from them or ensuring they were not around when their parent was unwell (Mordoch, 2009; Murphy, et al., 2016). This resulted in siblings becoming hypervigilant to their parent’s mental distress in order to protect the other siblings (Murphy et al., 2016). However, the need to protect and keep information a secret alongside an intensity

in parental distress appeared to compound the experience for both siblings, with them reporting a lack of understanding about the parent and the family (Murphy et al., 2016).

The feelings of anxiety and the need to protect siblings was also evident in siblings when the parent was experiencing a crisis with increased fear and worry being reported as siblings felt they or their siblings were at risk of physical harm from their parent, or who believed that their parent's safety was at risk.

*“Some of the experiences – I’m thinking of things like she had paranoid schizophrenia ...She would always tell us about a man and how he was going to come and get us. We had to lock up at night and he was always there to attack us.”* (Murphy et al., 2015, p. 296).

In line with the adoption of the parental role, some studies talked about the emotional labour one sibling did on behalf of the other sibling (Murphy et al., 2016; Petrowski & Stein, 2016).

*“I kind of dealt with more of the delicate things, like how my brother is feeling... I kind of feel like I had a pseudomom kind of role when we were younger.”* (Petrowski & Stein, 2016, p.2880)

A few of the studies discussed the impact of taking on responsibilities for the family and looking after a sibling. For example, it was reported that parentification can result in colluding with the parent with PEMD, perpetuating the stigma and feelings of anxiety for the parentified child (Dam et al., 2017). Some participants became distressed when discussing the responsibilities they had for their siblings, with the adult children reflecting that they had not

been able to protect their younger siblings, resulting in additional feelings of guilt (Murphy et al., 2016).

Participants identified a range of different feelings about their role and the felt sense of responsibility. For example, some participants reported that it felt like a “weighty responsibility” (Kadish, 2015) while others did not express any resentment or negative feelings about caring for their siblings (Petrowski & Stein, 2016). It was clear from the studies that there was an impact for the sibling who adopted the position of responsibility.

*“...being a serious girl and feeling responsible for my brother and sister. Because at a certain moment, my mother didn't get up anymore in the morning, then I set my alarm and woke my brother and sister and prepared breakfast.” (Van Parys et al., 2014, p.9)*

### **2.13.2. Sibling support**

Sibling support was also another prominent theme in the literature with nine studies discussing the support siblings provided each other. Siblings, along with the children’s parents, were identified as individuals’ whom they would refer to for social support (Kahl & Jungbauer, 2013). Pólkki et al., (2004) described participants as having good social support, usually a sister, brother, or friend they could share their experiences with. They reported that family members could understand each other in a situation which outsiders might have found strange. There was a common thread that the support was mutual and was helpful because the siblings shared the experience of living with PEMD.

*“I feel like we kind of took care of each other in that way. It just felt natural.”*  
(Petrowski & Stein, 2016, p.2880)

The mutuality of the support had served to bring siblings closer together both emotionally and in their daily activities (Kadish, 2015; Petrowski & Stein, 2016).

*“We bonded over our mother’s condition and I always think if I was an only child, I’d probably be somewhere in an insane asylum, because it really is helpful to have somebody there that’s already been through it. At the end of the day, nobody knows except your sister because she was there...”* (Petrowski & Stein, 2016, p.2880).

The meaning of support was deconstructed and explored to gain a better understanding of what support might be for siblings. For example, in one study, sibling support was viewed as being a sounding board for one another, bringing some normality back into their lives, and having a shared understanding of PEMD (Kadish, 2015; Petrowski & Stein, 2016).

*“The only support I did get was from my sister, and I gave support to her in that we’d always use each other to get some sense of normality. So at least we had like a sane person to talk to.”* (Kadish, 2015, p.489).

In the study by Nieto-Rucian and Furness (2018), participants with supportive siblings who talked openly about the situation, reported feeling 'happier' and 'more normal'. In this regard, mental health professionals can be more attuned to the potential positive role of siblings in the context of PEMD.

However, not all reports of sibling support were viewed as mutually supportive (McCormack et al., 2016; Nieto-Rucian & Furness, 2018). It was documented that some siblings fell out over who had the bigger burden of caring for the parent with PEMD (Nieto-Rucian & Furness,



2018). Furthermore, siblings who did not wish to discuss their parent's difficulties and offer support to their sibling left the other sibling feeling particularly alone and isolated (Nieto-Rucian & Furness, 2018). This lack of support appeared to be due to the individual coping strategies of the sibling (Nieto-Rucian & Furness, 2018). Sibling relationships had also become strained or damaged in adulthood in the context of PEMD, with siblings acknowledging that they were still attempting to unravel some of the damage caused to their relationship (McCormack et al., 2016).

#### **2.14. Clinical implications**

The review highlighted some implications for clinical practice and further support for family inclusive services. The participants in the review reported parental distress and their own mental distress, identifying family systems characterised by high levels of stress and psychological difficulties. Consequently, it is necessary to consider the whole system when delivering an intervention and help support the family to draw on their strengths in times of difficulty. It was also acknowledged that communication can be hard for this group, yet the effectiveness of successful communication aids a shared understanding and normalisation of the situation. Supporting families to improve communication around parental mental distress may be a useful initial intervention.

#### **2.15. Conclusion**

The findings of the meta-synthesis suggest that siblings feel a sense of responsibility in providing care and protection towards the other siblings in the family. This can result in one sibling adopting a parentified position in relation to the other sibling. The consequences of this felt sense differed across the studies identified, highlighting both positive and negative outcomes. The meta-synthesis also identified sibling support as being important in how

siblings construct their experience in the context of PEMD. Sibling support was identified as having a shared experience and listening to each other. Despite siblings offering support to each other, some studies indicated that siblings did not offer support to each other which was attributed to their individual coping strategies which negatively impacted on the other sibling. There was an acknowledgement that sibling relationships are shaped one way or another by living with PEMD.

However, these findings must be interpreted cautiously as sample sizes were small and there was an over reliance on female reporting of experiences and those seeking support. Furthermore, the studies included both young children and adults and this may have diluted the generalisability of the findings, as young children may not be able to verbalise their understanding of the sibling relationship in this context and there was limited data that explored the sibling experience within these studies. It is worth considering how research in future can facilitate the representation of men, exploring barriers to participation for males and fathers experiencing mental distress in clinical practice. Additionally, the studies focused on the individual exploration of PEMD and consequently, data concerning the sibling experience, and the consideration of multiple perspectives in the construction of the experience was limited and thus impacting the findings of the meta-synthesis.

## **2.16. Rationale for current project**

While there is a good body of research on children's experiences of living with a parent with mental distress and the risk and protective factors for these children, and research on the positive and negative aspects of the sibling relationship. There has been no research carried out exploring the sibling relationship in the context of living with PEMD. It is therefore the aim of the following study to explore how siblings with PEMD story their lives and experiences

over time. Furthermore, the study will seek to explore the stories around whether the sibling relationship is affected by having a parent with PEMD. The study will also seek to understand the stories that may contribute to a positive or negative sibling relationship and what prohibits and facilitates conversation among siblings with PEMD in the context of wider societal discourses.

### **2.17. Aims of the research and research questions**

The aim of this research is therefore to examine sibling stories of PEMD. This will be explored through the following research question:

*How do siblings living with a parent experiencing mental distress construct the meaning of their relationship and the experience of PEMD?*

## **Chapter 3: Methodology**

### **3.1. Overview**

This chapter provides an explanation for the rationale of the chosen research methodology and considers the merits of the design and analysis employed; narrative inquiry and analysis. It addresses how the methodology relates to the researcher's aims and epistemological position and how the study was conducted including the recruitment of participants, ethical considerations, procedure, and service user consultation. Finally, the quality of the research will be discussed.

### **3.2. Qualitative research**

Historically, in psychological research, there has been a focus on research that investigates procedures for measurement, utilising quantitative analysis which takes a positivist epistemological stance, and has tended to overlook qualitative research methods (Wertz, Charmaz, McMullen, Josselson, & McSpadden, 2014). Qualitative methods aim to gather and make sense of the contextual, subjective experience of participants, including the processes and potential change over time (Wertz et al., 2014). Qualitative studies usually take place in the field without clearly defined hypotheses and involve the recruitment of small numbers of individuals or groups, using various methods to engage and elicit participant experiences (Kidd, 2002). There is an emphasis on depth over breadth (Kidd, 2002). The findings from these studies are illustrated linguistically, reflecting the rich descriptions, and privileging depth of understanding over the scope or generalisability that is omnipresent in quantitative methods (Bhati, Hoyt, & Huffman, 2013). More recently, there has been a significant increase in the number of qualitative studies being conducted, which has occurred alongside the increase in service user consultation and involvement resulting in interest in learning from individuals experiencing the phenomenon (Parry, Mumford, Bowers, & Watts, 2014).

Consequently, for the reasons discussed and the study's aim of exploring sibling stories of PEMD, qualitative methods were deemed the most appropriate method to aid further understanding in this area and to elucidate the meaning making siblings attribute to their experiences. Qualitative methods will allow for a rich and detailed understanding of sibling relationships; something that does not yet exist in the literature.

### **3.2.1. The case for narrative inquiry (NI)**

There are a variety of methods available in qualitative research and it is important to consider which method is the most suitable method for the current study, taking account of the research aims and the epistemological position of the researcher. Narrative as a method refers to an approach that aims to bring different and sometimes opposing meanings to the fore to understand individual and social change (Andrews, Squire & Tamboukou, 2008). It enables researchers to understand the complex personal and social relationships (Andrews et al., 2008). It draws on a social constructionist approach in offering an alternative in understanding the production and analysis of qualitative data (Earthy & Cronin, 2008). In this regard, narrative analysis seeks to understand different levels of stories rather than acknowledging one coherent and unified account which supports the constructionist ideas that there are multiple realities and no single truth (Andrews, Sclater, Rustin, Squire, & Treacher, 2004; Burr, 1995). The study is interested in the personal relationships of the siblings and how their understanding of PEMD is constructed on different levels.

A key aim of the research is to explore how siblings construct meaning making from their experiences of living with a parent with PEMD. It has been proposed that people are natural storytellers and stories are told or performed across different cultures by drawing on the

language that is available to them (McAdams & McLean, 2013). The use of language reflects the social constructionist perspective of the role of discourse in constructing social phenomena (Burr, 1995). Furthermore, language is pivotal within the interaction through which one understands the world and others which connects with the importance of language and meaning making in narrative inquiry (Esin, Fathi, & Squire, 2014).

Another epistemological assumption is that narratives are co-constructed within a certain context and that people are motivated to narrate their stories in particular ways, reflecting their understanding of the situation at a particular point, in how the account is relayed and with consideration of the audience listening (Josselson, 2004). Bamberg (2011) discusses how stories are multi-layered and there are different stories that we tell about ourselves at different times. The stories therefore reflect the preferred identities of the storyteller (Langellier, 2001). NI privileges the importance of the interaction between the storyteller and their audience, creating a dynamic process for both real and imagined audiences, such as ghost (absent) audiences, that supports how knowledge is co-constructed (Bamberg, 2011). Therefore, narratives are dynamic and not static and are contingent on the interactions and social context in which the narrators are situated, in this instance the participants and researcher.

Other qualitative approaches such as Interpretive Phenomenological Analysis (IPA) (Smith, 2011) and Grounded Theory (Glasser & Strauss, 1967) are concerned with the content of written or spoken data in a similar way to NI. However, NI expands on the exploration of the content and is interested in how language and stories are told and experienced into a coherent unified narrative (Bamberg, 2011). NI is also interested in why certain narratives are privileged over others and why they are organised in a particular way in that context (Riessman, 2008). Bamberg (2011) suggests the narrators tell stories in the way they want themselves to be

understood which the current research was interested in exploring.

Consequently, NI is consistent with the current study's epistemological assumptions, recognising that the sibling's identities are created and maintained through language and social interactions both at a local and societal level. The current study employed an experience-centered narrative approach which assumes there are four characteristics of narratives, with narratives being sequential and meaningful; are definitively human ; 're-present' experience through the construction and expression of stories and; which may bring about a transformation or change in the personal narrative of the storyteller (Squire, 2008).

### **3.3. Design**

#### **3.3.1. Service-user consultation**

Consultation in mental health research involves the exchange of thoughts and information with individuals, groups, or the wider public (Minogue et al., 2009). Consultation as participation can include a greater or lesser extent of service user engagement and involvement (Minogue et al., 2009). The consultees or experts by experience, who participate in consultation, may or may not be service users, and therefore this is reflected in the various terms used to refer to them. For this project, I was fortunate enough to have two expert consultants who provided feedback and advised on the design of the study. The consultants were identified through work and peer networks and agreed to provide feedback. Both consultants lived with a parent with PEMD and had at least one sibling.

The consultants looked at the information sheet, poster, and interview schedule and suggested thoughtful amendments, which were then adopted (Appendix 2 for evidence of correspondence). Interestingly when designing the poster (Appendix 3), I was mindful of

getting the right balance between being transparent about recruiting for participants and being sensitive and respectful to potential participants. With this in mind, I went for a smaller font and a neutral colour to represent the sensitivity of the topic. However, feedback was provided that the poster needed to be more visible with bolder larger font. While I appreciate that this was one person's perspective, it enabled me to be more assertive in the recruitment of participants, which I had found challenging initially. Further suggestions were incorporated into the interview schedule based on feedback from one of the consultant's reflections on their relationship with their sibling. It was reflected that their experience of PEMD was very different to their sibling's, despite sharing some similar experiences, which I felt was an important amendment to make to the schedule to explore this idea of difference.

### **3.3.2. Recruitment strategy**

Purposeful sampling was used to identify information rich accounts, in this instance, sibling pairs who had PEMD (Palinkas et al., 2015). This sampling strategy was an appropriate strategy as it sought to recruit participants with knowledge about an experience, who were available and consented, and were able to communicate their experience. Four sibling pairs were recruited to participate, including three female sibling pairs and one male and female sibling pair. It could be argued that this is a relatively small sample size. Wells (2011) purports that smaller sample sizes are suitable for narrative studies because of the rich depth of information that narrative research generates and that the attempt is not to generalise the findings to all siblings with experience of PEMD.

As the research aims to explore sibling experiences of a parent with PEMD, the following inclusion criteria were applied:



1. Sibling pairs over the age of 18 with a parent<sup>1</sup> with mental distress
2. Mental distress<sup>2</sup>
3. Siblings who have lived with a parent with mental distress
4. To be fluent in English<sup>3</sup>

### **3.4. Procedure**

#### **3.4.1. Recruitment of participants**

The recruitment process was carried out between November 2018 and March 2019 and involved several calls out for participants. Initially, an email (Appendix 4) was sent to all UK DClinPsy programmes, any forums that were relevant to the area of interest, and research interest groups. Information about the study was also shared online through Facebook groups, Twitter posts, and Instagram. Interested participants were invited to contact the researcher and at this point the participant information sheet (PIS) was sent to them (Appendix 5). Having read the PIS and contacted the researcher, participants were screened to see whether they met the inclusion criteria which involved participants sharing information about the parent's mental distress. No collateral information, such as information from the participants about their experience of PEMD or from external agencies, was collected as it was important that the participants framed the experience using their language and construction of mental distress. When inclusion criteria and consent to participate was agreed, participants were invited to provide background information about the parent with PEMD and demographic information

---

<sup>1</sup> Parental status was considered an assigned identity, independent of legal, biological or social conceptions of parenthood (Meyer, 2006).

<sup>2</sup> This was an assigned label by participants which may be understood through a diagnosis such as Anxiety, Depression, or Bipolar Disorder which caused a significant impairment at least once during the sibling lives.

<sup>3</sup> Given the emphasis on the importance of language in narrative inquiry, a level of fluency in the English language was required to participate in the study.

about themselves and their sibling. Contact was initiated via one sibling initially. Verbal consent was then obtained, and a time, date, and location were arranged for the interview to take place. Interviews took place at a location convenient to the participants and the University's lone working policy was followed to minimise any potential risk to the researcher (Appendix 6).

Formal consent was acquired prior to the interview being conducted (Appendix 7). Participants were provided with the opportunity to ask follow up questions and reminded that they were still able to withdraw from the study at this point. A debrief form was provided at the end of the interview (Appendix 8).

Demographic information was gathered before the interview and through the interview process which is detailed in Table 4 below.

Table 4: Demographic information

	Pseudonym	Age	Parent Identified as having MD	Diagnosis
Pair 1	Lana	28	Mother	Bipolar Disorder
	Shelby	28		
Pair 2	Anna	30	Mother	Bipolar Disorder, Depression, Borderline Personality Disorder
	Karen	26		
Pair 3	Aaron	30	Mother	Bipolar Disorder
	Hannah	25		
Pair 4	Jane	56	Mother	No formal diagnosis received
	Denise	54		

### 3.4.2. Collecting stories

According to Clandinin, Pushin and Orr (2007) there are three commonplaces in narrative inquiry. These commonplaces were constructed as focal points of attention when undertaking a narrative inquiry (Clandinin, Pushin, & Orr, 2007). The three commonplaces are sociality, temporality, and place and these underpin a narrative framework. It was reported that in order to undertake a NI, all three commonplaces should be considered (Clandinin et al., 2007). Temporality speaks to an event or a person having a past, present and future. Sociality encompasses the personal experience, feelings, and the social context of the individual and the

relationship between the participants and researcher. Place includes the place the interview occurs and the places within the events (Clandinin et al., 2007). The interview schedule was structured holding these commonplaces in mind, with a particular emphasis on temporality, as the researcher was interested in any transformation or change in the stories over time. Similarly, Riessman (2008) acknowledged the importance of the interview context, and participants were invited to choose their preferred location for the interview. Therefore, one of the interviews took place at the participants' home, two in a public space suitable for both siblings to access and one interview took place at the researcher's home.

The interview schedule (Appendix 9) was divided into sections that considered the co-construction of the siblings' early experiences and how experiences and meaning making changed over time. Prompts were devised; as it was felt that some of the questions were quite broad and it may have been difficult for participants to answer such open-ended questions from the outset. To ensure participants were empowered to tell the stories that were important to them, a flexible approach to the schedule was adopted. In this regard, participants were not asked the same questions in the same order to maximise a guided conversational approach and in keeping with the notion that narratives are co-constructed (Lofland & Lofland, 1984). It will be evident which questions were not covered in the following chapter which highlights the transparency about which questions were asked. All interviews lasted between 85 – 126 minutes and took place at one time point.

### **3.4.3. Interviewing sibling pairs**

I was interested in interviewing sibling pairs together as there was no literature on their co-constructed experience of living with PEMD. This process is known as paired depth interviewing and defined as one researcher interviewing two people together for the purposes

of collecting information about how the pair perceives the same event or phenomenon (Arksey, 1996). However, this interviewing style has received relatively little attention and used sparingly within qualitative research (Wilson, Onwuegbuzie, & Manning, 2016).

I was curious about whether the co-construction of the sibling experience would privilege preferred stories or elicit different stories that had not been told before. I also felt it was important to empower both siblings to share their stories. Therefore, I was conscious of how the interview process might evolve and how to ensure individual stories and co-constructed stories could be told, but also adhering to the narrative principles in allowing stories to unfold naturally. This tension was spoken about during supervisory meetings and it was agreed that my role as researcher was to facilitate the collective and individual stories by addressing a sibling if I felt that their story was being silenced. The understanding and meaning could then be considered in the analytic process.

### **3.5. Ethical considerations**

Prior to recruitment, ethical approval was sought and obtained from the University of Hertfordshire Advisory Committee on Ethics on 30<sup>th</sup> August 2018 (Protocol number LMS/PGT/UH/03356) (Appendix 10).

Narrative inquiry is a highly relational form of inquiry and therefore ethical consideration needs to be thought about throughout the process (Clandinin, 2006). Consequently, I also requested amendments to the original ethics application which were approved (Appendix 11). I will briefly set out some of the ethical considerations that were considered initially.

### **3.5.1. Explaining the research**

Participants who expressed an interest in the study were given the PIS and offered the opportunity to ask questions about the study. On the day of the interview, the PIS was provided, with the research aims explained to the participants again. Potential distress was also covered in the PIS along with services that participants could access if they felt they needed to. Participants were provided with the contact number for the researcher and email address of both the researcher and the principal supervisor. They were informed that they could contact us at any time if they had further questions.

### **3.5.2. Consent and confidentiality**

Potential participants were provided with detailed information about the study and what participation would entail in order to make an informed decision. Having agreed to take part, a consent form was signed on the day of the interview. Participants were given the option of withdrawing from the study up to six weeks after the interview took place. They were informed that after this point, their data would not be able to be removed from the study.

As part of the informed consent process, information was provided about how confidentiality would be adhered to and how personal identifiable information would be anonymised, stored, and used. Confidentiality was ensured through anonymity within the transcription process, with identifiable information being removed. Participants were also informed that either the researcher or a transcription service would be used to transcribe the interviews and that an anonymised abstract of the interview would be presented within the appendix of the final project.

A transcription service was used to transcribe two of the interviews and a confidentiality agreement was signed (Appendix 12) to protect the confidentiality of the participants. Raw data was stored on an encrypted device and all personal identifiable data was anonymised with pseudonyms provided to aid the analytic process.

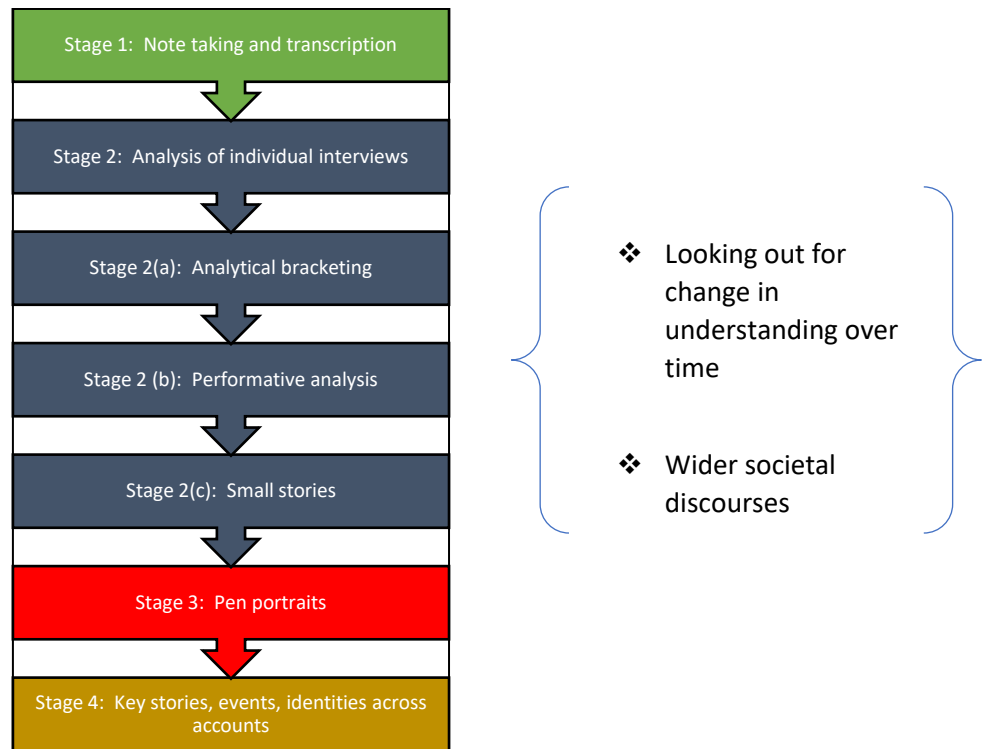
### **3.5.3. Potential distress**

Participants were siblings who have or had lived with PEMD. Previous reported experiences of children and adults who participated in research in the area have described both negative and positive experiences associated with the parent. Therefore, it was important that any discomfort or distress and awareness that the stories could potentially elicit difficult feelings were considered. Having a parent with PEMD might still be an ongoing challenge within participants' lives, for example, if the parent was distressed at the time of the interview. It might also be the first time that participants share their experiences with someone outside of their support network which could provoke feelings of anxiety. Consequently, during the ethics application process, I developed a protocol for how I would manage the distress and potential risks within the context of the interview (Appendix 13). For example, I reported that I was well placed to manage distress given my role as a therapist which can involve managing distressing emotions in a clinical context. Some of the strategies I included in the protocol involved using a calm voice and empathising with participants to acknowledge any distress caused.

### **3.6. Analysis of the narratives**

It is worth noting that there is no single procedure to analyse narratives, however; there are guiding principles that underpin the analytic process (Wells, 2011). My process of analysis was informed by Clandinin (2006), Riessman (2008) and Bamberg (2011). This

multidimensional approach has been considered to be suitable as the more viewpoints that are employed the more revealing the stories complexities are (Coffey & Atkinson, 1996). A summary of the analysis can be seen in Figure 2.



**Figure 2: The narrative analytic process**

### 3.6.1. Interview transcription

All interviews were transcribed verbatim and to represent figures of speech that were important, such as features of conversation and expressions of emotion. For example, pauses, laughter, crying, and non-lexical expressions such as ‘Mm’, ‘Uh’ and ‘Um’ were transcribed as they were considered key features of narrative performance. Two of the interviews were transcribed by the researcher and two were transcribed by a professional transcription service. A confidentiality agreement was signed by the service to ensure confidentiality.



### **3.6.2. Framework of the analysis**

It is worth noting that the process of analysis begins even in the interview stage and through notetaking and transcription (Mischler, 1991). Therefore, the initial task of the analytic process was to record my initial impressions of the interviews (Appendix 14).

Proceeding to the more formal part of the analysis, the aim was to immerse myself in the interviews, with each narrative analysed in its entirety, rather than being separated into discrete units or categories (Riessman, 2008). Narrative accounts were initially analysed employing Gubrium and Holstein's (2000) 'analytical bracketing' procedure. Analytical bracketing is described as a procedure for familiarising oneself with the data and focusing on the 'what's' and then the 'hows' of interpretive practice.

Riessman (2008) also proposed a three-tiered division of the analytic process differentiating between thematic, structural, and performative approaches to the data. 1. Thematic analysis which involves the content of what is being told; 2. Structural analysis which looks at how the stories are put together and the use of language; 3. Performative analysis which explores how narratives are co-constructed and created within the interview context. Attention was also paid to how meaning making changed over time (Clandinin et al., 2007) and the wider societal discourses (Wells, 2011) (Appendix 15 example of analysed transcript). The analytic process also involved asking who an utterance was being directed to, when and why and what was the point, and listening for small stories where identities are practiced and tested out (Bamberg & Georgakopoulou, 2008). Small stories tend to be brief and on the periphery. However, they reflect something about the relationship between the participants (Bamberg & Georgakopoulou, 2008). For example, the siblings in the current study all told a story about what they planned to do after the interview which contributed to the overall narrative of their relationship. This level

of analysis reflects the in-depth intricacy of narrative analysis, with the researcher attending to different aspects of the data at each level (Smith & Sparkes, 2009).

### **3.6.3. The analytic process**

The aim of the initial task was to immerse myself in the narratives. This was achieved through listening to the audio-recording of the interviews while simultaneously reading the transcript following the framework described above. Interviews were also listened to individually to enable the identification and review of the interaction between researcher and participants that would not necessarily be readily captured through reading a transcript i.e. tone, intonation, and cadence. Reflective notes were made alongside this. This was an iterative process with each listening and reading, becoming more immersed in the data.

Once the narratives had been read and listened to several times, a narrative ‘impression’ was written. This supported the researcher in summarizing and reflecting on key preliminary interpretations of the narrative. Each narrative was then read with the approaches outlined in the previous section.

Prominent ‘storylines’ were listened out for that spoke to the relational identities of the siblings and the events that they privileged about their experience of PEMD during the narrative. Stories were considered important by their frequency throughout the accounts or by how important the researcher thought their story was which may have been highlighted through the structural use of language and the co-construction of the meaning between participants and researcher.

Pen portraits detailing the siblings' demographic details, a summary of the interview and mind maps (Appendix 16) were written for each interview, which are described in further detail in Chapter four. This process was completed for each narrative in turn. Once all four transcripts had been analysed individually in this way, they were then considered collectively. The principal focus was on the key stories, events, and identities that had been privileged, and any areas of similarity or difference between or across the narratives.

### **3.7. Attending to quality**

Attending to quality in qualitative research is an important part of the research process and helps maintain good practices. The following section describes how the study adhered to quality guidelines considering credibility, the pragmatic use of research, and reflexivity. Additionally, I have adhered to the guidelines employed in the literature review (Elliott et al., 1999) to demonstrate the quality of the current study.

#### **3.7.1. Credibility**

Qualitative research aims to meet quality through its' design and application within the research process. In short, credible studies are those that readers feel are trustworthy to put into practice and make decisions from (Tracey, 2010). For quantitative research, credibility is measured through reliability, replicability, consistency, and accuracy (Golafshani, 2003). However, these criteria only slightly map onto qualitative research. Qualitative credibility is achieved through methods such as thick descriptions of data, triangulation, or multivocality (Tracey, 2010). Credibility is also achieved by situating the researcher and participants, using examples from the data, presenting the results coherently to aid transparency, and demonstrating general versus specific research tasks. I have sought to ensure the findings and analysis of the study are credible and highlighted how these criteria were met in the table below (Table 5).

Table 5: Self-evaluation of quality standards employed

<b>Criteria</b>	<b>Approach employed to maintain standard</b>
Explicit scientific context and purpose	Systematic literature search carried out with the rationale for the current study provided, research aims stated, and UK context considered.
Appropriate methods	Narrative inquiry employed to explore siblings experience of parental mental distress and framework followed.
Respect for participants	Careful consideration was given to ensure no intended distress was caused to participants. This was achieved through the ethics process, informed consent, and confidentiality. Additionally, consultation was sought from individuals with lived experience of PEMD.
Specification of methods	Method detailed in full, including the design, procedure, and development of interview schedule. Analytic process was also described.
Appropriate discussion	Discussion was based on findings from the study and considered in the context of current research and how it contributes to the knowledge in the area. Consideration for future studies also provided.
Clarity of presentation	Presented using conventional framework for research, including tables and diagrams for clarity.
Contribution to knowledge	Findings were discussed in relation to current research in the area of PEMD and furthers the literature about family and sibling experiences.
Owning one's perspective	Explicitly stated epistemological position and personal stance from the outset which was considered throughout the study.

Situating the sample	Demographic information provided about the participants and pen portraits written about each interview which further illuminated the participants.
Grounding in examples	All findings were supported with examples from the data.
Providing credibility checks	Supervisory team looked at two interviews, literature from the systematic review and discussed these with the researcher. Furthermore, a section of data was reviewed and compared.
Coherence	Coherence was achieved by comparing similarities and differences across accounts in the experiences of the sibling pairs, which was grounded in the data.
Accomplishing general vs specific research tasks	The research was specific in its' aims and these were revisited throughout the study. The researcher was tentative in the applicability of the findings to a more general population.
Resonating with readers	Narrative inquiry explores the retelling of participant stories in-depth and it is likely that these stories, brought to light with participant quotes, resonate with the reader.

### 3.7.2. Pragmatic use

None of the findings, analysis, or transcriptions were shared with the participants, reflecting the epistemological position that the stories were co-constructed and reflected my interpretations of them. However, participants were offered the opportunity to be sent a summary of the research once it was completed to which all participants agreed would be useful. Research findings can and should be used to form useful contributions to clinical practice and guide future research (Riessman, 2008). Implications for services and future

research will be discussed in the final chapter. The potential outcome in disseminating the research could contribute to how services are set-up to support the needs of the family. Finally, on completion of this thesis, I will prepare an article for publication in an academic journal and present the findings at a conference to ensure the research gets shared with a wider audience.

### **3.8. Reflexivity**

To demonstrate the integrity and trustworthiness of the research project, it was important to consider my own position in relation to the research topic and to reflex on all aspects of the process. From the beginning of the research process, I kept a reflective diary that recorded some of my concerns and thoughts at each stage of the process. It was also used to make notes of areas of interest for conversations with my research team that I wanted to consider. During the interview stage, I reflected on the interviews, including the process, and how each sibling positioned themselves in relation to the other sibling and to the researcher. I also considered the emotional impact and the interconnectedness of my different identities i.e. being a sibling, a daughter, and a mental health professional and the potential impact this may have had on me in my role as researcher during the interviews and the lens that I may have been drawn to in the analysis. I considered the audiences that the participants were speaking to at different times and updated the journal throughout the analytic process, making notes after each reading and listening of the interviews. An example of my reflections can be found in Appendix 17.

Supervision with my research team was also helpful in considering my position within the construction of the research and to reflect on the different stages of the process. I was fortunate to have two supervisors who were thoughtful and generous in their reflections and with lots of experience in qualitative research who similarly offered their reflections on their own positions in relation to the research or in similar research that had been conducted. I also met with peers

on three separate occasions where we considered topics such as interview structure, recruitment, the emotional aspects of conducting the interviews, the impact of how participants may have viewed us, and read each other's transcriptions offering our own interpretations and reflections.

## **Chapter 4: Results**

### **4.1. Introduction**

This section contains the analysis of the four interviews that were conducted. As previously discussed, there is no prescribed method in carrying out the analysis or presenting the findings (Riessman, 2008). Therefore, the results are presented in such a way that reflects the research aims and epistemological position of the researcher. In support of the position, the stories are considered within the socio-cultural context in which they are constructed in. Additionally, the research is interested in the collective accounts that support or challenge the ‘dominant’ stories within society concerning children living with PEMD. The researcher was also interested in the stories told by each sibling pair within the interview context and how they may have changed over time. Therefore, the analysis commences with an introduction to the participants, including demographic information, and an interpretation of each interview. It is hoped that this will contextualise the accounts for the reader.

### **4.2. Reflections on the stories**

Even though listening to people’s stories is routinely part of my role as a mental health practitioner, listening to the siblings’ stories touched me personally as they sought to convey their experiences which had a profound and lasting impact on themselves and their sibling relationships. It was evident that each sibling pair had experienced childhood stress and challenges, however, their relationships had endured, and they were able to reflect on their experiences of PEMD. While the study explored the co-construction of sibling stories of PEMD, it felt important to each participant to reflect on their experience individually and collectively and this is highlighted throughout the results.



### **4.3. Introduction to the participants and global impressions of the interviews**

To ensure participant anonymity, names have been changed and identifiable information has been removed. The demographic information presented below represents the language that was used by the participants to describe themselves and the parent with PEMD. The participants are introduced in the order the interviews were conducted.

#### **4.3.1. Lana and Shelby**

Lana and Shelby, 28-year old White British female twins originally from the North of England and now residing in the South East of England were interviewed at the home they share together. They have no other siblings and their mother received a diagnosis of Bipolar Disorder when they were aged two or three years old. Their mother experienced several hospital admissions for her mental distress. Lana and Shelby's parents live together in the North of England.

#### *Overall impression*

Lana and Shelby strongly identified as twins and a 'team' in coping with their mother. This was supported in how the interview transpired with very little input from the interviewer, almost as if a conversation was being witnessed in action. Lana and Shelby tended to speak quite quickly and softly, speaking over each other and finishing each other's stories, reinforcing the shared co-construction of their experiences. Interestingly and unlike the other sibling pairs, they gave a similar recounting of their experience, acknowledging that they had shared everything, which may have been a recognition of the twin identity. Lana and Shelby moved between the present and past which gave the impression that they were still attempting to make sense of their experience.

Lana and Shelby spoke about growing up and feeling different from their peers. They attributed this to their mother's mental distress as she sought to protect and keep them safe. This meant they were unable to go on school trips or spend time with friends:

Lana: *"...so, you don't really get a chance to go and do your own thing because yeh well we couldn't do our own thing she was quite overprotective."*

Consequently, reflecting on their childhood, they described being shy and not feeling prepared for becoming an adult, yet, also acknowledging that they felt emotionally mature because of the experience of PEMD.

Shelby: *"But I feel like weird its sort of like on the one hand we were like that very naive in certain ways but in other ways I felt like much older than other kids in other ways."*

There was a narrative about protection throughout their story. Lana and Shelby felt that their mother was overprotective towards them, yet they also felt protective of her, and very protective of their sibling relationship. Lana and Shelby described feeling protective of their mother, when as a family, they disclosed their mother's mental distress. As adults, they commented that they felt guilty discussing their mother's mental distress, despite their mother sharing her story with other people. It appeared that keeping it a secret for so long and then sharing her mental distress with others, elicited guilty feelings, which they felt could result in a judgement or criticism from others, highlighting the societal discourse of stigma and distress.

Shelby: *"We're quite protective of our mum of like not wanting them to think she was*

*weird or [bad]...*

*Lana: [felt a bit torn about it] you know, because I just, you want to tell people it's going to be kind of like intense because now she finds social interaction like quite difficult and she's kind of intense but she's lovely."*

They also spoke about being protective of one another; replicating the world that was created for them as children and constructing a sense of unity and protection against the world.

Lana and Shelby described a very close sibling and twin bond, with Shelby identifying as the younger twin by a minute. They talked about growing up together, sharing everything and being treated equally by their parents, which they reflected had helped their relationship. They spoke about a period in their lives where they did not live together; and this appeared to be a difficult time for them as they transitioned from adolescents to adults. Lana and Shelby used language such as being a 'tag team' and 'this little like tight unit' when describing how they looked after their mother, reflecting that communication was crucial in keeping their relationship as close as it is. Their notion of a tag team could be seen in the ways in which they finished each other's sentences in order to convey their shared experience in the interview.

Lana and Shelby also described a very close relationship with their mother, which at times, meant that they were hyper attuned to her moods and acted as advocates on her behalf with other family members and mental health professionals. While this led to feelings of frustration, there were stories of pleasant memories and of their mother being a good parent which highlighted the close bond they had with her. The twins appeared to be a strong protective factor for their mother, and they told of times when she was proud of them and of who they have become.

Shelby: *“...and really encouraged us to do whatever we wanted which is really nice. So there’s a load of things she’d be really good about and when she was actually like, you know, because she never wanted to be, she always wanted to be a really good mom.”*

#### **4.3.2. Anna and Karen**

Anna and Karen, 30 and 26- year old White British female sisters, living separately in the North of England at the time of the interview. Both siblings work in healthcare. The interview took place in a library room in Manchester.

Anna and Karen have a biological mother, Deirdre, whom they lived with until they were ten and five years old respectively. They described their mother as receiving a diagnosis of postnatal depression after Anna’s birth and subsequently she received a diagnosis of Manic Depression. More recently, a diagnosis of Borderline Personality Disorder was given. Anna went to live with her father after the marriage broke down while Karen remained living with her mother for a couple of years, until her mother left with their stepbrother and did not return. Anna and Karen then both lived with their father. Their father subsequently remarried Sarah, a woman who also had a diagnosis of Bipolar Disorder, whom they both described as neglectful. After this relationship ended, their father married Laura, a woman who also experiences mental distress, whom they refer to as their mother. Their biological mother Deirdre and Sarah received input from mental health services and had periods of inpatient admissions.

### *Overall impression*

Anna and Karen's story evoked a sense of incredulity in what they had experienced, and it was also striking to hear how the sibling relationship had survived and thrived. Anna and Karen's account was punctuated with laughter especially at difficult parts of the story, which appeared to serve a helpful function in helping them retell their story.

Anna and Karen's strongest sibling narrative was the change in their relationship over time in the context of very difficult and chaotic experiences. Anna and Karen told a story rooted in chaos, reminiscent of Frank's (1995) chaos narrative in which individuals have no control over life events and therefore making it difficult to understand them. The language the sisters used to describe their experiences of PEMD was filled with terminology such as feeling 'scared', 'frightened', and 'unsafe' which highlighted their shared struggle. Anna identified herself as the 'big sister'; speaking more resolutely about their experiences which was supported by determined language and a tone that contrasted Karen's quieter and slower tone and occasional whispers. At times she tended to tell Karen how she felt in situations which had taken place.

Anna and Karen both described a 'violent' sibling relationship when they were younger with Karen reflecting "that we mainly tortured each other". They both felt that Anna stepping into a parentified role had created conflict in their relationship, which was further exacerbated when their stepmother would play them off each other. Anna stated that:

*"...then when I got to the point where I had to parent you that's when I just lost my rag with it."*

Karen also agreed that she did not want Anna to adopt this position and recognised that the

blurred boundary was confusing for her:

*“I don't remember feeling much towards you in all honesty and I know that sounds awful but like you were the person that was cooking me dinner, but also to be annoying.”*

Despite this, they both acknowledged times they supported each other when they were younger with Karen reporting:

*“I remember there being some phases like we used to play like teacher and student and you used to draw out little worksheets because I just loved like doing Maths and stuff like that and you used to like design them and we used to play a little bit.”*

Anna and Karen recounted how close they were now as adults and attributed the change in their relationship to becoming peers and growing up. It also appeared that getting to know one another outside of the family home had helped them foster a mutual appreciation and a different way of relating to one another. Karen commented:

*“...this is probably the first time that we've ever spent time together and only time that we would of spent time together was on the family holidays, but we'd have gone and done our own thing but because I'd come up to visit you can't exactly go off and read a book.”*

Their close relationship was underlined in the way they spoke conversationally and faced each other. Both Anna and Karen would often look and speak to each other, checking facts, and

filling in gaps in their stories. I wondered how important the success of their relationship was to them, given their struggles, and in helping them share their story with me. The idea of the quest narrative (Frank, 1995) supports this idea and their narrative that although they had a challenging early relationship, there was a positive outcome because of their experience.

### **4.3.3. Aaron and Hannah**

Aaron a 29-year old and Hannah, a 24-year-old, White British brother and sister, from the South East of England were interviewed at the researcher's home. Aaron and Hannah described having a middle sister Clare, 27, a father and mother at home. Aaron and Hannah's mother received a diagnosis of Bipolar Disorder at the age of 40 after several years of experiencing mental distress resulting in several inpatient stays.

#### *Overall impression*

Aaron and Hannah marked their story by the 'episodes' and 'situations' that their mother experienced with her mental distress often resulting in the story lacking chronological coherency. Aaron appeared to be conscious of the purpose of the interview and often brought the stories being told back to the original question of the interviewer. Aaron also referred to himself in the second person, using the pronoun 'you', when discussing how he reacted to situations that occurred in the context of his mother's mental distress. Hannah, on the other hand, told stories based on memories of their mother's behaviour which appeared to be a helpful strategy as it provided a distinction between their mother and the behaviours and enabled her to retell her story. There were moments of laughter and sibling joking that conveyed to the audience how they might be in their family environment.

There were clear roles for the siblings in their accounts with Aaron clearly positioning himself

as ‘the parent’ and ‘the man of the house’ who took on the main share of responsibility when their mother became unwell. Hannah supported this narrative and reflected on how helpful it was to have Aaron “step up” and to have been there for the family. Hannah acknowledged that she had more freedom in the early stages of their experiences as she did not adopt a similar role to Aaron which was attributed to her role as the youngest member in the family. She told a story of being able to be more preoccupied with her own day to day activities:

*“I was probably a bit more like free. Not really focusing on what was happening with mum. I was aware of what was happening, but I wasn't really focused on. Didn't really want to understand I guess, and I think with Aaron it's like straight away he had to step in.”*

Hannah spoke about taking Aaron’s place in being the parent and supporting their mother after Aaron left to go to University. Hannah reflected that she felt that she had been there for all their mother’s ‘episodes’ and seemed to attribute her presence in some way to their mother’s distress. Aaron commented how moving away from the family home to go to University had been a difficult transition for him and how he had to learn to let go:

*“I suppose I had to kind of let go a bit. Once everything was okay, then there was an element of that just like okay I don't need to come back every weekend.”*

There was a narrative of a strong family identity throughout the account. Both Aaron and Hannah spoke about the close family relationships they have with each other and with other family members. They talked a lot about working together to help their mother and having conversations about what to do, with communication being particularly important in them



forming a close relationship. They commented that their close relationship was very much a result of their mother's mental distress as they had to trust each other, an acknowledgement that they had all been through the experience together and the respect that had been fostered as a result of their experiences. They had a shared narrative which was performed through supportive language and utterances of agreement.

Hannah and Aaron also discussed having a sibling code, a shared language, that they and their other sibling would use when speaking about their mother, catching precious moments to check in with each other, enhancing the alignment they felt as siblings. They also used terminology about their mother, describing her as someone foreign, which appeared to help them separate the mental distress from their mother's identity. Aaron and Hannah spoke about their other sister Clare frequently which gave the impression that she too was very important in the story, however in a different way. They both considered that Clare might not have been able to take on the role they both adopted however Hannah spoke about Clare supporting her when she was younger. Aaron and Hannah shared the view that when they were able to reflect on their experiences with humour within the family a good outcome had been reached.

#### **4.3.4. Jane and Denise**

Jane, a 55-year old retired Public Servant, and Denise, a 52-year old Mental Health Professional, originally from the North of England, met with me at a public library in Nottingham. They have no other siblings. Both their parents had passed away in 2016 and 2017. They spoke about their mother who had experienced mental distress. Although their mother never received a formal diagnosis, Jane and Denise believed she experienced anxiety, panic, episodes of depression and paranoia throughout their lives.

### *Overall impression*

Jane and Denise's story was interlaced with grief having recently lost both parents and consequently the interview context was fused with emotion. Denise spoke for Jane at times, when she felt too tearful to continue speaking. Denise also became tearful during the interview and they were both offered breaks. Jane and Denise described a rural upbringing, brought up by their mother and their father who was away a lot. They reported having a loving and close relationship with their mother, whom they described as overprotective and possessive. Their story, punctuated by events, was portrayed through laughter and tears.

Jane and Denise spoke about their mother not being aware of or acknowledging her own mental distress. They appeared to think that their mother was unable to confront the mental distress, as it was potentially too difficult for her to deal with.

Jane: *"...but she hated I think maybe you...[PAUSE] not tuning into it but what's the word? Being caught out."*

They also talked about how they did not know their mother experienced mental distress until they were much older. Denise reflected that despite her role as a mental health professional, she did not recognise any signs until she was older as the sisters revealed that it had become their version of 'normal'. Their story spoke to the lack of awareness or discussion around mental health for that generation and the discourse that mental distress did not exist. This appeared to contribute to feeling confused and angry about what had occurred, with Jane feeling particularly angry when recounting their mother's lack of awareness:

*"...and then that, not being, not being able to, in my mind for her to not to be able to*

*recognise it, that was irrational made me very angry (sniffles). ”*

Jane and Denise’s story was marked by differences in how they are and were as siblings in the context of PEMD. As children, the sisters described differences in how they coped with PEMD. Denise spoke about cutting herself off from what was happening around her, making recollection at times hard. Jane talked about wanting to know everything that was going on, describing herself as “the eyes and ears”. She spoke about leaving home when she was a teenager as she could not cope living at home, and she reflected she had transformed away from the family. Jane became tearful recounting this as she felt she had abandoned Denise.

As they grew up, Jane spoke about trying to provoke a reaction from her mother to help her make changes or to help their mother see that some of the behaviour was irrational. Denise felt that she would often be left to deal with the fallout of this provocation. Jane and Denise spoke about trying to help change circumstances for their mother but acknowledged an acceptance that their mother would not have done anything differently if she had received mental health support.

*Jane: “[Yeah] we did everything. I lived with her, I, I, I lived with my mum, I didn’t do it because I thought ‘Oh I’d better live with my mum’, I did it because [pause] I loved her. And I wanted, wanted [crying] wanted her to have nice days.”*

Jane tended to describe herself as overt, aggressive, and more assertive when supporting her mother, whereas Denise described herself as the peacemaker, and a quiet and calm person. Jane and Denise spoke about having a complex relationship, identifying times when they were really close with Jane reflecting that Denise had been her world as children. Jane told how they had

shared a bedroom with each other until Jane was approximately 14 years old, despite having their own bedrooms, which felt important for the audience to know about their relationship. When Jane moved out, they talked about a change in their relationship and not spending time together as they established their identities outside the family home. There were also times in childhood where there was much rivalry which had spilled into adulthood with them admitting that they have this game they play with each other to provoke a particular response. This brought to light the discourse around sibling competition. While they both acknowledged the complexity of the relationship, they also reported to being very close and told how they speak every day. They reflected that their differences may have contributed to the closeness of their relationship.

Jane: *“It’s very, Denise and I love each other that’s no doubt you know that’s without question you wouldn’t have to you know question that. We are, we have a very complex relationship.”*

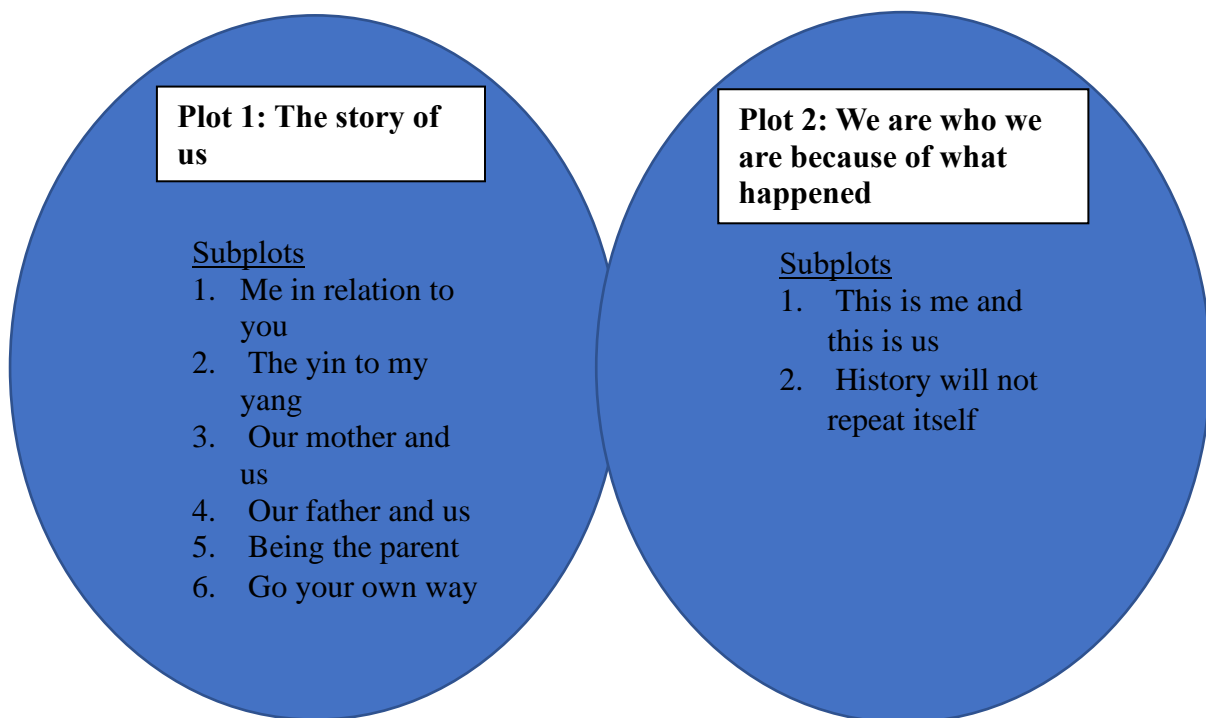
Denise: *Yeah well. Whereas-People say we’re very very close and in some respects we are, but because we are so very, very different.”*

#### **4.4. Emerging storylines**

The following section describes the researcher’s interpretation of the emerging stories across the four interviews, including the similarities and differences, enabling a construction of broader storylines, in keeping with the research aims and methodology. In particular, there was an emphasis on the emergence of key storylines in relation to sibling relationships and identities in the context of PEMD and the emotional experience of the storylines. Additionally, all of the interpretations of the storylines and identity construction are considered within the local and

broader context in which the stories were co-constructed, reflecting the epistemological position of the researcher.

Two main plots were identified from the data, *The story of us* and “*We are who we are because of what happened*” which was a quotation from one of the participants. Within these, there are subplots that bring to light the main plots that the data referred to (Figure 2). These will be discussed in further detail in the following sections.



**Figure 2. Plots and subplots**

#### **4.5. Plot 1: The story of us**

The plot *The story of us* reflected the co-constructed story of the siblings as they grew up in the context of PEMD and the wider societal discourses of mental distress at the time of childhood and later in adulthood. Unsurprisingly, given the title of the research and questions in the interview schedule about their relationship, this plot emerged. Nevertheless, the siblings were keen for their story to be heard. Despite the joint sibling narratives, the participants also wanted

to put forward the differences in their stories, reflecting some of the individuality in themes within the subplots, and at times telling their story to the other sibling as a way of informing them about their individual experience. Five subplots were identified as part of the plot.

#### **4.5.1. Me in relation to you**

Stories of identity formation in relation to the other sibling were clearly spoken about throughout the accounts. Siblings can directly influence the development of the other and play a role within the family structure, for example, by holding a favoured family niche or by diluting family resources (McHale, Kim, & Whiteman, 2006). The co-construction of these identities appeared to be in response to the PEMD, in relation to the sibling, and also formed outside of this experience. The recognition of the identities was framed in familiar concepts that did not appear to be exposing for the other sibling.

In the story of Anna and Karen, Anna clearly positions herself as older sibling the one who takes the role of ‘big sister’, with Karen’s consensus, and there is a tacit agreement that certain characteristic assumptions come with being a ‘big sister’. This role has been maintained throughout their relationship.

*Karen: “I think you keep a role maternal role still a little bit like not take over as in I push you towards the leader role a lot to take charge make decisions.*

*Anna: Yeah, I'm still big sister aren't I, and I still organised things because I know you don't want to and stuff.”*

Anna’s role as the older sibling was evident throughout their account of how they grew up together. Anna tended to perform the ‘big sister’ role during the interview, placing herself in an expert position within the story and Karen performing the role of the younger sibling. In

this regard, at times Anna would comment on how Karen was feeling at the time of a particular event and provide examples of when, as children, Anna would make decisions on their behalf.

*Anna: "Yeh to be honest I don't think that you really wanted to go did you? But I just thought we should do it once and see how you feel."*

Anna's assertive tone of voice contrasted with Karen's soft-spoken approach, which highlighted their different roles.

Similarly, Aaron and Hannah talked about the older sibling role and Aaron's identity as the older sibling. Aaron described his role in 'stepping up' and taking a lead on things to do with his mother and siblings. Kelly (1994) identified certain genres that underpin most narratives including the heroic genre. Aaron's use of a heroic narrative when conveying his role within the family provided him with an identity that he maintained during the interview, telling stories of how he tried to prevent anyone from 'triggering' their mother. Aaron appeared to position himself in this way in order to minimise the emotional impact of his mother's hospital admissions and to help him cope with the senior role he adopted with his two sisters, Hannah and Clare.

*Aaron: "Em when, so after my mom started getting, or our mum started getting sick em she was, she spent a lot of time just lying in bed just like, I kept saying zombie it was but she was just lying in bed. So I think that changed the dynamic of the house as a whole. Mm where Clare maybe just kept herself to herself, em that didn't really change but there was there was a bit of stepping up I think, where previously the household chores and stuff would be shared my dad would take the load of that I think so he would where I maybe took a bit more of the the, I don't know the role as the parent in dealing with situations..."*

Hannah acknowledged how helpful it had been to have an older brother who helped them cope with some demanding experiences and supported the performance of the heroic narrative told by Aaron.

Hannah: *“You don't you probably didn't realize what you I don't know you were just very very supportive.”*

Aaron: *hmm*

Hannah: *Very very very good older brother, role model.”*

Hannah spoke about her ‘stepping up’ after Aaron left to go to University however she did not fully feel able to take on the role and would regularly contact Aaron to provide him with updates and seek his advice which Aaron conceded was important for him in feeling connected to the family, and maintaining the heroic narrative. Both Anna and Aaron performed this older sibling role through their interaction with their siblings at the interview, placing themselves in an expert position. Anna and Aaron asked their younger siblings questions during the interview process shifting the dynamic of the context and appearing to move towards a family homeostasis. It was important for Anna and Aaron to be perceived as the older siblings as it validated the sacrifices and responsibilities that they had adopted and portrayed them in a positive light which contrasted the reality of their situation growing up.

Lana and Shelby, because of their twin identity, did not have clear roles in relation to each other, however Lana was identified by the family as the older sibling. Lana contextualised this by describing how Shelby was smaller and more fragile when they were younger. Their



account spoke to the societal discourse of being the younger sibling and reflects the cultural need to classify hierarchical family structures.

Lana: *“Now mom and dad look at me as the slightly older one...”*

Shelby: *...but you've always been seen as that the older one.*

Lana: *Yeah...*

Shelby: *...one minute.”*

Despite the family narrative, Lana and Shelby very much co-constructed a shared and equal experience. They recounted how their mother tended to reach out to them individually when looking for a certain response or need to be met. Neither Lana nor Shelby positioned themselves as the ‘older’ sibling in terms of taking responsibility or ownership in situations which was evident in the two accounts above. In this regard and previously mentioned, they mirrored their equal partnership by finishing each other’s sentences and in the way they described their relationship with language such as ‘merged’ together. This appeared to be important for them at this particular point in their relationship as they had spoken about having difficult times recently.

Conversely, Jane and Denise talked about the family order within their relationship with Jane recounting how from a young age she felt older than her age. However, this was not in relation to being Denise’s older sibling or in how support was provided to their mother. Jane talked about the construct of age in terms of feeling mature and older, which enabled her to go to bars and be treated more like an adult. Contradicting the socio-cultural discourses of being the older sibling, Denise mentioned that she felt that she had been the more mature and responsible sibling, which Jane agreed with. The disruption in the family order appeared to have influenced their relationship, with Denise remaining at home to support their mother. Interestingly, this

dynamic had been maintained and was brought to light by Jane in the opening interaction as Jane talked about deferring to Denise on her recent career decisions, akin to a conversation one would witness a couple to have. Similarly, Denise tended to take over when Jane became overwhelmed and appeared to have a more coherent narrative about her story, performing a hierarchical sibling structural interaction.

Denise: *“Em and sometimes, although I’m the younger sister there’s been situations where I’ve had to, em, be the responsible- err.. [be the].*

Jane: *[Very much so]*

Denise: *I’ve had to, err take charge of [situations].”*

Denise acknowledged that she did not bear any resentment towards Jane for the role that she took in the family. Nevertheless, Denise employed negative language at times towards Jane and referred to her by name which created some distance in the relationship within the context of the interview. The recognition that Denise bore a lot of the responsibility for their mother and within their relationship appeared to have created tension, with them reflecting that they have a very complex relationship, which differed to the other sibling accounts. It was evident that their relationship had endured some difficult times, which they both wanted to convey to the audience, and it seemed important for Denise to convey this message to Jane also through the occasional use of negative and impersonal language.

In the counter narrative to the older sibling identity, it was apparent that the siblings identifying as the younger sibling had a different role and understanding of the story. Karen, Hannah, and Jane seemed less assured of their understanding of PEMD which was demonstrated by hesitations and incomplete sentences. This may have been as a result of age and not comprehending what was happening at home when they were younger, or they might have been

adequately protected by the older sibling. However, it may also be explained by the concept of sibling de-identification whereby siblings decide to adopt a different position to the other sibling within the family to protect themselves from social comparison, rivalry, envy and possible resentment (Whiteman & Buchanan, 2002). In this regard, these siblings may have decided to take a more distant role to minimise competition and therefore their understanding was less clear.

The need for the siblings to create a family hierarchy and structure based on socio-cultural discourses around family roles was in contrast to the chaos narratives told by the siblings in relation to PEMD.

#### **4.5.2. The Yin to my Yang**

The siblings all discussed the ebb and flow of their relationship reflecting on times of closeness and distance and being similar and different. A common story also acknowledged the changing way in which the siblings related to each other as they got older or as different life events took place. Three of the sibling pairs told a story of how close they were as children with Aaron asserting that his close relationship with Hannah was a direct result of living with a parent with PEMD.

Aaron and Hannah discussed their close relationship in terms of belonging to a sibling club and having a secret language when they wanted to talk to each other. They recalled this shared experience through corroboration and joint construction of sentences, speaking over each other, replaying the excitement of the secrecy they may have experienced as children and the sense of pride that they were able to do this.

Aaron: *“I think we became quite clever at sending messages to each other.”*

They also valued having conversations together “in the loft” as a means of catching up about how things were at home and checking their understanding of what was happening with each other. This was performed in the interview as Hannah and Aaron checked their understanding of their experiences with each other.

Lana and Shelby also described feeling like they were closer and similar than other twins and siblings because of their experience and reported being a “tight little unit” and feeling merged together when they were children. This was conveyed using the pronoun ‘we’ and the co-construction of them being ‘shy’ and ‘odd’ as children. The language used helped the audience identify the pair as different from others and the same as each other, therefore convincing the audience of their merged narrative. They clearly had struggled with their shared identity as they got older and Lana told a story of changing her hair as an adult to ensure they were viewed differently. I felt it was an important part of their story, negotiating the feeling of being merged to independence, that they wanted to acknowledge in the interview context.

Jane and Denise discussed the changing nature of their relationship from childhood to adulthood. Jane talked about when Denise was born and reflected that Denise was “my world”. She spoke about how she slept in with her mother and Denise for a long time wanting to be close to Denise. Jane performed this in the context of the interview, positioning Denise in a more knowledgeable role by directing questions to her about their sense making. There was some uncertainty as to whether their relationship was like other sibling relationships given their experiences of PEMD and how they related to each other as children and now as adults.

Denise: *“[Some], some people don’t make- aren’t as involved with their sisters and brothers as much, so you will have relationships where they’re extremely close and that’s always been or you might have brothers and sisters that maybe see each other twice a year or something or, or who are not as involved in everything everything, so I would say [ours is]*

Jane: *[We’re very]*

Denise: *[Is slightly] different, I don’t know if it is different from other people because of how we’ve been brought up I don’t know*

Jane: *Mmm*

Denise: *This sort of, what’s the word, I want- don’t want to say enmeshed, what’s that word?*

Jane: *No it is, it’s for me wanting to be, its wanting to be involved with Denise’s [life]...”*

The close relationships were aided by good communication skills, trust, forgiveness, respect, having each other for support and helping each other cope with some of the challenges. Communication felt like an important component as to why the siblings had been able to navigate their experiences of PEMD. This will be discussed in more detail later.

The story of difference was evident throughout the accounts. Three of the four sibling pairs spoke about their experiences of PEMD being different from each other. The question ‘how was your experience similar or different?’ was asked to three sibling pairs and not to the twins as their account had been a co-constructed account of a shared experience. The main reasons provided for this was the role that the sibling adopted in the story either willingly or through an enforced need, and a sibling not being around for a particular event. For example, Aaron

and Hannah described having a different sibling experience in the context of PEMD because of Aaron's role, which was shaped by their mother's mental distress. Hannah reflected that because of Aaron's age and position in the family when their mother had her first episode, she was able to be more childlike and freer whereas Aaron had to take a responsible role at the time. They both commented that there were some similarities as Hannah adopted a more active role in relation to their mother after Aaron left to go to University.

Similarly, Anna and Karen acknowledged that they also had a different account, reflecting that they still do not really see each other's perspectives although they had been able to overcome this difference and form a close sibling and friendship bond. Anna appeared to have experienced frustration with Karen, as Karen would get them into trouble with her behaviour as she struggled to understand the rules of their situation. Anna appeared to speak to a ghost audience of them as children when reflecting on this, using language like 'hated you' and 'annoying', words usually associated with a younger developmental stage. Denise and Jane were at odds as to whether they had similar or different experiences with Jane reporting that their experience had been the exact same. Denise did not agree with this appraisal and acknowledged that while their experiences had been the same, the way in which they both had reacted to the situations had been very different.

Both Aaron and Hannah, and Anna and Karen made sense of the differences as age-related. Karen and Aaron also felt that the differences were related to different personality styles, with Jane and Denise presenting clear assertive reflections on their differences through the repetition of each other's attributes. Aaron also proposed the structure and dynamics of the family made things different for each of them.

Aaron: *“...age. I think just generally the family dynamic like older brother middle sister younger sister. Em I suppose I was I had more closer than an adult relationship with Dad. So I we dealt with that I think because Dad in some cases wasn't able to kind of step up and naturally I would so I suppose there that's hierarchy or the the family dynamic that played a part is suppose of personality traits I have a tendency to take on quite a bit and just deal with it so there's that aspect of it. We are quite similar in that respect.”*

### **4.5.3. Our mother and us**

The accounts had a central focus on the relationship with the parent with PEMD, in this study, the mothers of the children. Active voicing techniques were employed by some of the narrators to illustrate their mother's behaviours. This enabled an emotional distancing between them and their mother which helped them tell their story. Aaron and Hannah employed language such as 'foreign' and 'alien' when discussing their mother's mental distress, which introduced the idea that it was something unusual and disturbing to them and their family by evoking an image of their mother as a foreign person in their house. While Anna and Karen had a somewhat different relationship with their mother, in that, they did not spend a lot of their childhood living with her; the other narrators grew up living with the parent with PEMD.

Reflecting on and attempting to understand the experiences elucidated a lot of challenging and conflictual feelings for the sibling pairs as they discussed their mother. On the one hand, three of the sibling pairs talked about the love they had for their mother growing up and as adults, however this was complicated for some of the sibling pairs. Jane and Denise and Lana and Shelby described their relationship with their mother as very close and commented that their mother tended to worry about their safety and wanted to protect them from the world which resulted in them not having normal childhood experiences. The pronoun 'my' and 'hers'

conveyed the closeness of the relationship. Jane reflected that she and Denise were their mother's world, while Lana and Shelby talked about their mother who "clung really tightly". All the sibling pairs talked about frightening and tough experiences when their mother was experiencing symptoms of distress, which felt confusing and hard to make sense of.

Hannah: *"...you were having loads of work so I think for me, I didn't, at some points I was like crying down the phone just like screaming and then you were like, I remember this one time I spoke to you and I was like Aaron I'm scared, I don't like it and you were right I'm leaving."*

The confusion was compounded by the lack of conversations around mental distress, which was exacerbated by the limited societal discourses of mental health at the time. This confusion was demonstrated in the context of the interview in incomplete sentences by the narrators. All the participants talked about the lack of conversations that occurred about their mother's mental distress as children. Explanations provided by the siblings included the fear of the children being removed from their families, a lack of awareness of mental distress, and wanting to protect their younger siblings. The idea that they were their mothers' protector was highlighted by some of the sibling pairs appearing to be on the look-out for any unusual signs shown by her. This vigilance served as a protective function for the children and enabled them to respond accordingly.

Denise: *"But it was very derogatory. Erm, and, em. So, you don't want people to talk of her in a bad way, [do you know what I mean?]"*

The lack of conversation permeated to wider family members with some narrators reporting



that they felt family members knew of their mother's distress yet maintained a silence around it. This appeared to create a silent shame that the young children internalised and felt guilty about when they did want to talk to friends or family about their mother's mental distress as the stigma and shame lingered.

Shelby: *"...this is my mom's got bipolar and...it is that thing of guilt about don't want to colour someone's perception of her."*

Additionally, at least one of the sibling's in each pair talked about not understanding what was happening to their mother and the impact that had on them.

Jane: *"My understanding was that I couldn't understand, I. I didn't understand (whispers), I didn't understand the irrationality, I was very aggressive about it, I was very overt, I'd swear at her, I'd throw typewriters down the stairs, I've even pushed her down the stairs, I've assaulted her."*

This lack of understanding on Jane's behalf had created intense angry feelings and behaviour as a young person and an aggressive relationship with her mother. Jane appeared exasperated during the interview, reflecting on her own and her mother's behaviour, which was evident by incomplete sentences. Jane appeared remorseful of how she had responded and addressed the ghost audience of her parents and sought assurances and checking out with the interviewer, through the use of rhetorical questions e.g. "that sounds awful?" The guilt of criticising their parent was evident through rhetorical questions to the interviewer and following up a criticism with a compliment, demonstrating the conflictual feelings they had experienced. However,

they also invited the wider audience to consider a different perspective on maternal mental distress by telling stories of enjoyable times spent with their mother.

All the narrators appeared to have moved from a place of blame or confusion about the parent with PEMD to an acceptance of the experience and of their mother. This seemed to have required a lot of emotional labour and meaning making with their sibling, which appeared to be an ongoing process for three of the four sibling pairs as Karen and Anna demonstrated when reflecting on their biological mother.

*Karen: "I'm not sure because I still don't think I know Deirdre's story."*

*Anna: I really struggle with it because I don't understand where it's all come from like I think because I know about borderline personality disorder, it's a thing and it's often comes from trauma and it often comes from certain experiences and I'm like, I just don't see that in what I know about her. I just don't see any of these things you might expect to see with someone that behaves in that way so that makes me feel like I don't get it and it also makes me just a bit."*

Anna and Karen, despite cutting contact with Deirdre, addressed her during the interview, which reflected the complexity and enduring bond of a mother daughter relationship. The acceptance of what had happened was also aided by having conversations with each other and friends and a greater understanding of mental distress at a societal level.

*Aaron: "Yeah, I suppose I've got quite close friends that have depression or have had depression or have depression and so friends and family that are going through other difficulties with mental health and mental health conditions help em because it makes you realize that it's you're not the only one and it's and just reading about it."*

The construct of the mother is a powerful ideology and reaches deeply into the lives of individuals and family processes shaping women's identities (Arendell, 1993). Unsurprisingly given the portrayal of motherhood culturally, both Denise and Jane and Anna and Karen referenced their mother as being different from other mothers, perpetuating the dominant discourse that poor maternal mental health does not support the wider ideology. Despite this, the narrators also spoke about wanting to protect their mother from any perceived criticism from other agencies such as school or social services reinforcing the societal narrative that a parent with PEMD may have their children taken off them by services by the very existence of mental distress.

#### **4.5.4. Our father and us**

All the accounts talked about the other parent who did not experience mental distress. The accounts described the impact that their mother's mental distress had on the other parent reflecting that their mother's distress impacted the marriage and caused conflict at home. Furthermore, the accounts spoke about the siblings' relationship with their father in that context.

*Shelby: "...so he would sort of just get really angry and just start throwing stuff around and being quite physically and they would argue quite a lot and then I think sort of seeing that when we were young and sort of trying to deal with it was quite weird (laughs)."*

Additionally, the sibling pairs reflected that they could not recall their father being around when they were smaller. Jane and Denise talked about how they believed that their father knew they were looked after but that he had to work. Similarly, Anna and Karen and Shelby and Lana spoke about their fathers working a lot and not being at home.

*Anna: "I think it was hard for Dad to sort of keep an eye on it I think as he was just working so much. Dunno how he stuck it out to be honest."*

The absence of their father created a distant relationship with him when they were younger which contrasted with the very close relationship Lana and Shelby and Denise and Jane had with their mother. There was recognition from the siblings, as they got older and understood more about their mother's distress, how difficult it had been for their father and an appreciation of the reality of the situation. It appeared, in Lana and Shelby's case, that the understanding had created a new way of relating to their father that had not been present when they were younger.

All accounts talked about the conversations or lack of conversation they had with their father and how they felt their father did the best he could do in the context of PEMD. Strategies that helped the siblings included being able to talk to their father about what was going on and using distraction techniques when their mother was not feeling well as illustrated by Aaron and Hannah's account. Anna talked about having a very close relationship with her father and appreciated how much he did to minimise the impact of PEMD by taking them on holidays or allowing them to spend time with other family members.

*Anna: "So I think that Dad did his best to make sure we weren't there as much because they weren't those awful times of both of us have sort of found her after she's made an attempt and stuff and that's obviously horrendous."*

It appeared that being able to talk through what was happening at home with the other parent

helped the relationship and helped the siblings understand more about what was going on. Denise and Jane and Shelby and Lana talked about how their father had a different perception of their mother's mental distress, which made it difficult to have open conversations with him. Jane became exasperated when reflecting on his awareness of their mother's distress, with the tone of her voice becoming louder.

The fathers appeared absent in the emotional care or support they provided their children which resulted in them being peripheral characters within the context of the interview. In particular, the interviewer asked a direct question about the father as the relationship had been absent from conversation. The absence of the father offered support to the discourse around gender roles in parenting and the dominant discourse that mother's do more of the parenting. The siblings tended to be cared for by another female relative such as an Aunt or Grandmother in Jane and Denise and Anna and Karen's account, reflecting the gender bias in caregiving. In contrast, Hannah and Aaron talked about how conversations brought about a closer relationship with their father similar to Anna and Karen's story.

Aaron: *"...and particularly with me and my dad as well, that through that that we became incredibly [close]*

Hannah: *[Mmm]*

Aaron: *and I think he's needed that as well because he sometimes is quite distant."*

The fathers were portrayed as men who did not talk about feelings and were hard working. Three of the sibling pairs identified themselves from a working-class background, which

seemed important in how they made sense of their father being absent at times.

Shelby: “...he was very like quite macho quite not very emotionally like aware or emotionally intelligent necessarily...”

The portrayal of fathers’ in the interview spoke to the socio-cultural ideas of fatherhood and gender for the siblings. Fathers were conceptualised as men who worked to provide for the family while the women raised the children, speaking to the provider role of men in society. This invited the interviewer to consider whether this had been a helpful way of making sense of their father’s role and absence.

#### **4.5.5. Being the parent**

The siblings spoke about not having a ‘normal’ family life or childhood. The use of the word ‘normal’ in the four accounts highlighted their sense of feeling different from others and the isolative effects of their experiences.

Jane: “*But it’s only when you grow up and become an adolescent or you mix more, that you realise...*”

In particular, the siblings talked about not having a childhood and having to grow up sooner than they may have wanted to. There were contradicting narratives of having to be a responsible young person, adopting a parent role, and the recognition that they were unable to be children at home, with stories about going to other people’s houses or when their parents were away and being able to be children and play which were valued greatly.

Karen: *“I used to go on lots of family days out with other families I’d just be the weird tag along [Anna: laughs] like it was just really nice just being part of that like and everyone was comfortable and like I dunno just felt normal, and I remember being at a friend’s house and I’d hear the doorbell go and then, I remember that it was Sue or Dad picking me up and I would feel this horrible drop in my stomach, I’d have to go back to my life now [laughs].”*

Denise spoke about how she would view other children getting upset when going on school trips and think to herself “get a grip” as she felt very differently when she was away from her home, evoking a sense of false maturity that she may have embodied as a child to help her cope.

Additionally, each sibling pair talked to the concept of parentification. The roles that were adopted by the participants ranged from providing practical or emotional support to siblings and their parents, talking to mental health professionals about their mother, and being advocates and advisors for the other parent. For Anna and Karen, the parentified role adopted by Anna created conflict in their relationship when they were younger as Anna positioned herself as a parent for Karen.

Anna: *“I was in charge basically, Matt had gone to America, I was, had to parent you Dad worked all the time. So, I was basically your mum.”*

Anna performed this role during the interview, taking a more authoritative role towards Karen which may have prevailed since childhood. Karen recalled feeling angry towards Anna for her role. While Aaron clearly positioned himself as the ‘leader’ and ‘responsible’ sibling who

advised his father and was a confidante to his mother, this did not appear to elicit any conflict with Hannah who readily praised Aaron for the role he took in supporting the family. Hannah reflected that she too had taken on a parentified role when Aaron left. However, she looked for guidance from Aaron when this occurred.

Hannah: *“So when you went off to University, that was when I think I had to step up and then I still felt myself though I still I still found myself on the phone being like Aaron what do I do?”*

Aaron welcomed this as it appeared, he felt guilty that he was unable to be there for the family after he moved out. Lana and Shelby told of being very close to their mother as children and providing care to her, which made them feel they were able to deal with difficult situations.

Shelby: *“...growing up with mom as well like so we were always like very close and I think we definitely I definitely feel like I took on this which is like I’m fine and I can look after her she definitely gave us a lot of reinforcement like you two are so good and you are [so like]*

Lana: *[understand]*

Shelby: *you are the only ones that understand me and things like that so we took it on feel better yeh.”*

This dependence by their mother and their position as her protective factor placed a lot of responsibility and burden on them. They reflected that it had stopped them from becoming



more independent and having adolescent experiences as they were conscious of not causing any further distress for their mother.

Shelby: *“It would have been really dramatic really horrible so there's like that weight of like consequence of like your mum's feelings that I think definitely kept us in check but it's quite a frustrating thing.”*

While this was a consequence of parentification, there were other implications from adopting the parental position. For example, Shelby reported that she felt emotionally mature as a child however both siblings did not feel that they had the social maturity to cope with the outside world, as they got older due to their lack of freedom in childhood. Similarly, for Anna and Karen, Anna acting as Karen's parent, caused tension and confusion for Karen and resentment for Anna that she had to take on this role.

Despite adopting an adult role at times, Anna and Karen and Jane and Denise also spoke about having no control over what happened to them as children because they were children. Jane had often gone to the pub when she was younger to buy alcohol for her mother however this is in stark contrast to feeling like she had no control over the situation. The feeling of having no control over the situation was evoked by emotive language such as feeling 'traumatised', 'frightened' and 'scared'.

These identities formed in relation to each other and performed in the context of the interview were an important part of demonstrating to the audience a sense of pride in their resilience and ability to adopt a mature role when they were younger. However, there was a strong sense of not having control also because they were children that reflects socio-cultural norms of the power structure of the parent-child dyad and ideas around children lacking autonomy. This tension of being mature yet not having control appeared to cause difficulties when they were

growing up which will be discussed in the following section.

#### **4.5.6. Go your own way**

Sibling relationships, some of the longest relationships that one will have in their lives can change over time (Whiteman et al., 2011). This was evident in all the accounts as the siblings negotiated life transitions from living with each other to spending time apart. The older sibling, except for Lana and Shelby, left the family home first because they were going to University or to protect themselves from the impact of PEMD. Anna and Karen's story was interspersed with times when they were together and times when they were apart. In the early years their separation was a consequence of their parent's divorce as Karen chose to live with her mother and Anna chose to live with her father. When they came to live together again, they spoke of the tension this created as they negotiated their new roles and home life situation. Later, as teenagers, Anna reflected that they did not spend time together and attributed this to being teenagers and being independent from each other. Their relationship appeared to change when Anna went to University and left the family home. Anna recounts that their close relationship has only developed recently. Karen felt that spending time together when she went to visit Anna in University was the first time that they had ever spent time together where they were able to sit down and talk and find things out about each other.

*Karen: "You had to spend time with me, and I don't think we'd had that, so actually when we sat down, we were like oh we actually have a lot in common. We actually can talk about things and we had never bothered to have done to do that before."*

*Anna: No and I guess there's a freedom that you get from being outside of the family home is that you got to see me with all my mates living independently and being who I was."*

Lana and Shelby also talked about moving out of home for the first time and living independently from each other. They described it as a very difficult time for them and their relationship as they negotiated the separation and learnt to be different outside of their twin identity. Shelby spoke about the challenge of then living together again and the realisation that they had changed. Lana recounted how she had shaved her head so that they would look different which felt significant to retell in the interview context.

Shelby: *"...[laughs] like so it's sort of like, we're really happy to come back together and still am*

Lana: *[yeah yeah]*

Shelby: *massively [but it]*

Lana: *[different person]*

Shelby: *but it's just different and we have got to get re used to it."*

Aaron and Hannah talked about the transition of Aaron going to University. Both Aaron and Hannah found this a challenge as they adopted new roles outside and within the family respectively. For instance, Aaron talked about finding it hard to settle into University life, reflecting that he experienced anxiety, and felt guilty for not being at home to help his siblings and family. Aaron appeared to find it difficult to cope with the change in his role as 'man of the house' to a student and commented:

Aaron: *"So I would phone for a catch-up maybe twice three times a week or you'd phone me, so we just make sure I was fully aware here."*

Hannah also talked about the change in her role as the baby sister to taking a more responsible role as she ‘stepped up’ when Aaron left. Both Aaron and Hannah talked about their relationship now and with their sister Clare and felt that they have an unusual relationship in how much they keep in contact and enjoy spending time together. They spoke about this as something that they were proud of.

Jane and Denise also spoke about the time they spent apart. Jane reported that she would spend nights away at the age of fourteen as a way of coping with her situation at home. In contrast, Denise remained at home till her late twenty’s. Denise talked about how she understood Jane’s decision to distance herself from the family however Jane felt guilty for leaving Denise at home, which Jane conveyed in the interview, expressing her disdain if Denise had done this to her. Denise felt that being on her own enabled her to become more independent.

The change in context and separation appeared to create some ruptures however it also enabled a different way of relating to each other that had not been in existence when they shared a living space. The stories of being together and separating and then telling their story together within the context of the interview conveyed to the audience the importance of their sibling relationship framed within a quest narrative (Frank, 1995). It appeared that the sibling pairs were informing each other and the audience they are there for each other.

#### **4.6. Plot 2: “That’s made us who we are if you know what I mean”**

Research which considers the link between life stories and adjustment demonstrate that narrators who find a redeeming understanding from adversity, and who construct stories that feature themes of personal agency and exploration, tend to enjoy higher levels of mental well-being, and maturity (McAdams & McClean, 2013). There was a common narrative across the

four accounts about whom the siblings have become in adulthood originating from the context in which they grew up. Additionally, they had a good understanding of their sibling relationship and how that has been shaped by their shared experiences. The narrators also spoke about not wanting to become like their parent and the measures and resources they have drawn on to ensure that mental distress is not a significant presence in their lives. These subplots will be explored below.

#### **4.6.1. This is me and this is us**

Each sibling has developed an identity, both personal and professional, in adulthood that was borne out of his or her experiences. For example, Shelby spoke about how she is studying to become a mental health professional. Similarly, Anna and Denise are also working in mental health, which seemed to be an important part of their story. Karen talked about how she has entered the healthcare profession even though there were challenges associated with the career due to her experiences of maternal mental distress. Jane recounted how she worked in the public sector, as she needed the discipline.

*Jane: "...well I always say one of the reasons why I joined the XX, I joined the XX, cos I only adhere to discipline, I need discipline if I don't have discipline, I, I, I need that discipline in my life, and I obviously did as a child but this extrovert I made, I made myself the centre of attention I know that."*

Five of the eight participants had entered or were entering professions where helping the public were at the forefront of their work. The experiences they had as children, caring for and supporting their parents, had shaped who they were, and it seemed that it had led them into a profession that replicated the roles they had taken. The impact of living with a parent with PEMD had transposed from their personal identity to their professional identity, which could

be viewed as useful in their professional identities. The mental health language employed by some of the participants when discussing their experiences reflected the dual identities of being a child of PEMD and their professional identity.

I was conscious also of my role as a mental health professional which potentially elicited these narratives in this context with some participants performing within their professional identity during the interview. The success of the participants countered the socio-cultural narrative of children of PEMD as being some of the most vulnerable and at risk, as the siblings told a different story about themselves.

The siblings also demonstrated beliefs about who they were as individuals in adulthood. This was conveyed through statements such as 'I am'. For example, Denise reported that "I am a peacemaker". The siblings were keen to emphasise who they are now and introduced other characters to their stories such as boyfriends, husbands, and peer groups to portray the transformation in their life stories. The audience felt that this was important to the siblings in the context of what they had spoken about when growing up to convey the change in their lives. The introduction of the characters and events such as going on holidays and getting married support the wider societal views of how success is measured and the influence of societal norms. It also supports the concept of resilience for these individuals in being able to overcome stressful life events.

The siblings privileged their relationship with each other as adults. Drawing on the quest narrative (Frank, 1995), Aaron and Hannah and Anna and Karen told of the special relationship that they have now in adulthood as a consequence of the experiences they went through.

Similarly, Lana and Shelby described their relationship as being close and considered it was closer than other twin and sibling relationships.

Shelby: *"...with them, with us I think it's made us closer*

Lana: *than other twins*

Shelby: *than other twins than probably most other siblings."*

Jane and Denise also described a relationship that was characterised by speaking to each other daily. They understood the special nature of their relationship and attributed it to being good communicators, which they deconstructed as being transparent with each other, which was something that had developed over time.

Denise: *"Em, I think we're quite open with each other...*

Jane: *Very*

Denise: *... and we [say*

Jane: *very.*

Denise: *We say it as it is and, [Jane: laughs] erm, so I think sometimes though, erm, I don't- I don't know we do talk and we say it as it is, and we go over things. Em, em, yeah I don't."*

Aaron and Hannah also talked about how communication and having a shared experience enabled the close relationship that they now enjoy as adults.

Aaron: *"I feel like we had the kind of this understanding and respect for each other that helped foster a much closer relationship and we could communicate better, understand each other a bit better, and I could probably wind you up of little bit easier. [Yeah,] we we have quite unique relationship and a really quite a healthy one I think em...*

Hannah: *Yeah I think it's established now to the point where we're just loving and caring*".

Anna and Karen reiterated the idea that their shared experience had fostered a sense of closeness in their relationship that would not have existed because of their unique experience.

Karen: *"...I also think it brought us closer because you'll be the only person in the world that understood what I went through because you were there..."*

Anna: *...yeah, I think now it means that I can talk to you about anything because like you just know all."*

Some of the siblings felt protective of their sibling even in adulthood and felt the need to look out for them. In particular, Denise spoke about talking to Jane daily and this being a lifeline for Jane who lived on her own. Humour was also an important component of the relationships and being able to share a joke, and laugh about difficult times, which was evident in the relationship during the interviews through moments of humour and laughter.

Narrative analysis considers the rationale for why stories might be told at a particular point in time. Each pair seemed to have a different reason as to why they wanted to share their story and for parts of the interview they appeared to be telling their story to each other. The audience felt that it was important for the siblings to tell their story within the context of the interview as they had a strong belief in who they were and who they were in relation to each other.



#### **4.6.2. History will not repeat itself**

Due to living with a parent with PEMD, the narrators were very conscious of the idea that mental distress runs in families with the potential for them to experience their own mental distress. There was a determination about not repeating the experiences they had with regards to their own mental distress, which was conveyed by language such as Anna's below and through the vigilance that Lana and Shelby and Anna and Karen attended to each other's well-being.

*Anna: "I've just always thought that it's so inevitable that we were going to be mentally unwell, I've always just thought that was written in in our genetics and I was absolutely not gonna let that happen."*

Aaron talked about the idea that he had some of his mother's "behavioural traits" which he observed. The siblings narrated stories of not wanting to experience what their mother had, and this had made them more vigilant about their own well-being entering into adulthood. The siblings appeared to want to inform each other in this context that they would support each other and that it was permissible to have difficulties of their own. This theme spoke to the medical discourse of the genetic vulnerability of families and the risk of children of PEMD experiencing their own mental distress.

Despite some of the participants working in the mental health field, there was confusion still about their mother's experience and disbelief, which was evident in the often fractured and non-chronological retelling of the stories. This story invited the audience to consider how hard the experiences had been for them as children and even as professionals working in the field. There was also a determination not to experience mental distress which made the interviewer

consider how even as mental health professionals, there can still be stigma associated with mental distress.

Seven of the sibling's spoke about accessing therapy for their own issues, with some of them speaking about their own mental distress. I wondered whether, given my role as a therapist, the siblings unconsciously felt this was important to mention and acknowledge the benefits in helping them understand their experiences. Anna was the only participant to talk briefly about the therapist while the others briefly alluded to accessing therapy. It made me consider broader issues around therapy and how therapy is framed for those accessing it, as the audience felt that despite the acknowledgement of having therapy, the conversation did not develop further, highlighting a silence around the topic. This may have been that the narrators believe that therapy is perceived negatively or perhaps the rationale for receiving therapy was not clear to those in receipt of it.

Lana spoke about having bouts of low mood, and Aaron and Denise spoke about anxiety while Jane talked about having traits similar to her mother. Additionally, one sibling was about to commence therapy, which highlighted the importance of having their own space to consider what had happened.

Denise: *"It's more spoken about but also we've accessed counselling."*

As a result of some feelings of inevitability around intergenerational mental distress, some of the sibling pairs had also put in preventative measures to minimise the likelihood of any further distress. For example, Lana talked about staying away from drugs which she perceived might contribute to the development of mental distress.

Lana: *“...yeah it like put me off all that kind of stuff at massively.”*

Karen reflected that herself and Anna have been “very proactive with our mental health” and use each other as a resource, checking in with each other, if they think one of them is experiencing difficulties.

Anna: *“...that’s cause of that, and I feel like we can support each other in that way because we can see the little nuances in our behaviour our own kind of mental health difficulties.”*

Likewise, Shelby and Lana also spoke about recognising symptoms in themselves and supporting each other through their own mental distress.

Shelby: *“...we know what it would look like if either one of us started being like that. Those were essentials that I can and there was a feeling of like I’ll be able to see it in myself if I start getting ill just so surrounded by it.”*

A lot of the language used by the participants in talking about the prevention of mental health difficulties reflected current societal discourses around mental health and medication, which had helped the participants look after themselves and prioritise their own well-being. In this regard, some of the siblings talked about speaking to their friends more openly about their mental well-being and drawing on the resources available to them such as counselling services within educational settings. The siblings appeared to position themselves as advocates for less negative attitudes towards individuals with mental distress within their personal contexts and the reframing of their position also seemed to contribute to their well-being. The siblings also viewed medication as being helpful for their parents and some were of the view that they would

take medication if they needed it, acknowledging the prevailing medical discourse around distress.

This concludes the results section of the study and the findings will be discussed in the next section.

## Chapter Five: Discussion

### 5.1. Overview

At this point, it is worthwhile revisiting the research aims set out in chapter two before presenting an overview of the findings. The overarching research question was:

*How do siblings living with a parent experiencing mental distress construct the meaning of their relationship and the experience of PEMD?*

The study also sought to explore whether the sibling relationship is affected and how it is affected by having a parent with PEMD. The study looked at the factors that contribute to a positive or negative sibling relationship and what prohibits and facilitates conversations among siblings with PEMD. The research findings for each of these aims will now be summarised.

#### 5.1.1. Making meaning of the experience

The narrators recounted stories of confusion and a lack of understanding of what was going on when they were young, in particular this was evident in the subplots *Our mother and us* and *Our father and us*. The confusion and lack of understanding of the situation seemed to be in line with their developmental stages as children which has been highlighted in earlier studies (Mordoch & Hall, 2008). Some participants described having a very close relationship with their mother and sibling, which elicited behavioural changes in the siblings to help support the parent. There was a shared sense among participants that when they were younger, they had little control over the situation, however this contradicted a story of feeling emotionally mature and being viewed as a responsible young person due to the roles that they adopted in the family. As the siblings grew up, there was a shift in their sense making in how they understood the experiences. They described knowing that their parent had been different, and it had not been

a normal experience, yet it was their normal. This was described in the context of, and exacerbated by, silence within the family and societal stigma.

Talking about their parent's distress as adults elicited feelings of guilt, which was heightened by the love they felt for the parent and wanting to convey their parent positively. These findings have also been reported in other studies (e.g., Murphy et al., 2015). In the subplot *Yin to my Yang*, most of the siblings shared an understanding that although each sibling had lived through similar events, their individual experiences as young children had been different from each other. This was reflected in and appeared to be influenced by the positioning of the siblings and the role that each person adopted within the family system. The finding sheds new information on the sibling experience of PEMD.

The parenting narrative featured throughout the stories with narrators reflecting on how they were parented compared to others. They also reflected on the absence of their father during childhood. These narratives spoke to wider societal narratives such as the 'disengaged father', 'the normal family' and 'the mother figure'. These narratives support dominant discourses on gender-based roles in society such that the father is seen to be less present in the parenting of the child as they are out working, whereas the mother is the main primary caregiver. These role and gender distinctions around caregiving also contribute to the ideology of a 'normal family' and this was referred to by the siblings as they felt they had not experienced a normal family life. It would be interesting to explore whether these discourses feature in a sample of young children today given the slight shift towards more equal gender roles. Furthermore, at a societal level, conversations about different family roles and ways of being a family would be helpful so that families not considered the norm can also feel validated within their family system.

Experiencing serious mental distress has been shown to negatively affect an individual's ability to parent (Akerson, 2003) but it is possible, with adequate resources, that many individuals are able to successfully care for their children (Akerson, 2003). There were conflicting narratives about the parent's ability to parent with stories told of times when the narrators' mothers were unable to provide care for them but also times when they were. According to family systems theory, family members are part of an interactive, interdependent network in which the behaviour of one individual or subsystem affects the others (Minuchin, 1974) and therefore the impact on the family subsystem in the absence of a parent will be discussed below. Furthermore, parenting is culture-bound, characterised in many cultures by parental rights and child duties, in contrast to parental responsibility and children's rights (Göpfert, Webster, & Seeman, 2004) which spoke to the narrators' accounts of being children, having duties and a lack of control over the situation in which they were in. In the UK, there has been a shift in how families are viewed with legislation reflecting parental responsibilities and children's rights (e.g. The Children's Act, 1989). These findings might reflect the context that the young siblings were growing up in however it may also suggest that PEMD may disrupt this social norm.

### **5.1.2. The sibling relationship**

The narrators told stories about their relationships and the impact of PEMD. The relationships with each other were dotted through both plots as they reflected on their relationship during childhood and in the present. Some of the siblings were more resolute in stating that their relationship was the way it was because of the context in which they grew up and affirming a shared sibling identity. All of the pairs described having a close relationship with each other in adulthood. For one pair, their close relationship felt complicated. As children, the narrators

told varied stories about their relationship. For two sibling pairs, their sibling identity had been less fixed and cohesive. In this regard, they reflected they had a tumultuous childhood relationship because of the position they took in relation to the experiences of the family and the PEMD. However, there were counter narratives and some narrators indicated that they had always been close.

These results support previous sibling research outside of the PEMD field, purporting that sibling relationships are emotionally ambivalent and can be warm as well as conflicted (Deater-Deckard et al., 2002). Dunn (1992) noted that sibling relationships could be highly adaptive to stress in family life, whereby siblings can become closer and more supportive in the face of major life events such as parental illness, hospitalisation, and unemployment, although day-to-day stress is linked to more negativity in the sibling relationship. Previous sibling research demonstrated that the intensity and frequency of positive and negative interactions decrease as children get older (Buhrmester & Furman, 1990; Dunn & Deater-Deckard, 1999; Hetherington, & Clingempeel, 1992) which also appeared salient within the current study, and data suggests that the quality of the sibling relationship is stable from middle childhood into adolescence (Brody, Stoneman & McCoy, 1994). This was somewhat different for some of the narrators in the current study as there appeared to be conflict in middle-childhood and older age which had changed over the course of time indicating that living with PEMD differed from other family stressors such as marital conflict. This appears to be a significant and specific finding from the research.

The sibling relationships were affected by PEMD as individuals recounted the roles and positions they took in the family as was needed, which was referred to in the subplot *Me in relation to you*. Structural theory purports that a family can be defined as functional or



dysfunctional based upon its ability to adapt to various stressors which also depends on the subsystem boundaries and the organisational characteristics of the family at any point in time (Vetere, 2001). For the siblings, the structure of the family subsystems had been disrupted, with some siblings adopting a parental position, and some of the narrators talked about being enmeshed with the parent experiencing distress and their sibling. Enmeshment is characterised by psychological and emotional fusion which can lead to problems in independence and psychosocial maturity (Barber & Buehler, 1996). In *Go your own way*, most of the sibling pairs narrated the separation from each other as a troubling time as they navigated their independence away from each other and their family.

Additionally, family subsystems are characterised by hierarchical power, with the parental subsystem at the top. Mixed subsystems and uneven power hierarchies create dysfunctional families (Minuchin, 1974). At least one of the siblings in each pair adopted a responsible role in helping the family and looked out for and protected the other sibling. These siblings tended to perform the role during the interview, portraying a sense of ‘precocious competence’ (Aldridge & Becker, 1999) when retelling the additional responsibilities they took on as children. It appeared that when one sibling took an affirmative position of action, the other sibling took a position that balanced this, maintaining a sense of homeostasis, and potentially mirroring the parental system. It has been reported that older siblings may feel responsible in becoming the ‘man of the house’ or suppress feelings when there is a crisis (Aldridge & Becker, 1999) which was characterised in some of the stories. The change in the hierarchical power structure within the family had negative implications for the sibling relationships. In this regard, siblings reported the challenge of separating from each other or remaining at home. Furthermore, when one sibling adopted a parentified role, the role had created conflict for the sibling pair and the role appeared to have endured into adulthood and become an important part

of their identities.

Accordingly, parental roles can become part of a child's identity and can be enduring for a lifetime with core beliefs such as 'I look after others' (Byng-Hall, 2008). Adopting caring roles for family members is an important part in developing caring skills and empowering a child if the tasks are age appropriate and culturally relevant (Byng-Hall, 2008). However, the way in which this role is assigned is an important factor for the sibling relationship. Therefore, the role should be assigned by parents in front of siblings as it is assumed that this minimises any resentment towards the parentified child by other siblings, for example, being perceived as a bossy sibling (Byng-Hall, 2008). Other features, such as age, influence who is to be drawn into which role and roles can be taken on by other siblings over time, for example, a younger child may take over as the other siblings leave home (Byng-Hall, 2008). In the current study, the parentified child tended to be the older sibling, supporting the correlation between age and role. Furthermore, there appeared to be an expectation about the roles the siblings performed both when they were younger and in adulthood, in the context of their parent's distress and within their relationships with each other, which supports the theory of family scripts whereby individuals may feel pressure to perform a role or become identified by others as taking on these roles (Byng-Hall, 1995).

The co-construction of "very close" sibling identities and the individual identities in relation to each other and as children of PEMD reinforced the narrative that their relationship had survived and thrived some challenging and stressful life situations. This story seemed particularly important to tell in the context of the study and contradicts the dominant discourse of children with PEMD as being the most vulnerable and at risk which supports the thinking that other determinants may exacerbate risk and vulnerability other than mental distress.

### **5.1.3. Factors that contribute to a positive or negative sibling relationship**

Factors such as individual characteristics, coping strategies, communication styles and the connection between siblings, the perception of the role that the siblings took with each other and in the family system contributed to the quality of the relationship. The narrators provided varied accounts of their individual characteristics however these were framed in the relationships that they had with each other and other family members and were discussed throughout the plots. For example, Jane described herself as aggressive and Denise described herself as calm and these characteristics had endured in adulthood. Brody (1998) spoke about the impact of individual characteristics contributing toward sibling attitudes and interactions with each other, highlighting how difficult temperaments were connected to difficulties in sibling relationships, which could be intensified by the effects of stressful family circumstances. However, it was somewhat beyond the scope of the current study to explore this. Nonetheless, there appeared to be conflict in some narrators' accounts of their relationships on account of the individual characteristics of the siblings.

The sibling pairs appeared to cope with PEMD quite differently from each other. The strategies adopted by siblings varied from taking a parental role, as discussed in the subplot *Being the parent*, and protecting the other sibling, to using distraction techniques as children to help cope with the stress. Later in adolescence and adulthood, there was an acknowledgement that becoming more peer like and decentering the sibling role had helped maintain the closeness of the relationships for a number of the siblings. The sibling pairs had appeared to cope relatively robustly with the stressors associated with PEMD. Not only were they able to draw on their own resources, they were able to demonstrate resilience and respond positively to adverse conditions.

Foster, O'Brien, and Korhonen (2011) introduced the concept of family resilience which considers problems as being influenced by individual, family, and socio-cultural factors. Family resilience acknowledges the strengths and resources within a family and the bonds and connections as being central in overcoming adversity which can be a fluid and dynamic process over time (Foster et al., 2011). This concept emphasises the relational aspects of families and the relational processes that enable survival and growth. It appeared that interconnectedness and communication enabled the resilience that was evident in some of the narrators' accounts. Nonetheless, caution is required as narrative inquiry states that the stories told can only be connected to the particular time and context in which they were told and therefore, the quest narrative (Frank, 1995) may have been an important story that the siblings wanted to tell in this context. The accounts also did not involve all family members perspectives and therefore, conclusions cannot be drawn on the wider resilience of the families.

#### **5.1.4. Having conversations**

All narrators reported not speaking about the parent with PEMD with each other when they were young. They cited that they were unable to understand what was going on at home and therefore not able to verbalise it, which made the situation feel confusing. This finding was supported by previous research reporting how children of a parent with PEMD do not receive enough information about their parent's mental health (Gladstone et al., 2011). This lack of information and communication around PEMD created confusion and feelings of being scared and frightened. Some of the narrators also reported internalising the parent's distress as their fault. The silence around their mother's distress at wider family occasions and having to make up excuses resulted in the narrators feeling isolated from the wider family, not feeling understood, and a sense of shame around their mother which appeared to remain into

adulthood.

The parent with PEMD was also portrayed by some narrators as being in denial about their mental distress which evoked feelings of frustration and disbelief compounded by the lack of conversations with the absent father. This further created a sense of the topic being off-limits that prohibited the siblings from talking together about PEMD. For one pair, they were able to have conversations about their mother which they constructed as helpful as this appeared to be in the context of their father also demonstrating a more open communication style. Open communication patterns whereby individuals are able to share and express their emotions contribute to family resilience in overcoming challenging life events (Oh & Chang, 2014).

In adulthood however, conversations with each other and external people became easier which was reflected in the subplot *This is me and this is us*. The siblings spoke about becoming more open with family and friends which was supported by their own increased awareness of mental distress and the wider societal discourses which helped contribute to a more coherent conceptualisation of their experiences. Families have been identified as linguistic systems and problems can be framed as a result of talking about each other's actions and beliefs (Dallos, 1997). Therefore, the language employed to talk about problems is also important in sense making. For the narrators this resonated as they tended to describe their parent's distress by the observation of the behaviours and the actions they took. The study demonstrated that as new ways of talking about the parent's distress were introduced their perspectives changed.

## **5.2. Implications for clinical practice**

The current study was undertaken to explore and understand sibling experiences of PEMD. By carrying out the research, the researcher hopes to highlight the importance of including family

members and the children affected by PEMD and to make some further recommendations for clinical practice. These suggestions will be explored in the following section.

### **5.2.1. Clinician level**

The research identified that the absence of conversations about the stress at home resulted in a lack of understanding about what was going on which appeared to exacerbate the feelings of worry and confusion for the siblings. Furthermore, all siblings felt that they had no control over the situation. Therefore, these are areas where clinicians can be of influence. It is important for clinicians working with young people to consider inquiring about their parents and whether they experience mental distress, as this has been overlooked. Working in a Child and Adolescent Mental Health Service (CAMHS) currently, this is something we have introduced in the assessment phase in the hope to elicit more open conversations about the impact of PEMD.

Including this information in the psychological assessment acknowledges that having a parent with PEMD may contribute to a child's emotional difficulties and mirrors transparency for the family when discussing PEMD. Additionally, it is crucial that clinicians in adult services become more open and curious about the impact mental distress has on parenting and to acknowledge the effect on children which has been demonstrated by the increased funding into perinatal mental health in the last five years (Mental health taskforce, 2016). While services are stretched, these seem relatively inexpensive and effective practices that can be implemented at the individual clinician level.

Some participants talked about the absence of mental health professionals from their parents' care or not feeling included in the care, despite the responsibilities they had within the family.

Stigma and the fear of removal of the children from the parent's care were also identified in the narratives which may lead to a reluctance by parents in disclosing the seriousness of their distress. As mental health professionals, it is a core responsibility of the role to explore these worries and provide information that is helpful to the family in their meaning making of the experience. Providing a child with insight and knowledge into PEMD is a key resilience factor within the literature (Riebschlager et al., 2017). While the participants talked about very difficult times, they also provided stories of good parenting which disputes the dominant narrative of PEMD. These accounts are powerful and may help other families experiencing similar challenges. How this may be achieved will be considered shortly.

### **5.2.2. Systems level**

Widening out the thinking to include the systems involved in supporting children with a parent with PEMD, all participants talked about immediate family members, members of the wider family, peers, and the systems involved in their care such as education, and mental health services. The narrators identified a helpful member within the system who supported them during stressful times. It would be worthwhile to consider exploring these wider family support systems as individuals that can be invited into the family system as additional resources to help support both the young person and the parent with PEMD.

The educational system also plays a crucial role in supporting young people with PEMD. Some participants spoke about being supported by a teacher and how important this person was in helping them make sense, while others spoke about their disbelief that teachers did not notice that something was wrong. There has been increasing discourses about the role the education system plays in the mental well-being of young people, with mental health practitioners and well-being 'hubs' becoming more common in schools than when the participants were in

education. This has been in response to the reported rise in mental distress among young people (NHS Digital, 2017). Despite this, schools are under pressure to produce academic performances which can mean that adequate mental health support is not provided. Schools and teachers need to be encouraged to prioritise mental well-being and ensure that conversations are taking place at school that recognise both adult and young people's mental health. Additionally, there is a role for psychologists in providing consultation to teachers and further joint working with schools to develop this as a priority.

With respect to mental health services, family inclusive services where appropriate should be encouraged. It should be considered normal practice to invite family, partners, and other support for this population to encourage a systemic approach and to reduce the localisation of the distress within the parent. It is also worth considering more joined up working between CAMHS and adult services to support families and reduce the risk of these children not being identified as having PEMD while also drawing on the expertise across both services. Furthermore, families should be encouraged and supported to get involved in participation of services at a number of different levels. For example, consultation, decision-making around the interventions delivered, attending conferences, and sharing learnings from their experiences with services where commissioners and MP's are present can have benefits for the family, and other families in a similar situation, in terms of feeling empowered, providing support to others, and working together.

### **5.2.3. Societal level**

The epistemological position of the research is informed not only by the relationships between participants but also that knowledge is culturally and socially bound (Harper, 1995). Participants told stories of a lack of understanding about mental distress and how this changed



as they got older. This may have been informed by their developmental age. However, given the changing social discourses around mental distress, it appears that this also contributed to the understanding and meaning making of their experiences. Psychologists have an important role politically in highlighting the factors that may impact on the well-being of a family, such as chronic stress resulting from marginalisation, poverty, and austerity policies. This may be achieved by raising awareness of the links between mental distress and poverty and advocating for increased financial support for these families. Furthermore, the political uncertainty has impacted on services nationally resulting in the removal of community centers for families and integrated care for those most disadvantaged which are needed now more than ever. It is the researcher's position that psychologists should be having these conversations at a policy level, using their training to bring awareness, and acting to ensure families needing support are best served on a political level and receive services that minimise the impact of distress.

### **5.3. Methodological Considerations**

Transparency and reflection on the strengths and limitations are important aspects of the research process. Research is rarely seamless and identifying limitations can help contextualise the findings while also proposing future research in light of the limitations and further contributing to the knowledge base.

#### **5.3.1. Strengths**

A main strength of the current study is that it explored the storied experiences of siblings with a parent with PEMD which had not been carried out previously. The study enabled siblings to construct their meaning-making together and sought to elucidate some of the factors that contribute to a good relationship and communication in often challenging situations. Qualitative research can be theoretically generalisable in so far as relevance outside the

participants in the study can be generated. Green (1999) proposed two questions when reflecting on how useful the research has been.

1. Has the research made me think differently about my practice, or the motivations of the participants?

This question was answered in the implications for clinical practice section which identified potential areas for change.

2. If this report is about a different client group, or a different community, are the general ideas relevant to the community within which I work?

Question two speaks to theoretical generalisability. The findings from the current study supported previous findings in the area of PEMD and added new information to the knowledge base on PEMD and siblings within the PEMD literature which could be applied to different groups.

### **5.3.2. Limitations**

The role of the researcher plays an important part in the construction of the research. The researcher's dual role as a therapist based in mental health settings may have influenced the research, as the researcher too leads a storied life which can be seen as a strength and limitation of the current study. For example, the participants were cognisant of the researcher's dual role as a therapist when they told their stories consequently the story was shaped by the audience and the context in which it was told (Mischler, 1991). However, it may have also enabled participants to share their story without feeling judged.

The telling and retelling of the data may have detracted from the storied lives of the participants

(Trahar, 2009). Andrews (2008) states that for narrative researchers the interpretations of the data are always from the position of how the researcher views the world. The researcher was aware of this dilemma and sought to minimise the bias through reflexivity and reflection in supervision with peers and supervisors and using a reflective diary throughout the process.

The study included a small sample and therefore, this limits the generalisability and conclusions that can be extrapolated. The study would have benefitted from a larger sample and this may be an area for future exploration. The sample were drawn purposively and the siblings who agreed to participate may have been more able to reflect and articulate their experiences and may not represent stories told by other siblings with PEMD. Furthermore, most of the participants had engaged in talking therapy with may have meant that they were more insightful as they had been able to tell their stories and attribute meaning to them. Additionally, parental diagnoses were reported by the participants to the best of their knowledge however, this was not supported by collateral information or clarified independently by the researcher as diagnostic labels do not fit with the researcher's position. Therefore, the diagnoses attributed to the participant's parents may or may not be representative. Recruitment within the PEMD field is notoriously hard however recruiting through NHS Trusts may have brought other stories to the fore.

The siblings told their stories together which may have facilitated an honest account or may have acted as a barrier, potentially with one sibling within the pair disclosing more or less of their truth. For instance, in the Anna and Karen story, Anna appeared to be the expert of the story and it made me consider whether Karen wanted to add to the story and whether there was an opportunity for either sibling to bring a different narrative to the accounts. Furthermore, in two stories there was another sibling in the family who was absent from the interview and both

were storied as individuals who had found it difficult to cope with their parent's mental distress. Potentially the participants who had come forward were those who had been able to reflect and make sense of their experiences in order for the stories to be retold.

Credibility in narrative research involves the consideration of what is privileged in the interview schedule and reflecting on whether the person would have told a particular story if they had not been asked that question, encouraging scrutiny on the methods employed. The current study presented a transparent account of the interview schedule, so it is possible that the structure of the interview influenced the narratives that were reported and those that remained silent. Although the researcher took this into account within the interviews themselves through reflexivity, reflective journals and supervision, nonetheless, the questions asked of participants are likely to have influenced the narratives that were constructed. Finally, given the emphasis on language within NI, participants who were fluent in English were eligible to take part in the study. Therefore, the study does not consider alternative cultural discourses that may exist among siblings with PEMD.

### **5.3.3. Suggestions for future research**

As there were no studies carried out in the area previously, the researcher felt it was important to broadly explore the sibling's experience of PEMD including their stories growing up and as adults. Stories around their childhood identified the difficulties in recollecting events from childhood as adults. The participants in the current study ranged in age from 25-58 and therefore the developmental stage at which the impact of the parent with PEMD varied for participants, which may have contributed to the understanding and the relationship with the sibling. Furthermore, given the range in ages, societal discourses may have changed for participants which could have affected the meaning making and the stories told. Therefore, a

potential area for future research would be to explore young siblings experience of PEMD to elicit more detailed information from a younger sample within this population.

In keeping with the epistemological position of the researcher and the recognition of the multiplicity of reality. A future study could involve inviting all family members to explore the sibling experience of PEMD as the researcher was struck by the absence of the voices of the parents and siblings and was curious about what their stories might be. It would be helpful to consider interviewing siblings separately and then together to enable stories of the individual and the pair.

Ackerson (2003a) identified that a parent with PEMD regarded the bond between their children as strong, mutually interdependent, and especially close which was reflected in stories in the current study. A future area of investigation could further explore this bond, considering the constructs of enmeshment and examine the factors that may determine a close, healthy bond. The research on siblings lacks a coherent model to understand the relationship in times of stress and any research in the area could help create a more unified construct that could contribute to helping families with PEMD.

#### **5.4. Personal reflections**

Throughout the process, I have endeavored to reflect on the experience of carrying out the research, my position, and the siblings who participated in the study. First and foremost, I felt compelled to honor the stories shared with me as they told stories of success and adversity. However, there was a tension between sharing their stories yet also holding in mind the aim and rationale for the project. This meant that I may have asked particular questions or did not explore areas that the siblings may have wanted to explore further. This tension also resurfaced

during the analytical process and making decisions on the lens and position I took with the data, while attending to my role as a professional, researcher, therapist and sibling in the construction of the stories. Interestingly, all the sibling pairs commented that they thought they were going to cry while retelling their stories which made me reflect on the challenge it may have been for them to participate in the research.

This process has taught me about the importance of enabling people to tell their stories and how important stories are in people's meaning making of experiences. I have developed my confidence in deciphering the multi-layers of stories and have a greater awareness of what I bring to stories told at a particular time and the importance of telling those stories at that timepoint. I will endeavor to bring this awareness with me more in my day to day practice.

I think there was some learning around the dual role that I held throughout the project i.e. being a therapist and researcher. I think sometimes as therapists we become desensitised to the stories told to us and inhabiting a different role for the study made me reflect on the stories in a different way which evoked a strong emotional response. Additionally, the role of researcher and therapist are very different and at times, I struggled with this, as I allowed the stories to unfold with minimal input. I found this challenging as I wanted to normalise their experience and empathise with them during particularly emotional parts of the story and demonstrate connectedness with them through non-verbal cues. I also found it hard to portray parents with mental distress negatively as there are prevailing stigmatising narratives about this group of individuals that I did not want to contribute to in the research and in my position as an advocate for mental distress. However, this was superseded by my desire to share the accounts of the siblings. It made me reflect on the stories that are privileged and subjugated. Finally, this study has given me hope that there can be different outcomes for this population and in my role in

advocating for family inclusive services.

## **5.5. Conclusion**

The study set out to employ a narrative approach to develop an understanding of sibling experiences of PEMD and understand the wider societal discourses that may influence the lived experience of these siblings. The research questions considered the quality of the relationship and factors that may foster or disrupt a close relationship, including communication, and the exploration of similar and different experiences in the context of PEMD. Narratives were identified that spoke to the meaning making of the experience of PEMD which changed over time. The sibling relationship was affected by PEMD however the narratives spoke to the closeness and importance of the sibling relationship which had withstood adversity. These moments of challenge were conveyed to the audience through confusion and humour which supported the struggles and ultimate acceptance and success of their relationships.

## 6. References

- Ackerson, B. J. (2003a). Coping with the dual demands of severe mental illness and parenting: The parents' perspective. *Families in Society, 84*, 109–119.
- Aldridge, J., & Becker, S. (1999). Children as carers: the impact of parental illness and disability on children's caring roles. *Journal of Family Therapy, 21*, 303-320.
- Andrews, M., Sclater, S. D., Rustin, M., Squire, C., & Treacher, A. (2004). Introduction. In M. Andrews, S. D. Sclater, C. Squire & A. Treacher (Eds.), *Uses of Narrative* (pp.1-11). New Brunswick, NJ: Transaction.
- Andrews, M. (2008). Never the last word: Revisiting data. In M. Andrews, C. Squire & M. Tamboukou (Eds.), *Doing Narrative Research* ( pp.86-101). SAGE Publications.
- Andrews, M., Squire, C., & Tamboukou, M. (2008). *Doing Narrative Research*. SAGE Publications.
- Arendell, T. (1993). Conceiving and Investigating Motherhood: The Decade's Scholarship. *Journal of Marriage and Family, 62*(4), 1192-1207.
- Arksey, H. (1996). Collecting data through joint interviews. *Social Research Update, 15*. Retrieved from <http://sru.soc.surrey.ac.uk/SRU15.html>
- Bamberg, M. (2011). Who am I? Narration and its contribution to self and identity. *Theory & Psychology, 21*(1), 3-24.
- Bamberg, M., & Georgakopoulou, A. (2008). Small Stories as a New Perspective in Narrative and Identity Analysis. *Text & Talk, 28*, 377-396.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.
- Bank, S.P. & Kahn, M.D. (1982). *The Sibling Bond*. New York: Basic Books.



- Barber, B., & Buehler, C. (1996). Family Cohesion and Enmeshment: Different Constructs, Different Effects. *Journal of Marriage and Family*, 58(2), 433-441. doi:10.2307/353507
- Bateson, G. (1972). *Steps to an Ecology of Mind*. University of Chicago Press.
- Bauer, R., Spiessi, H., & Helmbrecht, M.J. (2015). Burden, reward, and coping of adult offspring of patients with depression and bipolar disorder. *International Journal of Bipolar Disorders*, 3(2), 1-7.
- Beavin, Bavelas, J. & Segal, L. (1982). Family Systems Theory: Background and Implications. *Journal of Communication*, 32, 89-107.
- Beresford, P. (2002). Thinking about 'mental health': Towards a social model. *Journal of Mental Health*, 11(6), 581-584.
- Bhati, K. S., Hoyt, W. T., & Huffman, K. L. (2013). Integration or assimilation? Locating qualitative research in psychology. *Qualitative Research in Psychology*. 11(1), 98-114. doi:0.1080/14780887.2013.772684
- Boer, F., Dunn, J., & Dunn, J.F. (1992). *Children's sibling relationships: Developmental and clinical issues*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Bowen, C., Yeats, G., & Palmer, S. (2010). *Brain injuries series. A relational approach to rehabilitation: Thinking about relationships after brain injury*. London, England: Karnac Books.
- Bowlby, J. (1980). *Attachment and Loss: Loss, sadness, and depression*. New York: Basic Books.
- Braun, V., & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brody, G. (1998). Sibling relationship quality: Its causes and consequences. *Annual Review of Psychology*, 49, 1-24.

- Brody, G. H., Stoneman, Z., & McCoy, J. K. (1994). Forecasting sibling relationships in early adolescence from child temperaments and family processes in middle childhood. *Child Development, 65*, 771 – 784.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Harvard University Press.
- Buhrmester, D. (1992). The developmental courses of sibling and peer relationships. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 19-40). Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc.
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development, 61*(5), 1387-1398.
- Burr, V. (1995). *An Introduction to Social Constructionism*. Florence, KY, US: Taylor & Frances/Routledge.
- Burnham, J.B. (1986). *Family Therapy*. London & New York: Routledge.
- Byng-Hall, J. (1995). *Rewriting Family Scripts, Improvisation and Systems Change*. NY: The Guildford Press.
- Byng-Hall, J. (2008). The crucial roles of attachment in family therapy. *Journal of Family Therapy, 30*(2), 129-146.
- Carr, A. (2012). *Family Therapy: Concepts, Process and Practice* (3<sup>rd</sup> ed.). Wiley-Blackwell
- Clandinin, D.J., Pushin, D., & Orr, A.M. (2007). Navigating Sites for Narrative Inquiry. *Journal of Teacher Education, 58*, 21-35.
- Clandinin, D.J. (2006). *Handbook of narrative inquiry: Mapping a methodology*. Sage Publications Inc.
- Cleaver, H., Unell, I., & Aldgate, J. (2011). *Children's Needs – Parenting Capacity Child abuse: Parental mental illness, learning disability, substance misuse, and*

- domestic violence*. London: TSO.
- Cicirelli, V. G. (1982). Sibling influence throughout the life span. In M. E. Lamb & B. Sutton Smith (Eds.), *Sibling relationships: Their nature and significance across the life span* (pp. 267-284). Hillsdale, NJ: Lawrence Erlbaum.
- Cicirelli, V. G. (1992). *Sage library of social research, Vol. 186. Family caregiving: Autonomous and paternalistic decision making*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Cicirelli, V.G. (1995). *Sibling relationships across the life span*. Springer US.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data: Complementary research strategies*. Thousand Oaks, CA, US: Sage Publications, Inc.
- Dallos, R. (1997). *Interacting Stories Narratives, Family Beliefs, and Therapy*. London: Karnac Books.
- Dallos, R. & Draper, R. (2010). *Introduction to Family Therapy*. McGraw-Hill Education.
- Dallos, R. & Vetere, A. (2003). *Working Systemically with Families: Formulation, Intervention and Evaluation*. Routledge.
- Dam, K., & Hall, E. O. (2016). Navigating in an unpredictable daily life: a metasynthesis on children's experiences living with a parent with severe mental illness. *Scandinavian Journal of Caring Sciences*, 30(3), 442-457.
- Dam, K., Joensen, D. G., & Hall, E. O. C. (2018). Experiences of adults who as children lived with a parent experiencing mental illness in a small-scale society : A Qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 25(2), 78-87.
- Deković, M., & Buist, K. L. (2005). Multiple perspectives within the family. *Journal of Family Issues*, 29, 467-490. doi:10.1177/0192513X04272617
- Department for Education and Skills. (2003). *Every child matters*. London: The Stationery Office.

- Department for Education and Skills. (2005). *Children and Young People's Plans*. London: The Stationery Office.
- Department for Health and Social Care. (2011). A cross-Government mental health outcomes strategy for people of all ages. London: The Stationery Office.
- Deater-Deckard, K., & Dunn, J. (1999). Multiple risks and adjustment in young children growing up in different family settings: A British community study of stepparent, single mother, and nondivorced families. In E. M. Hetherington (Eds.), *Coping with Divorce, Single Parenting and Remarriage: A Risk and Resiliency Perspective* (pp. 47–64). Mahwah, NJ: Erlbaum.
- Deater-Deckard, K., Dunn, J., & Lussier, G. (2002). Sibling relationships and social-emotional adjustment in different family contexts. *Social Development, 11*(4), 571-590.
- Drost, L.M., van der Krieke, L., Sytema, S., & Schippers, G.M. (2016). Self-expressed strengths and resources of children with a mental illness: A systematic review. *International Journal of Mental Health Nursing, 25*(2), 102-115.
- Dunn, J. (1992). Siblings and Development. *Current Directions in Psychological Science, 1*(1), 6–9. doi.org/10.1111/1467-8721.ep10767741
- Dunn, J., Slomkowski, C., & Beardsall, L. (1994). Sibling Relationships From the Preschool Period Through Middle Childhood and Early Adolescence. *Developmental Psychology, 30*(3), 315-324.
- Earley, L., & Cushway, D. (2002). The Parentified Child. *Clinical Child Psychology and Psychiatry, 7*(2), 163-178.
- Earthy, S., & Cronin, A. (2008). *Narrative Analysis In: Researching social life*. London: SAGE.
- East, P. L., & Rook, K. S. (1992). Compensatory patterns of support among children's peer

- relationships: A test using school friends, non-school friends, and siblings. *Developmental Psychology*, 28(1), 163-172.
- Elliott, R., Fischer, C.T., & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Erikson, E.H. (1959). *Identity and the life cycle*. New York: International Universities Press.
- Esin, C., Faithi, M., & Squire, A. (2014). Narrative Analysis: The Constructionist Approach. In U. Flick, *The SAGE Handbook of Narrative Analysis* (pp. 203-216). London: SAGE Publications Ltd.
- Falkov, A. (1999). *Crossing bridges: training resources for working with mentally ill parents and their children – for managers, practitioners and trainers*. Great Britain: Department of Health.
- Falkov, A. (2011). *Parents as Patients*. London: Royal College of Psychiatrists.
- Feinberg, M.E., Solmeyer, A.R., & McHale, S.M. (2012). The third rail of family systems: sibling relationships, mental and behavioral health, and preventive intervention in childhood and adolescence. *Clinical Child & Family Psychological Review*, 15(1), 43-57.
- Finlay, L. (2003). Through the looking glass: intersubjectivity and hermeneutic reflection. In L. Finlay & B. Gough (Eds). *Reflexivity a Practical Guide for Researchers in Health and Social Sciences*. Blackwell Publishing, UK.
- Fitzsimons, E., Goodman, A., Kelly, E., & Smith, J.P. (2017). Poverty dynamics and parental mental health: Determinants of childhood mental health in the UK. *Social Science & Medicine*, 175, 43-51.
- Foster, K. (2010). 'You'd think this roller coaster was never going to stop!': experiences of

- adult children of parents with serious mental illness. *Journal of Clinical Nursing*, 19(21-22), 3143-3151.
- Foster, K., O'Brien, L., & Korhonen, T. (2011). Developing resilient children and families when parents have mental illness: A family-focused approach. *International Journal of Mental Health Nursing*, 21(1), 3-11.
- Frank, A. (1995). *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Frankel, R.M., & Devers, K. (2000). Qualitative research: a consumer's guide. *Educational Health*, 13(1), 113-123.
- Gass, K., Jenkins, J., & Dunn, J. (2007). Are sibling relationships protective? A longitudinal study. *Journal of Child Psychology & Psychiatry*, 48(2), 167-175.
- Gatsou, L., Yates, S., Goodrich, N., & Pearson, N. (2017). The challenges presented by parental mental illness and the potential of a whole-family intervention to improve outcomes for families. *Child & Family Social Work*, 22(1), 388-397.
- Gergen, K.J. (1999). *An invitation to social constructionism*. London: SAGE.
- Gladstone, B. M., Boydell, K. M., Seeman, M. V., & McKeever, P. D. (2011). Children's experiences of parental mental illness: A literature review. *Early Intervention in Psychiatry*, 5(4), 271-289.
- Goetting, A. (1986). The developmental tasks of siblings over the life cycle. *Journal of Marital & Family Therapy*, 47, 703-714.
- Golafshani, N. (2003). Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report*, 84(4), 597-606.
- Göpfert, M., Webster, J., & Seeman, M.V. (Eds.). (2004). *Parental Psychiatric Disorder Distressed Parents and Their Families* (2<sup>nd</sup> Ed). Cambridge: Cambridge University Press.

- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Green J. (1999). Qualitative methods. *Community eye health*, 12(31), 46–47.
- Griffiths, J., Norris, E., Stallard, P., & Matthews, S. (2012). Living with parents with obsessive-compulsive disorder: Children's lives and experiences. *Psychology and Psychotherapy: Theory, Research and Practice*, 85(1), 68-82. doi:10.1111/j.2044-8341.2011.02016.x
- Griffiths, C. & Sin, J. (2013). Rethinking siblings and mental illness. *The Psychologist*, 11(26), 808-811.
- Gubrium, J. F., & Holstein, J. A. (2000). Analyzing interpretive practice. *Handbook of qualitative research*, 2, 487-508.
- Harper, D.J. (1995). Discourse analysis and ‘mental health’. *Journal of Mental Health*, 4, 347-357.
- Hetherington, M.E. & Clingempeel, G.W. (1992). Coping with marital transitions: A family systems perspective. *Monographs of the Society for Research in Child Development*, 57(2-3)[Serial No 227], 1-242.
- Hetherington, E. M., Henderson, S. H., Reiss, D., Anderson, E. R., Bridges, M., Chan, R. W., . . . Taylor, L. C. (1999). Adolescent siblings in stepfamilies: Family functioning and adolescent adjustment. *Monographs of the Society for Research in Child Development*, 64(4), p. 222. <http://dx.doi.org/10.1111/1540-5834.00045>
- Hinshaw, S.P. (2005). The stigmatization of mental illness in children and parents: developmental issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry*, 46(7), 714-734.
- HM Government. (2018). *Working Together to Safeguard Children A guide to inter-agency working to safeguard and promote the welfare of children*. HM Government.
- Hooper, L. M. (2007). *The Application of Attachment Theory and Family Systems Theory*

- to the Phenomena of Parentification. *The Family Journal*, 15(3), 217–223.
- Jenkins, JM. (1992). Sibling relationships in disharmonious homes: Potential difficulties and protective effects. In: Boer, F., & Dunn, J., (Eds). *Children's sibling relationships: Developmental and clinical issues* (pp. 125-138). Hillsdale, NJ: Erlbaum.
- Jenkins, J.M. & Smith, M.A. (1990). Factors protecting children living in disharmonious homes: Maternal reports. *Journal of the American Academy of Child & Adolescent Psychiatry*, 29(1), 60-69.
- Jonssen, P.D., Skarsater, I., Wijk, H., & Danielson, E. (2011). Experience of living with a family member with bipolar disorder. *International Journal of Mental Health Nursing*, 20, 29-37.
- Josselson, R. (2004). The Hermeneutics of faith and the hermeneutics of suspicion. *Narrative Inquiry*, 14, 1-28.
- Kadish, Y. (2015). Five women's recollections and reflections on being raised by a mother with psychosis. *South African Journal of Psychology*, 45(4), 480-494.
- Kahl, Y., & Jungbauer, J. (2014). Challenges and Coping Strategies of Children with Parents Affected by Schizophrenia: Results from an In-Depth Interview Study. *Child and Adolescent Social Work Journal*, 31(2), 181-196. doi:10.1007/s10560-013-0316-2
- Kahn, M.D. & Bank, S.P. (1982). *The Sibling Bond*. New York: Basic Books.
- Kelly, M. (1994). *Coping with chronic illness: a sociological perspective*. Inaugural Lecture, University of Greenwich.
- Kidd, S.A. (2002). The role of qualitative research in psychological journals. *Psychological Methods*, 7(1), 126-138.
- Lachal, J., Revah-Levy, A., Orri, M., & Moro, M. R. (2017). Metasynthesis: An Original



- Method to Synthesize Qualitative Literature in Psychiatry. *Frontiers in psychiatry*, 8, 269. doi:10.3389/fpsy.2017.00269
- Langellier, K.M. (2002). Performing family stories, forming cultural identity: Franco American Mémere stories. *Communication Studies*, 53(1), 56-73.
- Legislation.gov.uk. (2017). Children Act 1989. [online] Available at: <http://www.legislation.gov.uk/ukpga/1989/41/section/17> [Accessed 02 June. 2019].
- Loftland, J., & Loftland, L.M. (1984). *Analyze Social Settings: A Guide to Qualitative Observation and Analysis*. Wadsworth Publishing Company.
- Martinsen, E.H., Weimand, B.M., Pedersen, R. & Norvoll, R. (2019). The silent work of young next of kin in mental healthcare. *Nursing Ethics*, 26(1), 212-223.
- Mattejat, F., & Remschmidt, H. (2008). The children of mentally ill parents. *Deutsches Arzteblatt international*, 105(23), 413–418. doi:10.3238/arztebl.2008.0413
- McAdams, D.P. & McLean, K.C. (2013). Narrative Identity. *Current Directions in Psychological Science*, 22(3), 233-238.
- McCormack, L., White, S., & Cuenca, J. (2017). A fractured journey of growth: Making meaning of a ‘broken’ childhood and parental mental ill-health. *Community, Work & Family*, 20(3), 327-345.
- McHale, S. M., Kim, J.-Y., & Whiteman, S. D. (2006). Sibling Relationships in Childhood and Adolescence. In P. Noller & J. A. Feeney (Eds.), *Close relationships: Functions, forms and processes* (pp. 127-149). Hove, England: Psychology Press/Taylor & Francis (UK).
- McHale, S.M., Whiteman, S.D., Kim, J.-Y., & Crouter, A.C. (2007). Characteristics and correlates of sibling relationships in two-parent African American families. *Journal of Family Psychology*, 21(2), 227-235.
- McKie, L. & Cunningham-Burley, S. (2005). *Families in society – Boundaries and*

- Relationships*. Bristol University Press.
- McGuire, S. & Shanahan, L. (2010). Sibling Experiences in Diverse Family Contexts. *Child Development Perspectives*, 4(2), 72-79.
- Meadus, R.J. & Johnson, B. (2000). The experience of being an adolescent child of a parent who has a mood disorder. *Journal of Psychiatric and Mental Health Nursing*, 7(5), 383-390.
- Meyer, D. (2006). Parenthood in a Time of Transition: Tensions between Legal, Biological, and Social Conceptions of Parenthood. *The American Journal of Comparative Law*, 54, 125-144.
- Milevsky, A. & Levitt, M.J. (2005). Sibling support in early adolescence: Buffering and compensation across relationships. *European Journal of Developmental Psychology*, 2(3), 299-320.
- Minogue, V., Holt, B., Karban, K., Gelsthorpe, S., Firth, S., & Ramsay, T. (2009). Service User and Carer Involvement in Mental Health Education, Training and Research – A Literature Review. *Mental Health and Learning Disabilities Research and Practice*, 6 (2). pp. 211-227.
- Minuchin, S. (1974). *Families and Family Therapy*. Cambridge, MA: Harvard University Press.
- Mishler, E. G. (1991). Representing discourse: The rhetoric of transcription. *Journal of narrative and life history*, 1(4), 255-280.
- Mordoch, E. (2010). How Children Understand Parental Mental Illness. “You don’t get life insurance. What’s life insurance?” *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 19(1), 19-25.
- Mordoch, E., & Hall, W. A. (2008). Children's perceptions of living with a parent with a mental illness: finding the rhythm and maintaining the frame. *Qualitative Health*

- Research*, 18(8), 1127-1144.
- Mowbray, C.T., & Mowbray, O.P. (2006). Psychosocial outcomes for adult children of parents with severe mental illnesses: Demographic and clinical history predictors. *Health and Social Work*, 31(2), 99-108.
- Murphy, G., Peters, K., Jackson, D., & Wilkes, L. (2011). A qualitative meta-synthesis of adult children of parents with a mental illness. *Journal of Clinical Nursing*, 20(23-24), 3430-3442.
- Murphy, G., Peters, K., Wilkes, L., & Jackson, D. (2015). Childhood Parental Mental Illness: Living with Fear and Mistrust. *Issues in Mental Health Nursing*, 36(4), 294-299.
- Murphy, G., Peters, K., Wilkes, L. M., & Jackson, D. (2016). Adult Children of Parents with Mental Illness: Losing Oneself. Who am I? *Issues in Mental Health Nursing*, 37(9), 668-673.
- National Service User Network (NSUN, 2015) The language of mental wellbeing. Retrieved from <http://www.nsun.org.uk/assets/downloadableFiles/4PiLANGUAGEOFMENTALWELLBEING.V42.pdf>
- NHS Digital. (2017). *Mental Health of Children and Young People in England*. NHS Digital.
- Nieto-Rucian, V., & Furness, P. J. (2018). The Experience of Growing Up with a Parent With Schizophrenia-A Qualitative Study. *Qualitative Psychology*. Advance online publication. <http://dx.doi.org/10.1037/qup0000112>
- Nolte, L. & Wren, B. (2016). Talking or keeping silent about parental mental health problems – A grounded theory of parents’ decision making and experiences. *Journal of Marital and Family Therapy*, 42(4), 731-744.

- O'Connor, T., Hetherington, E.M., & Reiss, D. (1998). Family systems and adolescent development: Shared and nonshared risk and protective factors in nondivorced and remarried families. *Development and Psychopathology, 10*(2), 353-375.
- Oh, S., & Chang, S.J. (2014). Concept Analysis: Family Resilience. *Open Journal of Nursing, 4*, 980-990.
- Office for National Statistics. (2015). *Families and Households*. London: Office for National Statistics.
- Ostman, M. (2016). Interviews with children of persons with a severe mental illness- Investigating their everyday situation. *Nordic Journal of Psychiatry, 62*, 354-359.
- Oyserman, D., Mowbray, C.T., Meares, P.A., & Firminger, K.B. (2010). Parenting Among Mothers With a Serious Mental Illness. *American Journal of Orthopsychiatry, 70*(3), 296-315.
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health, 42*(5), 533–544.
- Parker, G., Beresford, B., Clarke, S., Gridley, K., Pitman, R., Spiers, G., & Light, K. (2008). *Research Reviews on Prevalence, Detection and Interventions in Parental Mental Health and Child Welfare: Summary report*. York: Social Policy Research Unit.
- Parry, K., Mumford, M. D., Bower, I., & Watts, L. L. (2014). Qualitative and historiometric methods in leadership research: A review of the first 25 years of The Leadership Quarterly. *The Leadership Quarterly, 25*(1), 132-151.
- Perera, D. N., Short, L., & Fernbacher, S. (2014). "It's not that straightforward": When family support is challenging for mothers living with mental illness. *Psychiatric Rehabilitation*

*Journal*, 37(3), 170-175.

- Petrowski, C. E., & Stein, C. H. (2016). Young women's accounts of caregiving, family relationships, and personal growth when mother has mental illness. *Journal of Child and Family Studies*, 25(9), 2873-2884.
- Pölkki, P., Ervast, S.-A., & Huupponen, M. (2005). Coping and Resilience of Children of a Mentally Ill Parent. *Social Work in Health Care*, 39(1-2), 151-163.
- Prior, V., & Glaser, D. (2006). *Child and adolescent mental health series. Understanding attachment and attachment disorders: Theory, evidence and practice*. London, England: Jessica Kingsley Publishers.
- Raffaelli, M. & Larson, R.W. (1987). *Sibling interactions in late childhood and early adolescence*. Paper presented at the biennial meeting of the Society for Research in Child Development, Baltimore.
- Reupert, A., & Maybery, D. (2007). Families affected by parental mental illness: a multiperspective account of issues and interventions. *American Journal of Orthopsychiatry*, 77(3), 362-369.
- Reupert, A. & Maybery, D. (2016). What do we know about families where parents have a mental illness? A systematic review. *Child & Youth Services*, 37(2), 98-111.
- Riebschleger, J.L. (1991). Families of chronically mentally ill people: Siblings speak to social workers. *Health and Social Work*, 16, 94-103.
- Riebschleger, J. (2004). Good days and bad days: The experiences of children of a parent with a psychiatric disability. *Psychiatric Rehabilitation Journal*, 28(1), 25-31.
- Riebschleger, J.L., Grové, C., Cavanaugh, D., & Costello, S. (2017). Mental Health Literacy Content for Children of Parents with a Mental Illness: Thematic Analysis of a Literature Review. *Brain Sciences*, 7(141), 1-19.
- Riessman, C.K. (2008). *Narrative Methods for the Human Sciences*. USA: SAGE

Publications.

- Rose, H., & Cohen, K. (2010). The experiences of young carers: a meta-synthesis of qualitative findings. *Journal of Youth Studies, 13*, 473–487.
- Rothbaum, F., & Rosen, K., Ujiie, T., & Uchida, N. (2002). Family Systems Theory, Attachment Theory, and Culture\*. *Family process, 41*, 328-50. 10.1111/j.1545-5300.2002.41305.x.
- Rutter, M. (1993). Resilience: Some Conceptual Considerations. *Journal of Adolescent Health, 14*, 626-631.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health, 18*(2), 179-183.
- Sandelowski, M., Barroso, J., & Voils, C. I. (2007). Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. *Research in nursing & health, 30*(1), 99–111. doi:10.1002/nur.20176
- Sarbin, T.R. (1986). *Narrative Psychology: The storied nature of human conduct*. New York: Praeger.
- Scotland, J. (2012). Exploring the Philosophical Underpinnings of Research: Relating Ontology and Epistemology to the Methodology and Methods of the Scientific, Interpretive, and Critical Research Paradigms. *English Language Teaching, 5*(9), 9-16.
- Siddaway, A.P., Wood, A.M., & Hedges, L.V. (2019). How to Do a Systematic Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses, and Meta-Syntheses. *Annual Review of Psychology, 70*, 747-770.
- Social Care Institute for Excellence. (2011). *Think Child, Think Parent, Think Family*. London: SCIE.
- Smith, J.A. (2011). Evaluating the contribution of interpretative phenomenological analysis.

*Health Psychology Review*, 5(1), 9-27.

Smith, B., & Sparkes, A. C. (2009). Narrative inquiry in sport and exercise psychology: What can it mean, and why might we do it? *Psychology of Sport and Exercise*, 10(1), 1-11.

Sorenson, H.J., Mortensen, E.L., August, G.W., Juel, K., Silverton, L., & Sarnoff, A.M. (2009). *Suicide and mental illness in parents and risk of suicide in offspring*. *Social Psychiatry and Psychiatric Epidemiology*, 44, 748-751.

Squire, C. (2008). Experience-centred and culturally oriented approaches to narrative. In M. Andrews, C. Squire & M. Tamboukou, *Doing Narrative Research* (Eds, pp.41-63). SAGE Publications.

Stanley, N., & Cox, P. (2008). *Parental mental health and child welfare: reviews of policy and professional education*. London: Social Care Institute for Excellence.

Stenager, K., & Qin, P. (2008). Individual and parental psychiatric history and risk for suicide among adolescents and young adults in Denmark. *Social Psychiatry and Psychiatric Epidemiology*, 43(11), 920-926.

Stewart, R.B., & Marvin, R.S. (1984). Sibling Relations: The Role of Conceptual Perspective-Taking in the Ontogeny of Sibling Caregiving. *Child Development*, 55(4), 1322-1332.

Teti, D.M., & Ablard, K.E. (1989). Security of attachment and infant-sibling relationships. A laboratory study. *Child Development*, 60(6), 1519-1528.

The Kings Fund. (2018). *Funding and staffing of NHS mental health providers: still waiting for parity*. The Kings Fund.

The Mental Health Taskforce Strategy. (2016). *The Five Year Forward View for Mental Health*. NHS England.

Tracey, S.J. (2010). Qualitative Quality: Eight “Big-Tent” Criteria for Excellent Qualitative

- Research. *Qualitative Inquiry*, 16(10).
- Trahar, S. (2009). Beyond the story itself: Narrative inquiry and autoethnography in intercultural research in higher education. *Forum: Qualitative Social Research*, 10(1).
- Tunnard, J. (2004). *Parental mental health problems: key messages from research, policy and practice*. Research in Practice.
- Updegraff, K. & Obeidallah, D.A. (1999). Young adolescents' patterns of involvement with siblings and friends. *Journal of Social Development*, 8(1), 52-69.
- Van Parys, H. & Rober, P. (2012). Trying to comfort the parent: A qualitative study of children dealing with parental depression. *Journal of Marital & Family Therapy*, 39, 330-345.
- Van Parys, H., Smith, J.A., & Rober, P. (2014). Growing Up with a Mother with Depression: An Interpretive Phenomenological Analysis. *The Qualitative Report*, 19(15), 1-18.
- Van Parys, H., Bonnewyn, A., De Mol, J., & Rober, P. (2015). Toward understanding the child's experience in the process of parentification: Young adults' reflections on growing up with a depressed parent. *Journal of Marital & Family Therapy*, 41(4), 522-536.
- Vetere, A. (2001). Structural Family Therapy. *Child Psychology & Psychiatry Review*, 6(3), 133-139.
- Von Bertalanffy, L. (1968). *General Systems Theory*. G Braziller.
- Waldinger, R., Vaillant, G.E., & Orav, E.J. (2007). Childhood Sibling Relationships as a Predictor of Major Depression in Adulthood: A 30-Year Prospective Study. *American Journal of Psychiatry*, 164(6), 949-954.
- Wells, K. (2011). *Narrative Inquiry*. Oxford: Oxford University Press.



- Wertz, F.J., Charmaz, K., McMullen, L.M., Josselson, R.E., & McSpadden, E. (2014). *Five ways of doing qualitative analysis*. Guildford Publications.
- Whiteman, S.D., & Buchanan, C.M. (2002). Mothers' and children's expectations for adolescence: The impact of perceptions of an older sibling's experience. *Journal of Family Psychology, 16*(2), 157-171.
- Whiteman, S.D., McHale, S.M., & Soli, A. (2011). Theoretical Perspectives on Sibling Relationships. *Journal of Family Theory & Review, 3*(2), 124-139.
- Widmer, E.D. (1999). Family contexts as cognitive networks: A structural approach of family relationships. *Personal Relationships, 6*(4), 487-503.
- Widmer, E.D., & Weiss, C.C. (2000). Do older siblings make a difference? The effects of elder sibling support and older sibling adjustment on the adjustment of socially disadvantaged adolescents. *Journal of Research on Adolescence, 10*, 1-27.
- Wiener, N. (1948). *Cybernetics or Control and Communication in the Animal and the Machine*. MIT Press.
- Wilson, A.D., Onwuegbuzie, A.J., & Manning, L.P. (2016). Using Paired Depth Interviews to Collect Qualitative Data. *The Qualitative Report, 21*(9), 1549-1573. Retrieved from <https://nsuworks.nova.edu/tqr/vol21/iss9/1>
- Woodall, J., Raine, G., South, J., & Warwick-Booth, L. (2010). *Empowerment and Health & Well-Being Evidence Review*. Centre for Health Promotion Research, Leeds Metropolitan University.

## 7. Appendices

### 7.1. Appendix 1: Summary of the literature review

Author	Explicit purpose of study	Appropriate Methods	Respect for participants	Specification of methods	Appropriate discussion	Clarity of presentation	Contribution to knowledge	Strengths	Limitations
McCormack, White & Cuenca (2017)	✓	✓	✓	✓	✓	✓	✓	two authors checked data, reflections on difference in analysis, section on credibility including how they ensured rigour note taking diagrams, table on analytic process, reflexive	6 females and only one male, use IPA needs homogeneity but diagnosis different
Kahl & Jungbaeur (2013)	✓	✓	✓	✓	✓	✓	✓	Large sample size, findings support previous studies	Not a representative sample as families come from a stable family unit, biased sample
Dam, Joensen & Hall (2017)	✓	✓	✓	✓	✓	✓	✓	Participants offered to check interviews, showed an example of the analysis process, reflexivity reflected on preconceptions, analysed data individually and together, illustrated procedure in tables	retrospective nature of the study subject to forgetting and bias

Foster (2010)	✓	✓	✓	✓	✓	✓	✓	Member checking, researcher was also a participant, quotes illuminated the analysis, accessible, clinically relevant	small sample size and findings not generalisable to others and not representative due to lack of cultural diversity
Griffiths, Norris, Stallard, & Matthews (2012)	✓	✓	✓	✓	✓	✓	✓	Position stated and reflexivity,	small opportunity sample from those receiving support and parents provided consent so therefore OCD would have been discussed before, so may not reflect all experiences, cannot make results comparable to other experiences of mental distress
Nieto-Rucian & Furness (2018)	✓	✓	✓	✓	✓	✓	✓	Reflexive, owning perspective, author's personal relevance to topic, participants reported feeling easier to open up, helps generate insights into experiences of growing up with a mother	small sample and not representative, five participants had university degrees which limits representativeness, sample selected from an organisation where participants sought out support, interviews

									translated by first author into English - not native language may have lost some meaning
Mordoch & Hall (2008)	✓	✓	✓	✓	✓	✓	✓	Good sample size for grounded theory, encouraged children to draw as a method of communication	2 children wanted parents in the interview may have limited the openness of participants, children and parents read questions beforehand may have been able to rehearse answers, parents put forward themselves and children so looking to discuss their mental distress not representative
Mordoch (2009) secondary analysis	✓	✓	✓	✓	✓	✓	✓	Rigour demonstrated through memo writing and reflexivity, embedded drawings and metaphoric language	2 children wanted parents in the interview may have limited the openness of participants, children and parents read questions

									beforehand may have been able to rehearse answers, parents put forward themselves and children so looking to discuss their mental distress not representative
Murphy, Peters, Wilkes & Jackson (2015)	✓	✓	✓	✓	✓	✓	✓	Specific focus on one theme from a larger study, provides a good understanding of living with fear	Study would have benefitted from a table of giving an example of the analysis, no reference to limitations
Murphy, Peters, Wilkes & Jackson (2016)	✓	✓	✓	✓	✓	✓	✓	table identifying participants and family context and hospital admissions, in-depth discussion on one theme provides a greater understanding of loss for individuals with a PEMD	Study would have benefitted from a diagrammatic representation of the theme
Riebschlager (2004)	✓	✓	✓	✓	✓	✓	✓	Interview schedule devised in conjunction with stakeholders, high interrater reliability	convenience sample and therefore not generalisable as sample were in prevention programme

Van Parys, Bonnewyn, Hooghe, De Mol, & Rober (2015)	✓	✓	✓	✓	✓	✓	✓	Large sample size for a qualitative study good for grounded theory, external auditors employed to enhance reliability of coding, results displayed diagrammatically	
Kadish (2015)	✓	✓	✓	✓	X	✓	?	Researcher knew participants may have enabled a more honest account	Very small sample, only 3 participants, all female, another analysis other than thematic would be better, researcher knew participants may have affected responses
Petrowski & Stein (2016)	✓	✓	✓	✓	✓	✓	✓	In depth exploration from the perspective of young women, consideration of the role of gender, clear evidence of analysis	Participants were a small, non-random sample of mostly Caucasian female college students from a Midwestern, public university
Van Parys, Smith & Rober (2014)	✓	✓	✓	✓	✓	✓	✓	homogenous sample good for IPA, provided examples of a code, good coherence, all data reviewed by second author, reflexive of	small sample size, all female participants, retrospective study so potential for forgetting and social desirability

								position both as researcher and personal, compared findings with previous studies	
Meadus & Johnson (2000)	✓	✓	✓	✓	✓	✓	✓	homogeneous sample, participants mother's had unipolar and bipolar disorder, good description of the family context including living and not living together, field notes used to record observations, description of analysis, reviews by two people, bias considered, quotes highlight the themes	Very small sample, only 3 participants, all female
Ostman (2008)	✓	✓	✓	?	✓	✓	✓	Demonstrate both positive and negative experiences of being a child to a PEMD, makes comparisons with previous studies - contributes to knowledge, resonates in the scheme of other literature,	Unclear methodology does not explicitly state the design just says it uses an open-ended interview, no quality checks employed, no description of how themes were arrived at, did not use many quotes

								acknowledged limitation of not using another researcher, consideration for participants	to highlight analysis
Pólkki, Ervast, & Huupponen (2004)	✓	✓	✓	✓	X	?	✓	Carried out two small scale studies with different age ranges to capture experiences	Could have benefitted from tables to make results clearer, no quality checks



## 7.2. Appendix 2: Evidence of consultant correspondence

I think the wording of the poster is fine, it tells you what is needed and the tone is really good.

I like how you frame it as a story, which makes it something much less fixed, but something subject to change and development. I also really like that you acknowledge that whilst some experiences will be similar between the siblings, others may be very different, and you are encouraging the participant to think about this. I know me and my sisters experience where very different, but elements were shared. There is also a really nice flow to the questions, that I think will ease the participant through the interview.

There are lots of things that would be interesting to find out, and I'm aware you wont be able to ask everything. But the first 3 questions are similar, I imagine you wanted to get the participant to expand on what they have said, but I wonder if there should be something about how they made sense of their parents mental illness? And also how was it spoken about between people in the family, and what remained unspoken.

With the question regarding the relationship with the sibling. Its really nice that you start broad, and don't lead them, giving them the opportunity to talk about it as they wish. However, it may be useful to also have a question that's a bit more specific in referring to their relationship in relation to their parents mental distress. For example, it would be interesting to find out how or if they supported one another, especially in times of crisis. But of course this may actually come out anyway just from the general framing of the interview.

I hope that's useful. If you need more, just ask.

### 7.3. Appendix 3: Recruitment poster

**Have you and your sibling been affected by  
Parental Mental Distress?**

**PARTICIPANTS NEEDED FOR  
RESEARCH IN *Parental Mental Distress***  
We are looking for sibling pairs to take part in a study of  
*'Sibling Stories of Parental Mental Distress'*

Your participation is **entirely voluntary** and would take up approximately one hour of your time. By participating in this study you will help to understand how relationships within the family are shaped in the context of Parental Mental Distress.

To learn more about this study, or to participate in this study,  
please contact:

**Principal Investigator:**  
***Wendy O'Neill***

**wendyoneill101@yahoo.co.uk**

This study has been reviewed by the University of Hertfordshire Research Ethics Board

#### **7.4. Appendix 4: Recruitment email**

My name is Wendy O'Neill and I am a third-year trainee clinical psychologist at the University of Hertfordshire. I'm emailing to ask if you would consider sharing the attached information regarding my doctoral research project with your current (and recently qualified) clinical psychology trainees.

As part of my major research project on clinical psychology training, I am inviting adult sibling pairs who have lived with a parent with mental distress to participate in my study 'Sibling stories of parental mental distress' (protocol number: LMS/PGT/UH/03356).

It is estimated that in the UK alone, over 2 million children are living with a parent who has a common mental health disorder. Research has highlighted that families affected by parental mental distress are among the most vulnerable in our community and that interventions are more successful when the social and family contexts are considered. Although there is some research on adult children who have experienced childhood parental mental distress, there are no studies which explore how siblings understand this experience.

It is hoped that this project will provide some understanding on how relationships within the family are shaped in the context of parental mental distress and add to the literature on the importance of considering and working with the family in clinical practice.

I would be grateful if you would consider circulating the attached information sheet to your current trainees, which includes further information on taking part.

Please do contact me at [wendyoneill101@yahoo.co.uk](mailto:wendyoneill101@yahoo.co.uk) if you have any questions or concerns.

Thank you very much for your time.

Best wishes,  
Wendy O'Neill

Trainee Clinical Psychologist  
University of Hertfordshire

## **7.5. Appendix 5: Participant information sheet**

**UNIVERSITY OF HERTFORDSHIRE**

**FORM EC6: PARTICIPANT INFORMATION SHEET**

**Title of study**

Sibling Stories of Parental Mental Distress

### **Introduction**

You are being invited to take part in a study. Before you decide whether to participate, it is important that you understand the research that is being carried out and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or should you require further information to help you make your decision.

Thank you for taking the time to read this.

### **What is the purpose of this study?**

The purpose of this study is to look at the experiences of siblings living with a parent with mental health difficulties and how the sibling relationships are experienced and shaped within this context. The study seeks to explore aspects of the sibling relationship that might have helped or not helped when living with a parent with mental health difficulties. The study will also seek to explore the conversations that were privileged or not privileged within the relationships.

### **Do I have to take part?**

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

### **Are there any age or other restrictions that may prevent me from participating?**

In order to participate in the study, you will need to be aged between 18 and 65 years. You will also need to be able to speak English fluently, be living in the UK, and not currently experiencing an episode of acute mental health difficulties yourself.

Additionally, in order to participate, you will need to have a sibling who would also like to participate in the study and have experience of living with a parent who has had mental health difficulties. You will be asked some questions before the study begins to find out about your parent's mental health difficulties.

### **How long will my part in the study take?**

If you decide to take part in this study, you and your sibling will be involved in it for 1-1.5 hours, which is the time it will take to complete the interview.

### **What will happen if I agree to take part?**

The first thing to take place is that we will arrange a time which is convenient for you and your sibling to take part in the interview. You will choose where you would like the interview to take place, and we will ensure that it is both private and available at the time that we want to meet.

Following this, we will meet to complete the interview. Prior to commencing the interview, I will talk through the structure of the interview, what to expect, and answer any questions you or your sibling may have.

During the interview I will ask you and your sibling a number of questions about your experiences, and I will record the responses that you give. The interviews will be audio-recorded so that I can analyse your responses at a later time. At the end of the interview I will provide you with further information about the study and other areas of information and support which you may find helpful, as well as my contact details should you have any further questions.

### **What are the possible disadvantages, risks or side effects of taking part?**

The only possible risk identified is that you may find the process of reflecting on and discussing your experiences generates an emotional response. Although this can be a normal response, some people may find it distressing to experience strong emotions while participating in an interview. Should this occur, I will check with you about whether you feel able to continue, or whether you would like to have a break or to discontinue the interview. You will not be expected to talk about anything that you do not wish to talk about, and can choose to stop the interview at any time. After the interview, I will provide information on relevant support agencies which may be beneficial if you wish to access additional support.

### **What are the possible benefits of taking part?**

The potential benefits are that you will have the time to reflect on and explore your experiences, which may further develop your view of yourself as a person and your understanding of the experience of living with a parent with mental health difficulties. Additionally, it is possible that others will benefit from your contribution as there is a lack of research in the qualitative, lived experience of adult children who have experienced parental mental health difficulties and the sibling relationship.

### **How will my taking part in this study be kept confidential?**

The interviews will take part in a location which can maintain your privacy, with only the researcher and participant being present. Your personal data will be treated carefully – you will be assigned a participant identification number which will be used instead of your name to maintain confidentiality. Additionally, information with your name included, such as consent forms, will be kept separately from the interview data, so that anonymity is preserved. Hard copies of written data (e.g. signed forms) will be kept in a locked filing cabinet. Electronic data will be held securely in password protected files, on either a password protected computer or saved on an encrypted external hard drive which will also be kept in a locked filing cabinet. These will only be accessible by the researcher. Access to viewing the data will only be available to the researcher and the researcher's supervisory team. The data will be deleted or destroyed five years after completion of the project

### **What will happen to the data collected within this study?**

The data recorded will be held securely, as stated above, for up to five years following the completion of the project, in line with British Psychological Society Guidelines. At the end of this period, written materials will be destroyed and all electronic data will be deleted. Should you wish to withdraw your data from the study, you are required to inform the researcher within six weeks of completing the interview.

The results will be used for the researchers Doctorate in Clinical Psychology thesis, and may potentially be used for journal publications and conference presentations. Any extracts of interview transcripts in the research report or any publications will be fully anonymised. Feedback on the results of the study will be made available upon request.

Ethical approval for this study has been obtained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority and the UH ethics protocol number is: LMS/PGT/UH/03356

### **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Wendy O'Neill  
Department of Clinical Psychology  
Health Research Building  
University of Hertfordshire  
Hatfield  
AL10 9AB  
wendyoneil101@yahoo.co.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar  
University of Hertfordshire  
College Lane  
Hatfield  
Herts  
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

## 7.6. Appendix 6: Lone working policy

### UNIVERSITY OF HERTFORDSHIRE SCHOOL OF LIFE AND MEDICAL SCIENCES

## Lone Working Guidance

### 1.0 Introduction

Lone working increases the risks of work for several reasons. There are many examples both at Universities and in Industry, where relatively minor injuries have become life-threatening or even fatal because the worker was alone. This document aims to introduce a uniform approach to such lone working conditions in Life and Medical Sciences (LMS).

### 2.0 Definition of lone working

A lone worker, for the purposes of this guidance is defined as someone who is working on their own with no close or direct supervision.

Lone working is not where individuals experience transient situations in which they find themselves alone, but where individuals are knowingly and foreseeably placed in circumstances in which they undertake work activities without direct or close supervision.

In practical terms, persons are considered to be lone working if they have neither visual nor audible communication with someone who can summon assistance in the event of an accident or illness.

Because 'Lone working' situations apply both on and off-campus and the hazards change dependent on the time (normal hours v out of hours) the basic control measure for Lone Working is identifying the risks and managing them.

### 2.1 Examples of Lone Work

- Staff and post-graduate students undertaking research
- Work out of hours
- Persons visiting / interviewing people in their homes or working in areas known to be antisocial, crime hotspots or otherwise problematic Urban areas or Countryside. Here the specific risks of personal violence add to the lone working risks.

It is important that we consider lone working as it may increase the likelihood of an accident being caused by violence at work, there may be reduced support such as first aid in the event of an accident and the person may be unable to summon assistance etc.

In this document the term 'lone working partner' is loosely used to include colleagues and workmates who are undertaking the 'supervision' of the safety of a 'lone worker' and is therefore not intended to denote managerial control..

It is acceptable to work alone as long as a risk assessment has been carried out and control measures identified and put into place that ensure the task can be carried out safely. Control measures may include instruction, training, supervision, protective equipment, use of the lone worker alarms etc.

### 3.1 Responsibilities of line manager or supervisor

Line managers or research supervisors have the responsibility to ensure that:

- All lone working activities are identified and risks identify the risk to lone workers and the control measures implemented to minimise those risks, as far as reasonably practicable.
- Arrangements for lone working are communicated effectively and the details of what can or cannot be done while working alone is clearly understood.
- The lone worker is made aware of the hazards and understands all the necessary control measures that need to be put in place.

- Adequate supervision, instruction and training are in place. The extent of the supervision/monitoring is a management decision, which should be established through the assessing the risks involved. It should not be left to individual members of staff or students to decide if they require assistance/supervision.
- Monitoring/supervision of lone working practices is in place to ensure that control measures identified in the lone working risk assessment are being adhered to.

### **3.2 Responsibilities of staff and post-graduate students**

Staff and post-graduate students also have statutory responsibilities to take reasonable care of themselves and other people affected by their work. They should not knowingly place themselves in situations which expose them to additional risk by working alone. If a person finds that they are placed in a situation, which may be considered that of 'lone working', they should ensure that their line manager/research supervisor is made aware of the circumstances at the earliest opportunity, and then assist in the process of identifying steps needed to either prevent the lone worker situation from arising, or, if this is not possible, assist in developing the control measures necessary to ensure their own safety.

Lone workers have a responsibility to inform their line manager/research supervisor if they have any concerns over the effectiveness and efficiency of the agreed arrangements and also if there are any reasons why they would not be able to work alone, or continue to work alone in safety.

They also need to co-operate with management in meeting their legal obligations.

The risk assessment process should help decide the right level of supervision. In some situations, additional arrangements for providing help or back-up should be put in place. More than one additional person may need to be present or be within sight. Lone working is not permitted if the proposed work is high risk or if a suitable risk assessment has not been undertaken. Examples of high risk activities include working with high hazard chemicals or biological hazards.

### **4.0 Risk Assessment**

Risk Assessment for lone working situations must be signed by the following:

- Assessor (and supervisor if the assessor is a student)
- Local Health and Safety Advisor or Laboratory Manager

These must be separate individuals - it is not permissible for someone to sign in more than one category.

### **4.1 Hazards & Risks**

The first stage of the risk assessment process is to identify what hazards the lone worker may be exposed to and the extent of the risk. Questions which may help you identify possible hazards associated with lone working include the following:

- Does the workplace present a special risk to the lone worker?
- Is there a safe way in and a way out for one person?
- Can all the equipment and hazardous substances involved in the work be safely handled by one person?
- Is there a risk of violence to the worker, and if so who from?
- Is the lone worker more at risk due to their gender or inexperience?

### **4.2 Control Measures**

The next stage of the risk assessment is to decide how you are going to control the risk in terms of either reducing the severity of the injury or likelihood of the accident occurring. This can include measures such as training the lone worker and putting procedures in place which take account of communication and supervision. The risk assessment needs to include routine activities that the lone worker will carry out as well as emergency situations.



### 4.3 Training

Lone workers need to be sufficiently experienced and to understand the risks and precautions fully. Training is particularly important where there is limited supervision to control and guide. Lone workers need to be able to deal with circumstances which are new, unusual or beyond the scope of normal activities, for example people need to know when to stop work and seek advice from their line manager/supervisor. The line manager or research supervisor needs to arrange or provide this additional training, and should agree limits with the employee or student as to what can and cannot be done while working alone.

### 4.4 Supervision

The line manager or research supervisor of the lone worker or student should:

- Ensure that the employee or student understand the risks associated with their work and that the necessary safety precautions are carried out.
- Provide guidance in situations of uncertainty.

The extent of supervision required depends on the risks involved and the ability of the lone worker to identify and handle health and safety issues. The risks include the environmental risks as well as the risks from the work being undertaken.

New staff (including those undergoing training such as post-graduate students) and staff doing a job with special risks or new situations may need to be accompanied at first.

The level of supervision should be agreed between management and the lone worker as part of the risk assessment. The higher the risk, the greater the level of supervision required. This needs to take into account the environmental conditions as well as the risks from the work being undertaken and account for the actions that need to be taken in an emergency situation.

Procedures need to be put in place to monitor lone workers to see they remain safe. Safety considerations can often be incorporated into progress and quality checks.

Monitoring systems may include:

- Line managers, supervisors or lone working partners visiting and observing people working alone, such as periodically 'looking in' on lab staff working elsewhere in the building.
- Lone worker alarms which are in place in certain areas, which are designed to raise the alarm in the event of an emergency and operate automatically. Regular checks must be made of any lone worker alarm system which is in use.
- Checks that a lone worker has returned to their base or home on completion of a task.

Any contact used as part of a monitoring system should be readily contactable at any time during the planned lone working period.

A clear escalation process must be included in the risk assessment in case of a situation where the required checks have not been complete (eg lone worker does not contact within a specific amount of time to report that they have left the site). This could include:

- Calling the lone worker if they have not made contact when they should
- Calling the external place being visited by the lone worker to check that they left safely
- If on campus, calling security to ask them to check the areas the lone worker was working in. If they can't be found in the specific labs ask security to widen the search to include any other areas that they may have been in eg other buildings.
- Continuing to call the lone worker in case they were unable to answer the phone previously, eg they were driving.

There are specific legal responsibilities in the case of junior staff and postgraduate students that must be fulfilled by their line manager/research supervisors. Use of 'lone worker partners' are not acceptable for high hazard situations with trainees or inexperienced individuals.

#### **4.5 Communication**

Communication is important in lone working situations. This may be regular contact between the lone worker and supervisor either face to face or using either a telephone or radio.

This should take account of practicalities such as if a mobile phone is to be used off site, this should be able to pick up a signal. For this reason, first visits to remote sites should routinely be done with accompanying persons enabling this type of information to be gathered and then the Risk Assessment for subsequent visits can be revised if appropriate.

It is essential that the whereabouts of the lone worker are known to colleagues, especially if there is travelling between sites or buildings. This may be done by writing the details of the visits on a marker board or in a diary. Whatever system is used it should be specified in the Risk Assessment and should also be known and routine for the persons involved.

#### **4.6 Emergency Considerations**

Lone workers should be capable of responding correctly to emergencies. Risk assessment should identify foreseeable events. Emergency procedures should be established and the people concerned trained in using the procedures (especially if they are complex as can be the case in some lab based emergencies).

Emergency Procedures may include,

- Procedures to deal with what needs to be done to someone who has had an accident, especially important in high hazard laboratories).
- Actions to be taken in case of a chemical spill or equipment failure
- Actions to be taken in the event of power failure (for example where the person is reliant on power for their safety systems)

Information about standard emergency procedures and danger areas in your control should be given to lone workers.

The risk assessment must also consider how the lone worker will raise the alarm in the event of an emergency. In some situations, it may be useful to have a mobile phone, but care will need to be taken to ensure that it is fully charged prior to the lone working situation.

Lone workers should have access to adequate first-aid facilities and mobile workers should carry a first-aid kit suitable for treating minor injuries. Occasionally risk assessment may indicate that lone workers need training in first aid, for example when working in remote areas on field trips.

If the lone worker does not return when expected there should be a procedure where to look for them. This could include the make and registration of any vehicle they are using as well as the route that they are expected to have used (where possible), as well as the time they were due to arrive at a place, and an expected time of return.

#### **5.0 Reporting of Accidents and Near-Misses Incidents**

All accidents and near-miss incidents must be reported using the UH [online reporting form](#).

#### **6.0 Office work**

It is not uncommon for staff and research students to work alone in an office. Office work is generally a low risk environment, and additional precautions for reducing the risk to these lone workers are not complex. The risks involve personal safety issues, evacuation during a fire and raising the alarm if an incident occurs.

On many occasions when working early or late, an employee may find they are the only person in the building. The following precautions should be taken to reduce the risk to an acceptable level are:

- Notify security on ext 1010 and give your name, location and building. If working at an external site which UH security cannot reach in a reasonable length of time, an alternative out

of hours individual must be identified.

- Check that there is a working telephone nearby so that you can summon help in the event of an accident, or if you are worried about personal security. Mobile phones can also be used, but you should check that you have good reception.
- Avoid lifting/heaving objects
- Arrange a system for regular communication – this may be a regular phone call, and could involve a family member.

## **7.0 Laboratories**

Laboratories are potentially high risk places for lone working due to the presence of equipment, chemical or biological agents. If an accident occurs when handling hazardous substances or equipment then it is very important that help can be summoned immediately.

The risk assessment must be taken into account when formulating safe working procedures.

**Lone working involving the handling of highly toxic, highly flammable substances, and large volumes of corrosive substances or asphyxiants when a person can be quickly overcome by the effects of exposure is not permitted.**

*Unattended operations in laboratories:* Experiments that malfunction while running unattended, can present particular risks for lone workers, for example during inspection visits or when they are working nearby. Appropriate risk assessments must be undertaken before unattended operations are carried out and an Authorisation for Unattended Running of Experimental Apparatus Outside Normal Working Hours form should be completed for all laboratories (except Toxicology where other arrangements are in place) – these forms can be obtained from the Technical Office 3J011.

Where it is necessary to rely on monitoring by a person patrolling a laboratory or associated work area, he or she must be adequately trained and should have clear written instructions on how to shut down equipment safely in cases of accident or malfunction. The person patrolling must be able to make urgent contact with the person in charge or a named deputy. If the operation requires fume extraction or other external control measure, e.g. pressurisation, there should be a means of alerting an appropriate contact should the system fail. The Authorisation for Unattended Running of Experimental Apparatus Outside Normal Working Hours form will provide useful information regarding immediate actions and preferred contacts.

## **8.0 Work on Non-University Premises – Another Employer's Workplace**

There may be situations where a member of staff or post-graduate student is working at another employer's workplace. In this case there should be liaison between the University and the employer to ensure that any risks have been identified and the control measures that should be taken. In particular, the lone worker should be informed of emergency procedures in place at the other employer's site. This is especially important for high hazard sites such as hospitals, chemical works, quarries, etc.

## **9.0 Door to Door and Street Canvassing and Interviewing.**

All canvassing or interviewing type activities in the field, whether in an urban or rural environment, must be risk assessed in advance of the work commencing. Typical canvassing/interviewing type issues which will require consideration during the risk assessment process include (this list should not

be considered exhaustive):

- Environment / location;
- Aggressive response, physical or verbal – this will need to include psychological trauma, as a result of actual or threatened violence or the nature of what is disclosed during the interview;
- Travel issues; (see UK & Foreign travel guidance)
- Interview techniques;
- Causing psychological or physical harm to others;
- Comprising situations which may lead might to accusations of improper behaviour;
- Exposure to infectious illness.

As with all field-based activities the key to successful and safe interviewing is thorough planning, care and common sense. The following points should be considered during the planning phase:

- Arranging training in good interview techniques;
- Awareness of any delicate issues involved with discussions or interviews (before asking the question explain why you need to know). Issues concerning race, culture and gender may prompt hostility;
- Consider "vetting" interviewees first over the phone, especially if you have never met them before, try to check that they are who they say they are by, for instance, ringing them back at a later time and checking their address in the telephone directory;
- Dependent on the nature of the research, consider meeting local 'community leaders', groups or statutory bodies such as the police, to ask to explain the research, possible risks in the research area/topic and gain their endorsement;
- Conducting interviews at neutral locations or public spaces or where neither party could be at risk;
- If in doubt about the safety of the location, familiarise yourself with the area in advance and assess the need for accompanied interviews, shadowing and pre-arranged pick-ups;
- Seeking permission from any relevant authorities to work in your chosen location;
- Leaving details with your department and/or home, of:
  - What you will be doing;
  - When you will be doing it (specify dates and times of departure, appointments and return);
  - The area in which you will be working (include route details, names, addresses and telephone numbers of people being interviewed);
  - Your contact details (name, address, telephone numbers);
  - If your plans change notify someone immediately.
- Instigating a "check-in" system with a line manager/research supervisor/lone working partner - phone in at regular intervals. If you do not phone or return at a certain time arrange for suitable action to be taken.
- You should also consider other subject/project relevant guidance which may be available, eg from the local NHS Trust or the British Psychological Society.

### **9.1 General Personal Safety Considerations when canvassing/interviewing**

- Where possible avoid lone work, carry out the task as a minimum in pairs;
- Carry a fully charged mobile phone and a personal attack alarm whether female or male, all are equally vulnerable, particularly when alone;
- Always carry enough money for both expected and unexpected expenses, including the use of taxis but do not carry large sums of money or valuables unless you really need to, ensure wallets, cameras, jewellery and expensive watches etc, are not on display;
- Do not stand in places where you will be causing an obstruction;
- Always carry your staff/student ID card and be prepared to identify yourself.

### **9.2 Visiting Other People's Homes**

In addition the considerations listed in section 9.1

- Find out who will be present during the visit, prior to the visit.
- Do not enter a house if the appropriate person is not available;

- Wait to be invited in or at least ask to enter, let them lead the way;
- Let them know how much of their time you will need;
- Do not enter if the person is drunk or aggressive;
- Ensure you can get out quickly if necessary;
- Do not spread out your belongings in case you need to leave the premises quickly.
- If you feel threatened at any point, abandon the visit and report to the line manager/supervisor ;
- Try not to react to dirty or smelly surroundings;
- Pets - remember not all pets are "friendly". If you are entering a house with a dog or cat, ask that the animal be put in another room if you feel uncomfortable. If you are "wary" of a dog, do not enter the house unless the owner is prepared to remove the animal from the room you are going to be in.
- In some situations, you may wish to set up a code word with your lone working partner, to enable you to signal that you have a problem. The risk assessment will need to make it clear what should be done if the code word is used.

If you are working with another organisation, such as the NHS, you must ensure that you are aware of their lone working policies and follow them. If there are any problems with their lone working policy, you should bring this to the attention of your line manager/supervisor, it may be that lone working in this situation is not appropriate.

## 7.7. Appendix 7: Consent form

### CONSENT FORM

I, the undersigned [*please give your name here, in BLOCK CAPITALS*]

.....  
of [*please give contact details here, sufficient to enable the investigator to get in touch with you, such as a postal or email address*]

.....  
hereby freely agree to take part in the study entitled Sibling Stories of Parental Mental Distress

*Please read the following statements before you agree to take part in this study.*

- 1) I confirm that I have read and understood the participant information sheet and I understand what my participation in this study involves.

Yes      No

- 2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I withdraw from the study after six weeks of when the interview has taken place, the data that I have submitted will also be withdrawn at my request.

Yes      No

- 3) I understand that the information that I will submit will be confidential and anonymous, used only for the purpose of this study

Yes      No

- 4) I agree that research data gathered for the study may be published and if this occurs precautions will be taken to protect my anonymity.

Yes      No

- 5) Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.

Yes      No

- 6) I agree to take part in the above study.

Yes      No

Signature of participant.....Date.....

Signature of (principal)  
investigator.....Date.....  
*WENDY O'NEILL*

## 7.8. Appendix 8: Debrief form

Dear Participant,

Thanks for taking part in the study 'Sibling Stories of Parental Mental Distress'. The information that you have provided will be kept confidential and all personally identifiable data will be destroyed after the completion of the research. You can ask to have your contribution removed from the study without giving a reason up to 6 weeks after participation.

1. What are the aims of the study?  
To look at sibling stories of parental mental distress.
2. What if I have any questions about the study that I would like to ask now?  
Please contact the researcher Wendy O'Neill at [wendyoneil101@yahoo.co.uk](mailto:wendyoneil101@yahoo.co.uk)
3. How can I contact the researcher if I have any further questions or if, for any reason, I wish to withdraw my data once I have left?  
Please contact the researcher Wendy O'Neill [wendyoneil101@yahoo.co.uk](mailto:wendyoneil101@yahoo.co.uk)
4. Can I obtain a summary of the results of the study? What form will this summary take?  
To obtain details of the results of the study, which will take the form of a written report, please contact the researcher at [wendyoneil101@yahoo.co.uk](mailto:wendyoneil101@yahoo.co.uk)

If the study has raised personal issues that you are not comfortable discussing with the researcher now – what should you do? Please seek advice and support from the following support networks included below.

Your local GP  
Your local IAPT service  
The Samaritans Telephone: 0800 11 11

If you have concerns about this study, or the way in which it was conducted, please contact the Wendy O'Neill (Principal Investigator) at [wendyoneil101@yahoo.co.uk](mailto:wendyoneil101@yahoo.co.uk) or Dr Pieter Nel at [p.w.nel@herts.ac.uk](mailto:p.w.nel@herts.ac.uk)

Thank you again for your participation and support.



## 7.9. Appendix 9: Interview schedule

### *Background and early experiences*

1. Tell me your story of living with a parent with mental distress?  
Prompt: Can you tell me about when you were first aware of your parent's mental health difficulties?
2. Can you say more about what it was like growing up with a parent with mental distress?  
Prompt: How did it impact on relationships in the home, outside of the home, school, how you were at home?
3. How did you make sense of your parent's difficulties?  
Prompt: what helped/ what didn't help?
4. How were conversations negotiated around your parent's difficulties at home?  
What was spoken about/ What remained unspoken?

### *Over time / Transitions*

5. How did this change as you got older?  
Prompt: on relationships in and out of the home, school, work, becoming a parent
6. How did your understanding of the difficulties change as you got older?  
Prompt: What helped/ Didn't help?

### *Sibling relationship*

7. Tell me what your relationship with your sibling was like?  
Prompt: Was your relationship affected by parental mental distress? In what way? How did you communicate with each other around your difficulties? How did you support one another? (in crisis)
8. How did this change as you grew up?  
Prompt: How did having a parent with mental distress affect your relationship over time? Is how you communicate now different? How do you support one another now?
9. How would your sibling's story be similar to your story?  
Prompt: In what way? Why do you believe this to be the case?
10. How might it be different?  
Prompt: in what way? Why?

## 7.10. Appendix 10: Ethical approval



### HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA ETHICS APPROVAL NOTIFICATION

**TO** Wendy O'Neill

**CC** Dr Pieter Nel

**FROM** Dr Kim Goode, Health, Science, Engineering & Technology ECDA Vice  
Chairman

**DATE** 30/08/18

---

Protocol number: LMS/PGT/UH/03356

Title of study: Sibling stories of parental mental illness

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

This approval is  
valid:

From: 30/08/18

To: 31/03/19

Additional workers: no additional workers named

Please note:

## 7.11. Appendix 11: Amended ethical approval



HEALTH SCIENCE ENGINEERING & TECHNOLOGY ECDA

### ETHICS APPROVAL NOTIFICATION

**TO** Wendy O'Neill

**CC** Dr Pieter W Nel

**FROM** Dr Simon Trainis, Health, Science, Engineering & Technology ECDA Chair

**DATE** 11/12/2018

---

Protocol number: **aLMS/PGT/UH/03356(1)**

Title of study: Sibling Stories of Parental Mental Illness

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**Modification:** Detailed in EC2.

This approval is valid: From:

11/12/2018 To: 31/03/2019

Additional workers: no additional workers named

**7.12. Appendix 12: Transcription contract**

**Doctorate in Clinical Psychology**

**University of Hertfordshire**

**Transcription confidentiality/ non-disclosure agreement**

**This non-disclosure agreement is in reference to the following parties:**

**Wendy O'Neill ('the discloser')**

**And**

***Insert Transcriber's Name Here* ('the recipient')**

**The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.**

**The recipient agrees to stop transcription immediately if they recognise any parties mentioned on the audio recording, and to return the recording to the discloser.**

**The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.**

**The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.**

**Signed:.....**

**Name:.....**

**Date:.....**

### 7.13. Appendix 13: Protocol for managing distress

Activity Description				
1. IDENTIFY RISKS/HAZARDS	2. WHO COULD BE HARMED & HOW?		3. EVALUATE THE RISKS	4. ACTION NEEDED
<p><u>Activities/tasks and associated hazards</u> Describe the activities involved in the study and any associated risks/ hazards, both physical and emotional, resulting from the study. Consider the risks to participants/the research team/members of the public.</p> <p>In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.)</p>	<p><u>Who is at risk?</u> e.g. participants, investigators, other people at the location, the owner / manager / workers at the location etc.</p>	<p><u>How could they be harmed?</u> What sort of accident could occur, e.g. trips, slips, falls, lifting equipment etc., handling chemical substances, use of invasive procedures and correct disposal of equipment etc. What type of injury is likely? Could the study cause discomfort or distress of a mental or emotional character to participants and/or investigators? What is the nature of any discomfort or distress of a mental or emotional character that you might anticipate?</p>	<p><u>Are there any precautions currently in place to prevent the hazard or minimise adverse effects?</u> Are there standard operating procedures or rules for the premises? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc/</p>	<p><u>Are there any risks that are not controlled or not adequately controlled?</u></p> <p><u>List the action that needs to be taken to reduce/manage the risks arising from your study</u> for example, provision of medical support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects NOTE: medical or other aftercare and/or support <b>must</b> be made available for participants and/or investigator(s) who require it where <b>invasive procedures</b> have been used in the study.</p>
<p>1. Interviewing participants about their sibling relationships and living with a parent with mental health difficulties. This may cause emotional distress and discomfort. It may also cause some anxiety as it may be that participants have not discussed their experiences previously.</p>	<p>Participants</p>	<p>Distress, discomfort or anxiety may result as a consequence of participants discussing their experiences.</p>	<p>Participants will be provided with all the information to make an informed decision about taking part in the research. Participants will be provided with information on how to seek additional support and also will be given the option of withdrawing from the study up within a</p>	<ul style="list-style-type: none"> <li>• Provide a comprehensive participant information sheet</li> <li>• Obtain informed consent</li> <li>• Provide the option to withdraw from the study up until a certain point</li> <li>• Provide information on where to seek support</li> </ul>

			six-week timeframe.		
Lone working by the investigator who will be interviewing participants about potentially difficult and distressing events.	Investigator	Verbal or physical aggression	Where possible interviews will be conducted in a quiet and confidential environment within a public place to minimise any negative risk to the investigator.		<ul style="list-style-type: none"> <li>• Arrange interviews to minimise risks of lone working</li> <li>• Adhere to lone working policy</li> <li>• Provide supervisory team with timings and location of interviews</li> <li>• Use de-escalation techniques if required</li> <li>• Terminate interview</li> </ul>

#### **7.14. Appendix 14: Example of initial impression of interview**

Aaron and Hannah

Tone of voice changes and Aaron speeds up when discussing his mother's behaviours. Hannah's voice becomes louder when she is describing difficult experiences.

Clear gender roles in the account, Aaron identifies as protector and shoulders the responsibility. Language of 'stepping up' supports this identity.

Interesting discussion about the absent sibling and their understanding of how she experienced it. Lots of language like 'zombies', 'possessed', 'dead', 'alien', 'creep', 'paranoia'.

It felt like they were still trying to make sense of it, lots of unfinished sentences.

Aaron positions himself as an expert of his mother's distress and asks Hannah questions in the interview.

Felt like there was a shared closeness and ease about their relationship despite not talking about their experiences together much before.

Because of their experience more interested in advocating and making other people's lives better than have similar experience.

Family identity strong and supportive and draws on the quest narrative.







<p>right, I think we should take you to the hospital, because she was so erratic and like her emotions were coming out so much like she would she would be so extreme and then she'd be suddenly like I'm gonna pass out and faint, like it was just it was really weird, and obviously then because she was loud at some points, the neighbors came out and got involved and she kept she just started punching dad and then yeah then the ambulance phoned and then they, I don't know what happened because Dad took me in</p> <p>A: Yeah</p> <p>H: and yeah, and I remember watching Finding Nemo [laughs] because he was just trying to distract me.</p> <p>A: Yeah, there's, a lot of distraction took place.</p> <p>H: Yeah</p> <p>A: Yeah from that point onwards, I think you were quite exposed to it, i think [Clare didn't see]</p>	<p>Distraction</p>	<p>Speaking to Hannah affirming her experience</p>	<p>Contrast in what was happening conflicting events at the same time</p>
---	--------------------	--	---

<p>H: [but like, three times]. (sounds slightly exasperated – raises voice, wry laugh)</p> <p>A: [Yeah]</p> <p>H: I was always there. [It was always like me]</p> <p>A: [for some reason]</p> <p>H I don't know why [Exasperated laugh]</p> <p>A: I know</p> <p>H: it was always me. (voice is louder)</p> <p>A: But yeah, that's the first kind of, when we think back and</p> <p>H: Yeh</p> <p>A: think when when did it start, it obviously didn't, that's when it first kind of came to the surface.</p> <p>W: Okay</p> <p>H: I don't know what triggered it. I don't know if something triggered it or what, but it just was like this one day</p> <p>W: um</p> <p>H: It just all came out and then she was sectioned and she</p>		<p>Emphasising the identity construction Speaking to Aaron and family</p> <p>Audience – researcher</p> <p>Mental health language</p>	<p>I am to blame/ identity</p>
--	--	--	--------------------------------



<p>H: She was on olanzapine</p> <p><b>A: Yeah</b></p> <p><b>H:</b> and that was what drove her</p> <p>A: yeah, it was the mixture of [I think]</p> <p>H: to suicidal thoughts</p> <p>[H: Yeh]</p> <p>A: of antidepressants</p> <p>H: Yeah, so she had a breakdown and then she got sectioned, she went into hospital and then it wasn't until she got , she came out she's very clever though, Mum's very clever.</p> <p>A: Yeh</p> <p>H: She's very good at pretending that she was good.</p> <p>A: But then all these kind of, all the the behaviors, kind of , her own kind of behaviors developed and we weren't entirely sure whether she's being genuine</p> <p>H: Yeh</p> <p>A: and we're going around the houses a bit . But yeah I remember, I used to</p>	<p>Disbelieving of mother's behaviour</p>	<p>Speaking to researcher, experts of their mother's distress, parental position</p> <p>Acknowledgement of research context – language used evokes a horror movie image</p>	<p>Identity of parentified children</p> <p>Wider societal discourse stigmatising</p>
---	---	---	--



<p>A: we tried to carry on as normal [after] that</p> <p>H: [Yeah], but you can't the thing is because you know what no one really understands what you're going through and you can't really share it either cos you can't really be like, oh, yeah well my mom's in the hospital. Oh, why is she in a hospital? Oh cos she's got mental problems</p> <p>A: Um</p> <p>H: because then it it I don't know it separates you from your friends, a little bit. So it's like no one else around you could really understand what's going on. But you had to pretend like you were normal, just very bizarre. Continue as if life is still fine. But really</p> <p>W: So I guess how did that impact on your relationships at home and school?</p> <p>A: So yeah for me, eh it moved from being us just having to emotionally support each other in the moment. Em it was a bit difficult with my dad because</p>	<p>Isolating</p>	<p>Trails off as finds it hard to put language to experience</p> <p>Confirming Aaron's story</p>	<p>Pretending things are normal</p> <p>Parentified child</p> <p>Helpful needed child</p>
--	------------------	--	--

<p>he was in a way the target a lot of the em the situation's, he was the target so he almost have to kind of take a step back and in a way, I think I kind of stepped forward at that [point].</p> <p>H: [Yeah] you had to take the role.</p> <p>A: Em so I , in a roundabout way became a little bit more kind of getting things done and also my mom responded quite positively to me sometimes so in the night sometimes if she was , I used to have to sometimes sleep on the floor, in the same room, and when she'd wake up and react em not many other people could, I dont think you or Clare probably reacted, you didn't like those situations [at all]</p> <p>H: [No, that's because] she used to do like demon faces.</p> <p>A: She used to think she was possessed, so so I used to, (H: inaudible) see things like that just to give you an idea of the kind of the situations it's why naturally I</p>		<p>Childlike language for mother</p>	<p>Leader</p>
--	--	--------------------------------------	---------------



<p>took a bit more of a lead role I suppose</p> <p>H: Yeah</p> <p>A: em but at the same time I became more aware of how you and Clare eh were I guess, I was worried about how you experiencing it trying to also protect you both from it.</p> <p>H: Yeah</p> <p>A: and em my dad as well, we had a couple of heart to hearts and thats the first time really because we were quite distant [before that]</p> <p>H: [But] I feel like I never really truly understood it</p> <p>A: No</p> <p>H: until I was probably like 16 when mom relapsed.</p> <p>A: Yeah, that was probably the second or third time but but in a way like we always when we look back at it and when we look at back at that first maybe first situation, or the second situation in a way, that's when we all , that's when we really started to through</p>	<p>Lack of understanding about PEMD</p> <p>Conversation facilitated understanding</p>	<p>Pronoun 'we' does this allow for other stories</p>	<p>Protector Role Hannah silent on her</p> <p>Quest narrative – relationship of father</p> <p>Change in understanding as Hannah got older</p>
---	---	---	---

<p>the kind of horrible situation was when we really started to talk more</p> <p>H: Hmm</p> <p>A: and feel like in a way I feel like going through those various situations did as cheesy as that sounds it did bring us all together, it did step by step. We became quite resilient to it, not resilient but we became better at dealing with it</p> <p>H: Yeah</p> <p>A: At knowing how to respond to each other and yeah if you know occasionally I'd be</p> <p>H: We were very calm</p> <p>A: like can you deal with this</p> <p>H: [quite calm]</p> <p>A: [Yeah], It's bizarre really at the [time]</p> <p>H: [Yeah], just think like the way Mum used to sometimes pick up like a coat hanger (laughs) or even a knife or something I don't know. She used to sometimes yeah do</p>	<p>Resilience</p> <p>Knowing how to respond and remaining calm were positive strategies</p>		<p>Quest narrative – relationship thrived</p> <p>Contrast in stories of being calm to a story about their mother's behaviour</p>
--	---	--	--

<p>that and we used to just be quite calm and be like Mum [do you mind]</p> <p>A: [You could], you could get quite intense at times.</p> <p>H: Yeah</p> <p>A: you just kind of roll [with it at the time]</p> <p>H: [I think] it made us more like you say just made us more aware of like, okay well, she's not actually going to physically hurt us</p> <p>W: hmm</p> <p>H: and she knows that if she did on that level it would it would push her completely away from us and deep down we knew that she didn't really want to do that , like it was it was the demon inside her that we used to say it was a demon inside her.</p> <p>A: But trust I think trust is a big one trust changed em. I think we all all four of us basically me you Clare and Dad to a certain extent we became quite trusting of each other and it's quite</p>	<p>Trust in relationships</p>	<p>Pronoun – You potentially creates distance</p> <p>You</p> <p>“Demon” talking to Aaron</p>	<p>Story of change in understanding</p>
--	-------------------------------	--	---

<p>ironic really because the whole and probably the biggest thing with our mum was trust. She didn't trust anyone or anything so we had to kind of be more, I dont now, sure [in our]</p> <p>H: [Yeah] She put a lot of trust into me that time that I went to work with her</p> <p>A: Oh yeah</p> <p>H: and then she relapsed. Yeah.</p> <p>A: But yeah, I think yeah, I think in a way its where we really see um, now our relationship like, between me and you, me and Clare and you and Clare is really when it started , probably the last, the third relapse is where you can see it right I'm trying to think (trails off) .</p> <p>H: [Yeah. Well, that's when] I grew up.</p> <p>A: [That's the start]. It's when we were all adults [at that point]</p> <p>H: [and then Yeah]</p> <p>A: whereas the first time it was kind of me the adult</p>	<p>Growing up and experiencing a number of events helped the understanding</p>		<p>"I could be depended on"</p> <p>Parentified role</p>
---	--	--	---

<p>H; taking</p> <p>A: and you two just em enduring it in a way and then second time Clare and me I think were a bit more</p> <p>H: hmm mm</p> <p>A: and then so it's almost like by the end point we were all kind of adults and we were all, I keep saying resilient, but that's not the word.</p> <p>H: Laughs</p> <p>A: But yeah [(slight laughter)]</p> <p>H: [We were warriors]</p> <p>A: but yeah we were much more better at dealing with it.</p> <p>H: Yeah</p> <p>A: and from that point, we've had a much stronger bond collectively</p> <p>H: Yeah</p> <p>A: and individually and as pairs and for me yeah with my dad like I feel like I really got to bond with him properly during that and we we regularly say like, oh</p>	<p>Sibling bond</p> <p>Father son bond</p>	<p>Not able to find language to describe</p> <p>Warriors</p> <p>We pronoun</p>	<p>Hero narrative of what was endured</p> <p>Contradicts of disengaged father</p>
---	--	--	---

<p>H: Oh I... its lucky that we got</p> <p>A: [we've been through everything]</p> <p>H: [like an] older brother really because like I feel like if you weren't obviously there then Dad would have massively struggled.</p> <p>A: Yeah but likewise I would have struggled without dad</p> <p>H: No</p> <p>A: so, we occasionally we acknowledge it almost I dont know, we find periods of time where things are particularly tricky and we're like oh we've been through that collectively, even if we're talking as siblings or</p> <p>H: Yeah</p> <p>A: or with with parents and that's so nice. I think it's nice to take a positive from a quite very negative situation and thats what we've done as a family really.</p> <p>H: Yeah we kinda laugh, well we don't</p>	<p>Sibling order of responsibility</p> <p>Positives of having an older sibling</p> <p>Resilience and being an adult</p> <p>Family support</p> <p>Talking helps</p> <p>Use of laughter as a coping strategy</p>	<p>We used for stories of success</p> <p>Pronoun 'we' supports family identity of togetherness</p> <p>We</p> <p>Laughs to support the story</p>	<p>Strong family identity</p> <p>Quest narrative that the family have taken positives from a difficult situation</p>
--	--	---	--

<p>laugh but try to just try (small laugh)</p> <p>A: try to</p> <p>H: to shrug it off. Yeah. We're just like do you know what, my mom's here now, she's fantastic. So and we're all close we're all great we all communicate, communications key as well massively so</p> <p>A: But it has shaped our relationships.</p> <p>H: Yeah</p> <p>A: It really really has like more than anything else, it's it's</p> <p>H: Well it's made us who we are now</p> <p>A: exactly. It's it's made the family more</p> <p>H: Resilient</p> <p>(Laughs)</p> <p>A: more, kinda more stronger, I think, through it,</p> <p>H: Yeah, massively</p> <p>A: collectively, all of us including my mom as well so.</p> <p>W: And I was just wondering Aaron kind of had the</p>	<p>Communication is helpful</p> <p>MD shaped relationships</p>	<p>Reiteration of something that works</p> <p>Co-constructing by confirmatory dialogue</p>	<p>The family is doing well</p> <p>We are because of the experience – identity family as strong</p>
---	--	--	---

<p>relationship where he took on a parent role it sounds like</p> <p>A: Um</p> <p>W: What was your relationships then like with the rest of your family at that time when your mom first became unwell?</p> <p>H: I think I struggled. I don't know. I think em I relied on a lot of people probably more than became a responsible adult, or responsible child, because I was young so young. I didn't really understand it and I was a bit like discombobulated with it all so I don't know I think my role was to just try and carry on as I could be supportive or help out like help out as much as I could as well really. I don't know there was like little things but when you're 14 or 15, you still leave mess in the living room and you're a teenager so you kind of I don't know, you don't have as probably as much of the utmost respect as what you had and Dad and stuff. So that's where I feel like felt like me and Clare</p>	<p>Family alliances</p>		<p>Story of coping and needing support because of her age – identity as a supportive and helpful child – contrast in having a caring role while also trying to be a child</p>
--	-------------------------	--	---



<p>probably took more of a bonding sesh through it. Until like the third relapse, so I don't know really.</p> <p>W: Yeah</p> <p>H: It's quite difficult.</p> <p>W: What do you mean when you say a bonding sesh?</p> <p>H: Well, we were I don't know because we were both in the same room. We both shared a room together and [we were both]</p> <p>[A: yeh that's true]</p> <p>H: we both woke up at the same time when you were holding mum up or whatever.</p> <p>W: Mmm</p> <p>A: That's like that's like the biggest situation we ever had that was like one night and I think you know yeah</p> <p>H: where it really</p> <p>A: we, thats when it was like, oh gosh that's something else and em you I forget you were sharing a room.</p>	<p>Close proximity to sibling and close – other sibling</p>		
--	---	--	--

<p>H: yeah, so me and my sister used to share a room that's why I thought like oh me and her yeah.</p> <p>W: So would you talk about what's going on for your Mom at the time?</p> <p>H: yeah yeah we used to speak not a lot, Clare [A: no Clare was] was still she was she was quite distant from it or she seemed like she was quite distant, she's kind of dealt, she's very individual. Em so she kind of dealt with it in our own way, but I felt myself opening up a lot more to her and I felt I off loaded a lot</p> <p>W: mmm</p> <p>H: and she would just sort of sponge up a little bit and then probably deal with her own issues and mine.</p> <p>A: She would get emotional very easily.</p> <p>H: [she did]</p> <p>[A: when she was]</p> <p>H: she was she was more sensitive than me actually, I think</p>	<p>Sibling support and story of other sibling – different experiences</p> <p>Talking helped</p> <p>Sibling support – listening to me and balancing her own needs</p> <p>Impact of the support</p>		<p>Discussion around the other sibling makes me think what their story might be and how she would construct her story in the context</p>
---	---	--	--

<p>she was quite sensitive</p> <p>A: Yeah</p> <p>H: with</p> <p>A: Yeah I remember just her crying a lot, very easily</p> <p>H: Yeah</p> <p>A: very easily. Yeah, yeah. Yeah you and her, your relationship changed through all three of the relapses and now do you ever talk about it? [ soft tone of voice]</p> <p>H: Uh uh, no we just talk about boys (laughs).</p> <p>A: true.</p> <p>H: [laughs]</p>	<p>Still hard to talk about it</p>	<p>Aaron performing researcher's role</p>	
---	------------------------------------	---	--



## **7.17. Appendix 17: Reflective diary example**

### Reflections on the recruitment process

Once I started the recruitment process, a lot of things came up for me. I felt nervous posting on a social media site for mental health users as I felt the members of the site were coping with lots of difficult life events and distress and my study request felt an imposition. I have just received one inquiry from my post on Facebook. This made me think about how my information sheet is being perceived. Just read through it again and thought how I could make it more accessible.

I am also considering how difficult it might be to recruit a sibling pair as chances are, I will only be making contact with one sibling. I think it would be good to discuss this in supervision next time we meet.

### Reflections after interview 2 – Anna and Karen

Very broken family context – 3 mothers with MD. Anna and Karen made lots of eye contact and took turns, did not speak over each other. Karen tended to speak first and appeared disconnected emotionally growing up. Anna appeared to be absent in the early story of childhood. I was struck by how they recalled their story, they spoke measuredly, had talked about it before. There appeared to be lots of content and less emotion both said after that they thought they would cry but the interview felt lacking in emotion. I felt like I had lots of empathy for them and felt somewhat tearful thinking about their experience. I felt they were engaged, reflective and used humour to convey difficult times. Anna might have been speaking to me as a professional at times. I wondered about my use of questioning and whether I use too many prompts however they were less talkative than interview 1 and prompts felt needed.

This interview was very different from the first interview as their biological mother was not in their lives. They had no contact with her.

Second interview completed and I have found the interviews so engaging and want to honour their experiences and stories.