

**A retrospective study of young carers'
experiences of supporting a parent with
psychosis**

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“You never understand a person until you consider things from his point of view...until you climb into his skin and walk around in it.”

Harper Lee, *To Kill a Mockingbird*

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1. ABSTRACT

There are a considerable number of children who fulfil a young carer role for a parent, sibling or relative. Research into the experiences of young carers is growing, and has explored the areas of supporting parents and siblings with physical and mental health difficulties. Although research into the experience of adult carers of individuals with psychosis-related difficulties is well established, the experience of young carers supporting a parent with a psychosis-related difficulty are yet to be studied. The aim of this study was to gain a richer understanding of the lived experience of young carers supporting a parent with a psychosis-related difficulty from a retrospective position. Semi-structured interviews were conducted with seven adults who were young carers for a parent with a psychosis-related difficulty. The interview transcripts were split into two parts and analysed using Interpretative Phenomenological Analysis. Part one explored the experience of caring at the time, with two themes emerging from participant's accounts: 'Feeling isolated and alone' and 'Caring was taking the parent role'. Part two explored the integration of the experience into the current self, with two themes emerging: 'Understanding the experience is an ongoing struggle' and 'Making sense of the person I have become'. The findings are discussed in light of the current research literature and show both areas of agreement and unique insights into the experiences of this particular group. Clinical implications in light of the findings and future research suggestions are also considered.

2. INTRODUCTION

2.1 General Introduction

There are many children in the United Kingdom (UK) who live with and support a parent experiencing illness, disability or mental health difficulties. These young carers are now beginning to be acknowledged as significant providers of care, with research and policy into their experiences and needs beginning to emerge. However, there is still much to be explored and understood about the experience of supporting a parent experiencing psychological distress. In particular, the experiences of children who have supported a parent experiencing a psychosis-related difficulty are largely absent in the research literature, although research into the experiences of adult carers of individuals experiencing psychosis-related difficulties is growing. As such, this study aims to explore how young carers have experienced supporting a parent with a psychosis-related difficulty, and how these young carers have understood their experience in their later life.

2.2 Use of Language

This doctoral thesis will predominantly be written in the third person. However, on occasions the first person is employed to make explicit the stance of the researcher.

In referring to individuals who have cared for a parent with mental health difficulties, the term 'young carer' will be used. While recognising that this term may not feel appropriate to some individuals who have provided care to their parent(s), much of the literature within this area highlights the significant level of care offered by children and the largely unrecognised nature of this care giving. As such, in an effort to acknowledge and raise awareness of this significant caring role it feels important to use the term 'young carer'.

The term 'psychosis-related difficulties' will also be used throughout, unless referring to literature which has used different terminology. This decision stems from acknowledgement of the highly contested validity of psychiatric diagnoses, particularly schizophrenia (see Bentall, 2003, 2014; Van Os, 2016) and also a desire to recognise the variety and differences in how psychosis-related difficulties are experienced. At times, terms such as 'disability' or 'disorder' or particular mental health diagnoses may be used, to remain congruent with the sources which have used these terms within their explanations.

2.3 Definition of Key Terms

1. What is meant by the term 'Young Carer'?

Due to growing awareness, the definition of a young carer has undergone significant change over recent years and often differs across services and agencies (Doutre, Green & Knight-Elliott, 2013). The definition used within this research will be that of Becker (2000, p378):

Young carers are children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult.

This has been chosen due to its use within research and policy in the UK. Additionally, this definition highlights both the completion of caring tasks and the elevated level of responsibility associated with caring for a parent experiencing mental health difficulties.

2. What is meant by the term 'Psychosis'?

The term psychosis is used as a broad categorical term associated with a number of diagnoses which historically were grouped together and distinguished from 'mood disorders' (Hayward, Meddings & Harris, 2015). A common feature for individuals experiencing psychosis seems to be a sense of loss of connection with what others typically experience as reality. However, there is considerable debate about what may be the most helpful term to refer to experiences which are often described as psychosis, which is reflected in the use of several different terms (Division of Clinical Psychology, 2014). For this research, a definition based on the experiences of psychosis reported by the Division of Clinical Psychology (2014, p10) will be used:

Experiences which include those sometimes called hallucinations (for example, hearing voices, seeing, smelling or tasting things that others do not), holding strong beliefs that others do not share, difficulties with thinking and concentrating and difficulties with motivation and engaging in everyday living.

This was chosen due to its recognition of the multiple experiences that individuals with a psychosis-related difficulty may report and as it is hoped that potential participants within the study will find the definition easy to understand. Faulkner (2012) suggests that health professionals focussing on particular symptoms and diagnoses often results in people having little opportunity to tell their stories and make sense of their experience. Therefore, a broad definition of psychosis will be used in this study to help minimise this, rather than having a narrow focus which employs diagnostic criteria. There is debate regarding the validity of diagnoses within the mental health field, and the search for a more effective system continues (See Bentall, 2003; 2014).

2.4 Position of the Researcher

2.4.1 Personal Relationship with the Research Topic

In completing this research, it is important to acknowledge and reflect upon my position as researcher. Finlay (2002) highlights how research is a co-construction between those involved, with the researcher being a central figure of influence in the collection, selection and interpretation of data. Therefore, it is important that the researcher engages in reflection and self-reflexivity in order to acknowledge these areas of influence.

My interest in young carer related issues stems from my experience of being a young carer for a parent with a physical health problem. I found that after leaving my family home environment, I was able to begin the process of reflecting on my experience and understanding how it influenced my values and life decisions. In particular I feel the experience influenced my choice of a healthcare career, and has provided me with some skills necessary to fulfil this role.

Prior to clinical psychology training, I was very fortunate to work within a psychology and family therapy team who actively sought to raise awareness and meet the needs of carers and service-users who were experiencing severe mental distress. This was my first introduction to the Triangle of Care approach (Worthington, Rooney & Hanan, 2013), and through this team I was able to witness the importance of recognising the effects of mental distress on both the person experiencing it and all those around them. It particularly highlighted how often the needs of children living with parents experiencing psychological distress were overlooked. This experience has certainly shaped my beliefs around the importance of recognising all those who may be affected when someone is experiencing psychological distress, and particularly those closest to that person such as children and family members.

2.4.2 Theoretical Position

It is impossible to engage in knowledge creation without at least tacit assumptions about what knowledge is and how it is constructed, and so epistemology is inescapable (Carter and Little, 2007). The views and assumptions which I hold will influence each aspect of the completion of this research study, and so I will attempt to make these explicit as much as possible.

My reflection upon my epistemological position has developed through my doctoral training in clinical psychology. Over recent years I have been invited to consider my position in relation to the creation of knowledge, and have found it both a frustrating and fascinating process to engage with. Initially, I found it quite disconcerting to move away from the safe certainty of objective truths. However, the more I have engaged in both clinical and theoretical work, the more I have found it helpful to draw on a position of tentativeness and multiple truths. Although my position may change, at present I feel most drawn to considering the social construction

of knowledge, as this corresponds with my beliefs of knowledge being both culturally and time bounded (Burr, 2003). I now reject the positivist idea of determinable objective 'truths', instead believing that all information is co-constructed through interchange between people (Gergen, 1985), and that this co-construction may differ at different times and places.

Therefore, I have sought to develop a study which can acknowledge the multiple views and meaning-making which can be co-created about the experience of caring for a parent experiencing a psychosis-related difficulty. In order to work towards this, I will attempt to be explicit in my contribution throughout the study.

2.5 Prevalence

Statistics from the 2011 census suggest that around 244,000 people under nineteen years are fulfilling carer roles within the UK, with 23,000 of those being under nine years old and the majority being female (Office for National Statistics, 2013). This is an increase from the figures gained through the 2001 census data, and in light of current economic and political influences this number is likely to increase further in future. Children in single parent families are more likely to become young carers (Deardon & Becker, 2000). It is likely that young carer numbers are under-reported, as several barriers affect the visibility of children who fulfil caring roles. Children may fulfil carer roles for their parents, siblings or extended family. As Doutré et al. (2013) highlight, there is no agreed definition of a young carer, and the 'young carer' label is often given in relation to the young carer services available, which themselves vary considerably.

2.6 Awareness and History

Providing care and support to others can be considered a culturally held value within the UK. However, the recognition of carers and the level of support that they provide has only in recent decades become an area for research and exploration. For the first time, the 2001 UK census asked the entire population about caring responsibilities and general self-rated health (Doran, Drever & Whitehead, 2003). With this growing awareness, carers and their needs within healthcare and governmental policy are slowly becoming more recognised.

Despite significant developments in recognition and research into adult carers, the experiences and awareness of children as carers has not experienced the same level of attention. It is expected that some degree of caring in childhood will occur, and is encouraged as part of 'healthy' child development (Aldridge & Becker, 1999). However, it is the degree to which children are fulfilling this role which requires recognition. Children's involvement in care giving has been slow to come to the attention of academics, researchers and policy makers (Earley, Cushway and Cassidy, 2007). In recent times, young carers have received some recognition within health and social care policies, leading to the development of support

services. Additionally, researchers have begun to explore both the prevalence and the experiences of young carers.

2.7 Philosophical Issues in Young Carer Research

2.7.1 The Disability Rights Perspective

Developed from a social model of disability, the disability rights perspective holds the position that the person experiencing a disability requires adequate recognition and their needs to be addressed, within the context of their family and social connections (Aldridge and Becker, 1999). As such, in situations where a child is providing care for a parent experiencing disability or illness, it could be argued that the attention and support needs to be focussed on the needs of the parent. Olsen (1996) suggests that research so far into young carers has paid inadequate theoretical attention to disabled people as parents. Furthermore, Newman (2002) states that the preoccupation with the rights of children has diverted attention and possibly resources away from the needs of families. Aldridge and Becker (1999) suggest that this stance implies that if the needs and rights of the disabled parent were adequately recognised and supported, there would be no need for children to fulfil young carer roles.

A central criticism of young carer research is the portrayal of the experience as mostly negative and potentially damaging. Newman (2002) suggests that many disabled parents feel pathologised and disempowered through the increased perception that their impairments are seriously affecting their children's welfare. He suggests that there is a lack of empirical evidence to support claims that fulfilling a young carer role is likely to lead to mental and physical health degradation, lowered educational attainment or long-term consequences in adult life. Parents with mental health difficulties are likely to feel highly pathologised and judged in their role as a parent. Additionally, both Olsen (1996) and Newman (2002) highlight the potential importance of external factors such as poverty, social exclusion and inadequate parenting support as being influential in how well families are able to manage the difficulties associated with a parent experiencing illness or disability.

2.7.2 The Children's Rights Perspective

The children's rights perspective has emphasised the importance of recognition, identity and agency of young carers (Aldridge & Becker, 1999), as well as the need to listen to their views about their own experiences and needs. As such, the implication of this stance is that young carers need to be recognised and supported in their own right. Research which adopts a children's rights perspective often focusses on how children within their caring role exercise their competency and experience their role adoption as a consequence of parental illness (Aldridge & Becker, 1999).

Aldridge and Becker (1997) state that regardless of intervention, it is likely that children will always provide care in some instances. Therefore, the suggestion of the disability rights movement that adequate services for the parent would diminish the need for young carers is unlikely to be supported in practice. In relation to the assertion that much of the literature surrounding young carers focusses on the negative implications of fulfilling this role, Aldridge (2008) highlights how the caring role can be associated with many positive gains. However, these benefits can be undermined by a lack of recognition of the potential needs of young carers, again supporting the need for a children's rights perspective within both research and policy. Another criticism of young carers research from a disability rights perspective is based on the belief that research, policy and practice which focus on children's caregiving is not helpful to parents living with the reality of impairment or illness or to their children (Morris, 1997). However, these perspectives do not have to be mutually exclusive, as there is need to explore and understand the reciprocal roles and relationships that occur between young carers, their parents and other members of their family (Aldridge and Becker, 1999).

2.7.3 Current Philosophical Position of Young Carer Research

At present, there appears to be an acknowledgement of how both the children's rights and disability rights perspectives can be held within young carer research. Olsen (2000) stated that the debate between the disability and children's rights perspectives has now matured, with recognition that it can no longer be seen in simple, dichotomous terms. Both sides of the debate agree that better service provision is required for parents experiencing illness or disability as well as for their children, and that external factors such as disadvantage worsen the situation for both groups (Fives, Kennan, Canavan & Brady, 2013). Similarly, Aldridge and Becker (1999) highlight that young caring cannot be viewed in isolation from the family, with needs and responsibilities associated with all family member roles. This is reflected in recent policy, where a 'whole family approach' is encouraged (The Children's Society, 2014).

A key critique of young carer research is that of the comparison of young carer experiences against a supposed 'normal' childhood, which invariably highlights areas of loss. O'Dell, Crafter, de Abreu and Cline (2010) suggest that this comparison risks over-simplifying complex family systems, ignoring young people's agency and depreciating disabled parents' actions and wishes. They suggest that it is important to acknowledge that the dominant Westernised discourses of childhood privilege individualistic notions of development which are ultimately based in the assumption that children should be cared for rather than provide care themselves. Therefore, within young carer research it is important to consider the social construction of childhood, and how these discourses may reflect the cultural discourses surrounding childhood and individual development.

2.8 Children's Development and Understanding

2.8.1 Developmental Frameworks of Childhood Development

The experience of young caring occurs during an important time of individual development, which in itself adds to the conceptualisation and understanding that an individual makes of the experience. Theories of childhood psychological development include Piaget's (1971) Cognitive-Developmental theory and Vygotsky's (1978) Sociocultural theory. Additionally, Erikson's (1950) Theory of Psychosocial Development also offers a framework for understanding individual development across the lifespan. Piaget (1971) proposed a stage model of childhood development, with brain development occurring in the context of expanding experience, which it is suggested results in four distinct stages within a child's thinking processes. Piaget proposed that the thinking of a child is distinctly different to that of an adult, and that as a child ages and moves through each stage of development, their cognitive capabilities become more complex and refined. However, this theory has received some criticism, particularly that it underestimates the competency of infants and pre-school children (Berk, 2007). As such, when applied to a young carers situation, this theory proposes that a child's thinking and understanding of their experience will differ according to their age and stage of development, and that as adults, they are likely to think in significantly different ways about their experiences to when they were children.

Vygotsky's (1978) Sociocultural Theory of Development focuses more on the culture in which a child grows up and suggests that this has a great influence on their development. It is suggested that cognition is a socially mediated process, with children's development being dependent on the assistance of adults and expert peers (Berk, 2007). When applied to young carer experiences, Vygotsky's theory would suggest that the child's skill development will be based in what they are modelled by the adults and expert peers around them. As such, if their parents or older siblings are more absent, the young carer's cognitive development may be hampered. However, if the young carer has adult support and guidance, their caring skills and capabilities may become highly developed, as this is the culture that they are growing up within.

Finally, Erikson (1950) proposed a stage model of psychosocial development which spans the lifetime. Erikson (1950) suggests that there are a number of stages within life which individuals are required to resolve fundamental crises on their journey towards developing a robust and healthy personality. Erikson (1950) proposed that failure to complete these stages will result in the individual carrying issues forward, and so not developing a healthy personality, although it is suggested that these crises can be worked through successfully at later stages of life. In terms of young carers, Erikson's theory may suggest that due to their experiences, children may be unable to resolve some of the crises associated with different life stages, which may

affect their personality development. An example relevant to young carers may be managing the life stage of Industry versus Inferiority, which Erikson proposed to occur between the ages of six and eleven years. This stage is underpinned by the child's ability to feel competent at home and school, which may be understandably affected by their caring role, leaving them with the belief that they are inferior in comparison to others.

2.8.2 Children's Understanding of Parental Mental Health Difficulties

In line with their developmental stage, children are likely to have different understandings of their parent's mental health difficulties at different ages. Bromley, Hadleigh and Roe (2012) suggest that an understanding of how children make sense of their experiences of parental mental health difficulties is important in understanding resilience; however, in their review of the literature, they suggest that a common theme is young people's lack of understanding about their parent's difficulties. Similarly, Walsh (2009) commented on how research investigating children's understanding of mental health is scant, but suggests that research into this area appears to suggest that children who can conceptualise their parent's mental health difficulties as something 'outside' of them tend to have better outcomes than children who see these difficulties as embedded within their parent. However, Walsh (2009) also states the importance of recognising cultural understandings, and states that research into the area of parental mental health appears to assume that there is an agreed definition of mental ill health which children's understanding is compared to.

Mordoch (2010) also reported that children appeared to have a limited understanding of parental mental health difficulties, and stated that this lack of information resulted in undue hardship for these children. Additionally, Mordoch (2010) found some differences in the understanding of children at different ages, perhaps in line with their developmental progress, where younger children were concerned that their parent may die and older children were concerned with developing mental health difficulties themselves. Overall, the research literature acknowledges the lack of investigation of how children understand and make sense of their parent's experience of mental health difficulties. Generally, a lack of understanding is reported, which is associated with increased hardships and reduced resilience. However, there are also some findings to support that children's understanding differs at different ages, potentially due to their own cognitive development.

2.9 The Recognition of Young Carers in UK Policy

The importance of recent policy to support the service provision for young carers was highlighted by an expert by experience who provided consultation on the research project. They reflected on how policy has evolved over time, highlighting how although there are many helpful resources made available through this, carers are often unaware of the legislation there to support them.

Young carers were included for the first time in governmental policy in the Carers (Recognition & Services) Act 1995. Within this, young carers became able to request a carer's assessment from local authority services. As time has passed, there has been growing recognition of the role of a young carer and their associated needs. Caring about Carers: A National Strategy for Carers was published by the Department of Health (DoH) in 1999 which highlighted how carers can expect to receive information, with a chapter dedicated to recognising young carers and highlighting associated areas of support and care.

In 2009, the Office for Standards in Education, Children's Services and Skills (Ofsted) surveyed how well councils identified, assessed the needs of, consulted with and addressed the needs of young carer's supporting a disabled parent. They reported that young carers in the areas they visited were not known about or receiving support. Key barriers of a lack of professional awareness and reluctance of families to engage with support services were identified. Additionally, councils were not routinely considering the views of young carers when assessing the needs of, and delivering care to their disabled parents. Therefore, it was recommended that young carers are given sufficient priority within councils, that professionals raise their awareness of young carers and ensure that young carers are aware of their right to an assessment of their needs.

More recently, the majority of young carers' right to access assessment is upheld through the Children's and Families Act 2014, which requires councils to check what help a young carer may need once they are aware that there is a need. However, several barriers may prevent young carers from requesting an assessment of their needs, including a lack of knowledge of the availability of this service, their own beliefs about involvement from outside agencies, and potential reluctance of local authority services to offer assessments when support services may not be available. Although the recently updated Care Act 2014 relates mostly to adults, it encourages awareness of family circumstances which may help prevent the role of a young carer being overlooked. The act also sets out new rules about working with young carers and ensuring effective planning for support.

2.10 The Development of Young Carers' Projects

In recent years, emphasis has been given to developing effective support services for young carers. There are a number of young carer services in the UK, which typically offer support to young people who are fulfilling a caring role, and also promote access to breaks and leisure activities. Additionally, they provide access to a supportive social network of other young carers. Aldridge and Becker (2003) suggest that what young carers most need is access to services, support to make decisions about their caring role and opportunities to discuss their experiences. As the 2014 Children and Families Act now requires an assessment of young

carers' needs to occur as soon as local authorities become aware of their young carer status, it is important that there are appropriate services to offer support after these needs are identified.

2.11 Invisible Carers

Despite the growing interest in researching and supporting young carers, they largely remain a 'hidden group'. This may be exacerbated through professionals not actively seeking out young carers or recognising their contribution to their parents' care. Seeman & Göpfert, (2004) state that in many mental health services, parenting identity does not receive sufficient recognition, irrespective of the 'patient's' diagnosis or type of service provided. Similarly, Aldridge and Becker (1993) suggest that professionals were not engaging in discussions with young carers about their caring role or experience. More recently, the Care Quality Commission (CQC) and Ofsted (2013) reported that young carers were still poorly identified.

Gray, Robinson and Seddon (2008) reported that professionals perceived isolation as the biggest challenge to young carers and described this group as 'invisible'. Additionally, Thomas et al. (2002) described the most striking feature of their research into the experiences of young carers in Wales was the extent to which their needs appear to go unrecognised. The authors targeted schools for their research population and experienced very little response or a claim that no young carers were present, suggesting difficulties in the recognition of young carers by professionals within the education system. Similarly, Fives et al. (2013) proposed that the difficulty they experienced with recruiting young carers into their study based in Ireland was itself a finding, as it highlighted the hidden and covert nature of caring in this group. They also identified gaps in the awareness of professionals about the prevalence of young carers. This invisible status also remains into adulthood, with adults who have previously been young carers often not recognising themselves as 'young carers' (Lackey and Gates, 2001). These research findings highlight the need for greater recognition of young carers by the different professionals which may be influential in their lives.

2.11.1 Reluctance to Come Forward

The visibility of young carers is often influenced by the beliefs that both they and their family may hold about the risks of letting others know of their situation. Aldridge and Becker (1993) report how one of the effects of providing care was that young carers appeared reluctant to discuss their experience with others, which silenced them further. Banks et al. (2002) highlight how young people's reluctance to discuss their experiences may contribute to their 'hidden' nature and found that young carers were encouraged by their parents not to discuss their situation to maintain family privacy. Young carers are often reluctant to identify themselves or to discuss how much care they provide for fear of professional intervention (Jenkins and Wingate, 1994). This may include fears of the family being split up and the children being

taken into care. Similarly, Underdown (2002) reported how many young carers felt isolated and unable to disclose their difficulties due to fears of being bullied by other children or being taken into care by the authorities. This reluctance expressed by young carers combined with the difficulty that professionals experience in identifying potential young carers is likely to serve to keep them 'hidden' from services which may potentially provide support.

2.12 Young Carers: A Diverse Population

As expected with a large group, there can be considerable differences in the care offered, responsibility undertaken and person who is cared for by young carers. Young carers are not a homogenous population and often have diverse families with varied needs (Doutre et al., 2013). Some of this diversity will be briefly discussed below.

2.12.1 Caring for Parents with Physical Health Needs

Many young carers support a parent with a chronic health condition. Lackey and Gates (2001) investigated the experiences of children caring for a parent with chronic physical illnesses, such as cancer or stroke. They highlight factors such as longer life expectancies and increasing single parent families as likely to contribute to growing numbers of children offering care to chronically ill adults. They report that personal care tasks were most frequently performed by young carers, and were perceived as the most difficult. Additionally, they found that changes in family dynamics and stress levels occurred, and young carers reported less time to engage in schoolwork.

Prilleltensky (2004) investigated the views of mothers with chronic physical illness and offers a different perspective. The author, who is a parent with a chronic health problem, highlights how disability is often viewed as dependency, and suggests that many parents with disabilities are reluctant to come forward for support due to potential assumptions about their reduced parenting ability. A theme of parents attempting to protect their children from any burden associated with their disability was highlighted, as well as there being no indication of children adopting caring roles within the study. The conclusions reached suggested that parental disability need not compromise the welfare of children, and the impact of factors such as single-parent families and poverty require recognition.

Although only a brief snapshot, these studies exemplify the debate inherent in young carer research. Young carers supporting a parent with physical health issues report areas of their lives which are affected, while parents report working hard to try and limit this. A key finding is the barrier of perceived attitudes of inadequate parenting which may prevent parents with difficulties from coming forward. It is arguably likely to be similar or intensified for parents with mental health difficulties, who are already likely to experience significant stigma. What is similar across the research into parents with physical health difficulties and their children is

that support is often lacking at the family level, and if this could be addressed it would likely lead to better outcomes for all family members.

2.12.2 Caring for Siblings

Recently, the experiences of young carers who support a sibling with a disability or illness have been recognised. Aldridge and Becker (2004) completed a large-scale survey of young carers within the UK accessing specialist services, and found that 31% provided care to a sibling. Hartling et al. (2014) suggested that illness and disability in children can impact negatively on the psychological health of their siblings, through reorganisation of family roles and shifting of goals and values. However, Damiani (1999) reviewed the research into the psychological adjustment of siblings of children with disabilities, and concluded that both higher levels of responsibility in siblings, and the classification of responsibility as a risk factor were not supported.

Barnett and Hunter (2012) indicate that a considerable number of studies have investigated siblings of children with medical, physical and developmental difficulties, but that the experience of siblings supporting children with mental health difficulties has been largely overlooked. Additionally, a substantial focus of the research is on the role of adult sibling carers, particularly in light of managing without parental support later in life. Overall, the area of young carers of siblings requires further investigation, particularly looking at the experience of supporting a sibling with mental health difficulties.

2.12.3 Caring for Parents with Mental Health Difficulties

Research into the experiences of children of parents with mental health difficulties is growing. However, at present there is no research into the experiences of young carers for a parent with a psychosis-related difficulty, although research into the experiences of carers for adults experiencing a psychosis-related difficulty is established and offering insights into the support which carers require to fulfil their role. As such, a brief exploration of the experiences of adult carers of individuals with psychosis-related difficulties will be presented.

McCann, Lubman and Clark (2009) investigated the experiences of adult carers for individuals experiencing their first episode of psychosis (FEP). They reported that caregiving is a highly unpredictable, burdensome activity. Participants described an increased sense of responsibility, along with increased isolation due to the perceived stigma surrounding FEP. However, some participants reported experiencing a closer relationship with the person they cared for. Similarly, Wainwright, Glentworth, Haddock, Bentley and Lobban (2015) investigated relatives who supported a family member experiencing early psychosis. Relatives reported finding it difficult to understand both the diagnostic terms used and the lived

experience of psychosis. Additionally, participants reported a strain on family relationships and difficulties in gaining recognition and support from healthcare services.

Although many research findings report the difficulties associated with caring for relatives experiencing psychosis-related difficulties, there are also some positive aspects. Family members providing care is important for the recovery of individuals with psychosis-related difficulties, which subsequently reduces the burden experienced by the family (Ewertzon, Lützén, Svensson, & Andershed, 2010). Additionally, caregiving gains are prevalent in families supporting an individual experiencing schizophrenia, and include becoming a better and more understanding person, while gaining an inner strength (Chen and Greenberg, 2004). As such, it is suggested that caring for a relative is a complex role, associated with increased responsibility and potential isolation due to stigma and changes in family relationships. However, fulfilling a carer role is also associated with positive gains for both the person experiencing psychosis-related difficulties and the carers themselves, including enhancing recovery and gaining personal development and strength.

2.12.4 The Relationship between Gender and Caring

As the 2011 census data showed, the majority of young carers are female (Office for National Statistics, 2013). This is in line with research into caring populations generally, which typically report greater numbers of female, rather than male, carers. McKie, Bowlby and Gregory (2001) highlight how employment and social policies continue to support a gender template of caring which assumes that adult women are or should be natural carers. Although there appears to be little research into the relationship between gender and young caring, Eley (2004) reported that girls were more likely to be involved in all aspects of caring, and highlighted the expectation held in some families that these young women would 'naturally' possess the skills required, and also would want to do it. Additionally, Cree (2003) reports that girls in a caring role were far more likely to report problems and worries than boys, and discuss how this may be suggestive of girls being more willing to express their feelings or possibly that there are issues related to young caring which are more troublesome for girls than boys. As such, gender appears to have an important influence on those assigned as young carers and also on the experience of the caring relationship.

2.13 Theoretical Models

2.13.1 Parentification

A commonly applied theoretical framework for understanding the experiences of children whose parents experience mental health difficulties is parentification. Boszormenyi-Nagy and Spark (1973) define parentification as the distortion of a relationship between parent and child, where the parental figure expects that a child will fulfil a parent role within the family system.

Similarly, Minuchin (1974) proposed the term 'parental child' and described this being evident through the child's crossing of the boundary of the parental subsystem in order to care for siblings. This was considered a natural act to support families which may be strained by the size of the parent's workload, but also noted that this boundary crossing may contribute to wider family issues. Jankowski, Hooper, Sandage and Hannah (2013) describe parentification as the child carrying out instrumental tasks such as caregiving for siblings or emotionally comforting a parent. Earley and Cushway (2002) state that 'role reversal' is another term describing the phenomenon of parentification, and defines it as a child acting as a parent or a 'mate' to their parent.

The potential long-term consequences and negative outcomes for individuals who have experienced parentification have been explored within the literature. Hooper, Marotta and Lanthier (2008) suggest that parentification could arguably constitute neglect, as the parent relinquishes their parental role in order to gratify their own needs. Byng-Hall (2008) suggests that parenting roles can form part of a child's identity within a family, which may prevail for a long time within their life. Similarly, Boszormenyi-Nagy and Spark (1973) suggest that the interpersonal patterns of relating gained from parentification are likely to be passed down generations, as the adult seeks to address their childhood losses through their own relationships. Wells and Jones (1998) suggest that parentified individuals who have had to deny their own needs often use the mechanisms of splitting and dissociation to protect against uncomfortable feelings of separation and disappointment with their parent. Finally, when a parental-type role becomes a consistent way of systemic functioning it is thought to have negative consequences for that parentified child (Jankowski et al., 2013).

However, parentification should not be unconditionally described as pathological or relational dysfunction, as it is a core component of even balanced, sufficiently reciprocal relationships (Boszormenyi-Nagy and Spark, 1973). More recently the focus has shifted from investigating negative consequences to considering the strengths and resources that parentified individuals may possess. Byng-Hall (2008) suggests that children taking on appropriate parental tasks which are validated, while maintaining their child identity, can lead to greater self-esteem and a repertoire of abilities. Similarly, Hooper et al. (2008) found that parentification can also serve a protective function in that it predicts a level of post-traumatic growth.

The parentification literature relates directly to caregiving by children (Earley & Cushway, 2002), with parentification theory being embedded in notions of reciprocity and balance in relationships. It is therefore a potentially useful framework for understanding the underlying processes of children providing care for a parent with mental health difficulties. However, as much of the research into parentification has centred on negative experiences and

consequences, it is important to also acknowledge its association with potential growth and positive outcomes. The notion of parentification also reflects current western ideas of childhood and family functioning, and certainly in recent history and different cultures this theoretical understanding of family dynamics would not be relevant. In particular, the notion of parentification is based within the assumption that children should be the recipients, rather than givers of care. It is also important to consider that the dominant discourses of what constitutes a 'normal' childhood may amplify the perception of parentification for young carers, particularly when considered in light of other Western assumptions of child development (for example, the assumption that children develop through movement from dependence to independence). Similarly, the notion of parentification can also be based in an over-simplified notion of a hierarchical family structure, again which is unlikely to be reflective of the diverse way in which families organise and structure themselves. As such, it is important that the complexity of family systems is appreciated (O'Dell et al., 2010) rather than drawing on the assumption that an 'ideal' family structure exists.

2.13.2 Attachment

The psychological concept of attachment both contributes to parentification, and has potential theoretical offerings for understanding the experiences of young carers. Attachment theory (Bowlby, 1969) focuses on the emotional bond between infant and caregiver, which is thought to inform the 'internal working models' for relationships within the infant as they grow and develop. However, for the purposes of this study attachment theory will not be considered, predominantly due to the critique of the theory in relation to understanding the experiences of children supporting a parent with a mental health difficulty set out by Murphy, Peters, Jackson and Wilkes (2011). They highlight that Bowlby's (1988b) theory proposed that attachments are formed within the first year of life, which limits the theory's applicability to those whose parents developed difficulties after this time. Additionally, they report finding that narratives generated about these childhood experiences are not framed within the realms of attachment theory.

2.14 Literature Search Strategy

A preliminary broad search of the literature highlighted that few studies use a 'young carer' frame. There appears to be a dominance of research focusing on the potential risks and negative consequences of growing up with a parent who experiences psychological distress. Although these findings will be acknowledged and considered, the focus of this review will seek to gain a balanced view of both the potential risks and gains of supporting a parent with a mental health difficulty. Additionally, there appears to be less qualitative research in this area, especially research exploring the perspectives of adults who have previously fulfilled a supportive role for a parent.

Scientific journal articles were obtained for this review by using the Scopus, PubMed, PsychArticles, CINAHL, MEDLINE and EBSCO databases, as well as reviewing references of relevant studies. The search terms used are detailed below, and were chosen from reviewing common terms used in studies identified through the preliminary literature search. A staged strategy of reviewing the search findings was used, where initially the duplications were removed, followed by screening titles for relevance. The abstracts of the articles left from the title screen were reviewed, and the full-texts were read of those which remained. This strategy and the associated figures is documented in a flow diagram (Appendix 1).

Table 1: Literature Search Terms

And	Not
Young Care*or Parent or Parent Child Relations or Family or Adult Children	Physical Health or Disability
Parental Mental Health or Parental Mental Illness or Psychiatric Disorders or Psychosis	
Experience or Risk or Coping Strategies or Resilience	
Qualitative Study or Retrospective Study	

2.14.1 Experiences of Children Supporting Parents with Mental Health Difficulties

Research into the experiences of young carers of parents with mental health difficulties is quite varied. This variety is reflected in research examining the different types of mental health difficulties which parents may experience and also in the different perspectives from which this experience can be explored. Research into the experiences of children supporting a parent with a mental health difficulty often falls into two categories; young carer research and parental mental health research. As both are considered likely to provide useful insights into the experiences and caring roles taken by children, the review here will draw on findings from both these research areas.

2.15 Systematic Review of the Literature

The purpose of this review is to gain an appreciation of the research evidence related to fulfilling a young carer role for a parent with a mental health difficulty. Following the procedure outlined above, a total of fourteen studies were identified for review. The key findings of the studies are discussed below, along with an evaluation of their contribution and the areas yet to be addressed sufficiently within the literature. A table summarising each of the contributing papers can be found in Appendix 2.

2.15.1 Overview

All of the studies included in the literature review explored children’s experiences of living with or supporting a parent with a mental health difficulty, with both contemporary and retrospective studies being included. All studies are qualitative in design and draw on different analytical

methods. The majority of the studies used semi-structured interviews as their primary data source, although one study used a focus group design. No date limit was used within the review and studies from different geographical regions have been used in order to gain relevant evidence.

2.15.2 Negotiating Relationships – Closeness and Distance

Several of the studies reviewed commented on the influence of parental mental illness on the negotiation of relationships within the family. Foster (2010) used an interpretative qualitative approach including ethnography to explore the experiences of adult children of parents with 'serious mental illness'. They reported the theme 'struggling to connect' which highlighted participants' experiences of closeness and distance in relationships, difficulties connecting emotionally with their parents and experiencing relationship difficulties in adult life. Similarly, Mordoch and Hall (2008) in their grounded theory study of children's perceptions of living with a parent with mental health difficulties also found that participants described needing to have a safe distance from their parents in order to preserve the self and develop their own lives. Van Parys, Smith and Rober (2014) investigated the experience of growing up with a mother with depression using interpretative phenomenological analysis. Their findings highlighted how at the time, participants described experiencing tensions in relationships, distance, and missed the emotional bond with their mother. Additionally, they also found that in attempting to integrate their childhood experience into their adult lives, participants described trying to find balance in their continued bond with their parents, allowing for self-protection while balancing the needs of both the parents and self.

Riebschleger (2004) interviewed children living with a parent with mental health difficulties, finding that on 'good days' participants felt more connected to their parent. Whereas on 'bad days' participants reported that their parent tended to withdraw, leaving them feeling less connected and often leading to them withdrawing too. Cogan, Riddell and Mayes (2005) reported that child participants within their study were aware of the stigma surrounding mental health difficulties, and so concealed their parent's difficulties through not inviting friends over and keeping their experiences a 'secret'. As a result, these participants often felt isolated and disconnected from others. Murphy, Peters, Wilkes and Jackson (2015a) conducted a retrospective study into the experiences of adult children affected by parental mental illness and highlighted how feelings of fear and mistrust were common for the participants, resulting in feelings of isolation from others. Additionally, they highlighted how this mistrust may also be compounded through living in the parameters of their parent's paranoid beliefs, which potentially give the message of others being a source of risk.

Meadus and Johnson (2000) investigated the experience of adolescents supporting a parent experiencing a mood disorder. In their theme 'Unavailability of ill parent' they reflect on the

disruption which the mood disorder causes in family relationships, with participants describing their parent as being unavailable and unreachable. Östman (2008) reports the theme 'Loneliness', reflecting children's feelings of being completely alone with no-one communicating with them. Additionally, the focus of attention tended to be on the parent, resulting in the child being overlooked. Finally, Doutre et al. (2013) employed a strengths-based perspective to listen to the voices of young carers, using interpretative phenomenological analysis. Participants described experiencing tensions in their family relationships resulting from their caregiving role and complex family situation, as well as valuing the closeness and interdependence they experienced in family relationships.

These findings suggest that a key issue for children of parents with mental health difficulties is the negotiation of closeness and distance with others, particularly in the parental relationship. This appears to function as a method of protecting the self in a difficult and emotional environment, and seems to be carried forward into adult patterns of relating.

2.15.3 Lack of Information and Support

The majority of studies also described children experiencing difficulties in managing their home situation due to lacking information and support. Dunn (1993) completed a retrospective qualitative study of nine adult children who had grown up with a mother experiencing schizophrenia. Thematic analysis of the data revealed the theme of 'Isolation', which referred to limited relationships within the family and community which resulted in little information being shared with children. Additionally, the theme of 'Social support' was also identified, highlighting the importance of having safe and helpful people to go to, lifelines to the outside world and a loving relationship with their mother. Van Parys et al. (2014) also found that participants described lacking information and support, with supportive others only occasionally being present. Similarly, most participants in Mordoch's (2010) study reported being poorly informed, and so struggled to make sense of their parent's difficulties. Additionally, they reported that this silence around the parent's difficulties led to children developing misinformed perceptions.

Meadus and Johnson (2000) report the theme 'Lack of knowledge and understanding' which reflects their participant's frustration around lacking the information they required to make sense of the situation and be supportive. Furthermore, this lack of information often led to participants fearing that they too would develop difficulties in future. Riebschleger (2004) reported how children appeared to have little information about their parent's mental health difficulty, and so attempted to understand it through the effects which it had on their lives. Similar to this, Cogan and colleagues (2005) reported how one of their most striking findings was that children commonly requested information about their parent's difficulties. Few of their participants reported gaining information from healthcare professionals, and so tended to rely

on their own judgement and sense-making. Finally, Garley, Gallop, Johnston and Pipitone (1997) completed a qualitative focus group study of the experiences of children of parents experiencing mental illness. Their theme 'Understanding the illness' highlighted how children desired information about their parents' difficulties, and often found trying to gain this information a frustrating process.

As most studies within the review commented on a perceived lack of information and social support, it suggests that information provision and supportive relationships are key issues for children supporting parents with mental health difficulties. This is particularly concerning for young carers, who will require a significant amount of information in order to care safely and effectively, and also to understand the experience within their family. The studies reviewed cover almost two decades of research, and still the modern studies are reporting this difficulty, suggesting that this issue has not yet been fully resolved.

2.15.4 Responsibility and Role Reversal

Another key theme found in the reviewed papers is that of increased responsibility and role reversal in children living with parents experiencing mental health difficulties. Foster (2010) reported the theme of 'Being responsible', which included experiences of being emotionally responsible for the family while having no choice in this, fulfilling practical roles within the home and the responsibility of contact with mental health professionals. Additionally, their theme 'Struggling to connect' highlighted the reversal of roles which participants experienced with their parents, affecting the emotional closeness within their relationship. Dunn (1993) found that participants often took a caregiver role for their siblings and parent, and framed this in terms of abuse and neglect. Garley and colleagues (1997) also discussed the overwhelming burden, the pervasive experience of role reversal and sense of responsibility experienced by children.

Griffiths, Norris, Stallard and Matthews (2012) researched the experiences of children living with parents diagnosed with obsessive-compulsive disorder, using thematic analysis. Within the theme 'Doing what I can to help', the subtheme of taking on extra responsibilities was noted. Participants described having extra responsibilities within the home, particularly around household tasks. Van Parys et al. (2014) developed the theme 'Growing into the caring role as a way to keep standing', and within it discussed the experiences of responsibility that participants held. This included being responsible for their mother's wellbeing in daily life and for younger siblings, and was often elicited by one or both parents being absent in some way. Additionally, Meadus and Johnson (2000) reported that due to their parent's unavailability, participants reported assuming some parenting roles, which included becoming caregivers for their parent and siblings.

Similarly, Östman (2008) reported that children of parents with severe mental health difficulties experienced increased responsibility, as there was no-one else to fulfil this need in the family. Alongside this, participants reported also gaining greater maturity, which appeared to support their self-esteem. However, Aldridge (2006) reports finding that although children did experience role transfer with their parents, this was typically a temporary event, and described the parent continuing to maintain their status of parent.

These findings suggest that it is relatively common for children to take on a parental role at times where their parent's difficulties are influencing their ability to parent. This involves taking care of the parent, self and potential siblings, and is sometimes associated with a greater sense of independence and maturity. Additionally, this reversal in roles may only be temporary, and may occur in the context of the parent still maintaining their parenting status.

2.15.5 Summary

The reviewed literature highlights several key experiences and concerns for children supporting a parent with a mental health difficulty. Many studies highlighted the fluctuating experiences of closeness and distance in family relationships, with some participants seeking closeness with their parent, family members or friends, while others reported isolating themselves and withdrawing and therefore being overlooked. A similar finding was reported by Gladstone, Boydell, Seeman and McKeever, (2011) in their related thematic review of studies exploring children's experiences of parental mental illness. They identified the theme of 'Experiencing family relationships' which highlighted participants' desire to keep their family together and remain emotionally connected to each other, with some participants describing opting out of parental relationships in order to preserve a sense of self.

Additionally, findings within the review suggest that many children experience a lack of information and support, which is likely to affect their coping and caregiving. The findings suggest that children are keen to access information, which if not provided can result in them making sense of their situation alone and potentially reaching inaccurate conclusions. In line with the review findings, the importance of information is highlighted by LeFrançois (2010), who completed a meta-analysis of studies concerning the experiences of distressed fathers and their children. It was reported that resilience of children was bolstered by the provision of information, with this being particularly important for young carers. As such, the provision of information is highly important, but unfortunately often lacking.

Finally, the experience of role reversal and parentification was often highlighted within the review. For many participants, their parent's difficulties result in them needing to fulfil a parenting role, leading to them being responsible for their parent, themselves and their siblings. Although this may be only a temporary change in roles, many participants described

caring both emotionally and practically for their family. Within their literature review, Gladstone and colleagues (2011) highlighted how children often balanced their parent's needs with their own, and sometimes had difficulty with recognising their own needs above those of their parents. They discuss that although professionals and parents often view this role reversal negatively, children themselves wish to help and desire to be recognised as important in supporting their parent's wellbeing. Therefore, although greater responsibility may put additional strain on children, they appear to wish to take on these roles as part of supporting their parent and will likely require support to manage the extra responsibility.

2.16 Areas Not Yet Fully Explored and Rationale for Current Study

On reviewing the literature, it is evident that a number of areas require further exploration. Within this review, samples were typically derived from support services, either providing the parent with treatment, or providing young carer support. While this is understandable in light of the well reported recruitment difficulties encountered in young carer research (discussed later, see Kennen, Fives & Canavan, 2012; Thomas et al., 2002), it is likely that a sample taken from those already receiving support may report different experiences to those who have not accessed support services. A significant finding within the review was the lack of information that participants reported having about their parent's difficulties. This may suggest that many potential participants also lack knowledge of available support services as a result of this, and while they could offer valuable insights about their experience, they would remain 'hidden' in terms of potential study recruitment.

Within the review, only one study (Dunn, 1993) addressed the experience of growing up with a parent experiencing psychosis, namely schizophrenia. However, this study is limited by its age, apparent focus on the negative experiences and lack of exploration of the meaning-making of this experience. While some recent studies have investigated diagnosis-specific experiences, (such as Griffiths et al., 2012; Van Parys et al., 2014), it is more typical for studies to use the more generic term of 'parental mental health/illness'. Growing up with a parent experiencing a psychosis-related difficulty is likely to have its own unique features, for example around negotiating connection with a parent who may not share your sense of reality. Indeed, Murphy and colleagues (2015a) have highlighted the influence of parental delusions and paranoia on a child's sense of trust in others. Several studies within the review employed the term 'severe parental mental illness' which sometimes encapsulated psychoses, but in addition to a number of other mental health difficulties. LeFrançois (2010) reported that researchers tended to 'lump together' fathers on the basis of having severe mental health problems, rather than distinguishing between the problems experienced. This distinction would allow for both greater accuracy, and for the potential differences in experiences that supporting parents with differing difficulties be become apparent.

Additionally, only four retrospective studies were identified within the review. Van Parys et al. (2014) highlight how a retrospective design can allow for new meanings of the participants' experiences to emerge, as the distance from the experience may allow for connection with more difficult memories and emotions. Therefore, retrospective studies are likely to give greater insight into the experience of supporting a parent with a mental health difficulty as new meanings may be developed and the integration of that experience into later life could be explored. Similarly, Bauer, Spiessl, and Helmbrecht (2015) report that adult children of parents with psychiatric disorders are able to reflect on their experiences from a more distant perspective, allowing this process to be a positive learning and self-enriching experience. As several studies have reported findings of children using emotional distancing as a coping strategy, arguably children currently caring and using this technique may not be able to connect to their experience within a research interview. However, re-connection with those experiences may be facilitated by the passing of time and physical distance which adulthood brings.

Finally, the review highlights a lack of research adequately exploring the experiences of those who identify themselves as young carers. Although many studies highlighted caring as a significant part of the experience of children of parents with mental health difficulties, only two studies (Aldridge, 2006; Doutre et al., 2013) used the frame of young carer. The studies looking at experiences of parental mental health are likely to offer important insights, but arguably those who identify themselves as young carers may have different insights and meanings about their experience, which have not yet been fully explored. As Doutre and colleagues (2013) state, the individual experiences of young carers remain poorly understood.

2.16.1 Conclusion

As the review has highlighted, there is limited research into the experiences of individuals who identify themselves as young carers for a parent with mental health difficulties, no research exploring the experiences of young carers of parents with psychosis-related difficulties and few studies which have been retrospective in nature. Additionally, many studies have recruited participants or parents who have been actively involved in support services at the time of the research. As such, the current study will aim to address these gaps in the research by employing a qualitative approach to investigate the experiences of adults who view themselves as having been young carers for a parent with a psychosis-related difficulty. It is hoped that this will allow these often hidden voices to be heard and for a detailed insight into both the experience and the coping mechanisms developed over time, as well as an appreciation of how the experience is made sense of and integrated into the self.

2.17 Aims of the Research and Research Questions

The aim of this research is therefore to explore the experiences of adults who were young carers for a parent with a psychosis-related difficulty. This will be explored through the following research questions:

- How do adults who were young carers for a parent with psychosis-related difficulties retrospectively describe their experiences of caring for or supporting their parent?
- What meaning do adults who were young carers give to their experience now?

3. METHODOLOGY

This section details the methodology used within the study, including the rationale for this approach. Details of participants, recruitment, ethical considerations, data collection and analysis and quality assurance are provided.

3.1 A Qualitative Approach

Doran and colleagues (2003) suggested that a 'deeper insight' from qualitative studies about the experiences of children who care for a parent with mental illness is missing from the research field. Some progress has been made in gaining more qualitative research of young carers' experiences, however, there is still much yet to be explored. Barker, Pistrang and Elliot (2002) state that qualitative methods are good for exploratory, discovery-oriented research and allows for an individual's experience to be studied in detail. As such, a qualitative approach was chosen for this study due to its suitability in appropriately addressing the research aims.

3.2 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is a qualitative approach committed to examining how people make sense of major life experiences (Smith, Flowers & Larkin, 2009). Since its development in 1996, IPA has grown from initially being applied to health psychology research to now being used broadly across a number of research areas (Wagstaff et al., 2014). The researcher is required to collect detailed, reflective accounts from research participants, to which IPA offers an established, phenomenologically focussed approach to the interpretation of these accounts (Larkin & Thompson, 2012). Overall, IPA aims to fully explore an experience within a person's life, and examine the meaning ascribed to it.

3.2.1 Theoretical Underpinnings

The underlying philosophy of IPA is just as important as the procedure (Smith et al., 2009). IPA is rooted within phenomenology, idiography and hermeneutics. Phenomenology is concerned with the phenomena which appear in a person's consciousness as they engage with the world around them (Willig, 2013). Drawing on the ideas of Husserl, Merleau-Ponty, Heidegger and Sartre, IPA seeks to examine the embodied, lived experience of a person, embedded within their world and relationships. This requires the researcher to approach their data with the aim of understanding their participants' world, and to develop an interpretative analysis which positions the participants' descriptions in wider social, cultural and theoretical contexts (Larkin, Watts & Clifton, 2006).

The idiographic level of analysis allows for the particulars rather than the general to be focused on (Larkin & Thompson, 2012). The idiographic approach promotes a particular focus at two levels: the detail and depth of analysis and through understanding from particular people's

perspectives, within a particular context (Smith et al., 2009). In order to achieve this, IPA tends to involve intensive and detailed analysis of a small number of participant accounts (Larkin et al., 2006). However, at the same time IPA recognises that there is not a direct route to experience and that research is really about striving to be 'experience close' rather than 'experience far' (Smith, 2011).

Hermeneutics refers to theories of interpretation and has grown to be applied to a wide body of texts, including the human sciences (Smith, 2007). Husserl and Heidegger were the first major contributors to phenomenological hermeneutics, with Heidegger having the most impact (Porter & Robinson, 2011). Wagstaff et al. (2014) suggest that IPA draws on interpretation to make manifest what is normally hidden, and to look for meanings embedded in human experience.

IPA acknowledges the interpretative element of the researcher's engagement with the text, while allowing possible access to an individual's inner world through careful interpretive methodology (Biggerstaff & Thompson, 2008). IPA involves a 'double hermeneutic', where the researcher attempts to make sense of the participant, who is attempting to make sense of their experience (Smith et al., 2009). As such, an underlying assumption of IPA is that in order to make sense of participants' experiences, the researcher will be required to both identify and reflect upon their own experiences and assumptions (Larkin & Thompson, 2012). Therefore, it is necessary for researchers to continually engage in processes of reflexivity, to help identify their contribution to the interpretative process.

3.3 Strengths and Weaknesses of IPA

3.3.1 Strengths

Although a relatively young analytical method, IPA has become a popular method of analysis since its development in the mid-1990s. A central tenet of IPA is the stance that the participants are the experts in their experience, and are able to offer researchers insight into their experiences through telling their stories (Reid, Flowers & Larkin, 2005). The idiographic foundation of IPA allows for detailed, unique and novel explanations and understandings to evolve through its commitment to understanding how particular events are understood by particular people at a particular time (Smith et al., 2009). Additionally, the appreciation of the 'double hermeneutic' within IPA allows for the influence and contribution of the researcher to be fully accounted for in the interpretation of the research data (Willig, 2013). Finally, a detailed and informative outline of the IPA method had been produced by Smith et al. (2009); allowing less experienced researchers to have guidance on successfully and appropriately applying the method.

3.3.2 Weaknesses

Although IPA has many strengths, there are arguably several limitations to its use. Wagstaff et al. (2014) highlight how IPA is a relatively new methodology, potentially leading to issues with implementing the analysis. Similarly, Hefferon and Gil-Rodriguez (2011) suggest that IPA has become almost the 'default' option for students, sometimes resulting in poorly constructed studies which do not represent high quality IPA. To help counter this, structured guidance on the analytical process has been provided (Smith et al., 2009) and the importance of supervision has been highlighted (Reid et al., 2005).

Additionally, IPA places emphasis on the participant's ability to provide rich, detailed accounts of their experiences (Smith et al., 2009) which may be difficult for individuals reflecting on challenging life events and who may actively avoid thinking and talking about these events due to the emotions connected to them. Due to these potential weaknesses, the structured guidance was closely implemented within this study and supervision was actively sought.

3.4 Why IPA was chosen

The purpose of IPA is to explore and examine how people apply meaning to the life events which they experience. As the aim of this study is to explore how people have experienced providing care to a parent with a psychosis-related difficulty, and what meaning they have ascribed to this experience, it was considered the best suited methodology to achieve this.

Narrative analysis was also considered as a potentially suitable analytical method due to its focus on the human means of making sense (Murray, 2008). People often make meaning of events through the construction of particular narratives in response to difficult times, and it is argued that the process of constructing these narratives can render them meaningful (Silver, 2013). Although the temporal aspect of narrative analysis would have offered an interesting perspective in this research, it was felt that IPA with its focus on the lived experience of the participants and in-depth attention to the particulars of this experience, would be best suited to the research aims.

3.5 Reflexivity

Qualitative research acknowledges that the researcher influences and shapes the research process, both as a person and as a theorist (Willig, 2013). Reflexivity involves sensitivity to the ways in which both the researcher and the research process have influenced the data collected, requiring personal and intellectual biases and personal characteristics to be made plain from the outset (Mays & Pope, 2000). I feel that my experience of being a young carer, outlined in the introduction chapter, allows me to have empathy and insight into the experiences of the study participants, without being so close that I find it difficult to separate my own assumptions and experiences from theirs. I am a 30-year-old, white British working-

class female, and have spent most of my life living in the south-west of England. My mother has experienced chronic and quite disabling physical health problems since my teenage years, and I understand this to have significantly impacted on my development, academic ability, relationships and identity.

My epistemological stance on the research was one of co-creation between the participants and I throughout the research process. As part of this, I appreciate that my experiences, beliefs and values may have influenced the research process. Additionally, I am aware that the research is bounded by the time and culture, and different results may have been gained if it occurred at a different time or in a different place. During the research process I attempted to bracket (Ahern, 1999) my experiences and assumptions through use of a reflective diary (Appendix 14). I sought supervision to aid with this, and found gaining another perspective helpful in determining how my interpretations of the data may be influenced by my experiences. For example, supervision helped me notice that I tended to highlight emotions in participants which I too had experienced. Similarly, I invited members of an IPA peer-support group to analyse an extract of data so that I could compare my interpretations with theirs. However, I felt that my experience also offered positive aspects such as empathy and closeness with the experience of my participants, in line with the theoretical stance of IPA (Smith et al., 2009).

Throughout the interviews I endeavoured to encourage participants to share what was important for them about their experience. I worked hard to create a space for participants to share their experience and consider the influence of that on their current self, resulting in rich and detailed accounts from those who participated.

3.6 Participants

3.6.1 Recruitment

The initial phase of the recruitment strategy involved approaching local carers' organisations who offer services for young carers and asking if they could facilitate the recruitment. Unfortunately, one of the organisations contacted was unable to support participant recruitment, and so a national carer network was contacted to identify other potential young carer services in the local area. Further voluntary agencies were identified and contacted following advice from professionals in the field and carer consultation.

As the initial recruitment strategy did not produce any participants, a secondary phase was initiated. As such, a reapplication was made to the university ethics committee to accommodate for an amended recruitment strategy and widened participant age range (Appendix 6). The rationale for initially using a narrow and younger age range was that it was felt that this would facilitate participants' recall of events. However, through considering the

research literature and discussion with the research supervisory team, it was felt that there was not a justifiable reason to exclude potential older participants. In support of this, Van Parys et al. (2014) found that although participants were discussing their distant past, they were able to discuss their childhood experiences in a vivid, detailed way. The amended strategy focused on recruiting participants from the university population, through advertising on the university intranet (Appendix 4). Additionally, relevant carer and mental health agencies within a wider geographical area were contacted and asked to advertise the study (Appendix 5). Social media such as Twitter and Facebook was also used to support this. Furthermore, the Service User and Carer Committee attached to the clinical psychology training programme was approached, and several members provided further links for organisations who were able to advertise the research.

3.6.2 Reflections on challenges in recruitment

Recruitment into the study proved initially challenging, with many voluntary organisations being unable to provide assistance. Due to the focus on recruiting adults who had been young carers, the young carer organisations often felt that they would not be an appropriate source for recruitment. Other carer organisations expressed reluctance at advertising the study due to their members being inundated with requests for participation in research when they are trying to access support services. At several times I found the negotiating of advertising the study to be quite a frustrating and demoralising process, as organisations often expressed a desire to be made aware of the findings of my proposed study, but were not prepared to support recruitment.

Difficulties with recruitment for research looking at young carer populations are well documented. Kennen and colleagues (2012) found that despite using a comprehensive recruitment strategy, very few participants were identified either through self-referral or through professional identification. They similarly reported difficulties with gaining support for their project through relevant organisations. Thomas et al. (2002) reported significant difficulties with recruitment into their young carer research. Despite providing comprehensive information to relevant organisations such as schools and education welfare officers, very few potential participants were identified. Both studies highlight the 'hidden' nature of young carers, with professionals provided with specific information still having difficulty identifying young carers. Both studies highlight the benefit of specific young carer agencies in supporting recruitment; however, due to the retrospective nature of my study, I found that this route was also limited in its potential to provide participants. These challenges are returned to in the discussion chapter.

3.6.3 Inclusion and Exclusion Criteria

In order to be included in the study, potential participants were required to be between 18 and 65 years of age and to have been a young carer for a parent with a psychosis-related difficulty. Their suitability for the study was measured through an informal discussion with each participant prior to being recruited, where their experience of caring and their parents' mental health difficulties were discussed and reviewed against the definitions stated in the introduction. This sought to ensure that there was a shared understanding of what was meant by 'young carer' and 'psychosis-related experiences' and resulted in exclusion of one participant from the study.

Participants were excluded from the study if they could not speak English, due to there being limited resource for the use of translators and the focus of qualitative research being based heavily on language use. Additionally, participants were excluded if they were currently experiencing psychological distress themselves, due to the ethical implications of the risk of the research causing them further distress.

3.6.4 The Sample

As the primary concern of IPA is with the detailed account of the individual experience, IPA studies usually benefit from focussing on a small number of participants (Smith et al., 2009). Considering this, and guidance provided by the research supervisory team, it was decided that a sample of 5-8 participants would be sought.

A total of 7 adults participated in the research. They were all female, with 6 identifying themselves as white British, and one person from a mixed ethnic background. All but one of the participants' parents had received a formal diagnosis of a psychosis-related difficulty. The person whose parent had not been formally diagnosed reported this being due to their parent's concerns about the diagnosis impacting their career. All of the participants were no longer living with their parent; however, two people reported returning to the family home during university breaks. All but one of the participants reported that their parent had been hospitalised due to their difficulties, often on a number of occasions. Finally, three of the participants were parents themselves.

Two further participants were identified and recruited to the study. However, one required the interview to be rescheduled a number of times before eventually withdrawing, and the other experienced further caring responsibilities and so withdrew. The majority of participants indicated that although their young carer role had ended, they continued to provide support for their parent.

Table 2: Participant Demographic Information

Participant Pseudonym	Age	Employment	Parent Affected	Participants' Description of Parent's Mental Health Difficulty
Emma	27	Postgraduate Health Profession Training	Mother	Schizoaffective Disorder & Paranoid Personality Disorder
Laura	28	Undergraduate Social Care Training	Father	Depression with Psychotic Episodes
Anna	30	Youth Worker	Mother	Psychosis - never formally diagnosed
Ellen	50	Healthcare Lecturer	Mother	Schizoaffective Disorder, Depression and Hypomania
Karen	20	Undergraduate Humanities Degree	Mother	Paranoid Schizophrenia & Paranoid Personality Disorder
Serena	20	Undergraduate Computing Degree	Stepfather	Depression with Psychotic Episodes
Chloe	38	Undergraduate Healthcare Degree	Father	Schizophrenia & Bipolar Disorder

3.6.5 Context

The majority of the recruited participants were accessed through advertising within a university setting. This brings with it a particular context, as it is possible that the experiences of young carers who have gone on to complete a degree course differ to those who either could not follow this path, or chose not to. As a recent government initiative has highlighted the need to address barriers for young carers in entering higher education, it is likely that a significant number of individuals who are eligible for the research will not be present in a university population.

3.7 Expert by Experience Involvement

Within the National Health Service (NHS) in the UK there has been growing recognition of the importance of including service-users and carers in both healthcare service design and research. This was underpinned by the development of Patient and Participant Involvement in the new NHS (DoH, 1999) policy, which highlights the importance of patient involvement in the research process in order to develop the health service. More recently, the Department of

Health have developed the Research Governance Framework for Health and Social Care (2005), which states that service-users and carers should be involved as much as possible in research activities.

Although there is little actual 'evidence' of the benefits of service-user involvement in research, many researchers, service-users and service-user/survivor researchers have written of the benefits which they have experienced or witnessed (Faulkner, 2012). As such, it felt important to invite an expert by experience to offer their thoughts on the design and completion of the study. The University of Hertfordshire Doctorate in Clinical Psychology Service User and Carer Committee was approached, and a carer within this group offered to take on the role. Although the consultant had not been a young carer, they were currently caring for a family member experiencing psychosis-related difficulties, and so could offer a wealth of knowledge and experience. They contributed by reviewing the materials developed for participants as well as the interview schedule, and provided knowledge of local carer organisations to aid recruitment. Although consultation from experts by experience can be beneficial in all parts of the research process (Faulkner, 2012), it also felt necessary to balance this with the burden that this may place on the consultant. As such, the extent of the consultant's involvement on the project was contracted from the start, ensuring it was convenient and manageable for them.

The expert by experience consultant made several helpful contributions to the research process. They held a good understanding of the growth of carer-related policy over time, and were able to suggest useful areas to research in relation to the study. They also reviewed all of the study materials to check that they were accessible and fit for purpose. They reviewed the interview schedule, and although no specific changes were suggested, they made reference to the need to make sure that the questions were not written in an overly 'academic' style, and were easy for the participants to understand. All of these suggestions were used to guide the subsequent development of the research.

3.8 Ethical Considerations

Ethical approval was granted by the University of Hertfordshire's Ethics Committee. It was necessary to amend the ethics application during the recruitment period to allow for a greater number of potential participants, and so the ethics approval application for the study was resubmitted and subsequently approved (Appendix 6).

3.8.1 Informed Consent

Each participant received a full explanation of the research, including explanations of how their data would be used and stored, both verbally and in writing. This information included the purpose of the study, the principles of confidentiality, how their information would be used and stored and anonymity procedures (Appendix 7). After reading the information provided and

asking any questions which they had, each participant was asked to sign a consent form confirming that at that time they had given their informed consent to participate in the study (Appendix 8). Additionally, one participant consented to the inclusion of a copy of their interview transcript (Appendix 9).

3.8.2 Confidentiality

The principles of confidentiality and its limitations were given verbally and in writing to all participants. It was explained that confidentiality would be upheld at all times, unless a risk issue was expressed [this did not occur within this study]. This was achieved by ensuring that participants were not identifiable by their data, removing all identifiable information from the transcripts and using an anonymised number system for data identification.

3.8.3 Potential Distress

As with all interviews, there was a possibility that through reflecting on past experiences participants may experience some emotion or distress. To help minimise this, the questions were reviewed by an expert by experience who deemed them suitable. Additionally, a pilot study confirmed the suitability of the interview schedule. Feedback suggested that the questions were appropriate and not especially provocative or emotive.

Additionally, it was made clear both in the written information and prior to the interview that participants could choose not to answer a question or to finish the interview at any point. Participants were also given information at the end of the interview with contact details for supportive agencies (Appendix 11), and given time to discuss the interview, ask any questions and debrief.

3.9 Data Collection

3.9.1 Pilot Interview

A pilot interview was completed to check the suitability of the interview schedule and to estimate the potential length of the interview. The participant was recruited through word of mouth, and had been a young carer for her mother who experienced a psychosis-related difficulty. The interview took place via video-calling as the participant lived a significant distance away. The participant consented to taking part and for the interview to be audio-recorded.

Sampson (2004) states that pilot studies in qualitative research are often used in a haphazard way, potentially leading to their benefits being overlooked. Therefore, an emphasis was placed on making good use of the opportunity. Throughout the interview, thoughts and reflections were noted about the questions as they were asked, especially if the response given was unexpected. After completing the interview, the participant was asked for their views about the

questions asked, the interview length and any further suggestions they had for fully capturing the experience.

Overall, the participant felt that the interview was a good length, and was fairly comprehensive. Some useful suggestions for further questions were made, including asking about managing romantic relationships while trying to fulfil a carer role and the influence of stigma when discussing the experience of caring with friends. The suggested changes were all implemented into the interview schedule.

3.9.2 Interviews

A semi-structured interview was initially developed by the researcher using relevant research literature (Appendix 10), and later refined through discussion with research supervisors, expert by experience consultation and pilot interview feedback. As interviews should facilitate movement from general talking to specific accounts (Smith et al., 2009), the schedule was developed to try and encourage participants to expand and elaborate their descriptions of their experiences with examples of their thoughts, interpretations and feelings. The first part of the interview focussed on the experience of young caring at the time and their meaning-making around this, with the second part of the interview focussing on how the experience influenced their life and identity development.

Participants chose where they would like the interview to take place, ensuring their comfort and convenience. Five participants chose to be interviewed within a university library setting (four at the University of Hertfordshire), one in a public library, and one in their workplace. All interviews took place in private rooms and lasted between 40 and 120 minutes. Each interview was audio-recorded and later transcribed.

Following each interview, the researcher completed a reflective worksheet (Appendix 12). This sought to promote reflexivity and to begin the process of noticing themes which may be useful in the analysis. Additional factors which may have influenced the interview such as rapport and interruptions were also noted. Additionally, throughout the study a reflective diary was kept by the researcher (Appendix 13).

3.10 Data Analysis

The data was analysed following the method described by Smith, Flowers and Larkin (2009). Additionally, guidelines to ensure that quality is upheld in qualitative research were also followed (Elliott, Fischer & Rennie, 1999; Yardley, 2000) and analysis was supervised by an experienced IPA researcher.

3.10.1 Individual Case Analysis

IPA follows an idiographic approach to analysis, starting with the particular and working up to generalised classifications (Smith & Osborn, 2008). As such, the first stage involved analysing

each individual case. Transcripts were formatted to include two columns: one for initial noting of descriptive, linguistic and conceptual comments, and the second for developing the emergent themes. The transcript was read and listened to repeatedly to facilitate 'immersion' into the participant's world. This first stage ensures that the participant is the focus of the analysis, and not lost in a quick reduction of the data (Smith et al., 2009). Following this, the transcript was explored on a line-by-line basis with detailed notes about the use of language, semantic content, similarities and differences and initial interpretations on the right hand column of the transcript. A comprehensive set of notes was produced for the data before moving on to the next level of analysis.

3.10.2 Emergent themes

The following stage of analysis sought to capture the emerging themes. This involves a balance between reducing the volume of the data while maintaining the complexity and closeness to the participant's experience (Smith et al., 2009). The emergent themes were recorded in the left hand column of the transcript, and were predominantly generated from considering the initial noting. Where possible, the participant's own words were used to develop emergent themes, maintaining closeness with the data. The emergent themes were then listed and grouped together to reflect important and interesting aspects of the participant's account. These clusters of themes were then reconsidered to identify the potential super-ordinate themes with their related subthemes. The techniques of abstraction and polarization (Smith et al., 2009) were used to help define the super-ordinate theme that clusters of emergent themes appeared to speak to. To ensure that the identified themes were grounded within the participant's experience, data extracts which represented each theme were collated (Appendix 16).

3.10.3 Cross Case Analysis

At this stage, all of the themes for each participant were considered with an aim of identifying patterns and connections. The themes from all seven participants were combined and condensed to generate overarching themes at the group level. The transcripts were then revisited in light of these master and super-ordinate themes, and a table of the themes and related data extracts was produced. This table in turn was used as a framework for the results section of the research study. An audit trail of the analytical process is included (Appendix 16).

3.11 Quality in Qualitative Research

Due to the increased use of qualitative methods in health research, it is necessary to consider the value and rigour of a piece of qualitative research. A number of guidelines have been developed in recent years to aid the evaluation of quality in qualitative research (Elliott, Fischer & Rennie, 1999; Spencer, Ritchie, Lewis & Dillon, 2003; Yardley, 2000, 2008). For the purposes of this study, Yardley's (2008) four principles of evaluating qualitative research were

chosen as they are commonly cited by IPA-related authors (e.g. Hefferon & Gil-Rodriguez, 2011; Smith & Osborn, 2008; Smith et al., 2009). The principles include: Sensitivity to context, Commitment and Rigour, Coherence and Transparency and Impact and Importance.

3.11.1 Sensitivity to Context

Qualitative research allows for new meanings and phenomenon to be discovered, and so being able to show sensitivity to context is essential in demonstrating the validity of a study (Yardley, 2008). It is important to consider the previous theoretical understandings in the empirical literature, which is evidenced in the current study through completing a systematic literature review drawing from clinical psychology, education and health and social care research. This review allowed for an understanding of what is already reported within the literature while identifying a gap in knowledge which was incorporated in the current study's research question.

Additionally, Yardley (2008) states that good qualitative research must show sensitivity to the perspective and socio-cultural context of participants. Through developing an interview schedule based around open-ended questions, participants were able to freely give their perspectives. Additionally, conducting a pilot interview and consulting an expert by experience allowed for assessment of the sensitivity and relevance of the questions. The influence of researcher characteristics and the context in which the research took place were also considered. In particular, I endeavoured to be transparent in my role and relationship with the research, and invited participants to ask any questions of me that they had. Additionally, participants chose where they wished to complete the interviews, allowing them to choose comfortable environments. Throughout the analysis, I attempted to be mindful of both what was and what was not said, and considered the potential reasons behind this. From an analytical perspective, IPA allows for close engagement with the idiographic and the particular, while appreciating the interactional nature of the data (Smith et al., 2009). This allowed for different interpretations of the data to be made, while acknowledging how these interpretations are related to my experiences and meanings, ensuring reflexivity throughout. Sensitivity to the data was ensured by regularly revisiting the data in light of the themes being developed, and the subsequent gathering of verbatim extracts to support the themes generated.

3.11.2 Commitment and Rigour

Commitment and rigour can be evidenced through completing a comprehensive analysis that has breadth and depth to add significant insights to the topic under investigation (Yardley, 2008). Within this study, a significant effort was made to complete an in-depth analysis. This was aided by my focus on becoming immersed within the data, consistent application of the analytical model outlined by Smith et al. (2009), receiving formal supervision of the analysis from a researcher experienced in IPA and through engaging in an IPA-focussed peer-

supervision group. My research supervisor read a full transcript and expressed agreement with the emergent themes developed. Additionally, I attended several teaching sessions on the application of IPA, including a session led by Jonathan Smith.

Rigour was evidenced through developing a high-quality semi-structured interview schedule, drawing on the guidance of my research supervisor, an expert by experience and pilot interview feedback. Participants within the study were carefully selected to ensure a homogenous sample, with efforts made to discuss their caring experience and parents' mental health difficulties prior to recruitment to compare their experiences with the definitions used within the study. Additionally, a reflective diary was kept throughout the data collection and analysis to help bracket my experiences (Ahern, 1999).

3.11.3 Transparency and Coherence

To carry out coherent qualitative research it is necessary to have a solid grounding in the methods used and their theoretical background (Yardley, 2008). Within the present study, the introduction and systematic literature review provide a strong rationale for the research undertaken. Additionally, the theoretical underpinnings, strengths and weaknesses and method of application are all provided within the write-up (Smith et al., 2009).

Yardley (2008) described transparency of a study as being how well the reader can see what was done and the rationale behind it. Throughout this study, the methods used and their rationale have been made explicit. Using IPA allows for a transparent analytical process, as exemplified in the inclusion of an analysed transcript and an audit trail for the analysis within the appendix, which aims to promote the readers understanding of the analysis. Additionally, verbatim extracts for the themes generated are consistently provided, and are used within the write up to highlight interpretations and connections. Transparency was also supported through the researchers use of a reflective diary throughout the study.

3.11.4 Impact and Importance

Ultimately, the validity of a study is related to its potential to make a difference (Yardley, 2008), and through telling the reader something interesting, important or useful (Smith et al., 2009). Within this research a strong rationale for the study, related to the dearth of understanding in the area under investigation, was made. As little research has occurred with this particular group, it is likely that the findings will have clear impact and importance. The findings will be considered in light of how they could inform future clinical practice, in ways which are relevant and beneficial to the group under investigation. Furthermore, dissemination through publication in a peer review journal and through young carer organisations will be prioritised.

4. RESULTS

This section reports the findings of Interpretative Phenomenological Analysis of the seven interviews which aimed to explore the experiences of adults who had been a young carer for a parent with a psychosis-related difficulty. The findings are split into two sections reflecting a focus on the experience at the time and associated meaning, and the participants' integration of the experience into their current life and selves. Quotes¹ are used to illustrate the themes generated. Two master themes for each sections of the analysis were found:

Part One: What life was like for a young carer of a parent with a psychosis-related difficulty

- Feeling isolated and alone
- Caring was taking the parent role

Part Two: Integration of the experience into current life

- Understanding the experience is an ongoing struggle
- Making sense of the person I have become

The master themes and corresponding subordinate themes are summarised below.

Table 3: Master and Subordinate Themes for Part One

Master Themes	Subordinate Themes
Feeling isolated and alone	<ul style="list-style-type: none">• Having no-one to turn to• Longing for connection• Support made a big difference, but it had its risks• Learning how to cope
Caring was taking the parent role	<ul style="list-style-type: none">• Holding responsibility• Feeling exposed and overwhelmed

¹ Where necessary, quotes have been altered to improve readability. This includes the removal of hesitations ('um') where appropriate, and the inclusion of words to offer context (enclosed in square brackets).

Table 4: Master and Subordinate themes for Part Two

Master Themes	Subordinate Themes
Understanding the experience is an ongoing struggle	<ul style="list-style-type: none"> • Trying to make sense, but yet to fully understand • Losing childhood
Making sense of the person I have become	<ul style="list-style-type: none"> • Developing into a better person while acknowledging vulnerabilities • Still feeling affected

4.1 Part 1 – What life was like for a young carer of a parent with a psychosis-related difficulty

4.1.1 Feeling Isolated and Alone

This master theme reflects the great sense of isolation and loneliness experienced by most participants in supporting their parent. Many described having no supportive other to go to, and a sense of not having someone who held them in mind, with those who did have a supportive other still reporting a sense of isolation. Many participants strongly desired gaining some sense of being connected to others, rather than feel distant and alone. However, closeness and connection appeared to often be in flux, changing frequently and never guaranteed. Some participants described being able to reach out and access support, finding it beneficial and instrumental in their ability to cope with their parent’s difficulties. However, many participants were fearful of reaching out due to being given messages that in doing so they risked being removed from the family. Similarly, some described expecting to be dismissed and not taken seriously, which sadly was the experience of some participants. Coping skills were often developed out of necessity, due to participants often feeling that they were the only person that their parent could rely on and so had to find a way to manage.

4.1.1.1 *Having no-one to turn to*

This reflects the sense of isolation and aloneness which participants spoke of when recounting their childhood experience of supporting their parent through their difficulties with psychosis. A contributing factor for many participants was experiencing relationship breakdowns within their family, particularly within their parents’ relationship. Alongside this, participants recounted how both their parents and others were preoccupied with their own concerns and so not able to hold them in mind and respond to their needs. It seemed common for the participants to experience others around them as either physically or emotionally unavailable, encouraging

the need for self-sufficiency. Although some participants reported that their parents avoided engaging with support services, others reported being aware of the involvement of professionals, but not being included within their intervention.

Laura² spoke of coming to support her father through there being no-one else to take this role.

“My mum, she was doing like six days a week working just to cover the bills, and you know pay for all our stuff and that, um, my sister and brother would, they'd just disap... I don't remember them much when I was little to be honest 'cause it just seemed like they didn't want to be a part of that house sort of thing, so they'd just sort of go away and do their own thing.”

Anna also reported that as well as her mother, her father also experienced mental health difficulties:

“I've kind of been a young carer for my dad just as much as my mum when I think about it”

This highlights the strain often put on families, whether due to financial constraints or another family member's mental health. Fulfilling the young carer role appears to be a result of necessity rather than choice, as they seemed to be the only people available to care. Anna highlights the natural fulfilment of this role, as it seems that only her reflection on the situation at home has brought into awareness that she was caring for both parents. Perhaps the assignment of the carer role within families related to the availability and health of others present, rather than their maturity and age.

Without other family members being present, there was often a sense of not being held in mind by others. Participants spoke of a lack of care and support from their parent, but also from other adults around them.

“I've never had that sort of person who was always there for me, but [sigh] you know that's how it is” (Ellen)

Ellen illustrates the loneliness which she experienced, along with a sense of having no-one to look after or protect her. Her sigh mid-sentence may reflect her sadness and sense of loss at realising this, and also hints that this may be a long-term experience for her. Several of the other participants also shared similar experiences of there being no-one else to turn to, leaving them feeling isolated and unimportant.

² Pseudonyms have replaced participant names

Many of the participants described their parent with psychosis-related difficulties not having access to support agencies, with some making sense of this as a historical lack of services, as Laura describes:

“I don’t remember anyone coming to the house or helping us in any way. Um, which I think everything is just how it was back then”

Similarly, Karen reported that her mother was supported by mental health services, but that she was not involved in this.

“she had the crisis team come out a lot when I was younger. Um, so multiple different occasions, I think mostly they came when I was at school though.”

This lack of involvement with professionals, sometimes due to the parent’s wishes not to be involved with mental health services, added to the participants’ lack of visibility and further limited their opportunities for support from others.

This theme expresses how the sense of isolation that participants experienced in their caring role went far beyond their parental relationships. Wider family members and professionals were either not available to step in, were not involved at all or were not aware of the participant’s involvement. This left the participants with feelings of loneliness and helplessness, as well as developing beliefs of themselves as not being worthwhile or important.

4.1.1.2 Longing for connection

This theme relates to the consequences of having no-one to turn to, and reflects the participants’ expressed desire to feel connected to someone. Looking back, many participants described experiencing fluctuations in their relationships with family and friends over time. In particular, it seemed that others around the parent with psychosis-related difficulties tended to use physical distance as a way to manage their relationship with them. The consequences of this for the young carers, who due to their age could not use the same strategy, was that others became beyond their reach. With age, participants often report beginning to use physical distance from their parent, which for some enabled them to develop more connections outside of the home, although understandably impacting on their relationship with their parent.

Ellen described being particularly affected by the loss of her hoped for mother-daughter relationship. She reflects on her realisation that she may never have this connection and her subsequent seeking of this elsewhere.

“I always had this thing, like one day we'll have a normal mother-daughter relationship, and then suddenly at university I suddenly began to realise that actually that was never going to be the case”

“the special relationship in my life with an older woman is my grandma, you know, not my mum, it's my grandma I would think of as having that sort of loving bond”

Ellen highlights the longing for a loving relationship with her mother, holding this desire right through her childhood. Although perhaps not consciously aware of it at the time, Ellen appeared to seek a replacement loving bond with her grandmother, and seemed particularly driven to establish a connection with someone who could care for her. The emotional bond with her grandmother appeared crucial to Ellen, perhaps offering some safety and containment in an unpredictable family environment.

All of the participants described how their parents' psychosis-related difficulties had a profound impact on the family as a whole. Several shared a sense of experiencing their family members becoming more distant, both physically and emotionally. As a result, several participants described having fragmented relationships with their family members, particularly their siblings. Most participants reported being unable to overcome this distance and reconnect with their family members; however, one participant described how she was able to overcome this distance to fulfil the desire to feel connected.

“my sister and brother, my brother especially, he didn't know what to do with it, how to handle it, so he'd usually stay away from it” (Laura)

“my mum had to send my brothers to their different dads, so that fragmented the family, and ultimately our relationships have suffered” (Anna)

Anna reflects on the necessity of her brothers being removed from the family home, but also expressed the impact which that had on their relationships. She uses the word 'fragmented', generating the image of lots of separate, perhaps broken parts of her family which are too physically distant to feel connected. Several participants shared Laura's experience of family members being more distant, with some, like Laura, attributing this to their lack of understanding. Ways of making sense of this included perceiving it as a deliberate choice to withdraw, or reflecting on their own experiences and empathising with why family members may struggle to be closer.

Although Serena's described her family members remaining physically close, she felt that they had become more emotionally distant. However, Serena goes on to describe how despite this, she was able to gain a close relationship with her family members and maintain this.

“Things are, you know, they’re good now and we’re even more close I think, so we were able to keep it throughout”

Serena appeared to use the physical availability to support her seeking of a relationship with her family members, rather than let the emotional distance form a barrier. Although this will have taken determination from her, it seemed to result in her having the close relationships which she desired. This suggests that the emotional distancing used by family members to cope can possibly be overcome and lead to developing closeness and connection.

Some participants reported that physical distance helped them cope with the effect of supporting their parent with psychosis-related difficulties, either as they got older and were able to have time away from home, or as a result of breakdown in their parents’ relationship.

“when they’d broken up I found that I could have a more normal-ish life, as bad as that sounds, but it kind of gave me more freedom to go home ‘cause I didn’t feel like I needed to be at home to look after him, I felt like I could go to my friend’s house. Because if he was at home I’d feel ‘oh no, I don’t want to go round’ you know? ‘I should be at home looking after my dad” (Laura)

The opportunity for distance from the parent that they supported seemed important in allowing them a break from that environment and also providing space for their own reflection and self-development. For some, having friendships outside the family home helped to create space from their parent. However, for Laura it seems that her guilt for not spending time with her father prevented her from engaging in her friendships, with this only being possible once her father had left the family home. Similarly, later in life participants reported finding their move to university important in helping them to gain distance from their caring experience.

Desiring connection was a strong theme for the participants, with many reporting experiences of feeling disconnected and isolated from family members. In order to manage their experiences, many participants report distancing themselves from their parent which too contributed to their feelings of isolation.

4.1.1.3 Support made a big difference, but had its risks

Although feeling isolated was the predominant experience, some participants when reflecting on their childhood experiences described exceptions where they felt supported and cared for. However, most participants feared the consequences of reaching out, due to being given messages that they may be taken away, there being an atmosphere of secrecy in the family or through their own difficulties with trusting others. Some participants reported how the paranoia which their parent was experiencing affected their ability to reach out to others. However, in those exceptional times where participants described connecting with support,

they shared a sense of feeling protected and being able to share the weight of their experience.

Some participants reported having a protective relationship with a family member.

“Nan really protected us you know and as I say I dread to think what would have happened if she hadn’t of been around because there wasn’t anybody else” (Chloe)

Chloe experienced a supportive and loving relationship with her grandmother, viewing her as a source of protection and safety. However, Chloe reported feeling very lonely despite having this relationship with her grandmother, and questioned how she would have managed without her.

Serena reported being able to maintain a closeness with her mother while supporting her stepfather, and was also the only participant to gain support from a young carer organisation.

“it was really, really, helpful talking to this (...) lady; she was trained, she was, you know, young as well so I felt like I could connect to her”

Serena found this outside support very beneficial and shared a sense of feeling contained and protected through accessing this young carer service. However, prior to this she reported feeling misunderstood and dismissed by a teacher who knew about her home situation.

“my (...) teacher was like, “Oh, what’s wrong?” and ...I think she heard me talking about stepdad’s problems once and she said, “Oh, did you have a fight with your stepdad? That happens”, you know, “Every teenager has that, you’ll get over it” and I think that put me off talking to teachers, you know, ‘cos it’s like, “You don’t know what I’m going through, how can you just say that?” as if it was just some teenage problem”

This experience of reaching out to teachers or educational professionals was shared by two other participants, who similarly experienced a lack of response to their disclosure.

“if I said to a teacher, like, “oh my mum’s got schizo-affective disorder”, they would just be like “ooh, don’t know what that is, don’t talk about it, people might judge you for it”. And I was like, now I don’t know what to do because I really want to talk about it” (Emma)

For Emma, this experience seemed to leave her feeling unsure of who else to turn to, whereas Serena expressed a sense of anger and frustration at feeling dismissed by her teacher. It is unsurprising that the participants reported fears of sharing their difficulties when the response of professionals was to dismiss their concerns or seem overwhelmed by their disclosure.

Another barrier which participants reported to seeking support was their parent's behaviour in relation to the psychosis-related difficulty which they experienced. Several participants reflected on times when their parent actively encouraged them not to share their experience with others or intervened in their relationships.

"I was always scared that they would judge me or... and I think it came from my mum as well you know 'cause my mum used to say stuff like 'oh don't tell anyone how crazy I am 'cause they'll take you away'." (Karen)

These messages and behaviours of the participants' parents appear to reflect their own struggles with paranoia and mistrust of others. However, being given these messages seemed to perpetuate feelings of fear and guardedness within the participants, which in turn could affect their relationships. Another participant described her parent monitoring her communication with others, which appeared to both damage their relationship and leave the participant feeling even more isolated.

Many participants described a need to keep their experiences a secret, for fear of judgement or dismissal, or due to messages expressed by their parent. As a result, many did not reach out to others for support, or if they did, they confided in a family member who was already aware of the situation and so 'safe' to share their experiences with.

4.1.1.4 Learning how to cope

In order to support their parent, participants described developing a number of coping strategies during their childhood which tended to reflect just finding a way to survive in the moment, the most common of which was to 'block out' difficult experiences in order to not feel painful emotions. Additionally, participants described comparing their situation with others and appreciating what they did have. Most participants reported developing their coping strategies in isolation rather than having others to ask or guide them. Some did learn strategies from their parents, but these were mixed in terms of their helpfulness.

It was interesting to notice that although each participant had described coping with very difficult experiences, which for some included suicide attempts by their parents, most struggled to articulate their coping strategies. This is reflected in Karen's response when asked about her coping:

"As they occur? I ignore them, I don't know [laughter], ignore my responsibilities, ignore the stresses, don't deal with them until they blow up, which is basically not dealing with them. Um, I don't know. Don't think about them too much." (Karen)

The uncertain and limited responses when asked about coping strategies gives the sense of participants not being consciously aware of what they have learned to cope. It also suggests

that perhaps the participants may not have interpreted their home situation as something that needed to be 'coped with', but rather saw it as natural, everyday life. In fact, some participants expressed this sense of not knowing anything was different about their home lives for many years, as discussed later.

Several participants described coping by 'blocking out' and disconnecting from what was going on around them, as a way of protecting themselves from painful emotions.

"It's like holding your emotion inside, holding the memories inside and the emotions that come with them. Because if you remember them it starts the pain. The painful emotions. So if you don't talk about them and you keep them in Pandora's Box. It doesn't hurt then" (Chloe)

Two participants talked of using cognitive strategies to disconnect themselves from painful emotions related to their experience, whereas another participant reported using drugs to bring about a similar state of disconnection and 'numbness'. From just expressing the need to disconnect from their experiences, it suggests that each of these participants managed experiences which felt beyond their coping capabilities at the time. Some described ongoing use of these strategies, suggesting that they are still very affected by their experiences and do not yet feel they have the resources to bring them back into conscious awareness. As a common strategy, it could be suggested that this emotional disconnection may play a role in the participants' difficulty in articulating their coping strategies, as to discuss their coping they may need to consider what it was that they had to cope with.

Some of the participants reported seeking coping strategies from others, including their parents, which had mixed results.

"Mum always said, "Go cool your head if you're stressed, you know, go for a walk, get out of your room, you know, the computer isn't helping" so, you know, I thought, you know, one day I would try that so I put, you know, my headphones on and I just walked for hours and it really helped" (Serena)

Serena and another participant reflected on helpful strategies given to them by their parents. With a lack of connections to others who could provide support with developing healthy coping strategies outside of the family, it is reassuring that the family environment itself could help support the coping of some participants. However, one participant described witnessing her parent self-harming, and questioned whether she learned this coping strategy as a result. This adds the possibility that unhelpful coping strategies used by parents could potentially be witnessed and used by their children too.

Predominantly, participants reported developing their coping strategies individually. In particular, some participants reported using cognitive strategies of comparing themselves to others who were less fortunate, or taking a more 'global' perspective on their experiences.

"I think of the bigger, bigger picture really. Like is this really the end of the world (...), or if this doesn't happen, or if this don't go right? I kind of think it a bit like that" (Laura)

Some participants used comparison with others to gain a different perspective on their experience, which appears to have helped them manage their home situations. However, in doing so they also prevented themselves from reflecting on the difficulties which they experienced and so again limited their connection to their emotional responses.

Overall, coping appeared to be a lonely endeavour with participants predominantly using strategies which helped them disconnect from their experience. Potentially resulting from this, several participants were unable to fully articulate their coping behaviour. Participants described finding several ways to distance themselves from the emotional effects of their experiences, which although likely to be adaptive at the time, may contribute to ongoing difficulties in managing difficulties and emotions in future.

4.1.2 Caring was taking the parent role

This master theme captures how participants recalled experiencing their caring role. All of the participants spoke of an increased sense of responsibility for their parent with a psychosis-related difficulty, as well as often assuming a parental role for their siblings. Some participants reported feeling that it was natural to care for their parent, whilst others described a sense of resentment at being positioned in this way. Additionally, many participants described how their feelings about the responsibility they held fluctuated over time and in response to their own coping ability. Many participants described times where they felt overwhelmed within their caring role, and exposed to issues or experiences which were not appropriate for their age. They reflected on both the emotional and physical effects this had on them.

4.1.2.1 Holding responsibility

Many participants spoke of experiencing a reversal of roles between themselves and their parent with a psychosis-related difficulty and saw that as underpinning their carer role.

"it means to be a young carer you have an increased responsibility that is really beyond your years that you shouldn't really be having to deal with" (Chloe)

Several of the participants felt that the carer role involved taking care of someone who should be taking care of you, and considered their responsibility to be beyond that of what would be appropriate at the age they were. Perhaps a reflection of current Western cultural beliefs, they

appear to consider childhood as being a time of feeling protected and carefree rather than feeling weighed down by feelings of responsibility.

Karen talks of how her mother was unable to fulfil the parent role, and so she stepped up to fill it herself, suggesting that the parent role within a family is a crucial one, and one that cannot be left unfilled. Additionally, she describes the ever-changing nature of her care for her mother which highlights her sense of responsibility for keeping her alive.

“one minute I was a child, you know, baby of the family, um with all the attention, and then the next minute you know I'd have to be there, you know trying to convince my mum not to kill herself, you know?”

Although expressed in a fairly matter-of-fact way, this statement highlights the deep sense of responsibility held by Karen. In positioning herself as ‘the baby of the family’ the stark contrast with then having to talk her mother out of killing herself really highlights how quickly the roles can reverse, and the necessity of Karen holding this responsibility in order for her mother to survive. It is quite shocking to consider how the responsibility of a person’s life or death could fall to a ‘baby’, but highlights the sense of isolation experienced by Karen and her family.

Ellen described a slightly different experience of caring, one in which she gained independence quickly in order to not burden her mother.

“I became quite independent so she didn't have to care for me, if you know what I mean, so that was... 'cause I knew she couldn't perhaps always do that or she wasn't willing to or she couldn't manage that”

For Ellen it seems that her mother’s difficulties in fulfilling the parent role resulted in her parenting herself instead. She hints that perhaps her mother ‘wasn’t willing’ to parent her, potentially leaving her with feelings of being unwanted or not important to her mother and resulting in relationship difficulties between them. This contrasts with Anna’s experience, who acknowledges her mother’s difficulties in parenting, but attributed this to her difficulties functioning rather than as a sign of her not caring for her.

“I think my mum's tried to do the right thing, but she just doesn't quite function as an adult” (Anna)

Several participants also described taking on the additional responsibility of parenting their younger siblings.

“make sure she got up in the morning, to make lunch for me and my brother and make sure we got off to school, that we didn't miss school days and things like that” (Emma)

Several participants described having siblings in their life which also needed their support, with one person viewing this as parenting their sibling, and others understanding this to be a part of their sister role. They all describe fulfilling tasks which would not usually be expected of a child in our culture. In particular, one participant reported caring for her disabled sister, which was likely to result in her developing specialist care skills beyond those which she will have learned in taking care of herself.

Several of the participants reflected on how natural a process it was to hold so much responsibility in their families.

“to an extent it was normal but there's also a sense of ‘I'm being a big girl’. Umm, I'm being a grown up, like I have something to offer” (Emma)

“as a kid I think you just get on with it” (Laura)

Several participants viewed responsibility as being a very ‘normal’ part of life, and did not think of it as being different or unusual in any way. This may underlie why the majority of the participants did not seek support from young carer services, as they typically thought their role was a natural part of family life. Emma reflects on how it was important for her to feel like a ‘big girl’, perhaps alluding to the ideals within our culture of quickly gaining independence and achieving rather than seeking support from others. She states how she gained a sense of ‘having something to offer’ which sounds important in building her self-esteem.

However, Serena had a very different experience of being assigned responsibility and described actively seeking to hand this back to her parent.

“I didn't like it ‘cos, you know, it's not my job, he's a grown man, you know, it's got nothing to do with me (...) I always wish that he would have taken responsibility and done things himself, you know, ‘cos he is a grown-up”

Serena describes resenting her position, and wishing that her stepfather would take responsibility for himself. She seems to frame this expectation in the belief that ‘grown-ups’ should be responsible for themselves and not relinquishing this to younger family members, again in line with current Western cultural beliefs. However, given her stepfather's difficulties it is unlikely that he could have fulfilled the ‘grown-up’ role she expected, which further suggests that she may not have been informed about the nature and effects of her parent's mental health difficulty and so struggled to empathise with him.

Feeling responsible for their parents, and feeling as though they had reversed roles with them was a strong theme for the participants, resulting in them carrying responsibility for their own, their parents and at times their siblings' wellbeing. Most participants described a natural and

almost unnoticeable progression into this role, perhaps reflecting their desire to disconnect from their experiences to avoid experiencing difficult emotions which may be generated in recognising the responsibility which was assigned to them, especially in light of not having others to help them contain these emotions and or anything to compare their experiences with. However, caring within the family and becoming independent are sought-after qualities within our culture, and so the experience could also have offered opportunities to build self-esteem, self-care skills and confidence in their own ability.

4.1.2.2 Feeling exposed and overwhelmed

This subordinate theme acknowledged the intense emotions experienced by participants as part of their young carer role. Many of the participants reported feeling overwhelmed, stressed and frightened as a result of caring for their parent. There were often times where the participants described being faced with situations where they felt they did not have the resources to cope, and also occasions where their parent's behaviour was both frightening and bewildering. Being exposed to an emotional environment had significant consequences for some participants in terms of their own physical and mental health, as well as their education.

Many participants described living in a highly emotive atmosphere where their parent's mood and needs could change rapidly. Emma and another participant spoke of needing to 'walk on eggshells' to prevent provoking an emotional reaction from their parent.

"Everyone was kind of always walking around on eggshells, because no-one ever really knew what was going to make my mum react, or how she would react" (Emma)

Emma expresses how the confusion and lack of understanding was shared by her family members, and so not something which she could attribute to herself. This may have protected her from developing a sense of responsibility and blame for the changes in her mother's mood. Some participants reflected on the unpredictable nature of their parent's mood and the fear this instilled in them, as well as a sense of not being able to understand what it was that would cause this often rapid change.

Chloe and Anna described witnessing their parent engage in bizarre and baffling behaviour, which left them feeling frightened and bewildered.

"it was my birthday on the day that she actually went completely crazy. And um, and yeah I was scared, I was scared of her" (Anna)

"he also ripped our house to pieces like including pulling the light fittings out. There were things thrown through the windows, um so it was very, very scary at times" (Chloe)

In recounting their experiences, both use repeated words to emphasise just how scary and frightening it was to bear witness to their parent's behaviour. While Chloe expresses fear at being within that situation, Anna states feeling afraid of her mother and what she might do. This is likely to have had a significant effect on their relationship, and possibly led to Anna taking a similar approach to Emma in not risking provoking her mother in future for fear of what she might do.

Several participants also described feeling exposed to issues or information which should not be shared with children and reflect on having to manage this. Anna in particular reflects on feeling overwhelmed and exposed through supporting her mother:

“my grandad died, he committed suicide, and my nana died of cancer, and then [brother] got diagnosed with schizophrenia all the way through my teens. So I supported my mum through all of that and had those conversations with her, and knew what happened because she found my grandad so she told me all of that in detail and everything”

Anna's example is particularly striking as she highlights the accumulative trauma experienced by her family and talks of providing a confidant role for her mother throughout this, which results in being exposed to age-inappropriate details of her grandad's death. Furthermore, she reports having to manage her own grief alone, while constantly providing emotional support to her mother. Other participants also shared this sense of their parents struggling with boundaries, as well as feeling overwhelmed and exposed in their home environment and feeling resentful of this.

For some of the participants, their caring role and exposure to stressful environments led to them developing physical and mental health difficulties. Serena described experiencing a number of health complaints which she attributed to the stress of her family environment.

“my hair started falling [out] at that time, I would bite my teeth when I was asleep (...) I would be grinding all my teeth at night time and it really hurt, like I really hurt myself during sleep and that was stress related”

Serena's statement illustrates the amount of stress which she was experiencing, and also suggests that the level of coping she required was beyond what she had available to her at the time. Other participants noticed that their mental health suffered as a consequence of coping with many stressors, perhaps suggesting that if they had received support then this could have been prevented.

Another consequence of living in a highly emotional environment was finding it difficult to fully engage with schoolwork. Anna describes how in order to support her mother she would miss school to help in the house, which affected her ability to achieve academically.

“when I was younger kind of it was I had a Monday off, I had a Friday off, I had a Thursday off, and she used to write a list of like, um, dates of when I was off school and used to say ‘well [Anna] was poorly on these dates, it would be like the nineteenth, the seventeenth, the twenty-first, the twenty-eighth. (...) So I missed a lot of my education because of it”

Through recounting how many dates would be recorded on her school note, Anna gives a rich impression of how much time she sacrificed to supporting her mother, understandably impacting on her ability to engage in her education. Additionally, as Anna was both supporting her mother and coping with difficulties that her family were experiencing without her own support, it is likely that feelings of being overwhelmed would also have prevented her from learning and engaging in academic work.

This theme acknowledged the difficult emotions experienced by young carers while trying to support their parent and manage their family environment. Although the participants have shared some insight into their own emotional reactions and the consequences of these, there is a sense of there being much more which is perhaps still too difficult to say or not within conscious awareness. It is concerning that participants reported the stress of the situation affecting their own mental and physical health, as well as their education.

4.2 Part 2 – Integration of the experience into current life

4.2.1 Understanding the experience is an ongoing struggle

This master theme highlights the participants' struggles with understanding their experience over time as they look back from an adult perspective, and acknowledges the difficulty in ever feeling as though it can be fully understood. However, through the passage of time different meanings are developed and evolved, and shape how the young carers relate to their parents and also their own identity development. Looking back, participants expressed a sense of missing out on the childhood they would have hoped for, and mourning the loss of the happy memories which they wished for. Finally, this theme captures the experience of meaning-making as being a journey over time, with many twists and turns, but one which is yet to be completed.

4.2.1.1 *Trying to make sense, but yet to fully understand*

From their adult position, participants described continually attempting to understand the experience of supporting their parent experiencing a psychosis-related difficulty, but rarely feeling that they had made any real sense of it. The meanings which participants evolved tended to flow with their growing age, with there being much similarity in the attribution that participants made about their experiences at particular life stages. This tended to reflect an acceptance of the situation when young, and seeing it as normal family life which then developed into resentment within their teenage years and finally moved on to a position of empathy for the parent. However, for several participants there remains a sense of confusion and having many unanswered questions.

As discussed before, at the time participants reported seeing their caring role and their responsibility within it as a natural part of life, no different to that of others. However, a consequence of this was that the participants therefore did not see themselves as providing a caring role, and so were unable to access young carer support. Additionally, for those who began to recognise their carer role, they appeared to struggle with the difficult dilemma of whether they were deserving of help.

"I didn't know that there was support, and I didn't, kind of think that I deserved it, so it was very much, I'll keep going so that I'm doing what I need to for my mum, rather than any kind of sense of trying to feel better myself" (Emma)

Emma highlights the consequences of young people being unaware of their caring role and the possible support which is available. Her use of language suggests her position now as an adult looking back has allowed her to see how she considered her young self as undeserving and that she was not considering her own needs at the time. Additionally, another participant

described being aware of young carer support, but deciding not to access this as she felt her mother's needs were not great enough rather than considering her own needs.

With growing age came the opportunity to experience other families' lives, which provided a comparison and the realisation that perhaps their experience was different to that of other young people.

"I was probably about eleven, twelve, when you start going to your friend's house more and, yeah it was definitely around that time you start realising this ain't, this ain't really right" (Laura)

Many of the participants described a process of becoming aware of the difference in their family life through comparison with their friends' families. This tended to occur in their early teenage years, a time of great emotional and physical development. One participant described the process of becoming aware that friends' parents were different to her own as 'weird' and disconcerting. It seems like the opportunity to experience their friends' parents provided a challenge to their view at the time of their family life being 'natural', which then left them with the understanding that their parent was different in some way.

For Chloe, this recognition of her family being different to others was particularly difficult to manage, and left her with feelings of shame and isolation.

"There was a lot of anger and things going on then, to be honest with you. You know, ashamed and you know just thinking 'why can you not just be normal, be a normal family?'"

Chloe describes the realisation that her family is different as quite a painful process which evokes strong emotions. For many participants this realisation coincided with their teenage years where self-awareness becomes far more established and where feeling different to others often generates embarrassment and shame.

For several participants, the realisation that their parent is 'different' coupled with a very limited understanding of why, brings feelings of anger and resentment, which in turn lead to rebellious behaviour.

"there was a lot of, a lot of resentment sometimes, a lot of, especially in my teens I was quite angry, very much an angry teenager, um and I think that was just my way of, you know, my way of coping with it to be honest, but all teens are a bit [laughter] ain't they" (Laura)

Laura seems to describe some embarrassment at her 'rebellious' behaviour, perhaps from developing more empathy for her parent subsequently and now viewing her behaviour as not

fitting with her carer identity. Although, as she acknowledges, this sense of rebellion and resentment is often a common experience for those in their teenage years and seen as part of their development within Western culture.

At the current time, participants still gave a sense of being confused and having further questions about their experiences growing up.

“still kind of quite hard to understand” (Emma)

“I still find that quite bizarre to be honest” (Chloe)

However, they described gaining an acceptance of what had happened and a desire to move on with their lives.

“in the grand scheme of things it doesn't matter. I suppose because I'm at peace with it, like, how can you be angry at people when they've been poorly?” (Anna)

Emma and Chloe both reflect on experiences which they are yet to make sense of, but there appears to be an acceptance that there will always be things that will be difficult to understand, rather than a desire to seek answers. This acceptance is evident in Anna's statement which expresses an empathic, balanced view of her parent's behaviour and home life. This more balanced perspective and ability to manage not understanding expressed by some participants may be reflective of their continued development, suggesting that time and distance may allow for reflection on their experiences and integration of them into the self. However, it is also possible that this acceptance may represent further distancing from their experience and a desire not to dwell further on past events and to move on instead.

Participants appear to experience a journey of meaning-making over time. There are several factors which seem to influence understanding at different times, including the information available, access to others for comparison and age and self-development. It is also important to highlight how this ongoing struggle with understanding, and perhaps sometimes misunderstanding is almost in parallel with the experience of psychosis. As Ellen describes, *“the effects just ripple out”* and so having psychosis within the family is very likely to be contributing to an atmosphere of confusion and doubt. Despite this, participants describe reaching some acceptance of their parent and family, and seemed to have reached a position of empathy which they now look back from.

4.2.1.2 Losing childhood

This subordinate theme speaks to the profound sense of loss described by participants when reflecting on their childhood experience. In particular, from their adult perspective they describe losing the opportunity to be a child through having to grow up so quickly, and also

the chance to have a carefree childhood. A sense of longing for a happier past is reflected in some participants wishing to have parental figures as well as happy memories or mementoes, whilst acknowledging that these do not exist for them.

The feeling of losing their sought-after childhood was strong for most participants, as reflected below:

"I lost the ability to just be a child. Umm, and not have worries and just to play and run around and laugh and finger-paint and all that kind of thing" (Emma)

"Yeah I've lost a mum and a dad, like a full mum and a dad. I think I've still got a mum and a dad, but I've probably got about a quarter of them, whereas a lot of other people have a full mum and dad" (Anna).

Emma reflects on losing the ability to be a worry-free, playful child, suggesting she took an adult role from an early age. Additionally, she appears to compare her situation to that of an idealised family which really highlights how different her experience was to what she would have wished for. Anna's statement really illustrates how much her parents' capacity to be there for her was affected by their own difficulties, but she is still able to acknowledge the small part of them that was there for her. Other participants also express a loss of a 'normal' childhood, which includes having the opportunity to be carefree and childlike instead of needing to grow up quickly and manage serious situations.

Additionally, others describe missing out on having happy memories of their childhood, like those that they feel others have.

"Yeah I feel I lost um ... my happy memories that I should have had [pause 6 seconds]. It's like a you know, it's, there's Pandora's Box of all the horrible things but also that's made me with good things as well. They also unfortunately get locked away in Pandora's Box but there's a lot of them I do not remember" (Chloe)

"I don't have a single memory of us all being happy together. And it's all, and even if we do have, if there are good memories they're always peppered, you know, with little bits of sadness of little bits of... just something that only, any other family from my perspective that doesn't have that, you know, and it's, it's sort of different from the inside and watching from the outside but I'd like to have a little bit you know I think normalness" (Karen)

Chloe's statement almost mourns the loss of her happy memories, which seems to be compounded by the fact that her coping through disconnection also means disconnecting from the happier memories too. Much like how hope was also trapped in Pandora's box in the fable,

Chloe describes how in order to cope she has needed to sacrifice the positive memories of her childhood. This gives a strong sense of how difficult some of her experiences are likely to have been, as for her the preferable choice is to disconnect from all of her memories for fear of connecting to the most painful ones. Karen similarly cannot recount a happy memory, and explains how even those memories which seem happy on the surface are actually “peppered” with sadness when you look more closely. Both illustrate the big sense of loss associated with their experience of supporting their parent.

This theme acknowledges the profound sense of loss expressed by the participants. They report missing out on opportunities to be carefree and happy within their childhood years, and instead needed to hold responsibility in their family. Additionally, participants describe not having happy memories of their childhood years, and expressed a sense of mourning this loss too.

4.2.2 Making sense of the person I have become

This master theme refers to the participants’ current understanding of themselves and their identity, in light of their experiences of supporting their parent. Many participants expressed a sense of gaining from the experience and held the view that they are a better person as a result. However, some participants reflect on also being left with some vulnerabilities, such as lowered confidence and ongoing anxiety. Additionally, many participants share a sense of still being affected by their early experience in terms of feeling that they may not have reached their academic potential and also feeling unable to engage in and develop their own family relationships as they would have hoped to.

4.2.2.1 Developing into a better person while acknowledging vulnerabilities

This subordinate theme reflects the sense of having developed personally in light of caring for a parent with a psychosis-related difficulty. All of the participants were able to identify, sometimes unprompted, the strengths and skills which they had gained from their experience. Participants spoke of developing the skills necessary to effectively care for others, understand and empathise with those experiencing difficulties and to develop close relationships. Additionally, they reflected on having greater resilience, gained from having survived difficult and traumatic experiences when young. Participants also described their journeys of understanding themselves, sometimes through comparison with their parent, while some acknowledged the ongoing nature of gaining understanding. Finally, some participants share their acknowledgement of some of the vulnerabilities which they carry forward from their caring experience, including difficulties with confidence, insecurity and anxiety.

Several participants expressed a sense of having a greater understanding of and empathy for people from their experiences, as highlighted by Emma:

*“it’s given me a lot more empathy towards other people, umm, and a lot more patience”
(Emma)*

Participants suggested that their experience had provided them with the ability to empathise with other people who experience difficulties. Some talked of being less judgemental and more patient, and using their experience to help inform how others might be feeling and coping.

In line with this, some participants reflected on how their young carer role has allowed them to develop skills in caring for others now.

“I think it’s given me the ability to... um, well just be there for people. And I think that’s a good thing” (Karen)

Karen’s statement highlights that for some, the experience has provided a very unique sensitivity on an emotional level which in turn allows them to understand and support others in similar circumstances. The ability to look after others is something which participants tend to express pride in, perhaps as it allows for confirmation of their positive qualities and capabilities.

However, as Karen acknowledges, there are potentially negative consequences to continually fulfilling a carer role.

“You can always, you know be there too much for someone and they can take advantage of you, which has happened”

This highlights the ongoing negotiation of relationships and learning how much to offer to others and how much to take care for yourself. An ongoing task for the participants will be to find ways to effectively show their caring skills while being able to protect themselves from being taken advantage of, and allowing themselves to be cared for.

For several participants, their career offers the opportunity to use their caring skills, but within predetermined boundaries. Emma reflects on her experiences of this:

“there was a focus on looking after yourself and reflective practice, umm, and so there was an element of, actually this is quite good for me, and it’s quite self-affirming, and actually it made it easier to keep some of those boundaries and start to understand why I want to put boundaries in certain places”

For Emma, her career choice and training has provided an invaluable opportunity to develop the self-awareness and boundaries needed to effectively use her caring skills while not depleting herself. Many of the participants had chosen a career in helping professions and expressed ambivalence about whether this was due to their early experiences. However, as

Emma's experience shows, the training and structure provided through caring careers can allow for effective use of the skills gained from their early experiences, while providing the knowledge and self-awareness necessary to promote self-growth.

Several participants also reported feeling closer to family members as a result of their experience, as reflected by Chloe:

"it brought me and my bigger sister in later life really close together" (Chloe)

This reconnection may be due to there being a 'shared experience' from which they can understand each other, allowing for greater empathy between them, as they both know and understand what they have lived through.

Many of the participants reflect on how their beliefs and perspectives have changed over time, in relation to understanding themselves and others. This is reported as a positive development of the self, and is seen to facilitate relationships with both their parents and others.

"because of dealing with my mum over the years it, you do see life a bit differently, perhaps more tolerant of certain things in your life or things that happen in your life, you know it gives you a different perspective. So you know in a strange way there's some positives, it's not all negative" (Ellen)

As highlighted by Ellen, some participants talked of how their perspectives have changed in light of their experience of supporting their parent. Ellen reports gaining more tolerance and empathy, and reflects on how her caring experience actually had positive effects too. Other participants described having a richer understanding of the human experience and the world generally.

Some participants made comparisons between themselves and their parents, as a way of developing a sense of self, as expressed by Laura:

"I think emotionally, um, I think I'm different to my dad"

By describing herself as 'emotionally different' to her dad, Laura may be suggesting that she feels her mental health and coping is possibly more effective than his. She does not elaborate further on how she is different, but expresses a sense of confidence that she can manage emotional issues more effectively than her dad. The differentiation of the self from the parent may serve the purpose of reassuring the participants that they are not likely to experience similar difficulties, especially in relation to mental health.

The majority of participants reported feeling that they had good mental health, and good insight into the factors which influence this. However, Laura did raise the potential of being susceptible to mental health difficulties:

“depression runs in genetics, apparently, I've heard. Um, and, you know me and my sister and brother always joke, like it's not funny, but it's going to be one of us 'cause one in three get it [laughter]. Um, but I think, yeah I think emotionally we're all wired a bit differently”

Laura presents the possibility of a genetic susceptibility in a light-hearted way, and describes the playful exchange between her and her siblings in terms of who “is going to get it”. The humour in discussing this may defend against a deeper fear of experiencing difficulties much like her parent, and so reassurance against this can be gained from differentiating the self from the parent in terms of emotional coping. Laura uses the term ‘genetics’ and “one in three get it” which suggest an inevitability that one of her sibling group will experience difficulties, but then counteracts this by expressing how they are all “wired a bit differently” and so unlikely to experience difficulties, further illustrating the potential fear and need to be different. However, as the participants have acknowledged, the experience has given them skills and insight into managing psychological distress, potentially giving them a sense of protection from developing their own issues.

Although the participants have shown considerable reflection and integration of their experience into their identity, there also remains a sense of this being an ongoing, rather than completed experience. Ellen described realising this having reached the likely mid-point of her life.

“last year made me think I've not completely reconciled myself with it, but you sort of begin to reconcile yourself and live with it, you have to so, you don't know any different”

Ellen is the only person to explicitly reflect on her awareness of still being in the process of reconciling who she is in relation to her caring experience, which was brought into her mind partly through reaching middle age. This highlights how the passing of time and reaching of milestones will likely encourage further reflections and meaning-making within the participants and continue to contribute to their identity in future.

Many of the participants described gaining an identity of being a strong, resilient person, with their experience giving them confidence in their ability to cope. Anna expresses a sense of confidence in her coping from having managed very difficult situations in her early life.

“I suppose that’s one of the skills that I’ve got out of it as well is that things don’t, like I don’t, like other people would not be able to cope with that, whereas I can cope with very difficult things, very difficult disclosures and stuff, and it doesn’t faze me” (Anna)

Although these skills in coping have been developed from managing very difficult circumstances, Anna is now able to recognise the resilience that this has given her and also use this to offer containment and support to others who may also have experience very difficult life experiences.

Several participants expressed ongoing vulnerabilities which they attributed to their caring experience, which included lowered confidence and anxiety. Chloe expresses ongoing difficulties with confidence and needing ongoing reassurance of her capabilities and worth as a person.

“I feel like I have a lack of confidence and I’m a bit insecure and I need lots of reassurance. I put myself down a lot, I feel I don’t see my full sort of potential”

Although Chloe has a loving and supportive family, these fears about her capability and acceptability appear to persist and affect the opportunities which she is prepared to engage with, highlighting an ongoing vulnerability.

Within this theme, participants shared their understanding of themselves and sense of becoming a better person who has many strengths. Participants report becoming skilled in empathising and understanding others and developing closer relationships. They describe often choosing careers which make use of their skills while offering the development of self-awareness and boundaries in order to prevent self-depletion. Integration of the experience and its meaning to the self is acknowledged as an ongoing process, with new meanings and understandings about the self potentially being developed in future. However, some participants also acknowledge their more vulnerable side, and link these ongoing struggles to their earlier experiences.

4.2.2.2 Still feeling affected

Participants described how they continued to be affected by their caring experience. Most participants questioned whether they had reached their academic potential, and reflected on the repercussions of not being able to fully engage in their education when young. Additionally, some participants also reflected on how their caring experiences now influence their behaviour in relationships and in particular, struggling with being very self-sufficient and fearing that others will not be dependable. Finally, most participants expressed the desire to parent very differently to what they experienced, and for some this significantly impacted on their own family relationships.

Many participants questioned whether their experience when young had affected their ability to fulfil their academic potential. Although most expressed uncertainty on how much impact their home life had exerted, it was nonetheless mentioned by most participants.

"I'm only going to uni now. I left school with rubbish grades. Um, and I've had to do like an access course and things to get into it, but... yeah I, I'd probably say if I had, mm, I don't know. I'd probably say if I had, (...) if everything was a normal household my mum would've had more time to focus on me and my education" (Laura)

Many participants questioned whether their experience had a detrimental effect on their education and academic achievement. Like Laura, some participants expressed a sense of being held back, while others felt that with greater educational support, they may have had more career opportunities.

Several participants connect their past experiences to current day difficulties which they struggle with. Ellen reflects on how her development into an independent, self-reliant person has impacted on her relationships.

"I've possibly at times pushed people away because I don't want people to get too close in case, you know emotionally it doesn't work, and it's too hard to deal with. (...) So I think that's, yeah and possibly it's made me a little bit cold at times or a bit too independent"

Ellen describes pushing people away as a protective strategy to prevent her getting hurt by others who she cannot depend on, informed by her experience with her mother. However, she now recognises that this has a negative impact on her relationships, with others viewing her as 'cold' and so not fulfilling the dependable role she seeks.

Karen describes a similar difficulty of seeking a dependable other in relationships, but describes herself as becoming needy and distressed at the prospect of someone not being there for her.

"I definitely have issues with relationships now. Um, and had difficulty making friends growing up. Um, and have little kind of like abandonment issues (...) it's difficult to have a level head in any kind of relationship because I don't know I'm a lot like my mum I guess, and I don't know whether it's, I don't know whether it's my own psychological issues or whether it's learned behaviour"

Karen recognises the similarity in her and her mother's behaviour and questions whether her own difficulties are the result of psychological issues or learning to behave this way from her

mother. She goes on to acknowledge how others find her behaviour in relationships difficult to manage, but still gives a sense of feeling unable to adapt or change.

Finally, most participants described a desire to prevent their children from having a similar experience to themselves. Participants described choosing to limit their children's contact with their parent or made sure that they themselves did not require their children (or potential children) to take the caring role for them.

"in terms of having children myself, umm, I know absolutely in myself that, because my mum doesn't have those boundaries, and doesn't know what is not okay to say to children, because they will internalise it, umm, I couldn't have children and have them have contact with her. Umm, so at the moment, I'm, is, it's kind of the question of do I not want children ever?" (Emma)

"it definitely makes me think you know I don't want to put my daughter through that situation. So I think it makes me... not a better parent, but perhaps a more stronger parent than I would have been, because I don't want her to ever rely, like for her to look after me or anything like that, she should rely on me" (Laura)

Emma describes the incredibly difficult dilemma of wanting to both protect her children from being exposed to what she was, while wishing to protect her mother from not being involved in her grandchildren's lives. At present, Emma appears to feel that her choices are very limited and so instead of risking difficulties for others she is questioning whether or not she should have children at all. This decision is likely to have significant consequences for her, her identity and her relationships, but it seems that the potential risk that her children may face is greater than the consequences she may experience. Laura already has a child and expresses firm beliefs that it is her role to be a parent, and not for her to rely on her child. She reflects on how this has required her to become a stronger parent than she expected, but appears absolute in her belief that it is how it should be in order to protect her child.

This theme highlights how the participants caring role has had a number of consequences which have been carried through into their adult life. In particular, most of the participants questioned whether they had fully reached their academic potential. Some also recognised how their past experiences were now impacting on their current relationships, ultimately leaving them feeling less connected to others while longing to have someone to depend on. A shared concern for most participants was the need to prevent their children from having similar experiences as they did growing up, resulting in some difficult decisions regarding their family relationships.

This concludes the results section of the study. The findings are discussed within the next section.

5. DISCUSSION

The following section includes a discussion of the study results in relation to the research questions, previous research findings and theory. Following this the clinical implications, methodological issues and potential areas for further work will be considered.

How do adults who were young carers for a parent with psychosis-related difficulties retrospectively describe their experiences of caring for or supporting their parent and what meaning do they give to this experience?

5.1 Feeling isolated and alone

Many participants described their childhood as a time of feeling isolated and lonely, with few others to turn to. Participants often shared a sense of longing for connection, in the context of their family members often being more distant and their parental relationship often breaking down. Where the parental relationship was intact, participants described their other parent as being emotionally and physically distant, similar to the findings of Dunn (1993). Interestingly, very similar experiences of isolation are also reported by mothers experiencing mental health difficulties (Dolman, Jones & Howard, 2013), indicating how the presence of mental health concerns for a parent can impact on connection and intimacy for all in the family. The retrospective view allowed for awareness of how these early experiences of isolation may have influenced later connections to others, including ongoing challenges with maintaining their relationship with their parent, difficulties with intimacy in romantic relationships and challenges in developing their own parenting role.

Although it has been described in the literature (e.g. Foster, 2010) that some children are able to form a compensatory relationship with either the other parent or a family member, participants within this study only rarely reported having close relationships with others. Several participants reported feeling supported by siblings, and although this connection was often disrupted, it helped the participants feel supported and able to start to make sense of their experiences. Maybery, Ling, Szakacs and Reupert (2005) found that children of parents with mental health difficulties reported having generally positive relationships with their siblings, with both them and their parents highlighting the importance of sibling support when the family experiences difficulties. The current study findings support this, but also highlight the fragility of these sibling relationships, suggesting that they cannot be relied upon as a potential source of comfort and support. Good relationships with family members and friends help children to both feel connected and share their problems, highlighting the importance of support for young carers to help them gain and maintain relationships (Drost, van der Krieke, Systema and Schippers, 2015).

Participants also reported finding trust challenging, both in relation to their parents and others outside of the family. This sometimes stemmed from parental messages that they would be removed if they spoke out, potentially reflecting the parents' fear and suspicion of services. Parents struggling with paranoia-related difficulties may be less likely to access services, and through encouraging these beliefs in their children, they may also reduce their visibility and contact with support. This is supported by Murphy et al. (2015a) who report that children experiencing situations which had which generated a sense of fear within them resulted in an emergence of mistrust of others. Several participants also feared reaching out to others outside of the family. Unfortunately, for some within the present study this mistrust appeared justified, as their attempts to reach out to educational professionals and hence trust them with their difficulties, was met with dismissal or inaction. As such, participants were reluctant to reach out again and were doubtful of others' desire to help, perpetuating their feelings of isolation. As Drost et al. (2015) highlight, professional recognition of children's roles in supporting their parents is essential, and so it is necessary that professionals who come into contact with young carers are both aware of their presence and able to offer effective support.

Within this context of isolation, participants reported having to generate understanding and coping strategies alone. This arose due to the lack of trusted others to model or educate them in adaptive and restorative coping strategies. Some developed strategies through witnessing how their parent and family members seemed to cope, while others turned to strategies they described as negative, such as taking drugs. This fits with research of others like Totsuka (2013) who described how, in the absence of being given information, young people often learned about parental mental health concerns and how to cope by observing their parents and others. It is interesting to note how participants in the current study found it difficult to identify or name the ways they coped, or are continuing to cope with their experiences now, which Stern, Doolan, Staples, Szmuckler and Eisler (1999) suggest may be due to the story remaining stuck at the point of disruption. Several participants reported using physical distancing strategies such as going to their room or escaping to a friend's house (when old enough to do so), which may be understood in terms of attempting to create a safe distance from their parent in order to allow for their own development (Mordoch & Hall, 2008; Riebschleger, 2004). Many described continuing using such strategies into adulthood, for example, cutting off from their parent as adults.

Most concerning was the finding that, despite such attempts at distancing, most participants reported times where their home experiences and accompanying emotions were inescapable and caused considerable distress. In particular, being exposed to paranoid or bizarre behaviour was often terrifying and beyond their understanding. At times where physical escape was not possible, several participants developed the strategy of 'blocking out' their

emotions, similar to Mordoch and Hall's (2008) findings who liken this to 'emotionally leaving the room' in order to protect the sense of self. Similarly, Wells and Jones (1998) suggests that dissociation may be a mechanism to help escape intolerable feelings which may challenge the core sense of self. For participants within this study, disconnecting from their difficult experiences may have served to protect them from painful and overwhelming emotions, in the context of not feeling connected to and contained by others around them. Furthermore, the retrospective design indicates that using these strategies of distancing and disconnection can continue into adulthood. Thus, it is important to consider the implications of these coping strategies on family relationships. Murphy, Peters, Wilkes, and Jackson, (2014) highlight how this emotional distancing by the child towards the parent can contribute to a parent perceiving their parenting role to be disenfranchised, and so the cycle of distancing continues. Additionally, although this 'blocking' may be considered an adaptive way of coping in light of not having containing others to support them in managing emotions, the current study indicates how it can potentially have long-term implications for their relationships into adulthood, their mood and wellbeing.

5.2 Caring was taking the parent role

Participants often described their caring relationship as an act of reversing roles with their parent, which appeared to be a relatively stable and unfluctuating change of roles. At times this was associated with a sense of capability and independence, both encouraged within a Western culture. However, at other times this increased responsibility brought the need to manage intense and difficult situations, often leaving the participants feeling overwhelmed and exposed. Participants within this study reported many different family strains including bereavement, financial hardship and parental conflict, alongside the parental psychosis-related difficulties, similar to the findings of Doutré and colleagues (2013). Dolman et al. (2013) report that mothers with mental health difficulties are aware of the increased responsibility placed on their children and feel considerable regret about this. However, participants within this study report that in their younger years they felt that their caring role was natural and something which they wished to do, realising retrospectively the level of responsibility which they held.

A common finding in the parental mental health literature is interdependency within the relationships between children and the parent experiencing mental health difficulties (Aldridge, 2006; Van Parys & Rober, 2013; Nolte & Wren, in press). However, the findings of this study suggest that these young carers did not experience an interdependent relationship; instead they felt predominantly responsible for their parent's wellbeing the majority of the time. This may be due to the emotional distancing used by participants, coupled with them identifying themselves as independent and self-sufficient in response to their experience, resulting in

them potentially being less able to acknowledge times of dependence on their parent. Additionally, the retrospective position may result in participants remembering a more global sense of the direction of care, potentially losing sight of the moment-to-moment shifts in care described in other studies. The implications for young carers of not having a sense of reciprocity needs to be considered. Furthermore, previous research findings suggest that having a more interdependent relationship may help strengthen the relational bonds between child and parent (Aldridge, 2006), and so interventions which help re-establish the parent-child roles, even if briefly, may help strengthen relationships overall. This point is explored within the clinical implications.

A potential theoretical frame for understanding the reversal of roles between parent and child is parentification (Boszormenyi-Nagy & Spark, 1973), discussed previously in the introduction. Although not necessarily a negative phenomenon, issues may occur when parenting roles become part of the child's identity within the family (Byng-Hall, 2002), as that child may become fixed in this position within the family. The present study findings appear to suggest that participants did feel fixed into a role of parental figure. Byng-Hall (2008) suggests that although outwardly children can appear competent, they often feel inadequate and overstretched which potentially leads to the development of an 'incapable' personal identity. Nolte and Wren (in press) found that parents described their children as more mature, which influenced the information which they shared with them. Similarly, participants in the present study reported feeling overwhelmed at times by their caring role, yet aware that there was no one else who could step in. Thus, it is possible that they hid these feelings behind a persona of capability and maturity in order to reassure both themselves and their parent.

Many participants within this study reported the dilemma of caring feeling natural and the right thing to do, versus finding it overwhelming and exposing. Similar to Foster's (2010) findings, there was a great sense of uncertainty about what would occur from one day to the next. Some participants described providing crisis support at times when their parent experienced a downturn in their mental health or a significant life event, similar to the findings of Aldridge (2006). These experiences felt beyond that which the participants had the resources to cope with at the time, and so as Byng-Hall (2008) suggests, it is possible that the participants were left with a sense of inadequacy which they may use to inform their sense of self. Within this study, participants predominantly described there being a lack of information, but at times when it was provided it was often inappropriate for their age, leaving them feeling exposed. However, the opposite appeared to occur for participants in Van Parys and Rober's (2013) study, who reported often feeling protected when they attempted to find out information about their parent's difficulties. Within the present study this may reflect the difficulties the participants' parents were described to have in holding them and their needs in mind. These

findings highlight the need for careful consideration of the type and amount of information to make available to young carers, and is likely to be dependent on their emotional development.

While some participants described school as an 'escape', for several participants their carer role impacted on their ability to engage with their education. Becker and Becker (2008) highlight how a potential consequence of young caring is missing school and having a poorer educational performance, and so experiencing restricted educational opportunities. Farahati, Marcotte and Wilcox-Gök (2003) also found that parental mental health concerns increased the probability of school drop-out for children. While participants within the present study did not report dropping-out of school, the findings show that their education was clearly affected. Most participants questioned whether their caring role influenced their academic achievements, expressing a sense of having 'unfulfilled potential'. Although most participants within the present study had studied for university degrees, this often took place later in their lives than they would have wished, or required the completion of further qualifications to allow them access to university. This highlights the need for young carers to be recognised within education and supported to fulfil their potential.

Finally, it is important to consider that the experiences of providing care and the participants' meaning-making around this is situated within a particular cultural and societal context. All participants were female, perhaps reflecting a dominant societal discourse of the female gender being more closely connected to caring and nurturing others. This is in line with Eley's (2004) 'hierarchy of care', where gender and age are used to determine who cares in a family. The acceptance of this greater responsibility by young carers themselves may reflect the dominant discourses within Western culture about the importance of gaining independence and becoming a contributing member of society. A further powerful discursive context for the current findings is that of the stigma attached to having a mental health difficulty (Hinshaw & Cicchetti, 2000; Hinshaw, 2005). Some participants feared their parent being perceived as 'crazy', and described this preventing them from discussing their experiences. This mirrors the findings of Murphy, Peters, Wilkes and Jackson (2015b), who highlight that awareness of social stigma is present from a young age. Awareness of such gender imbalances in caring and the stigma that persists in relation to mental health concerns needs to be held in mind by clinicians.

5.3 Understanding is an ongoing struggle

Participants described ongoing difficulties in making sense of their experiences as a young carer, and reported still now feeling confused about some aspects of their experiences. Typically, when young participants described considering their experiences to be fairly 'normal', which for some prevented them from seeking support. However, at times participants

also reported experiencing considerable fear when faced with aspects of their parent's psychosis-related behaviour, in line with Dunn's (1993) findings. Experiencing the distorted beliefs of their parents, especially if this invades their thinking, is a key area where children will need help and protection (Cooklin, 2013). The current findings highlight the highly changeable nature of the experiences which children were faced with, which they often considered to be part of everyday life at the time.

Most participants noticed how in adolescence their view moved to feeling very different from their peers, bringing feelings of frustration and resentment. Greater access to other families as they aged provided a comparison by which to gauge the 'normality' of their own family life. Both Doutré and colleagues (2013) and Mordoch and Hall (2008) report similar findings of adolescents experiencing tension in their caregiving identity in light of greater awareness of 'ideal' family life. Erikson's (1950) psycho-social stages of development suggests that adolescence is a time of developing identity and individuation, with the adolescent becoming more aware of societal norms and subsequently concerned with fitting in. Having a different experience of family life to others may potentially challenge this area of development, leading to feelings of frustration and resentment and the potential desire to distance the self from the family. Some participants reported feeling ashamed or embarrassed of their parent's unusual behaviour during their adolescence, similar to Dunn's (1993) findings. The majority of participants also reported feeling overwhelmed, confused and distressed, which Murphy and colleagues (2015b) suggest may be due to greater questioning occurring in adolescence. Consequently, participants within the current study reported 'rebellious' against their carer role and putting more distance between themselves and their home situation, perhaps as a way to try and establish their identity beyond that of carer. Additionally, several participants expressed anger and frustration at their experience, similar to the findings of Earley et al. (2007), but appeared to manage this through distancing themselves from their parent.

As participants moved into their adult years, some reported a greater understanding and empathy towards their parent's experience. This mirrors Van Parys and colleagues (2014) findings, where participants described gradually becoming more aware of their home situation through conversations with others. However, they report some participants also expressing a sense of still not fully understanding what happened in their past, which too was also present for some in the current study. This suggests that although significant time has passed since the participants fulfilled a young carer role, their difficulty in making sense of it remains.

The reported changes in how participants made meaning of their experiences at different times may reflect the changes in their development over time. Piaget's (1971) theory of cognitive development would suggest that children would not gain the skills necessary to fully appraise

and make sense of their home situation until they had reached adolescence and early adulthood, and so at a young age children are arguably more likely to accept their situation as 'normal'. Vygotsky's (1978) theory of sociocultural development suggests that children will develop through their exposure to adults or expert peers, and so at a young age and in light of the young carers experiences of isolation, their understanding is likely to be reduced. However, adolescence appeared to provide participants with the opportunity to consult peers and witness alternative family experiences, allowing for some appraisal of their situation to be developed. As such, the participants' description of a process of increased questioning and attempted meaning making as they become older is very much in line with what would be expected as part of their developmental process. However, for participants within this study it appears that there is ongoing difficulty with gaining a comprehensive understanding of their experience of caring for their parent with psychosis-related difficulties, potentially related more to the complexity of their experience rather than their developmental capabilities.

The retrospective nature of the study also appears to facilitate the participants' connection to unhappy memories of childhood. From their adult position, several participants reflected on the losses which they had experienced, including losing the happy, carefree childhood which they wished for. Gaining slightly different findings, Mordoch and Hall (2008) highlighting how participants attempted to overlook losses despite feeling disappointed, perhaps to maintain a connection with their parent. It may be that within the present study, the time elapsed since childhood and the lessened pressure to maintain a relationship with their parent may have facilitated the participants' connection with their experiences of loss. Surprisingly, young carers' experience of loss is rarely present within the literature, perhaps reflecting a sense of continuing to fulfil the carer role through putting the parent and their experiences first, or possibly through the use of 'blocking out' by young carers in other studies to protect themselves from painful memories. This deep sense of loss described by participants in the current study will be returned to within the clinical implications section.

It is important to note that the participants within this study were reflecting back on their meaning-making at different life stages from an adult perspective, which is likely to be different in some way to the meaning-making that they may have developed at the time. Van Parys et al. (2014) suggest that a retrospective approach may facilitate connection to painful childhood experiences, which may not have been as accessible as a child, and also acknowledge how those now in adulthood are likely to reinterpret their experiences through a different lens. This reinterpretation of childhood events is also likely to be influenced by the current relationship between the parent with psychosis-related difficulties and the participant, with those with more strained or distance relationships potentially reinterpreting their childhood experiences through a more negative lens. Earley and Cushway (2002) suggest that retrospective accounts

may be problematic because forgetting, defensiveness and social desirability are likely to influence the recall of events and family functioning. However, these factors appear to be less influential than the influence of the current relationship with the parent, as participants gave rich, balanced accounts which did not appear to be shaped by the need to appear socially desirable.

5.4 Making sense of the person I have become

Participants described looking back over their lives and gaining some understanding of the person whom they had become, through comparing their past and current selves and noticing the areas of development. They expressed a sense of becoming a better person through their experiences, and valued the skills and views which they had gained. From having coped with adversity when young, some participants reported developing a sense of themselves as being a strong and resilient person. However, there were ways in which participants still felt vulnerable and affected by their caring experiences. In particular, all participants reported wishing to parent differently to their parent, which had potential consequences in terms of their family relationships.

Looking back on their experience, some participants described now having a better understanding of the person who they had become. This appeared to be facilitated through looking back and comparing their earlier sense of selves with how they perceived themselves to be now. Similarly, Mordoch and Hall (2008) described participants using comparison between past and present to gauge how they and their family were doing. In particular, several participants within this study reflected on how their beliefs about the difficulties their parent had experienced had changed over time and described themselves as more empathic and tolerant, and as having a more positive outlook on the world.

For some participants, their sense of self was informed by comparing themselves to their parent and noticing the differences. Although the use of comparison by children supporting parents with mental health difficulties is well described within Mordoch and Hall's (2008) study, there is no mention of participants comparing themselves with their parent in order to inform their identity. This may be a unique finding of the current study, and is possibly facilitated by the retrospective design. However, within this act of comparison with the parent, there may be a need to differentiate the self in order to feel reassured that they are less likely to experience the mental health difficulties which their parent did. As Cooklin (2010) suggests, children commonly fear that they will develop mental health problems similar to their parent's. As such, part of the need to define the self as different to the parent may be to seek reassurance that their own development of mental health difficulties is not inevitable and to identify 'signs' of resilience or psychological well-being.

For several participants the carer identity appeared to be integrated into the self, with many participants reflecting on how they care for others in their current life. This supports Earley and Cushway's (2002) suggestion that young carers go on to adopt 'caretaker' roles in adulthood. Byng-Hall (2008) suggests a 'little parent' as a child is likely to prevail for a long period, often a lifetime, as part of looking after others, which appears to be reflected in the findings of the current study. Therefore, young carers may benefit from gaining an awareness of how their earlier caregiving role may inform their adult relational styles. Those who enter into caring careers, of which several had in the present study, may gain the benefit of using their caring skills while learning how to take care of themselves and allowing others to care for them at times. Most participants did not reflect on their own self-care, which combined with some also having little awareness of their coping resources, suggests that support with learning skills in self-care and effective coping may be beneficial for this group. Furthermore, reflecting on mutuality and interdependence in relationships would be a further area of interest for consideration.

A further important finding was that many participants described experiencing considerable gains from having fulfilled a young carer role. Some participants reflected on how their experiences of having to cope with very difficult situations when young had given them confidence in their future coping ability. These findings mirror those of Kinsella, Anderson and Anderson (1996) who described participants expressing a sense of confidence and self-assurance from having survived their difficult childhood experiences. Similarly, Bauer, Spiessl and Helmbrecht (2015) found that participants reported considerable rewards, including that of developing positive personality traits. The current study supports this as several participants viewed themselves as a 'better', more empathic person. With young carer research historically focussing on the ongoing risks and vulnerabilities of young carers, it is important to highlight the sense of gain that some participants within this study reported.

Finally, a particularly poignant finding of the current study was the ongoing impact on participants' consideration of themselves as a parent, including their future or current parenting approaches, within the context of their own experiences of being parented. Similar to the findings of Van Parys et al. (2014), all participants reported a desire to parent their children differently to what they had experienced. Additionally, some participants felt it necessary to protect their children from having similar experiences with their parent, and so limited their contact with them. For one participant this went as far as considering whether or not she could risk having children at all in future, highlighting the very sad and limiting impact this could have. Byng-Hall (2008) suggests that some parentified children find their experience in childhood so painful that they strive to do the opposite by being very parental to their own children, and so implement a corrective script. Similarly, within this study it seems that participants' early

experiences were still affecting the families which they developed, either through them attempting to provide a corrective parenting script to their children, or through protecting their children from having similar experiences with their parent, potentially affecting their family relationships. This will be returned to in the clinical implications section.

5.5 Clinical Implications

The clinical implications of these findings will now be discussed, including a consideration at a community, family and individual level.

5.5.1 Community-Level Implications

At a community level, there is much which should be done to reduce the stigma experienced by parents with mental health difficulties and young carers, which in turn may facilitate their access to support. This includes educational programmes within schools and greater provision of information about mental health difficulties through accessible literature, for both parents and children, in line with the 'Time to Change' (2008) initiative. The need to consider mental distress in the context of trauma, marginalisation and disadvantage is gaining awareness (Smail, 2005), with the clinical psychology profession being encouraged to become more active in addressing these societal contexts (Harper, 2016; Psychologists Against Austerity, 2015). In light of the study finding of the long-term impacts of parental mental distress on all of the family, this seems particularly important.

Additionally, the study highlighted how families often experienced multiple strains including financial hardship, which too may be addressed through the development of community-based support projects, which are distant from mental health provisions. This may feel less stigmatising for parents experiencing psychosis-related difficulties, allowing both them and their family to benefit from support. Family reluctance to engage with services is a key barrier in supporting young carers (Ofsted, 2009) which may be avoided if less stigmatising community-based projects are developed to address the multiple needs of families.

5.5.2 Service-Level Implications

At a service level, early identification of young carers is essential. The predominant identification routes are likely to be via schools and mental health professionals working with parents, as children themselves are unlikely to come forward (Cooklin, 2013). A close bond with a stable schoolteacher has been shown to be a protective factor for resilient children (Foster, O'Brien & Korhonen, 2012); therefore, the findings in the current study indicating the lack of awareness and support participants experienced within school, is of great concern. Educational professionals require awareness of and skills in supporting young carers. One possible way of achieving greater school-based support is through developing befriending or mentoring roles where children with similar experiences offer peer support to each other,

which children may find preferable to professional support (Cooklin, 2010). Similarly, both education and mental health professionals can signpost to young carer services which provide peer support and respite. Mental health professionals in particular need to be routinely recording the parenting status of service-users from the earliest point of contact and enquiring into the family's wellbeing (Ofsted & CQC, 2013).

Similarly, the societal discourses which appear to support the assumption that caring is primarily associated with the female gender can also be challenged with service-level interventions. In particular, it is important that professionals in positions of recognising and supporting young carers appreciate and understand that both male and female genders can and do take up a caring role. Furthermore, it is important to highlight and challenge the potential expectation that girls should take up caring roles within families, potentially leading to a greater sharing of responsibilities between both genders and a reduction in the responsibility held for all. Additionally, teaching professionals are well placed to invite discussion into nature of young caring and be able to dispel some of the assumptions commonly held in society that caring is more associated with, and appropriately assigned to a female gender. These discussions or more specific teaching could take place within the school environment, perhaps as part of the teaching included in Personal and Social Education.

5.5.3 Family-Level Implications

This study highlights several relational impacts on young carers and their families where a parent experiences psychosis-related difficulties, including greater distancing between family members and longer-term influences on parenting practices. One aspect to consider is how family members and young carers often distance themselves from the parent experiencing psychosis-related difficulties, which often becomes more pronounced when young carers reach adulthood. This is likely to be the last resort in coping, as both children (Mordoch & Hall, 2008) and parents (Nolte & Wren, in press) express a desire to remain connected to each other. As such, family-based interventions drawing on systemic theory (Dallos & Draper, 2010) to help strengthen family relationships are likely to be beneficial, particularly in reducing isolation. Family therapy can offer the opportunity for meaning-making to be supported, and also provide a model for parents in providing information while maintaining boundaries (Daniel & Wren, 2005). Similarly, drawing on the ideas of Minuchin (1974), a structural family therapy approach may support families to re-establish parent-child roles and help foster interdependence.

Narrative family interventions, particularly those using externalising practices (White, 2007), which may help families position problems outside of individual family members, are also likely to be beneficial in strengthening relationships through both engendering a sense of agency in being able to address the 'problem' and also considering ways of minimising its influence on

family relationships. Through externalising the psychosis-related difficulties, family members may be able to assign a new meaning to their experiences and connect together, rather than distance themselves, in order to address the 'problem' as a family. Additionally, through the parent being identified as separate from the problem, there is potential for them to reconnect with aspects of their parenting role, allowing for greater interdependence with their children to develop. Family interventions are recommended within National Institute for Health and Care Excellence guidelines for psychosis as a routine treatment (NICE, 2014); however, many families are not offered these interventions (Schizophrenia Commission, 2012) and young carers may be overlooked as potential participants within this process. It is essential that family interventions are more routinely offered to families experiencing psychosis, in line with clinical guidance and research evidence.

Early preventative strategies are likely to be of most benefit for families, in light of the study findings of participants distancing themselves. Young carers commonly express the need for information (Bilsborough, 2004), which may have addressed participants' confusion and difficulties making sense within the present study. Psycho-education is the common ingredient across interventions targeted at children of parents with mental health difficulties (Reupert et al., 2012), although the current study, alongside previous research, has highlighted the importance of information being provided in accessible and age-appropriate ways. An example of a family-orientated psycho-education based intervention developed in the UK is the Kidstime project (Cooklin, 2013). This multi-family group intervention includes all in the family in work to address the impact of parental mental health concerns. It is important that interventions like this are robustly researched to assess the effectiveness for young carers. Although psycho-education is a well-evidenced intervention for families experiencing psychosis (McFarlane, Dixon, Lukens & Lucksted, 2003), psycho-education targeting the needs of young carers of parents with psychosis-related difficulties are not yet appearing within the research literature. As psychosis has many unique features potentially not experienced with other mental health difficulties, it is likely that a specific psychosis psycho-educational programme will be most beneficial.

5.5.4 Individual-Level Implications

There is also a potential role for psychological interventions for adults who were previously young carers. Narrative based therapeutic interventions (White & Epston, 1990), supported by a growing evidence-base, may help address some of the difficulties identified within the current study. Many participants reported disconnecting from their memories of their experiences, which although potentially adaptive when young, there are possible long-term implications for their own mental health if they continue to cope in this way. A potentially transformative way of facilitating connection to past events is offered by Denborough (2010),

who describes supporting individuals to connect with their history, 'excavate multiple meanings' about what occurred and recognise the skills and strengths carried forward. From this, individuals may develop richer accounts of the relationship experienced with their parent and also consider how to helpfully integrate their experiences into their parenting identity. Furthermore, this could also allow for the significant experience of loss to be acknowledged and witnessed, while also allowing reflection on what has also been gained.

It is important to acknowledge that many participants were aware of the stigma associated with mental health difficulties. This coupled with the likelihood that they would not meet thresholds for mental health services, suggests that individual-level interventions are likely to have the greatest benefit if offered through the voluntary sector. In particular, carer organisations could develop the abovementioned interventions for those who have previously been young carers. Similarly, healthcare professionals who support families, such as health-visitors and midwives are helpfully placed to discuss the parenting experiences of adults who had previously been young carers and the potential implications of this on their own parenting practices, while providing information about potential support.

5.6 Suggestions for Further Research

Qualitative research into the experiences of young carers of parents with mental health difficulties is in its early stages. Therefore, there is great scope for further research to build on the findings of this study.

Within this study, participants described still holding some confusion and unanswered questions about their experience. Research focussing on how young carers make sense of their experiences, and exploring whether there are themes in the issues which remain associated with a sense of confusion would be valuable, and potentially lead to the development of targeted interventions. Similarly, participants within this study reported developing different meanings for their experience at different stages of their lives. This could be further explored through an explicit focus on meaning-making across the lifespan, either retrospectively or longitudinally.

An interesting finding from this study was the participants' fluctuating experiences of closeness and distance in family relationships. Although distancing appeared to be a coping mechanism, it often placed strain on relationships. A greater understanding of how family members experience closeness and distance in their relationships when supporting someone with a mental health difficulty, and the underlying processes of this, is likely to be important in developing family support interventions. What is also important to note is the relative lack of reflection on how the young carers within the study now negotiate their relationship with their parent as an adult. For those who did discuss this, they predominantly described there being

established distance in their relationship with their parent. Greater exploration of how young carers negotiate their relationships with their parent as an adult would shed light on the relational processes and understandings within this and potential issues and difficulties which may be faced.

It is also interesting that all of the participants within the study were female. It would be helpful to consider the role of gender and whether it influences the development of carer identities. As Cree (2003) reports that there are differences in how girls and boys experience their young carer role, it would be of benefit to explicitly target a group of men who had previously been young carers for a parent with a psychosis related difficulty. This too may offer insight into why few men came forward for the present study. Additionally, investigating the influence of cultural discourses on those who take up carer roles, and exploring whether these discourses are more influential with women would help gain insight into the potential populations likely to be fulfilling a carer role and the most helpful interventions needed.

Within this study, most of the participants were currently engaging in higher education, which may be suggestive of them having access to particular resources which others may not have. A sample of participants who had not experienced higher education would help understand whether there are additional factors associated with young caring which affect access to further education or training. Similarly, the sample within this study was predominately made up of individuals who identified themselves as white British. An interesting area for future research would be investigating young carer roles in families of differing ethnic backgrounds, and their meaning-making about their parent's mental health difficulties.

The retrospective design allowed for unique insights into the meaning-making of participants and the longer-term implications of their caring experience. Further retrospective research of different groups of young carers of parents experiencing particular mental health difficulties would broaden our understanding of the lived experiences of young carers over time, and the implications of these experiences. This may provide insight into the similarities and differences of young carers supporting parents with differing mental health difficulties. Furthermore, a contemporary research study of young carers supporting parents with psychosis-related difficulties will provide greater insight into current experiences of support services.

5.7 Methodological Considerations

The idiographic focus of IPA paired with the epistemological assumptions of the research does not allow for the generalisation of the results to the population of young carers supporting a parent with a psychosis-related difficulty. Instead the focus of the study was to privilege the voice and lived experiences of the participants, in line with the aims of IPA. Thus, rather than making any specific truth claims, it adds to and enriches our existing knowledges and

understandings of the experiences of those who care for a parent with mental health difficulties and should be read alongside this literature.

Although transparency through reflexivity has been upheld throughout, it is not possible to bracket the influence of the researcher completely (Ahern, 1999). As such, the beliefs, values and experiences of the researcher have influenced the interpretations made and the results reported. The researcher worked throughout to make these influences available to the reader and these should be held in mind while reading the study findings.

Although the chosen methodology was appropriate for the research questions, the retrospective nature of the research did add an element of temporality in the results. However, as IPA has recently been adapted and applied to retrospective data (e.g. Van Parys et al., 2014) it is considered an appropriate choice of analytical method for the data generated within this study in the light of the research questions asked.

The retrospective nature of the study may have facilitated the participants' connection to more difficult or emotive aspects of their childhood experiences. In support of this, several of the participants reported 'blocking out' the emotions associated with their difficult experiences when young as a way to cope and manage. However, the meaning-making that an individual ascribes to childhood events is likely to be influenced by other factors, particularly the nature of their current relationship with their parent. As a result, it is possible that the retrospective position of the research allowed for participants to potentially reinterpret their childhood experiences through a more negative lens, particularly if their current relationship with their parent was strained. However, within the study several participants were able to reflect on difficult times while still maintaining a good relationship with their parent, suggesting that the retrospective position is both a relevant and illuminating one.

A total of eight participants were sought for the study, in order to gain sufficiently rich data. Although nine were recruited, two participants withdrew from the study prior to interview. Having completed the study, it is felt that seven participants gave sufficiently rich and detailed data, allowing for a comprehensive analysis and development of distinct themes which were strongly grounded in the data.

Additionally, the participants included within this study were all female. Although male participants were not actively excluded, only two expressed interest in participating. Of those two, only one fulfilled the inclusion criteria but later withdrew due to his caring role. The greater representation of female participants may reflect broader societal attitudes which assign caring more to a female gender. Aldridge (2006) suggests that being of female gender is an influential factor in who takes on the caring role in a family. Some participants described their male relatives and siblings taking a more distant position towards the person experiencing

psychosis-related difficulties. It is possible that male young carers will have differing experiences that may have added to the richness of the data, and so future research may benefit from actively seeking male participants.

Difficulties were experienced in attempting to recruit participants into the study, which is a common finding within the literature (e.g. Kennen et al., 2012; Thomas et al., 2002, etc.). As such, the majority of participants were recruited from advertisements within universities. This may have led to the participants in this study being considerably different from those who may have been recruited either through carer-related agencies or through the general public, as higher education is often associated with access to financial and class-based resources. However, as IPA seeks to understand the individual experience and meaning-making rather than produce transferable findings for populations, as well as requiring a homogenous sample, it is not felt to be especially problematic. However, understanding the experiences of those from different backgrounds would be a useful aspect of future research.

Finally, member validation was not used within the study, despite the view that the quality of the research is enhanced by checking the understandings made with the original informants (Elliott et al., 1999). This decision stemmed from researchers of similar studies reporting that their participants experienced distress at being asked to comment on the findings (e.g. Nasr, 2014; Bromley, 2009). Additionally, in light of the message received from carers' organisations during recruitment, it was felt that requesting participants to give additional input may risk overburdening them and potentially leave them with the impression that research participation is an arduous experience. Although this particular form of validation was not pursued, throughout the study considerable effort was made to fulfil Yardley's (2008) quality criteria. Also, it is hoped that findings will be disseminated not only within peer-reviewed publications, but also within the grey literature, e.g. through the National service-user and carer network newsletter.

5.8 Final self-reflections

Reflexivity is important throughout the research process, including post-analysis (Ahern, 1999). Throughout the research process I attempted to maintain a reflexive stance, using the completion of a reflective journal and discussions within both research and peer supervision.

Throughout the process of this research I have endeavoured to consider my role in the shaping of the stories which were told to me. One aspect of the research process which may have been influential in shaping the accounts which participants gave was the construction and delivery of the interview schedule. In an attempt to construct a thorough schedule which was grounded in and progressed beyond the research findings in the literature, it is likely that I provided a framework on which the participants based their stories. This may have led to them

adapting their experiences in order to answer my questions, or potentially not sharing experiences due to feeling that they may not have been relevant. In particular, as much of the previous research into young carer experiences tends to report negative experiences, it is possible that the potential to highlight potential negative consequences was increased within my interview schedule. This was addressed as far as possible through gaining the views of an expert by experience on the interview schedule, completing a pilot interview and gaining feedback and also through using open-ended questions, but it is possible that the participants were influenced by this.

Despite having fulfilled a young carer role myself, I was moved and surprised by the level of responsibility described by the participants within this study, feeling both a mixture of sadness and awe in response to their experiences. I am particularly struck by the number of participants using 'blocking' strategies to disconnect from the painful emotions associated with their experience, and associated this with a more hidden vulnerability. However, it is also possible that both my own experiences of caring and my political position of wanting to raise awareness of young carer experiences influenced my interpretation of the accounts shared with me, potentially inviting me to place increased emphasis on their experiences of difficulties or adversity.

During the interviews I often experienced the dilemma of wanting to probe sufficiently to gain a rich picture, but not so intensely that the participants felt uncontained and exposed. Following the interviews, I often felt the need to reassure through suggesting that they were not alone in their experiences and that support services were available if necessary. In these moments, I feel it was difficult for me to put aside my therapist role and allowed my desire to help others manage emotional difficulties to inform my experience of interviewing. However, through both reflection and analysing the data I can see that each participant had strength and resilience, and had developed strategies in managing stressful and emotional situations. This is an important piece of knowledge for me, which I will carry forward in both my clinical and future research work.

Perhaps mirroring the participants' experiences, throughout the analysis I often felt overwhelmed with the amount of important features which had been reported. Possibly through understanding that young carers are often overlooked and not spoken for, I found myself wanting to include as much detail of their experiences as possible in order to feel justified in advocating for their needs. As such, I found it difficult to amend and adapt themes once I felt I had identified them, as I felt that in doing so I may lose something important. However, on reflection I feel that this struggle may in fact have been beneficial in highlighting

to me, and hopefully through me to others, just how complex and multi-faceted the experience of being a young carer for a parent with a psychosis-related difficulty is.

Another dilemma which I have held throughout the research, and have not yet fully reconciled, is that of potentially portraying parents with a psychosis-related difficulty as lacking competence and potentially damaging their children. There are many stigmatising discourses surrounding mental health which are further amplified for parents with mental health difficulties. In order to do justice to my participants I feel compelled to report their experiences as fully as possible and do not wish to temper the results through a frame of others potentially reaching negative conclusions about the participants' parents. Throughout the research process I have shared this dilemma with my peer researchers and within supervision and have attempted to remain alert to how this may influence the interpretations made and results reported. This dilemma has illustrated for me the importance of acknowledging the prevalent discourses surrounding those who experience psychological distress and their families, and I will continually attempt to reflect on my role in privileging and subjugating certain views.

Throughout this research I have endeavoured to be as reflexive as possible. I have found completing a reflective journal and supervision conversations to be key within this. This has included reflection on how the participants of the study have positioned me as a researcher and what assumptions they may have made about my interest in their experiences. Through being aware of my gender and profession, they may have inferred that I too had experienced a caring role, and so expected a shared understanding between us. Indeed, in some interviews I remember having to ask for explanations when I felt there was an assumption that I understood what they meant. Additionally, there may have been things left unsaid between us. Perhaps from meeting with someone completing their second degree in relation to many of the participants' struggles to gain access to higher education, there may have been an assumption that I would not understand some of the challenges which they had faced. Also, I may have represented one of the professionals which did not recognise that they needed help when younger. Although it is not possible to know, the practice of reflexivity has allowed me to have a greater understanding of my own influences on the research, and highlighted the importance of bracketing these where possible.

5.9 Conclusion

The aim of this study was to gain a rich understanding of the life experiences and meaning-making of a group of adults who were young carers for a parent with a psychosis-related difficulty. It is hoped that the findings of this study help to provide some understanding of the longer-term influences of being a young carer for a parent with a psychosis-related difficulty, to begin to address the paucity of information in this area (Murphy et al., 2014). Within this

study, all of the participants reconnected with their childhood experiences, and shared the sense they had made of them over time and the ongoing effects which they still carry. There was much within these reported experiences which was supported by previous literature findings, with the retrospective design allowing for the journeys of understanding to be made apparent. Like many young carers and children supporting parents with mental-health difficulties, participants described intense feelings of isolation. Within this, participants described experiencing fluctuating closeness and distance in their familial relationships, while often longing for a sense of connection with someone. Additionally, they described often feeling solely responsible for their parent's health and wellbeing, and reflected on how at times this felt beyond their coping abilities. Looking back, participants were able to acknowledge the different understandings they attributed to their experiences at different times, offering insight for mental health professionals and support services into what support may be most beneficial at different times. Additionally, participants were able to recognise some of the ways in which their experience informs the identities which they have developed, and also highlight how their caring experiences may influence their later relationships and parenting.

Through the reported experiences of participants within this study, potential new understandings of the nature of young caring for parents with psychosis-related difficulties have emerged. In particular, the experiences of the participants suggest that their relationship with their parent is one where they assume responsibility, with little fluctuation in this, whereas other studies have found a more interdependent relationship between parents and young carers. Additionally, whereas previous research into young carer and parental mental health populations has often taken a risk and vulnerability focus, participants within the present study were spontaneously able to reflect and acknowledge some of the skills and resources which they had gained from their experience, and integrate this into their adult identities.

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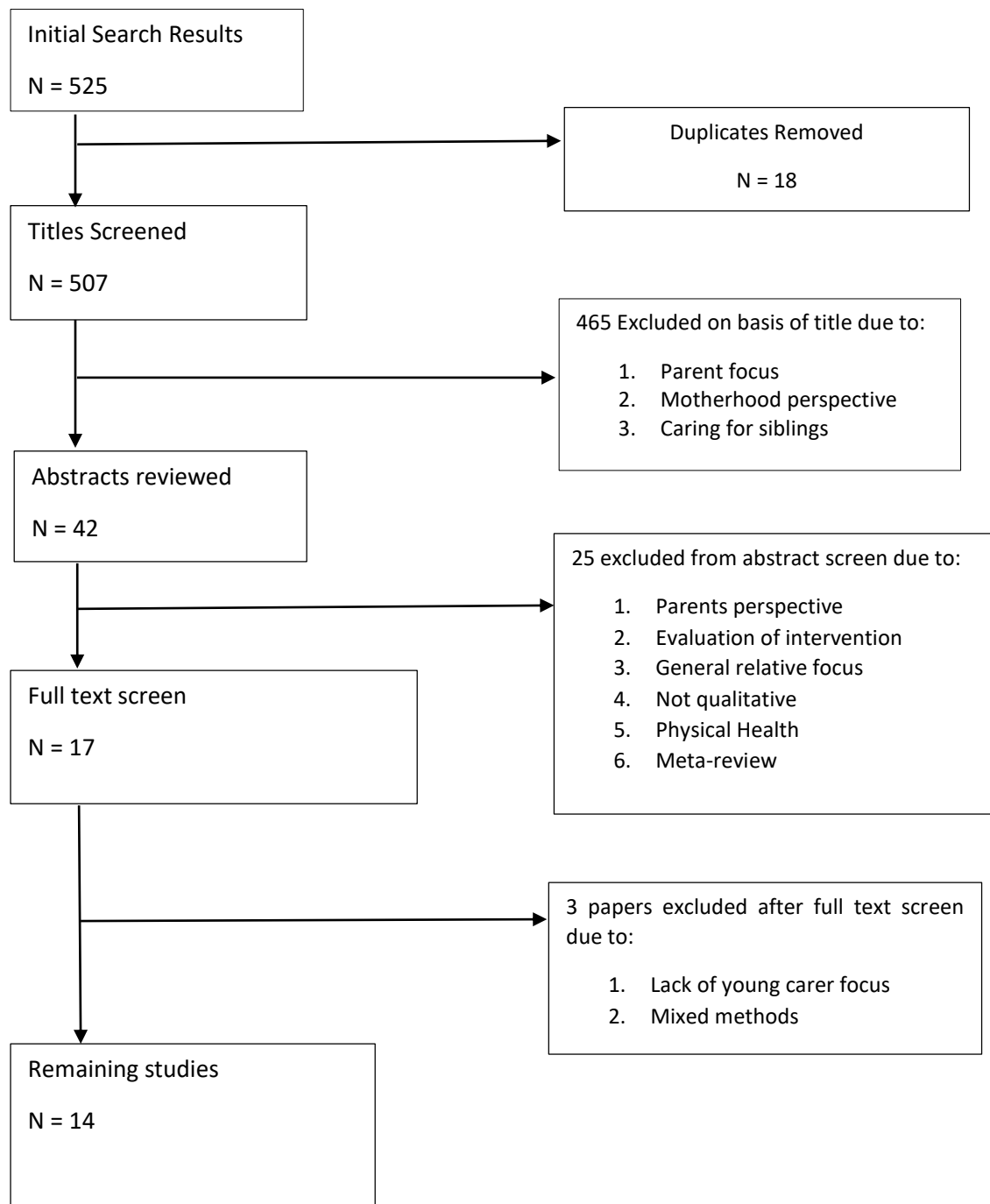
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7. APPENDICES

7.1 Appendix 1: Literature Review Flow Chart



7.2 Appendix 2: Summary of Reviewed Literature

Title	Author & Date	Sample Details	Study Design	Findings	Key Implications	Critique
You'd think this roller coaster was never going to stop': experiences of adult children of parents with serious mental illness.	Foster, K. 2010	8 women and 2 men recruited including researcher, aged 27-25. Inclusion: Over 18, English speaking and spent time with at least one parent who they understood to have serious mental illness. No exclusion criteria evident.	Interpretive qualitative approach, purposive sampling and used ethnography to include researcher as participant. Unstructured interviews asking only one question. Retrospective design.	Themes: Being uncertain; struggling to connect; being responsible and seeking balance	High number of participant's reported own MH difficulties, although experience did bring some gains. High level of abuse and anger reported as well as attachment related difficulties. Family focused care likely to be most helpful.	<ol style="list-style-type: none"> 1. Checking transcript accuracy with participants-improving quality 2. Generalised use of 'serious mental illness' instead of diagnosis-specific 3. Reported a 'striking finding of participants' experience of parental explosive anger, but only appeared to be one/two participants who highlighted this - overemphasised? 4. Focussed on negative impact - consequences of abuse, neglect 5. No discussion of researchers contribution within paper (lacking transparency)
Listening to the voices of young carers using Interpretative Phenomenological Analysis and a strengths-based perspective	Doutre, G., Green, R., & Knight-Elliott, A. 2013	6 young carers aged 11-13 years. Identified by keyworkers in YC service. Inclusion: Aged 11-13 years, male or female and known to YC project for 2 years. No exclusion criteria.	Qualitative design using 3 semi-structured interviews and photo elicitation. Used Interpretative Phenomenological Analysis.	Overall themes: Caregiving as a positive response to complex lives with multiple disadvantages. Subthemes: Tensions and adaptations in participants' identity and family relationships & Tensions for participants' in maintaining familial	Complexity of lives reflected in individual accounts. Perception of lives was growth oriented. Caregiving role preserving sense of self. Feeling different to peers. Benefit of feeling loved and building close relationships with cared-for person. Close family	<ol style="list-style-type: none"> 1. Limited information on inclusion/exclusion criteria and justification 2. Mental illnesses of parents not described or defined, 3. Small sample 4. YC who are accessing services - potentially different (more supported) experience

				relationships and sustaining a life outside of a caregiving relationship.	relationships important for maintaining continuity in difficult times. Need family focus in interventions.	5. Acknowledgement of co-construction between participant and researcher but no evidence of reflexivity.
Growing up with a psychotic mother: A retrospective study	Dunn, B. 1993	9 adults: 4 men 5 women. Aged 21-41yrs, 1 diagnosed with schizophrenia. Inclusion: parent diagnosed with psychosis, lived with parent during early childhood years and no longer living with parent. Exclusion: Having a psychotic father, living >1hr away from researcher.	Retrospective qualitative design with purposive sampling and 3 part semi-structured interview. Thematic analysis of results.	Themes: Abuse and neglect; Isolation; Guilt and loyalty; Contacts with MH services and Social supports	Children would benefit from information and inclusion in family interventions. Professionals need to be aware of the loyalty and guilt felt by children, and help strengthen parent's role. Therapists require awareness that loyalty and guilt may play out in later relationships. Clinicians need to address children's fears of experiencing MH difficulties themselves.	<ol style="list-style-type: none"> 1. Highly focused on negative experiences- questioned under-reporting of traumas (assumption that participants were traumatised) 2. Not explored the caring role of children 3. Small sample, exclusion based on researcher preferences 4. Exclusion of experiences with fathers 5. Specific psychosis focus
Children of the mentally ill: A qualitative focus group study	Garley, D., Gallop, R., Johnston, N., & Pipitone, J. 1997	6 male and female children aged 11-15yrs, with a parent who had accessed the mood disorder centre of a university based clinic. Inclusion: Biological children between 11-15yrs, living with/in regular contact with the parent. Exclusion: Children who were mentally challenged, history of drug/alcohol	Qualitative design using 4 focus groups and ethnographic approach. Use of semi-structured interview of open-ended questions. Continued until theme saturation reached.	Two themes with subthemes: Understanding the illness: Personal concerns; illness attributions; quest for information; recognising the 'signs' and impact of hospitalisation. Managing the illness: Coping with impact on self; Coping with impact on ill parent; Perceptions of help for ill parent and	Need for awareness and intervention before young carers become symptomatic. Potential for group interventions to provide normalisation, support and learning. Research to address ways of reducing risk of symptoms in future young carers.	<ol style="list-style-type: none"> 1. Parents with a mood disorder, not psychosis 2. Focus group method - difficult to gain individual experience 3. Seeking objectivity - use of objective validity checks 4. No reflection on limitations of the study by authors 5. Parents in active treatment - family supported

		abuse, 'acting out' behaviour or not fluent in English		recommendations for others.		
Living with parents with obsessive-compulsive disorder: Children's lives and experiences.	Griffiths, J., Norris, E., Stallard, P., & Matthews, S. 2012	5 girls and 5 boys, age range 13-19 years, 3 pairs of siblings. Inclusion: Live with one parent with OCD. Exclusion: Parents with comorbid psychosis	Qualitative cross-sectional design using one-off semi-structured interviews. Thematic analysis	Themes: Control and boundaries; Doing what I can to help; Telling: Embarrassment and pride; Do I have OCD? and Getting the right help for me.	Children placed under similar caring burden to adult relatives. Parental OCD compromising parent-child relationship. Embarrassment, stigma and fear of developing OCD. Family life predominantly affected, school, leisure and relationships were not affected. Importance of developmental stage - attempting to develop autonomy during adolescence. Age appropriate support, offered routinely and with a choice about who provides it.	<ol style="list-style-type: none"> 1. Only included parents already receiving support 2. Focus on OCD, ruled out parents with psychosis 3. Critical realist position taken - assumption that the person's account will be an accurately reflect their experience 4. Use of reflective journal to address researcher influence 5. Transparency in presentation of method
Growing Up with a Mother with Depression: An Interpretative Phenomenological Analysis	Van Parys, H., Smith, J.A., & Rober, P. 2014	5 women, aged 39-47. Inclusion: Mother had been hospitalised with depression. Exclusion: Men, insufficiently rich data prior to analysis.	Retrospective, qualitative design using Interpretative Phenomenological Analysis. Use of semi-structured interviews. Analysis split into childhood experience and adult reflections.	Part 1: Themes: Feelings of desolation contrasted with exceptional support; Context-related dwelling on own experience and Growing into caring role as a way to keep standing. Part 2: Themes: Growing understanding of the situation at home; Coping with own vulnerability; Trying to make a difference in	Children take on caring roles, contributing this way seemed crucial to sense of well-being. Shift from avoiding own experiences to more conscious coping with past emotions. Desire to protect own children. Retrospective focus allowing connection to painful events. Children may present as 'okay',	<ol style="list-style-type: none"> 1. Acknowledgement of the quality of data required for appropriate analysis 2. Inclusion of researcher reflexive practice 3. Experiences of parents with depression only 4. Exclusion of men who may offer richer understanding 5. Transparency in method of analysis

				current family life and Trying to find a balance in continued bond with parents.	but really using silence to cope.	
Children's Perceptions of Living With a Parent With a Mental Illness: Finding a Rhythm and Maintaining the Frame	Mordoch, E., & Hall, W.A. 2008	22 children, aged between 6-16, 14 boys and 8 girls. Inclusion: living with a parent being treated for depression, schizophrenia or bipolar, English speaking. Exclusion: If parent couldn't read & speak English	Initially purposeful sampling, later used theoretical sampling. Grounded theory analysis.	Two basic social psychological processes were constructed: 1. Finding the rhythm and Maintaining the frame	Children value the relationship with their parent and actively try to maintain it. Healthcare professionals are not thinking of patients as parents. Importance of age - adolescent children struggle more due to recognising differences between own and others family. Adolescents may 'opt-out' of relationship with parents and engage in more risky behaviours.	<ol style="list-style-type: none"> 1. Explicit about theoretical framework 2. Experiences of children whose parents are in active treatment 3. Most children referred to study by parents - potential bias 4. 13 children were siblings - more of a family perspective 5. Not looked at contribution of specific diagnoses 6. Use of quality checks within analysis
The experiences of children living with and caring for parents with mental illness	Aldridge, J. 2006	40 parents with severe and enduring mental health difficulties, their children (number unknown) and 40 key workers (MH service and YC service workers). Identified through carer projects, all parents under care programme approach.	Qualitative, 2-part design. Interviews. No information on analysis provided	Children providing emotional care, preventative interventions and critical crisis support and need their contributions recognised. Parents maintain status of parent. Parenting capacity assessments can serve to undermine parents with MH difficulties. Require family focussed assessment of needs.	Young carers require recognition. Family focussed approaches are most beneficial.	<ol style="list-style-type: none"> 1. No information about analysis used and few participant details 2. Little information about the MH difficulties experienced by parents 3. Parents all receiving treatment, unclear if YC's are being supported 4. Large number of participants 5. Includes perspectives of YC's, parent and key workers 6. No mention of quality process being used

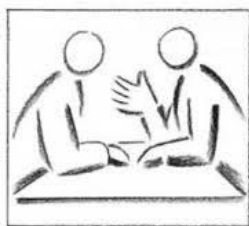
				Young carer services are valued.		
Childhood parental mental illness: Living with fear and mistrust	Murphy, G., Peters, K., Wilkes, L., & Jackson, D. 2015	13 adult children, 3 men, 10 women aged 30-late 70's. Inclusion: experienced childhood parental mental illness, parent was hospitalised, English speaking, over 18, now parents themselves, no MH diagnosis or treatment of own.	Retrospective qualitative design, interviews, narrative enquiry and analysis.	One main theme: Living with fear and mistrust. Included: lack of understanding about parent's illness, worry about hospitalisation, parents wellbeing, potential for parent to harm self, aggression and threat, emotional distress, ongoing hypervigilance.	Longitudinal nature of fear. Societal discourses about trusting others paired with parental delusional beliefs may exacerbate mistrust in others. Stigma contributes to isolation and social exclusion. Importance of children and adults being able to voice their concerns and access support to prevent cyclical experience of mistrust.	<ol style="list-style-type: none"> 1. Sample from general public 2. Greater number of female participants 3. Large age range, experiences will have spanned changes in MH service provision 4. Reflection on the impact of delusions/psychosis symptoms 5. Using strategies to improve rigour, transparency through detailed methodological explanation
The experience of being an adolescent child of a parent who has a mood disorder	Meadus, R.J., & Johnson, B. 2000	Three 17-year-old female children of parents experiencing a mood disorder (2 bipolar, one depression). Recruited from psychiatric facility or voluntary support agency.	Qualitative design, 2 unstructured interviews. Giorgi's (1985) principles of phenomenological analysis used.	3 Themes: Unavailability of ill parent; Lack of knowledge and understanding and Coming to terms	Children often dealing with parent's difficulties in isolation. Family focussed care needed to meet needs, rather than individual focus. Policy changes to support family focussed approach. School nurses and counsellors require awareness as in unique position to support. Psychoeducational groups in community may help young people share their concerns and gain information.	<ol style="list-style-type: none"> 1. Used independent rater for rigour to reduce bias (although potentially not fitting with phenomenological method) 2. Major difficulties with recruitment leading to small number of participants 3. All female gender 4. Recruitment all from support services 5. All participants the same age - homogenous sample

						6. Limited discussion and linking to previous theory and findings
How children understand parental mental illness: "You don't get life insurance. What's life insurance?"	Mordoch, E. 2010	22 children, aged between 6-16, 14 boys and 8 girls. Inclusion: living with a parent being treated for depression, schizophrenia or bipolar, English speaking. Exclusion: If parent couldn't read & speak English	Qualitative design using grounded theory analysis. Used data from interviews within an earlier study	Core variable of Fitting the Pieces together, with properties of: Having part of the story; Kaleidoscopic parental behaviour; Finding out and Telling other children	Children know there is something wrong, shielding them increases concern. Health care providers need to understand that children have questions and provide support and education. Schools have a crucial role in providing support and education. Systematic approach by services of assessing and addressing children's issues is needed.	<ol style="list-style-type: none"> 1. Secondary analysis may not be as rich as conducting further interviews, although it does allow for greater understanding to be gained from current data 2. Use of audit trail for rigour, transparency in method used 3. Parents were receiving current treatment 4. Sample contained a large number of siblings - more family experience focus
Interviews with children of persons with a severe mental illness - Investigating their everyday situation	Östman, M. 2008	8 children, 5 females. 4 parents diagnosed with schizophrenia, 4 with affective disorders. Inclusion: parent admitted to psychiatric hospital, aged 10-18years.	Qualitative, using an open ended interview. Data analysed with thematic analysis	Themes: Conversation; Love; Maturity; Fear; Blame; Loneliness; Responsibility and Associated Stigma.	Need for children of parents with mental illness to be better recognised and investigated in psychiatric services. Both negative and positive experiences for children. Children need a good social network.	<ol style="list-style-type: none"> 1. Good ethical practice around using children as participants 2. Transparency of analysis, lack of rigour commented on 3. Several themes, but potentially not fully analysed - potentially not found links between some themes 4. Interviewing children either while their parent is in hospital or only recently discharged - may affect their ability to reflect on their

						experiences, possibly more negatively skewed? 5. Maturity and responsibility seen as positive outcomes, but could actually be felt to be negative (researchers own bias, affected by cultural norms?)
The understanding and experiences of children affected by parental mental health problems: A qualitative study	Cogan, N., Riddell, S., & Mayes, G. 2005	Inclusion: Children of parents with ICD-10 affective illness diagnosis, currently using psychiatric services, English speaking and still living with parent Exclusion: Children affected by alcohol/drug misuse, children in care. Same criteria for comparative study, only no diagnosis and/or no CMHT support. 10 male and 10 female 'focus' participants between ages of 12-17 and 10 male and 10 female 'well parents' participants aged 13-17.	Qualitative comparison design using a semi-structured interview. Analysis using NUD*IST computerised programme and Huberman & Miles (1994) interactive model.	Six themes identified: Alternative choice of language; Distinctions from physical health problems; Source of understandings; Reasons for mental health problems; Stigma of mental health problems and Request for information.	Children with personal experience of parental mental illness are less likely to convey stigmatising messages. Both groups had difficulty defining mental health problems and used comparisons to help understand. Both groups able to give reasons for mental health problems - majority gave social and environmental explanations. Few were given information. Education and clinical professionals need to recognise these children and uphold their rights	1. Experienced recruitment difficulties 2. Parents were currently using services 3. Transparency in method and analysis 4. No mention of ensuring rigour or quality 5. question whether groups for comparison can be a true comparison - likely to be different in many ways
Good days and bad days: The experiences of children of a	Riebschleger, J. (2004)	11 female and 11 male participants, aged between 5-17 years. Inclusion: One parent	Secondary analysis of interview and focus group data from an earlier	Four themes/areas identified: Good days; Bad days; Children's descriptions of	Children need help earlier. Need to be informed that it is not their fault and require	1. Calculated inter-rater reliability, potentially suggesting realist perspective

parent with a psychiatric disability		with disability who was involved in community treatment. Exclusion: not stated. Parents diagnosed with mood disorders, schizophrenia, PTSD and one unknown.	study. Analysis using Strauss and Corbin's (1990) method - grounded theory	psychiatric disabilities and Children's perceptions of psychiatric rehabilitation services.	information about psychiatric conditions, psychoeducational interventions and support to develop coping skills. Avoid stressful situations and maximise opportunities for 'good days'. Development of family support system and advocacy roles to support families. Changes in policy are needed to increase family based services.	<ol style="list-style-type: none"> 2. Both parents and children were receiving support 3. Sample of parents with very mixed difficulties 4. Considerable range in children's ages - likely to be associated with developmental differences in understanding 5. Little information in method about original data collection
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7.3 Appendix 3: Study Advertisement



Research Study: How have young carers' experienced supporting a parent with psychosis?

Hi, my name is Katie and I am a trainee clinical psychologist at the University of Hertfordshire. I am hoping to recruit participants for my doctoral research project.

The study hopes to explore the experience of individuals who have supported or cared for a parent with psychosis related difficulties during their childhood. There is currently very little research in this area, and this study hopes explore these experiences and also understand what might be helpful for families who are affected by psychosis.

What is psychosis: Psychosis is a mental health condition which causes people to perceive or interpret things differently to others around them. It may seem like they have lost touch with reality, and they may experience hallucinations and delusions. Psychosis is linked to a number of mental health conditions, such as schizophrenia, bipolar disorder and depression.

Who can participate: Anyone aged between 18 and 65 years, who has supported or cared for a parent with a psychosis related difficulty in their childhood. You will need to be living in the UK, and not currently experiencing an acute mental health difficulty yourself. You may still be caring for your parent, or in a different caring role altogether or perhaps no longer within a caring role.

What it will involve: A one off interview of your experiences, which will last between 1-1.5 hours. All information will be kept securely, and you are free to withdraw at any time.

Will it be kept confidential: The data from the interview will be processed so that you are not identifiable to others, and will be kept securely. The principles of confidentiality will be maintained throughout, and the data will be destroyed when no longer needed.

The study has gained ethical approval from the University of Hertfordshire Ethics Committee (protocol number: LMS/PG/UH/00402). It is supervised by Dr Lizette Nolte, Clinical Psychologist.

If you are interested in taking part or would like to find out more, please email me **k.turner3@herts.ac.uk**. Additionally, if you know of someone who may be interested in taking part, please feel free to pass on this advert and my contact details.

7.4 Appendix 4: StudyNet Advertisement

Did you support a parent with psychosis while you were growing up?

I am a third year student on the Clinical Psychology Doctorate and for my research thesis I am interested in talking to people who have supported or cared for a parent with psychosis during their childhood. Psychosis is a mental health condition which causes people to perceive or interpret things differently to others around them. It may seem like they have lost touch with reality, and they may experience hallucinations and delusions. Psychosis is linked to a number of mental health conditions, such as schizophrenia, bipolar disorder and depression.

Anyone aged between 18 and 65 years, who has supported or cared for a parent with a psychosis related difficulty in their childhood can participate.

For more information please see the attached information sheet or contact me on k.turner3@herts.ac.uk.

(Study approved by the Psychology Ethics Committee at the University of Hertfordshire (Protocol number LMS/PG/UH/00402)

Link to participant information sheet.

7.5 Appendix 5: Email Advertisement

Hello there,

I am a trainee clinical psychologist at the University of Hertfordshire. For my doctoral thesis I am researching the experience of adults who were young carers for a parent with psychosis. I was wondering if you would be able to disseminate this to members of your carer service, through email and your monthly ebuletin?

Attached is a more detailed advert for the study. I am looking to recruit individuals between 18-65 years, who have experienced caring for a parent with a psychosis related difficulty while they were growing up. The study involves a one-off interview and has gained ethical approval from the University of Hertfordshire. If you need me to write anything else, then just let me know.

I appreciate that you probably receive many requests like this. It is quite difficult to gain access to anyone who has been in this situation and who may wish to share their experiences, so anything that you can do to help will be really appreciated.

If you require any further information, please do not hesitate to ask.

I look forward to hearing from you.

7.6 Appendix 6: Ethical Approval



UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Katie Turner
CC Dr Lizette Nolte
FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman
DATE 5/6/15

Protocol number: **LMS/PG/UH/00402**

Title of study: A retrospective study of young carers' experiences of supporting a parent with psychosis

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 5/6/15

To: 30/7/16

Please note:

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

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

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

Students must include this Approval Notification with their submission.

UNIVERSITY OF HERTFORDSHIRE
HEALTH AND HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Katie Turner
CC Lizette Nolle
FROM Dr Richard Southern , Health and Human Sciences ECDA Chairman
DATE 26/10/2015

Protocol number: aLMS/PG/UH/00402(1)

Title of study: A retrospective study of young carers' experiences of supporting a parent with psychosis

Your application to extend and/or modify the existing protocol as detailed below has been accepted and approved by the ECDA for your School.

Modification: Age range of participants has been increased to 18-45 years
The stipulation that participants should have ended their caring role with their parent has been removed.

This approval is valid:

From: 01/11/2015

To: 30/09/2016

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

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

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

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

Students must include this Approval Notification with their submission.

7.7 Appendix 7: Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
(‘ETHICS COMMITTEE’)

FORM EC6: PARTICIPANT INFORMATION SHEET

Title of study

How have young carers’ experienced supporting a parent with psychosis?

Introduction

You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the research that is being done 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 for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of this study?

The purpose of this study is to explore the experience of individuals who have fulfilled the role of a young carer for a parent with psychosis. The aim is to understand what this process was like for each individual, and to gain a sense of what factors were important or influential during this time. It is also hoped that by reflecting on these experiences, participants may be able to discuss the meaning of being a young carer, and how this role has influenced their development over time and their identity development.

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 be experiencing an episode of acute mental health difficulties yourself.

Additionally, in order to participate, you will need to have fulfilled the role of a young carer for a parent with a psychosis related difficulties in the past. Young Carers are defined as children and young people under 18 years of age who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would normally be associated with an adult (Becker, 2000).

Psychosis is a mental health condition which causes people to perceive or interpret things differently to others around them. It may seem like they have lost touch with reality, and they may experience hallucinations and delusions. Psychosis is linked to a number of mental health conditions, such as schizophrenia, bipolar disorder and depression. In order to participate in the study, you will need to have had a parent who has had psychosis-related experiences. However, it does not matter if you do not know what condition your parent was diagnosed with.

How long will my part in the study take?

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

What will happen to me if I take part?

The first thing to happen will be that we arrange a time which is convenient for you 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 and what to expect, and answer any questions you may have. During the interview I will ask you a number of questions about your experiences, and will record the responses that you give. I will audio-record the entire interview 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 within you. Although it is quite normal, 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. 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. Additionally, it is possible that others will benefit from your contribution, as it will help develop a better understanding of the role of a young carer in the wider society and also help important messages about this role be heard.

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 three months 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.

Feedback on the results of the study will be made available upon request.

Who has reviewed this study?

This study has been reviewed by:

The University of Hertfordshire Health and Human Sciences Ethics Committee with Delegated Authority

The UH protocol number is *LMS/PG/UH/00402*

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:

Katie Turner

Department of Clinical Psychology

Health Research Building
University of Hertfordshire
Hatfield
AL10 9AB
k.turner3@herts.ac.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.

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

7.8 Appendix 8: Consent to Participate

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS

(‘ETHICS COMMITTEE’)

FORM EC3

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

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:

How have young carers’ experienced supporting a parent with psychosis?

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, and the risks and potential benefits. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study within 3 months of participating, without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place.

4 I have been given information about the risks of my suffering harm or adverse effects. I have been told about the aftercare and support that will be offered to me in the event of this happening, and I have been assured that all such aftercare or support would be provided at no cost to myself.

5 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that if anything is discussed within the interview which creates concern for my safety and wellbeing, or the safety and wellbeing of others, the research has a duty of care to pass information on to relevant agencies.

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

8 I have been told that I may at some time in the future be contacted again in connection with this or another study.

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

Signature of (principal)
investigator.....Date.....

Name of (principal) investigator [*in BLOCK CAPITALS please*]

.....

7.9 Appendix 9: Participant Consent to Include Transcript Consent form for inclusion of transcript in Examiners' copy of Appendices

Title of Project: How have young carers' experienced supporting a parent with psychosis?

Name of Researcher: Katie Turner (University of Hertfordshire)

Participant Identification Number:

Within interview research it is necessary to be clear about how the researcher reached their conclusions about the main findings of the study. For this reason, we would like to include a transcript of your interview, in the appendix section of this study. If you agree:

- This would be available in the copies for examination only (i.e. it would only be read by the two examiners)
- This would be fully anonymised with any names/identifying information (e.g. names of others, places etc.) removed/changed.

You do not have to say yes, this is completely up to you. You may find it helpful to discuss this with others before making your decision. Alternatively, if you have any questions for the researcher, please contact her using the details below.

Katie Turner
Trainee Clinical Psychologist & Chief Investigator
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

by email: k.turner3@herts.ac.uk

Agreement

If you are happy to give your consent for your transcript to be used as set out above, please sign below.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

7.10 Appendix 10: Semi-Structured Interview Schedule

Part 1: The experience and impact of caring at the time

1. Could you tell me about how you came to support your parent?
 - a. What did you experience?
 - b. How did you become involved in supporting them?
2. Could you describe what it means to you to be a young carer, in your own words?
 - a. Did you think of yourself as a 'young carer' at the time?
 - b. If not, then why not/If so, why?
3. How did you make sense of your parent's difficulties at the time?
 - a. What did your family think?
 - b. What did school/friends/others think?
 - c. How did you feel about offering care and support to your parent?
 - d. Did it feel good/helpful etc/ did it feel awkward/uncomfortable etc?
4. Would you use the term 'psychosis' to describe your parent's difficulties? How would you define it?
 - a. How would you describe your parent's mental health experience?
 - b. Does this term feel relevant to them? What would be a better term?
5. How did you feel about having a parent with a psychosis related difficulty?
6. What kinds of things did you do to support your parent?
 - a. Offer practical help?
 - b. Offer emotional support?
7. Did you have access to any networks for support or other resources, such as financial help or help from outside agencies, or emotional support?
 - a. Did your parents have any access to support including emotional support etc?
8. Can you describe what life was like in your family during the time that you were caring for your parent?
 - a. How did your family relate to each other?
9. At the time, did offering care to your parent affect your life in any way?
 - a. Eg. School, friends, self-care, health, *romantic relationships*, *friends coming home*
10. How were your family affected at the time?
 - a. Did you experience any changes in relationships etc?
11. Did your caring role have any impact on your relationships with others?
 - a. If so, how/if not, how prevented?
 - b. E.g. friends, family members

Part 2: Retrospective view of experiences and the impact on current self

12. Looking back now, how would you describe the impact of being a young carer on your life now?
 - a. How does it influence your current life – the job that you do etc?
 - b. Has your experience of supporting a parent with a mental health difficulty influenced your beliefs or views about mental health problems/has this changed over time?
13. Do you feel that the experience affected you later prospects in life in any way?
 - a. E.g. further education, employment, developing own mental health difficulties, *intimacy and relationships*
14. How do you cope with life stresses and difficulties when they occur?
 - a. Where did you learn these strategies?
15. Do you feel that you gained something from having had this experience of supporting your parent?
 - a. If so, what?
16. Do you feel that you have lost something from having had this experience?

**Italics represent additional points gained from pilot interview*

7.11 Appendix 11: Participant Debrief Sheet

How have young carers' experienced supporting a parent with psychosis?

PARTICIPANT DEBRIEF SHEET

Thank you for participating in the study, your contribution will help inform others about the experience of being a young carer for a parent with psychosis related difficulties.

The aim of the study was to explore how adults who have been young carers for parents with a diagnosis of psychosis make sense of their experience and the factors that they identify as influential in their experience. Although the needs and experiences of young carers are now starting to receive greater recognition, there is still a great deal which is not known or understood about the experience, especially for individuals who have supported a parent with psychosis related difficulties.

Should you wish to withdraw your data from the study, please contact me within three months of your interview. If you would like to receive a summary of the results of the study, please contact me at k.turner3@herts.ac.uk.

I hope that participating in this research has been a good experience for you. However, if you feel that you would like any further support or information at a later time, there are a number of organisations which you can contact:

Carer Related Organisations

Carers UK	www.carersuk.org	
Carers in Herts	www.carersinherts.org.uk	01992 586969
Carers in Bedfordshire	www.carerinbeds.org.uk	0300 111 1919
<u>Mental Health Support</u>		
Mind	www.mind.org.uk	
Rethink Mental Illness	www.rethink.org	0300 5000 927
Samaritans	www.samaritans.org	08457 90 90 90

Or contact your GP who can provide you with information about psychological support in your local area.

Thank you for your time.

7.12 Appendix 12: Interviewer Reflections Prompt Sheet

Participant Number:

Completion of Interview

- Interruptions
- Conditions of room
- Any issues which arose?

Process of the Interview

- Rapport established?
- Impression of interviewee – relaxed, anxious?
- Non-verbal communication of interviewee
- Transference?

Content of the Interview

- Key themes?
- Any conflicts in responses?
- Any unexpected information/area not yet considered?
- Any issues which required further exploration? If didn't occur, why not?
- Were prompts required?

Reflections on Interviewing

- Relaxed, open style of questioning?
- Flexibility in questioning and covering topics?
- Adequate exploration of all topics?
- Were the questions clear, did they require further explanation?
- Initial thoughts about theory/practice links?
- What can inform the next interview?

7.13 Appendix 13: Reflective Diary Extracts

Following Anna's Interview:

As this person was slightly late prior to the interview, and it took place in a place that I had not been to before, I was a little anxious at the start. However, once she arrived she appeared relaxed and talked about how good it was that I was doing the research. As I had noticed when arranging the interview, she tended to talk at length about her experiences, and due to my anxiety about not gaining 'mediocre' data, I tended to encourage this by asking further questions. As a result, the interview was longer than the previous interviews, but still within the 1.5hrs suggested. During the interview the theme of role reversal came up a lot, and I felt slightly disappointed by this, as I felt that this reflected an attachment based negative experience. However, with further reflection I can see how this concept can account for the experiences described without doing so in a blaming way.

She also spoke of quite extreme coping strategies, such as drug use, and the development of her own mental health difficulties, and I thought about how her experiences were likely to have heavily contributed to her mental health difficulties. Additionally, MH difficulties seemed very prevalent in her family, which may have accounted for the subsequent problems that she and her siblings have experienced. The idea of distance and closeness also came up again, and left me thinking about whether there is an adequate model or theory to account for this. For future interviews I think I need to continue focusing on the meaning making and how experiences have been carried forward to own beliefs, parenting etc.

Following Serena's interview:

Prior to the interview I had some fleeting worries about the length of time which had passed since the last interview, and whether I would be 'good enough'. I still keep coming back to JS warning of 'mediocre data leading to a mediocre analysis'. The participant was 30mins late, but when I checked my email she had been in touch to let me know this. I had some concerns about having enough time, but once I had reassured myself that the room was booked for long enough, I settled and used the time to go through the interview schedule.

When the participant arrived we quickly went through the consent form and began the interview. As we got into the interview I noticed that she was skilled in answering questions in a very concise way, and so attempted to start encouraging her to give more detail. I also noticed at times how her accent affected her pronunciation, and I wondered whether this would be picked up on the transcription. I felt that I would have to check the transcription carefully once it was returned. As the interview continued I felt very aware of not much time passing, and so tried to lengthen the interview through more exploration and prompting. I was stuck in the belief that an interview that is only 30mins long could not be sufficient, and so worked to try and lengthen the time spent talking.

I was very struck by how the psychosis had affected the participant and her family, and got a sense of it being like a cloud of suspicion and confusion which permeated the whole family. Afterwards she talked of how in order to cope with the suspicion, she often did the things her parent accused her of (e.g. lying), and I thought this was a good example of the unhelpful patterns which can be associated with psychosis. Towards the end, she reflected on the sense of being 'old before her time' and serious, and I found myself really connecting with this. We shared a similar experience of going to university and being shocked at how

little others knew about how to take care of themselves. I also thought of how my family would describe me as serious, and how this seriousness often got in the way of me being able to enjoy myself and accept opportunities, just as the participant had experienced.

I noticed how the theme of role reversal/parentification has come up throughout the interviews, and think that this is going to be a significant theme within the research. I also noticed that she was either the only or one of the few participants who had accessed support via a young carer's agency. It seemed that this had made quite a significant difference for her, especially in terms of being heard and listened to. Additionally, I was struck at how her parent hadn't sought help, and this got me thinking about the disability vs. children's rights perspectives and what can account for supporting children whose parents do not wish to access services (which is potentially more relevant to parents experiencing the suspicion often associated with psychosis).

Following Chloe's interview:

The participant was really friendly on arrival and it felt easy to get started and explain everything. She was quite firm that she would not withdraw her data, which left me thinking that she was very invested in the study. I felt grateful for this, and felt that as a result she would likely share more of her experience, as she put importance in the fact that research of this nature isn't really out there and wanted to contribute towards this.

As the interview progressed I was struck at how much she was giving and the richness of what she was saying. I also noticed how some things were becoming very familiar in each interview – parentification, responsibility, role reversal, anger etc. As I'm currently thinking about themes of a different interview, it feels reassuring to know that certain aspects continue to come up, and can hopefully be recognised within the data.

During the interview it was apparent that some questions were quite difficult for her to answer, and I felt the need to balance wanting to know more with not wanting to cause unnecessary upset. At one point in the interview she did cry, but seemed to be able to contain this herself and bring the topic back round to what was comfortable.

At the end of the interview, she stated that she felt like she wanted to cry. Although I had some concern for her wellbeing, it felt in the moment that this was more due to connecting with some of her past difficulties rather than feeling overwhelmed. We had a conversation about what had moved her, and how she had made many achievements in life, especially in her own parenting. She expressed a sense of guilt about talking about difficulties as she expected that her parent would have been upset to think that he had caused her difficulties. We talked this through and normalised the feelings, while acknowledging the difficulty of the situation for everyone involved.

7.14 Appendix 14: Transcription Confidentiality Agreement

University of
Hertfordshire



Doctorate in Clinical Psychology

University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

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

Katie Turner ('the discloser')

And

Executive Typing ('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.

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A handwritten signature in black ink that reads "BMECLOW".

Signed:

Name: Brenda Margaret Clow

Date: 18th December 2015

7.15 Appendix 15: Extract of Transcript for Emma

Participant: Emma Interview Date: 21.11.15 Underlined: Interpretation Italics: Linguistics Plain text: Descriptive

Initial emergent themes		Original Transcript	Exploratory Comments
	1	R: So it would be good to hear from you just to start	
	2	off, umm, to tell me a bit about how you came to	
	3	support your mum.	
	4		
Mum's difficulties long-standing	5	P: Okay, so my mum, umm, was diagnosed with schizo,	Name change over time, importance of particulars. <i>Was this for my benefit? Assumed professional knowledge?</i>
	6	w' originally with schizophrenia before I was born, um,	<u>Diagnosis=certainty?</u>
	7	and then they changed the diagnosis to schizo-affective	Mum's difficulties predating birth. <u>A way of not being</u>
	8	disorder. Umm, my dad had to travel quite a long way	<u>responsible? They – power of others?</u>
Other parent was limited in their availability	9	for work, umm, so kinda like when I was in primary	Young child taking parents role. Both parents have demands
	10	school, umm, my mum if she was ill found it really	Parent unable to function. <i>Had</i>
	11	difficult getting up in the morning, keeping track of	<u>Keeping track – what else is missed?</u>
	12	when we were s'posed to go to school. Was really	<i>Paranoid and its link to psychosis – professional language?</i>
Mum paranoid about school	13	paranoid about going to the school 'cause she worried	
	14	about what other parents would think about her.	Age used to assign responsibility <u>Paradox with mother and</u>
	15	Umm, so kind of just, I was the oldest so I was asked to	<u>child. Unfairness – why because I was older</u>
Responsibility for mum and brother	16	make sure she got up in the morning, to make lunch for	
	17	me and my brother and make sure we got off to school,	Responsibility for food and education of self and brother.
	18	that we didn't miss school days and things like that.	<i>Hesitation, umm's.</i> Exposure to emotional things. Having to
Exposure to emotional things	19	Umm, and then also, umm, my mum found it quite	respond <u>Needing to perform, having to manage others</u>
	20	hard with kinda with what's appropriate to tell	<u>emotions. What about own emotions?</u>
	21	children, umm, so she would be telling us quite	
	22	emotional things and then, I think when you are in that	<u>No choice?</u>
	23	situation you just kinda have to respond to it.	<u>Distance from emotions? Use of You instead of I</u>
	24		
	25		
	26	R: Okay. And how was it that you became involved in	
	27	that care for her?	Naturalness of assuming caring role
Felt really quite natural to care	28		
	29		<i>Use of just to minimise?</i>

Awareness of caring role from others pointing out	30 31 32 33 34 35 36	P: It felt just really quite natural, umm, it was just supporting someone who was upset, and distressed. Umm, and just kind of like being a normal person. It didn't feel, umm, like a kinda conscious thing. Like it probably wasn't even until I was like 15 or 16 and someone said, "oh you are caring for your mum", and I was like "oh am I, really?". Umm, so, I guess that it, it, just felt kinda normal to slip into some of those things. Things need doing, so you do them.	Normal, didn't have to think about it. <u>Minimisation of caring role?</u> Others recognising carer role. <u>Lack of inner recognition? – defined as young carer by others; for her, just doing something natural</u>
Others defined her as young carer	37 38 39	R: And could you describe to me what it means to you to be a young carer?	Do what needs doing. <u>Family value, cultural value?</u>
Young caring is complicated	40 41 42	P: Umm, I guess it's quite complicated. Umm, it means, I mean I guess one of the, the biggest things that it meant to me at the time was that I always felt a little bit different from the other children, and I didn't really know why. Because I didn't really appreciate that I was having more responsibility than they were. Umm, so I guess it means you grow up quite fast. Umm, kind of the same time there are lots of positives that come with that. Umm, so like I do manage stressful situations better because I've had to. Umm, and I'm probably,	<u>Multifaceted, not easy to understand?</u> Difference to other children, difficult to understand <u>Others could see the difference, but not self? Transparency?</u>
Grow up quite fast	43 44 45 46 47 48	people always as I was growing up, they always say, "oh you are so mature for your age", and I was like, "am I, really?" [laugh]. But, you have to be, umm, so, I guess it gives you, kind of a little bit more strength, a bit more resilience, umm, if you are able to cope with it and if you have some support. Umm, and I was really lucky to have my brother as well, so it wasn't just me.	More responsibility. Growing up fast, pressure, not the same.
Different to other children, but didn't really know why	49 50 51 52	Does that answer your question?	Positives also - <u>Difficult to stay with negatives/losses? Loss of part of self? No choice. Ambivalence about experience?</u>
Manage stressful situations better	53 54 55		Others noticing difference. <u>Laughter as disbelief?</u> Not seeing what others see. No choice, have to be this way <u>little bit of sense of pride in being seen as mature?</u>
More strength	56 57		<u>Hesitation</u> Gaining strength and resilience. <u>Tentative when referring to strengths</u>
Lucky to have my brother, not just me.	58 59 60 61 62		Needed support. Not alone

	63	R1: Yes, yes absolutely. Did you think of yourself as a young carer at the time?	<i>Uncertainty</i>
	64		
	65		
Just thought of myself as a daughter	66	P: No. No, I just thought of myself as a daughter, and like I said it wasn't until I was like 15, 16, umm, and someone said, "oh you, you are caring". And I was like, "am I, really?"[smile/laugh]	Reassurance from me
	67		
	68		Daughter before carer. Not recognising carer role. Need for others to point out. <u>Difficulty acknowledging carer role herself – keep coming back to others pointing it out.</u>
	69		
	70	R: So it was someone pointing that out...	
	71		Highlighting labelling by others
	72	P: Yeah	
	73		
	74	R: it kind of made you aware of...	
	75		<i>Just normal Others have made it abnormal?</i>
It was just normal until others pointed it out	76	P: Yeah, absolutely, it was just normal to me until then.	
	77	R: Yeah, yeah... And how did you make sense of your mum's difficulties at the time?	<u>Evolving understanding of mental health problems over time</u>
	78		
	79		Change over time. Explanations withheld when young
	80	P: Umm, so I guess that changed a lot as I grew up.	<i>Medical language – confirming there was a true, recognisable problem?</i>
	81	Umm, when I was little I didn't, I mean no-one actually sat down with me and explained to me what schizophrenia is or schizo-affective disorder or psychosis. Umm, so when I was little it was just like "oh, mum talks to herself, presumably everybody talks to themselves". Umm...., and so that was just my mum and then there would be angry outbursts and what have you, but that was just life, umm, and I kinda thought everyone's life was probably something like that. Umm, and then I think when I got to kinda 12, 13, umm, I started realising not everyone's life is like this, cause I was spending more time at friends' houses and things. Umm, so then I guess I started thinking, you know actually what's going on, and what are these	Made sense of it alone. Generalised to others. <u>Desire to avoid difference?</u>
No-one explained when I was young	82		Paradox of just being her mum.
	83		
Made sense of it alone	84		Anger as part of life <i>Just life Minimising?</i>
	85		
	86		Generalise own experience to others. Age linked to different understanding. Experiencing home life of friends. <u>Social comparison, developmental aspect?</u>
Mums angry outbursts just part of life	87		
	88		
	89		
	90		
Friends experiences highlighted difference	91		<i>Tentative</i>
	92		
	93		Questioning, investigating to understand.
	94		
	95		

7.16 Appendix 16: Audit Trail

Example of Clustering for Emma

- 1) Young Caring was complicated
 - a. Just thought of myself as a daughter
 - i. *Felt natural to care*
 - ii. *It was normal until others pointed it out*
 - b. Mum's difficulties were complex, I couldn't always cope with it
 - i. *Cared for her, but couldn't always deal with it*
 - ii. *Try hard to make mum happy,*
 - iii. *Mum experienced complex difficulties*
 - iv. *Practical support showed I cared*
 - c. Always walking on eggshells
 - i. *Emotional support was draining*
 - ii. *Paranoia all consuming*
 - iii. *Highly emotional environment*
 - d. The roles were reversed, I had to grow up quite fast
 - i. *I had to take care of myself*
 - ii. *Felt good to be a 'big girl'*
 - iii. *Role-reversal*
 - iv. *Parenting sibling*
- 2) Ongoing struggle to understand
 - a. I didn't understand mum's behaviour, I took it more personally
 - i. *Lacking information*
 - ii. *Anger*
 - iii. *Seeing myself negatively*
 - iv. *Difficulties making sense*
 - b. Age brought a different perspective, now understand mum and self better
 - i. *Empathy for self and mum*
 - ii. *Recognise own needs*
 - iii. *Beliefs about mental health*
 - iv. *Mum is fragile*
- 3) Feeling supported was important, but I didn't know who to trust
 - a. Being close to others helped me feel supported
 - i. *Lucky to have brother*
 - ii. *Support network disconfirmed mum*
 - b. Don't ask, don't tell
 - i. *Teachers encouraged me not to talk*
 - ii. *Mum convinced others she didn't need help*
 - iii. *Tried to express needs in teens, was dismissed*
 - iv. *Family ran away*
 - c. It took time to develop trusting relationships
 - i. *Paranoia affected relationships*
 - ii. *Not cared for or loved*
 - iii. *Superficial relationships*

- 4) I just had to keep going
 - a. Trying to be a train on a track
 - i. Grit your teeth and get through it*
 - ii. Time away from problems*
 - iii. Having distance helped*
 - b. Gaining coping skills from multiple sources
 - i. Gifts from parents*
 - ii. Witnessing how others cope*
 - c. It was really hard, but I'm grateful to develop into the person I am
 - i. Appreciating my strengths*
 - ii. Career a good way to make use of skills*
 - iii. Have gained direction, drive and determination*
- 5) Young caring has cost me a lot
 - a. I lost the ability to be a child
 - i. Difficult to stand up for myself*
 - ii. Missing out on childhood*
 - iii. I didn't matter*
 - b. I can't allow my children to have the same experience
 - i. Difficulty of having own family*
 - ii. Making choices about which relationships to engage with*

Unclustered: *Financial limits*

Italics: Emergent themes

Example of quotes for Emma's Themes

1) Young Caring was complicated

Subtheme	Quotes
<p>a. Just thought of myself as a daughter</p>	<p>"It felt just really quite natural, umm, it was just supporting someone who was upset, and distressed probably wasn't even until I was like 15 or 16 and someone said, "oh you are caring for your mum", and I was like "oh am I, really?"</p> <p>"I just thought of myself as a daughter"</p> <p>"it was just normal to me"</p> <p>"to an extent it was normal but there's also a sense of 'I'm being a big girl'"</p> <p>"then I think mostly because I didn't recognise myself as a carer. Umm, and I don't really know if my teachers did either, even though I talked about it."</p> <p>"when I was younger, kind of the relationship with my mum felt, umm, I thought we had quite a good relationship, because that was kind of all I knew."</p>
<p>b. Mum's difficulties were complex, I couldn't always cope with it</p>	<p>"my mum found it quite hard with kinda with what's appropriate to tell children."</p> <p>"mum, umm, was diagnosed with schizo, w' originally with schizophrenia before I was born."</p> <p>"you know what other people just go out and have fun, and they're not worry about all of these things."</p> <p>"And they don't have to deal with a mum who doesn't know what the boundaries are, in terms of what's appropriate to say to children."</p> <p>"a couple of years where I was quite rebellious, and quite like "this is not okay""</p> <p>"quite angry at the time, because I was like I want a mum who can be a proper mum and actually look after me and put me first, whereas my mums very much, she needed to put herself first"</p> <p>"when I was a teenager I kind of tried and then kind of, like, I'm going through stuff as well, and I think for my mum it was like, "you're going through SATS, that's really not a big deal"."</p> <p>"when I was feeling more rebellious, I was like, "I don't care, cause no one is talking about you". And, that's just life, and I know it was really difficult for her, but at the time, I was just caught up in being a teenager I guess"</p> <p>"gets very very paranoid about anyone and everyone is out to get her. That they are talking about her times that she would shout a lot more"</p> <p>"when I was a teenager, she had a lot of physical health problems,"</p>

	<p>“when I was a teenager, early teenage years, she was very unwell, umm, and that probably coincided with when I was more rebellious”</p> <p>“there was a part of me that was like, it’s difficult seeing her that way, and there was another part of me that was like, I just can’t deal with this, and this, 12 year olds don’t have to deal with this stuff”</p> <p>“so I probably kind of blocked out a lot of how difficult it was for her”</p> <p>“and I was also born quite unwell so I was in intensive care. We didn’t have a lot of contact, and so she would bring this up a lot and be like, we need to have a better bond, we need to have a better relationship.”</p> <p>“ kind of holding in my own opinions”</p>
<p>c. Always walking on eggshells</p>	<p>“there would be angry outbursts and what have you, but that was just life,”</p> <p>“suddenly everyone’s talking about her, everyone hates her, nobody really wants her there. And so she can kind of flip quite a lot between being, really wanting to engage with the world and really energetic, and thinking that everything is going to be fine. And then go to actually everything’s horrible, and nobody cares and the world is a really dangerous place to be.”</p> <p>“big, umm, kind of emotional aspect, where she would be talking about how upset she was, and how horrible people were and because she was”</p> <p>“but I would try really hard to be like, what can I do that’s gonna make mum happy.”</p> <p>“And she studied psychology for a while. Umm, and so she’d have like experiments that she wanted to do that I really didn’t want to do. But I knew that if I did them, that was to her, was like proof that I loved her, so I would do them anyway.”</p> <p>“she would phone quite a lot, pretty much every day. And if you weren’t there to answer the phone and you weren’t available to speak for about an hour, and you didn’t contribute to the conversation, then she would take that as you didn’t want to know her, and you were invalidating her. Umm, but equally if you said too much or you disagreed with her, then you were kind of overwriting, over-riding her freedom of speech, umm, and being cruel to her.”</p> <p>“Almost that felt more draining, because it became very emotional.”</p> <p>“Everyone was kind of always walking around on eggshells, umm, because no-one ever really knew what was going to make my mum react, umm, or how she would react”</p> <p>“and there was never really any particular thing to kind of put it on to, to kind of say x is feeling y because of this. It was always just, there would be anger and there would be suspicion, and there would be kind of</p>

	feelings of betrayal and loss and sadness, resentment, and all of this, just kind of always in the air, so it, it “felt like quite a heavy place to be quite a lot of the time.”
d. The roles were reversed, I had to grow up quite fast	<p>“I guess it’s quite complicated. Umm, it means, I mean I guess one of the, the biggest things that it meant to me at the time was that I always felt a little bit different from the other children, and I didn't really know why.”</p> <p>“Because I didn't really appreciate that I was having more responsibility than they were. Umm, so I guess it means you grow up quite fast.”</p> <p>“so I was asked to make sure she got up in the morning, to make lunch for me and my brother and make sure we got off to school, that we didn't miss school days and things like that.”</p> <p>“Like waking her up in the morning, making sure that she had a coffee, going back to check that she was still awake. Pretty much, you know, nagging her until she got out of bed”</p> <p>“similarly in the evening kind of being like, you can't just stay up or you won't get up in the morning.”</p> <p>“making lunches as I said earlier, for me and my brother for school, making sure that we did get to school on the right days. Umm, and that we didn't try and go in during the holidays”</p> <p>“I was little, sort of primary school, probably I took care of myself better than most children, because I had to.”</p> <p>“I didn't really know how to take care of my emotional health, because I was so used to, you put your needs down the ladder and you put somebody else first.”</p> <p>“because it's really easy when she's saying all of these things that I heard all through my childhood, to go back into the, the kind of way that I responded as a child, which is very much 'okay, I need to make up for this, I need to make it right'. Umm, so I need to remind myself a lot to take a step back, and remember that actually, I haven't actually done anything wrong”</p>

2) Ongoing struggle to understand

Subtheme	Quotes
a. I didn't understand mum's behaviour, I took it more personally	<p>“I mean no-one actually sat down with me and explained to me what schizophrenia is or schizo-affective disorder or psychosis.”</p> <p>“and what are these words like schizophrenia mean, and kind of looking some of those up on the internet. Umm, so that kind of helped me kinda make a bit more sense, of actually her experience being really different to mine,”</p>

	<p>“was still kind of quite hard to understand”</p> <p>“I didn't really understand it, umm, and I probably took a lot of that personally, so I just got really tangled up in that, and then at the same time I was really angry with my mum because what she was saying was confusing me so much.”</p> <p>“you're worthless and she wished that someone would just take us into care so that she wouldn't have to deal with us.”</p> <p>“so like my mum's absolute opinion, umm, is that I'm not a very good person, and that I'm filled with hate and have no capacity for empathy. Umm, and so, there was a bit of me when I was like 18, that was like, "I'm quite interested in mental health, but there's no way I could do that because if I have no empathy, then I can't possibly go into that job""</p> <p>“particularly when I was a young child, and you've got somebody saying the world is horrible and dangerous and people are out to get you. That was really confusing compared to how I was experiencing the world”</p> <p>“I think that when I was younger there was the sense of my own mental health not mattering, and you have to have good mental health because you are supporting somebody who doesn't.”</p>
<p>b. Age brought a different perspective, now understand mum and self better</p>	<p>“I think when I got to kinda 12, 13, umm, I started realising not everyone's life is like this, 'cause I was spending more time at friends' houses and things.</p> <p>then it probably wasn't until I was kind of 14, 15 maybe a little bit older, that I really had the kind of empathy, to be able to see actually, what she was going through and kind of put some of my own needs to one side a little bit more</p> <p>then kind of came back to being probably a bit more caring [laughs], umm, when she was, when I was slightly older”</p> <p>“it's okay to have your own needs and recognise those”</p> <p>“I just got really sad for her because I think her life is so restricted compared to mine now”</p> <p>“so now it feels really different again, actually it's much easier to offer her that support, because I can see her problem more as a whole person.”</p> <p>“I don't have to take on board what she says quite so much. I can make my own judgements”</p> <p>“I guess I have to see it that way, cause otherwise I can't make any sense of it.”</p> <p>it wasn't a healthy relationship when I was 18. Umm, and it was very much about his needs and what he wanted. Umm, and it probably was the end of that relationship that made me realise that actually I really needed to focus on myself.”</p>

	<p>“and it wasn't until I did some volunteering and I was ... and actually, I can do this, and I'm good at this.”</p> <p>“no matter how much shit life throws at you, excuse my language, there's a way forward and you kind find a way to cope with that. And, there is something that you can learn from it.”</p> <p>“I've had to develop a kind of internal sense of actually who I am and how I see the world, and so because that feels quite strong, it feels like stepping into someone else's world doesn't threaten that”</p> <p>“it's definitely given me a sense of how fragile someone can be when they've got mental health problems”</p> <p>“so it's given me a real kind of sense of even the most fragile, vulnerable person has something to offer.”</p> <p>“people are responsible for themselves, and not for the way that other people respond to them”</p> <p>“I feel much more in tune with it, so much more like I can say actually, 'yeah I'm having a bad day, but I'm well enough to go out and interact with other people and do my job' or 'actually things are a bit dodgy right now, maybe I need to go and get some help'.”</p>
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3) Feeling supported was important, but I didn't know who to trust

Subtheme	Quotes
<p>a. Being close to others helped me feel supported</p>	<p>“I was really lucky to have my brother as well, so it wasn't just me.”</p> <p>there was a bit of recognition from my friends, and they were really supportive”</p> <p>“when we were little, me and my brother, as I understand it were really close. Umm, and he would just follow me around all the time”</p> <p>“so actually as we've got older we've got closer again, umm, because I think we have a bit more of a sense of actually what's normal for starters”</p> <p>“my brother will absolutely be there to back that up.”</p> <p>“me, my brother and my dad are much closer now, than we were when I was younger.”</p> <p>“if it gets really difficult, then I've got loads of friends I can talk to”</p> <p>“So I think that kind of support network is really important there.”</p>
<p>b. Don't ask, don't tell</p>	<p>“if I said to a teacher, like, "oh my mums got schizo-affective disorder", they would just be like "ooh, don't know what that is, don't talk about it, people might judge you for it"”</p> <p>“When I was younger it was very much "don't tell anyone, because they will take you away, or they'll judge me, or they'll start talking about me, me being my mum”</p> <p>they don't have to deal with sitting with the social worker with their mum saying "well [Emma] feels this way about it" while you are thinking "no I don't"”</p>

	<p>“with my friends, I would just say "my mum's difficulties".”</p> <p>“I had known about that, if I'd known that I would qualify for it, then that would have been really handy”</p> <p>“And my mum did a very good job of convincing the social worker that everything was hunky dory a lot of the time.”</p> <p>“my mums very, umm, independent as well, so she doesn't wanna admit that she needs any help. Umm, and so if you suggest to her that she had a carer or has a carer, then she'll be like, no I don't need that, there, there isn't any such thing like that in my life.”</p> <p>“So the wider family, kind of ran away, if I'm honest. They were just like, don't know how to deal with this, not gonna, not going to.”</p> <p>“they would kind of put up with the fact that you were there, but not talk about your mum or why you were there”</p>
<p>c. It took time to develop trusting relationships</p>	<p>“my dad wasn't really around very much, and my mum, as I understand it could be quite defensive when he had kind of contact with us”</p> <p>“like I didn't really have a very good relationship with him.”</p> <p>“my mum started to get quite paranoid about my dad”</p> <p>“and there was a time where I was like, is he abusive and I'm not seeing it”</p> <p>“and so there was a period when me and my dad really didn't get on because I was really like, do I need to be wary of him, is mum right?”</p> <p>“there's the sense that, actually at some point I'm going to protect myself as well”</p> <p>that you knew a lot of people on a very superficial level rather than really having good relationships”</p> <p>“that I had, where people would kind of take advantage a little bit, and I would just kind of let that go”</p> <p>“when I was older, everyone would always say how nice I was. And I would always be a bit like, oh really? I don't think you know me to say that I'm nice or not. Umm, so I guess I was quite guarded and quite cautious, umm, because I had grown up with messages of you don't trust anyone, you don't let people in. Umm, and so it took me a long time to really, let go of some of those”</p> <p>“I probably didn't have really close friends until, sort of, I'd say the people, I knew the people who I became close friends with when I was kind of 12, but I wouldn't have said that we were really close until I was kind of 14, 15”</p> <p>“so I didn't really have a romantic relationship until I was 18. Umm, partly because I didn't have the confidence.”</p>

4) I just had to keep going

Subtheme	Quotes
<p>a. Trying to be a train on a track</p>	<p>“I was probably depressed, but I wasn't gonna say that I was struggling because I had to be there for my mum. Umm, and it, it was like, you, you just have to keep going. One of the things from my dad that I got was, it doesn't matter how hard things are, you just keep going.”</p> <p>“so even when it was like, dragging myself through treacle, I was like, I'm just gonna keep keep going”</p> <p>“I'll keep going so that I'm doing what I need to for my mum, rather than any kind of sense of trying to feel better myself”</p> <p>“grit your teeth and get through it”</p> <p>“and just keep going as best you can”</p> <p>“like trying to be a train on a track and just keep going forwards somehow”</p> <p>“I still find it quite difficult to put myself first, and that's something that has to be a conscious thing that I think about”</p> <p>“there is stress or challenge, I very much see it as something that's transient, that will pass, umm, kind of just keep going”</p> <p>“think if you're gonna try and just keep going, you have to find a way to cope from somewhere, otherwise sooner or later you collapse”</p>
<p>b. Gaining coping skills from multiple sources</p>	<p>“what helped was when I actually went away to uni”</p> <p>“I guess also it meant it was really hard for me to be assertive for a long, long time. That was something I really had to put effort into learning, umm, and probably didn't really do again until I went away to uni.”</p> <p>“working in the field, first of all made it easier to relate to my mum, because I could see that some of what she was saying wasn't personal”</p> <p>“there was a focus on looking after yourself and reflective practice, umm, and so there was an element of, actually this is quite good for me, and it's quite self-affirming, and actually it made it easier to keep some of those boundaries and start to understand why I want to put boundaries in certain places”</p> <p>“and I've learned how to, kind of process and let go of some of the emotional intensity that comes with that”</p> <p>“so I volunteered, umm, in a physical health hospital doing some befriending, and mentoring some of the other volunteers and doing kind of leadership programmes. Umm, and so that gave me, kind of in a more</p>

	<p>concrete way, some of the skills, and you know, how to make the decisions and strategize and really think things through”</p> <p>“because school was very much my escape, so I did quite well academically”</p> <p>“I do a lot of singing, which is fantastic for physically releasing tension, for stress, anxiety, because you have to breathe properly, umm, and just having a sense of kind of community, and that you're doing something that contributes to something”</p> <p>“I did a lot of reading when I was younger. Umm, and so I think there is a lot of things that I picked up from books”</p> <p>“music is something that was kind of given to me by my parents, because they said 'we want you to have music in your life”</p> <p>“my brother, as I say, I think one of the most helpful things was seeing him go through the same stages that I'd gone through, 'cause then I knew I wasn't being weird and I knew it was a fair kind of response to what was going on.”</p> <p>“but I think seeing and hearing the things that they've been through, and helping them find ways to cope, umm, and sometimes they suggest things that I think 'I'm gonna do that”</p>
<p>c. It was really hard, but I'm grateful to develop into the person I am</p>	<p>“I do manage stressful situations better because I've had to.”</p> <p>“it gives you, kind of a little bit more strength, a bit more resilience”</p> <p>“It's given me a lot more empathy towards other people, umm, and a lot more patience”</p> <p>“actually I can get through that, and I can find a way forwards”</p> <p>“I can just be with them, and it doesn't scare me. I'm really comfortable with it but I'm also, and this is probably took longer than being comfortable with their world, but I'm, I'm quite comfortable with just saying "Okay, that's your world, and that's, mines a little bit different"</p> <p>“I think it's given me a lot of determination, and a sense of, actually if you want something, you damn well go for it”</p> <p>“I have so much confidence that I know my world. Umm, because I've had to fight for what that is when I was younger”</p> <p>“and its kind of having that balance between not letting it take over, but also not running away from it”</p> <p>“I don't think without it that I'd have the kind of direction in my life that I have. I don't think I'd have the drive and the determination. I don't think I would've, this might sound a bit strange, I don't think I would've had the emotional maturity”</p>

	<p>I feel like a lot of the confidence that I have has derived from being a carer and going through that and knowing that I've coped with that"</p> <p>"I feel like, although it was really, really hard, umm, and still has moments when it's hard, umm, mostly I'm really, quite grateful that I had that opportunity to kind of develop and become the person that I am, and a person that I quite like"</p>
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5) Young caring has cost me a lot

Subtheme	Quotes
a. I lost the ability to be a child	<p>"I certainly played a lot less with other kids, because my mum was so worried about what they would say to their parents, what their parents would say to them"</p> <p>"looking back, I can see there were a lot of things that I didn't have the opportunity to do, umm, that other children did"</p> <p>"sleepovers, umm, having friends round for dinner"</p> <p>"so where some of my friends would go on holiday, umm, we never really did that"</p> <p>"in terms of mental health, I think that has suffered. Umm, because I think it was really hard to develop a sense of how to cope with all of these things, because there wasn't a lot of support, and I didn't really understand what was going on when I was, particularly in primary school"</p> <p>"I lost the ability to just be a child. Umm, and not have worries and just to play and run around and laugh and finger-paint and all that kind of thing."</p> <p>"I feel like I lost kind of, having a mum that could really support you"</p> <p>"guess I lost to some extent the sense of belonging somewhere when I was younger, because I didn't fit in at school, and home was weird even though actually I didn't know it"</p> <p>"there wasn't a real sense of being cared for and being loved, and being worthwhile. And I feel like I've been very lucky that I've developed those things later, but I feel like that kind of took away the opportunity to enjoy being a child and developing and learning and growing"</p> <p>"so there's always been a bit of the sense of being kind of slightly different and the odd one out."</p>
b. I can't allow my children to have the same experience	<p>"in terms of kind of having a family and that kind of side of things, umm, that's much more difficult, because I think you then have to find someone who, as a partner can be understanding of the fact that actually there will be times where my mum does get really quite horrible, and nasty and it can be quite vicious"</p>

	<p>“So to find someone with the, the kind of emotional maturity I guess, to, to be able to do that I think is quite challenging”</p> <p>“I know absolutely in myself that, because my mum doesn't have those boundaries, and doesn't know what is not okay to say to children, because they will internalise it, umm, I couldn't have children and have them have contact with her”</p> <p>“that's, that's left me with a really big question mark about kind of family generally, and how I wanna take that forward.”</p> <p>“So I don't wanna put huge amounts of investment into a relationship with someone who definitely does want children, when I'm kind of leaning towards probably not, and if I do it won't be for a while.”</p>
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Themes and Subthemes for Individual Participants

Emma:

1. Young caring was complicated
 - a. Just thought of myself as a daughter
 - b. Mums difficulties were complex, I couldn't always cope with it
 - c. Always walking in eggshells
 - d. The roles were reversed, I had to grow up quite fast
2. The ongoing struggle to understand
 - a. I didn't understand Mum's behaviour, I took it more personally
 - b. Age brought a different perspective, now understand self and mum better
3. Feeling supported was important, but I didn't know who to trust
 - a. Being close to others helped me feel supported
 - b. Don't ask, don't tell
 - c. It took time to develop trusting relationships
4. I just had to keep going
 - a. Trying to be a train on a track
 - b. Gaining coping skills from multiple sources
 - c. It was really hard, but I'm grateful to develop into the person that I am
5. Young caring has cost me a lot
 - a. I lost the ability to be a child
 - b. I can't allow my children to have the same experience

Laura:

1. *Managing alone, not being able to let others know*
 - a. *Concern about sharing experience*
 - b. *Addressing parent's loneliness while feeling isolated myself*
 - c. *My ways of coping*
2. *Changing relationships in the family*
 - a. *Experiencing closeness and difference over time*
 - b. *Living in a strained family environment*
3. *Experiencing a very different childhood*
 - a. *Missing out on a normal childhood*
 - b. *There was no choice*
 - c. *Reversed roles, feeling responsible*
4. *The ongoing struggle to make sense*
 - a. *Still uncertain, trying to understand*
 - b. *Journey of gaining awareness*
 - c. *Understanding myself through comparisons with others*
 - d. *Who I am now*

Anna:

1. Too much, too young
 - a. Finding life tiring and chaotic
 - b. Being exposed, not protected
 - c. Experiencing emotional turmoil
 - d. Having to be the parent
2. Struggling to feel connected

- a. Living in a fragmented family
- b. Seeking a solid sense of belonging
- 3. There was no-one to turn to, I had to find my own way
 - a. No-one was there for me
 - b. Ongoing struggle to make sense
 - c. Learning how to cope
 - d. Caring has made me who I am

Ellen:

- 1. It was pretty grim at home
 - a. Living in toxic and traumatic environment
 - b. Dealing with mum's behaviour
 - c. We're an informed family, but we still couldn't cope
- 2. Finding ways to cope with the experience
 - a. I took care of myself
 - b. Developing lifelong coping strategies
 - c. Becoming aware of the cost of my coping strategies
- 3. Missing out on the irreplaceable mother-daughter relationship
 - a. Mourning the loss of a special relationship
 - b. Trying to fill the void, seeking connection
 - c. No-one was there for me
 - d. Protecting my children from what I experienced
- 4. Ongoing struggle of understanding the experience and its influence on me
 - a. I was so hard to make sense of, I still can't understand it
 - b. Never free, it comes back to haunt me
 - c. Not realising my potential
 - d. How I see myself now

Karen:

- 1. Caring was taking the parent role
 - a. I was responsible for her survival
 - b. Constantly giving support and encouragement
 - c. Growing awareness of carer role
- 2. There was so much to cope with
 - a. I felt overwhelmed with multiple stresses
 - b. Mum's behaviour was unpredictable; I was scared of what she might do
 - c. Managing with limited coping strategies
- 3. Seeking recognition and connection, while fearing it too
 - a. No-one thought it affected me, I felt insignificant
 - b. Feeling disconnected and unsupported by family
 - c. I sought acknowledgement, but feared being judged
- 4. I missed out on a normal childhood
 - a. Longing for some happy memories
 - b. It left me with some issues and regrets
 - c. I'm a better person because of it

Serena:

1. Seeking support but not always getting what I needed
 - a. The whole family was affected, everyone closed down
 - b. Seeking help but fearing dismissal
 - c. Having supportive others made all the difference
2. It was overwhelming, I couldn't escape from it
 - a. Feeling engulfed by the paranoia
 - b. Always stepping on eggshells
 - c. The battle to not take responsibility
 - d. It was too much for me
3. Although I didn't understand it, I had to find a way to cope
 - a. I was clueless, I couldn't make sense of it
 - b. I had to grow up fast, find ways to cope
4. It's given me strength, but cost me my innocence
 - a. I'm better equipped now
 - b. I'm still affected by it and have ongoing worries about the future
 - c. I lost my chance to be care-free

Chloe:

1. Caring was natural, but family life was dark
 - a. I loved dad and supported him, but it was frightening
 - b. Daunted by responsibility but there was no-one else
 - c. It got more difficult in my teenage years, I rebelled
5. I felt isolated, I had to keep the secret
 - a. I had no voice, I couldn't tell anyone
 - b. I had virtually no-one, it was very, very lonely
 - c. Having someone for protection made a big difference
6. The never-ending process of trying to understand
 - a. It was all so difficult to make sense of
 - b. Age has brought awareness, but I still don't fully understand
7. I coped mostly through disconnection, but I'm developing more strategies now
 - a. Put memories inside Pandora's box, disconnect from pain
 - b. Gradually finding other ways to cope
8. It's had a big influence on the person I have become, for better and worse
 - a. It made me stronger, wiser and more determined
 - b. Experience of caring helps me connect to others
 - c. I had potential, but I missed out on childhood
 - d. It scarred me, I carry a lot inside

Development of Themes Across Participants

Part 1: What life was like for a young carer of a parent with a psychosis-related difficulty

1. Feeling alone and isolated

a. Having no-one to turn to

<p><u>There was no-one to turn to, I had to find my own way</u> <u>No-one was there for me</u></p>
<p><i>Managing alone, not being able to let others know</i> <i>Addressing parent's loneliness while feeling isolated myself</i></p>
<p>I felt isolated, I had to keep the secret I had no voice, I couldn't tell anyone I had virtually no-one, it was very, very lonely</p>
<p><u>Struggling to feel connected</u> <u>Living in a fragmented family</u> <u>Seeking a solid sense of belonging</u></p>
<p>No-one was there for me</p>
<p>No-one thought it affected me, I felt insignificant</p>

b. Longing for connection

<p><i>Changing relationships in the family</i> <i>Experiencing closeness and difference over time</i> <i>Living in a strained family environment</i></p>
<p>Missing out on the irreplaceable mother-daughter relationship Mourning the loss of a special relationship Trying to fill the void, seeking connection</p>
<p>The whole family was affected, everyone closed down</p>
<p>Feeling disconnected and unsupported by family</p>

c. Support made a big difference, but it was risky

<p>Having someone for protection made a big difference</p>
<p>Feeling supported was important, but I didn't know who to trust Being close to others helped me feel supported Don't ask, don't tell It took time to develop trusting relationships</p>
<p><i>Concern about sharing experience</i></p>
<p>Seeking support but not always getting what I needed Seeking help but fearing dismissal Having supportive others made all the difference</p>
<p>I sought acknowledgement, but feared being judged</p>

d. Learning how to cope

There was so much to cope with Managing with limited coping strategies <i>Finding ways to cope with the experience</i> Developing lifelong coping strategies Becoming aware of the cost of my coping strategies
I just had to keep going Trying to be a train on a track Gaining coping skills from multiple sources
<i>My ways of coping</i>
<u>Learning how to cope</u>
I coped mostly through disconnection, but I'm developing more strategies now Put memories inside Pandora's box, disconnect from pain Gradually finding other ways to cope
<i>I had to grow up fast, find ways to cope</i>

2. Caring was taking the parent role

a. Holding responsibility

Caring was taking the parent role I was responsible for her survival Constantly giving support and encouragement
<i>Daunted by responsibility but there was no-one else</i>
<i>I took care of myself</i>
<i>The battle to not take responsibility</i>
The roles were reversed, I had to grow up quite fast
<u>Having to be the parent</u>
<i>There was no choice</i> <i>Reversed roles, feeling responsible</i>

b. Feeling exposed and overwhelmed

<i>It was overwhelming, I couldn't escape from it</i> <i>Feeling engulfed by the paranoia</i> <i>Always stepping on eggshells</i> <i>It was too much for me</i>
<i>I loved dad and supported him, but it was frightening</i> <i>It got more difficult in my teenage years, I rebelled</i>
Mums difficulties were complex, I couldn't always cope with it Always walking in eggshells
<u>Too much, too young</u> <u>Finding life tiring and chaotic</u> <u>Being exposed, not protected</u> <u>Experiencing emotional turmoil</u>
<i>It was pretty grim at home</i> <i>Living in toxic and traumatic environment</i> <i>Dealing with mum's behaviour</i>

Part 2: Integration of the experience into current life

3. Understanding the experience is an ongoing struggle

a. Trying to make sense, but yet to fully understand

Ongoing struggle of understanding the experience and its influence on me I was so hard to make sense of, I still can't understand it
The ongoing struggle to understand I didn't understand Mum's behaviour, I took it more personally Just thought of myself as a daughter
<i>The ongoing struggle to make sense</i> <i>Still uncertain, trying to understand</i> <i>Journey of gaining awareness</i>
<u>Ongoing struggle to make sense</u>
Although I didn't understand it, I had to find a way to cope I was clueless, I couldn't make sense of it
The never-ending process of trying to understand It was all so difficult to make sense of Age has brought awareness, but I still don't fully understand
Growing awareness of carer role

b. Losing childhood

I lost the ability to be a child
I missed out on a normal childhood Longing for some happy memories
I had potential, but I missed out on childhood
I lost my chance to be care-free
<i>Experiencing a very different childhood</i> <i>Missing out on a normal childhood</i>

4. Making sense of the person I have become

a. Developing into a better person while acknowledging vulnerabilities

I'm a better person because of it
It was really hard, but I'm grateful to develop into the person that I am Age brought a different perspective, now understand mum and self better
It made me stronger, wiser and more determined Experience of caring helps me connect to others
I'm better equipped now
<i>Who I am now</i> <i>Understanding myself through comparisons with others</i>
<u>Caring has made me who I am</u>
How I see myself now

b. Still Feeling Affected

Young caring has cost me a lot I can't allow my children to have the same experience
It left me with some issues and regrets
It scarred me, I carry a lot inside
I'm still affected by it and have ongoing worries about the future
Never free, it comes back to haunt me

Master and Subordinate Themes with Quotes

Part 1: What life was like for a young carer of a parent with a psychosis-related difficulty

1. Feeling alone and isolated

a. Having no-one to turn to

Emma	<p>“so there's always been a bit of the sense of being kind of slightly different and the odd one out”</p> <p>“so there wasn't a real sense of being cared for and being loved, and being worthwhile. And I feel like I've been very lucky that I've developed those things later”</p>
Anna	<p>“my mum was dealing with herself, she found it, she didn't have the time or capacity to kind of... support me in order to achieve what I wanted to achieve. Um, but I've done that by myself now”</p> <p>“because no one had taught me, like I just kind of figured it out on my own [laughter] kind of thing you know? So um, so she's kind of, like through knowing her I've learnt a lot of things like money management, and um like just, just knowing stuff, like I just didn't, because I just wasn't taught it you know?”</p> <p>“Um, but that's just who she is so, but she sees herself as her, not her and us if you see what I mean? Like whereas my aunts and uncles it's like them and their children are their priority, whereas my mum's kind of like 'well this is me and that's you and you're an adult”</p> <p>“I didn't have any of that so like, and also to steer me into a career, or something that was valuable, to sit with me and make sure that I could read, you know by a certain age, like um, there just wasn't the time for it, there wasn't the capacity to be able to do that for me, um because they were coping with what they were coping with, um, and that was hard enough as it is.”</p> <p>“when you're ignored or you're not, or you're silenced, anyone, that's, that's harder than anything, really”</p> <p>“So I've kind of been a young carer for my dad just as much as my mum when I think about it, even though it's not psychosis it's like um, yeah so it's both really.”</p>
Laura	<p>“after school I'd often sit with my dad because I know he'd been alone the majority of the day.”</p> <p>“I don't ever remember coming into contact with anyone. Um, even when, even when my dad had been admitted, um I don't remember anyone coming to the house or helping us in any way. Um, which I think everything is just how it was back then”</p> <p>“My mum she was doing like six days a week working just to cover the bills, and you know pay for all our stuff and that, um, my sister and brother would, they'd just disap... I don't remember them much when I was little to be honest 'cause it just seemed like they didn't want to be a part of that house sort of thing, so they'd just sort of go away and do their own thing”</p> <p>“Um, and it was just really, yeah it was just seemed like it was me and my dad a lot when I was little.”</p> <p>“like everyone just kind of carried on with their own lives, tried their best not to be, like all together”</p>
Chloe	<p>“as a child it was all very secretive and, there you know, there wasn't anybody, which horrifies me actually to think”</p> <p>“so I mainly came to support my Dad because my Mum had difficulties with alcohol”</p> <p>“It was only in his um, later years that he got I'd say you know a lot of input and support...We didn't have anything, no. There was no support at all. What's going on there? How times have changed now but no there was no support.”</p> <p>“Um it was horrendous. It was horrible. Very, very lonely indeed”</p> <p>“Um, I don't know if anyone told us not to say anything I don't know, I don't think they did. It was just sort of it was I think it was just something unsaid like an unsaid rule. But that's you know, I never said anything to anybody [laughs], til I was a teenager. But as a younger child, nobody”</p>

Ellen	<p>"I've never had that sort of person who was always there for me, but [sigh] you know that's how it is isn't it"</p> <p>"'cause I knew she couldn't perhaps always do that or she wasn't willing to or she couldn't manage that"</p> <p>"So in terms of... really what I found was that there was this sense of my mum that you couldn't rely on her. You know you couldn't expect her to be there for you, and I mean that in an emotional way really, not in a, you know she did make me dinners and, and generally the house was clean and all that, my washing was done"</p> <p>"'cause I'm the only child I'm going to be the main one to deal with it"</p>
Karen	<p>"I felt like such, I just felt like I was just, just a baby, just a baby like in the family and nobody listened to me and everyone thought I didn't understand anything, I was really insignificant and there was no point, you know I didn't really add anything to the family, I was a kid you know, I was pretty much the youngest one in the family. Um... so, you know what was I going to do? Nothing"</p> <p>"no-one really noticed, and you know what I, it just always so, so surprising, why did nobody care? Why is nobody talking about my sister like? And I was still a pipsqueak I can't do anything"</p> <p>"like feelings of maybe you're not, um, like, important enough. I don't know, just that's what for me anyway, but I don't really know."</p> <p>"I know she had the crisis team come out a lot when I was younger. Um, so multiple different occasions, I think mostly they came when I was at school though"</p> <p>"having to overlook things that you would normally get upset about and just deal with them"</p>

b. Longing for connection

Emma	<p>"So the wider family, kind of ran away, if I'm honest. They were just like, don't know how to deal with this, not gonna, not going to."</p> <p>"I lost to some extent the sense of belonging somewhere when I was younger, because I didn't fit in at school, and home was weird even though actually I didn't know it"</p>
Anna	<p>"Well them just being pulled away, so like they had to be somewhere that was different or they would've been took into care. So it was like my mum had to send my brothers to their different dads, so that fragmented the family, and ultimately our relationships have suffered"</p> <p>"so my brothers and me got separated because they went to their dads, and um, I stayed with mum, and that in itself has fragmented us as a family"</p> <p>"more that I seeked love elsewhere. Like and seeked that... I don't know that support and that, kind of, solidness. Sense of belonging I guess with them, so I suppose yeah I've got four friends who I'm really close to and I'd do anything for them. Whereas I think maybe if I had my family; my mum, my dad, my brothers, then they would be kind of, that would be my solid sense of belonging, whereas it's not, it's my friends"</p>
Laura	<p>"my mum and dad broke up when I was younger"</p> <p>"'cause my sister and brother, my brother especially, he didn't know what to do with it, how to handle it, so he'd usually stay away from it, he's always be... he's still like it now"</p> <p>"So it was like when they'd broken up I found that I could have a more normal-ish life, as bad as that sounds, but it kind of gave me more freedom to go home 'cause I didn't feel like I needed to be at home to look after him, I felt like I could go to my friend's house. Because if he was at home I'd feel 'oh no I don't want to go round' you know? 'I should be at home looking after my dad"</p> <p>"because my relationship with my dad got worse as I grew up, so it's probably something that I'm more, I dunno, I dunno it's hard to explain. Like we, we had a good relationship when I was little but then obviously the more I grew up the more it became harder, and he got very difficult to be around the older I got. Just, like some things you blame on the depression and some things you blame on the psychosis, but</p>

	<p>there was certain things that you could, it felt like you couldn't like make excuses for him. It felt like a lot of the time people made excuses for him, like especially my sister. Um, so it kind of felt, I don't know the more I grew up the more I couldn't, I struggled to have a relationship with him sort of thing.”</p> <p>“my sister and brother they weren't really, I think they just did their best to not be in the house”</p>
Ellen	<p>“In fact if I'm being honest probably when I think of, that's not quite my mother related, but that's the special relationship in my life with an older woman is my grandma, you know not my mum, it's my grandma I would think of as having that sort of loving bond really. Um, so that's, so that was lovely, I mean I had that and that was good”</p> <p>“she's not [laughter] a normal parent in the sense of it, that you would expect a parent child relationship to be, even, and now even as you get older all of that changes”</p> <p>“what was it in my dad that really, um, made me um, you know really I sort of, I just got assurances from, reassurances from so I've thought about that”</p> <p>“I always had this thing like one day we'll have a normal mother daughter relationship, and then suddenly at university I suddenly began to realise that actually that was never going to be the case.”</p> <p>“And I think my grandma, bless her, never, never really realised this but I was, I was always like the favourite grandchild. Um, I was always, I was the youngest grandchild but I was definitely like you know I knew that. You know I mean it was a bit hard on the others but it was clear that I was the favourite grandchild as she spent a lot of time with me growing up, and looked after me a lot”</p>
Karen	<p>“they're all supportive to an extent, my nan didn't turn round and say you know your, it's, you know 'you're completely wrong' she just found, she made it very obvious she found it very difficult to get her head around”</p> <p>“I had my sister I guess to talk to, but... she was always really a closed book about it so at least, I don't know, she didn't talk about it at all”</p> <p>“So it was just kind of... all a bit up in the air, there was no security I guess, there was no, like even now there's no, I don't know who my family is because everyone so distant and you know different, everyone's really different”</p> <p>“Nobody really um had any time for each other, they still don't really. Um, nobody will listen to each other and if they do they'll be really dismissive. Everyone's always really dismissive of everyone's mental health and health in general I think in my family. And, so no one's really there for anyone”</p>
Serena	<p>“my Mum was a lot more closed off, she became more of a quiet person ...mmm ...she would also, you know, be stepping around eggshells with my stepdad”</p> <p>“my sister who was always like a really bubbly person, she became, you know, more closed off as well, she started staying in her room all the time and stuff “</p> <p>“I did become closer to my Mum during that time”</p> <p>“Things are, you know, they're good now and we're even more close I think, so we were able to keep it throughout”</p> <p>“I was seeking help, I didn't feel I could go outside and obviously my Mum was in the house so she mostly saw what was going on so, you know, I just needed to talk to her, like, “He's doing this”, you know, “Am I wrong? Am I the selfish one here?” and, you know, it was seeking that support, we became close”</p>

c. Support made a big difference, but it was risky

Emma	<p>“and I was really lucky to have my brother as well, so it wasn't just me.”</p> <p>“there was a bit of recognition from my friends, and they were really supportive.”</p>
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	<p>"When I was younger it was very much "don't tell anyone, because they will take you away, or they'll judge me, or they'll start talking about me, me being my mum"</p> <p>"but equally, like if I said to a teacher, like, "oh my mums got schizo-affective disorder", they would just be like "oooh, don't know what that is, don't talk about it, people might judge you for it". And I was like, now I don't know what to do because I really want to talk about it."</p> <p>2they don't have to deal with sitting with the social worker with their mum saying "well [Emma] feels this way about it" while you are thinking "no I don't" [Laughs]"</p> <p>"and I don't really know if my teachers did either, even though I talked about it."</p> <p>"And my mum did a very good job of convincing the social worker that everything was hunky dory a lot of the time."</p> <p>"guess I was quite guarded and quite cautious, umm, because I had grown up with messages of you don't trust anyone, you don't let people in. Umm, and so it took me a long time to really, let go of some of those"</p>
Anna	<p>"and it was my friends really that supported me, like they were the ones that kind of went 'get up'"</p> <p>"No, an educational psychologist spoke to me at school, and that was meant to be to do with my dyslexia, and I told her everything that was going on and they kind of, she was kind of like 'whoa!' like and then nothing came of it. Um, she was quite shocked I think."</p>
Laura	<p>"when I was younger, like it's not, I think now mental illnesses are more, you know they're more talked about they're more discussed. Whereas when I was younger it was like you couldn't really tell people, like people would say 'oh your dad's crazy' or things like that, and you, it was just, it was all very, just, dunno it's just not talked about, it wasn't discussed, it was like 'your dad's not well' that was it, that's how, if anyone asked about my dad or you know 'how come he don't take you to school' or anything, it was just 'oh my dad's not well' it wasn't really spoken about"</p> <p>"I think 'cause I didn't want people thinking, 'cause like my friends had been around my dad, some had said the odd comment like 'your dad's a bit odd' or you know things like that [laughter] but no one actually like, they didn't think too much on it, they didn't ask too many questions on it so I think I didn't want you know like 'your dad's crazy', 'your dad's this, your dad...' you know what kids are like, I know what kids are like"</p> <p>"It wasn't until I was about fifteen, sixteen that I said to my friends you know 'my dad's not well' and even then it was like a very tight circle. Even then it wasn't... it wasn't like I'd go in, I'd never like have gone into it, like now all my friends know but it's different now. But at that age I would've just said 'oh he's not well' that's how it was left."</p>
Chloe	<p>"luckily we had our Nan so that really helped and made a difference, a big difference."</p> <p>"Nan really protected us you know and as I say I dread to think what would have happened if she hadn't of been around because there wasn't anybody else and obviously my Mum was you know was suffering her problems as well"</p> <p>"and I remember getting, having to get the chair to stand on to unlock the top of the door and then I used to have my sister in her pram and I used to run, run off, I used to run in the darkness and run away from it all to my Nan. And then it was like 'going to Nan's and it was like [sigh] it's safe here"</p> <p>"And it was horrible because you couldn't tell anyone so you couldn't like go to the teacher and you know you just sort of like, like I said leading like another life on the outside so, it was horrible and I wouldn't ever want my children to go through that."</p> <p>"but I never really trusted people very much. Um yeah, I never, you know a bit cautious of people, of who I can trust so I've always sort of been a person who would have like just one or two very close friends, I cannot hang in groups. I don't do groups, of people, I just can't do that."</p>
Karen	<p>"I didn't really tell anyone, really, I didn't really think it was that different."</p>

	<p>“So we kind of got onto the topic and I said oh well my mum’s like, my mum like self-harms and stuff and she's really quite ill. And they were all really surprised and stuff but... we like just never spoke about it again. It was just I think, I don't know how old we were, we were really young, this is I mean primary school.”</p> <p>“So I don't know why we were talking about that but, nobody really... in particular knew, or even if they did know they didn't really understand. And if they did understand I never really got any support”</p> <p>“I was always scared that they would judge me or... and I think it came from my mum as well you know 'cause my mum used to say stuff like 'oh don't tell anyone how crazy I am 'cause they'll take you away' and she now knows, she now knows that that's wrong, she shouldn't have said that, but at the time you know she, she would do it, she was just doing what she thought was best, like 'don't tell anyone because otherwise you know you'll have to be taken away from me' and that terrified me, so I didn't really tell anyone.”</p>
Serena	<p>“teachers at school said, you know, “We're open if you need help, talk to us, and come to us” but I never did 'cos I felt ...it wasn't the right thing to go to a teacher.”</p> <p>“I just didn't feel like that would take me seriously or know what to do and it wasn't something that I just wanted to tell anyone so they would feel pity for me or ...or just say, you know ...'try' you know just offer some useless way of dealing with it”</p> <p>“my [subject] teacher was like, “Oh, what's wrong?” and ...I think she heard me talking about stepdad problems once and she said, “Oh, did you have a fight with your stepdad? That happens”, you know, “Every teenager has that, you'll get over it” and I think that put me off talking to teachers, you know, 'cos it's like, “You don't know what I'm going through, how can you just say that?” as if it was just some teenage problem, so ...yeah, I think that was, um, an issue you know, that put me off speaking to teachers.”</p> <p>“I went to a support group, you know, after a while, um what are they called, [name], do you know them? A young adult's centre, um, in [name]; they help people in this situation. So after a while I did go to them”</p> <p>2it was really, really, helpful talking to this, you know, lady, she was trained, she was, you know, young as well so I felt like I could connect to her and, you know, she was trained to help and listen so she wasn't just telling me, you know, silly things like, “Oh you'll get over it, it's passing” you know she really listened and offered support. And the counselling, it was really good to get things off my chest, so, you know, I wasn't carrying my anger around like I always did. So I got it out, went home a lot more, you know, my thoughts less clouded.”</p> <p>“she tried to help me as much as she could but then my stepdad would get angry about that as well, like, “You're both planning against me””</p>

d. Learning how to cope

Emma	<p>“It was just kind of the sense of "grit your teeth and get through it", and just keep going as best you can.”</p> <p>“I didn't really know how to take care of my emotional health, because I was so used to, you put your needs down the ladder and you put somebody else first”</p> <p>“because school was very much my escape, so I did quite well academically”</p> <p>“I did a lot of reading when I was younger. Umm, and so I think there is a lot of things that I picked up from books, and like, umm, Enid Blyton, where lots of stories are people being quite resourceful, umm, and generally having relatively healthy relationships with each other and friendships, and so I think I took some things from that”</p> <p>“music is something that was kind of given to me by my parents, because they said 'we want you to have music in your life'. Umm, but it's something that then I've kind of taken on and owned, in a way. Umm, I don't really know how that became a coping strategy, it was just kind of there, and so it was”</p>
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Anna	<p>"I moved out. I think that was one of the main things. Um, when I was seventeen I moved out, um, so, and I kind of, I put boundaries in place"</p> <p>"As logically as possible. Um, how do I cope? Drugs. Diazepam generally. [Laughter]"</p> <p>"From books, knowledge I would say, like from books like um... philosophy. Err, documentaries. Um, conversation with friends."</p> <p>"instinctively; through having to cope with so much when I was younger. I just learnt how to cope"</p> <p>"I started taking drugs though to kind of, um, numb myself I guess against it. Um, I don't do drugs now but at the time I smoked, from about thirteen I smoked weed every day, and my mum didn't know about that either"</p> <p>"it was just too much. It was like, it was just easier to go out and take drugs and forget about it, really. Especially with my dad, like, um... as well, like it was just easier to do that"</p>
Laura	<p>"Definitely like there's worse, people out there worse off but, I think it wasn't as good as what it should have been sort of thing."</p> <p>"I think I've always been like that. I've always been quite positive."</p> <p>"I try not to worry. I'm not a worrier, I don't like to worry [laughter]. I don't think you should worry about anything until it's actually happened"</p> <p>"I just, I think of the bigger, bigger picture really. Like is this really the end of the world if this (...) Or if this doesn't happen, or if this don't go right? I kind of think it a bit like that, and there's always, always other ways and, you know to do things, so, I'm quite a note-taker as well; any worries I have I find that I'll write, I'll write them all down and I'll just gradually tick 'em off"</p> <p>"I always take that [laughter] perspective on it. Um, yeah I try not to, I try not to worry about anything really."</p> <p>"you just get on with it, you know it's just one of those things, you can't change it, nothing you can do"</p>
Chloe	<p>"I tend to have blocked a lot of my memories out. Um it's just like if people I don't know say, once my partner was talking about oh the past and he's like oh asking me questions and I don't wanna talk about it, I just don't like it, so I try not to bring it up. It was really, really painful, really lonely."</p> <p>"mean I think a lot of what you do have to do is you have to become numb as well, you have to become quite numb to some things. Um ... So, I'm just trying to think of an example really. Yeah you know like silly things. ... You're very, very numb and just I suppose, just sort of scared to feel cos it hurts so you numb yourself and I still do that to this day and I have, what do I call it? ... Pandora's Box. I have a Pandora's Box which is kept closed and then now and then things will come out of that Pandora's Box."</p> <p>"It's like holding your emotion inside, holding the memories inside and the emotions that come with them. Because if you remember them it starts the pain. The painful emotions. So if you don't talk about them and you keep them in Pandora's Box. It doesn't hurt then, so yeah. It's like a separate part of life now to me."</p> <p>"So coping with stress. So ... So obviously I take my tablet. Um I also er I dunno see I spend a lot of time sort of trying to do you know simple things like just walking in the woods and things like that really."</p> <p>"I take my medication and just simple things in life really. Um and I like to just keep my life organised. Um and I don't drink alcohol and I don't take drugs"</p>
Ellen	<p>"I think I just developed them. I think I just, you know that's how I developed them."</p> <p>"I probably do block things out, I probably compartmentalise things that I don't want to deal with or I'm not happy with. I sort of put them on one side and compartmentalise certain things. Um, I probably do go into sort of busy mode when I don't want to deal with things"</p> <p>"suppose I sort of covered some of that up and would just put a front on that everything was fine and just normal you know"</p> <p>"if you close off you can, you know you don't get hurt or you don't have to deal with, you know the fallout of the relationship not working or something"</p>

Karen	<p>“As they occur? I ignore them, I don't know [laughter], ignore my responsibilities, ignore the stresses, don't deal with them until they blow up, which is basically not dealing with them. Um, I don't know. Don't think about them too much. Talk to my mum. Um, what stuff do normal, what do people normally do to deal with stresses?”</p> <p>“when I was about eleven or, eleven or twelve, secondary school, that's year seven isn't it, it got hard, more hard for me to cope with.. things, and that's when my sister left.”</p> <p>“I always ask, I always ask my mum for advice. So if there's anything going on I ask her ‘what do you think I should do?’ maybe that's not the best thing to do because you know she's pretty ill so she's going to give me maybe not the best advice, but you know it's your mum so you listen to her. Um... so I do whatever she says.”</p> <p>“see my mum used to, well I think, I don't know if she still does, she used to self-harm a lot, and I guess for a lot of children you know it wasn't really in the forefront of their mind you know, if they even knew that it was a thing, you know most people know that it's a thing but they don't, you know most people don't consider it. You know maybe more like nowadays because I know a lot of sixteen year olds in my class and stuff that do it. Um, it's kind of really a lot of people know about it so I guess people just use that as a way to cope. But I don't know, I mean I started self-harming a bit as well. Um, from I don't know like twelve to nineteen. So I don't know, if my mum, if my mum didn't self-harm at all I don't know if I would have or wouldn't have or, you know it's difficult to say but I don't want to blame her because it's not her fault, but, and maybe it's something that I learned that it was a possible way to deal with things and cope and make things, make yourself feel better, or at least you know punish yourself for feeling certain ways and then you would feel better because you know you felt at peace then. So I don't know”</p>
Serena	<p>“and I would just stay in my room most of the time”</p> <p>“Mum always said, “Go cool your head if you're stressed, you know, go for a walk, get out of your room, you know, the computer isn't helping” so, you know, I thought, you know, one day I would try that so I put, you know, my headphones on and I just walked for hours and it really helped, so I kept doing that.”</p> <p>“I talk to people a lot, even if they're not saying anything, I just want to get it out ...um, I play games to get my mind off things ...and, um ...yeah, going for walks as well or for a jog to help clear my mind. If things are too stressful I like to do that.”</p> <p>“I just did not want to go back home. I was in school until, I don't know, eight o'clock when they closed. I was always going to my friend's house. I stayed there until I could ...I was going on night walks ...I just didn't want to go home 'cos I soon as I stepped in, you know, it was constant worry, like, when is it going to come”</p>

2. Caring was taking the parent role

a. Holding responsibility

Emma	<p>“Because I didn't really appreciate that I was having more responsibility than they were. Umm, so I guess it means you grow up quite fast.”</p> <p>“so I was asked to make sure she got up in the morning, to make lunch for me and my brother and make sure we got off to school, that we didn't miss school days and things like that.”</p> <p>“Like waking her up in the morning, making sure that she had a coffee, going back to check that she was still awake. Pretty much, you know, nagging her until she got out of bed”</p> <p>“similarly in the evening kind of being like, you can't just stay up or you won't get up in the morning.”</p>
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	<p>“making lunches as I said earlier, for me and my brother for school, making sure that we did get to school on the right days. Umm, and that we didn't try and go in during the holidays”</p> <p>“I was little, sort of primary school, probably I took care of myself better than most children, because I had to.”</p> <p>“to an extent it was normal but there's also a sense of ‘I'm being a big girl’. Umm, I'm being a grown up, like I have something to offer”</p>
Anna	<p>“well my dad is like a nightmare as well. So that's kind of like, so it's both I suppose in a lot of ways. So it's role reversal quite a lot of the time. Sometimes my mum does step up and kind of be a really good mum, like um, she has done at points when I've been really poorly. But I've had to demand that also almost”</p> <p>“it's almost like that psychosis side of it stops her from stepping up to that point”</p> <p>“she was cry and be upset, like um, and I would have to reassure her, and she would, I'm pretty much the only person she talks about with the psychosis to date”</p> <p>“every time I go to my mum's it's not like, it's not like she's my mum and I'm the child, it's like we're two adults”</p> <p>“So it was like I didn't go to school like five days a week, um sometimes I stayed at home and cleaned, or sometimes I cooked dinner a lot of the time, um and also um like she would, it was like I would, she was telling me stuff as an adult rather than as a child.”</p> <p>“I think my mum's tried to do the right thing but, but she just doesn't quite function as an adult.”</p> <p>“[name] being intermittently poorly, and therefore being a parent for him. Um, whenever I go, whenever I take him out I'm the one that's responsible.”</p> <p>“also the realisation that just because someone's called an adult doesn't mean to say that they're necessarily the one with all the answers, you know? Like an adult, some adults, some children cope better than adults. So... it just, it just depends on what bag you get”</p>
Laura	<p>“'cause I found that he was taking up a lot of my sort of like time and energy, and I found the more I looked after him the more I wasn't focusing on other aspects of my life.”</p> <p>“I couldn't just go and, you know ‘just going to the park’, ‘okay’, it was like I had to come home and, especially 'cause my mum was working lates it was like I'd like to go home and just make sure everything was okay at home. Um, like make sure my dad had eaten, make sure he'd bathed, basically things like that you know and, it was like if I didn't go home and do that no one else would really go home and make sure that was done until my mum would come in and then she'd obviously check on him and make sure he was okay, but half the time I used to come in and he'd still be in bed and it would be like half three.”</p> <p>“as a kid I think you just get on with it”</p> <p>“it's looking after someone. Um, in my words it would probably be looking after someone who you kind of feel should be looking after you in a sense. Um, I don't think any young person should, I've got a daughter myself and I couldn't imagine her looking after me in that, in that way, but you know things happen.”</p>
Chloe	<p>“very scary for us as well, um you know especially when we were younger but obviously we got used to it as we got older, um but basically he didn't have anybody else um so it was really down to me and my sister or he wouldn't have had anybody. Um, so it was sort of you know ... I wouldn't say by choice it was like we had to really, we couldn't abandon him”</p> <p>“Ok well it's a lot of responsibility. Um yeah it's very daunting, it makes you feel a bit more a bit, well I didn't realise at the time but I see now you know it makes you feel that you're more grown up than you actually are because you've got that increased responsibility”</p> <p>so basically a lot of responsibility. Um it's emotionally draining as well, um yeah, it's difficult as well when it's your parent because normally it's your parent that looks after you isn't it? And then to have them not be able to look after you and you, the roles have reversed is, is very difficult”</p>

	<p>“it means to be a young carer you have an increased responsibility that is really beyond your years that you shouldn’t really be having to deal with”</p> <p>“and I had my disabled sister who had cerebral palsy um and I used to spend a lot of time having to look after her.”</p>
Ellen	<p>“I think for me, maybe not so much caring for my mum, I think for me probably I became quite independent so she didn’t have to care for me, if you know what I mean, so that was... 'cause I knew she couldn't perhaps always do that or she wasn't willing to or she couldn't manage that. So it's a slightly different thing but that was in a way so that she, you know, 'cause she couldn't do it, so it a way of like, in a way taking, so it's not taking the burden off, I wouldn't even think of it in that way, but if in a way it was a way of... you know something else that she wouldn't have had to do really for me”</p> <p>“I can do it myself, I'm, I mean it is a bit of a trait of my family but I just think 'well I'll do it myself because my mum won't be able to manage that' it's quite hard to sort of explain it really”</p> <p>“I wouldn't ask her to support me with something at school or, and I would never ask her to help me with work or anything like that”</p>
Karen	<p>“I've been with her to A&E a few times, um make sure you know, and she says 'I feel this terrible, what should I do?' and I said 'well I think you should go to the hospital' you know that kind of thing, just giving her a bit of advice”</p> <p>“my mum wasn't, you know a parent really in that, so you know you do become, you become a parent, you become the adult. Um so it's kind of difficult really to explain.”</p> <p>“I can't talk to my mum because she will just be constantly worrying about that and really upset and she'll need my support so she'll have to come first 'cause you know”</p> <p>“there's no really like, lots of things; um, you know making sure that she got up and like cooking, cleaning, things like that.”</p> <p>“just taking on the parent role, you know not being a kid so much anymore, and having to overlook things that you would normally get upset about and just deal with them. Um, and just I try and do more of the parent things that your parent should be doing those things and you're doing them instead, or as well as”</p> <p>“I didn't want to leave my mum because she was, I knew she was really ill and I knew she was self-harming a lot, and I thought if it stayed with her all the time she wouldn't, 'cause she couldn't do in front of me.”</p> <p>“one minute I was a child, you know, baby of the family, um with all the attention, and then the next minute you know I'd have to be there, you know trying to convince my mum not to kill herself, you know?”</p> <p>“I felt very responsible. Um... for my mum and like, if I said something and she would get upset you know that was it, it was my fault and I felt awful and there was nothing I could do to make it better, and you know what was I supposed to do anyway. You know, I just kind of a bit helpless. I don't know you know there's nothing really that I could do, but I did my best so.”</p>
Serena	<p>“it means that you're dealing with things that you shouldn't be dealing with, um, and it just means that you've got to grow up very fast and, you know, become independent very fast, because you're dealing with a lot of serious issues there.”</p> <p>“I just wanted him to take ...a responsibility and look after himself. I know people with depression and mental disorders need help from others and support from others but to just completely blame all your problems on someone and not take any responsibility yourself, you know, I thought that was just horrible”</p> <p>“I didn't like it 'cos, you know, <i>it's</i> not my job, he's a grown man, you know, it's got nothing to do with me (...) I always wish that he would have taken responsibility and done things himself, you know, 'cos he is a grown up.”</p> <p>“I feel it's unfair ...because ...you know ...I wasn't equipped to deal with that, um ...it just felt annoying ...like, why me?”</p> <p>“I think, 'cos I never really got on with him so to have to take on that as well, you know, it was just too much. It wasn't what I wanted.”</p>

b. Feeling overwhelmed and exposed

<p>Emma</p>	<p>“then I went through a couple of years where I was quite rebellious, and quite like “this is not okay”. Umm, and then kind of came back to being probably a bit more caring” “phone quite a lot, pretty much every day. And if you weren’t there to answer the phone and you weren’t available to speak for about an hour, and you didn’t contribute to the conversation, then she would take that as you didn’t want to know her, and you were invalidating her. Umm, but equally if you said too much or you disagreed with her, then you were kind of overwriting, over-riding her freedom of speech, umm, and being cruel to her. So kind of really trying to walk that balance of being available to show her actually someone does care, umm, but also, kind of holding in my own opinions” “she can kind of flip quite a lot between being, really wanting to engage with the world and really energetic, and thinking that everything is going to be fine. And then go to actually everything’s horrible, and nobody cares and the world is a really dangerous place to be. have to deal with a mum who doesn’t know what the boundaries are, in terms of what’s appropriate to say to children.” “Everyone was kind of always walking around on eggshells, umm, because no-one ever really knew what was going to make my mum react, umm, or how she would react” “it felt like there was always a lot of emotion in the house, and there was never really any particular thing to kind of put it on to, to kind of say x is feeling y because of this. It was always just, there would be anger and there would be suspicion, and there would be kind of feelings of betrayal and loss and sadness, resentment, and all of this, just kind of always in the air, so it, it felt like quite a heavy place to be quite a lot of the time.” “there would be angry outbursts and what have you, but that was just life, umm, and I kinda thought everyone’s life was probably something like that.”</p>
<p>Anna</p>	<p>“she was just on another planet, like absolutely on another planet. And then she went to the doc... I remember her coming back after a couple of days from the hospital, and she was like feeling round the car, um round the seat of the car with her fingers and she had like an, a, like a playing card with her, and she was just a different person” “when I was younger kind of it was I had a Monday off, I had a Friday off, I had a Thursday off, and she used to write a list of like, um, dates of when I was off school and used to say ‘well [Anna] was poorly on these dates, it would be like the nineteenth, the seventeenth, the twenty-first, the twenty-eighth. (...) So I missed a lot of my education because of it” “What life was like... um, chaotic, err, tiring...” “she told me like lots of stuff that she was kind of experiencing, and um she told me lots of things.” “my grandad died, he committed suicide, and my nana died of cancer, and then [brother] got diagnosed with schizophrenia all the way through my teens. Um, so, um, I supported my mum through all of that and had those conversations with her, and knew what happened because she found my grandad so she told me all of that in detail and everything.” “it was my birthday on the day that she actually went completely crazy. And um, and yeah I was scared, I was scared of her” “the people that my mum used to bring home like and my dad used to bring home bag ladies and stuff, and my mum used to bring home druggies”</p>
<p>Chloe</p>	<p>“because he you know had some very terrible times and it was very scary for us as well, um you know especially when we were younger was we had to offer a lot of um emotional support to him, there was a lot of listening to him um when he was very sick you know, a lot of it often didn’t make sense, it’s quite scary and bewildering as well some of the things that he would come out with.” “I remember him going ‘What are you ...’, shouting at me or something and I thought ‘Oh God my Dad never shouts at me’ which was like oh my God you know scary to see someone that you’ve grown up with you know been so close to, be like a totally different person.”</p>

	<p>“when I was younger you know I found it really frightening and I thought he was like angry with me and things.”</p> <p>“so you tend to sort of lose out on a bit of your childhood in some ways because you see things that really you wouldn’t want, children to see or hear”</p> <p>“at the time, I didn’t understand when I was younger and it was very, very frightening indeed and I think I mentioned to you about something that really stands out to me, um was coming home with my Mum um ... And he had put um, pages of the Bible, stuck them around um and he put a crucifix on the front door and he also ripped our house to pieces like including pulling the light fittings out. There were things thrown through the windows, um so it was very, very scary at times.”</p>
Ellen	<p>“it was a lot of arguments and a lot, you know she had affairs, my dad had an affair, you know I mean it was all very, you know? So it was a pretty, it was a pretty sort of toxic and traumatic environment really”</p> <p>“the thing would be you would go home, um, and if she’d been in a period of depression and not well you’d think ‘what am I going home to? How’s my mum going to be? What might have happened”</p> <p>“my mum was always a bit chaotic”</p> <p>“it was grim really [laughter] you know you’d just think what’s the n... what is the next thing that’s going to happen.”</p>
Karen	<p>“one minute I was a child, you know, baby of the family, um with all the attention, and then the next minute you know I’d have to be there, you know trying to convince my mum not to kill herself, you know? So it was just, there was, there was just always you know you didn’t know what day, when you woke up what would you do today, you know it was never stuck down to anything.”</p> <p>“It was about that time my mum started revealing more about um how she felt, because she thought I was old enough to know and understand”</p> <p>“I always wanted to be at home with her 'cause she made me feel safe and I made her feel safe and we kind of like, it was a bit of a co-dependent relationship to be honest with you, like it wasn't, it wasn't how a mother daughter relationship should be, it was a more friends and, and who looked after each other”</p>
Serena	<p>“I feel like I couldn’t respond or do anything because I was really young ...um, so I kind of just ...I just listened to his rambling and ranting and, you know, um, anything he had to say”</p> <p>“it was really stressful ‘cos there was nothing I could say or do, um, you know, to make him ...feel better or, you know, stop those thoughts so I just ...you know, it was very frustrating ‘cos I just had to listen to it, like three times a day for, you know, three or four years without doing anything”</p> <p>“cos I was always so worried and stressed out about things and ...always being controlled”</p> <p>“I became, um, more a closed person ...definitely more grumpy. I would let my anger out on my friends ...mmm ...yeah but I definitely became a more horrible person during that time”</p> <p>“it was sad and it was ...confusing because at times we would all be like, you know, watching TV and having dinner, like a family, everyone having fun, but ...um ...you know, you never knew when it was going to turn upside down ...it was like always stepping on eggshells, you know, if my stepdad saw me texting someone his mood would, would like switch. If I said I was going out with friends he would start probing, you know, um, and then from then on for a few days things would be really bad at home, like a very heavy atmosphere ...um ...people would be scared to speak ...um ...yeah, things just went a bit, you know, kind of dark for a few days”</p> <p>“it was just too much. It wasn’t what I wanted.”</p> <p>“my hair started falling [out] at that time, I would bite my teeth when I was asleep (...) I would be grinding all my teeth at night time and it really hurt, like I really hurt myself during sleep and that was stress related”</p>

Part 2: Integration of the experience into current life

1. Understanding the experience is an ongoing struggle

a. Trying to make sense, but yet to fully understand

Emma	<p>“so when I was little it was just like "oh, mum talks to herself, presumably everybody talks to themselves". Umm...., and so that was just my mum and then there would be angry outbursts and what have you, but that was just life, umm, and I kinda thought everyone's life was probably something like that.”</p> <p>“I started thinking, you know actually what's going on, and what are these words like schizophrenia mean, and kind of looking some of those up on the internet. Umm, and thankfully found Mind and not a kind of, awful resource [laugh]. Umm, so that kind of helped me kinda make a bit more sense, of actually her experience being really different to mine”</p> <p>“still kind of quite hard to understand”</p> <p>“I just got really tangled up in that, and then at the same time I was really angry with my mum because what she was saying was confusing me so much.”</p> <p>“I didn't know that there was support, and I didn't, kind of think that I deserved it, so it was very much, I'll keep going so that I'm doing what I need to for my mum, rather than any kind of sense of trying to feel better myself”</p> <p>“there would be times that she would shout a lot more, and I didn't really understand it, umm, and I probably took a lot of that personally, as something that I had done, rather than realising that actually, any of her experiencing was to do with other things”</p> <p>“I went through a couple of years where I was quite rebellious, and quite like “this is not okay””</p> <p>“whereas my mums very much, she needed to put herself first and I can see that now but at the time I couldn't.”</p> <p>“when I was a teenager, early teenage years, she was very unwell, umm, and that probably coincided with when I was more rebellious [smiles], so I was kind of, there was a part of me that was like, it's difficult seeing her that way, and there was another part of me that was like, I just can't deal with this, and this, 12 year olds don't have to deal with this stuff”</p> <p>“It felt just really quite natural, umm, it was just supporting someone who was upset, and distressed. Umm, and just kind of like being a normal person. It didn't feel, umm, like a kinda conscious thing. Like it probably wasn't even until I was like 15 or 16 and someone said, "oh you are caring for your mum", and I was like "oh am I, really?”</p> <p>“then I think when I got to kinda 12, 13, umm, I started realising not everyone's life is like this, cause I was spending more time at friends' houses and things”</p> <p>“as I got older, I got more resentful, because I was like, do you know what other people just go out and have fun, and they're not worry about all of these things”</p> <p>“I didn't recognise myself as a carer”</p> <p>“as I got older, again, I just got really sad for her because I think her life is so restricted compared to mine now”</p> <p>“now it feels really different again, actually it's much easier to offer her that support, because I can see her problem more as a whole person. Whereas when I was a teenager maybe that wasn't quite so developed”</p>
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Anna	<p>“in the grand scheme of things it doesn't matter. I suppose because I'm at peace with it, like, how can you be angry at people when they've been poorly?”</p> <p>“now when I look back on it like, what the hell?”</p> <p>“but I love her so much like, so, it's kind of like it's forgiven instantly. Same with my dad like it's forgiven”</p> <p>“And because I was nine I kind of interpreted it as um like we were investigators, me and my brother, like finding out what was wrong, do you know what I mean? Because like this is really weird.”</p> <p>“psychosis to date, but I was quite angry at it, um because it kind of took my mum away, um but now I'm not so angry at it, like now I'm older I kind of like get that, like I almost associate it as someone believing in god, and she believes in whatever's going on with her, I kind of think 'well you know if someone believes that then they can also believe something that's very different as well'”</p>
Laura	<p>“<i>And did you think of yourself as a young carer at the time?</i> No. <i>Why not?</i> I just didn't, 'cause it's the life that you, that you're used to.”</p> <p>“and I was only little I remember thinking like 'what's going on?' I didn't know what was going on”</p> <p>“it's the life that you, that you're used to. Like that was my life and that was, that was all I knew sort of thing.”</p> <p>“we had a good relationship when I was little but then obviously the more I grew up the more it became harder, and he got very difficult to be around the older I got. Just, like some things you blame on the depression and some things you blame on the psychosis, but there was certain things that you could, it felt like you couldn't like make excuses for him. It felt like a lot of the time people made excuses for him, I was probably about eleven, twelve, when you start going to your friend's house more and, yeah it was definitely around that time you start realising this ain't, this ain't really right.”</p> <p>“there was a lot of, a lot of resentment sometimes, a lot of, especially in my teens I was quite angry, very much an angry teenager, um and I think that was just my way of, you know, my way of coping with it to be honest, but all teens are a bit [laughter] ain't they?”</p> <p>“I'm definitely emotionally stronger than my father”</p> <p>“I think emotionally, um, I think I'm different to my dad.”</p> <p>“when my best friend when I was younger I used to go round there and look at how their household was and thinking 'oh their dad's out working and you know he'd come home and help with the dinner and help with everything, and homework and that' whereas we didn't really have that, because my mum, my mum used to work lates, so she'd do take us to school, do the lunches and that, and then my sister would pick me up after school and my dad would just be at home and we'd have to come home and my older sister she'd like sort the dinner some nights, and my brother would and, it was kind of like you used to look at the other families and think 'well why, why's that different? Why is, yeah it's not until you're older you realise.”</p> <p>“not until I was older that I probably started to think 'okay so what's actually, what's wrong with him, like why is he like this?' um, but yeah, as a kid I think you just get on with it.”</p> <p>“depression runs in genetics, apparently, I've heard. Um, and, you know me and my sister and brother always joke, like it's not funny, but it's going to be one of us 'cause one in three get it [laughter]. Um, but I think, yeah I think emotionally we're all wired a bit differently”</p>
Chloe	<p>“There was a lot of anger and things going on then, to be honest with you. You know, ashamed and you know just thinking 'why can you not just be normal, be a normal family?’”</p> <p>“Being ashamed. Just being ashamed, like having no respect for yourself really. I think I went through a time when I didn't think I was worthy of having respect for myself. I don't know why that it is, but I clearly remember that around like 14 to 16 particularly.”</p> <p>“there was a lot of embarrassment as well when I got older, I must say”</p> <p>“when I was a teenager I did rebel a bit against it”</p>

	<p>“especially with you know this character or I don’t even know what it was(...), you know, in the psychosis episode was very prominent. You know, I don’t know, I don’t know, I didn’t really, I didn’t ever ask you know, we just sort of went along with it, I didn’t even question who it was”</p> <p>“I still find that quite bizarre to be honest”</p> <p>“so basically it didn’t really I dunno I can’t recall like thinking about it when I was younger at all. So it’s more as I’ve got older.”</p> <p>“I had sort of anxiety and depression, I know I did, but I didn’t know what it was. I thought it was you know normal to feel that way and then it’s not till you’re a bit older that you put it together of what you’re going through.”</p>
Ellen	<p>“I’d think ‘oh god’ you know that’s when in a way I couldn’t come to terms I’d think why, you know even though I knew she wasn’t all there I don’t think ‘why does she do those stupid things, why does she do that?’ do you know what I mean? I couldn’t make sense of that sometimes, and the overdoses as well you know, really, I couldn’t make sense of that”</p> <p>“gradually over time I’ve accepted that. It’s taken a long time but probably in my teenage years I began to see that that was how it was going to be. I sort of had a recognition that that was how it’s going to be.”</p> <p>“probably only as I got older, probably like more sort of nine, ten, eleven I began to realise that there was something a bit different about my mum and that she obviously wasn’t quite the same as other mums in terms of her mental health”</p> <p>“I got to university and again I saw the world in a different way and met different people from different backgrounds, from very different social backgrounds, and also how they were with their parents and their mum’s... I really began to have this thing; my mum is not like other mum’s, I’m not going to be depe... I always had this thing like one day we’ll have a normal mother daughter relationship, and then suddenly at university I suddenly began to realise that actually that was never going to be the case.”</p> <p>“I just sort of got on and managed my life really on a day-to-day basis so I didn’t have to bother if you like about my life you know, I just got on with it really.”</p> <p>“yeah it just ripples out doesn’t it, the effects do ripple out, people don’t know”</p> <p>“I suddenly thought ‘I think now my mum can’t do this, she’s not like other mums, she’s not dependable, I can’t depend on her, um I’m more mature I can see...’ you know you suddenly sort of see, see that, and it is, not shocking but it’s sort of, it is a bit of a wake up scenario, it’s hard to explain.”</p> <p>“as I got older I could see she was quite immature really, she was very immature, she’s still very immature you know, and it became, almost becomes like you suddenly realise you’re more mature than your parents in the way that you’re dealing with things and the way that you see the world, that you see it in a more mature way.”</p> <p>“as I got older, particularly into the teenage years, you sort of begin to sense that um, something’s not, you know something’s not right”</p>
Karen	<p>“you know I’ve not really known much difference so it was weird like going to other kids’ houses and their mums and dads being different. obviously as I’ve got older I’ve realised there isn’t normal in families um so I accept it more”</p> <p>“I did when I was about, I was fourteen, think about applying for you know to be a young carer, or young carers’ allowance, that’s what I thought but um, I think my mum started to get a little bit better so I didn’t, I didn’t feel that was necessarily so much. I was about fifteen, fourteen, fifteen maybe”</p>
Serena	<p>“I didn’t really understand because to me it seemed like it didn’t make any sense at all and then I started to think that, you know, maybe I’m being self-centred and maybe he’s right, you know, maybe it is my fault”</p> <p>“He said ...he had depression but ...I ...I didn’t really know, you know, what living with someone like that would be like so, um, a lot of his behaviour to me just seemed like he was being over the top and overprotective ...um ...I just didn’t really understand it, I didn’t know what to make of it really.”</p> <p>“I just felt clueless as well, ‘cos I didn’t understand, you know, why and what to do, and what’s the cause, yeah, I felt clueless and confused.</p>

	<p>I feel it's unfair ...because ...you know ...I wasn't equipped to deal with that, um ...it just felt annoying ...like, why me?"</p> <p>"I just wanted him to take ...a responsibility and look after himself. I know people with depression and mental disorders need help from others and support from others but to just completely blame all your problems on someone and not take any responsibility yourself, you know, I thought that was just horrible and, ah, I always wish that he would have taken responsibility and done things himself, you know, 'cos he is a grown up."</p>
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b. Losing Childhood

Emma	<p>"looking back, I would say, you know, I played a lot less than other kids. Umm, and I certainly played a lot less with other kids, because my mum was so worried about what they would say to their parents, what their parents would say to them."</p> <p>"looking back, I can see there were a lot of things that I didn't have the opportunity to do, umm, that other children did."</p> <p>"Umm, sleepovers, umm, having friends round for dinner. Umm, just kind of because of my mum not being able to work, financially things were quite tight. Umm, so where some of my friends would go on holiday, umm, we never really did that. Umm, and also there would be quite large chunks of time, where, umm, we'll be, kind of, like my mum was in hospital, my dad was working, we would spend a lot of time with kind of babysitters or aunts"</p> <p>"I think, umm, I lost the ability to just be a child. Umm, and not have worries and just to play and run around and laugh and finger-paint and all that kind of thing."</p> <p>"I lost kind of, having a mum that could really support you."</p> <p>"I feel like that kind of took away the opportunity to enjoy being a child and developing and learning and growing with everybody else"</p>
Anna	<p>"Yeah I've lost a mum and a dad, like a full mum and a dad, I think I've still got a mum and a dad but I've probably got about a quarter of them, whereas a lot of other people have a full mum and dad"</p>
Laura	<p>"my memories of my father, even though he was about, he hasn't, he hasn't been ill my whole life but I don't have many memories where he wasn't , okay sort of thing. So to me that's all I, all I understood about him sort of thing."</p> <p>"probably only my friends. Um, definitely like I couldn't, I couldn't just go and, you know 'just going to the park', 'okay', it was like I had to come home"</p> <p>"I wouldn't have friends round when I was little, I remember that. I would never have, I always used to go to my friend's house, um, or like parties or anything, I don't remember ever having parties or that when I was little. There was no birthday parties."</p> <p>"I probably lost a childhood like, and like a normal one sort of thing. I don't have many memories of like me playing, you know with friends and family and things like that, and it wasn't, it was always like a drama in our family, it was always, my mum and dad like they used to get in like big, these arguments, and sometimes it would turn physical and things like that"</p> <p>"I wouldn't say it was bad, I'd never say my childhood was terrible. Definitely like there's worse, people out there worse off but, I think it wasn't as good as what it should have been sort of thing. I think yeah that would be what I lost."</p> <p>"I think socially definitely I kind of missed out on that period of time"</p>
Chloe	<p>"so you tend to sort of lose out on a bit of your childhood in some ways because you see things that really you wouldn't want, children to see or hear"</p>

	<p>"Yeah I feel I lost um ... my happy memories that I should have had. [pause 6 seconds]. It's like a you know, it's, there's Pandora's Box of all the horrible things but also that's made me with good things as well. They also unfortunately get locked away in Pandora's Box but there's a lot of them I do not remember."</p> <p>"should just be carefree and you know, being free and. So I feel like I didn't have that, so yeah, I feel like I've lost"</p> <p>"I feel like I lost sort of some of my innocence so to speak, sort of 14, 15 years um, you know with my behaviour. So I feel like I, I lost respect for myself around then so perhaps that's to do with the confidence issue as well now"</p> <p>"it's just not the way to, to bring children up in that sort of environment. It's awful. Um so yeah it's definitely scarred me a lot"</p>
Karen	<p>"I lost my childhood, just in general. There's that, I don't know. There are no photos of us as a family, which I would love, you know. Even with my dad in it, I would love a photo of me and my dad and my mum and my sister, but there are none."</p> <p>"You know I don't want to be normal but I'd like a bit of normality, you know I'd like a bit you know, I'd like to be able to show someone 'oh this is my family, we were happy here' and, but there was never a time when, there's never"</p> <p>"I don't have a single memory of us all being happy together. And it's all, and even if we do have, if there are good memories they're always peppered you know with little bits of sadness of little bits of... just something that only, any other family from my perspective that doesn't have that, you know, and it's, it's sort of different from the inside and watching from the outside but I'd like to have a little bit you know I think normalness"</p>
Serena	<p>"I've lost some ...um ...I don't know if the word innocence is the right word but, for example like my friend says I'm like an old lady, you know, I think I would have been more carefree maybe, and more fun-loving if this hadn't happened"</p> <p>"I missed out on a lot of, um you know, teenage life, fun, 'cos, you know, I avoided going to parties or I couldn't go to parties, um ...I think, you know, I missed having a normal teenage relationship with that boyfriend then, it shouldn't have been that stressful and it probably wouldn't have lasted long if, you know, the whole thing hadn't happened, um, yeah I missed out on probably travelling with my friends, even if it was just to, you know, to London ...to have fun, you know, I missed out on that, yeah, I missed out on, you know teenage experiences a lot 'cos I was always so worried and stressed out about things and ...always being controlled"</p> <p>"I would just shut myself off from people because I just wanted to be alone. So I think I missed out on lots of opportunities"</p>

2. Making sense of the person I have become

a. Developing into a better person while acknowledging vulnerabilities

Emma	<p>"I still find it quite difficult to put myself first, and that's something that has to be a conscious thing that I think about"</p> <p>"I do manage stressful situations better because I've had to"</p> <p>"it gives you, kind of a little bit more strength, a bit more resilience"</p> <p>"It's given me a lot more empathy towards other people, umm, and a lot more patience. So much more patience"</p> <p>"given me more confidence in the long run..., because I know that things can be really difficult, and actually I can get through that, and I can find a way forwards"</p> <p>"I think it's given me a lot of determination, and a sense of, actually if you want something, you damn well go for it. And the worst that happens is that something else comes out of it, that you learn from it, or you develop from it, or, umm, even if you don't get there, you might"</p>
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	<p>realise actually there's something else that you want to do, or that you have skills that would help you get there, but you can use them in a different way or a different place"</p> <p>"I don't think without it that I'd have the kind of direction in my life that I have. I don't think I'd have the drive and the determination."</p> <p>"I guess also it meant it was really hard for me to be assertive for a long, long time. That was something I really had to put effort into learning, umm, and probably didn't really do again until I went away to uni."</p> <p>"there was a focus on looking after yourself and reflective practice, umm, and so there was an element of, actually this is quite good for me, and it's quite self-affirming, and actually it made it easier to keep some of those boundaries and start to understand why I want to put boundaries in certain places"</p> <p>"I feel like, although it was really, really hard, umm, and still has moments when it's hard, umm, mostly I'm really, quite grateful that I had that opportunity to kind of develop and become the person that I am, and a person that I quite like"</p>
Anna	<p>"so it's always knowing how to kind of... what to do to make that successful and functional and make sure that I'm well to be able to be well for that, but, so like what's going to work"</p> <p>"it's made me who I am, that's it really. Like all of that that I've just said; it's made me who I am."</p> <p>"yeah I would say that I've got, I'd say I've got a lot of strength"</p> <p>"that's made me be able to be socially, like adapt, to be able to recognise psychosis, recognise mental health issues, recognise people's needs, have more empathy for people, have more understanding, have more kind of like, um, you know understand someone's complex situation rather than just making a judgement."</p> <p>"I naturally have those abilities now, whereas if I had, if I hadn't have had that then I wouldn't have that understanding. Like people only get angry or upset or, or, get comp... like don't understand the complexity of something because they don't understand"</p> <p>"I'm probably too kind sometimes, I need to be a bit better with that, like in terms of protecting myself."</p> <p>"I would automatically be able to cope with that even though if it was horrific I would be able to cope with something so horrific, and it wouldn't wobble me because I've been so poorly and I've seen my dad be nasty, and I've seen my mum be ill and I was there, like after my grandad committed suicide and then I like helped my mum care for my nan when she had cancer, and then I've been and visited my brother four times in hospital a week, and he's been like dribbling at the mouth or like running around crying, like running around being manic"</p> <p>"I suppose that's one of the skills that I've got out of it as well is that things don't, like I don't, like other people would not be able to cope with that, whereas I can cope with very difficult things, very difficult disclosures and stuff, and it doesn't faze me"</p>
Laura	<p>"I'm not so quick to, to judge people with mental illnesses I don't think at all. Um, one of my best friends she's got depression actually, um, and she's on anti-depressants for it and, like, some of our friends you know they're like 'I don't, I don't understand it like why doesn't she just snap out of it, she doesn't need to take these meds' and you know I'm kind of the one to say 'well she does, it's not something she can just snap out of it it's just, one of those things."</p> <p>"depression runs in genetics, apparently, I've heard. Um, and, you know me and my sister and brother always joke, like it's not funny, but it's going to be one of us 'cause one in three get it [laughter]. Um, but I think, yeah I think emotionally we're all wired a bit differently"</p> <p>"he's very negative [laughter] he's probably the most negative person I've met. Um, yeah, do you know what? Probably, it's probably all the times that I've had to boost him up and you know 'come on it's not that bad, it will be okay, you're just in a bad patch' it's probably all that talking that's made me how I am. Definitely."</p>
Chloe	<p>"I think you know confidence wise, I found that difficult"</p> <p>"obviously as a child it was all kept inside and it was all undercover and secret um, like feeling ashamed but I still have quite a low self-esteem sometimes and I need a lot of like reassurance and confidence"</p>

	<p>“... I think I’ve got a lot of um, I’ve got a lot in there, inside, um there’s a lot in there and I have had, you know I’ve suffered depression and anxiety myself. Um, yeah quite a low self-esteem, um so this is sort of getting older but not older, older, not at my sort of age now.”</p> <p>“So I think that it has actually in the long run made me stronger but it’s also I you know, have a lack of confidence so that is something that not so positive.”</p> <p>“I feel like I have a lack of confidence and I’m a bit insecure and I need lots of reassurance. Er I put myself down a lot. Um I feel I don’t see my full sort of potential”</p> <p>“also made me want to be strong as well and to look after other people, so that nobody else has to suffer like that. So that’s why I want to look after children because I feel I can recognise and I can support them and I think that when you’ve got an understanding, it supports people better.”</p> <p>“it brought me and my bigger sister in later life really close together”</p> <p>“I’m also very loyal, very loyal person um to those who are you know my, my close. I’m also very forgiving as well so I think that is something you know going through all of that business it’s made me very forgiving, I’m also very sort of understanding and tolerant of people as well and I don’t, I try not to judge people. And I always um think there must be a reason behind their behaviour.”</p> <p>“but I think what it has impacted on me is, is that I see the whole person and I’m, I feel that some people are a bit shallow and they overlook things and I’m quite, I see a lot of detail in people, if that makes sense? Um it’s actually made me today, like really, well I’m obviously doing my children’s nursing so that is something that I feel has come from all of my experiences in life. So I’m basically gaining strength. The more, the older I get the more strength I gain from the experiences that I’ve been through”</p> <p>“I’m a lot more determined so I am actually the older I’ve got stronger, it’s actually made me which is quite bizarre really cos you’d think it might be the other way round but actually the older I’m getting, the stronger I’m getting.”</p>
Ellen	<p>“I think it made me more independent. I mean I think that is, perhaps maybe that’s the biggest positive for me. It made me very, very independent.”</p> <p>“it just gave me a different view of, you know that people aren’t all sane and normal, whatever that is”</p> <p>“I think you do accept people more readily when you’ve, you’ve dealt with this”</p> <p>“I’ve probably you know generally I’m a sort of a glass half full sort of person and, and I think I’m lucky in that I feel I’ve had, you know whether that’s an innate thing this resilience, or whether I’ve developed the resilience over time, 'cause I suppose you do, your tolerance for certain things does... well for me I think my tolerance has increased with what I had to deal with with my mother. Maybe some other people it would have been, would have broken them and you know it would have reduced their tolerance”</p> <p>“because of dealing with my mum over the years it, you do see life a bit differently, perhaps more tolerant of certain things in your life or things that happen in your life, you know it gives you a different perspective. So you know in a strange way there’s some positives, it’s not all negative”</p> <p>“I think it does give you a really, really different perspective on life, and not all bad, you know it does make you, in a way it probably makes you more rounded in some ways, although perhaps it warps you in other ways, but in other ways maybe it makes you more rounded 'cause you can see life differently”</p> <p>“last year made me think I’ve not completely reconciled myself with it, but you sort of begin to reconcile yourself and live with it, you have to so, you don’t know any different.”</p>
Karen	<p>“it was me and mum for a long time, and you know she wasn’t necessarily, she wasn’t very healthy and, and um, there were a lot of issues I have I think because of that.”</p>

	<p>"I was also in, so insecure about these people liking me, and um, you know if they didn't talk to me all the time then they didn't like me. So obviously if you're being really clingy and needy in a friendship that really pushes the other person away, so that's what happened."</p> <p>"just massive insecurity. I don't know never knowing where you stand"</p> <p>"I think it's given me the ability to... um, well just be there for people. And I think that's a good thing"</p> <p>"You can always, you know be there too much for someone and they can take advantage of you, which has happened."</p> <p>"I hope anyway I'm able to understand people and the world a little bit better because of it."</p> <p>"I always want to be caring and always be there for people. And I do want to be like that because it's nice to be nice"</p> <p>"Like deeper understanding of the human mind [hint of laughter]. I don't know. I just... I don't know whether it is a good thing to be more emotional."</p> <p>"But I think you have to have, you know a bit of ups and downs, because you only truly understand what happiness is when you have it. And just a more well-rounded person. Make deep and meaningful connections when they arise, you know when, so you know, I know that maybe at the moment I don't have that many really deep connections with anyone, but I haven't given up hope yet. So I hope that you know if you talk to someone about your innermost thoughts and they talk to you about theirs then you can connect, so at least I'm able to do that."</p>
Serena	<p>"definitely I have more anxiety as well, like, to this point I'm still trying to deal with things"</p> <p>"just the whole being on edge back then, you know, when, when 'is he going to lash at me, lash out at me?' and things like that, you know, I was always waiting. I didn't relax. I was always on, on my toes doing something, you know, waiting, scared ...so I think that's still a feature that I have ...um, I find it hard to chill and especially when I go back home I can't relax and we're actually going to move out because the vibe is just ...um ...like we need to start clean because that house has so many bad memories. I can't relax, I can't sleep at home, like I get really, really bad like ...um ...yeah I just get really restless at night, like ...scared and things like that"</p> <p>"I'm still scared that my stepdad's going to like seriously relapse and then, you know, I'm scared he might go even further and maybe, you know, commit suicide, I don't know, um, and that would definitely impact me, and you know, my whole family."</p> <p>"I'm um definitely a stronger person ...I think it helped me cope with stress which is really good 'cos my course is extremely stressful, um, yeah, I've just become a more resilient person I think"</p> <p>"just being a more resilient, patient, person ...um ...yeah ...I think that's it. I'm just a more hardened person, like there's not anything that will upset me or take me down."</p> <p>"well I've been through the most stressful time of my life so now, you know, if I've got someone saying stuff about me, um, if I've got drama in my friend group, like, I'm not even bothered, like this doesn't faze me, I've seen worse. So, you know, it's hardened me up."</p>

b. Still feeling affected

Emma	<p>"in terms of kind of having a family and that kind of side of things, umm, that's much more difficult, because I think you then have to find someone who, as a partner can be understanding of the fact that actually there will be times where my mum does get really quite horrible, and nasty and it can be quite vicious."</p> <p>"So I don't wanna put huge amounts of investment into a relationship with someone who definitely does want children, when I'm kind of leaning towards probably not, and if I do it won't be for a while."</p>
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	<p>"in terms of having children myself, umm, I know absolutely in myself that, because my mum doesn't have those boundaries, and doesn't know what is not okay to say to children, because they will internalise it, umm, I couldn't have children and have them have contact with her. Umm, so at the moment, I'm, is, it's kind of the question of do I not want children ever?"</p>
Anna	<p>"I think what I really lost was support with my education, and support with my choices of career"</p> <p>"I feel like time is against me, because, because everything's been late."</p> <p>"like if I had children now I'd be supportive, there's so many things that I would do for my children, whereas mum just wasn't capable of it at the time."</p> <p>"I would support them into a career that would be um, you know something they were interested in, and give them that knowledge and have those conversations with them. I would make sure that, um, you know that they were helped with their homework and I was interested in their homework. Um, I would say that I would've helped them emotionally, talk about relationships, things like that, talk about drugs and how they're bad for you. Just like all the stuff that you would do, but I think because she was functioning on such a low level it was like she was just coping. So none of those things happened."</p>
Laura	<p>"I'm only going to uni now. I left school with rubbish grades. Um, and I've had to do like an access course and things to get into it, but... yeah I'd probably say if I had, mm, I don't know. I'd probably say if I had, if my, yeah if, if everything was a normal household my mum would've had more time to focus on me and my education. Because 'cause she wasn't that home a lot it was like things got slipped, like work, um, like my homework slipped and my grades slipped, and 'cause my mum was busy you know trying to earn money and whatever she didn't have that focus on any of our education. So I think if everything had been okay she would've been able to focus on that and push us differently, but you don't know do you?"</p> <p>"when they split up that time I think at school, I don't think I was missing school but I don't think I was doing as much work as I, I should have done, I don't think I was concentrating and things. I remember my mum coming into school a couple of times round that period to talk with teachers and things. Um, so yeah, maybe a little bit grade-wise."</p> <p>"I reckon it's probably affected my relationships with men, as cliché as that sounds, [laughter]. Um, I don't, I find the men that I date, my ex had depression. Um, and I was with him for four years. Um, and I think it's that whole caring thing; like I wanna make everyone better. My friends always say it to me, like 'you can't fix everyone' which might be, it's probably true, um, but I do find I do date the kind of men that I have to look after, and I don't know if that's anything to do with it"</p> <p>"it definitely makes me think you know I don't want to put my daughter through that situation. So I think it makes me... not a better parent, but perhaps a more stronger parent than I would have been, because I don't want her to ever rely, like for her to look after me or anything like that, she should rely on me, that's how I kind of view it"</p>
Chloe	<p>"When I was um like junior primary junior school I was like top of the class and I was really good with writing and spelling, reading, um yeah, I was quite bright. And then when I became a teenager, I basically was like 'I'm not doing that' so I just turned up for the GCSEs I wanted to um, it was just like I had no idea of how I was setting myself up for the future you know. I didn't have that and I don't think that was really important either at the time to me cos there was so much else going on around that your education you know, nothing."</p> <p>"I feel that if I hadn't have had to go through all of that then um I probably would have been a lot more settled. I would have done my GCSEs. Um I would have gone to college and completed it. Um I hopefully would have gone to university but instead, I'm now 38 and I'm doing it all now so I've done it all the wrong way round and I feel that it's because it was a very unstable, unsettled environment"</p> <p>"And also you know it's difficult, when people are suffering, the last thing that they think about is 'oh you're doing really well, yes you know go and do that course and' so I didn't have any of that so it's like I was left to my own devices so to speak."</p> <p>"the way I parent my children is a totally, totally different"</p>

	<p>“But with my children, we have a very close relationship. I like to be a stable Mum that is always the same ok. I just want to be the same for them. I don’t want to have highs and lows. I want, we’ll have the highs if they’re good but I just want them to see stability and touch wood, they have turned out to be very, very lovely children and they’re very caring about other people. And they’re sensible and they’re you know they’re confident.”</p> <p>“I don’t want them to, you know be embarrassed and have secrets and we’re all very open with each other. We all talk about anything at all. They would come to me and talk about everything.”</p>
Ellen	<p>“I think it has made me quite an independent soul. So that’s probably carried forward in the way I do my job or, you know the way I live my life, the way I get on with things at home. Um, I have to say I may as well tell you this; I mean at the moment my marriage is breaking up, and um I mean one of the things that’s coming out there is you know I have been quite independent and very, and I’m striving a lot and... that’s affected the relationship”</p> <p>“not soured our relationship, but it, it changed the dynamic in the relationship, and I don’t know whether that’s, I’ve ever really reconciled that throughout my whole relationship with him. Um, and whether I’ve always had this thing that ‘here we go again, I’ve got to be the independent one who’s got to get on and do that’ or whether that’s just me anyway, whether whoever I’d have been with would have been like that. I can be a bit too self-reliant sometimes. I won’t, I don’t want to depend on somebody else. I do worry about needy, dependent people who are quite needy and want to, to be dependent on me. I find I do have a little bit of a thing about that because I think about my mum.”</p> <p>“So I think that’s, yeah and possibly it’s made me a little bit cold at times or a bit too independent, and not, you know, I wouldn’t ask for help or, I tend to just do it myself because that’s how it’s got to be. So it does affect you like that. I think it has affected me like that long-term.”</p> <p>“I think it sort of does stay with you those things”</p> <p>“I just wondered if home had been a bit more stable and there’d been a bit more of a push to... I don’t know, I wonder, but then you know the other side of that is that is that my parents were pretty working class so they didn’t have aspirations for university, not everybody went to university and certainly where I was from nobody went to university. You know, so they didn’t have those aspirations anyway, so there was that, you know it’s not just about the fact that my mum had mental health problems and their relationship was bad and they were very distracted with that.”</p> <p>“it is difficult this not having somebody you could dependent on. It’s um, it did sort of [crying] it stayed with me anyway, whether it stays with other people I don’t know, but for me I think it has, it has a, it has affected me in a way, my life. So I think it’s hard”</p> <p>“when I was growing up, um, that you had to deal with again, and you think you’re sort of on top of it, but it does, every now and then it sort of comes back to haunt you a little bit”</p> <p>“think I can come across as quite confident and, but I think underneath you know I’m probably um, more susceptible than people would think, you know in terms of relationships.”</p> <p>“I just had to distance the family from her because I just thought she can’t do, because they got upset when they realised what had happened, so she can’t do what she’s done to me to them and that that’s just how I saw it.”</p>
Karen	<p>“this wasn’t my first course in university. And, I didn’t get in because I didn’t have good enough grades, and that was a lot because of my own mental health. Um... so I don’t know, and I don’t know there’s always been occasions where I’ve not done something ‘cause I’ve stayed home with my mum, because I wanted to because I didn’t feel safe anywhere else and because I wanted her to be safe so we stayed together.”</p> <p>“I just haven’t gained as much that I could, than I could have. I don’t know maybe that things would be really different if I hadn’t have experienced a lot of the things that I did experience. You know I could be... maybe I could be a doctor or something, like or I could have a better degree, like I failed last year, maybe I wouldn’t have done had I just been a happier person because I had a better childhood. I don’t know”</p>

	<p>"I definitely have issues with relationships now. Um, and had difficulty making friends growing up. Um, and have little kind of like abandonment issues (...) it's difficult to have a level head in any kind of relationship because I don't know I'm a lot like my mum I guess, and I don't know whether it's, I don't know whether it's my own psychological issues or whether it's learned behaviour."</p> <p>"her relationships are very similar to mine. And yeah we're quite clingy and needy. So, and people don't really like that so it does get quite difficult."</p> <p>"I don't know what role, what role you have in life. That's, you know because I struggle with that massively now because I never, I mean I don't, maybe it's 'cause I never understood what role I had in the family. It was always changing you know."</p> <p>"but then also you put other people before yourself and that can be dangerous."</p> <p>"... I would hope I wouldn't be like that with my kids, I wouldn't be, you know I wouldn't treat them like a friend if I, like, you know, especially when they're young you know, I'd be more assertive and have more of a disciplinary role. Because there was none."</p> <p>"You know be more, just consistent I think would be the biggest thing."</p> <p>"I think I... if I do have children I'll be a better mum because of it. Because I know there's lots of things that I would do, but there's things that I wouldn't do."</p>
Serena	<p>"In some ways I don't like it because, you know, my best friend always calls me, "Oh, you're like an old lady", you know, "Live a little", it's like, "I can't help it, this is just who I am", you know, I'm serious, you know I'm not very immature I don't think, I think sometimes that's bad"</p> <p>"I think the whole protective thing, um, is something that I need to be careful of because ...I think that's where it ...you know, in being protective he ended up over going, going over the top and ...you know, ruining things so, I think that's something I need to be aware of, 'cos I am quite, um, a protective person, of friends, of my sister, because, you know, I've seen people out there, they're not nice, and I wouldn't want anything bad to happen to my children. So I will be very protective but I need to really watch out for, you know, boundaries."</p>

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