

Growing up with a parent with mental ill health: making sense of the experience through the reflection of adult offspring

PhD Thesis

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Abstract

This thesis reports a qualitative study undertaken to explore the experiences of adults who grew up with a parent with a severe and enduring mental ill health. It fills a significant gap in the research literature in that it examines an experience that has been previously underexplored. It also provides a lifespan perspective, which gives insight into the impact on the individual and their understanding of their experiences through childhood and into their adult life.

The study uses a biographical method in order to elicit rich narratives from 20 individuals. When analysed through a combination of narrative and thematic methods, these narratives give insight into lived experiences and reveal how perceptions and needs shift throughout childhood and into adulthood.

Participants spoke of a sense of vulnerability, which threaded through the course of their lives influencing, and at times, defining significant points such as going to school, leaving home and becoming a parent. This vulnerability affected their relationships both within their family and with the world around them. Constructing an identity for themselves, participants developed a projected self that appeared competent, compliant and resilient. However, at times, this was built upon a flawed model of understanding and emotion, which is developed here into a model of acquiescence, within which the individual's needs are subjugated in response to others.

Participants did not regret remaining with their ill parent, but were frustrated that while they had been very involved in their parent's illness, their needs had not been considered nor had they been included in the care planning for their parent in a meaningful or genuine manner. Thus, support for children growing up with a parent with mental ill health needs to be readily accessible and responsive to their individual needs throughout not only childhood, but also continuing into adulthood.

Introduction

This exploratory study seeks to develop our understanding of the subjective experiences of adults who grew up with a parent with severe and enduring mental ill health and the impact across the life course into adulthood. Specifically, it will focus on how, as adults, they made sense of their childhood, their family narrative and how it impacted on their own evolving adult identity.

Motivation for the study

The initial interest and motivation for this research came from my years of social work in secondary mental health services. Through my practice it became apparent that although it is generally accepted that a significant number of children grow up with a parent or parents with mental ill health (Abraham and Aldridge, 2010; Cooklin, 2010), my experience was that this was not reflected in any provision within community mental health or acute services. Unless there were clear child protection concerns, little consideration appeared to be given to a 'patient's' family or their associated needs. Occasionally children with a family who had multiple generations accessing mental health services would be discussed with an almost implicit assumption and acceptance of 'we will see you in five years' time'. However this prediction did not trigger any discernible effort to intervene in the child's life or attempt to break the intergenerational cycle of mental distress.

At one point this was sharply contrasted by my experience of working with a woman, a single parent with three children aged between 15 and 26, who was diagnosed with a severe and enduring mental illness. The way that they functioned as a family piqued my interest further. The mother's mental ill health significantly affected her mood, perception and living skills: over the years she had experienced multiple relapses of her illness and periods of crisis that necessitated admission to psychiatric hospital. Nevertheless, her children all appeared to be happy, confident and relatively unaffected. The youngest was doing well at school, the middle child enjoying university and the oldest living independently with a professional job and a family of their own.

As a family they appeared to be very close and supportive of each other. They spoke openly and positively about their mother's mental ill health and associated care needs, while also being very in tune with their own needs and the needs of their siblings. The apparent success of this family in comparison with the almost hopeless projection of the trajectory of others, prompted me to question, why? Why do some children growing up with a parent with mental ill health flourish while others seem to struggle?

Rationale for the study

Significant numbers of children are cared for by parents with mental ill health, which can impact both on their experience of childhood and their formation of adult identities (Darlington, 2005; Mason, 2007). Historically, research has been risk driven, focusing on the detrimental effects of the physical and psychological outcomes for these children. However, many of the previously accepted psychopathological theories of genetic vulnerability and transmission of mental illness are being tempered by a growing understanding of the influence that social and psychological factors have upon our children's development and wellbeing (Garley *et al.*, 1997). Indeed, increasingly studies indicate that psychosocial factors can have a transformative effect on a child's wellbeing (Somers, 2007; Duncan and Browning, 2009). Nevertheless, very few children growing up with parents with severe and enduring mental ill health come to the attention of statutory services or receive the support it is argued that they so critically need (Knutsson-Medin, Edlund and Ramklint, 2007; Slack and Webber, 2007; Mahoney, 2010). Research suggests that there are a multitude of possible reasons for this. From a familial level, the stigma of mental ill health, assumptions of poor parenting and subsequent fear of intervention inhibits both parents and their children from seeking support (Bassett, Lampe and Lloyd, 1999; Cleaver, Unell and Aldgate, 2011). This combines with an institutional lack of awareness of the difficulties that these children face, and the disparate roles and criteria of the services which touch such children's lives (as delivered by teachers, health visitors, and secondary mental health services). They often appear to remain the responsibility of "everyone and no one" (Cooklin, 2010 p143) falling through the gaps and remaining hidden (Aldridge, 2002).

Mental ill health may be as varied as physical illness in terms of its manifestation and impact. The type, duration and severity of the parent's illness influences the impact on the child. Equally the child's age, temperament and intellect are strong factors in determining how the child experiences their parent's illness (Evans and Fowler, 2008). As such, the impact on and needs of the child cannot be measured by parental psychiatric diagnosis alone, but rather needs to be assessed within an understanding of their individual experience. This study is a contribution to that understanding of childhood based on reflections in adulthood.

Prevalence of children growing up with a parent with mental ill health

In terms of justifying why the needs of children living with a parent or parents with mental ill health is a worthwhile area of study, we turn to how many children there are living in such families in the UK. However, there is no clear statistical data collected about these families. The Mental Health Minimum Data Sets, which examine, on a monthly basis, the diagnosis, age, gender, legal status, housing and employment of individual psychiatric patient episodes, do not include whether the patient has dependent children. While this variable was included in the original draft of the dataset design, it was subsequently removed due to professionals being reluctant to record this information as they felt it was not relevant or significant (Howard, 2000).

Given that the Office for National Statistics report that in any one year 1 in 4 British people experience at least one episode of mental illness (Singleton *et al.*, 2001) and in 2012/13 there were nearly 1.6 million (1,590,332) adults in contact with specialist mental health services, of which over 1 million (1,001,002) were under 65 (NHS Digital, 2013), it is reasonable to assume that large numbers of children grow up with a parent with severe and enduring mental ill health. Aldridge and Becker (2003) suggest that between 6000 and 17,000 children in England and Wales will be caring for a parent with severe and enduring mental ill health at any one time. However in their wider research looking at young carers, they have concluded that 170,000 children are caring for a parent with a physical illness, disability or mental ill health, and that about a third of those parents would have mental ill health (Abraham and Aldridge, 2010). This then

raises the number of children affected by a parent with severe and enduring mental ill health to approximately 55,000. Aggregated figures from other studies, which include children not defined as a young carer, increase the estimation further to 1 million (Cooklin, 2010).

The wide spread and level of approximation in these figures is indicative of the lack of knowledge and recognition of the needs of children growing up in these circumstances. The failure of services to recognize and respond to the family needs where a parent has mental ill health may be due to oversight, lack of awareness, or stigma (Howard, 2000; Corrigan, 2004; Cooklin, 2009). Howard (2000) also attributes this to the antiquated assumption that adults with severe and enduring mental ill health, specifically a psychotic disorder, had lower fertility rates compared to the general population. This was largely understood in terms of the biological aspects of the disorder, the use of neuroleptic medication and the gender segregation in long stay hospitals and institutions. This assumption still seems to be present despite the past 25 years of care in the community, the development of atypical antipsychotic drugs which have improved symptoms of disorders and significantly reduced side effects, and changing attitudes which appear to correlate with an increase in adults with mental ill health expressing a desire to have children (Jeffery *et al.*, 2013).

Regardless of the difficulties around identifying the numbers of children growing up with a parent or parents with severe and enduring mental ill health, it is universally agreed that the numbers of this 'hidden' population are significant (Aldridge and Becker, 2003; Cooklin, 2010). Furthermore, the need to understand the impact upon these children through to adulthood is accepted as a matter of social and theoretical significance (Creswell and Brereton, 2000).

Policy initiatives to support children growing up with a parent with mental ill health

There are a range of policy and legislative directives across health and social care which should be applicable to the needs of children growing up with a parent with mental ill health. A key piece of mental health policy published under the Coalition Government was No Health without Mental Health (Department of Health, 2011)

which pledged amongst other things to equip professionals to identify and help parents, children and young people who required support with their emotional or mental health, by increasing the workforce and reviewing the models of service for both health visitors and school nursing. This included funding early intervention and preventative services for children, young people and their families. This funding was allocated for programmes which sought to target mental health support for vulnerable children and their families, such as the Targeted Mental Health in Schools programme. However these primarily attended to the needs for children with clinically recognised mental health problems themselves (Department of Education, 2011). This focus and commitment to improve support for children's mental health was reiterated by the current government's commitment to transform mental health services for young people by training teachers to identify and respond to early signs of mental health problems amongst pupils (Prime Ministers Office, 2017).

Again, No Health without Mental Health recognised that despite often having detailed knowledge of their parent's mental health needs, children growing up with a parent with mental ill health are generally not acknowledged or supported. It sets out a commitment to support children to identify themselves as a carer at an early age, and access the subsequent support they require. This was reiterated in the political priorities stated in the coalition government's discussion paper, Closing the Gap (Department of Health, 2014), which identified the needs of young carers along with 24 other targets of mental health care as being areas within which the public could expect to see significant improvement in service provision over the next two years. The government promised simplified carers' assessments for children and to involve them more in the way their parent's mental health services are planned and delivered. However, with the change in government in 2015 these political priorities appear to have lost their impetus. Despite the changes within parliament and the impact this can have on policy and guidance, there remains a legislative framework which makes the assessment of need for vulnerable children a statutory duty regardless of the incumbent government.

Young carers are defined as children under 18 who provide care, support and assistance to another family member. They carry out, often on a regular basis,

substantial and significant care tasks and assume a level of responsibility that would usually be associated with an adult (Aldridge and Becker, 2003). However, working within a whole family approach, the needs of children growing up with a parent with mental ill health should be considered even if they have not been explicitly identified as carers (Social Care Institute for Excellence, 2012). This is enshrined within their rights to an assessment of need in the Children Act 1989 (s17) and the Children and Families Act 2014. Local authorities have a duty to assess the needs of young carers 'on the appearance of need' regardless as to whether or not the child identifies as a young carer or if a request has been made. This assessment will look at the appropriateness of the care that the child provides, including the impact it has on their education, training, work and recreational activities and whether the child wishes to continue to care. If eligible needs are identified, the local authority can provide direct support for the child, or additional support to the parent with the intention of reducing the child's caring responsibility. The Care Act 2014 takes this further in including young carers in the duty for a local authority to carry out a transition assessment. This assessment includes a consideration of the young carer's current needs, what they are likely to need when they have turned 18 and the outcomes, desires and goals they want achieve in life. As such these assessments attempt to not only attend to the physical need but also the future aspirations and identity of a young person providing care. However, there is some discretion within provision, as local authorities are only required to carry out these assessments if it is likely that young carer will continue to have needs once they have turned 18, and if there is 'significant benefit' to the young carer of an assessment being made.

The gap in recognition of the needs of young carers became apparent through the Triangle of Care programme, which was developed to promote better collaboration and partnership between carers and mental health services. The research underpinning this programme found that many frontline staff were unaware who young carers were and what specific needs they had (Harwood *et al.*, 2013). Consequently supplementary guidance to the programme was published specifically identifying that young carers of a parent with mental ill health were under recognised and under supported through their caring journey (Mitchell and Hannan, 2015). This

lack of recognition and professional awareness was also evidenced in the Carers Trust review of the Care Act 2014 and its impact on carers. This clearly demonstrated that few carers had noticed a difference since the implementation of the Care Act 2014 and that very few young carers or frontline staff were aware of their right to a transition assessment (Carers Trust, 2016). This would indicate a significant lack of awareness of the care tasks and needs of children growing up with a parent with mental ill health, since an assessment should be offered on the appearance of need.

Children growing up with a parent with mental ill health also fall under the remit of the local authorities' duty towards children in need. The need for early help is defined in Working Together to Safeguard Children guidance which specifically includes young carers and a child whose family circumstances present challenges for the child, such as adult mental health problems (H M Government, 2015). This policy asserts that s11 Children Act 2004 places a duty on a range of organisations, including adult social care and NHS trusts, to ensure their functions and services are discharged in a manner which has regard for the need to safeguard and promote the welfare of children (HM Government, 2015). Many children growing up with a parent with mental ill health are also eligible for support within the Troubled Families Programme if they are also affected by worklessness, financial exclusion or poor school attendance (Department for Communities and Local Government, 2016b). This programme, which seeks to improve the outcomes for families with multiple problems by promoting a greater understanding and resourcing for whole family working and creating strong cross-service local delivery, and has been extended until 2020 (Department for Communities and Local Government, 2016a)

Drawing from both adult and children's social care services, the Social Care Institute for Excellence review of support available for disabled parents held the need for joined up working as key to meeting the needs of supporting disabled parents and their children (Morris and Wates, 2006). However, it also raised concerns regarding the differences between adult and child policy frameworks, which do not facilitate appropriate responses from those delivering and commissioning services. They argued that:

- Adult policy and legislation does not place parenting roles as central issue
- The drive to improve inter-agency relationships in adult social care have not included supporting disabled parents with their parental responsibilities
- The concern by previous generations of policy makers regarding the siloed nature of child and adult services have never fully been attended to and often falls from the agenda of political discourse.

Simultaneously, within children's policy and legislation:

- There is a limited understanding of the needs of disabled parents
- There is a patchy recognition of the need for adult and children's services to work together
- The importance of interagency relationships as promoted in Every Child Matters framework focuses on links between children's services in health, education and social care with very little reference to the role adult services can play within the whole family (HM Government, 2004).

Lack of knowledge and understanding of different needs, roles and responsibilities also creates a tension between adult and children's services. In the last decade, attempts have been made to address this through the development of disabled parent protocols, which have been jointly commissioned and implemented between adult and children services. These protocols have called for a range of service commitments, such as: the appointments of specialist liaison staff to bridge the gap between services, an increased recognition of parental needs within adult services and an increased understanding of disability from Children's services when making judgements regarding parental capacity. Additional support should be provided to families through the adjustment of eligibility criteria which would enable both adult and children's services to respond to lower levels of assessed need and also the joint commissioning of flexible and ongoing care which would anticipate the potential changes in need in relation to both illness and family circumstances (Morris and Wates, 2006). However despite the clear findings in Morris and Wates (2006) review, the same issues have hindered Think Child, Think Parent, Think Family (Social Exclusion Task Force, 2007)

and the Troubled Families initiative a decade later (Tew *et al.*, 2015; Department for Communities and Local Government, 2016b)

While I am sure, there would be little argument against the sentiments of the disabled parents' protocol or the commitments made within the raft of government policy and guidance, it would seem in the milieu of competing political discourses, austerity and the reduction of resources within both health and social care that the needs of children growing up with a parent with mental ill health have once again slipped off the table and indeed through the gap of service provision. This is evidenced in the Children's Commissioner's report on measuring the number of vulnerable children in England. Defining vulnerability as ranging between 'disadvantaged children who would benefit from extra help from public agencies in order to make the best of their life chances to children with complex needs or living below the poverty line' (Children's Commissioner, 2017: 1), the report asserts that vulnerable children growing up with a parent with mental ill health remain 'invisible' because they are: not known to services, not recorded as being in need within relevant authorities, are under researched and attracted little specific policy or media interest (Children's Commissioner, 2017). This means that their needs remain hidden and their voices and concerns silenced. It is also important to recognise that children growing up with a parent with mental ill health may face overlapping vulnerabilities, and while their parent's ill health may represent a risk factor for the child's welfare, arguably it is the co-existence of other factors such as poverty, poor housing and social isolation that amounts to a significant risk (Morris and Wates, 2006).

Research pertaining to children growing up with a parent with mental ill health

In the emergence of this field as an area of interest, the majority of research undertaken in the area of parental mental ill health focuses on the parents' needs and experiences (Bassett, Lampe and Lloyd, 1999; Nicholson *et al.*, 1999; Mowbray *et al.*, 2000; Jeffery *et al.*, 2013). The relatively small number of studies that discuss the children themselves focus more on quantifiable outcomes. This is considered either during childhood, in terms of child protection, child development and educational

achievement; or as reflected in their adult lives in terms of mental health, romantic relationships and socioeconomic status (Mowbray and Mowbray, 2006; Roberts *et al.*, 2008; Social Care Institute for Excellence, 2011). When discussing the impact on and needs of children, the weight of the research is still tipped towards the perspective of parents and professionals.

Almost all studies are gender biased, examining maternal responsibility and/or deficits (Aldridge, 2006), and focusing upon a specific diagnosis, such as bipolar affective disorder (Hollingsworth, 2004; Mowbray and Mowbray, 2006; Wilson and Crowe, 2009) schizophrenia (Somers, 2007; Duncan and Browning, 2009; Liu, Chen and Loh, 2010) or personality disorder (Dutton, Denny-Keys and Sells, 2011; Elliot *et al.*, 2014). Recognizing the paucity of empirical studies examining the experiences of children with a parent with mental ill health, Garley *et al.* (1997) bucked the trend by devising a series of focus groups each attended by six children aged 11-15. This emphasis on the children's perspective has been pursued within several studies over the past decade (Aldridge, 2006; Mordoch and Hall, 2008; Ireland and Pakenham, 2010; Trondsen, 2012; Zeighami, Oskouie and Joolaei, 2014). These studies are immensely valuable, providing a snapshot into individual children's experience and conceptual understanding. The first work seeking to engage with the child's perspective in depth, originating from the UK was undertaken by Jo Aldridge, Saul Becker and Chris Dearden in a two year study conducted by the Young Carers Research Group. This study collected data from parents, professionals and children who were selected from young carers projects (Aldridge and Becker, 2003).

Other researchers (Polkki, Ervast and Huupponen, 2005; Duncan and Browning, 2009; Ireland and Pakenham, 2010; Abraham and Stein, 2013; Zeighami, Oskouie and Joolaei, 2014) have also attempted to elicit a sense of the overall childhood experience by including adult offspring of parents with mental ill health in their studies. Key themes to come out of these studies include associated stigma, fear of separation, parentification and a lack of understanding of their parent's ill health and what that means for the child. This lack of understanding breaks down into three further areas: self-blame for the parent's ill health, fear of developing the illness themselves and feeling excluded from the discussion about the ill health and care plan.

With the development of this field, increasing consideration is being given to the crucial need of children to be able to understand and make sense of their parent's mental ill health (Cooklin, 2010). This is reflected in Alan Cooklin's work with the Kids Time foundation and has been demonstrated by the Australian program COPMI (Children of Parents with a Mental Illness). It has been suggested that it is not only an individual's actual experiences that are key, but the way in which they subjectively understand and make sense of them that is of importance (Emde, 1994). Currently there is very little that examines this particular area, especially from the perspective of adult offspring who can reflect on the biographical narrative and development of their understanding and experience. This study will seek to address that gap by asking adult offspring to reflect on childhood, and to recall their memories of the experience. How the individuals made sense of their parents' mental ill health, both as children and now as adults, will be sought and along with that, how they feel it has impacted on the development of their adult identity.

Choice of terminology

There are a vast array of models and conceptualisations of mental ill health, each with its own related terminology such as mental health problem, mental disorder, mental illness and mental distress. The manner in which these terms are understood and defined is shaped by contemporary discourse, geography, professional discipline and personal perspective (Glasby and Tew, 2015). While different terms are, at times, used interchangeably they are in essence derived from very different philosophical, theoretical and ideological perspectives (Coppock and Dunn, 2010) with each carrying subtle (at times unconscious) but powerful values and assumptions with them.

The way that language is used is crucial, in that it describes the concepts that structure our thinking and feelings (Cromby, Harper and Reavey, 2013). However there is a tendency for both lay people and professionals to subliminally align themselves with a specific lexicon (Glasby and Tew, 2015). Without consideration of the power of language, this alignment could unwittingly carry the risk of becoming oppressive. For example, a myopic focus on the dominant medically informed terminology of mental illness, psychopathy and disorder could imply a single conceptual model of understanding (causation and treatment) without acknowledging the inevitable

synthesis of other psychological or social factors inherent within the lived experience of mental ill health.

Language is also important to the individuals to whom it is applied (Cromby, Harper and Reavey, 2013). Often their experiences and identities are shaped by the assumptions, stigma and discrimination which is associated with language and labels. This insidious stigma is particularly pertinent for parents who have mental ill health and will be discussed further in chapter two.

The parents of the participants in this study would have been identified as having had a 'severe and enduring mental illness' using the criteria for secondary mental health services as discussed in chapter five. However the participant's narratives related to their parents in terms of psychological health, emotional responses, relational issues and general functioning as well as their 'mental illness'. While mental illness was the dominant term participants used this could have been indicative of an acceptance of the framework of language they were presented with by either the secondary mental health services that supported their parents, or the principal social representation they were exposed to throughout their childhood.

As this study does not attempt to define or cast light on each parent's experience, but rather explore the child's own understanding through personal narrative and experience, I felt strongly that I should remain as close to the language used by the participants as possible. However I also wanted to reflect the impact that the response to psychological stress and social adversity had upon the experience and narrative.

With this in mind I have chosen to use the term mental ill health within this thesis. This represents the severe and enduring nature of the difficulties that were manifest within the parent's behaviour and the subsequent impact that the associated childhood experiences had upon the child through their life course. My choice of this term does not diminish the validity of other perspectives or associated terms, but rather reflects as closely as possible both the participants' own representation of their parents' difficulties and the ideological framework which underpins this study.

Throughout the study I also generally refer to parent in the singular. This does not indicate gender unless specifically identified as mother or father. I also recognise that

many children grow up with both parents identified as having mental ill health. The difference between having one or two parents with mental ill health is not distinguished within the existing literature.

Structure of the thesis

This thesis will be structured into four parts: the first part consisting of four chapters will be made up of a comprehensive review of the literature. The second part of the thesis will attend to the details of the methodology and research experience. The third part will explore the findings of the study and draw upon the knowledge within part one. Finally the fourth part will discuss the relevance of the study's findings, highlighting the contribution to knowledge and the implications for policy and practice.

Part 1 - Literature review

This section of the thesis will attend to the existing body of literature relating to parental mental ill health, focusing on recent specialist work which examines the experiences and needs of the children who grow up with a parent with mental ill health from their own perspective. In order to begin to build an analytical framework which will enable me to make sense of the manner in which children growing up with a parent with mental ill health make sense of, cope with and are affected by their experience, I will then explore wider concepts. These include the contextual understanding and importance of family, mental ill health, stigma and parenting. How children adapt to adversity and develop resilience will be discussed before finally reflecting on how individuals make sense of their experiences and the influence this has upon their formation of identity.

Key sources drawn upon throughout this review include both empirical studies and theory from the UK and the wider international academic network.

Part 2 - Methodology

Moving on to the study, the epistemological foundation and methodological approach will be discussed. The research process is broken down into three sections: recruitment, interviews and analysis. Each stage of the process, the decisions made, difficulties faced and skills developed, are discussed in detail. I also found the experience of researching such a sensitive subject and the ethical considerations

inherent in the practice extremely poignant and as such I have reflected on this both in terms of what it meant to the participants within the research and to myself.

Part 3 - Findings

The narratives that inform the findings of this study are as powerful as they are complex and rich. In order to present them in a manner that is coherent I have structured the findings into themes which, where possible, mirror the way that the literature review was arranged. Beginning with a broad exploration of the context of the participants' family and circumstances of childhood, the focus then narrows to consider how the participants felt about their relationship with their parent and the manner in which they were able to make sense of and cope with their parent's mental ill health. The findings then focus onto the participants' own sense of identity and the impact they feel their parents' mental ill health may have had upon them as an adult. Finally, the interaction the participants had with statutory services as children will be discussed.

Part 4 - Discussion and Recommendations

In the discussion chapter the findings will be integrated with key issues from the literature review and my own social work practice to enrich our understanding and analysis of the experiences of children growing up with a parent with mental ill health. This is then located in the wider field of practice and policy. The model of acquiescence developed within this study will be reflected on with particular reference to vulnerability, resilience and the impact that parental mental ill health continues to have upon the participants adult lives. The original contribution to knowledge will be highlighted and reflected upon. Finally this work will be drawn to a conclusion and recommendations for future social work practice and research will be made.

Review of the Literature

Approach to the Literature Review

This study primarily seeks to explore adults' subjective experience of (children) growing up with a parent with mental ill health, asking questions about how they made sense of their parent's mental ill health, how they coped with it throughout their childhood and how they feel it continues to impact upon them as adults.

To date there are relatively few studies addressing children's experiences and perception of parental mental ill health within the UK. As such I intend to use the literature review to locate my study within the wider international body of knowledge and also within the context of wider issues such as family, mental ill health, stress and identity. The decision to include these specific areas was made through a combination of my own professional experience of working with parental mental ill health, my initial reading of research within this field and themes which began to emerge from the initial data collection and analysis of the study.

Chapter one situates the experience of growing up with a parent with mental ill health in the socio-cultural understanding of what family, parenting and mental ill health is. Within this context we explore the gendered construction of family relationships, the multi-dimensional impact of stigma and the effect of mental ill health on the family system. We look at the identities and roles of carers, specifically with regard to young carers, and finally the bearing that mental ill health may have upon parenting roles and responsibilities is considered.

Chapter two presents the findings from a review of the literature related to parental mental ill health. Using a traditional literature review method allowed for a flexible exploration of ideas in the field (Jesson, Matheson and Lacey, 2011). The specific design of this section of the literature review was that of a scoping review, which seeks to document what is known and critically analyse where the gaps in the knowledge may be. The ability to focus the literature review is key in the research area as preliminary reading showed that there were two distinct bodies of research.

The first wider body spoke of aspects of parental mental ill health and its impact on the parents, families and children. This was generally based around data drawn from

the perspectives of parents and professionals. The second, smaller but significant collection of studies which specifically attend to the experiences of children growing up with a parent with mental ill health had been emerging over the past 10 years. This second collection of studies have attempted to address the research gap by speaking to the children themselves about their subjective experiences.

In order to focus the review of the literature further I filtered the search using a structured approach to searching databases (Jesson, Matheson and Lacey, 2011). This enabled me to identify the qualitative studies which specifically gave voice to the child's experience, either through contemporary or reflected accounts. I was interested to see if there were similarities or differences between them and the secondary accounts drawn from parents and professionals discussed earlier and in doing so confirm or contest its strengths and validity.

The databases searched included ASSIA, Web of Science and Psych Info using the search teams 'parental mental illness' and 'children's experiences'. These were refined to peer reviewed articles published since 2000 and written in English. Of these searches 112 articles were selected which appeared to be written reflecting the child's perspective. These were then combined with articles, which had been found using the University of East Anglia Library search and Google scholar. Of these articles duplicates were removed reducing the total to 88 papers. These were then examined in detail and studies that directly interviewed children or adult off spring about their experiences were selected, this totalled 28 papers.

Given children's experiences in a field is in its relative infancy it is necessary to examine both bodies of research to gain a rounded understanding of the field as a whole. This enabled me to consider the impact that the differing perspectives of professionals, parents and children may have had on research findings. As such this first chapter seeks to explore the overview of the literature before looking closer at the themes of the specific studies drawn from the child's perspective.

Chapter three turns its gaze upon the specific experiences of children reacting and responding to their parent's mental ill health. Taking inference from both the literature and emerging findings, many of the most striking reported experiences are

imbued with a significant level of stress and/or trauma. Parallels can be drawn with research reflecting a growing understanding of the experience of children growing up with domestic violence, which is increasingly recognised as a form of emotional abuse. Parental mental ill health could also, under specific circumstances, present the same connotations of powerlessness, isolation and harm. Therefore, with the aim of identifying the manner in which children make sense and cope with their parents mental ill health, this chapter will seek to clarify and critique certain theories of stress, trauma, coping and resilience which most resonated with the emergent themes of both the literature and findings.

In order to make sense of the impact parental mental ill health has across the life course, the development and function of identity is examined in chapter four. Models of identity formation are discussed before examining the interplay between the child's narratives and that of their parents. Finally, the use of narrative and autobiographical memory are demonstrated as illustrative of how adults continue to strive to make sense of their childhood experiences of parental mental ill health.

Chapter One

Context of family and mental ill health

Introduction

In this chapter I will attempt to place the study within the ideological contexts of both family and mental ill health. The importance of understanding the family is born from the fact that this is the primary context in which a child experiences the world around them, develops relationships and builds a sense of understanding and identity.

However, exploring the experience of mental ill health is also required as the childhoods of the participants in my study have also been greatly influenced by parental mental ill health, shaping the family system and colouring the way they were able to make sense of their experiences, relationships and selves.

What is a family?

In western society in particular, the family is often seen as a universal institution, one which we take for granted while at the same time hold as deeply personal and unique (Scott, 2007). Therefore to understand the experience of childhood, the experiences and agency of the child must be examined within the dynamic processes, functions and relationships of their family.

Families are complex and dynamic, they can be experienced and defined in a multitude of ways, yet all provide the intrinsic frame through which we both engage in society and maintain social institutions (Cheal, 2002; McKie, Cunningham-Burley and McKendrick, 2005). Accepted as a social construct both rooted in history and culture (Scott, 2007), the understanding of family shifts with the broadening of definitions and complexity of modern life. In response, contemporary sociological definitions move away from the traditional classification of structure of the family towards a more

nuanced functional view of what it does. Cheal (2002) describes the core functions of a family as: sharing of resources, caring, responsibilities and obligations and the maintenance of a member's wellbeing through love. However, not all families function well, indeed some families are dysfunctional and the insular nature of the family can make this hard to see. Feminist critics argue that families do not function equitably between all family members (Fox, 2015), an argument which will be considered further in regard to the gendered nature of parenting roles.

A conceptual model of family drawn from systems theory is particularly relevant for this study (Bronfenbrenner, 2005; Tew, 2011). Within this model family consists of a web of interactive relationships, varying in importance, formality and permanence, but all sensitive to internal and external stresses. These relationships define the terms of family expectation and the shape of the role that each member plays. They develop a shared narrative giving a collective identity of how the family interacts with the wider world and also the level of status and internal positioning that each family member occupies. This is reinforced by the implicit family rules which can be either imposed, negotiated or may simply emerge through experience and tradition. However, the family system is also part of the wider social system and as such is located within broader cultural and social constructs of role expectations, power hierarchies, divisions and inequalities that could be fashioned around age, gender and disability. The organisation of the 'family system' generally works in enabling members to access support, resources, emotional connectedness and belonging with other family members, all of which is underpinned by a sense of mutual obligation, co-operation and protection. One of the traditionally pivotal roles with the family system is that of the parent, of which the relational bond and boundaries are of particular significance for this study.

Why are parents important?

As with family, parenting is socially constructed, with the expectation and value placed upon it dependant as much on subjective impressions (historical and cultural context and socio-political thresholds), as objective qualities. The term parent can itself cause confusion as it can be used in a range of spheres or to describe a host of individuals, including: biological parent, stepparent or grandparent. Whilst the bias of

contemporary research leans towards maternal (and to a lesser extent, paternal) biological parents, this is not always the case. It is important to appreciate that the emotional element to parenting is not reliant on biology, as this element is borne from the interpersonal history of the parent and child as opposed to their genetic history. Banton et al. (2000) considered this further in proposing that the notion of family life had shifted and it is now contemporarily characterized through change, diversity and uncertainty. Family systems are smaller, mothers older and single parent or blended families more prevalent (Waldfogel, 2006).

Jones (2001) put forward that this crucial emotional element to parenting could be defined as a set of behaviours and activities that primary caretakers have to fulfil in order to enable children to develop into autonomous adults. This benchmark is predominately representative of western cultures (Montgomery, 2013), and the behaviours and activities that Jones (2001) made reference to can be seen identified as core elements (Hoghughi, 1997):

- Care - meeting the physical, emotional, social and developmental needs of the child whilst also protecting them from avoidable illness, trauma, harm or abuse.
- Control – the setting and maintenance of appropriate boundaries.
- Development - the appreciation of a child's potential and the provision of appropriate encouragement and support.

In order to fulfil these core elements Hoghughi (1997) proposed that parents needed:

- Knowledge – an understanding how to meet the care needs of the child, to recognise potential and manage risk.
- Motivation – a desire to protect and place the child's needs above your own,
- Resources – both materially and personally
- Opportunity – having time and access with the child.

Another key component is that of the parent-child relationship, its interconnections, overlaps and boundaries. This relationship has a particular symbolic resonance as it is portrayed as one of the few social bonds which is permanent and carries a weight of obligation. Other relationships may shift in terms of their importance and obligation,

but generally a parent is always the parent and a child, forever their child. While the primacy of relationship is at its height while the child is young enough to be physically and financially dependent on their parent. The relational bond often remains significant even for non-resident or estranged parents and children. The boundary between parent and child is balanced upon the dimension of parental demandingness and responsiveness which can be classified into four parental styles; authoritative, authoritarian, permissive and rejecting/neglecting (Scott, 2007; Baumrind, Larzelere and Owens, 2010). However difficulties such as parental mental ill health can place a great deal of stress and transgressive forces across the boundaries, styles and capabilities of parents, which can cause their relationship with their children to become maladaptive and brittle (Bancroft *et al.*, 2005) and have significant impact on the attachment patterns developed.

Attachment bonds between parent and child

An understanding of the significance and influence of attachment theory is crucial in considering the importance of the parent/child relationship for an individual's psychological wellbeing. Examining the nature of the instinctive, powerful and enduring bond between parent and child, attachment theory begins from the stance that human infants cannot survive without care and protection. Bowlby proposed a biological basis to the affectional bond between infant and parent as such, evolutionary selected 'hard wired' dispositions that compel adults and infants to relate to each other in a predetermined way (Bowlby, 1988). Parents are programmed to engage in protective behaviours whereas infants are predisposed to behave in a manner that will elicit proximity and care (Duncan and Browning, 2009). However as a theory, attachment develops our understanding further to conceptualise how attachment relationships are fundamental in constructing how an individual make sense of themselves, and the social world around them.

The concept of attachment involves social, emotional, cognitive and behavioural components. The nature and manner in which they interrelate, changes to a certain extent over the life course with development and maturity. In terms of social relationships, attachment represents an individual's emotional ties to another and the mental representation they hold of that relationship and their role within it (Duncan

and Browning, 2009). Bowlby described this mental representation as the individual's 'working model'. As the child develops into adulthood it is this cognitive component of attachment and the internal working model that is key. He held that these working models served a very important purpose, namely, to help the individual organise experience, interpret and anticipate others behaviours, while also influencing memory, expectations, and their own response to subsequent social interactions (Waters and Waters, 2006; Huth-Bocks *et al.*, 2014). Bowlby used the term working model because it emphasised the dynamic and functional aspects of internal representations across the life course, however he also provided a counterbalance to this in suggesting that some aspects of the working model were subconscious and as such especially resistant to change.

The understanding of mental representation has advanced markedly since Bowlby's initial work, enabling us to be more specific about how attachment related representations evolve, interact, and influence an individual's mental well-being. The development of the Adult Attachment Interview was a watershed moment in attachment studies (Waters and Waters, 2006) which until then had focused exclusively on infancy. The Adult Attachment Interview offers a means of assessing differences in individual's conceptualisations of their early relationships with their parents, thus enabling the hypothesis about the importance of early experience for later relationships to be tested. It also facilitated research on adult attachment and its links to personality and parenting (Waters and Waters 2006).

Such detailed regard to adult attachment representations and their secure base experience can be seen in the development of Waters and Waters (2006) concept of a secure base script. The secure base script determines what we expect to happen within our relationships with others and what we perceive to be an appropriate response to a specific situation. Within their introduction of the secure base script Waters and Waters (2006) draw on Bowlby, Ainsworth and several generations of observational research focused on secure base behaviour. This concept asserts that a history of effective and reliable secure base support underpins the expectation that your primary caregiver (or relationship) will always be there for you, and that they will be powerful enough and competent enough to keep you safe and restore balance to

any emotional turmoil. Equally you will have a level of confidence and trust within your relationships and your own self-worth to be able to explore and develop outside of the confines of the relationship. For a parent who has not benefited from a secure attachment and a secure base themselves as a child, it is clear to see that they may struggle with both the lack of secure base script with which to base their own expectations and behaviour and a lack of confidence or trust in themselves to be able to provide a secure base for their own children.

While Bowlby's was not the only, or indeed the first theory of attachment (Bretherton, 1992; Barrett, 2006), it has become so widely recognised that it is often discussed as if no other similar theory exists. This said it has stood the test of time remarkably well. Current neurological studies confirm both the positive impact of sensitive parenting and the negative impact of insensitivity, abuse or neglect in terms of brain growth and development of neurological pathways (Howe, 2011). Indeed these studies give credence to the correlation Bowlby saw between dysfunctional families and the often pathological effect it could have on the personality development of the child (Marrone, 1998). However, consideration should also be given to the social enforcement of attachment in a culture's understanding of the parental role, function and status. In examining the power of such socially constructed and constricted roles, a question is raised about how the experience of motherhood or fatherhood it might differ for a parent with mental ill health who may already feel excluded and outside of these normative roles and expectations. If they are unable to engage with rituals and institutions that support these roles, such as baby groups and the school community, how does this affect their capacity to offer a secure base to their children?

Indeed in some academic dialogues Bowlby's theory it been criticised for the perceived responsibility and subsequent blame it places on parents, especially mothers for failing to create secure attachments (Harris, 1998). Sue Gerhardt (2004) attempted to temper this with her work 'Why Love Matters', where she diffused the responsibility afforded to parents by stressing that the care they give to their children is influenced by the care they themselves received as children. In their exploration on the attachment patterns of parents with mental ill health, Jeske et al (2011) also found that the adult attachment styles and working models of the parents affected how they

perceived the quality of life of their children. The results suggest that parents with mental ill health have a tendency to rate their children's quality of life lower than healthy parents. Whereas those with a secure attachment pattern, were more positive about their children's quality of life, and this appeared to correlate to their own perceptions of family functioning, personal self-worth and their willingness to involve and accept support.

At the heart of attachment theory and key to understanding the impact of caregiving by a parent with mental ill health on a child's sense of security is to understand how a child's anxiety is experienced and managed (Howe, 2011). If a child is supported by the other parent or by grandparents or in some cases older brothers or sisters to feel that there is a secure base for exploration available to them during periods when a parent (father or mother) is unwell, then it is possible for them to develop a secure internal working model. A supportive teacher can also help a child to manage anxiety and feel more confident and competent. However, if a child does not have a secure base caregiver available to them and is left not only with the normal anxieties of childhood but with perhaps additional anxieties about the well-being of their parent then they can become overwhelmed and may develop insecure attachment patterns / working models that make it more difficult for them to function happily and successfully in their peer group and at school.

The primacy of motherhood

The modern ideology of the "good mother" emerged in the nineteenth century placing mothers in the central role of preparing a child for success as an adult. With the rising popularity of Freud in the twentieth century, women were no longer only responsible for the physical health and good behaviour of their children, but also their emotional and psychological wellbeing (Fox, 2015). With the hegemonic neoliberalist political theory of the late twentieth century which emphasised the individual responsibility and private sphere of the family, more weight was placed on the shoulders of mothers for meeting the needs of their children and giving them a good footing towards a successful adult life (Fox, 2015).

One of the key theories emphasising the imperative for a responsive and robust parent and child bond came from the psychoanalyst Donald Winnicott. Whether it was the intention of Winnicott or his contemporary John Bowlby, the concern of the psychological fallibility of parents and the impact this had upon children was focused almost exclusively on the maternal relationship and continued to be so until the mid-1980s (Aldridge and Becker, 2003). This early developmental research (which was predominately conducted by white, middle class men) placed mothers at the heart of domestic duties and child rearing, and their mental ill health was considered within the context of failure of role and duty. This research which judged the domestic breakdown and any harm to the children as attributable to the inadequacy or deviance of the mother, neglected to consider either the father's role or the social issues such as poverty and available support.

This critical analysis of the function of parenting is often encapsulated within the concept of the 'good enough mother' (Duncan and Reder, 2000; Taylor *et al.*, 2009). Winnicott made detailed observations of the day to day interactions between infants and their parents, predominately their mothers. From these studies he concluded that the main tenet of successful parenting was that of adaptation. The ability to emotionally tune in to the child and to interpret their needs without imposing your own emotional agenda is core (Caldwell and Joyce, 2012).

I chose Winnicott's 'good enough' parenting as an illustrative theory because he went on to explore the potential impact of parental psychological frailty and the subsequent effects for the child. He proposed that to prematurely enforce psychological standards and expectations, such as demanding the child be compliant, stifles their psychological development. This can create a false self, within which the child's energy is directed towards demonstrating a persona which is outwardly compliant while internally suppressing their own emotions. This inhibits the child's capacity to develop into truly good and well-rounded adults (DeRobertis, 2010). Winnicott was extremely concerned that if the tuning in process was reversed, so that the child was forced to tune in to the parent, the ongoing persona and psyche of the child could be permanently damaged (Winnicott, 1964). He illustrated this by the concept of the child having to 'manage mother's mood', arguing for example that a child of a depressed mother may feel

compelled to compensate for this by appearing to be perpetually cheerful and not attending to their own melancholic emotions. He strengthened this argument by warning that such children could become the 'walking wounded' as adults, outwardly successful but somewhat empty and detached inside (Winnicott, 1964).

The gendered landscape of care and the emotional labour of parenting

Feminist care ethics emphasise the relational nature of care and challenge the assumption that caring is predominately 'women's work' sacrosanct to the private domain of family life (Barnes, 2012). However care and emotional labour within families continues to remain largely organised along gendered lines (Rina and Feinberg, 2012). Indeed whether a woman becomes a mother or not, motherhood (or its absence) is often central to the way they are defined by others and to their own identity (Phoenix and Woollett, 1991). Feminist perspectives prompt us to consider the influence that sexism and patriarchy have in the way that society constructs the role and expectation of women as mothers, along with the manner in which the prevailing narrative of good mothers often excludes and devalues the experience of mothers from marginalised groups, such as those mothers with mental ill health (Johnson and Yudilevich Espinoza, 2018).

Becoming a mother may be imbued with a heightened level of social esteem, however the socially prescribed expectations of a good mother mean that an individual woman's worth as a mother is measured against an unattainable idealised portrayal of motherhood (Phoenix and Woollett, 1991; Johnson and Yudilevich Espinoza, 2018). This can be made even more unfeasible for mothers with mental ill health who are often expected to fulfil their mothering role, without adequate support and in the face of social disadvantage, isolation and stigma.

The habitual and obligatory assumption of the woman's provision of care means that they may feel more enmeshed in the parenting role than fathers. The division of labour also frequently means that their maternal parental role may also be weighted towards task focused care which is defined as instrumental, routine, mundane and often devalued as opposed to the relationship focused care which is discretionary, enjoyable

and rewarding. The task focused care required within parenting is additionally associated with higher levels of parental stress, depression and overload which would, without acknowledgement and support, inevitably lead to an exacerbation of mental ill health (Rina and Feinberg, 2012; Mirick, 2018)

In considering the impact that psychological frailty or mental ill health may have upon the relationship of parent and child we must first clarify what is meant by mental ill health and how it is experienced.

What do we mean by mental ill health?

The language that is used to describe mental ill health is heavy with assumption and inference, often reflecting the model through which mental illness is understood.

Terms such as mental distress, mental health problems, mental ill-health, mental illness and mental disorder refer to the same condition of experiences and/or symptoms. However they hold heavy inferences towards the model of understanding being used. Regardless of which model is operational, a fundamental understanding is that mental ill health can affect an individual's ability to function on a daily basis and impacts on their overall quality of life.

Traditionally classified by medical professionals, symptoms of mental illness have been divided into neurotic, those which encompass extreme forms of normal emotions such as sadness, fear and panic and psychotic which refers to symptoms which interfere with an individual's perception of reality and may include hallucinations, paranoia and delusions (Halliwell, Main and Richardson, 2007). Both of these types of symptoms can range in their severity and can be experienced either separately or concurrently. The impact they have upon the individual's life is related not only to the severity of the symptom but also the psychological and social circumstances of the person's life.

As with family and parenting, the concept of mental ill health is socially constructed in the manner in which it is both experienced and responded to. From a wider cultural perspective, each culture has a notion of psychological or emotional difference, as well as a range of ascribed roles and expectations for the various groups within their society, be they men, women, mothers or leaders. Therefore, mental ill health is culturally and socially informed by normative beliefs and is dependent on the cultural

beliefs and traditions which denote how people who are marked as different or stand outside of their roles are identified and responded to (Abdullah and Brown, 2011).

Research and professional understanding of mental ill health within the UK is predominately driven from a medical model of mental disorder (Aldridge and Becker, 2003). This places the difficulties as internal to the individual, meaning that little consideration is given to the social network, families, friends or carers around them (Glasby and Tew, 2015). This increases the perception of difference and isolation, feeding into a legislative and social policy framework whose dominant discourse of risk is of protecting society from the mentally ill and the mentally ill from themselves (Aldridge and Becker, 2003). French philosopher Foucault spoke of this perception of difference and isolation as being the exclusionary ethos that society had always shown toward the mentally ill and illustrated it with the Ships of Fools within which the insane would be set adrift (Foucault, 1965). It is this ethos which is imbued in stigma which Kanwar argues is not only a consequence of mental ill health but also a key factor which hinders help seeking behaviour, rehabilitation and recovery (2015).

The role of stigma within mental ill health

In 2008 the national charity Rethink surveyed 3038 people with mental ill health finding that 87% of the respondents had experienced stigma which they felt had affected all areas of their lives from education, work, social life, relationships and willingness to discuss their difficulties (Corry, 2008).

Stigma is defined by the devaluation of an individual on the basis of characteristics they possess, and a membership to a group which is devalued or disgraced by general society (Hinshaw, 2005). This presents itself as labelling, stereotyping, isolation, discrimination and status loss, and can be compounded when the power balance inherent with stigma is considered. Mental ill health is one of the most highly stigmatised labels an individual can possess rendering them perceived as undesirable, deviant or incompetent. "In sum, stigma is a process of 'othering' whereby a clear distinction is made between 'them' and 'us'". (Reupert & Maybery, 2015 p51). Stigma occurs within a range of spheres including language, professional's responses, social policy, legislation and media portrayals (Glasby and Tew, 2015; Kanwar, 2015; Reupert

and Maybery, 2015). It has been found to be perpetuated and enforced by a sequence of four social cognitive processes. First, there is the cue which is the signal that mental ill health may be an issue, then the stereotype which is the belief about mental ill health. This informs the prejudice which is the assumption derived from the stereotypical belief, and finally discrimination, which is the action taken on account of the assumption (Corrigan and Miller, 2004). Stigma can also be differentiated between three different dimensions: public stigma, self-stigma and stigma by association.

Public stigma represents the widely endorsed perceptions of fear, derision and avoidance resulting in limited opportunities for relationships, housing and employment. It is proliferated both by media representations of mentally ill people being 'mad, sad, bad and dangerous' (Corrigan, Larson, *et al.*, 2015) and economic, historic and political forces which produce social structures that promote and maintain prejudice, discrimination and disadvantage (Rogers and Pilgrim, 2014).

Self-stigma is the insidious, internalised erosion of an individual's own sense of self-worth or social relevance, it instils a deep level of insecurity which inhibits the person from challenging injustice, seeking help or even acknowledging their illness (Teh *et al.*, 2014; Kanwar, 2015).

Finally stigma by association, or as originally named courtesy stigma by Ervin Goffman (1963) is a complex multi layered phenomenon experienced by family (and children) of people with mental ill health. On one level the family member is acutely aware of the stigma that their loved one is faced with and finds this extremely distressing (Corrigan & Miller, 2004). They may go to extraordinary lengths to protect their loved ones from stigma by minimising their difficulties or they themselves may avoid social contact and forego opportunities because of their caring responsibilities (Larson and Corrigan, 2008). On a more insidious level, family members themselves feel stigmatised. Parents feel they are to blame for causing the illness, partners feel they are held responsible for not ensuring the person adheres to treatment and children feel they will be considered genetically tainted (Abdullah & Brown, 2011; Corrigan, Bink, Fokuo, & Schmidt, 2015; Teh *et al.*, 2014). As such stigma overshadows both the lives of people with mental ill health and their families.

How does mental ill health affect families?

As discussed earlier, the family is an adaptive system within which there is a set of positions or roles, each of which has a relationship with each other and a subsequent pattern of interaction. When one member of the family is significantly impacted by an internal factor such as mental ill health the whole family system feels it to varying degrees and has to adapt to it as required. It is with this in mind that Reupert, Maybery and Nicholson described mental ill health as a "family affair" (2015 p51).

Several conceptual frameworks have been developed over the past 15 years which attempt to capture the complexities for families with a member or members who have mental ill health. Each of these frameworks have different foci ranging from the details of specific mental disorders and their manifestations to a more ecological view of the wider functioning of the family and their place within society (Reupert, Maybery and Nicholson, 2015).

In the UK the medicalised model of mental health services individualises provision towards the 'patient', giving little consideration to the impact on or influence of the family. This carries with it a sense that families are in the way of the services and at times counter intuitive to the recovery of the individual (Glasby and Tew, 2015). The 'Think Family' policy has attempted to readdress this by highlighting the needs of the family as a whole (Cabinet Office, 2007; Social Exclusion Task Force, 2007). However, implementation and achievements of this directive have been limited by a lack of alignment, professional understanding, targets and service boundaries (Glasby and Tew, 2015).

From the family systems perspective discussed earlier, the organisation and role distribution of the system can be radically changed when a member is mentally unwell. As such the family system can be at risk of changing from a supportive environment to one of oppression, conflict and potential abuse (Glasby and Tew, 2015). Channels of communication become restricted or distorted and schisms can form within the family dynamic within which some members may choose to opt out while others are drawn in. This creates an oppressive milieu in which the most vulnerable or relatively powerless members can become trapped in a relational double bind, unable to

negotiate between competing needs or demands of family members and themselves. This can become even harder to escape if the family feels that it has been 'othered' or fears stigmatisation and consequentially becomes increasingly introspective and isolated (Tew, 2011). Acute mental ill health can trigger such a seismic shift in family organisation with the rapid dislocation of both relationships and identities. However while a chronic (lower risk yet longer lasting) manifestation of mental ill health may not initiate these dramatic shifts in the family system, its effect on the family and its members can still be profound.

It is within the context of the family system that different attachment patterns can be transmitted down the generations (de Zulueta, 2006). Falkov's Family Model (2015) provides a biopsychosocial approach which illustrates the complexity of the multiple systems in which an individual exists and the proximal interaction and influence of each of the members of those systems. In considering the relationship between children and parents with mental ill health in a family system, Falkov proposes there are six areas in which they are intimately linked

1. Parental mental ill health can adversely affect development, emotional well-being and in some cases the safety of the child.
2. Children's own needs and particularly difficulties can precipitate or exacerbate the mental ill health of their parents.
3. The quality of a child's adjustment and transition to adulthood can be negatively affected by growing up with a mentally unwell parent. This includes the way they perceive key adult life stages such as becoming a parent themselves.
4. Both the parent and child are negatively impacted by social disadvantage such as; poverty, social isolation, lone parenthood and stigma.
5. A key protective factor for all family members is a positive relationship between individuals, family members and health and social care services.
6. The above five areas all coexist and interact within a community and wider social system which itself is imbued with cultural influences.

(Falkov, 2015)

Within this model is clear that there are multiple factors within both a family system and social system which influence the child, their parent and the relationship between them. It also demonstrates the links over time and the manner in which factors in a system can have influence across generations.

Carers created within the system

The term 'carers' emerged in the late 20th century and refers to the significant level of physical and emotional support that family members (predominately women) provide to adult relatives (Glasby and Tew, 2015). For some, this can be a positive choice but for others it can feel like a burden borne of obligation, enforcing restriction on the carer's life choices and opportunities. The term 'carer' itself can be controversial, family members can feel ambivalent about being called a carer as it further distorts the family relationship and can further remove them from their identity as parent, spouse or child.

For both children and adults, health and social care policy has sought to recognise and support carers within their role. However the focus on a single primary carer is contrary to the body of carers research which suggests that caring occurs within a complex and dynamic system. As such the carer is often identified through the professional's assumption of hierarchy within the family, for example the carer's assessment may be automatically offered to the spouse without consideration to the role that the individual's siblings or children may play.

In the UK, young carers' needs are reflected in health and social care policy and as such have a right to assessment under both the Children Act 1989 (Legislation.gov.uk, 1989) and the Carers Recognition Act 1995 (Legislation.gov.uk, 1995). This act was replaced in recent years by the Care Act 2014 (Legislation.gov.uk, 2014b) but remains relevant as it was the legislative framework that was present during the childhood and early adult years of the participants within this study. This legislation had serious shortfalls for children living with a parent with mental ill health. Often their role as a carer and subsequent needs were not identified and as such the carer's assessment was not requested for them, or the parent they were caring for was not receiving assessment or services under the Community Care Act 1990 (Legislation.gov.uk, 1990). If the

parent was not engaged with services, the carer was not entitled to an assessment in their own right. Evidence from national surveys found that only 18% of young carers had received a carer's assessment (Abraham and Aldridge, 2010) and these did not include the children who had not yet been recognised as a young carer. These barriers to obtaining an assessment of the caring role were addressed within the Care Act 2014 (which replaced both the Community Care Act 1990 and Carers Recognition Act 1995). This removed the need for an assessment to be requested and placed a duty on health and social care staff to initiate an assessment on the appearance of need. The carer also has a right to an assessment in their own right regardless of what statutory services are provided for the person they care for. Given what we know about the roles of and impact on children living with a parent with mental ill health it would be reasonable to assume that each and every child would be eligible for a carers assessment under the Care Act 2014. However recent reviews conducted by both the Carers Trust and the Children's Commissioner find that despite this eligibility few assessments are being offered (Carers Trust, 2016; Children's Commissioner, 2016).

How does mental ill health affect parents?

Since mental ill health can affect both daily functioning and the overall quality of life (Halliwell, Main and Richardson, 2007), it stands to reason that it will impact on the parental role. One example of this could be if a parent were clinically depressed, they may appear distant and unavailable as their emotional world closes in. This in turn could be perceived as them being emotionally detached from their children, which, according to the requirements of parenting as conceptualised by Winnicott and Bowlby would have significant detrimental effects for the children. This said, research evidence suggests that such manifestations of mental distress do not necessarily have an adverse impact on children if there is good support from other relationships for the child (Tew, 2011).

However, support is often limited particularly in terms of lone parents and the increased level of social isolation experienced by people with mental ill health. Furthermore, the stigmatising assumptions which equate mental ill health with poor parenting have profound connotations for parents (Ackerson and Venkataram, 2003; Nicholson and Friesen, 2014). This may lead to support being experienced as negative

and undermining or being actively avoided. Both the ideology of 'good enough parenting' which is based around adaptability and the ability to tune in to the emotional needs of the child, and the medicalised model of mental health services, which operate from a risk perspective, leave parents fearful that they are already painted as an inadequate parent just by virtue of their mental ill health and as such are reluctant to identify their need for support for either their mental health or with parenting (Aldridge and Becker, 2003; Bournsnel, 2007).

From a wider perspective, social and professional discourses surrounding mental ill health can result in a process of invalidation for both the parent and their family (Dallos and Boswell, 1993; Aldridge and Becker, 2003) which in turn can give the impression that adverse outcomes are inevitable. Overlaid with this is the ideology that the family sphere is private and sacrosanct unless there is clear evidence of risk to children such as abuse or domestic violence. Dallos & Boswell, argue that this anti-interventionist benevolence may be illusionary, instead perpetuating individualistic myths around mental illness and distracting from the contributory social problems and the consequential impact on the family and community. Retaining the statutory attention on the (medicalised) treatment of the mental illness as opposed to (social) responsiveness to the holistic needs of the parent and family (Ackerson and Venkataram, 2003) fails to acknowledge the impact that parenting may have upon the patient and the incompatibility that psychotropic medication may have with the demands of parenting. For example parents may be reluctant to take medication which is sedating as they choose to prioritise the needs of their children above their own (Nicholson and Friesen, 2014). The importance of the relationship between parent and child is also overlooked and parents may fear that their role as patient will overshadow their role as parent. This in turn could lead to an atrophying of their parenting skills and status (Aldridge and Becker, 2003). When parents recover a sense of psychological strength there can then be conflict/ambivalence about the re-establishment of the parent-child boundaries (Bancroft *et al.*, 2005).

Bournsnel's (2007) study of the qualitative experience of parents with mental ill health, found that despite their difficulties, the majority of parents expressed joy and love at being a parent and while they acknowledged that their ill health did at times interrupt

their experience of parenting, this was largely felt to be a positive aspect of their lives. However, the negative social discourse between mental ill health and parenting would “leave the silent parents and their hidden children in the margins, unsupported and unacknowledged” (Boursnell, 2007 :259).

Summary

It is clear that the family system is pivotal to the experience of children, and that a primary factor of this system is the relational bond and boundaries of the parent child relationship. Within the gendered landscape of traditional family systems the understanding and representation of mothers is central, as reflected in both theory and contemporary research.

Mental ill health has a significant impact on both an individual’s ability to function and the quality of their relationships. However mental ill health is largely treated in a medicalised individualistic manner which fails to address the social disadvantage, distress and stigma associated with it. Indeed it is evidenced that mental ill health has a significant impact upon families and the relationship between parents and their children, alongside an acknowledgement that the primary difficulties experienced by these families are grounded in stigma and lack of support and acknowledgement. Therefore, the fact that parents with mental ill health and their children are hidden in the margins is particularly poignant given that, as discussed in the introduction to the thesis, their numbers are significant. By definition more needs to be done to raise their profile, acknowledge their needs and challenge the stigma and discrimination that they face.

Chapter Two

Impact of parental mental ill health on children

Consideration and exploration of parental mental ill health has been present throughout the development of psychological and health science research. However, lived experiences of children who grow up with a parent with mental ill health have not been widely examined within the field (Bee *et al.*, 2013). Initial studies considering the impact of parental mental ill health on children were largely informed by data drawn from the parents themselves or professional records. This research also predominately focused on the risks to the child as opposed to the strengths of the child or their family (Duncan and Browning, 2009). Such a dominant narrative of risk can lead to a constriction of enquiry and diminished understanding by diverting attention away from what works well. Indeed, it could be argued that this construction of risk and blame has informed a professional ideology which has been experienced as inflicting a secondary trauma on the families it was seeking to serve (Muhlbauer, 2002).

Within the analysis of this wider body of literature key themes emerged which were present within the majority of studies, regardless of specific parental diagnosis or age of the child. Drawn together as a framework, an understanding can be developed relating to the research question: how did participants experience and feel about their parent's mental ill health?

Beginning with the wider issue of social disadvantage, I will first consider the impact of reduced social and developmental opportunities afforded to children with a parent with mental ill health. I will then move on to the sense of stigma documented within the research, building upon the meaning, cause and effect of stigma discussed in this

first chapter. I will focus upon the explicit concept of stigma by association, which is linked to the families and carers of those with mental ill health. Following this, I will discuss the potential caring roles taken on by children with parents with mental ill health and the extreme manifestation of this, which is understood as parentification. Consideration of how children made sense of their parent's mental ill health is given and this first section of the chapter will conclude with the final theme of lack of information. The chapter will then narrow the focus to consider the findings from studies which attended to the perspectives of children growing up with a parent with mental ill health. While many of the findings of these studies ran parallel to the wider body of research, different emphasis was apparent in relation to the relationship between parent and child, the manner in which they made sense of their parent's mental ill health and the caring role within it. There were also interesting themes around impact and vulnerability which will be discussed.

Social disadvantage

Across the body of social science literature, social disadvantage is discussed in terms of risk and vulnerability. For a child with a parent with mental ill health, this is predominately identified as reduced access to social opportunities, and the detrimental impact this has particularly on their experience of education. While some children describe using school as a refuge, providing a break from their caring responsibilities (Gladstone *et al.*, 2011), many described their education as suffering in three crucial areas. Firstly, the routine of education can often be disrupted in situations when a parent was admitted to hospital and the child received temporary care elsewhere. Secondly, attendance was reported as being poor. However this appeared to be less to do with truancy or the need to provide physical care but rather the anxiety of leaving the parent alone and the fear of what the child might return to. Finally, a significant weight of research points to the difficulties children of parents with mental ill health have in maintaining concentration in school. This is due in part to physical tiredness but, as with poor attendance it is also largely attributed to the on-going worry and anxiety they hold about their parent (Aldridge, 2002; Aldridge and Becker, 2003; Slominski, 2010; Gladstone *et al.*, 2011).

These difficulties are heightened for children of single parent families or families with poor social support, and are most powerfully felt in children where there is a high level of responsibility or expectation to provide care (Abraham and Stein, 2013). The anxiety and subsequent burden of responsibility, which detracts from a child's educational engagement, also blocks them from engaging with social activities outside of school. As such, the opportunity to build relationships with their peers can be severely undermined (Polkki, Ervast and Huupponen, 2005). This is exacerbated if they feel that they have to keep their experiences secret and hidden, or that their lives are so removed from their peers that they are not able to relate in a meaningful or satisfying way (Gladstone, Boydell and McKeever, 2006). Access to Young Carer's groups can be argued to be 'transformative' (Aldridge and Becker, 2003; Abraham and Aldridge, 2010). However, this access is largely dependent on the child being identified as an appropriate candidate for such a group and having the physical and emotional support to enable them to attend. Indeed the hidden nature of this sort of care means "most children and young people who have a parent with mental ill health will not think of themselves as carers. They may think themselves as surviving, as lonely and isolated...[additionally]... many parents with mental illness will not acknowledge their child has become their carer" (Cooklin, 2010 pg141).

It is also important to remember the other aspects of disadvantage that families with a parent with mental ill health are vulnerable to – housing problems, low income, lack of employment and inconsistent relationships (Halliwell, Main and Richardson, 2007; Perera, Short and Fernbacher, 2010; Department of Health, 2011). While these might not be directly identified by children growing up with parent with mental ill health, there is clear evidence that each of these factors would have had a significant impact on their experience of childhood. There is also evidence that the interaction between factors such as poverty and parental mental ill health can increase the chances of child abuse and neglect (Bywaters *et al.*, 2016).

Family composition

Family composition has some importance in understanding the influence parental mental ill health has upon children. Adults with severe and enduring mental ill health are at increased risk of relationship breakdown and/or discord (Dawson, Jackson and

Cleary, 2013). The breakdown of a relationship could trigger a period of mental ill health. However, it is also known that chronic mental ill health can be an enduring factor in the perpetuation of relationship difficulties and can be linked to domestic violence (Aldridge and Becker, 2003) both as a causal and consequential factor. Being a single parent regardless of mental health is often understood as a disadvantaged position, with factors such as loneliness, lack of support networks, a sense of being overwhelmed by daily responsibilities, feelings of inadequacy and concerns regarding a lack of security often being cited (Bassett, Lampe and Lloyd, 1999). However, when overlaid with the difficulties associated with mental ill health these factors are amplified, which in turn, can result in a further deterioration in the parent's mental health or the adoption of maladaptive coping strategies such as the misuse of drugs or alcohol (Dawson, Jackson and Cleary, 2013). Subsequently, this may have a significant effect on the daily life and experiences of the child. Research clearly demonstrates that children in a single parent household provide more of a caring function than children with both parents present, and that indeed they have a different perception of the burden of responsibility placed upon them (Aldridge, 2002; Abraham and Aldridge, 2010; Gladstone *et al.*, 2011). This requirement to provide care is also gender biased, it is twice as likely for girls as boys to take on a caring role, which is further exacerbated if the parent has a co-morbid difficulty with drug or alcohol misuse (Aldridge and Becker, 2003).

Child protection

Despite the focus on risk and parental deficits, there is little research that examines the correlations between parental mental ill health, child abuse and children in the care system. However a somewhat dated quantitative study which examined 57 birth families of looked after children found there was evidence that a disproportionately high number of children who reside in the care system (looked after children) for over 12 months, had a parent with severe and enduring mental ill health, and that these parents are often the most socially disadvantaged (Isaac, Minty and Morrison, 1986). The influence of social disadvantage and stigmatisation is further highlighted by Howard's (2000) preliminary findings, which suggest that Black families with a parent with psychosis are more likely to have a child placed within the care system than a

White family in similar circumstances. These findings are drawn from the recognition that not only are Black patients more likely to be detained under the Mental Health Act 1983, but that there is also an over representation of Black (Black African, Black Caribbean and mixed parentage) children in the care system (Howard, 2000). While the statistical evidence that underpins Howard's study (2000) is some thirty years old and therefore needs to be updated, it is a powerful illustration of the interdependency between (parental) mental ill health, social deprivation, the cultural gap between families and professional services and institutional discrimination. As there is little evidence that parental mental ill health is a direct causal factor of child abuse (Aldridge, 2006) this disproportionate presentation could potentially indicate discrimination based on stigma and the assumption of parental inadequacy.

Stigma

The second theme relating to the psychological impact of growing up with a parent with mental ill health is examined through the recognition of the connotations that stigma has across the whole family. Stigma is generally defined as a mark of socially ascribed disgrace associated with particular circumstances or qualities of an individual. Stigma and its relationship with mental ill health has been examined at great length (Ackerson and Venkataram, 2003; Zeighami, Oskouie and Joolae, 2011; Trondsen, 2012; Corrigan, Larson, *et al.*, 2015; Power *et al.*, 2016), however there are further complex dynamics when considering the manner in which children of parents with mental ill health experience and interpret stigma themselves. Ervin Goffman (1963) spoke about courtesy stigma in his seminal work, *Stigma*. He described this as the negative impact that results in association with a stigmatised person. In more contemporary literature this tends to be termed as associated stigma (Corrigan and Miller, 2004; Mordoch and Hall, 2008; Ostman, 2008), which relates not only to the stigma experienced by virtue of having a parent with mental ill health, but also the way in which children experience how people outside of the family view their loved one, and in turn themselves.

In considering the stigma experienced by children with a parent with mental ill health it is important to be mindful of the complex factors inherent with stigma, including cultural beliefs and taboo. Culture plays a key role in how mental ill health is

conceptualised, perceived and experienced. In Western societies, the individualised medical model is dominant and mental illness affects a significant proportion of the population (Tanner, 2000; Harstone, 2010). However, in Asian cultures it is argued to be less recognised or accepted and more likely to be hidden due to stigma (Bromley, 2008). Specific African American communities are believed to have a perception that admitting to mental ill health is a suggestion that your church has let you down, and that mental illness and mental health are luxuries for the rich (Corrigan and Miller, 2004). The experience of stigma is also enmeshed with gender and specific diagnosis (Harstone, 2010) and is exacerbated when the associated behaviour becomes taboo. For example, men with a mental disorder are portrayed as presenting a higher risk of violence and aggression whereas individuals with a diagnosis of Borderline Personality Disorder are stereotypically portrayed as female, manipulative and difficult to engage with (Glasby and Tew, 2015).

While there is a gap in research which specifically focuses on how stigma operates in the world of a child growing up with a parent with mental ill health, and their strategies to manage it (Mordoch and Hall, 2002), it appears to be omnipresent for these children and makes a significant contribution to their silence, invisibility and distress. Indeed, Ostman (2008) who interviewed eight children of parents who were currently receiving acute care upon a psychiatric ward, found that all the children, regardless of their age, held the belief that people were generally afraid of those with mental ill health.

Children as well as parents were fearful that speaking out would trigger professional intervention, which could result in family separation through the discriminatory assumption of parental inadequacy. This narrative of poor parenting and risk of family separation is prominent in the stereotypical assumption and stigmatizing beliefs surrounding parental ill health, despite parental illness or disability only being identified as the primary category of need for 3% of looked after children in 2015 (House of Commons, 2015). However the fear prompted though this narrative induces further secrecy and self-imposed isolation. Secrecy not only inhibits children from accessing appropriate resources, but also contributes to their sense of shame (Corrigan and Miller, 2004). In Tanner's (2000) recollection of her own childhood experiences,

she describes only using euphemistic terms to describe her mother's behaviour, in an attempt to minimize or normalise it for relatives and neighbours. This endeavour to maintain a pretence that everything was alright, meant that she could never openly acknowledge what was happening, or consider her own emotional response to the matter. In the shame and secrecy, it seemed that part of her mother's identity had to be denied and shut away. With the understanding of the interwoven nature of a parent/child relationship, it is reasonable to assume that the child must also feel that a part of their identity should also be hidden and denied. The stigma that necessitates such silence impedes the child's ability to make sense of their experiences and can result in them feeling unable to express their own feelings effectively (Tanner, 2000; Mordoch and Hall, 2002; Harstone, 2010).

Across a range of studies, children spoke of loyalty towards their parents and felt strongly that they did not want their parents or family to be pathologised or stigmatised. As the children grew into adolescence they began to anticipate stigma (Bromley, 2008), worrying that people would react differently to them if they knew. They expressed a desire to be normal which seemed to be borne out of a desire not to be stigmatised, however this was also embedded within their construction of difference and normality within their family.

Tanner (2000) argued that statutory intervention addresses only the child's response to the parent's psychiatric symptoms. However in her personal experience it was the social embarrassment arising from the actual or anticipated social reaction, which made her uncomfortable. This was due to her perception that the social reaction was marking her family (and therefore herself) as abnormal. She stresses that the majority of her distress was not a direct result of her mother's behaviour but rather the socially constructed stigma and shame associated with it. As it becomes more widely represented and normalised within the population, you would imagine that such stigma may be diminished by the emerging understanding of mental illness/distress. However, it would seem that in many cases the heightened awareness of the genetic factors of mental disorder further stigmatises children. This included being taunted that they will be crazy like their mother/father (Tanner, 2000) and fearing contamination themselves (Corrigan and Miller, 2004).

Stigma can also manifest as a direct discrimination or exclusion from opportunities, or through a less tangible avoidance or social distancing, which provokes feelings of shame and isolation. This sense of shame does not present itself universally across the field of illness and/or disorder but rather seems to be most attributed to mental ill health. Studies show that family shame is far more prevalent in families with a member who is mentally ill as opposed to families who have a member with a physical illness, such as cancer (Corrigan and Miller, 2004).

The stigma that is experienced by people with mental ill health and their families excludes them from many opportunities and resources that the rest of the general public are afforded. Through this sociological lens it is not difficult to see that children's experiences of parental mental ill health are heavily influenced by their social and economic circumstances, which links stigma back to the difficulties associated with social disadvantage. Indeed some researchers go so far as to argue that it is not the mental ill health itself that harms the child, but the social disadvantage that comes with it (Gladstone *et al.*, 2011). The idea that it is the level of poverty, instability and isolation which denotes to what extent the child's own needs are met, is in part supported by Aldridge and Becker's (2003) findings that children with a lower social status are more likely to be required to provide care for their parents than those from a higher social status or class.

The differences between the experiences of the social status are also related to financial security and therefore stability. No more than 13% of adults with severe and enduring mental ill health are in paid employment, this is lower than any other disability group (Aldridge and Becker, 2003). This can be extremely damaging on multiple levels. To begin with, the loss of work can be an indicative factor in the onset of mental health problems amongst adults. Similarly, continued unemployment and subsequent loss of self-esteem can affect the chronicity of an illness. Finally, the difficulty in finding and maintaining employment further reinforces stigmatising social stereotypes, perpetuating the myth that adults with mental ill health are lazy and feckless, preferring to live off government benefits than work. The aggravating or moderating factors of socioeconomic status and social disadvantage have, however, been examined in terms of the stress experienced by parents (Slominski, 2010) and the

response of services (Jeffery *et al.*, 2013) rather than through the narrative accounts of the children themselves.

Parentification

Within general child development research the concept of a child taking on a parental role is not a new one. In Bowlby's work on loss (1980) he wrote about 'inverted' child/parent relationships, and within the field of family therapy 'parentification' is discussed as the elevation of a child from sibling into the parental subsystem (Abraham and Stein, 2013; Park and Schepp, 2014).

Within the literature the term parentification is used interchangeably with inverted relationships and role-reversal. However, the latter two terms suggest an exclusive dynamic between the parent and child. The term parentification, also allows for the acknowledgment that parentified children often hold parental roles towards several members of the family. Furthermore this adoption of role does not always include a role reversal, since a child becoming part of the parent subsystem rarely comes with the power inherent within this system (Abraham and Stein, 2013). In some cases, rather than the child just taking over the functions and role of the affected parent, they also perform other adult functions such as confidant and "mate" (Knutsson-Medin, Edlund and Ramklint, 2007; Harstone, 2010).

The benefits and risks for parentified children may be finely balanced. On the one hand it could be seen as culturally appropriate and providing opportunities to develop competence, while on the other it could represent a form of deprivation or abuse (Byng-Hall, 2002).

In terms of the child's competence, the temporary provision of care for a family member in need is a naturally healthy response (Aldridge and Becker, 2003; Abraham and Aldridge, 2010). This in itself can be a creative and affirming process, enhancing the parenting role-play that naturally occurs from an early age (Aldridge, 2006). However, the major and prolonged care roles which some children attend to, both physically and emotionally can be beyond their chronological capabilities. This can delay their own personal growth and development, as they subjugate their own needs for those of the person they provide care for. This dichotomy of opinion leads to the

attempt to differentiate between adaptive parentification and destructive parentification. In his study on parentification, Jurkovic (1997) considered the value of the process and the definition of adaptive and destructive parentification.

He identifies adaptive parentification as generally transient, and if prolonged the child is not unduly constrained by their role. The child's identity is not formed around their parentified status and they in turn receive support for their own needs from others. Overall the expectation placed upon them appears to be fair, reasonable and proportionate.

Destructive parentification is diametrically opposed to the adaptive state. It involves emotional and instrumental care responsibilities, which are excessive and developmentally inappropriate. The role of the caregiver becomes the child's primary identity. They experience crippling guilt and/or self-blame if they feel they are not meeting the full requirements of the role, which are often far beyond their developmental capabilities. This sense of self-blame, can be reinforced by guilt provoking strategies deployed by members of the family, misunderstanding or resentment of younger siblings and social isolation. Without the social connection with peers, the child can struggle to maintain a perspective regarding the level and intensity of their care tasks and what is expected of them (Gladstone *et al.*, 2011; Abraham and Stein, 2013; Park and Schepp, 2014).

At the end of the spectrum represented by the concept of destructive parentification, children's development can be impaired and parentified children can struggle with internalized emotions such as, depression, low self-esteem, excessive guilt, fear, unrelenting worry and shame. These can then manifest in external behaviours ranging from a conduct disorder to feeling the need to present themselves as almost pathologically compliant and pleasing. These behaviours can obscure the needs of the child themselves and distract from the impact of their caring role. Jurkovic (1997) feared that parentification is often ignored or minimized and argued that it is such a powerful process for children that it should be classified as a separate form of abuse.

While often associated with lone parent families, parentification can also be seen within families where the parental relationship is fractured or the 'well' parent

struggles to meet the needs of the 'unwell' parent. Byng-Hall and Campbell (1981) addressed this using the conceptual framework of attachment. In what they described as a "too close/ too far" relationship between an adult couple. They explained that excessively needy or clingy behaviour on the part of one adult, may result in the other becoming increasingly avoidant as they attempt to distance themselves from the emotional demands of the other. However, this distancing could result in the activation of insecure attachment behaviours in an attempt to illicit closeness, which simultaneously provokes further distancing in response. If allowed to continue and escalate, this dynamic could climax in the breakdown of their relationship (either physically or emotionally). The insecure parent may then redirect their attention on to a child, who Byng-Hall and Campbell (1981) suggest is likely to have an insecure attachment themselves, and is therefore more receptive to parentification. This redirection of attachment behaviours may be felt to be a suitable solution, as the new configuration reduces the demands on the relationship and could be seen to prevent a frightening escalation of attachment seeking behaviours. The insecure parent may also feel safer within a relationship, within which there are no longer the adult demands of reciprocation. However this level of dependence placed on the child can have long-term detrimental effects if the child is left unsupported.

Several studies have gone on to consider the role of parentification with children who grow up with parents with mental ill health (Aldridge, 2006; Bromley, 2008; Foster, 2010; Harstone, 2010; Gladstone *et al.*, 2011; Abraham and Stein, 2013). In line with the general understanding of the process, parentification becomes more likely in a single parent family and if there are additional stressors, such as substance misuse (Abraham and Stein, 2013). It is also apparent that parentification often carries with it feelings of self-blame, persistent worry and dismissal of the child's own needs (Gladstone *et al.*, 2011). However it is also recognised that providing proportionate care for a parent can bring the parent/child relationship closer (Aldridge, 2006), and give the child a sense of control which can be in itself a protective factor.

In considering the caring role or parentified role for a child growing up with a parent with mental ill health the types of care could be clearly defined as practical (instrumental) support, such as household tasks, caring for siblings or managing

medication, and emotional support. The emotional element of the care that is provided is far more complex and harder to quantify. Some described it as 'being there' for their parent (Aldridge, 2006) whereas others spoke about having to 'save the situation', to anticipate and avert crisis, to adjust their behaviour to manage their parent's mood and to be extra helpful to avoid conflict (Foster, 2010; Gladstone *et al.*, 2011). There was in some cases an acceptance that their parent had 'two sides' and could become irrationally angry at times. For older children this linked with a sense that they needed to forego their childhood in order to protect their siblings (Foster, 2010). The level of responsibility embedded within emotional care could be significant. In Aldridge's (2006) study, parents explained that there were times when it was the presence of the child and the emotional support that they provided, which prevented them from self-harming or attempting suicide. While most parents felt that they kept this hidden from their children, interviews with adult offspring (Harstone, 2010; Gladstone *et al.*, 2011; Abraham and Stein, 2013) indicate that children often had a deeper awareness than was expected of them. This links in to the theme of persistent worry that threaded through the vast majority of research (Pretis and Dimova, 2008; Foster, 2010; Gladstone *et al.*, 2011; Trondsen, 2012).

There is some disagreement in the conceptualisation of parentification within the research. While one study claimed that parentification exclusively took place in the father/son relationship of paternal mental ill health, and was not recorded with mothers with mental ill health (Alexander, 2003), subsequent studies have stated that it is not gender specific and that indeed higher levels were identified with maternal mental ill health (Gladstone *et al.*, 2011). This difference in acknowledgement and perception could be linked to the gendered landscape of parenting as discussed in chapter one (Rina and Feinberg, 2012).

There is also a contradictory understanding of the nature of the caring role. In her phenomenological study, Bromley (2008) argues that evidence of children's desire to provide care for their parents, adds weight to the viewpoint that caring is a function of a strong parental bond as opposed to a process of parentification, questioning the validity of the concept of parentification itself. Abraham & Stein (2013) on the other hand, are committed to the concept of parentification and have examined closely the

links to the emergence of psychological difficulties within early adulthood for children that have experienced it. These difficulties are reflected in the challenges identified for children as they transition through childhood and adolescence into adult life, which link to the theories that the child's developmental needs are not chronologically addressed and therefore can be delayed (Byng-Hall, 2002; Harstone, 2010).

As stated previously, the care provided by a child to a parent with mental ill health is difficult to understand in terms of what they do and how much they do. From an overview of the literature, it is clear that understanding depends upon a sensitive and complex assessment of the intensity and duration of care, alongside the support that the child him or herself receives which defines whether the balance is tipped from care to parentification. While care is a natural element of a relationship and a great deal of research points to it as a positive element, strengthening the parent/child relationship and equipping the child with valuable life skills (Aldridge, 2006), it is equally clear, that when taken to the extreme and managed in isolation, it can become a dysfunctional and damaging experience for a vulnerable child (Juckovic, 1997).

The need for recognition from professional services is a key theme found across many of the studies (Foster, 2010; Gladstone *et al.*, 2011) Aldridge (2006) pulled this into sharp focus within her work with young carers. She revealed that when statutory mental health services are focused solely on the adult as a patient rather than a parent, young carers report having increased care responsibilities. This is also the case when services are inconsistent and discontinuous. She also argued that children were rarely consulted about their own needs as carers. This echoed the experiences of children who felt services relied on them to provide care, yet simultaneously excluded them from discussions and care planning regarding their parent (Foster, 2010). Without professionals actively engaging with children, it is hard for them to have their voices heard. Children worry that discussing their care role will elicit a negative response, find it hard to identify their own needs without support and do not want to be made to stop providing care entirely (Gladstone *et al.*, 2011).

Lack of information

The hidden nature of the care and a child's inability to conceptualise the true essence of their experience leads to the final powerful message that is woven through the majority of research in this field. This refers to the lack of access that children have to information about their parent's mental ill health and the impact that their understanding of the ill health has had upon their experience of it. While almost all the children (including adult offspring) interviewed across the studies said they were not given enough information about their parent's mental ill health, a large percentage also described that while it was never discussed, they always knew something was wrong (Gladstone *et al.*, 2011). For some, they always knew, however for others there was a complex process whereby, what they had first believed to be normal became increasingly problematic through their interaction with others (Bromley, 2008). This occurred either through the difficulties in aligning their parent's needs and behaviour with the expectations of the educational system, or through the comparisons the child would make as his or her social world widened, and they were able to observe their peers at home and with their parents. Others described a sudden enlightenment forced upon them by a traumatic incident or acute relapse of their parent's illness (Duncan and Browning, 2009). The way in which they became aware, conceptualised the illness and framed their understanding, directly impacted on their ability to cope (Slominski, 2010).

Child development theories teach us that children actively strive to understand the world around them from a very young age, they interpret information, messages and values from their parents and culture in an attempt to make sense of the world and their place within it (Harstone, 2010). This interpretation can be more powerful and carry more psychological resonance than an actual event. As such any explanation or understanding formed must be congruent with the child's developmental stage (Aldridge and Becker, 2003; Cooklin, 2010). Younger children often identify and describe physical feelings when attempting to make sense of emotions, such as stomach pain for anxiety and sadness (Aldridge, 2002; Boyd and Bee, 2012). Furthermore their understanding of their parent's mental ill health is not fixed to one explanation, rather they are able to hold many different explanations. In this sense

mental illness, physical illness and spiritual explanations do not have to be mutually exclusive (Bromley, 2008). Older children on the other hand tend to shift towards social and environmental explanations, for example poverty, traumatic experiences and self-blame in order to make sense, rather than identifying with bio-medical explanations (Cogan, Riddell and Mayes, 2005). Along with age, a child's ability to make sense of their experience is also dependent on the level of perceived threat, causal attribution (often linked with self-blame) and their confidence in their own ability to cope (Goodman, 2007). This is further complicated when the experience they are striving to make sense of also involves abuse either perpetrated against themselves or their parent (Slominski, 2010).

The ability to psychologically separate the illness from the parent is particularly healthy, as is the expansion of a personal emotional distance (Mordoch and Hall, 2008; Slominski, 2010). This is promoted through the development of an understanding of the illness through accurate and accessible explanation, thus lowering the child's confusion and moderating their self-blame. This in turn enhances their sense of self-esteem and capability and addresses any unrealistic beliefs about recovery (Cooklin, 2010).

Despite the clear understanding of the inevitable need to make sense, and the psychological importance of it, children are excluded from this process by the adults around them (Cooklin, 2010). There are several hypotheses about why this might happen in a Western society. Children are reluctant to raise the discussion, through fear and shame, they find the prospect of discussion outside of the family too risky and unpredictable. They also mask their emotions in order to protect their parents, to not appear selfish or simply because the emotions are too big and scary to express (Aldridge, 2002; Duncan and Browning, 2009; Gladstone *et al.*, 2011). This masking of emotions can give the impression that the child is happy and competent on the surface and detracts from the true complexity and immediacy of their needs (Cooklin, 2009). Adults also avoid engaging in discussions with children. For parents this can be done out of an attempt to shield and protect the child (Gladstone *et al.*, 2011). Parents worry about the long term effects on children while the children themselves worry

about the immediate well-being of their parent and are more aware than the parent realises (Aldridge, 2002).

Professionals fail to engage children in discussion through lack of awareness, oversight, stigma and the division in services, with professionals often believing this to be the responsibility of another section of the service (Howard, 2000; Aldridge, 2002; Cooklin, 2009; Jeffery *et al.*, 2013). This was illustrated by Cooklin (2009) through the study of three core services for children with a parent with mental ill health. It was reported that social workers from children's services tended to avoid detailed discussion of the parent's mental ill health as they felt that they did not have sufficient professional knowledge or training to address discussions around mental disorder competently. Similarly, professionals within community mental health teams described feeling reluctant to engage with the children of their patients, due to concerns that they did not have the necessary skills to communicate with children in a meaningful way or ascertain their level of understanding surrounding their parent's mental ill health. The Child and Adolescent Mental Health Teams appear perfectly placed to bridge this divide, however they rarely become involved at the level of sense making unless the child is presenting with a level of symptomology and/or distress that would justify the use of their sparse resources.

The individualised patient-focused ethos of services also concentrates on cause and treatment rather than impact and family. As such, parenting is not considered a mental health issue until it reaches the realms of child protection (Howard, 2000; Duncan and Browning, 2009). Rouf (2014) took this specific focus in his examination of the problems with inter-agency working, and the links between parental mental illness, drug and alcohol abuse and domestic violence and child deaths in serious case reviews. From the perspective of the mental health services, professionals reported being aware of their responsibilities towards children but felt restricted by the tensions of working across systems, high caseloads, balancing perceptions and feelings, striving not to damage a therapeutic relationship, as well as stigma and becoming saturated by risk (Cooklin, 2009; Rouf, Larkin and Lowe, 2012).

Even in acute episodes of their parent's illness, children and young people are not recognised as carers and despite often being the expert in their parent's needs, are not

consulted (Abraham and Aldridge, 2010; Cooklin, 2010). Children feel powerless to have their voices heard and worry that if they raise their own needs or ask for help they will be excluded from the 'care loop' entirely (Aldridge, 2002; Aldridge and Becker, 2003; Gladstone *et al.*, 2011).

Despite these barriers, the reality of what children need to help them make sense appears to be comparatively simple, as proposed in Alan Cooklin's work (2009)

- The opportunity to discuss and appraise a stressful situation with a "warm, concerned but relatively non-involved adult" (Cooklin, 2010 p142)
- To be acknowledged and recognised for what they do and to have access to information as required
- To be able to develop a realistic understanding of what is happening, why, what is likely to happen, how it might impact on them and what part they can play in their parents recovery
- To know that the situation is not uncommon
- To develop an understanding of what is and what is not acceptable behaviour from adults.

Focusing on the child's perspective

Of the 28 papers which spoke directly to children about their experiences and perceptions, several key themes emerged. There were many overlaps with the key themes found within the rest of the body of literature. As predicted, social disadvantage was not explicitly stated in the children's narrative, although aspects were present, such as access to peers. Relationships, a pivotal theme across the focused studies, was largely absent from the main body of research, specifically the emotional relationship of the child with their parents. The care they provided was explored, and while parentification was not explicitly expressed you could see that the main facets of the concept were mirrored in the child's experience. Another theme that was missing from the initial literature was how the children felt their parent's mental ill health had impacted on them, and the manner in which this impact was carried forward into their own adult lives. Other motifs of coping, resilience and

identity were also strongly prevalent throughout these 28 studies, however these will be examined in more detail in chapters three and four.

Relationships

In many of the studies participants spoke of the fractured and conflicted relationships they felt they had with their mentally ill parent, which were often illustrated as experiences of repeated rejections (Murphy *et al.*, 2015b), specifically as they felt they had to compete with the symptoms of their parent's mental ill health (McCormack, White and Cuenca, 2017). The manifestation of the parental mental ill health was often perceived by children as their parent being emotionally blunted, rejecting or unavailable (Harstone, 2010; Tabak *et al.*, 2016). This could also be exacerbated by sedating psychotropic medication and lengthy hospital admissions (Harstone, 2010). Duncan and Browning (2009 :84) described this from a child's perspective, as the parent being "there but not there". These feelings of rejection and emotional unavailability could also be overlaid with experiences of chaos and neglect. Yet Foster (2010), highlights the psychological conflict that some children experience while managing the emotions borne of rejection, fear and neglect whilst co-terminously still feeling strong emotions of guilt and loyalty. Regardless of the illness, children felt a bond of love towards their parent (Ostman, 2008). Issues of inconsistency within the parent/child relationship led to an avoidant or insecure attachment which in turn could lead to adverse outcomes for the child (Maybery *et al.*, 2005; Tabak *et al.*, 2016). The history, importance and quality of the parent/child relationship in terms of feeling loved, recognised and valued had a significant impact on how the burden of care and adjustments the child had to make in response to their parent's mental ill health was perceived by the child (Petrowski and Stein, 2016).

The impact on the attachment patterns for the child could also be greatly affected by the quality of the relationship they had with their other parent, specifically if it was experienced as close and compensatory (Foster, 2010). While the 'well' parent could represent a buffer against the adverse stress experienced from the mental ill health of the 'ill' parent, the literature suggested that this was often not the case. Indeed if this 'well' adult figure was absent or disengaged, the child developed a sense of betrayal or abandonment from the 'well' parents too (Valdez, Chavez and Woulfe, 2013). This

sense of abandonment was strengthened when the 'well' parent resided within the family home yet was not instrumental in the care of the 'ill' parent or underestimated the level of care the child provided (Ostman, 2008). Within the literature, this criticism was more often levied against fathers distancing themselves from the care of mentally ill mothers, by refusing to get involved, using work as an escape and maintaining traditionally gendered roles of parenting and care despite the mother's inability and increased needs due to her mental ill health (Foster, 2010; Valdez, Chavez and Woulfe, 2013; Petrowski and Stein, 2016). This distancing of the 'well' parent relates back to the redirection of attachment behaviours that were described by Byng-Hall and Campbell (1981). Siblings were also mentioned several times in terms of their importance for the child's sense of connectedness within the family (Maybery *et al.*, 2005; Bee *et al.*, 2013; Power *et al.*, 2016). Yet as with the 'well' parent the function and importance of the sibling relationship remains largely unexplored (Petrowski and Stein, 2016).

Relationships could be difficult for children outside of the family home as well, since they are both functionally and psychologically separated from their peers (Bee *et al.*, 2013; Nilsson, Gustafsson and Nolbris, 2015) and are inhibited through fear, uncertainty and stigma from forming trusted relationships with other adults (Murphy *et al.*, 2015a). As with the attachment patterns these difficulties with relationships, such as fear, detachment and unpredictability can be brought forward and generalised into adult relationships for the children (Duncan and Browning, 2009).

Caring

As stated in the general body of literature, the care that a child provides for a parent with mental ill health is difficult to define. This was borne out in the focused studies, which were not able to identify key aspects to define the care that was provided. As explored by Aldridge (2002), parents with mental ill health often rely on their children for immediate, flexible and continuous care and assistance with both their domestic and emotional needs. Much of the caring role, tasks and expectations are not directly negotiated with the child but rather grow out of a sense of obligation and a desire to connect and maintain closeness with their parent (Petrowski and Stein, 2016). Indeed young people who provide care for their parents have expressed that it can be a

positive experience for them, bringing them closer to their parents, strengthening the mutual bond of love and value between them and enabling them to feel more involved and in control when faced with the presentation of their parents mental ill health (Aldridge, 2006). However this suggests a mutual sense of obligation, caring and being cared for in turn. It would seem that difficulties begin to emerge when this balance is tipped to the child providing more care than they themselves receive (Petrowski and Stein, 2016) which in some earlier studies is understood within the concept of parentification.

While the children did not use the term parentification, the discussion was in line with the body of literature on the concept. In the focused studies, they described playing an active role in the family's functioning and the parent's emotional life, where they are acutely aware of the vulnerabilities of the parent and felt themselves responsible for compensating and managing their parent's needs (Foster, 2010; Van Parys and Rober, 2013). This role reversal also resulted in the child being 'told too much', being involved in emotional content that they are not psychologically equipped to deal with safely. Their status as 'in loco parentis' also extends to the other members of their family as they provide increasing care for siblings and their other parent (Valdez, Chavez and Woulfe, 2013). This distortion of role and responsibility was exacerbated by poor service provision (Aldridge, 2006).

McCormack's (2017) study which explored the experiences of seven adult offspring of parents with mental ill health took this concept further by considering it purely from the child's position. In doing so they were able to build a picture of a child's survival and connection being reliant on them becoming a "caretaker child". A child who developed intuitive behaviours designed to keep themselves and family members safe, who was aware of the disregard and minimisation of themselves as children and yet still fought to maintain an unconditional regard for their parent. Their advanced skills of reading and responding to threat while modifying their behaviour in response to unpredictable behaviour meant that they recalled being in a constant state of adaptive vigilance, ever alert. This portrayal of the caretaker child can be identified and extolled by both mental health and children's services as a demonstration of resilience and competence. Yet in reality it can be the development of outward competences to

manage feelings of chaos and distress. While apparently calm and coping, the child could be emotionally exhausted and scared (McCormack, White and Cuenca, 2017).

As suggested in the concept of the caretaker child, participants across the majority of studies spoke of having to provide care, but also having to accommodate the demands of their parent's illness and associated behaviour. This was repeatedly described as 'tiptoeing', shielding their parent from stress, mediating family conflict and doing all they can to prevent mental distress (Maybery *et al.*, 2005; Griffiths *et al.*, 2012; Bee *et al.*, 2013; Murphy *et al.*, 2016; Petrowski and Stein, 2016). On a more personal level, it would also mean dampening their own emotions and placing their parents needs before their own (Stallard *et al.*, 2004; Polkki, Ervast and Huupponen, 2005) a sense of holding themselves back, related to both not wanting to place additional strain on the parent but also an uncertainty about their own mental fragility (McCormack, White and Cuenca, 2017).

Making sense

Despite the intense involvement of the child with their parent's mental ill health, they often felt that they were invisible both to their parents, their community and professional services (Polkki, Ervast and Huupponen, 2005; Nilsson, Gustafsson and Nolbris, 2015; McCormack, White and Cuenca, 2017). With regard to professional mental health services, this ranged from a lack of understanding of the child's involvement, perspective or psychological needs (Stallard *et al.*, 2004; Aldridge, 2006), through to the point where the children were excluded entirely from the professional's consideration and dialogue, as exemplified by them not being routinely recorded as a relevant factor within the parents assessment or care plan (Somers, 2007; Murphy *et al.*, 2015a).

This lack of visibility meant that children of parents with mental ill health felt that they did not have the information with which they could begin to make sense of their parent's mental ill health and their role with in it. Fear and stigma not only prevented discussions about mental ill health in the wider community but also within the family home and immediate family (Murphy *et al.*, 2015a). Instead, their initial learning about mental 'illness' was derived through media representation and the inferred

attitudes of the adults around them (Cogan, Riddell and Mayes, 2005). This left the children feeling that they were left to make sense of the world through silence which in turn inhibited them from developing crucial elements required within resilience (Power *et al.*, 2016).

Children spoke of utilising different methods to make sense of their childhood experiences, such as creating a make believe world within which they could explore their emotions (Murphy *et al.*, 2016) or catching glimpses of the home lives of their peers (McCormack, White and Cuenca, 2017). However with the often unpredictable nature of their parent's mental ill health their sense of meaning was rarely fixed, stable or secure (Slominski, 2010). Their ability to comprehend the information given to them and the complexity of the information itself also changed as they travelled through childhood, adolescence and into early adulthood (Nilsson, Gustafsson and Nolbris, 2015). The importance of information was key across all of the studies, as was the sense that, for the child's emotional wellbeing, understanding and perspective was more important than the experience itself (Harstone, 2010).

Psychological impact on children

The strength of the impact that parental mental ill health had had upon participants was clearly illustrated throughout the cohort of 28 studies. However, contrary to previous literature which had focused on physical, developmental and material risks to the child, these studies giving voice to the children themselves drew primary focus on the psychological impact of living with fear, stress and uncertainty (Valdez, Chavez and Woulfe, 2013; Murphy *et al.*, 2015b). In the Knutsson-Medin, Edlund, & Ramklint (2007) study which involved 36 adult offspring of psychiatric patients, many of them recalled feelings of shame, loneliness, insecurity, anger and lack of confidence combined with a physical sense of poor concentration, stomach pain and feeling unable to enjoy things. When combined, this would suggest that they themselves were experiencing symptoms of depression within their childhood. This was also suggested in several other studies which linked the lack of understanding and unpredictability of their parent's mental ill health as being significant factors in the psychological impact of their experience (Foster, 2010; Power *et al.*, 2016; McCormack, White and Cuenca, 2017). This compelled them to develop a sense of hypervigilance

towards distress and risk, which could become overwhelming and contaminate their view of the world around them (Murphy *et al.*, 2015b). As discussed earlier, the child's own perspective was key to the emotional impact felt. The severity and chronicity of the symptoms were more important than the diagnosis of the parental mental ill health (Harstone, 2010; Kaimal and Beardslee, 2010) and manifestations of mental ill health which may have been deemed marginal by professionals, could still be experienced as harmful by the children exposed to them (Cogan, Riddell and Mayes, 2005).

Much of the psychological impact experienced by children was rooted in their lack of understanding and subsequent sense of self-blame (Ostman, 2008). There was also an impression that it was not related to the burden of the care tasks or their parent's disability, but rather to the overarching feelings of bereavement and grief for the loss of their parent. This was poignantly illustrated by one of Duncan and Browning's participants who described not feeling able to grieve for her mother as she was there, yet still feeling that she was "living with a ghost" (2009: 81). Another sense of hurt came from the loss of their own childhood which they felt was taken from them along with the care and protection they felt they should have received from their parents (Valdez, Chavez and Woulfe, 2013; McCormack, White and Cuenca, 2017).

Vulnerability

This impact was compounded by other adversities and risks that the children were exposed to, with many studies focusing specifically on experiences of abuse both within and outside of the family home (Duncan and Browning, 2009; Bee *et al.*, 2013; Valdez, Chavez and Woulfe, 2013; Murphy *et al.*, 2015b; Tabak *et al.*, 2016). Bee *et al.* (2013) spoke of the multiple risk factors that children were exposed to and the fact that within this dialogue of risk, parental mental ill health was overlooked. However other studies have suggested that growing up with a parent with mental ill health may increase the vulnerability to external abuse, partially because these children are less likely to be socially connected and visible (Murphy *et al.*, 2015b). They also considered themselves to be more self-sufficient and therefore had an expectation for themselves that they should be able to cope with risky environments or unpredictable situations within which they are vulnerable without support (Duncan and Browning, 2009).

Finally, the debilitating effects of their parent's mental ill health may mean that they were less able to safeguard their children, recognise signs of vulnerability or abuse and respond in a sufficiently robust or emotionally attuned manner (Valdez, Chavez and Woulfe, 2013; Tabak *et al.*, 2016). The different representation of risk and vulnerability between the focused studies of the child's perspective and what can be gleaned from professional assessment and intervention in the larger body of the research suggests that this issue is underestimated. This interesting discrepancy needs to be explored further and could be linked to the invisibility of the children and the masked nature of their needs.

The impact and vulnerability that participants recalled experiencing as children carried through into their adult lives, impeding their developmental transitions more than would ordinarily have been expected (Kaimal and Beardslee, 2010). Several studies highlighted the difficulty in balancing their parent's needs with their own. This included the tension between being overinvolved and at times engulfed, with maintaining a safe distance or detaching themselves from their family entirely. Either way, moving on and developing a sense of self as an adult was extremely difficult for many (Mordoch and Hall, 2008; Griffiths *et al.*, 2012). Practically, this was difficult for individuals who had to continue to provide care for their parent (Foster, 2010). Emotionally, it carried forward into their adult relationships, within which they reflected upon themselves as needing to feel in control, or caught in a cycle of obligation, control, resentment and guilt (Foster, 2010; Valdez, Chavez and Woulfe, 2013).

Valdez et al., (2013 :1098) spoke of the tendency some seemed to demonstrate towards becoming "wounded healers", where they would be drawn to a caring profession in order to make use of the skills they had developed as children (Petrowski and Stein, 2016) or in order to attempt to make sense of the experiences they had had as children (Murphy *et al.*, 2016). A more fatalistic explanation for this draw towards the care profession is that it could be indicative of the children's limited opportunities or resources to imagine themselves in any other role rather than providing care for another (Valdez, Chavez and Woulfe, 2013).

Gaps in the literature

All of the studies examining the subjective experiences of children originate from Western societies, with interesting differences in Australia and Scandinavia where there is a more developed socio-political framework regarding the recognition of children of a parent with a mental illness (COPMI) and their needs and rights (Morson *et al.*, 2009). While the UK does not currently have this model of service provision, there is an established network of young carers support organisations from which a majority of the studies were drawn. The samples for the American studies on the other hand were predominately recruited from universities. This may represent an overall sample bias towards supported, high functioning, articulate participants, which when considered in conjunction with small sample sizes across the studies, speaks of the hard to reach nature and ethical issues of this research area. However I feel that it is important that future research goals should include reaching out to a wider representation of participants.

There is very little published research on cultural diversity, for example the impact of different cultural frameworks of mental ill health. Additionally, given the correlation between mental ill health and social disadvantage, more attention could be given to subsequent impact this has upon the children growing up in these families.

As an emerging field of research there remain several areas of enquiry which could be explored further, this study intends to address some of the gaps in the knowledge, specifically around the findings of relationship, identity and impact on adult identity.

Summary

While this field of research is still relatively new and developing, there are seminal works such as Maybery *et al.* (2005); Aldridge (2006); Ostman (2008); Trondsen (2012); Grové, Reupert and Maybery (2016) over the past two decades which have spoken about the needs of children who grow up with a parent with mental ill health. Across all studies, regardless of their focus (risk, outcomes and experiences) the need for further understanding and action in this area is clear.

The emergence of research directly examining the subjective experiences of these children is powerful and as a result, new directions of enquiry are presenting

themselves. However there are also key themes of stigma, lack of information and support which have been conclusively demonstrated across the breadth of published research. The fact that these themes have remained largely unchanged, perhaps speaks to the ongoing social invisibility of these children and calls for a more driven approach to raise awareness and inform social policy and service provision.

Chapter Three

Models of coping

Introduction

Through messages drawn from the existing body of research relating to children's experiences of parental mental ill health and the emergent findings of this study, it became apparent that both children and adult offspring of parents with mental ill health can face short-term incidents and longer-term circumstances for which they have to develop coping strategies. Indeed this study's initial findings indicate a level of distress that reaches further than has been previously reported and considered in the existing body of literature. In response to this, I explore the core concepts that will allow me to construct a theoretical framework through which such significant distress may be understood. This includes the impact of stress and trauma, what is meant by coping and how resilience is developed as an adaptive coping strategy.

An understanding of stress and trauma

Originating from the 1930s, there are many theoretical views of what constitutes [human] stress. Historically, stress is drawn from an adult perspective and it is only in recent years that the stress experienced by children and adolescents has been considered (Skinner and Zimmer-Gembeck, 2007). The concept of stress itself, was originally borrowed from physics, where humans are compared to metals, which can resist moderate amounts of force but will inevitably be weighed down or bent under extreme pressure (Frydenberg, 2008). However this model does not factor in the individual nature of human beings, both in the way they respond to stress according to their personality, perceptions, resources, environment or indeed the context in which the stress occurs. The duration and persistence of stress is another important factor to take into account. Acute time limited stress such as sitting an exam, or a chronic stressor such as an ongoing illness, have markedly different potential consequences for the individual's long-term outcomes. Described as the phenomenon of persistent

anxiety, it is the continuance of stress which has an impact on an individual's well-being and motivation (Manning, 1996). Combining these factors leads to a more nuanced view such as that espoused by Lazarus (1991), who proposed that stress occurs where there is an imbalance between the demands of the environment and the perceived resources of an individual.

For some children, stress coincides with trauma, for example as a witness to a traumatic event or as the victim of abuse. The long-term consequences of this trauma are mediated by several variables, such as the genetic make-up of the child, the nature of the trauma and the social and cultural context within which it occurred (Everett and Gallop, 2001). The child's personal experience of the stress or trauma is also key, in terms of how it is situated within their family and environment and the associated level of perceived contextual threat it carries for them. Contextual threat for a child can include; loss of an attachment figure, loss of a valued idea, physical jeopardy, witnessing trauma and psychological challenge (Sandberg and Rutter, 2015). It is clear from the literature that many children growing up with a parent with mental ill health experience a significant level of stress which is both persistent and carries a high level of contextual threat, and as such can be significant to the way in which they are able to make sense of and cope with their parent's illness.

Another aspect of trauma which is pertinent for children growing up with a parent with mental ill health would be that of secondary trauma. Initially related to the transference of trauma from survivors (through) to a mental health professional, Lombardo & Motta (2008) propose that secondary trauma is not exclusive to the therapeutic relationship, and can also be identified in close family members. Indeed, the nature of the relationship is key in the transference of secondary trauma. If a person is significantly dependant on the victim of the trauma (as a child would be on their parent) the level of secondary traumatization may be worse than the trauma experienced by the victim themselves (Lombardo and Motta, 2008).

When does stress become abuse?

As discussed, trauma refers to a severely distressing event or events during which an overwhelming amount of stress exceeds an individual's ability to cope or integrate the

emotions involved with that experience. It is an emotionally painful or distressing phenomenon which often results in lasting mental and physical effects (Pilgrim, 2017). However trauma is a broad term encompassing a range of events, from single to multiple, natural disaster to conflict within the home, and as such distinct from the concept of abuse. While the correlation between trauma and abuse is complex and nuanced, the level of trauma associated with abuse is dependent on factors such as the specific nature of the abuse, the relationship between the victim and the abuser and the support that maybe available within the individuals family and friend networks (Everett and Gallop, 2001). The level of ongoing trauma is also shaped in part by the manner the individual is able to reflect on and react to the event, ranging from feeling isolated and helpless, to seeking support from others or taking agency and seeking redress.

Internationally abuse is defined as maltreatment and is defined as

“Any act of commission or omission by a parent or other caregiver that results in harm, potential for harm, or threat of harm to a child. Harm does not need to be intended”(Gilbert *et al.*, 2008:7)

It refers to non-accidental behaviour by individuals who hold a position of perceived power over a child, such a parent, caregiver, other adult or older child, which result in significant harm (Howe, 2005). Definitions of significant harm within the Children Act 2004 and the Children Act 1989 are concerned with the health and development of the child and how it could be compared with that which is reasonable to expect of a similar child and the parenting that we would reasonably expect them to receive from their parent/carer. It can be associated with both acts of omission or commission and as such is not indicative of intent.

Few studies concentrate on the correlation between parental mental ill health and an increased risk of child abuse or significant harm. It is clear that such a correlation could not be made with any strength or certainty and indeed an attempt to do so would overly simplify a vastly complex area and further stigmatise and discriminate against the parents and families that function well. However the interaction between mental ill health and other key factors such as its chronicity, severity, interpersonal difficulties

and psychosocial stressors can combine to place children and young people at risk of significant harm (Maybery, Reupert and Patrick, 2005; Morson *et al.*, 2009; Falkov, 2015). There are also the intersectionality and accumulative effect of risk factor such a parental mental ill health and substance misuse which can increase risk for children (Halliwell, Main and Richardson, 2007). This is reflected in trauma literature and serious case reviews (Sidebotham *et al.*, 2016). Physical and sexual abuse are more readily identified and defined, however descriptions of emotional abuse and neglect can be presented in a more nuanced uncertain manner.

Neglect in Working Together (HM Government, 2015) is defined as a persistent failure to meet a child's basic physical and/or psychological needs, including:

- Failure to provide adequate food, clothes and shelter
- Failure to protect a child from physical and emotional harm
- Failure to provide adequate supervision
- The neglect of, or unresponsiveness to a child's basic emotional needs.

(Jütte *et al.*, 2017)

Similarly, taking from the NSPCC 2017 report emotional abuse is defined as the persistent emotional maltreatment of a child, which could take the form of:

- Conveying to a child that they are inadequate, unloved and worthless
- Preventing or silencing them from expressing themselves
- Preventing them from participating in normal social opportunities
- Only valuing them insofar as they can meet the needs of another person
- Exposing them to interaction beyond their developmental capabilities.
- Bestowing on them expectations that are age or developmentally inappropriate
- Exposing them to witnessing the ill treatment of another
- Causing them to feel frightened or in danger

(Jütte *et al.*, 2017)

While taking care to avoid the potentially reductive abused-abuser theory (Kutuk *et al.*, 2017) with regards to parents with mental ill health, there could be aspects of intergenerational transmission of trauma (de Zulueta, 2006). There is a substantial body of evidence which indicates that experiences of child abuse can be a significant

causal factor in adult experiences of mental ill health, ranging from post-traumatic stress disorder and depression to psychosis and dissociation (Read *et al.*, 2005). Indeed studies suggest that psychiatric patients who have a childhood history of abuse (sexual or physical) have a higher rate of global symptom severity, receive longer admissions, spend more time in seclusion and display higher rates of self-harm and suicidality (Mullen *et al.*, 1993). Memories of childhood abuse and trauma can be triggered for the parent themselves as they experience their own children. As such they can get caught in a cycle of relived trauma which effects their mental health, their view of themselves as parents and their perception of how others would view them (Herland and Helgeland, 2017). Similarly parents with an insecure attachment pattern and a lack of mental representation available to them (as discussed in chapter one), overlaid with the disorganised cognition or emotional lability that can be associated with mental ill health, may be unable to provide a consistent and predictable response to their child. In severe cases this could mean that unwittingly “the caregiver not only induces traumatic states in her child but she cannot interactively repair the infant’s negative affective state” (de Zulueta, 2006: 338)

This consideration of the unintentional potential impact of parental mental ill health constituting a level of emotional abuse and/or neglect, parallels the acknowledgement that significant exposure to domestic violence is in itself a form of emotional abuse (Holt, Buckley and Whelan, 2008; Kitzmann *et al.*, 2013; Wortham, 2014). However, it is important to note that in contrast to exposure to domestic violence which is always harmful to children, the presence of parental mental ill health does not, in and of itself, necessarily indicate a risk of harm to children (Sidebotham *et al.*, 2016). Emotional abuse and neglect are by no means a factor in every child’s experience of growing up with a parent with mental ill health, but rather represents the far end of the spectrum of experiences. However for the minority of children who do experience such maltreatment it is significant in how they adapt as children and the impact that continues through to their adult life.

What is coping?

As discussed earlier, the parenting and the family system have an overriding influence and importance in an individual’s experience of childhood. Culturally, Western

children are generally both physically and emotionally dependant on their parents. Thus, a factor such as severe and enduring mental ill health experienced by a parent or close family member is likely to impact upon the child. The child, in turn, has little option to walk away from the situation and as such needs to develop ways to cope, to adapt, adjust and respond. These coping strategies alongside the impact of the mental ill health, the child's awareness and other influential factors in their life can be fluid, shifting and changing across the course of their childhood. Understanding the reasons for these shifts and the significance for later life is reflected within the research aims of this study.

Coping is defined as cognitive and behavioural efforts to manage external and internal stress and trauma (Rutter, 2006; Goldstein and Brooks, 2013). It is a complicated process, which changes across an individual's life course and is influenced by a multitude of factors. These encompass the nature of the individual placed under stress, their family coping style, and their social and cultural influences such as socioeconomic status, gender and ethnicity (Skinner and Zimmer-Gembeck, 2007; Frydenberg, 2008; Power *et al.*, 2016). Recognised as one of the most widely examined areas in psychology, research examining coping behaviours in children and adolescents has evolved from stress research. However it has moved from a deficit model of adaptation to one which explores the individual's capacity to manage adversity (Frydenberg, 2008). Previous studies have attempted to measure children's general coping styles and have relied on reports of overt behaviours of managing stress (Park and Schepp, 2014). However, in their longitudinal study of the specific stress of parental depression, Langrock *et al* (2002) identified that alongside these overt coping skills children also demonstrated covert cognitive responses. These included strategies to regulate their own emotions and adapt rather than trying to change their parent's behaviour or emotional state (Langrock *et al.*, 2002; Jaser *et al.*, 2005; Lombardo and Motta, 2008).

Taking the concept of overt and covert coping behaviours further, Fraser and Pakenham (2009) separated coping into voluntary and involuntary engagement with stress. Voluntary coping strategies include primary control skills which are demonstrated as problem solving and emotional regulation actions which seek to

directly manage the stress or their own emotional response to the stress. Secondary control skills facilitate the child's adaptation to the stress through cognitive restructuring and acceptance. Then finally occurs voluntary disengagement, where the focus is purposefully shifted away from the point of stress. Involuntary coping includes involuntary engagement of emotional and behavioural responses that are directed at the stressor, such as rumination or impulsive action and involuntary disengagement such as emotional numbing and cognitive blocking or denial of stress. In terms of outcomes and adjustment, research indicates that both primary and secondary voluntary engagement, are associated with better outcomes than voluntary disengagement and involuntary engagement (Lombardo and Motta, 2008; Fraser and Pakenham, 2009).

The activation of voluntary coping strategies suggests a level of awareness and a cognitive grasp of the stressor. Within the literature this is sometimes referred to as appraisal, which has a key role and influence on the coping process and the subsequent outcomes for a child. The ability to cognitively appraise the situation informs each stage of the coping process, from initially assessing the nature and level of the threat, to the child's reflection on what resources are available to them and finally evaluating how effective their efforts were (Frydenberg, 2008). However given what is known about the lack of understanding some children have of their parent's mental ill health and the risk of secondary traumatisation, it is reasonable to predict that this level of cognitive appraisal may not be available to many children growing up with a parent with a mental illness. Without guidance and support, these children could adopt maladaptive coping strategies which could fuel a negative spiral of emotional and behavioural patterns (Manning, 1996). These include distancing, (Harris *et al.*, 2016) behavioural disengagement and self-blame (Perlman *et al.*, 2016).

Both cross-sectional and longitudinal psychological studies have indicated that children's application of coping strategies shifts from their early, middle to late childhood beginning with avoidant and moving towards problem-solving and emotion-focused strategies (Maybery *et al.*, 2005; Frydenberg, 2008; Helitzer *et al.*, 2015). There are also gender differences noted in coping styles (Hampel and Petermann, 2005). However, these findings are based around a generalised idea of coping as

opposed to being contextualised within the need to manage a specific and extraordinary level of stress such as maltreatment and abuse (Park and Schepp, 2014).

In these specific cases, coping becomes equated with survival for the child, and as such, has been considered theoretically, in terms of attachment and accommodation. With respect of the parent/child relationship and attachment patterns, avoidant, insecure and anxious attachments are correlated with higher rates of maladaptive coping behaviours. These maladaptive behaviours include self-blame, behavioural disengagement and substance misuse. Subsequently, this reinforces negative attachment representations, which may have a long lasting impact on intra and interpersonal relationships, hinder the development of critical skills such as emotional regulation and distort internal working models of self and the world around them (Perlman *et al.*, 2016).

The specific interplay between attachment patterns and the effects of trauma and neglect has been explored by de Zulueta (2006) who proposed a potential consequence of dissociation for the child. The child's initial response to trauma is fight or flight as mediated by the sympathetic nervous system. However if neither fight nor flight is possible the parasympathetic system takes over, causing the child to psychologically freeze. As such, in response to a traumatic experience which encompasses a high level of perceived helplessness or "fear without solution" (de Zulueta, 2006: 339) both the sympathetic and parasympathetic responses are activated resulting in an 'inward flight'. Defining this as a dissociative response, de Zulueta describes the child creating a different mental representation of self in relation to their care giver. They develop an idealised version of their caregiver which enables them to maintain a sense of closeness and connection. However in order to retain this idealised portrayal of their caregiver they must cognitively attribute the blame, shame and responsibility of their own suffering to themselves. While psychologically protecting their attachment with their parent they also seek to find a way they can exercise agency in the situation; if I am to blame then I just need to try harder, behave better and then I will be able to get the love and care I crave. This strategy of moral defence can be deeply ingrained in the child and fiercely maintained in an attempt to protect themselves from feeling overwhelmed and helpless.

As with dissociation, accommodation can exemplify a protective strategy employed by both children and adults. In considering the concept of accommodation inferences can be drawn from Summit's (1983) Child Sexual Abuse Accommodation Syndrome. Despite criticisms being levied against its theoretical validity and the inaccurate manner in which it has been applied within a legalist and forensic sphere (O'Donohue and Benuto, 2012), the components of secrecy, helplessness and entrapment and accommodation (Summit, 1983) resonate with the traumatic experiences of children growing up with parental mental ill health. The isolation, stigma and fear of the experience of abuse imbues secrecy as both a source of fear and promise of protection. This secrecy also feeds in to the child's sense of helplessness. It is known that the inherent powerlessness and dependence of childhood can leave children feeling helpless and unable to communicate their feeling to uncomprehending adults. As such they instinctively learn to cope silently with their abuse (O'Donohue and Benuto, 2012). Their lack of ability to express themselves and reach for help in order to elicit change means that the child is left entrapped within maladaptive and potentially damaging relationship with no other option but to accommodate to the circumstances they find themselves in.

This accommodation does not just relate to the physical and psychological aspects of the abuse, but also within the context of children growing up with parental mental illness, the potential distortion of their relationship with their abuser, especially if that person is their parent. To conceptualise a parent, whom society projects as protective, loving and central to a child, as villainous and harmful would be tantamount to self-annihilation for that child (Summit, 1983). To avoid this, the child may construct a narrative in which it is themselves that are at fault, and with it, the hope that if they learn to be 'good' they would earn the love, acceptance and protection that they have been promised. Summit (1983) also described a 'classic role reversal' within which the abused child is bestowed with the power to destroy the family (by telling) and as such, bears the responsibility to keep them together. Therefore it is the child, not the parent, who must demonstrate the altruism and self-control to ensure the survival of others within the family.

Reflecting once more on what is known about the fear and distorted relationship expressed by some children who had experienced significant trauma while growing up with a parent with mental ill health, dissociation and accommodation speaks in some part about the emotions and adjustments they recalled. However it is important to note there are also many accounts of children whose parents had mental ill health and who experienced significant and persistent stress during their childhood and yet appeared to cope well, emerging into adulthood unscathed. This phenomenon is often conceptualised as resilience.

Resilience

Resilience is generally defined as a capacity to overcome adversity, or to thrive despite challenges or trauma (Trondsen, 2012; Power *et al.*, 2016). It encompasses the concept of successful adaptation (Moe, Johnson and Wade, 2007; Erdem, 2017) and the avoidance of maladaptive responses and long-term negative outcomes (Zolkoski and Bullock, 2012; Goldstein and Brooks, 2013). Moving away from the representation of a static portrayal of the presence or absence of risk, resilience represents a protective process in which developmental and situational mechanisms are applied in response to stressors (Rutter, 1987; Goldstein and Brooks, 2013). Within this process it is noted that different individuals respond differently to multiple stressors and that some individuals faced with recognised risk factors appear not to be adversely affected (Rutter, 1987; Moe, Johnson and Wade, 2007; Sandberg and Rutter, 2015) where others seem to be disproportionately troubled.

Drawn again from physics, resilience is likened to a material which is able to resume its original shape after being stretched, compressed and bent (Goldstein and Brooks, 2013). The concept was adopted by medical scholars in the 1970s as they began to recognise that some children who were considered to be at significant risk of developing psychopathology, namely children with schizophrenic parents, appeared to remain unaffected by their parent's illness (O'Dougherty Wright, Masten and Narayan, 2013). These children were referred to as 'invulnerable children' and were regarded as remarkable exceptions to the norm (Moe, Johnson and Wade, 2007; Zolkoski and Bullock, 2012; Goldstein and Brooks, 2013). However, as academics from the behavioural sciences began to examine this invulnerability, it was conceptualised as

resilience and was seen to be at one end of a continuum with vulnerability at the opposite end. Understanding what resilience was and how it acted as a protective factor against the development of psychopathology, made up the first of three waves of research in this area (Zolkoski and Bullock, 2012). From recognition and definition, the second wave emerged to develop an understanding of the fluid nature of resilience as a process and began to account for the protective factors inherent within resilience. Finally the third and current wave has arisen through an urgent imperative to respond to the needs of children growing up surrounded by adversity and, as such focuses on promoting resilience through prevention, intervention and policy (Zolkoski and Bullock, 2012; Goldstein and Brooks, 2013). This effort to promote resilience reflects a belief that everyone is born with an innate capacity for resilience (Zolkoski and Bullock, 2012). Indeed Benard described how “resilient children work well, play well, love well and expect well” (1993 p44) and as such they present with five attributes:

- Social competence – this includes flexibility, empathy, and sense of humour and communication skills. Socially competent children are able to easily establish positive relationships with adults and peers and as such feel accepted and close to those around them.
- Problem solving skills – such as the ability to think abstractly and generate problem solving solutions. They demonstrate an ability to plan and seek help and resources from others.
- Critical consciousness – which involves having an insight in to the structures of injustice and the aptitude to generate strategies to overcome it.
- Autonomy – this is understood as a person having a clear sense of their own identity and the capability to act independently, exerting some level of control over their own lives and experiences.
- Sense of purpose - referring to holding personal goals, educational aspirations and a belief in a positive future.

(Benard, 1993; Zolkoski and Bullock, 2012)

In more recent research these attributes of resilient children are seen in conjunction with other family and environmental factors such as positive attachment relationships, family structure and community based activities (Pretis and Dimova, 2008). The age,

gender and culture of the child is also recognised as influential in how their resilient behaviour is activated and understood (Slominski, 2010; Goldstein and Brooks, 2013; O'Dougherty Wright, Masten and Narayan, 2013).

Along with an increasingly nuanced understanding of the attributes of resilient children, research has also further explored the interaction between the other factors which contribute to resilience. These factors are defined as risk and protective factors and the relationship between them is the key tenet of resilience. Rutter asserts that “protection in this case resides, not in the evasion of the risk, but in successful engagement with it” (1987 p318). Risk factors refer to adverse life circumstances which result in the experiences of stress and trauma discussed earlier in the chapter. The circumstances that are considered risks for children, fall beyond the pressures and difficulties that would be expected within the general population. Parental mental ill health has been recognised as a key risk factor in the development of resilience as a theory as seen in the early studies of children growing up with parents diagnosed with schizophrenia (Zolkoski and Bullock, 2012). Additionally the fact that children growing up with a parent with a mental illness, or substance misuse, or homeless for example, are considered within a minority, is a key factor that exacerbates the risk factor (Zolkoski and Bullock, 2012). This happens not only due to the perceived level of threat to the child (Slominski, 2010) but also as a result of the stigma, silence and isolation that surrounds them (Trondsen, 2012). Protective factors are predominately internal genetic characteristics of the child, such as easy going temperament, hardiness and intelligence (Skinner and Zimmer-Gembeck, 2007; O'Dougherty Wright, Masten and Narayan, 2013). They also include family conditions, such as family size and cohesiveness as well as socio-economic and educational status (Zolkoski and Bullock, 2012). The role of family within resilience has been brought to the fore by recent research, as maladaptive coping had been attributed to insecure attachment. Erdem (2017) describes resilience as a positive outcome of secure attachment.

The consideration of the individual, family and environmental factors within both risk and protective factors form the biopsychosocial model of resilience, which notes the multiplicity of risk factors and the accumulative effect of stressors. These present a higher risk of negative outcomes than an isolated incident of trauma (Goldstein and

Brooks, 2013). The differences in the interaction between risk and protective factors are also reflected in the challenge models of resilience (Zolkoski and Bullock, 2012). Echoing the potential of the 'steeling effect' (Rutter, 1987; Gladstone, Boydell and McKeever, 2006), the challenge model treats stress as a possible enhancer of protective factors and resilient competence. The level of stress is crucial in this model, too little is insufficiently challenging to elicit change, whereas too much could result in the development of maladaptive behaviour.

Resilience, competence, social system modification and empowerment are the four attributes that indicate wellness in a child (Goldstein and Brooks, 2013). This somewhat contradicts the dominant medical model's measurements of (or the lack of) pathology in the child. This by definition presents a challenge for mental health professionals who are trained to look for symptoms which equate to psychiatric disorder, inadequate adaptation and distress (Goldstein and Brooks, 2013) as opposed to evidence of wellbeing and positive factors such as competence or empowerment.

Born of medical and behavioural science the concept of resilience itself has been criticised for the dominance of pathological and individualistic ideologies which distract from the everyday processes, wider context and incidental effects that have an impact on children (Trondsen, 2012). This places the onus on the resilient child to adapt and protect themselves against adversity as opposed to requiring professionals and society to intervene to alleviate the adverse pressures (Gladstone, Boydell and McKeever, 2006). It also does not account for the fact that resilience can ebb and flow throughout a child's life depending on their circumstances and the stressors they face. Furthermore children can also learn to mask their fear and distress by creating a false account of resilience to professionals (Rutter, 1987; Sandberg and Rutter, 2015) and are vulnerable to having their needs underestimated or overlooked.

Another criticism can be that research into resilience is concerned with the avoidance of adult pathology. The identification of the risk of developing mental ill health is a heavy burden for a child to carry and can add, exponentially to their stress and denial. The exclusive focus on adult outcomes disregards the current experiences of the child (Gladstone, Boydell and McKeever, 2006). Childhood is constructed as a critical period of development during which children require protection because of their physical and

psychological vulnerability, however this developmental model is rebuked for presenting an image of the child as passive and unfinished. Viewing childhood as a preparatory rather than a participatory phase of the life course neglects reaching for a phenomenological understanding of the everyday realities of the child. This overlooks the individuality of children and the distinctiveness of their situations, instead promoting universal claims about children's thoughts feelings and behaviour (Trondsen, 2012). It also neglects the subtleties of the processes of resilience and the negotiation of both risk and protective factors (Rutter, 1987).

Indeed a life course perspective is crucial in considering developmental psychopathology and the significance of resilience in gaining a sense of recovery from early adversity (Maughan and Collishaw, 2015; Rutter, 2015). Longitudinal research consistently demonstrates that the majority of adult mental ill health arises from childhood and childhood emotional and behavioral difficulties can often have a sequela which persists into adult life. Equally extensive well-replicated evidence demonstrates the associations between exposure to early adversity and the risk poor mental ill health and poor outcomes in adulthood (Maughan and Collishaw, 2015). In terms of early adversity, both chronic stress and acute traumatic experiences have been implicated, these represent in a wide range of experiences which include abuse, neglect, parental mental ill health and socio-economic disadvantage (Sandberg and Rutter, 2015). It is understood that children can simultaneously be exposed to multiple adversities and the cumulative effect of this, increases the risk of poor outcomes in adulthood. However the reduction of adversity where possible, combined with the addition of protective 'buffers' (Rutter, 1987) could mitigate some of the risk associated with adversity which cannot be removed (Maughan and Collishaw, 2015)

Reviewing research that directly explored the experiences of resilience for children who grow up with a parent with a mental illness, protective buffering factors emerged. These included; an awareness of the mental illness, being able to communicate their experience and being able to distance themselves from the emotional experience of the parent, to enable them to not feel guilty and promote self-esteem (Rutter, 1987, 2015; Polkki, Ervast and Huupponen, 2005). Additional challenges of growing up with a parent with mental ill health were raised by Pretis and Dimova who advocated that

“living with a mentally ill parent continually challenges the coping mechanisms of young children, and absorbs energy in terms of the child’s global functioning” (2008 :154). Yet they can be habituated to actively hide their emotions and not seek help for themselves (Murphy *et al.*, 2016), the most extreme manifestation of this would be a false presentation of responsibility, adjustment and resilience which gives professionals the space to avoid their responsibility to support the family (Gladstone, Boydell and McKeever, 2006; Rutter *et al.*, 2008; Trondsen, 2012). However it can also be argued that the stresses they face reach beyond a simplistic grounding in parental mental ill health and speak of a wider societal context. From this perspective activities such as providing care can be an adaptive coping mechanism and a protective factor for the child (Aldridge, 2002; Gladstone, Boydell and McKeever, 2006) and the parental mental ill health could be less damaging than the associated social disadvantage (Gladstone, Boydell and McKeever, 2006).

Summary

Initially related to adults, the understanding of stress and trauma is increasingly examined in connection with children and young people. The correlation of trauma and secondary trauma are at times associated with the experience of growing up with a parent with a mental illness, and in extreme cases this could fall within the conceptualization and definition of child abuse. Human nature denotes that individuals developed coping strategies in response to stress and trauma, some of which have maladaptive consequences for the child’s long term development. The models of Accommodation Syndrome and Stockholm syndrome are discussed and used as a conceptual frame which in some parts mirror the reported experiences and coping strategies of children who grew up with a parent with mental ill health and concurrent adversity. However given the right conditions and support, adaptive strategies can be developed and resilience can be established.

Chapter Four

Making sense and Identity

Introduction

In order to consider the impact a parent's mental ill health may have had upon a child and the subsequent influence coping strategies developed in childhood and maintained through to adulthood might have had, we need to reflect on the effect it has had upon their identity. To do this we must first have a sense of what we mean by the term identity; how identity is developed through adolescence into adulthood and how it is represented and strengthened through narratives, both of self and other. Finally the effect of stress and trauma upon identity will be reflected upon through the use of autobiographical memory and redemption stories.

What is identity?

"In the social jungle of human existence there is no feeling of being alive without a sense of identity" (Erikson, 1968 p130).

The concept of identity encapsulates the human need to understand self. While we can identify with particular groups and often enjoy the sense of belonging and connection, personal identity enables us to simultaneously recognise ourselves as individuals, independent and unique (Edwards *et al.*, 2006).

Presented as a psychosocial phenomenon, Erikson (1968) conceptualised identity as an interplay between biological endowment, personal experience and the cultural milieu. It is from this that we are able to draw meaning, form and continuity from the unique human experience. Identity is also linked closely with self-concept, the cognitive schema that comprises beliefs about self and rules for living and self-esteem which can be understood as the personal evaluation of self and self-worth (Manjula and Raguram, 2009).

As Erikson asserts, identity is an essential component of the human condition however it is not a static or inherent factor, nor is it conferred. Identity is a result of an exploratory, integrative and self-reflective process (Marcia, 2006). Erikson (1959) focused his theory of identity around the crisis of role confusion and subsequent resolution of identity attainment. This theory was elaborated by Marcia who hypothesised that rather than a pure reaction to crisis, ego-identity status is achieved through the experience of crisis, combined with a process exploration and commitment to an identity in a variety of life domains (Pasupathi and McLean, 2010). Identity is described as the sense of who you are based upon the reflection of who you have been and the projection of the person you can realistically imagine yourself to be in the future (Erikson, 1968; Marcia, 2002, 2006). The process of exploration and construction of identity could conclude in four different statuses:

- Foreclosure – relates to no exploration having occurred, instead the identity commitment has been conferred from childhood without question
- Moratorium – is defined as the period of exploration with no clear commitment to one specific identity
- Diffusion – refers to an apathy and lack of identity with no remedial exploration or commitment.
- Achievement – is the ideal state within which exploration has resulted in positive commitments and a robust sense of self.

(Marcia, 2006 p.581)

Each of these statuses can be related back to different childhood experiences and strength of the parent/child relationships (McLean and Pratt, 2006) and can be applied to differing relationship patterns, psychological adjustment and coping strategies in adulthood (Marcia, 2006).

However, while identity relates to individualism and the psychological understanding of self, it is not simply a private or internal matter, but one which is highly influenced by the social world, environment and structural context. Aspects such as gender, age, race, class and culture all combine to inform and shape an individual's identity (Edwards *et al.*, 2006) and in turn identity is also viewed through the prism of a

multitude of socially constructed roles or niches, such as parent, academic or artist (Marcia, 2006). These roles not only inform and add to an identity but can also change the manner in which an identity is presented. From a dramaturgical model of self, Miller et al (1990) propose that when a person encounters another person, they project a definition of the situation and thereby make implicit and explicit claims both about the kind of person they are and the aspects of their identity that they are willing to share. Identities are presented in the different domains of life in a manner which is felt to be culturally acceptable and which holds currency in the individuals society and community (McLean and Pratt, 2006). Just as gender shapes and informs a person's identity, research has also shown that men and women portray their identity differently based on the social construction of their gender (Pasupathi, McLean and Weeks, 2009).

Adolescence and the Development of Identity

The majority of research into identity focuses on the period of adolescence (Erikson, 1968; Kroger, 2002; Marcia, 2002; Reese *et al.*, 2010). This is seen as a key point within the life span because of a culmination of transformations of relationships and experiences which occur during this time (Tavernier and Willoughby, 2012). Within Erickson's eight life stages, adolescence is the age of identity vs role confusion, and it is when identity is formed (Erikson, 1968). Whereas Erikson was a clinician and theorist, James Marcia was a researcher who operationalised Erikson's concepts to generate new ideas. Marcia particularly concentrated on adolescence, viewing it not only as a chronological or physiological period between childhood and adulthood, but also as a period of the life cycle during which the individual explores important life options, with the aim of making the commitments crucial for the construction of identity. With this in mind he proposed that adolescence as a period of exploration may be delayed, for example a 15 year old and a 30 year old could both be faced with a level of exploration which would denote them as 'adolescing' (Marcia, 2002). This idea of delayed adolescence was later taken forward by Kaimal & Beardslee (2010) who suggested that the period of exploration and change endured until 25 years old.

Adolescence is also key within the development of identity as an age during which cognitive maturity is achieved, thus enabling an individual to engage in deeper levels of

self-reflection and complex or abstract thinking (Kaimal and Beardslee, 2010). Presented as the period during which children 'wake up' to a new level of self-reflection (Reese *et al.*, 2010), there is a risk that this could diminish the significance of the rest of childhood. As discussed in Chapter three, researchers have appeared to disregard childhood as a passive preparatory period (Gladstone, Boydell and McKeever, 2006; Trondsen, 2012). However this is contested as children are increasingly portrayed as active social actors in their own right. Indeed the experiences of childhood which are taken forward into adulthood, continue to shape and influence identity across the life course (Orellana and Phoenix, 2016). This said, while experiences are brought forward from childhood it is generally agreed that the ability to begin to extract a more sophisticated meaning from life events emerges during late adolescence (Tavernier and Willoughby, 2012). The rate at which these skills are mastered are demonstrated to be significantly influenced by both gender and levels of family or environmental adversity (Kaimal and Beardslee, 2010). Empirical research also suggests that young adults with a secure base relationship with parents, who encourage autonomy while continuing to provide them with a safe haven, also show higher levels of adjustment, self-esteem and potential for identity achievement (Kroger, 2002; Marcia, 2002; Kaimal and Beardslee, 2010). This can be significantly impeded for children growing up with a parent with mental ill health if they do not feel that their parent can represent that safe haven or secure base for them, or indeed, if their exploration and burgeoning autonomy and independence is restricted by the nature of the care they provide.

As ego-identity status grew from Erikson's concept of role confusion and identity crisis, the narrative approach to identity development, developed from Erickson's emphasis on the life span development and psychobiography (Erikson, 1959, 1968; McLean and Pratt, 2006). Within this approach it is understood that humans have a narrative mode of thought, as such, personal story telling plays an important role in the social construction of self throughout the lifespan (Miller *et al.*, 1990). The centrality of narrative, or stories is key to human life and the interrelational understanding between the individual and the world around them. In this model the narrative is not a methodological tool within which the story is assessed in order to gain a

measurement of self, but rather the story is an integral facet of self (McLean and Pratt, 2006). Narratives which embody autobiographical reasoning are characterised by: integrative memories, exploratory processes, meaning making and accommodation/integration (McLean and Thorne, 2003). These characteristics (which will be discussed in more depth later in the chapter) hold similarities with the reflection on experiences and exploration of options, which form the basis of the ego-identity model, thus creating a bridge between the different models of identity.

Narrative Identity

Narrative identity research draws on the everyday meaning making that almost all humans engage with:

We inhabit a world of stories. We wander in and out of them all the time. Yet we do not wander aimlessly. We do not hang on every story that chances across the eye or ear, or recall all the events of our lives. We grab on to certain stories, those that speak to us in some way, that are salient, and help us make sense of what often is a chaotic world. Of course we don't just hear stories: we make stories. It is a reflexive habit: with our uniquely human meaning making abilities, we create stories out of raw experience, out of raw data that the world and our senses provide us. (McLean, 2016 :2)

Experiences and the self are storied into culturally acceptable and valued narratives that hold currency in the individual's community and society. Stories can be told in a multitude of ways dependant on the audience and the perspective, not merely a factual recall or representation of events, they are a story of an experience (Orellana and Phoenix, 2016). In common with other theories of life course development and identity, the narrative model of identity espouses adolescence as a key period for the development of identity narratives. Children wake up to a new level of self-reflection in adolescence and are more able to differentiate between their own voice and that of their parents within their narratives (McLean and Pratt, 2006; Reese *et al.*, 2010; McLean, 2016). However, it can be argued that these developing abilities are built upon the capabilities that have grown through the culmination of childhood

experiences. A continuation of this is that life story narratives are never complete; they are continually revised and restructured through the entire life course (Reese *et al.*, 2010).

By pulling the past into the present, individuals are able to reconceptualise the past over time, in a process of narrative transformation. The autobiographical retelling becomes part of the process of imagining the future. Narratives imbue the individual with a sense of defined identity, answering the questions 'Who am I?' or 'How have I become the person I am today?' They also deliver a sense of consistency and credibility as they give a plausible account that one is the same person now as in the past (Negele and Habermas, 2010; Pasupathi and McLean, 2010; Tavernier and Willoughby, 2012; McLean, 2016). The importance of continuity of the sense of self is mirrored in Erikson's theory of broken self, which he observed through his work with veterans suffering post-traumatic stress disorder. He concluded that the root of their difficulties was situated in the fractured nature of their identities. Unable to fathom their own actions under fire, they had lost the sense of who they were. This meant they lost faith in their plausibility across time and as such, were unable to imagine themselves in the future. Erikson proposed this disconnect with identity and understanding of self could lead to significant mental distress and long-term difficulties (Erikson, 1959; McLean, 2016). This broken self can be seen when a child cannot understand traumatic experiences or their instinctive reactions and coping strategies.

Narratives also reveal (some of) the individual's personality, whether they are an optimistic or pessimistic person, how they make sense of their experiences and how they choose to present their life stories to others. Indeed Pasupathi *et al.* (2009) proposed that significant inference can also be drawn from the stories not told. Given that narratives are not purely personal but also socially constructed, individuals are not always free to construct the life story narrative of their choice and as such their identities can feel constricted or imposed (Miller *et al.*, 1990; Kaimal and Beardslee, 2010). Such constrictions could be culturally determined, for example gender, socioeconomic status or ethnicity which are imbued through master narratives. These master narratives are culturally shaped stories which, communicate what standards and expectations are placed on being part of a community. They guide individuals on

how to belong and how to define themselves. These master narratives are powerful constructs with often exclusionary and stigmatising consequences for anyone who might deviate from them (McLean, 2016). Given that families function as a micro culture, it is reasonable to deduce that they too have master narratives which, like cultural master narratives can create the expectation, rules and scripts of membership of the group. These master narratives can be both structural, such as a much-loved redemptive identity of the family – ‘we work hard and make the best of a bad situation’, and episodic, referring to specific episodes or events that are told repeatedly – ‘remember that time you lost all the family passports’. These family master narratives means that events that have not even been directly experienced by all members of the family may become idealised within the collective memory and therefore adopted in some form into the personal narratives of each member in turn (McAdams, 2006a; McLean, 2016). This also assigns roles and expectations on individual members of the family group, for example the episodic narrative of ‘remember the time you lost all the passports’ translates in to ‘you are the forgetful, unreliable one’, but this may be negative or treated humorously and affectively.

The interplay between individual construction of narrative and master narratives can be illustrated through the narrative ecology of self:



Figure 1: The Narrative Ecology of Self (McLean, 2016 :6)

The Co-Authored Identity

As shown within the narrative ecology, the construction of the personal narratives, which develop identity, is not a purely introspective experience. Not only do individuals define themselves in relation to other people but in turn others also define them. While they select from a plethora of potential stories drawn from a lifetime of experiences, to construct a coherent and plausible narrative arc with which to demonstrate and reinforce their ideology, beliefs, commitments and personal sense of self, they are also simultaneously subject to stories told about them and narratives ascribed to them. As such McLean (2016) expands the narrative theory of identity by advocating that identity is not the work of a sole-author but rather a collaboration of a co-authored self.

Of these 'other' stories, those of parents and families are the most powerful and influential. It is within these stories that identity takes on its earliest and, in many ways

its most enduring form. Parents tell stories about their children in their presence, implicitly providing information about the child's attributes, experiences and importance (Miller *et al.*, 1990). These 'small' stories of childhood accumulate, building into a larger story of self. Whether an individual accepts and values these stories or contests and rejects them, children use their family stories above all else to create and make sense of themselves and their place within the world around them (McLean, 2016). The layering of stories can enforce specific aspects of the child's character, for example if a parent chooses to focus on events when the child has responded in a manner which has been characterised as brave, the child may eventually build a self-concept of self as brave and self-reliant. Consequentially a child who identifies as brave may be more likely to notice and emphasise manifestations of their own bravery in subsequent experiences, thus reinforcing their parents' initial characterisation of them (Reese *et al.*, 2010). The manner in which parents tell everyday stories about their children in their presence is also critical in the development of children's own ability to construct a simple personal narrative from a young age. Not only do the parents' stories provide scaffolding for a child's development of narrative skills (Miller *et al.*, 1990) but also they implicitly convey messages about the significance and organisation of experiences. Parents who structure narratives about the past in a highly elaborative and evaluative form assist their children to develop the skills to tell richer and more reflective accounts of their own past, which in turn strengthens the foundation for enhanced meaning making and construction of a robust sense of self and identity (Reese *et al.*, 2010).

Parents are also individuals in their own right, a fact that is often missed by empirical research which studies them exclusively as parents not as people (McLean, 2016). The stories that parents tell are not simply there to scaffold and craft the narrative identity of their child, but are also a continuation of their own reconceptualising and construction of their personal narrative. As stated earlier, narratives do not represent a factual account of past events but rather the emotional tone and meaning making drawn from experience. As such narratives built around vulnerability, mortality and transformation often come to the fore. As McLean, (2016) suggests often parents resist revealing these stories to their children in the early years of their lives,

predominately because they wish to protect their child from things that might be upsetting or confusing, or they were fearful of altering their child's perception of them. Others feel their child would not be interested or that their story is too painful to discuss. Extrapolating this to parents with a mental illness, research suggest, that this boundary of age-appropriate parental narratives conveyed to the child can become blurred, with the child having to make sense of their parents' narratives of vulnerability and trauma before they feel they are equipped to do so (Polkki, Ervast and Huupponen, 2005; Gladstone, Boydell and McKeever, 2006; Mordoch and Hall, 2008; Ostman, 2008; Foster, 2010; Trondsen, 2012).

As with the adoption of master narratives into the collective memory of the family, parental narrative stories are not only revealed to children but also at times appropriated by them. Children take the stories of their parents and interlace them into their own narratives to create a greater coherence about who they are and where they come from (McLean, 2016). This can also be significant for children of parents with a mental illness, as the weighted significance of the stories could become skewed. This narrative adoption can be seen when some adults are able to give a much more detailed and considered account of their parent's childhood than their own. Also the structural consistency of the story could be obstructive to the development of reflection, flexibility and resilience. A strong sense of self and personal integration is not founded in an identity set in concrete, but rather in one that can demonstrate a level of flexibility within which an individual can reassess, re-evaluate, reconstruct and make new commitments to an ever evolving identity (Kroger, 2002; Marcia, 2006). Strength and resilience is the ability to withstand pressure and challenge and the skill to adjust when necessary. This could be contrary to the fixed and rigid thinking that can be associated with mental ill health (Halliwell, Main and Richardson, 2007). An adolescent, who is experiencing a great deal of development, transformation and identity crisis, during which flexibility and self-reflection are key, may be placed under extreme pressure and conflict while also surrounded by parental identities and family master narratives that are rigid, constrictive and brittle.

Autobiographical reasoning is particularly important when experiencing disruptive and confusing events. When something does not fit with our expectations we need to find

reason and explanation for what has happened. The need to integrate these unusual or unexpected events into our own narratives and to maintain a level of coherence is understood to occur through a process of either assimilation or accommodation (McLean, 2016). Assimilation occurs when the new information is relatively consistent with existing schemas; as such this information can be accepted and incorporated with ease. The assimilation process is defined by the seeking out and attending to information that confirms the individual's existing world view. Its function is to limit instability and maintain the homeostasis which enables the individual to function. Accommodation on the other hand is initiated when an experience is so discrepant with existing schemas it can neither be ignored nor distorted to fit. In this case, schemas are challenged, changed or abandoned. This is a psychologically risky and painful process and can be experienced as highly disruptive to an individual's narrative identity and also the master narratives that surround them.

The manner in which an individual is able to engage with autobiographical reasoning, and the subsequent way they story themselves, adopt or resist the stories ascribed to them by others and make sense of the master narratives around them, has profound implications for their own mental health.

Meaning Making

As discussed earlier in the chapter, narratives based around autobiographical reasoning are characterised by their function of meaning making. Such meaning making requires the ability to metaphorically step back from an experience and reflect on the implications for future behaviour, goals, values and self-understanding (McLean and Thorne, 2003). The emotional tone of experiences and narratives are strongly associated with meaning making. Disruptive events are more memorable, and feelings of conflict and negativity prompt a stronger desire to rework the narrative of the event in order to reduce cognitive dissonance and promote coping, resilience and resolution that may come from narrative reconstruction (McLean and Pratt, 2006; Orellana and Phoenix, 2016). Meaning making in narrative identity can be broken down into two factors, learning lessons and gaining insight. To learn a lesson is confined to a specific experience, and initiates a change in an individual's behaviour when faced with similar situations. Whereas to gain insight, impact is felt in greater areas of life, including

transformation in the manner in which the individual views themselves, their life and relationships, reaching far beyond the specific event experienced.

Meaning making refers to how individuals make sense of events in their life that they would define as turning points. During the turning points lessons are learnt and insight is gained and developed into cognitive transformation and a redemption narrative.

Redemption is a key process in an adaptive identity. This refers to the ability to draw a positive affect from a negative experience (Tavernier and Willoughby, 2012).

Individuals with the ability to situate redemption within their narratives showed higher levels of psychological adjustment and satisfaction in their lives than those unable to engage in this reconstructive meaning making (McAdams *et al.*, 2001).

Narrative identity enables individuals to recall and draw on past events which had initially been beyond comprehension, and in the application of newly developed skills and knowledge, to make sense of them (McLean, 2016). This process is particularly prevalent within adolescence and emerging adulthood, during which meaning making begins to focus more on gaining insight and cognitive transformation than lesson learning, which is more noted at a younger age (McLean and Thorne, 2003). However Orellana & Phoenix, (2016) cautioned against producing a binary between childhood and adulthood as they highlight that the diverse context, situations, activities and relationships of childhood are actively taken forward into adult life, “in this way temporality is not linear: rather, we see simultaneous and continuing traces of the past (childhood) in the present (adulthood)” (Orellana & Phoenix, 2016 :184). Indeed they suggest that the illusory borders between socially constructed stages of life deny the complexity inherent in some childhoods. Specifically these include those that are defined as ‘non-normative’ in that they diverge from the mainstream Western notions of what childhood is and what children should be allowed or expected to do within it. This generalised projection of a ‘normal’ childhood renders a great number of children unseen and silenced. Their experiences are seen as normal and sanctioned within the private domain of the family, but would be met with alarm if brought to the attention of the wider public.

Redemption Stories

Redemption stories refer to the reconstruction of negative events by drawing upon the positive outcomes of potential of emancipation, atonement and upward mobility (McAdams, 2006b). The redemption narrative can also be construed as a reinvention of self and a distancing from the master narrative or family story ascribed to you. As with meaning making, redemption stories are more highly correlated with adversity, mortality and life-changing events as opposed to experiences of achievement and award (McAdams, 2006b; McLean and Pratt, 2006; Tavernier and Willoughby, 2012). Redemption narratives can be applied to experiences of children who grew up with a parent with a mental illness. Participants in McCormack, White, & Cuenca's (2017) study recalled efforts they made to reinvent themselves from a victim, to a strong and resilient individual with enhanced empathy, compassion, tolerance and inner strength. Their redemption narratives enabled them to reflect on an experience and gain a psychological distance from it, for example reframing it as a blessing in disguise, which gave them the opportunity to grow and strengthen.

For many children who grew up with a parent with a mental illness, a key difficulty can be their lack of ability and resources to be able to sufficiently distance themselves from a situation, in order to reconstruct an experience or reinvent themselves. However, from a narrative point of view a psychological distance can be strived for. In the creation of redemption narratives individuals can build in distance, ownership and control, asserting their strength in statements such as 'it's my story' (McLean and Pratt, 2006).

Trauma and narrative construction

It is demonstrated across the body of research that growing up with a parent with mental ill health can have a profound impact on the development of identity; this includes the impact of trauma and the implications for memory. In childhood an individual's self-concept and identity is inextricably linked with their parent (Murphy *et al.*, 2016). Parents are expected to have reached the ego-identity status of generativity (a term coined by Erikson to describe the concern to care for guide and support the next generation in their development) (Erikson, 1959; Kroger, 2002) where

the inherent potential in the child is given the right conditions to flourish (Miller *et al.*, 1990; Marcia, 2002). It is also generally accepted that children with more defined senses of identity and higher self-esteem cope better with adversity (McCormack, White and Cuenca, 2017). However, as the children's narrative, family narratives and parent's narratives entwine with mental disorder, the development of a secure, adjusted identity in the child can, in cases of severe impairment, be distorted, delayed or fractured (Miller *et al.*, 1990; McCormack, White and Cuenca, 2017). In these instances, adult offspring recall losing themselves during their childhood, feeling overwhelmed and overshadowed by their parent's mental illness, unsure of their own emotions, story and sense of self (Murphy *et al.*, 2016). The risk of such impact is heightened with both the severity and chronicity of the parent's symptomatic experience of mental ill health (Kaimal and Beardslee, 2010). This confusion of boundaries, experience and narrative, combined with the necessity to withhold and conceal shameful secrets, or the lack of opportunities to discuss experiences in everyday conversation, means that individuals are not afforded the opportunity to capitalise on the narrative potential of making sense (Pasupathi, McLean and Weeks, 2009).

This disturbance of identity development is exacerbated when additional trauma is involved. The ability to dig deep into painful experiences and narrate personal suffering in an honest and convincing manner is indicative of psychological health and maturity in adulthood (McAdams, 2006a). However this needs to be done with caution. Trauma literature states that individuals who identify a traumatic or stressful experience as central to their identity, also report higher levels of rumination and post-traumatic symptoms (Kaimal and Beardslee, 2010; Harris *et al.*, 2016). The emotional distance that an individual is able to psychologically construct is key to enabling them to make positive meaning from the narrative of the experience (Tavernier and Willoughby, 2012). The reconstruction of what could be defined as survival narratives include themes such as, growth and optimism, grief and loss and self-reliance (Kosenko and Laboy, 2014). The process of reconstruction is key for individuals describing a feeling that a part of them had died during the trauma, thus leaving a gap in their identity (Murphy *et al.*, 2016).

Trauma and autobiographical memory

How people remember their past is a topic of interest within trauma research.

Autobiographical memory is specifically inhibited by a history of childhood trauma or abuse. This constriction of autobiographical memory could be an explanatory factor in individuals feeling a part of them had died as a result of the trauma. There is a hypothesis that reduced autobiographical memory results as part of a protective mechanism or affect regulation strategy which attempts to avoid the unpleasant and intrusive memories associated with childhood trauma (Harris *et al.*, 2016). The psychological impact of traumatic experiences on memory is exacerbated by feelings of guilt, shame and self-blame which are often reported by children who have grown up with a parent with mental ill health (Corrigan and Miller, 2004; Murphy *et al.*, 2015a; Harris *et al.*, 2016). Another strategy of distancing and protecting oneself from the memories of trauma can manifest in making light or minimising the situation (Harris *et al.*, 2016). At the extreme presentation of reduced autobiographical memory, some individuals describe complete gaps or black spots in their memory this is characterised as 'betrayal blindness' (McCormack, White and Cuenca, 2017).

Another theory behind the memory gaps that children who grew up with a parent with mental ill health sometimes experience may be attributed to 'childhood amnesia'. This concept suggests that young children have poor autobiographical memory before the age of three because they do not have the language skills necessary to tell stories as narratives, which enable the retention of memories in a recoverable (narrative/autobiographical) form (Orellana and Phoenix, 2016). It could be inferred from this that such amnesia may affect children who grew up with a parent with mental ill health for longer, as they report not having the cognitive understanding and language to describe their parent's illness nor the opportunity to construct and tell their narratives. Such a lack of autobiographical memory recall impedes the individual's capacity for meaning making, psychological adjustment or identity achievement (McLean and Thorne, 2003; Tavernier and Willoughby, 2012). As with identity, memory recall can shift and change across the life course and individuals social circumstances (Orellana and Phoenix, 2016).

Identity and the Caring Role

Providing sustained care for a parent with mental ill health can have a significant effect on the development of an individual's identity. Difficulties in achievement of identity can be rooted in the lack of opportunities to explore options and make commitments of personal identity, while having to balance reflection on the developing self with the emotional and practical needs of your parent (Marcia, 2002). Continuing responsiveness to the parent's needs also disrupts the separation and autonomous connection which usually signifies the shift in the parent/child relationship during adolescence (Kroger, 2002; McLean and Thorne, 2003; Pasupathi and McLean, 2010). Indeed, this process of adolescent independence and identity resolution can be delayed to emerging adulthood for some children growing up and caring for a parent with a mental illness. Furthermore the way individuals develop their personal narratives and sense of self has a profound influence on their own psychological sense of well-being and mental health (McLean and Thorne, 2003; McLean and Pratt, 2006). However, if the care that a child or young person provides for a parent with mental ill health is disproportionate and carries an exponential level of responsibility, their narratives can be shifted from I/myself to we/us. This is particularly difficult for adolescents who experience a higher level of disruption and change in other major areas of their lives such as education and peer relationships (Kaimal and Beardslee, 2010; Murphy *et al.*, 2016). The additional responsibilities and adoption of an identity as carer can result in the individuals retreating from other aspects of their adolescent transformation (Manjula and Raguram, 2009; McCormack, White and Cuenca, 2017) and assuming a foreclosed identity status with no personal exploration of alternatives, but rather an adoption of commitments conferred from childhood (Marcia, 2006). This could be seen in individuals who find it impossible to step away or adjust the level of care they had previously provided to a parent with a mental illness, or indeed projects their identity as carer on to other facets of their adult lives, such as relationships and career.

The parent's illness and identity becomes braided with the young person's own narrative and sense of self, while as the individual matures their perceptions change. However in a study by Kaimal & Beardslee, (2010) exploring young adult's perceptions

of parental depression, it appeared that their master narrative or stance remained largely unchanged. When exploring the stances drawn from master narratives they are defined as either persistently resistant or ambivalent. Persistent resistance, describes an on-going reluctance to dwell on the parent's illness or consider the impact on the family. Whereas persistent ambivalence is an on-going conflict driven by the acceptance that although the illness is beyond their parents' control, they still feel frustrated by their parent's failure to fulfil their parental role. Champlin's (2009) phenomenological study found a range of narrative responses expressed from individuals who care for a parent with a mental illness. These include (a) accepting the illness while grieving for the parent that once was; (b) taking action in challenging circumstances; (c) recognizing the persistent and unpredictable nature of the illness; (d) feeling isolated; (e) ambiguous connection in the relationship; (f) tireless strain of waiting; and finally (g) caring for the other and knowing them well (Champlin, 2009). The narrative responses are rooted in their relationship and caring responsibilities towards the parent, but also begin to colour the narratives which are constructed around other areas of their life as their identity as carer becomes primary and all encompassing.

Summary

Identity is the universal motivation of humans to develop a psychological sense of self. However it is constructed within and influenced by each individual's social context. The exploration, separation and increasing autonomy usually experienced through adolescence is key to the development of identity, as is the narrative representation of self that an individual holds.

However this adolescent development of identity and narrative can be significantly affected by trauma, and the co-authored construction of identity can be influenced by a competing narrative of mental ill health within the family system. This is most significant when the narrative of a parent's mental ill health and the care the child provides for their parent (through childhood and into adulthood) overwhelms their own sense of self-worth, autonomy and identity.

Part II

Methodology

Introduction

The first chapter addresses how the study was designed and conducted. It begins by discussing the decision making around the research aims and questions and is followed by an outline of the key features of the research planning process. A brief account is given of the sampling decisions and recruitment process including the inclusions and exclusions which strengthened the study's focus and purpose. The development of the interview technique is then detailed, a technique that was crafted to elicit the richest narrative data possible. An account is given of the way the data was analysed, demonstrating the way the analytic tools were developed and recorded. Finally, the presentation of narrative finding is discussed.

The second methodology chapter moves on to explore the ethical considerations inherent with researching sensitive topics, with consideration given to the impact on both the participant and the researcher.

Chapter Five

Design of the Study & Research Process

Research Questions

While some research has explored the possible correlations between mental illness, social disadvantage and poor educational attainment for children (Mowbray and Mowbray, 2006; Gladstone *et al.*, 2011; Social Care Institute for Excellence, 2012), or the difficulties experienced by parents with mental ill health (Montgomery, 2005; Jeske, Bullinger and Wiegand-Grefe, 2011; Elliot *et al.*, 2014), little is known about how it is experienced by the child themselves and the impact into adulthood. To address this gap, the following research question was developed:

How do adults who grew up with a parent with mental ill health make sense of their childhood, and what effect does this understanding have on them as adults?

In order to answer this question, I sought to design a study that would aim to:

- Describe how individuals understood and felt about their parent's mental ill health both as adults, and also through retrospective accounts of how they felt as children and adolescents.
 - When did they become aware of their parent's ill health?
 - Were they aware of stigma?
 - Did they discuss it with others?
 - Did they have to look after their parents?
 - How did they compare their childhood with their peers?
- Identify ways in which the individuals made sense of and coped with their parent's mental ill health at different points throughout their childhood

- What did they know about the illness – diagnosis/behaviour/psychological?
- Were there other difficulties/adversities?
- Were there other positive/protective factors?
- What was their role in the family system?
- When/how did they leave home?
- Investigate individuals' perceptions of the effect their parent's mental ill health had upon their development and their current interaction with the social world.
 - What is their adult relationship with their parent like?
 - What are their adult relationships with others like?
 - How do they see themselves as adults?

Conceptual Framework

The ideological framework of the researcher colours both the interest and direction of their research and the methodologies used (Holden and Lynch, 2004). I would consider myself a feminist, social constructionist, social work researcher with a strong foundation in social work principles and values. Approaches such as feminism and social constructionism represent an oppositional approach within social sciences which challenges the mainstream (post) positivist empiricist research design and practice (Braun and Clarke, 2013). Within my research, I seek to generate knowledge, not through the positivist approach of traditional scientific study, which attempts to create laws through generalisability and statistical accuracy, but rather through the elicitation of rich data of individual accounts and interpretations of their social and psychological life (Blaikie, 2007). From my professional social work experience, I am convinced that it is the person's understanding, construction of the world around them and their story of it, which is their truth. No one person can hold that theirs is the singular correct version of reality or knowledge, indeed there are a multitude of versions of reality for each experience. This can equally be true for each individual's understanding and narrative. Laced as they are with power relations and social discourse, they do not remain fixed or constant over time but instead are fluid and reflective of the specific circumstances the storyteller finds themselves in and the audience they present

themselves to (Riessman, 2001). As such, there is no reason to assume that a narrative will or indeed should remain entirely consistent from one setting or telling to the next, but each snapshot, however nuanced, is powerful and valid in its own right. My research seeks to use narratives to uncover subject meanings of lived experience while my professional qualification and experience enables me to reflect upon the application of intervention to support marginalised groups in a more effective manner.

In order to generate knowledge from individuals accounts, qualitative research strategies are most appropriate (Blaikie, 2007). I am drawn to qualitative research for its interest in process and meaning, reaching for deeper understanding. With my professional background in social work, I have the skills necessary to be reflexive and to apply a double-consciousness within which I am able to draw the most from a qualitative interview by both simultaneously listening intently while also critically reflecting on and analysing what is being said (Braun and Clarke, 2013).

From a feminist perspective I seek to use methodological tools which empower marginalised and silenced groups, placing the power in their hands as the experts of their own lives and experiences (Standing, 1998; Dickson-Swift *et al.*, 2007). However I acknowledge that through the constraints of this specific project, I was not able to co-create the research with the participants which would have required me to collaborate with them at every point of the research design and production (Aldridge, 2014). I also pay particular attention to the emotion of the research process for both the participants and myself. This reflexive practice enables me to be involved whilst keeping a critical distance from the relationships, ideas and assumptions that inevitably shaped my research. Feminist theory also strongly orientates my analysis and perspective, in that I am principally concerned with highlighting and challenging gender difference and critically evaluating the cultural and structural norms surrounding gender roles and relations. In this study this is specifically related to the deeply embedded gendered patterns of organising and valuing the parental care role and the identity of mothers.

From an interpretivist stance it is the meanings, interpretations and motivations that direct individuals' behaviour in everyday life (Blaikie, 2007). With this in mind, despite my professional experience artificially positioning me as an expert (Kanuha, 2000), not

having experienced parental mental ill health personally, I am firmly positioned as an outsider in the study. Thus, it is the interpretive voice of the participant which is key, rather than imposing the view of the outsider (expert) on a particular phenomenon. However, it would be disingenuous to suggest that I could be completely removed from the research endeavour. The narratives are co-constructed between the teller and the told, as is the analytic process (Langdridge and Hagger-Johnson, 2009; Braun and Clarke, 2013). There were limitations to the level of participation and co-construction the participants held within the study. While they were empowered to tell their own version and construction of their narrative, it was I, who undertook the analysis and interpretation of the narratives. I attempted to create rigour within this process by taking influence from the Interpretive phenomenological analysis method of a double hermeneutic dual interpretation process, whereby I remained cognisant of the fact that while the participants were trying to make sense of their experience; I as a researcher was trying to make sense of them making sense of their world. In order to do this I ensured at each point of the process that my analysis was explicitly guided by the inductive features of the data itself.

In choosing a qualitative method, I was not focused on generating theory and as such ruled out grounded theory (Langdridge and Hagger-Johnson, 2009). I considered interpretative phenomenological analysis but felt that the psychological tradition of this method was not best suited to this study. I was concerned that using a psychological lens would draw me to focus too much on the pathology of the mental ill health as opposed to the participant's own recollection of experience. I also explored the possibilities of biographic narrative interpretative method (BNIM), however the method uses three separate interpretive panels to augment data interpretation for each transcript (Wengraf, 2001) and as such was determined not to be viable for a PhD study. BNIM also reflects the focus of discourse analysis which attends to the textual structure of the narrative (Corbally and O'Neill, 2014). As I was speaking to a diverse range of participants rather than individuals who identified as belonging to a common community or cultural group, I was more interested in what was being said than how it was being said. Nevertheless, I did use one key aspect of the BNIM method. This was the single question aimed at inducing narrative (SQUIN),

further details of this tool and my rationale for using it will be discussed later in this chapter.

I also explored Riessman's (2008) method of thematic narrative analysis as the most appropriate for my study as the content of the narratives were the exclusive focus. This method also keeps the participant's story intact by initially theorizing from each case and drawing the subsequent themes together as opposed to breaking each case down into component themes (Riessman, 2008). This enabled me to attend to the patterns that may arise through the study while also protecting the narrative structure of the interview (Langdridge and Hagger-Johnson, 2009; Braun and Clarke, 2013).

Within a narrative approach, there are interpretive decisions that are made early in the research process which are shaped by the research questions, conceptual framework and theoretical interests. Social constructionism would hold that through the analysis process the resulting narrative of the research is a combination of the teller and the told, wherein both the researcher and the researched are located together in a hermeneutic circle (McLeod and Thomson, 2009). My own social constructionist framework also sought to not only draw light on subjective accounts of personal experience but also how they are understood in relation to the dominant social script surrounding both mental ill health and the parent/child relationship.

Analysis

It is through narrative that people make sense of their lived experience. We dream in narrative, we hope, plan, believe, revise, construct, despair, remember, learn, hate and love by narrative. We interpret, re-interpret and communicate our lives and our identities through narratives and as such story telling is the most enduring, primary and universal form of human communication (Riessman, 2008; McLean, 2016). Stories carry energy woven through them, they have the ability to resonate with us in ways that other forms of communication cannot. We relate to each other through stories, seeking out similarities, differences and narrative motifs that reverberate with our own. Therefore narrative research enables us to gain insight into the relation between individual's particular experiences, the manner in which they make sense of them and the social context within which they occur through the capture and analysis of stories.

Narrative work is considered a core skill of both social work and qualitative research (Riessman and Quinney, 2005; Shukla, Wilson and Boddy, 2014). Narrative research refers to a family of methods for interpreting texts that have a common storied form, widely used in other academic disciplines such as history, sociolinguistics and literature. Its use in social sciences has more recently acquired an increasingly high profile (Riessman, 2001; Tamboukou, Andrews and Squire, 2013). However, unlike many qualitative methodologies narrative research has no clear framework, indeed the definition of 'narrative' itself is often in dispute (Tamboukou, Andrews and Squire, 2013), and there are vast differences in the methods of analysis narrative researchers use including visual, thematic, structural and dialogical. Equally narrative analysis can be flexibly applied to provide either a descriptive surface analysis or a deeper interpretative analysis dependant on the requirements and aim of the study (Shukla, Wilson and Boddy, 2014).

Research does not occur in a vacuum, nor are the methods of social research always sacrosanct and distinct, there are frequently as many commonalities as there are differences between approaches and as such researchers can adapt elements of certain methods to fit the purposes of their study (Shukla, Wilson and Boddy, 2014).

It was with this in mind that the application of narrative and thematic methods to the same data set appeared best placed to provide an integrated robust conceptual framework. Within this framework I could strive to understand a participant's experience, with the narrative analysis providing temporality and plot while the thematic analysis allows patterns in the dataset to be revealed (Floersch *et al.*, 2010; Padgett, 2017). The narrative approach to the analysis also protected against the fragmentation of text that can be associated with other qualitative methods such as grounded theory (Braun and Clarke, 2013). Within the narrative approach, attention remains upon the story as a whole and the form in which it was delivered as well as its content. Hence, narratives provide some means of capturing the sense of movement and processes involved with meaning making and identity formation, as well as keeping sense of the individual intact while analysing the themes across the data set.

In order to stimulate analysis and help shape interpretation several framing devices such as turning points, strategies, typologies and identity enable researchers to

approach their data to ensure a conceptually rich interpretation. Within the discipline of social work research, interpretation is also influenced by other factors such as the tension between individual agency and wider structural forces, intersectionality and multiple identities and the systems thinking of families, communities and social structures (Padgett, 2017). For these framing devices to be effective, theoretical sensitivity is required as the researcher is attuned to relevant theories whilst not allowing them to dictate the terms of analysis or interpretation (Padgett, 2017).

Riessman (2008) discusses the application of thematic narrative for human sciences in detail and is careful to draw attention to the fact that thematic narrative analysis is not as straightforward or intuitive as it initially appears. As discussed earlier, complexities arise with the wide range of data, theoretical perspectives, epistemological positions, research questions and definitions of narrative. With such a flexible and adaptable research method it is important to have a clearly defined strategy regarding how and why the analysis process was conducted in the manner that it was.

Study Design

As signified in the research question, I made two clear decisions in the initial design of the study. Firstly, to interview adults who had grown up with a parent with mental ill health asking them to reflect back on their childhood and secondly to not define mental ill health by a specific diagnosis.

The decision to interview adults as opposed to children was relatively straightforward and made with three considerations in mind. Firstly, a child's understanding of their parent's health and behaviour would change over time as their understanding of self and the world around them developed. Secondly, the perceived impact of their parent's mental ill health maybe felt differently at different stages of their childhood, such as key stages in their educational or social lives. Finally, the third consideration was the ethics of asking a child to reflect on a potentially distressing subject with no resources to offer further intervention or support.

The second decision took considerably more exploration. When considering my project I was keen to capture the experiences of adults who had grown up with a parent with severe and enduring mental illness. However, I did not want to follow other studies in

making the research diagnosis specific (Mowbray and Mowbray, 2006; Wilson and Crowe, 2009) as many of the manifestations of symptoms are similar across multiple diagnoses and it was the child's experience not the etymology of illness that was of interest. This said, I felt it was important to distinguish between a mental health problem, which could be addressed through lifestyle changes and medication or brief intervention prescribed through a General Practitioner and severe and enduring mental ill health which had a long term, significant impact upon the life and functioning of the individual and their family.

Initially, I considered requesting that the participants could confirm that their parent had been held under the Care Programme Approach, the framework used in secondary mental health services, which would confirm the severity and complexity of their mental health needs. However, this would preclude some adults as the Care Programme Approach was not introduced until 1990 (Department of Health, 2008). Moreover it would rule out individuals who had grown up in a household where the parent had not received services from a secondary mental health team, even though they met the threshold for services. Some families endeavour to muddle through without the involvement of outside agencies and these stories are equally as valid as those who had received health and social care.

Sample size and interview criteria

Given the aims and methods of the study, my supervisor and I agreed that 20 would be a reasonable target number of participants to provide a sufficient range of data and depth of analysis, but that we would continue to monitor this with saturation in mind (Braun and Clarke, 2013). Inclusion criteria for participants included:

- Having been cared for by a parent who experienced a serious mental ill health for a year or more – a short term mental health problem would impact very differently upon a child.
- Any diagnosis – this study intends to focus on the manifestation of an ill health and the child's experience as opposed to specific diagnostic labeling.
- Any gender.
- Any culture.

- A specific age range of 25 – 55 years. The dramatic changes in the treatment of mental ill health over the past 30+ years will mean that different generations will have had starkly different experiences.

Exclusion criteria for the study included:

- Lack of mental capacity to give informed consent to the study.
- Psychological fragility affecting the individual's ability to participate safely. This would include their perceived risks and the level of support they could identify from themselves.
- Geographic Limits. Within the UK and dependent on the constraints of the study and resources.

I planned to speak to potential participants over the telephone, which served as a screening interview. During the interview I could give them further details about the study and what would be required of them and ascertain if they met the inclusion criteria. There were several occasions while conducting these telephone calls that the participants started to tell me their stories in detail. Each time I had to acknowledge their need and desire to tell their stories while asking them to hold them until the actual interview. With each participant I allowed them to choose the location of the interview, these were predominately in the participant's own home, however, I also interviewed participants in a room on a university campus, a coffee shop, a work place and at a friend's house. Following the telephone call I sent them more detailed information about the study and a copy of the consent form (Appendix 8 & 9). Before the interview I telephoned the participant to ensure they had received the information and were still willing to take part in the study.

Before the interviews began, I discussed the aims of the study with the participant again, we also read through the consent form and I asked them to sign it if they were happy with the contents. We then began the interview, recording it on a digital dictaphone. When the interview had finished we spoke about how they had found the experience and I gave them information about support available to them in the local area (Appendix 13). I then asked them if they would like to hear any more about the study, in terms of findings or a summary sheet. Finally, I gave each participant a £20 'Love to Shop' voucher to thank them for their time.

Criteria of Severe and Enduring Mental Ill health

Given that, from a phenomenological approach, it is the experience of the individual that I am seeking to elicit, I felt that the severity of the ill health as it was experienced was more important than a diagnostic label that may have been applied by a psychiatrist. Therefore in order to assist potential participants to decide whether their parent's illness was severe and enduring, I decided to devise a framework to enable them to assess for themselves. In doing this I first examined the various tools used by the professionals working within the field. These ranged from international diagnostic criteria to governmental frameworks and measures used within the third sector.

In asking the participant to assess the severity of their parent's mental illness, I felt it was important to focus on the factors that they would have observed or been privy to. Reflecting on the aspects explored within all of the frameworks above I began to consider how they overlap (Appendix 1) how the main themes taken from the methods may feed into a definition and finally how a child might have understood them. I then broke this down into four main areas: Experiences of illness, Self-care (and Life skills), Relationships and Participation (Appendix 2). These are not designed to elicit understanding of the child's experience at this point, but to give clarity to the severity of the parent's mental ill health in these different but over-lapping domains. I then considered questions that would enable us to explore each of these areas and asked that they either provided factual answers or scored them out of 5 (Appendix 3). The use of this screening tool, along with my own professional experience of secondary mental health care meant that I could confidently ascertain that the criteria were met during the initial telephone contact for the recruitment.

Research Procedures

Recruitment

I sought to recruit participants from across the UK. This, combined with the wide age range ensured that the study was about experience rather than an evaluation of local psychiatric services. I recruited participants through a variety of methods, which included speaking about my research proposal at the university and at a Young Minds conference. I also left project postcards (Appendix 7) in public places, a coffee shop,

three libraries and two community centres. Finally, I also created a page on social media, Facebook (Appendix 8). The Facebook page was made public and shared by friends on my personal account; this was then shared onwards through their friends and onto other platforms such as Twitter.

I also asked participants if they could recommend other interested people as detailed in snowball sampling, however it quickly became apparent that people who grew up with a parent with mental ill health did not necessarily form the type of commonality network that would be required for the snowball sampling method (Browne, 2005). The only success I had with snowball sampling was two participants recruited by their siblings who had also taken part in the study. This gave me an invaluable opportunity to see how their accounts compared given they had grown up in the same household.

Through my public engagement, contact with the coordinator of a young adult carers support group was made. The coordinator shared my postcards with their group members and then compiled a list of members who expressed an interest in participating. Despite there being 16 potential volunteers, I agreed with the coordinator of the project that I would only interview four. This was to prevent the research from becoming skewed to the experiences of young people in a specific area and in receipt of carers support. To date the majority of research addressing the experiences and needs of children growing up with a parent with mental ill health has included children known to services. While this gives a unique insight into the nature and extent of young carers in the UK, we know less about the children who are unsupported (Abraham and Aldridge, 2010) and I purposively sampled to ensure those voices were also heard. Below is a table representing the number of participants recruited by each method:

Recruitment methods				
Public speaking	Postcard drop	Social media	Recommended by participant	Young adult carers group.
4	0	10	2	4

Figure 2 – Recruitment methods.

The success of my recruitment through social media was contributed to by the fact that many of the people who shared the link for my page knew me either professionally or personally and added a comment of their own vouching for me. I feel that it was this personal touch and recommendation that made my page stand out from the sea of other adverts on social media and encouraged potential participants to believe that I was well intentioned and that the study would be worthwhile. I was also approached by participants following public speaking, listening to my presentation, while not directly about the study gave them a sense of my stance and credibility (Smith, 2001). Contrary to this the postcard drop, which conveyed the same information as my social media page, was unsuccessful as it lacked the personal touch or representation.

Once initial contact with potential participants had been made and I had ascertained they met the criteria for the study, a leaflet giving further information was sent. I contacted them one week later to confirm their consent to the study and make arrangements for an interview to take place. Immediately before each interview I confirmed that they had read the project leaflet and asked them to complete a consent form.

The relative ease with which I recruited participants to my study also speaks volumes about the way this group of people has been historically ignored. As a social worker I had heard countless accounts of family members and carers who felt they were not listened to and acknowledged. My assumption that there would be a large number of individuals keen to have their stories heard was proved correct. A brief overview of participant's details is shown in table below:

Pseudonym	Age	Gender	Parent with mental ill health
Karen	52	F	Father
Sophia *	24	F	Mother
Roman *	19	M	Mother
Jess	26	F	Mother
Jenny ~	20	F	Mother
Ethan ~	19	M	Mother
Vivienne	24	F	Father
Holly ~	21	F	Mother
Alicia ~	21	F	Mother
Mike	44	M	Mother & Father
Seb	35	M	Father
Georgina **	33	F	Mother
Emily **	29	F	Mother
Lucy	32	F	Mother & Father
Natalie	23	F	Father
Robyn	33	F	Father
Terry	48	M	Mother
Freya	32	F	Mother
Caroline	37	F	Mother & Father
Monica	54	F	Mother
* & ** Siblings. ~ Young adult carer Bold Text – Focused on that parent			

Figure 3 – Details of participants.

Exclusions during recruitment

There were two participants excluded from the study in the recruitment stage. The first was Paul, who had been recommended by his aunt, at the point that he initially agreed when he was in prison. His aunt stated he had had multiple short-term custodial sentences, from youth offending to adult prison sentences. His criminal history was primarily related to theft, which she believed was largely in response to his mother's mental ill health and her associated over spending. At the time that the interview was due, Paul had been recently released from prison, he agreed with his aunt that he would meet with me, however he did not respond to my telephone calls and letters. I took this as an indication that his consent to the study (through his aunt) was not valid. There was also a risk of psychological fragility, which could be triggered by asking him to reflect on his childhood. I therefore decided not to pursue him further, explained this to his aunt and gave him the option to contact me if he wished. I did not hear from him.

The second participant was a woman called Julie, who responded to my Facebook page and offered to tell me about her experiences of her mother. We were already passing acquaintances as our children attended the same school, so I wanted to explore further how she would feel participating in the research and then seeing me on the 'school run'. While we discussed this, she became very emotional and distressed in reflecting on her childhood. She stated that she had never spoken fully about her mother's illness and her own experiences. She was concerned that the study would be entirely confidential, as she had never revealed certain details of her childhood to even her closest family before. I suggested that with this level of distress and fear of exposure it might not be right for her to participate in the research. To begin with she insisted that she still wished to be involved and that she accepted that there might be negative consequences emotionally for her. When I explored her desire to participate, it transpired that it was not based on a perceived benefit for herself but rather a feeling of obligation and guilt towards me, that if she didn't participate she would be letting me down. I felt that given the level of emotional distress evoked by the consideration of participation combined with the overlap of our daily lives it would not be ethically appropriate to involve Julie in the research. I assured her that I had faced no difficulty in recruitment, her non-involvement would not negatively impact on my study and that I did not wish her to place herself in such an uncomfortable position on my behalf. Julie was palpably relieved by this decision and expressed how throughout her life she feels irresistibly compelled to help others, even when it is to the detriment of her own wellbeing, either emotionally, financially or practically. While I did not interview Julie, I felt that her placing her need to help me over her own personal wellbeing is indicative of my model of acquiescence discussed in the making sense of the illness findings chapter.

Recruitment bias

As discussed in the findings Chapter 10, a significant number of the participants in the study worked within what would be considered caring professions. Indeed, four of the participants had trained as mental health nurses. While it is possible that their childhood experiences may have led them towards such a profession, it is also worth noting that the number represented within this study could be due to recruitment

bias. As described earlier, the personal recommendation attached to my social media recruitment was particularly fruitful, however as a mental health social worker many of my friends and followers on social media are also mental health professionals. It is therefore reasonable to assume that as they shared it on their social media platforms, many of the people able to see their posts would also work in a mental health field.

There was a further bias in the recruitment that I had not anticipated. In my recruitment literature, I had been careful to not direct towards a particular diagnosis or experience. I had hoped to get a wide range of experiences and backgrounds. Nevertheless, it was clear as I began to recruit and interview participants that the majority had narratives of childhood adversity and in many cases trauma to share. I feel this is indicative that people are more motivated to give voice to experiences that are dramatic, emotional and/or unresolved (McLean and Pratt, 2006). We are more driven to complain than compliment. I chose not to attempt to balance this through seeking out positive narratives as the recruitment had always been based upon self-selection and I see the motivation for individuals to share narratives of sadness and trauma as reflective of the ongoing impact these childhood experiences still have upon them.

The final bias was that of gender. While I ensured my recruitment material was not gendered, the majority of the participants who volunteered for the study were women. Indeed, within the selection process I gave extra weight to male volunteers as I wanted to also hear the male perspective. Perhaps this is reflective of the notion that women are more able or willing to discuss emotion and that male and female expressions of emotion are interpreted and tolerated differently (Brandon, Philip and Clifton, 2017). This gender bias also extended to the childhood experiences as the majority of participants spoke about their mothers as opposed to their fathers. Further exploration of the gendered nature of parenting and care is discussed in the Family Dynamics chapter of the findings.

Practicalities

Given the open nature of the recruitment, practical considerations arose due to the wide range of participants, both in terms of their specific needs and geographical

location. Keen to keep the focus of the study on the adult's experience in childhood and not a review of local services, I travelled across the UK to conduct the interviews. This required exploration of the local area, firstly for my own safety as a lone researcher and secondly in compiling an information sheet of support services (which will be discussed later in the chapter).

I also recruited two participants who had disabilities which affected their cognitive processes and communication. In attempting to meet these individuals additional needs the research design had to be adapted for each interview (Aldridge, 2014) specifically as it had been suggested that the open style of narrative interview might be difficult for these participants. With this in mind, I developed a list of prompts that I could use to help them share their narratives. These prompts were as open and neutral as I could make them as I wanted to avoid a more structured interview schedule which would have influenced and constrained their own construction of their personal narrative. In both cases few of the prompts were needed, however these interviews were considerably shorter in length than others (approximately 40 minutes as opposed to the average two hours) and there were points when it felt like depth of reflection was missing. It was difficult to know whether this was indicative of the way in which they communicated their narrative or whether it was suggestive of a lack of self-reflection, understanding and connection. This was illustrated in Ethan's interview during which he described that he had recently had a "breakdown" during which he had attempted to take an overdose of painkillers and had persistent and distressing thoughts of drowning himself. He reported that he did not know where these thoughts had come from, despite having recalled earlier in the interview that between the ages of 12 and 15 he had had to physically pull his mother from the sea on three occasions when she had been extremely distressed and suicidal. This appeared to have a clear connection for me in terms of Ethan's own suicidal thoughts, but not one that he had recognised. As a researcher it felt that it was not my role to suggest that connection to Ethan and that given the highly fused relationship he had with his mother it may have been detrimental to do so. As such I choose not to prompt him to explore this further.

It is interesting to note that both of these participants still lived with their parents. Of the other three participants who also currently lived and cared for their parents, similarities were noted in the way in which they reflected on their parent's mental ill health and their role within it. Again an apparent reduction of in-depth reflection on their part seemed to have been indicative of the immediacy of their caring role and lack of psychological distance. This potential explanation was also evidenced by another participant who spoke of her inability to reflect on her situation and own emotions until she had left home:

I suppose in those type of situations, if you tap into, hang on a minute how do I feel about this, I wouldn't have had enough strength to keep going, to look after her. – Jess.

For these five participants I was aware of their on-going care responsibilities and the potential destabilising effect of their emotional response, and treated the interview with additional care. This care and additional consideration is particularly important when researching such an emotive subject.

Interview

Particularly in qualitative research, researcher influenced data generation and narrative formation is a much debated issue (Buckner, 2005). In seeking to gain insight into the participants' own subjective experiences of childhood and parental mental illness, I was cautious of the potential for my prior knowledge and experience to influence the interview and attempted to remove myself from the process as much as possible. With this in mind I explored a range of open and in-depth interview techniques (Padgett, 2017) and was particularly drawn to the Single Question Aimed at Inducing Narrative (SQUIN) techniques of interviewing used as part of the Biographical-Narrative Interpretive Method (BNIM) (Wengraf, 2001). One of the defining features of this method is that the researcher aims to relinquish control, allowing the narrative to flow fully from the participant and for them to construct and present it in any form or sequence that they choose (King and Horrocks, 2011).

As such, I devised a short semi-structured script that I delivered to each of my participants to begin the interview. Within the script I explained that I was interested

in their story of their parent's illness, how it had felt for them and how they made sense of it. I assured them that they could tell me as little or as much as they wished, and that I would not ask probing questions about experiences they might have chosen to leave out of their narrative. I explained that there was no time limit, they could structure their story in any way they wished and that initially I would not interrupt, just listen and make brief notes. Only once they had completed their story, might I seek some clarification about certain aspects from the notes that I had made. This method gives the participant control over the direction and flow of their story and the security that they would not be compelled to disclose or discuss anything they are not comfortable with (Wengraf, 2001; King and Horrocks, 2011). However as with the rapport and the risk of deceptive candour (Philip and Bell, 2017), this open technique of interviewing can be seen as potentially deceptive. The sense of control that the open nature of the narrative can give participants, can reduce the fear of difficult and unwanted questions being asked. However in presenting narratives, we are drawn to present a coherent and contextually complete story, as such participants may, with this sense of security be tempted to reveal more than they might have in response to direct questions.

Consideration also needs to be given to this type of autobiographical interview with regards to the nature of the memories, the manner they are recalled and the shape in which they are presented. Individual experiences are not generalizable or consistent, as such biographical truth is mythic but the manner in which it is portrayed is representative of its audience (Aldridge, 2014). Indeed memories themselves are 'occasioned' by the context in which they are enacted and as such are localised, projected and received dependant on multiple factors for both narrator and recipient (Brown and Reavey, 2013). Autobiographical memories can be either prioritised or constricted dependant on the participants' understanding of the design of the research project and their interpretation of which memories are most applicable. In presenting their narratives, the broader social and political environments have influence, as does the participants' perception of the role and motivations of the researcher. An individual would most likely provide a different account of their childhood if asked by a colleague, a friend, their own child or a researcher (Mihelj, 2013). This is particularly

evident for 'vital memories' which are simultaneously problematic (in that they contain painful emotions) and essential for the ongoing construction of identity. These vital memories for individuals can also be significant in the manner that they are received by the researcher. Riessman (2008) describes the concept of the 'teller problem' as a motivation of the narrator to convince the listener of the validity and value of their memory. As such the narrator positions themselves as the central agent who has been deeply affected by the experience. To do this they will strive to find a way to provoke a similar emotional state in their listener to the one that they are attempting to convey through their memory. With vital memories or recollections of trauma and/or adversity this emotional mirroring could potentially shift the researcher's already malleable perception of the participant's level of vulnerability.

This interview technique was received well by the participants who in general were able to speak at length with no assistance other than active listening techniques, such as non-verbal support, eye contact, nodding and sounds such as hmmm. I also took care to mirror rather than guide participant emotions, for example if a strong emotion resulting in crying arose during the interview I could show that the emotion was accepted and safe within the interview by saying 'that sounds really hard' rather than trying to rescue the participant by changing the subject or offering solutions (Wengraf, 2001). Initially I was concerned that I would struggle to not interrupt or insert myself into the narrative, however the technique felt natural and I was aware that topics were raised that would not have been considered had I been asking pre-defined questions.

The success of this technique was also largely attributed to the fact that my participants had come with stories to tell, they had reflected on them and had begun to construct them before the interview and it seemed, for the majority, that once I had delivered my short script the floodgates opened. As mentioned earlier in the chapter, this was slightly adjusted for two participants who had specific learning and communication needs. For these participants, I had developed a set of questions prior to the interview that might help them express themselves, as it was during the interview these questions were not needed. I merely supported them by prompting them with questions such as 'Are there any other things you can remember

happening?” and “that’s really interesting, does it make you think of anything else that happened between you and your mum?”

The majority of participants expressed during their recruitment to the study that they were motivated by the potential of helping future children growing up in similar circumstances to their own. With this in mind, I made the decision at the end of each interview to ask one question, “What could have helped?” This question was designed to facilitate my analysis of professional intervention and potential recommendations for policy and practice and ensured that the participant’s own expertise and views were valued.

With each participant’s agreement, the interviews were audio recorded. They were then transcribed verbatim. I transcribed the first five interviews; however, my dyslexia rendered this a particularly long and arduous process, especially in ensuring that they were accurately recorded. Therefore, the final 15 were transcribed by a professional (DBS checked) service funded through the Disabled Students Allowance. For all of the interviews, I read the transcripts while listening to the recording to check for accuracy.

Stages of analysis

The first stage of the analytical process was the immersion in data. For me this combined both reading the transcripts and listening to the interview on several occasions and creating a coding index for each participant (Appendix 10). I then annotated the transcript to highlight key points in the narrative, identifying framing devices such as turning points, strategies and identity statements (King and Horrocks, 2011). Emerging themes were visually mapped out for each participant. Themes were not selected to be statistically representative but rather were chosen to develop theoretical arguments (Riessman, 2008; Shukla, Wilson and Boddy, 2014).

I also developed a biographical account for each interview by isolating and ordering (where possible) episodes in the narrative into a chronological timeline. This was then annotated with my interpretation of the event as a researcher and a description of the participants own interpretation (Appendix 11). As mentioned earlier, narratives are socially constructed and in many cases co-authored (McLean, 2016). While using the BNIM method of interviewing removes the researcher as far as possible from the

construction of the initial narrative, it was however during the analysis that I truly became part of the construction as I interpreted the data and developed my own narrative of the study (Riessman, 2001, 2008).

In order to keep the narratives separate and whole I worked closely with each interview individually in blocks of four interviews at a time. With each block of interviews, I engaged in an iterative process of expanding and collapsing thematic categories and themes. Throughout this analytic period, I also met regularly with my supervisor to share transcripts, compare coding and to discuss emerging findings and interpretations. This is key in ensuring that the research process is robust, reliable and valid as we compared notes and understanding. Supervisory discussion was also extremely beneficial in the second stage of the analytic process as I 'zoomed in' (Riessman, 2008) to identify the deeper meanings and underlying assumptions in each account. Further refining my themes from a semantic to a more interpretive level, I used both the coding and the chronologies to examine the manner in which themes and narratives interacted within and across cases. Again, I mapped these themes visually to examine how they were represented across the data set (Appendix 12). I also explored these themes and potential patterns by plotting specific details about the participants work, relationships and own mental health on the table below.

	Health & Social Care	Public service	other	Unemployed	Continuing to provide care for parent	24 hr care	Still responsible	No additional care	No contact	Participants' view of own mental health	Difficulties Identified	Linked to trauma	Significant worry	none	Is the participant in a relationship	Yes	No	Does the participant have children	None	Would Like	Have	Not able to consider
Karen	X								X	X						X					X	
Sophia	X						X					X				X			C			
Roman			X		X					X						X			X			
Jess	X					X				X	X					X			C			
Jenny	X				X					X	X					X					X	
Ethan				X	X					X	X					X			X			
Vivienne			X			X						X			X						V	
Holly	X				X									X		X			C			
Alicia	X				X									X		X			X			
Mike		X						X				X			X					X		
Seb	X					X						X			X					V		
Georgina	X					X						X			X					V		
Emily		X				X						X			X				X			
Lucy	X						X					X			X				C			
Natalie	X					X				X						X		X	X			
Robyn			X						X			X			X					V		
Terry			X			X				X	X				X				X			
Freya	X					X				X					X					V		
Caroline	X					X								X	X				X			
Monica			X				X			X	X					X						X

Key

X – factor present

C – would like children but has significant concerns due to experiences of parental mental health

V – discusses need to manage relationship and protect children from grandparent's mental illness

Figure 4 – Further details of participants.

This analytic process worked well with my data and held a sense of coherence and fluidity throughout. However, the journey of the research was not as linear as it might appear. The learning and development of myself as a researcher took an undulating and cyclical path from confusion and disorder towards clarity and insight. This is indicative of not only my lack of research experience, but also the nature of qualitative research itself, which incorporates art as well as science. As such, it is inherently a process which requires the researcher to not only be able to conduct a systematic accountable piece of work but also to embrace intuition, coincidence and emotion as research tools.

Presentation of findings and anonymity

The presentation of my findings is also particular to the narrative and feminist approach where I continued to situate my participants at the centre of research. Using excerpts or (at times lengthy) segments of their transcripts interspersed with my own interpretation and theoretical formulation meant that I preserved the integrity of their voices. These voices spoke with more power and wisdom than I could ever hope to convey. A small number of excerpts have been repeated in different sections of the thesis, this reflects the richness of the data and the fact that at times multiple key themes could be drawn from a single piece of narrative.

However, presenting narratives without breaking them up brings with it risks to the participant's anonymity (Braun and Clarke, 2013). I attempted to balance this potential risk with my participant's expressed desire for their stories to be heard. I attempted to conceal their identities by giving them a pseudonym, which was completely different to their name (including the initial). I created the pseudonym immediately after the interview, and used it in the transcription, analysis and in any discussion I had with my supervisor. I also removed geographical details about where participants had grown up or currently lived. In the main, I spoke of participant's professions in broader fields, such as health and social care; the exception to this was the participants who had trained as mental health nurses. I was aware during recruitment that this may be an interesting aspect analytically and as such included potentially revealing their professional title with my discussion of confidentiality with these participants. Each of them gave me permission to identify their profession although I did not mention which specialism of services they worked in.

During the interviews I was careful not to discuss details of previous interviews. I was particularly mindful of this when interviewing siblings and extending this to not questioning or attempting to clarify when each of their narratives appeared contradictory at times. For example one participant omitted a significant event from their narrative that their sibling had discussed in detail.

In writing up I was aware that the extraordinary and deeply personal nature of the narratives means that a participant would be able to identify themselves, as would a

close friend or family member if they were already cognisant of the person's story. I discussed this with each participant prior to the interview. I reminded them that they could leave anything out of their narrative and I would not question them. Equally they could contact me within 28 days of the interview should they have concerns about their level of disclosure or confidentiality and request that I delete all or specific details they would like me to withdraw. None of the participants interviewed did this. I also offered to send participants a copy of the transcript for them to review and/or a summary of my findings once the study had been completed. This was unanimously declined with the majority of participants stating that were happy to share their story but did not feel the need to follow it up. This was potentially indicative for some of the therapeutic/cathartic nature of the interview during which they felt they could share their story without personal consequence (which will be further discussed in Chapter Six) where as others simply explained that they were busy and did not feel they would have time to read it.

Ethical approval for the study

Ethical approval for the study was granted through the University of East Anglia, School of Social Work Research Ethics Committee (Appendix 4). Through this process attention is given to recruitment, informed consent, confidentiality and risks to both participants and researcher. Given that I was interviewing self-selecting adults, there were relatively few ethical hurdles to cross. However, despite the apparent simplicity of the administrative process the consideration of ethics within this study (and all others) was complex and comprehensive.

In preparing for the study, I had wanted to pilot the SQUIN (single question to induce narrative) interview technique. For this purpose, I gained ethics approval to recruit students at the university to tell me about a childhood experience, which did not have to be related to their parents or mental ill health (Appendix 5). However, the first student who offered to be interviewed by me had experiences of growing up with a father with mental ill health, so we agreed to conduct the interview as part of the study and not the pilot interview. I felt comfortable with the SQUIN technique during this interview and decided to abandon the pilot interviews.

I amended my ethics approval during my recruitment stage as I was approached by potential participants who were over 18 but under the originally stated lower age limit of 25years. Within this amendment, I considered the additional vulnerability younger participants might have and how I would manage this (Appendix 6).

I spent a great deal of time planning and preparing to embark on this research project, both in considering the methods I would use and potential situations I might face. Reflecting back on the research process I believe that it was successful, the data I was able to gather was powerful and original. The multiple analytic methods worked well with my visual, non-lineal dyslexic thinking and I believe provided a depth and robustness to my findings.

Chapter Six

Ethical considerations of the research experience.

Researching sensitive topics

It is widely accepted that particular attention needs to be given to ethical considerations when exploring sensitive topics, such as domestic abuse, experiences of rape and trauma, or childhood abuse (Carlson *et al.*, 2003; Dickson-Swift *et al.*, 2007; Campbell *et al.*, 2010). From the initial design of this study it was clear that experiences of growing up with a parent with mental ill health could fall also into this category of sensitive research. Asking people to recall memories of a childhood growing up with a parent with mental ill health had the potential to evoke painful memories for the participants, both in terms of their own childhood experiences and the manifestation of their parent's illness. Some participants predicted the emotional impact of revisiting these memories and were keen to arrange the interview quickly. Indeed, they described the recruitment to the study as having triggered a re-emergence of some memories for them (which they did not want to sit with for longer than necessary). However, others were surprised by the strength and visceral quality of the memories and emotions that arose during the interview itself.

In order to conduct this research in a sensitive and responsive manner, a feminist approach to research was taken. This approach, amongst others, emphasises reducing the hierarchy between researcher and participant, providing information and resources and creating an emotionally compassionate and supportive setting (Dickson-Swift *et al.*, 2007; Campbell *et al.*, 2010). Many principles of feminist research echo humanist principles and the tenets of relationship based social work practice. While I would consider myself a feminist, I do not feel that this research approach is reflective

of the primacy of the ideological lens through which I viewed my participants. I did not aim to focus my research exclusively on the experience of women, and do not consider the topic to be a solely female experience (Blaikie, 2007). My understanding and commitment to the values of feminist research lie instead in the differential stance it holds against the traditional, hierarchical and patriarchal structures of both research and academia. Traditionally the research scientist holds all of the power, while the research subjects are there to be observed, manipulated, measured and assessed. Within feminist research, the research subjects are participants with their own position of status, expertise and influence on the research process (Gorelick, 1996). This shift is also reflected in narrative approaches to research which depart from positivist empiricism by adopting a holistic, humanist stance which gives regard to individual voices, experiences and biographies (Tamboukou, Andrews and Squire, 2013).

Providing a safe space

Participating in research that might lead you to recall and reflect on traumatic events and unhappy memories may be a risky proposition for some individuals. As such the emotional well-being of the participant must be a focus of concern of the researcher at all times (Campbell *et al.*, 2010). The relationship between a qualitative researcher and their participant can also be unique when particularly sensitive topics are shared. The participants give more than words and opinions, they give an insight into the most deeply held and personal parts of themselves. Often they invite you into their homes where you become immersed in the personal markers of their lives, such as family photos and decoration. In entering this sphere a rapport is created, where the researcher also has to decide on an appropriate or safe level of disclosure about themselves (Dickson-Swift *et al.*, 2009) thus demonstrating a level of reciprocity which could build the trust required for participants to share their stories (Dickson-Swift *et al.*, 2007). I tried to be as open with my participants as possible, responding to their questions without guard. However the personal exposure was still greatly skewed in our relationship, for example if they asked if I had children I was happy to share this information, but it was only surface information, they weren't invited into my home

(nor did they know my address), they didn't see my family photos or mementos or expect me to tell them how being a parent made me feel.

During my study I sought to give the participants as much control as possible, both in terms of when and where the interview would take place and exactly what they wanted to talk about (interviews will be discussed in further detail later in the chapter) and communicated with them in an open and non-judgemental manner designed to put them at ease and create a sense of confidence within the process. While this relationship building makes the experience feel positive for participants, there is also a risk that it could be seen as manipulation, as the softened boundaries and sense of friendship encourages them to unconsciously reveal more than they would have without the perceived relationship with you (Dickson-Swift *et al.*, 2007). It seemed to me that one of my participants was particularly mindful of this risk. During the recruitment conversations he was resolute that he wanted the interview to be conducted at his place of work, he explained this as being with regard to my safety and the risk of visiting people in their own homes. While this was a reasonable and thoughtful consideration, I also had a strong sense that he was protecting himself from over-disclosure or emotional distress by engaging in the interview in an environment within which he felt confident and emotionally contained. This was also reflected in his interview when he stated that he had promised his wife he would 'hold it together', asked if I was really assessing him, and how I would rate his mental stability if I were.

A final risk, is that you cannot guarantee the 'space' would be entirely confidential or safe. While you build a friendly rapport and the interview can have an almost confessional feel (as discussed in the next section), this is not without limits. There is the potential that unforeseen risks could occur or the researcher's perception of the participants' level of vulnerability may change during the interview (Aldridge, 2014), and the interview may be changed or terminated as a result. There are also certain situations where as a researcher and a registered social worker I would be duty-bound to report concerns, for example safeguarding or child protection, meaning complete 'confessional' confidentiality could not be assured. This was discussed carefully with each participant during the consent process.

Support and information

Providing support and information for participants was a key element of the interview process both in terms of preparing them for the interview and for concluding the process in a safe manner. Given the nature of the research and the acknowledgment that some difficult and distressing memories may be evoked by and through the interview, I felt it was important to ensure that the participants had access to support following the interview, discussing this at the recruitment stage. Many participants made plans themselves to have a friend or family member available to them following the interview. I also compiled a list of support services that the participant could access should they feel they required additional support (Appendix 14). I spent time researching local services for each participant and checked that the contact details of each service were up to date at the time of the interview.

Four of the participants disclosed childhood experiences of sexual assault and rape, two had reported this to the authorities and prosecutions had been made, of the two who had not reported their experience as a crime, one participant had spoken to her family and felt the situation had been resolved while the final participant had never disclosed her experiences outside her own personal therapy and close friendship group. We discussed their continued right to report their experience as a historic sex crime. Both participants declined to do so explaining that the crime had happened decades ago, one perpetrator was deceased and the identity of the other perpetrator was never known. I did however provide all four participants additional information about support services they could access should they want to discuss the matter further or if the interview had triggered difficult memories.

One participant, Jenny, became particularly distressed during her interview. I offered to call the interview to a close, but she was clear that she wished to continue. Throughout the rest of the interview I regularly checked on how she was feeling and if she still wanted to continue. At the end of the interview, Jenny spoke about her concerns about her own mental health and asked my advice about whether she should seek professional help. I felt at this point that it was necessary for me to 'step out' of my role as researcher and use my experience and knowledge of mental health to speak with Jenny about depression and advise her to access help through her GP. I also, with

Jenny's permission, contacted her keyworker at the Young Adult Carers group that she had recently joined to request that additional follow up support was made available for her.

This use of prior knowledge to offer support and information as part of the interview process also draws upon feminist scholarship, which puts forth that sharing knowledge and perspectives is particularly key given the level of social and cultural isolation of women who are experiencing oppression. While the experiences of my participants were not solely attributed to their gender, there was the same sense of isolation and a sense that their childhood experiences were isolated, unique and in some way shameful. Therefore being able to assure participants, 'you're not alone', 'this has happened to others', 'I've heard this before', helps them reconceptualise and 'normalise' their experiences which is in turn beneficial for individuals who carry significant self-doubt and guilt (Campbell *et al.*, 2010). This was illustrated in my interview with Lucy, who at the end of the interview became emotional as she discussed her desire to become a mother but her fear that she would be ill-equipped or destined to repeat the behaviour of her own mother. When I shared that her concern had been a common theme that had emerged from my research she became more tearful, and attributed this to an overwhelming sense of relief that she was not the only one, alone in her fears. Lucy explained that she had previously kept her fears secret, seeing them as personal weakness and further proof of her maternal unsuitability, but the knowledge that others felt the same as her gave her the confidence to potentially raise her concerns with her husband and explore them in a different way.

Participation as therapy

Several of the participants within the study commented on the therapeutic feeling of the interview process, for example Seb described it as "some kind of counselling session". This was not due to any advice or guidance that I was bringing to them nor did I present myself as a therapist. It was instead the opportunity and space the interview gave them to construct their own narrative and to be heard by an interested ear. It is this sense of being heard, accepted and validated that means that even when discussing sensitive topics, individuals participating in research find personal benefit in

the process and that higher levels of satisfaction can be found for participation of qualitative research than quantitative interview methods (Carlson *et al.*, 2003; Campbell *et al.*, 2010). For individuals who had historically felt silenced, the idea that their story could be of interest to others can be a surprising one. This surprise that their narrative might be valued was alluded to by several participants in the study and directly commented on by both Roman and Karen with the latter saying “I could write a book, but nobody would read it”.

The opportunity to thread their narrative together as a whole throughout the interview process also gave participants opportunities to reframe their thinking about their childhood experiences, making new connections and developing emergent insights which in turn alleviated their long held sense of guilt and self-blame (Dickson-Swift *et al.*, 2007; Campbell *et al.*, 2010). One of the most powerful facets of the interview process mentioned by participants was that they did not have to temper or adjust their narrative to accommodate others. For Georgina this meant not having to be mindful of how it might make her mother feel: “I’m not giving her enough credit here... well I don’t have to because it’s my story”. For others it was the confessional aspect of the interview, that I did not know them or their families and would have no reason to see them again. As such the sense of speaking to a stranger, who could then act as a secret keeper was freeing (Dickson-Swift *et al.*, 2009). I think the participants’ knowledge of my professional background in mental health also freed them up as they viewed me as somebody who would not be easily shocked or stand in judgement. Some participants reflected on the fact that they had never presented their narrative as a whole before, and three participants went on to disclose that there had been aspects of their narrative they had never shared at all and that the interview itself was experienced as cathartic (Padgett, 2017). The confessional nature and rapport which can quickly develop during these interviews must be carefully considered as the interview draws to an end, as such it was clear that in terms of the participants’ experience and evaluation of the research process, the conclusion and ‘goodbye’ was just as important as the introduction.

Emotional labour of research

The final aspect of researching sensitive topics that in many ways took me by surprise was the impact the emotional labour of the interviews had upon me as a researcher. Embarking on the research process I naïvely assumed that my years working in acute and crisis focused mental health settings would have accustomed me to working with others' expressions of trauma and distress. However I soon realised that I 'heard' and responded to these narratives in a remarkably different way. Dickson-Swift (2007) describe the emotional labour of research as producing and containing emotions in others while at the same time managing one's own. She speaks about it as an embodied practice during which the researcher is 'touched' both intellectually and emotionally and espouses the importance of emotion in research, despite this being counterintuitive to the traditional philosophical position of Western academia and scientific research (Dickson-Swift *et al.*, 2007).

Such emotional labour can also be increased when some of the boundaries between researcher and participant have been removed or diminished. As discussed earlier, a rapport is formed and often an interview will be taking place in a participant's own home. The complexity of managing differing points of emotion is best illustrated by an interview that took place in a participant's home. She showed an extraordinary level of openness and trust in me given that we had only just met, inviting me into her home, showing me her family photos and asking if I would mind holding her baby for part of the interview while she spoke about painful memories of childhood sexual abuse. I was mindful of the distress this was causing her and how I as a researcher could contain it or maintain it at a safe level for her. The rawness of her narrative was also difficult to listen to on a personal level and at the same time I was holding her sleeping baby who was teething and grizzly, waking each time I stopped rocking or patting him. When it felt that she was coming to a natural end of that section of her narrative, I suggested that we had a short break, to give her time to regain a sense of equilibrium and gather her thoughts before we continued with the interview. I returned her baby to her and offered to make a cup of tea for us both. While I would not usually invite myself in to a participant's kitchen, searching through cupboards for teabags and mugs, I felt it was important to give her a moment on her own with her

baby and it gave me an opportunity to begin to process what had been a highly emotional experience responding to both her emotions and the baby's. This also meant for the concluding section of the interview the emotion was able to dissipate and I felt confident to leave her at the end in the knowledge that she was no longer palpably distressed and her husband was on his way home. On a physical level I understood the embodied nature of research, as I left physically and emotionally exhausted. It was interesting that immediately after the interview I was not able to write memos or debrief with my supervisor, instead I drove to a nearby supermarket and distracted myself for an hour, before I felt able to begin to reflect on and analyse the interview or experience.

In the interviewing stage of a sensitive research project the intensity and frequency of participants' disclosures can also have an emotional toll on a researcher; while it has been suggested that showing the emotional impact a participant's narrative has upon you as a researcher can be affirming for the participant and further reduce the hierarchical imbalance between you (Dickson-Swift *et al.*, 2009), I personally felt that while I could show compassion and empathy I could not reveal to participants the fact that I found some of the interviews difficult to listen to, or distressing. This for me was intensified by my understanding that many of the participants had also been silenced throughout their lives by their fear and uncertainty about how others might react to their experiences. They had had to prioritise and take care of others' emotions over and above their own. I was therefore mindful that they should not have to feel responsible or concerned for my emotional reaction or wellbeing. It was however important to be mindful of the emotional impact that the research had upon me.

Emotional impact of research

With the level of emotional labour associated with some interviews it is unsurprising that the researcher can be left feeling emotionally and physically exhausted (Dickson-Swift *et al.*, 2009). I quickly learnt that I had to ensure there was sufficient gap between interviews and factor a time allowance directly after each interview that I could use to relax and reflect on both the interview and my emotional response. Narratives can provoke a strong and at times unexpected emotional response not only in the researched but also in the researcher. They can also prompt the researcher to

reflect differently on their own lives and emotional well-being, and in extreme circumstances could trigger an experience of vicarious traumatisation (Campbell *et al.*, 2010).

Within my study I was mindful of the emotional impact that some of the interviews had upon both the person who was transcribing the interviews and myself. I addressed this by warning the transcriber about particularly difficult interviews and checking in to see how she had found the emotional content of the interview once she had completed her transcription. I also debriefed the interviews with my supervisor and discussed the emotional impact of particular interviews and the study as a whole with a clinical psychologist colleague at the university. Finally, I was mindful of my own levels of stress and resilience throughout the process. This included taking a short break from the interviewing phase of the project following a death of a family member through suicide. As a researcher I felt I would not be able to divorce my own emotional state from the interview process, particularly as suicide or suicidal ideation could reasonably be expected to arise in any of the narratives. As such I felt that it could be potentially harmful for my own mental well-being and that of my participants to continue to interview until I felt I was robust enough to manage the emotional labour required.

As I have said, many of the interviews had a profound emotional impact upon me, these are stories that will remain with me for years to come. The emotional impact I felt was at times personal but also professional. The participants within my study gifted me a part of themselves that was deeply personal, precious and fragile and for that I feel privileged and grateful. However, with that privilege there also comes a sense of anxious responsibility and guilt. The guilt stemmed from the sense that in some way I was profiting from their experiences and the fear that I might become desensitised to their narratives, that the “extraordinary can become bizarrely ordinary” (Dickson-Swift *et al.* 2007 :341). Whereas the anxious responsibility lay in my desire to do justice to the narratives that had been given to me, to represent fairly the individuals who had so generously taken part and to ensure that their participation had purpose, that their voices were heard.

There was also a level of anxiety rooted in the sensitive and potentially inflammatory nature of my emergent findings. During the study some participants had shared stories of trauma, abuse and neglect, which continued to have far reaching consequences on their adult lives. For them these stories had been unseen, ignored and silenced and I felt a great responsibility that they deserved to be heard, acknowledged and respected. However, regardless of how pressing and powerful the research findings are they are still nuanced and contextual. As such the lack of control over their wider circulation can be problematic. Reinterpretations of research findings can result in what was first intended to be a healing narrative to becoming harmful, depending on the presentation and audience (Hyden, 2012). The messages and narratives in this study deserve to be heard even though at times they may feel uncomfortable. They are not intended to be used against parents with a severe and enduring mental ill health or to compound the discriminatory stigma that they face.

Part III

Findings

Introduction

This introduction offers a brief overview of main findings of this study and explains how these are organised into six chapters.

Each of the narratives in this study were a powerful portrayal of childhood, identity, relationship, adversity and love. Many of the narratives could have constituted a research study in its entirety, so powerful were their content.

The experiences and relationships described were complex and diverse with each portraying an intricate interplay of factors and its own unique history and context. However despite the individuality of the narratives, themes rose naturally from the data. Some of the themes that resonated most powerfully were those which had not been anticipated in the literature review. It was those themes, in terms of their significance and contribution to knowledge, that were selected above others to be further explored within the thesis.

In chapter seven the family dynamic is considered in terms of its composition, situation and functioning. Expectations of the role of parents and the representation of family is crucial for participants at a young age, as was the support they received from their 'well' parent. Siblings are also key in the sense of sharing the burden and not feeling alone. However, an unexpected correlation between birth order and care tasks is suggestive through many of the narratives.

Chapter eight zooms in on the narratives to explore the relationship participants had with their parent, both in terms of the bonds that drew them together and the insecurities that kept them apart. This is considered in terms of the relational reciprocity and roles taken on and the sense of loss of the idealised representation of the parental figure some participants held.

Chapter nine further explores this relationship in the light of the parent's mental illness, the associated behaviour and the potential risks. The dynamic relationship that the child develops between themselves, the parent and the parent's mental ill health is

illustrated within a model of acquiescence, within which the child's needs and expectations are modified in response to competing factors.

This relationship and acquiescence model is found within the participant's construction of identity in Chapter ten, and further explored in Chapter eleven which considers the current impact on the adults. A description is then offered of how they reconstruct their narrative identity and develop coping strategies whilst still experiencing an 'echo effect' of their parent's mental illness. A particularly interesting point that had not been anticipated, was the influence that growing up with a parent with mental ill health had on them as they considered embarking on their own journey into parenthood.

Chapter Seven

Family Dynamic

Introduction

In order to begin to make sense of the participant's experiences of growing up with a parent with a severe and enduring mental illness, how they understood the illness and how they felt it shaped their childhood and later adult life, it is necessary to first explore the wider context that their experience is grounded in. This includes the shape of their family, and the manner in which the significant members of their family functioned and related to each other. The functioning of the family also had a significant impact on the way that the parent's mental ill health was understood and represented within the family system.

A gendered reflection on parenting

As discussed within the methodology, it is important to note that fifteen of the twenty participants were women. It is also significant that the majority of participants (who choose to share their experiences of growing up with a parent with a mental illness) talked about their mother rather than a father with a mental illness. As illustrated in Figure 5, out of the twenty people interviewed, fourteen identified as having had a mother with a mental illness, three spoke about a father and three explained that both of their parents had been mentally ill. It was also noteworthy that of the three participants who identified both parents as having had a mental illness, two of the interviewees focused much more on the relationship and the difficulties that they had experienced with their mother as opposed to their father.

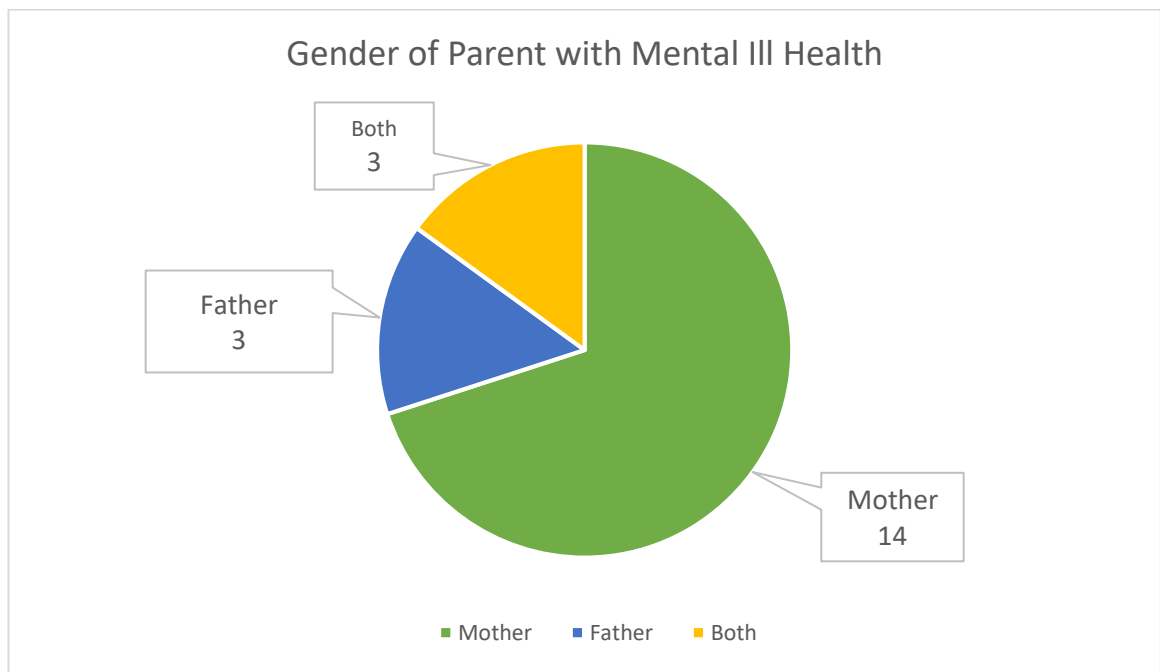


Figure 5 – Gender of parent with a mental ill health

This gendered nature of the research is reflective of the gendered nature of the existing body of research examining parenting and mental ill health, which predominately focuses on mental ill health and motherhood (Brandon, Philip and Clifton, 2017). It could also be indicative of the gendered way in which we attribute parenting roles, expectations and value to the parent/child relationship and how this differs between fathers and mothers.

Within the findings there were higher expectations of the mother's role and importance of her responsiveness to the child. Several participants spent time in the interview exploring what being a mother meant, for themselves both as a child and as an adult. In the main their representations of what a mother should be was based around the culturally dominant social construction of motherhood within the Western world (Fox, 2015). They spoke about the centrality of their mothers as being primarily a mother, emotionally available and physically nurturing; reading with them and going for walks. Emily painted a picture of her idealisation of motherhood:

When I was really little, so maybe three or four, erm... I remember my mum being a really wholesome type of woman she... all she did was be a mum, you know your typical type of flowery dresses and baking and she's a very creative person. – Emily

This presented a sharp juxtaposition to the mother she described coming home from school to, when she was nine years old, a mother who would regularly self-harm and require Emily to tend to her cuts, who lived in a makeshift room in their garage, chain-smoking, abusing alcohol, and neglecting her personal care. Both Emily and her sister Georgina drew vivid images of their mother sitting in a dirty blood stained dressing gown for weeks on end. They described her as emotionally labile and devoid of affection towards her children. Georgina mirrored Emily's contrast of their experience of their mother with their perception of what a mother should be by reflecting on the differences she sees in herself as a mother:

Having become a mum I just I don't understand how she can behave how she does ... I don't know how she coped with me not talking to her for four or five years... children don't stop talking to their parents, there is an untouchable level of love that you have for this small person and that doesn't go away ... I would literally walk over knives, fire, anything, I'd do anything to be [Harry's] mum, it'd be agonising like ... I don't ... love her. She's my mum but I don't like her very much. I tolerate her because since I've become parent myself I realise what that means ... It would kill me if [Harry] ever felt, about me as I feel about my mum. – Georgina.

For Caroline, Mike and Vivienne, who identified both their mother and father as having a mental illness, there was a clear weighting towards the impact that their mother's mental ill health had upon them. This appeared to be both because their mothers took the lion's share of their physical care, but also that they were more aware of the deficits with the emotional/attachment elements of their relationships with their mothers:

From a young age I was aware of my mum being... having a problem more than my dad actually and erm, and actually it used to make me quite angry. I used to be ... feel a little more bitter towards my mum for not like taking much interest in my life. – Caroline

Two of the participants, Natalie and Alicia grew up with their fathers as a single parent. Both expressed a significant emotional gulf between themselves and their mothers. Alicia described how this emotional distance was amplified by her perception of the social expectation that a mother would remain with the children, an expectation which was further used by her wider family to criticize her mother's value and ability:

A lot of my friends' parents were still together and if they weren't they lived with their mum and I always kind of felt a bit different and all I knew because I was only 6 and I didn't really understand it all and all, all I knew was that my mum had walked out and ... my dad worked such long hours trying to provide for me and my brother, like not having a mum there either and not having a dad there I guess that does have some kind of impact on a child as it is like just growing up with like almost like growing up without two parents ... spending time with [grandparents] they were feeding stuff into me about how she's a bad mum and how she shouldn't have left and stuff I think that's sort of why I held a bit of a grudge. – Alicia

Later in the interview Alicia questions the portrayal of the bad mother that had been presented to her. With adult hindsight she was able to consider her mother's emotional changeability and see that her mother removing herself from daily contact with them may have been a protective gesture. Within Alicia's quote it also appears that her father did not adjust his relationship with her or her brother to compensate for the loss of the maternal figure in their daily life. This adjustment and compensatory parenting was discussed by three participants, Robyn, Karen and Seb, all of whom lived with fathers with mental ill health and described their mothers stepping into the role of both mother and father, being the main source of income, the head of the household, performing all of the domestic duties and still providing the emotional

warmth and nurturing aspects of the parent/child relationship. Robyn further illustrated this as she compared her own situation with that of a peer whose mother had a similar illness to her father:

Seeing the difference between a mum with Schizophrenia and a dad with Schizophrenia really hit home to me. Because her dad was like a normal ... a normal dad, like your more traditional dad ... So her house was a ... you ... when you walked in it looked like a house that was struggling ... he probably did like the bare minimum so the house was very messy, she always had to do her own tea you know things like that, wash her own clothes and she was about 16 years old. So I do sometimes like, woah I was really lucky that it was the other way around and my dad had it because although I didn't have that relationship with my dad and I had a lot of issues, I think my mum did that maternal things and you know she kept the house running. Whereas my friend... I bet she grew up at about 12, 13 and thought right this is my life, I have to, do everything for myself. You know my mum did all my washing and you know I was still a, in that way I was still a child. Emotionally I might have had to grow up a lot quicker, but I think you know... I think maybe it would have been worse that if it had been the other way round. – Robyn

Relationship between the parents

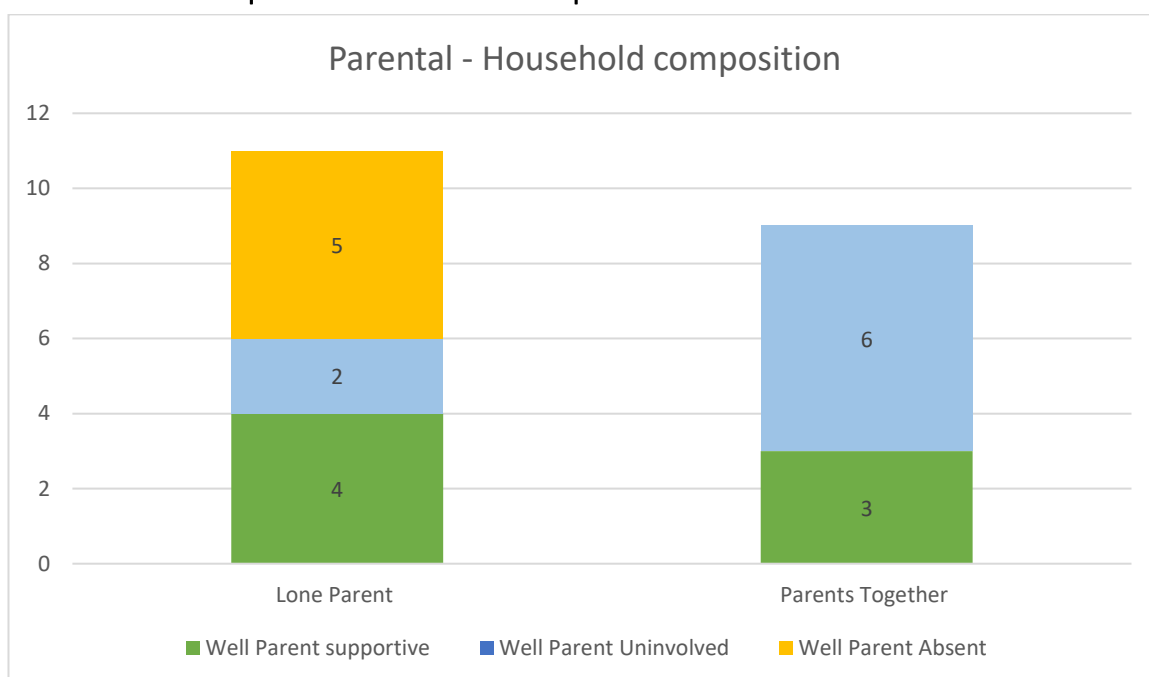


Figure 6 – Parental – Household composition

As seen in Figure six, the participants came from a range of household compositions which were significant when considering the relationship with their parents and the manner in which they experienced their parents' mental illness. The majority, eleven, identified themselves as growing up in a lone parent household, with the parent they lived with having a mental illness. Of these eleven, four felt that they had had a supportive relationship, two had minimal contact and five had no contact at all with their non-resident parent. Of these, eleven participants two remember their parents separating during their childhood, two were bereaved and the remaining seven had no recall of their parents as a couple. For the nine participants who grew up with both of their parents living within the family home, only three described their well parent as being supportive, the other six described their well parent as living in the home but remaining largely uninvolved.

The response of the 'well' parent in the nine participant interviews which described the parents remaining together, was a significant and potentially, extremely protective factor:

I never felt, I don't know like uncared for and I don't know if that's kind of a cultural thing with [Mediterranean] people in terms of how they manage situations like that or if it was just my mum. Or, yeah I don't know because she always managed She was very much the organiser in the family so she'd like I say do his meds, she'd do our dinner, she'd get us to bed, she'd get us up in the morning and stuff like that. So yeah I don't, don't know if that's kind of how, I never, like I say I never felt uncared for, it was always like I felt wanted and loved and okay with that I think in some respects she probably kind of hunkered down with the family a little bit, so kind of put her wings over all of us and became this kind of tight knot family relationship, which, which she kind of, yeah protected us all I think. – Seb

However, the majority of these participants described their well parent as being part of the household but noticeably absent. All of the six uninvolved well parents were fathers who were physically absent, working long hours and avoiding the family home. Freya recalls her father telling her later in her childhood that he had always worked so much because he didn't want to come home. An emotional absence was also frequently discussed, with Emily describing her father as “a very head in the sand kind of person”. So the mental ill health and behaviour of the other parent was rarely acknowledged or discussed. Many of these participants felt a range of emotions, from irritation to anger, toward their well parent for not being more involved. Jenny experienced her father's avoidance of her mother as an abandonment of her and her brother:

When we were growing up he was never there, never, and I understand that he had to go out and work and that but why weren't you there, you were meant to be, so I think I've got anger against him because he left me and my brother with my mum to deal with it and why weren't you there, like I needed you... so he wasn't there, I mean he should have been. That was my dad, he wasn't there and he left us with mum. – Jenny

This sense of abandonment was also experienced by three of the participants from two families who did not live with their well parent. When the circumstances reached a point where they had to be taken into care, moving in with their well parent was not offered as an option for them.

When talking about the relationship between their parents, the majority of participants described a relationship that was tense and fractured. Even in families which were portrayed as very supportive, such as Seb's, there was a sense of separation between the parent with the mental ill health and the rest of the family. Seb describes, with fond memories, family holidays where it would become a standing joke that wherever they went his father would just be left on a bench asleep as the family visited tourist attractions. Where there was further fracture this separation was exacerbated on a psychological level, Robyn has no memories of ever doing anything as a family with both her mother and father, she described her father as "flat, just nothing, really just a void of anything". This was intensified by the way he was viewed within the family home. Robyn recalls friends and friends of her mother's coming to the home and not acknowledging her father's presence (despite him being in the room), "treating him like a piece of furniture until he just slunk off". Because of this Robyn felt that she was never able to develop a relationship with her father:

My dad was just basically my taxi really, that was it. You know we had no sort of relationship it was just me and mum...I don't know my dad, like I know that sounds strange to grow up in a house with someone for 17 years and say I don't know my dad but I don't, I don't feel like I ever knew my dad because I feel like the illness took who he really was from us – Robyn

Karen also identified the tensions within her parents' relationship as shaping the manner in which she and her siblings responded to her father's illness:

[Mother] was very matter of fact about it not very kindly about it, so I suppose that sort of we didn't, sort of learn to be kindly about it either, you know we weren't really very compassionate about it - Karen

Many of the participants described growing up very aware of the tension and discord between their parents but not having been able to make sense of this until they were adults themselves. This lack of insight into the impact of mental ill health on the parents' relationship and individual wellbeing was stark in Lucy's interview. She predominantly spoke about her mother's mental illness, her emotional instability, impulsive behaviour and her repeated attempts at suicide and deliberate self-harm. However it was not until later in the interview that Lucy introduced her father into the narrative, describing him as suffering a psychotic mood disorder throughout her childhood and being supported by her mother until he committed suicide when Lucy was nine years old. It appeared that this was the beginning of her mother's acute manifestation of mental illness. However Lucy did not seem to draw any possible connection between her father's death and her mother's breakdown.

Siblings

As seen in Figure 7, the participants in the study came from a range of configurations in terms of siblings, varying widely from growing up as an only child to being one of six children. Five of the participants - Ethan, Vivienne, Terry, Caroline and Robyn, identified as only children (Terry had two half-brothers but never lived with or formed a relationship with them). Across the board all five of them expressed sadness that they had no siblings and believed that a sibling would have made the burden of their parent's mental ill health easier to bear. They spoke particularly of a loneliness throughout their childhood and the desire to be able to share the experience with another. Confirming the significance of shared experience, Mike described growing up in the midst of five siblings as being extremely protective. Despite both of his parents having a mental illness, he described his family as being chaotic and fluid just because of the number of people in the household. As such, he was never really sure what was general chaos, parenting or mental illness, nor did he feel individual responsibility for anything that was happening around him. He did however reflect that this probably was experienced very differently for his eldest brother and sister.

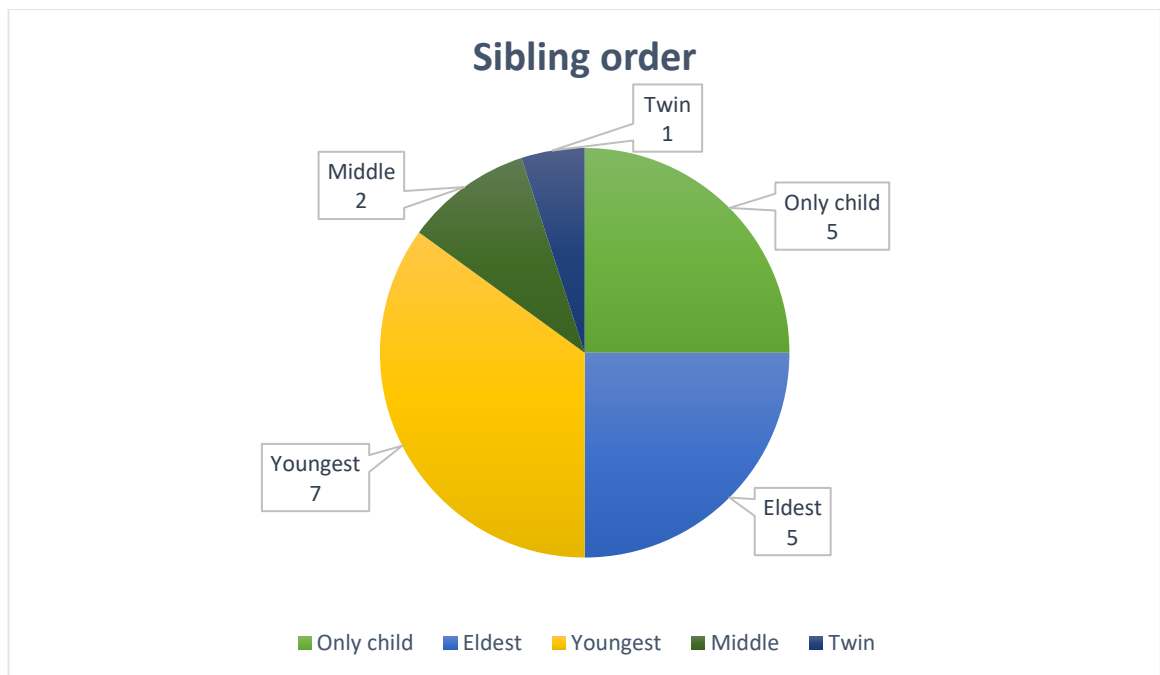


Figure 7 – Sibling order

Some of the participants recalled that they had markedly different circumstances to their siblings. On a physical level, Jess and Terry lived separately from their siblings, to the point that Terry identifies himself as an only child, and that while Jess was providing a high level of care for her mother, her siblings were not aware of the full extent of her mother's illness. There was also, for some, a psychological separation. An example of this was given by Monica, who felt she had caused her mother's 'mental illness' by giving her measles. Her overwhelming sense of guilt and personal responsibility for her mother's ill health meant that she felt she had no option other than to separate herself as much as possible from the family, including her younger brother. In a different manner, Karen also felt that she was psychologically separated from her siblings and she described being treated very differently to her brothers, while they went to school she was expected to remain home and look after the house and her parents.

However, during the initial stages of the interviews it became clear that even for siblings who grew up in what on the surface appeared to be the same circumstances, their understanding of their parents' illness and experience of their childhood was remarkably different. This was evident in each participant's account, within which they reflected themselves on how their parent's mental ill health may have been

experienced differently by their siblings and why. I was also able to interview two sets of siblings and as such gain a direct comparison of the differences within their narratives.

In terms of the sibling pair Sophia and Roman, they position themselves very differently in their perceived level of expertise and response to their mother's illness. While they are close as siblings some of their childhood circumstances were markedly different. Their mother raised them as a single parent but they have different fathers. While Roman's father appeared to be at the periphery of his life, with limited contact or interest, Sophia's father lived next door, remained friends with her mother and provided a strong father figure for Sophia. Also, in terms of their early years, Sophia was born in a psychiatric hospital and remained with her mother in a specialist unit for the first 18 months after which she lived with her aunt until she was eight years old. In contrast, Roman returned home with their mother after his birth and lived there alone with her until Sophia returned to the family home when he was five years old. Despite Roman having spent more physical time living with his mother during their childhood both Roman and Sophia place Sophia as the expert on their mother's needs. He also looked towards Sophia, above his mother, to give him general life support and guidance:

I can talk to my sister who has loads of information she has lived a whole life of it before me. – Roman

This expertise is also attributed because of the different ways in which they engaged with their mother's illness:

I was very, sit in front of the TV and chill, while she obviously got more involved in stuff that was going round so yeah I guess there are two ways of dealing with those kinds of situations, some just kind of block it out, in my sense, and others get more involved like her. – Roman

Sophia also saw that there was a wide gulf between how she and her brother experienced and responded to her mother's illness. In order to explain this she believed that the differences in their early years were fundamental.

The difference between me and my brother, is that [Roman] lived with her between the ages of 0 to 5, whereas I lived with my aunty so we did reading together, we did all those things together, means I'm probably more of a, we had a different upbringing whereas [Roman] watched a lot of TV he was like, so we've got really different relationships with her, me and my brother. – Sophia

However she also has a strong sense that her mother had always wanted a boy and as such had never fully accepted or liked her, whereas she was always demonstratively loving and preferential towards Roman. This has had such an impact on Sophia that she differentiates between her mother and Roman's mother:

When I talk about my mum and [Roman's] mum I talk about her like she's two different people which I always have and I've never changed it and I can't stop it because it's weird and I know I do it which is even more strange, erm so I don't know what that's all about but that's probably quite deep too. – Sophia

The differences in the siblings' experiences also related to the positions they ascribed to both themselves and their sibling within the family dynamic. For example, Georgina described herself as being the protector of her younger sister Emily, whom she sees as being less equipped to protect herself against the ill effects of their mother's illness:

You would get a very different picture from Emily, she might not even feel that I've been as supportive or helpful as I hoped I have been but she has been my, I think I was a mother figure to Emily, erm, because she just didn't, didn't have it with mum at all. Erm, so Dad and I have both been very protective of Emily, she's very much the baby but not in a negative way, she's not immature or anything like that, she's just the smallest and needs a bit, needs a bit of looking after. – Georgina

Nevertheless Emily recalled often being left at home alone with her mother as Georgina and their father stayed out late. She also references throughout her narrative her own emotional vulnerability and her sister's protectiveness, however it seemed that through their childhood she often experienced this protectiveness as more

frightening than supportive. This is perhaps indicative of the difficulties Georgina faced in attempting to protect her sister while she was also a child and deeply affected herself:

My sister was really angry all the time, she's only just started to calm down. I wasn't like a stompy around teenager because Georgina was a really scary teenager, and I decided I wasn't going to be like that, erm but yeah oh you know like between having eating problems and crying all the time and I was very, yeah, very emotional and needy but I suppose that makes sense doesn't it... between me and Georgina we'd erm we had a really funny relationship when we were growing up, I really, I loved her so much erm, but she terrified me. It's only in the past couple of years that we've sort of got an equal relationship. – Emily

Another interesting comparison in both of the narratives is that although they both represent Emily as the emotionally vulnerable sibling who was more susceptible to what they considered to be their mother's 'manipulation', this was not necessarily apparent in their interaction with their mother, for example Georgina described spending long periods of time in the garage with her mother trying to comfort her. Whereas Emily refused to spend time in the garage with her mother because it was "smelly and horrible" so she and a friend would watch television in the living room away from her mother. This difference in interaction could suggest that either Emily was actually more emotionally robust than she is given credit for, or that the care Georgina gave to their mother enabled Emily to take somewhat of a step back.

This difference in interaction and degree of connectedness was also striking in Natalie's experience. She grew up with her single father who had a Schizophrenic disorder and with her twin sister. Despite there not being the differential of age, their interaction and involvement with their father's illness appeared to be completely different. Natalie described herself as the only person her father would talk to or trust in regards to his illness. This was illustrated during an acute phase of his illness when Natalie describes being woken by her father and spending a night awake with him on

the balcony of their flat while he responded to hallucinations. All the time her sister slept on, completely unaware that anything was occurring. This difference in the interaction between Natalie and her sister with their father has also had a significant impact upon their relationship with him as an adult, which will be discussed later in the chapter.

Sibling order often seemed to have significance for participants. While Mike described himself as being relatively unaffected by his parent's illness, he also reflected how this might have been different for his eldest sibling whom he described as taking a parental role within the family and his youngest brother who he felt had a different emotional connection to his mother as her last baby. This is also mirrored in Freya's account when she highlights that she does not mention her middle sister within the narrative as she felt she was able to step away and not engage with her mother's illness.

With regard to sibling order, the clearest roles appeared to be attributed to the eldest and youngest sibling. Furthermore, it was within the consideration of these siblings that an interesting pattern emerged in relation to the level of protection that they afforded to each other and the weight of the care role that they took on.

Three of the older siblings, Sophia, Georgina and Jess spoke directly of their sense that they had to protect their younger sibling. As previously stated Georgina identified herself as providing the maternal care that she felt her sister did not receive from their mother. While Sophia and Roman's mother continued to take on the physical care tasks associated with motherhood, such as cooking and washing the clothes, Sophia left higher education on two occasions to return home and care for Roman while their mother had lengthy admissions in hospital, thus avoiding Roman being taken in to care. Both Georgina and Sophia place the root of their anger towards their mother in the damage they see has been caused as a result of her illness to their siblings. Jess explained that she made the conscious decision to protect her siblings by moving out with her mother and shielding them from her associated behaviour and risk:

When my siblings came over to stay I had to hide the whole thing from them because in my mind I didn't want them to lose their childhood and I didn't want them to know the all the horrible stuff

that was happening with my mum so I kind of hid it from them ... I got quite good at hiding it when they were around just managing to take them to the park or something ... and if I can maintain as much of a normal childhood for them and they enjoy it and play and all that other stuff that's really important to me erm you know I'd love to be in that situation but I'm not you know. – Jess

For Jess, this drive to protect her siblings' childhood and shield them from her mother's illness was made even more remarkable by the fact that she was only a year older than her brother and yet that sense of responsibility as the eldest sibling was still palpable. This was paralleled by Roman, Mike and Jenny who, as younger siblings felt that they had been protected by, and as such, relied on their older siblings. While this would suggest that the older siblings within a family take the primary role and responsibility as a young carer, not only caring for their parent but also striving to provide parental care for their siblings, a further step to the link between sibling order and caring responsibility materialised. While in the middle years of their childhood younger siblings were protected and cared for by their older siblings, however as they grew older the obligation of caring fell to them.

The notion of being 'last to leave the party' was raised by five of the seven younger siblings and by Natalie, the twin who had a more involved relationship with her father. Both Holly and Alicia, who were still living with and providing daily support to their mothers, reported that most of the young adult carers they knew were the youngest child. Alicia put this simply as:

I think it is because they [older siblings] grow up quicker so they have choice to leave before you do. – Alicia

Holly elaborated on the different level of choice and agency she feels she has compared with her elder sister:

I think it's her choice not to deal with it, I mean because when she needs to she can, but nine times out of ten she doesn't and I think that's her choice. Because she knows that she wants a family she wants, she wants to be able to have the freedom to move out when

she wants to have kids when she wants, to change her job when she wants, go to work when she wants, she wants to have that freedom and she knows if she's stuck in that caring role she's not going to have that freedom so she's made the choice to step away from it not the fact that she can't deal with it mentally she's made that choice to step away from it because she doesn't want it, whereas I can't make that choice because if I make that choice to do it then mum's got no one. – Holly

The tone in Holly's voice when she spoke about the choices that her sister wanted, suggested a level of anger and frustration. However this struck a chord with me, as an outsider the freedom of choice that her sister expected was reasonable, yet the impact it had on Holly's range of choices was overwhelming for her. This sense of being trapped within the care role was also noteworthy for Jenny as she described her brother's decision to go to university:

Where is he because he's not here, but I understand he's got to go get his own life, he's got a boat load of dreams so I've got to look after mum now ... but sometimes I am, I don't know, I know, I know he's gone sometimes that makes me more frustrated with myself like why can't I go, like he got there first. – Jenny

Of the sibling groups that I spoke to, Sophia had made a conscious effort to distance herself from her mother and expressed conflicting emotions of feeling that she needed to do that for her own mental wellbeing but also guilt that it left Roman in the position of caring for their mother:

I feel like I'm twenty fucking six I can't keep stopping everything because of my mother, do you know what I mean, but then I also know Roman is taking the brunt of it. – Sophia

Other family members

Several of the participants spoke of members of their extended family providing care for them, which ranged from spending periods of time with them over the school

holidays to living with them for prolonged periods of time. For Terry, who lived with his maternal grandparents for the first 10 years of his life, he was always very aware of the sacrifice he felt his grandparents had made to take him in when their own children had all grown up and left home. As such he described himself as ensuring he caused minimal fuss or difficulty for them as a child, and when his mother was discharged from hospital, despite having only ever visited her four times in hospital throughout his life he felt 'duty-bound' to move in with her to avoid his grandparents being 'burdened' further. For Sophia, who lived with her maternal aunt from the ages of 1-7 and 13-15, there was less of a sense of feeling as though she were a burden, she felt absorbed in to her aunt's family and viewed her aunt as a strong maternal figure in her life. Reflecting on her childhood, Sophia attributes a lot of her strength and resilience to her early attachment experiences with her aunt and as an adult describes looking to her aunt to compensate for the deficits she saw in her relationship with her mother:

It would actually be nice to have a mum, because I definitely don't feel as though I have one ... I think it would be nice to have some kind of parent especially when you're like really stressed and like you're doing loads of work and you just want to go somewhere and someone can make you some food erm or like where you could go there and then do work and they will just make sure you're okay ... I don't get any of that its always the other way around ... I sometimes if I'm really tired and I can't be bothered to just look after myself, I go to my auntys house ... I love my aunt. Do you know what I mean like she's my favourite adult person in my family. – Sophia

While Natalie paints a picture of a close relationship between herself and her father, whom she regards with admiration in terms of the approach he took to being a single parent, she also recognises that his mental ill health made parenting difficult for him and the positive role that her grandfather took in this regard:

My dad's probably not the most functioning of adults but my granddad really was, he was like really stable, like for me he was like a very stable figure and a very like safe erm predictable kind of, just

great grandpa kind of figure... he was the kind of adult that was an adult, he like, didn't...he held back from saying things to my sister and I ...like a healthy adult / child relationship I felt it was very much he was the adult I was the child. Whereas in my other relationships that's kind of like blurred a little bit. – Natalie

This significance of the adult/child relationship was also echoed by Vivienne who would spend her school holidays with her grandparents, where she felt she was able to enjoy being a child and would fantasise that she could stay there indefinitely.

Family approach to mental illness

Many of the participants spoke about fear of stigma and their attempts to keep their parent's mental ill health hidden from their peers. Some of the families also appeared to have had such a strong family rule about the taboo nature of mental ill health that it was inconceivable that as a child they would feel able to discuss their experiences with anyone outside of the immediate family. Indeed for three of the participants, they recalled not being able to discuss it within the family. For Karen, whose father suffered clinical depression and anxiety throughout her childhood and eventually took his life in later years, it was only as she and her siblings identified his body in the morgue that they experienced a brief moment in time when they could speak freely:

They were of the generation, or those generations that it was considered quite a taboo thing to talk about to have anything like depression or anxiety you just have to have a stiff upper lip and sort of get on with things ... that's how we were brought up you see you don't talk about it ... then suddenly over his body there was [Jonathon] and I one side, [Michael and Julie] the other side and there was this banter that went across, and I was almost, we were almost, we were shocked but we were shocked by what we were suddenly saying ... You know things shot across the body and that was just dreadful ... I mean we had been brought up to sort of button it up as well a bit like the royal family, very English and erm you know you don't really show your emotion. I remember sort of you know letting

a tear come out that's how buttoned up we had to be or we were and er saying it shouldn't have come to this, it didn't have to come to this and then my brothers and [Julie] pulled me away ... and my mum said shhh!! Like that that's enough don't speak like that. – Karen

This strict family rule of secrecy and avoidance of emotions had a fundamental impact on the whole of Karen's life. This prevented her as a child from disclosing experiences of sexual abuse and as an adult articulating her emotional needs to others. For Jess the secrecy that was imposed on her also prevented her from accessing support or disclosing other physical and sexual abuse. This was done by her father persuading Jess that if she told anyone or asked for help that she and her siblings would be taken away and this would cause her mother to kill herself, for which Jess would be accountable:

My dad he erm had basically made it very clear to me that that if I was to tell anyone that she was very ill that I'd be basically taken away and she'd probably kill herself. - Jess

At times the sense of taboo and secrecy within the family dynamic was not an imposed rule, but rather the child modelling their parent's inability to discuss their family's experience of mental ill health with them. For Freya, she could not recall either her father or other family members ever talking about her mother's mental ill health in front of her. This, in conjunction with the reluctance of society to acknowledge or discuss mental illness, meant that she found that she could not talk to anyone about her own concerns and feeling:

*He's not a big talker really, no, no, ...I've seen him cry once and that was after mum erm tried to commit suicide ... I don't think I've ever really had a serious conversation with him about mum really... also it was like something that people didn't really talk about either ... people didn't want to ask you about it or. You know if your mum had broken her leg or something they'd be like, oh how's your mum's leg or you know, whereas cos it was like...I think people are better now, but back then I think people didn't really talk about that kind of thing.
- Freya*

Both Sophia and Seb gave a positive account of how their parents' mental ill health was approached within the family. Sophia could not recall ever being aware of stigma or feeling embarrassed by her mother's mental illness. She attributes this to the fact that it was never "framed" as problematic by her aunt and other family members. Interestingly, it was noticeable that Roman, who did not spend his early years living with his aunt had a very different sense of the stigma associated with mental illness. He described feeling ashamed of his mother's illness and fearful of how that would reflect upon him within his peer group. For Seb, his family approach to talking about mental ill health was entirely different. He believes that his mother's open approach to discussing difficult topics as a family enabled him and his sister to make better sense of his father's mental illness:

So the fact that we were able to sit down as a family and talk about all the things that we were able to talk about, like I say, kind of you know from having a...an unwell dad to death to suicide to whatever came up, there's no taboo subject in our family and that was because my mum was willing to talk about it with us. So she's...so she's told us since that she never wanted to hide anything from us. – Seb

However, even with this is open dialogue, Seb still found it hard to express himself and talk about his own feelings:

So it's an open way of being in the family that we've never had any sort of...no secrets as such, but I'd hide my feelings certainly to not impact more on them. – Seb

This gave the impression that discussing his father's illness, feelings and behaviour was more important and valid than his own. This sense of the mental ill health being different, distinct and more important than 'normal' emotions can create a sense of difference and distance between the parent and child which can be seen in the complex manner in which participants viewed their relationship with their parents. This is discussed further in Chapter Nine when considering the model of acquiescence.

Summary

As previously discussed in the literature review, families' structures and the roles within them are complex and dynamic. They provide the primary frame through which children make sense of themselves and engage with the world around them. The gendered concept of parenting is written through the findings of this study. Not only are the majority of the participant's women talking about their mothers, but illustrated in all of the narratives were higher expectations of mothers to provide nurture and a greater awareness of mothers' deficits in this area. The relationship between the participant's parents was of significance for them, not in terms of the stigma from being from a 'broken home' but rather the manner in which the participants saw the 'well' parent as being able to act as buffer between them and their other parent's mental illness. Again, the way in which the 'well' parent provided this buffer was gendered with the 'well' mothers appearing to step in and step up, with many of the 'well' dads seeming to avoid this role. This was not always by physical absence. While five of the 'well' parents were absent from the child's life, several remained within the family home but avoided the difficulties of the other parent's mental illness, by using work as an escape or putting their 'head in the sand'. This awareness but lack of responsiveness resulted in greater feelings of resentment, frustration and abandonment for some of the participants than for those whose absent parent was seen as uninvolved and unaware.

The importance of siblings was also raised in all of the interviews, with the five only children expressing how they had always regretted not having a sibling with whom they could share their experience. However, it was also clear that siblings' experiences of parental mental ill health were different both in terms of practicalities and perception. An interesting dynamic emerged in terms of the adoption of responsibility and burden between siblings. In the early years of their shared childhood it was clear that older siblings took the lion's share of the responsibility for their parent but also for their younger siblings, attempting to protect and parent them themselves. However as they reached adolescence and early adulthood these older siblings moved away from the family home and the responsibility and burden was passed on to the younger

sibling. Many younger siblings felt trapped within the care role, with no one to pass the care of their parents on to.

Participants spoke of other family members (and in two cases close friends) such as grandparents and aunts who provided substantial care and support, but were still not privy to the complexities of the relationship between the child and their parent and as such were not able to make fundamental changes. The level of involvement of others was also indicative of how openly the family approached mental illness. For some it was a closely guarded secret which prevented help from being sought, whereas others described how it was 'framed' in a positive and normalising manner. This positive open approach was felt to be supportive for children and appeared to reduce their own sense of personal burden. This said, some of the participants described the open discussion and focus on the parent's mental illness, at times, as over shadowing their own needs, making them seem trivial in comparison.

Chapter Eight

Relationship with the ill parent

Introduction

Within this chapter the perception that the participants hold regarding the nature of the relationship they had with their ill parents as children will be considered specifically with regard to the impact they felt that their parent's mental ill health had upon this relationship. This includes the boundaries and roles that define their parent/child relationship and how participants felt that their parent's mental ill health affected their personal experience of this relationship. This includes the loss some participants felt of the parent/child relationship they had hoped for.

Childhood relationship with the ill parent

In discussing the relationship with their parent who had a severe and enduring mental illness, each participant demonstrated different ways in which they attempted to make sense of their parent as an individual within the context of their mental illness. For Ethan, Terry and Karen, who considered themselves to have a close relationship with their parent, it was noteworthy that they each used a significant section of their narrative to give a sense of who their parent was before they became unwell. For each of these participants this was before they themselves were born. Terry spoke at length about his mother as a teenager and young woman, speaking with pride about her achievements and daring spirit. Karen made sense of her father's illness as she situated him as a wartime child and described the experiences she believed that he had had as a child with his parents and his childhood understanding of the war and austerity.

For Ethan and Terry their portrayal of the person their mother was before their birth was particularly powerful as they both associated their birth with the breakdown of

their mother and father's relationship and the beginning of her mental illness. For both men this resulted in a sense of inferred culpability, guilt and subsequent duty:

I felt a duty to my mother. I think part of me felt that my father, because he'd... he'd run off with one of her friends erm while she was away, erm so that's all very bitter, huh, erm. But I think I always felt my dad had let her down so I can't. – Terry

For Ethan this mindfulness of duty extends to a sense of interdependence. He describes both his mother and himself as being rejected and isolated within their local community, with Ethan being particularly bullied by his peers at school. Ethan attempted to cope with this rejection by developing an exclusive relationship with his mother which meant he felt that they needed nobody else. In many ways, it seems that Ethan took on the role of partner as well as child for his mother. He described missing lots of school to be with her during the day, taking her out to the pub when he was 12 to cheer her up and reading to her each night to help her sleep. Throughout his narrative he repeatedly refers to the fact that they only have each other, for which he feels a great deal of sadness when he thinks about how she was before his birth:

Even today I cry for my mum, when I think of all she had gone through and lost... I always think what would mum do now, what would my life be without her, I feel like I've let her down. – Ethan

This leads him to making his relationship with his mother the main focus of his life. Ethan's core belief about himself and his own self-esteem is entwined with his mother, as he defines himself by his role as her carer and protector. The intricacies of this definition will be further explored in Chapter Ten, where the impact of growing up with a parent with severe and enduring mental ill health on an individual's adult identity will be examined:

We're on our own and I said to my mum I'll always be there for her... and I said that I'd always make her happy and that, I said I'd look after her from...from the start all the way to the end... So I told my mum if she ever needed me I'm only...I'm only in a light sleep so I

don't force myself into a deep sleep and that's how I always look after her. – Ethan

For Seb and Sophia there is also a sense of their parent before the development of the mental ill health and the manner in which this is reflected in their relationship. However Seb and Sophia experienced this through their parents seeing themselves in them and drawing upon their similarities. Both Seb and Sophia found this intrusive and uncomfortable:

Because he thinks I'm a chip off the old block, it's another phrase that he quite often spits out. But erm, yes so our relationship is odd, I think, just because he...he can't separate the...he can't see that we're separate people sometimes it seems. And I...I kind of struggle a bit with that because it's...it's a bit weird, I find it...I find it quite strange myself that he's kind of...he sees these parallels that I don't think are there... I don't know if that's to do with his un-wellness or he's living a bit vicariously through me. – Seb

Indeed, Sophia believes that on some level her mother resents her achievements as she sees them as a representation of what she could have achieved herself if it had not been for her mental illness. Sophia described what she felt was jealousy and resentment as fundamentally undermining their relationship:

Half the reason why our relationship is quite troubled is because I don't believe anything she says, in terms, of oh I love you or I'm proud of you she hasn't got a very genuineness about it, it sounds a lot more to me like jealousy than anything else ... I think what it is, is that we are quite similar and I think I might represent what she could have been if she wasn't ill and I think that's really been hard for her. Basically it's also been really hard for me because it means that the way she interacts with me, it's almost as if I am, like I stole her life as opposed to I am her child, do you know what I mean, which isn't cool really. – Sophia

Parenting the parent

Another apparent confusion between the child and parent relationship was also demonstrated in many of the participants feeling that they were taking on the position of having to parent their parent, in terms of providing both emotional and physical care:

My memories of when I was little are of my having to hug my mum to stop her crying, like come on mum you know, like it's okay, like when actually I was the child and we were reversed, I was looking after her and she should have been looking after me. – Jenny

Participants also take on the role of disciplinarian and responsible advisor. Both Vivienne and Sophia describe this 'parental' role as continuing long after they have left home and/or stopped providing physical care for their parents:

I can't even imagine the future right now. I don't know what to do with her I think I'm better off just being her mum because that's what I am really ... it's like having grown up children you never gave birth to ... I imagine its really similar like of a parent that's got like a rogue child I mean more like a child that's a drug addict or something like a child that continuously fucks up in the end. – Sophia

The acceptance of the role of parenting their parent also led participants to deviate from the usual expectation that a child would ordinarily have of a parent. In several narratives participants spoke about having to have lower expectations of their parents due to their mental illness. This relates to the care that their parents give them and also their belief that they cannot hold their parent accountable for their behaviour. This is often in contrast to the higher expectations they have upon themselves to cope, manage their parent's behaviour and meet their needs:

So that's where it gets stressful and yeah that gets annoying when she starts arguments and you shouldn't argue with someone with mental illness because it doesn't go anywhere, you just don't move, the rock just stays where it is. So then I need to do a bit of growing

up and a bit of realising what a mental illness is and how you should probably deal with it you know which means just putting in a lot of patience a lot of thinking and you know a lot of realising what it is you know. These are things you know people can't control. – Roman

However, other participants described their expectations and feelings towards their parent's accountability as changing as they grew older. Georgina spoke of her mother adopting what she termed a 'sick role' in order to avoid responsibility or recrimination for her own behaviour:

She just wanted people to take any responsibility that she had away from her cos she couldn't...well she didn't want it I guess. – Georgina

This perceived lack of responsibility or accountability was one of the main causes cited by the participants who described their relationship with their parent as being irrevocably damaged. As discussed earlier, Sophia and Georgina spoke of being particularly angry when considering the impact they feel their mother's behaviour has had upon their young siblings. For Lucy, in her account she differentiates between her mother's behaviour, which was at times extremely challenging, and the lack of her mother's acknowledgement of it. This indicates that Lucy has the ability to psychologically process and 'forgive' her mother for her actions but is not able to do this without her mother acknowledging what had happened and attempting to see it from the point of view of Lucy and her brother:

In family therapy what came out of that is my mum could not say she was sorry for what she put us through (tearful) and it came out that...and basically since then I've battled with the fact that she'll never be sorry and I'll never forgive her, I...I just can't forgive her for what she's done to us. Erm because she won't recognise what she's done because she doesn't remember, or if she does remember, oh but I was ill, so it's not my fault. It's like, like being ill absolves her of all responsibility of being a parent or being...you know, and that's what I find most difficult now. – Lucy

Emotional warmth and connectedness

The ability of the parent to acknowledge and respond to their child's emotional needs was also key to how the participants regarded their relationship. This could be referred to as warmth and connectedness. Across the participants it became apparent that the impact and damage caused to the individual's relationship with their parent was not necessarily caused by the severity of the parent's mental ill health or the associated behaviour but rather more by the manner in which the participant felt that their parent had viewed them as a child and the quality of the relationship they had with each other. Mike, who grew up with both parents with severe enduring mental illness, each requiring multiple hospital admissions and community support, felt that it was the fact they he was not made to feel personally responsible for, or less important than, their respective illnesses that was the defining protective factor throughout his childhood:

Although my mum and my dad had mental health problems... Erm I knew I was loved as a child... I wonder if you as a child in your development, I think if you're loved you can deal with anything basically or a lot of stuff. If you are unloved you struggle with a lot of stuff. - Mike

This felt presence of love and connectedness was also dominant within Natalie's narrative. Although she had to manage her father during acute phases of psychosis with extremely disturbed behaviour, this was interspersed with periods of stability during which she felt loved, valued and protected by her father. At the other end of the spectrum, Robyn's father's illness had no dramatic episodes and no apparently disturbed or risky behaviour. However as an adult Robyn has severed her relationship with her father because she feels that they had no connection between them:

He wasn't neglectful, he wasn't awful or horrible, even he...you know...cos he was so flat very rarely did he ever get cross or raise his voice. He was not an angry man, he was just flat, devoid of any sort of emotion. – Robyn

For Robyn she experienced her father's lack of emotion and apparent indifference to her interests and achievements as a child, as an indication of her being rejected as unworthy of her father's regard:

You can't truly know what's going on in someone's heart or someone's head, that's the problem and you're rejected so many times that you say enough's enough, you know I...I'm not at this point really bothered whether it's the mental illness or whether he can't be bothered. I can't do that anymore to myself, I can't sort of set myself up there and then (pause) be knocked back again because that's very...it's very tough... Even when you're older, you know you want your parents' love and acceptance, you want their support and when you don't get that you do take it to heart, you think, well what...what's wrong with me? – Robyn

Rejection and self-worth

For Emily her sense of rejection was also intertwined with her attempting to protect herself from the psychological harm caused by her mother's suicidal behaviour:

I just got more and more resentful of her and I was just like, you're so selfish and every time she tried to kill herself or went into [hospital] I'd just be like, oh you don't care about us then obviously, so I don't...I'm not going to care about you anymore. - Emily

This could also have been exacerbated by her idealised concept of motherhood as being wholesome and dedicated to the role of mother. This concept is reflected in current assessment of risk and protective factors within suicidal ideation, which cite children as being a strong factor in protecting mothers against suicide (McLaren, 2011). This is founded within the understanding that the mother's love and maternal instinct would prevent her from putting herself in a position where she would not be able to provide care for her child. This representation of the transformative nature of the bond between mother and child also influenced Sophia's understanding of her mother's mental ill health as a child:

When I was younger I was very much in the stage where I was erm oh I am going to make sure you know how much you are loved so that you can start to feel better about yourself and get happy, and like I just used to find letters that she would write about how much she hated herself and how she wanted to die and all these sorts of things. So I would write her letters back about how nice she was how lovely she was... Like for a long time when I was younger I really didn't understand how me existing like how me and [Roman] existing wouldn't make her better, like that was in my childhood brain do you know what I mean? It's like but you wanted kids now you've got kids I really thought like I used to think there was something I could do to sort it out. - Sophia

For Lucy the mother / child relationship and bond became painful and frightening, as her mother often associated her emotional instability with her overwhelming feelings of maternal affection:

I do have this vivid image of my mum lying on the kitchen floor, and being nine years old and walking in and finding her like, you know vomiting and crying and saying she wanted to kill herself. Erm, and saying that she'd taken an overdose and it was cos she loved us too much or she couldn't cope with...I don't know, we...we were always like drawn into her...her overdosing, like she couldn't cope because...because we were, you know like she couldn't cope with being a parent. And she loved...she loves us so much that she wanted to kill herself.... other traumatic things, erm, my mum took us out in the car and said she was gonna to drive off a cliff, cos she...if she was gonna kill herself then she was gonna kill us too because she loves us so much. She used to always tell us how much she loved us as a sort of guilt trip almost. – Lucy

As discussed earlier, now in a period which could be defined as recovery, Lucy's mother is unable to acknowledge the impact that her behaviour had upon Lucy and

her brother, which Lucy finds impossible to forgive. Nor does she feel able to accept it now when her mother expresses love towards her. This confusion between maternal love and emotional instability had also rendered Lucy terrified of what might happen if she were to become a mother herself, an issue which will be further explored in Chapter Eleven.

Mourning the loss of the relationship

A final theme that emerged while reflecting on the relationship between child and parent was that of loss and subsequent mourning. Caroline, Robyn and Freya described that loss of their relationship with their parents as a disconnect they felt was caused by the illness itself. Robyn described mental ill health as stealing the person from themselves and those around them. While Freya felt that the progression of her mother's illness slowly took her away from her:

I disconnect from her, she's gone off somewhere for a bit, she'll be back eventually. But it feels like more and more she's never...she never really comes back anymore. - Freya

Caroline also recalls a palpable sense of losing her mother to her illness, indeed her father too. In their attempt to support her mother, and perhaps protect Caroline and her brother she felt that she became disconnected from her whole family:

My mum and my dad and my grandparents became very insular, in like a little bubble around my mum trying to protect her and help her to get better. So we were cared for, like we had food and clothes and heating and shelter, but we were just suddenly on the outside ... We were suddenly on the outside of this bubble and we didn't know what was happening in the bubble, apart from what we could see ... I think I don't know whether it's on my side or whether it's just because it happened, there was this like dislocation of us as having a connection, a real connected relationship when I was eight or nine, we've never managed to get that back again. – Monica

Summary

The relationships participants described as having with their parent were very much coloured by the understanding of their parent's mental illness. For some they felt they were drawn closer, while others felt that the illness drove a wedge between them and their parents, disrupting the parent/child relationship. Many spoke of the boundaries and roles expected within a parent/child relationship becoming blurred. At times this seemed reversed as the participants recalled having to parent their own parent. The level of warmth and connectedness was key to participants, with several recalling feeling rejected and unworthy, which had long term impact on the participants own self-esteem. A theme that carried through into the participants' adult narratives, was that of mourning the loss of the relationship with their parent. For some this took a grieving aspect as they felt the mental ill health represented a figurative death of their parental figure.

Chapter Nine

Making sense of the illness, managing the risk

Introduction

The manner in which children become aware of their parent's mental ill health and experience the associated behaviour is key in how they make sense of it. This is also heightened by their perceived level of risk for both their parent and themselves. This chapter will consider the varying factors in making sense and feeling responsible, proposing a psychological framework that some individuals appeared to have employed in response to these extraordinary demands.

Becoming aware of the illness

Participants recalled different memories of how they became aware of their parent's mental illness. Fourteen of the participants felt that they had always known that their parent had a mental illness. This appeared to be linked to the illness being part of their life from a young age and the way in which it was discussed within the family. Seb reflects on how it might have been different for his older sister, and later in the interview expands on this to consider how she might also have had a sense of loss of the 'well dad' that he had never known:

I always knew to be honest, yeah there was no like light bulb moment or anything like that, it was just I've got a dad who's unwell ... Which my sister might have a different memory of that, but for me it was just I've got an unwell dad and just dealt with it and we always talked about stuff as a family. – Seb

Other participants described becoming more aware of their parent's illness through the comparison with the parents of their friends:

The more I sort of made friends with other people and went round their house and saw their family the more I realised that, oh we're not that...a normal family but that's okay, my mum still loves me. – Lucy

This comparison with friends' experiences of being parented, also continued throughout childhood and early adulthood. For Emily and Sophia, while they had grown up very aware of their mother's mental illness, it was when they began University that they reflected on the level of support that they felt their peers received from their parents, and indeed the different expectations that their friends had of their parents.

Sophia realised as an adult that some of the parents of her friends may have had a clearer understanding of her mother's illness than she did herself:

I never really thought about it before, but a lot of my friends' mums mothered me quite a lot erm like they would buy me really nice birthday presents and like you know really think of me and I think it's because they had an understanding, a better understanding of my story than I ever did. -Sophia

The developmental limitations of awareness of difference for a young child were also illustrated within Vivienne's narrative, during which she explained that both her mum and dad had severe and enduring mental illnesses. Initially she was more aware of her mum's illness because it necessitated hospital admissions, which fitted within her childlike understanding of illness, whereas her father's manic episodes appeared to her more as fun:

I obviously knew my mum did, because there were sort of lengthy periods where she was in hospital and she wasn't capable of erm sort of looking after me. With my dad I don't think I ever sort of realised that there was a problem because when you're a kid you don't. I just

thought he was like really fun, like. And looking back now I can see that, you know like, getting your kid up at four o'clock in the morning because you want to go to the beach. I never sort of thought erm you know that he was manic or that he might be drunk or anything like that. – Vivienne

However while she had stated that she had always know her mother was unwell, she was also often unable to distinguish between what was normal and what constituted behaviour driven by one of her mother's psychotic episodes. She recalled reflecting on this during a recent conversation with her father:

When I was really little I don't think I realised there was any...anything wrong with my mum either really. Erm I mean my dad tells me a story and I, it's funny because I do remember it really well having this day off school and my mum had got me this erm little mermaid rubber stamp kit, and I remember having this day off school and having a picnic on the floor in the living room and everything seemed fine. Then my dad and my granddad showed up and, then we went away with them and then my mum wasn't very well and went to hospital. And we were talking about it a few years back and I said like oh I sort of remember that and he said, oh we actually had to come and rescue you because your mum was in the middle of quite a major psychotic episode and had completely smashed the flat up and there was just glass everywhere. But I didn't remember that aspect of it at all, for me everything was quite sort of hunky dory and it was exciting having a day off school. – Vivienne

At the other end of the spectrum of recognition, six of the participants described having no awareness of mental instability until they were faced with a critical incident, in the middle years of their childhood (aged between nine and 13 years old). This sudden encounter with their parent's illness as opposed to the gradual development of awareness was described as dramatic and traumatic by all of the participants, and generally resulted in a significant change to their family dynamic and established

routine. For Holly, Lucy, Georgina and Jess it meant the immediate adoption of a caring role. The incident for Jess occurred when she was 13 years old. Her parents had recently separated and Jess and her siblings were living with their father. However at the end of a visit with her mother Jess felt that something was not right, that her mother was in some way saying goodbye. Jess did not want to leave her, but her father insisted that they returned home, conceding that Jess could check in on her mother in the morning:

I opened the front door there was like a suicide note on the side, broken glass, blood, pills er and it was my mum had tried to kill herself, but at the time I thought she had and then he [dad] turned round and said to me ohh well you better search the house for her and don't forget to check in the cupboards because sometimes they put themselves in there. So I searched for her, for my mum's body, erm luckily er I found out later she had called Samaritans and got support and ended up being er calling an ambulance, letting them call an ambulance and she went into hospital and she was okay. But that was the start of it really in terms of me looking after her because at that point I decided I wasn't going back to my dad's. - Jess

For Freya and Monica, they experienced it more as a loss of their parent. Monica described never being able to re-establish an emotional connection with her mother after her first episode of illness. Freya depicted her mother's illness as an inevitable diminishment of their relationship, explaining that she feels her mum "goes away" with each relapse and that each time less and less of her returns.

All of these six participants described the onset of their parent's illness as marking the end of their childhood, and the beginning of having to attempt to negotiate an adult world within which they felt ill equipped and unprepared. This was particularly stark in Monica's narrative. With no understanding or information about the precipitating factors of her mum's psychotic episode, she sought to make sense of it herself, concluding that she was to blame for 'infecting' her mum with a virus which caused

her illness. The subsequent crushing sense of guilt, combined with her family's immediate focus on her mum's needs left Monica feeling excluded and alone:

Mine was quite dramatic, it went from I had no sense of anything being wrong in any way in the world, except for the normal things like I wanted to ride my bike and I had to go in for my tea, that kind of thing... and then I caught rubella ... And my brother caught it and then my mum caught it and I got better but my mum, it hit her really badly and she was really quite ill with it. And as I understand it from talking afterwards, but at the time I didn't know, she had a nervous breakdown while she was ill with the illness. Erm which manifested itself, I went to bed one night and it was dark and I woke up in the middle of the night and my mum was screaming, I could hear her in the bedroom next door screaming and I could hear my dad talking but I had absolutely no idea what was happening, no idea at all. Erm and I'm not even sure I knew the next day, I'm not sure it was kind of resolved or explained what's going on, it was just all of a sudden my mum wasn't there anymore, she was just in her bed all the time, erm in the bedroom all the time. And my grandparents would come over quite a lot and my dad would be taking care of her and I knew she was ill. But I always...I thought immediately this is my fault because I've given her this illness, I've given her the German measles and that's what it is, I didn't realise that she was having, erm, psychological problems and erm, and mental breakdown and then she was on tablets and erm she tried to go to...she went to a psychiatrist and they put her in hospital and all sorts of associated problems. I didn't know that was happening, I just thought I've made my mum really ill erm and it's my fault. And I think a lot of the time at the time, my mum and my dad and my grandparents became very insular, in like a little bubble around my mum trying to protect her and help her to get better... We were suddenly on the outside of this bubble and we didn't know what was happening in the bubble, apart

from what we could see. Erm and I knew it was my fault, that I'd caused it all I remember thinking I just...I'm separate somehow now. So I went from a state of not even realising how secure I was to almost overnight and within the space of a few weeks feeling as though I was separate from them and I had to be an adult. This was when I was about eight I think, erm by the time I was nine or 10 I felt like an adult ... I am taking care of myself, I'm responsible for myself. -

Monica

The age and manner in which the participants became aware of their parent's mental ill health was also influential in terms of how they sought to understand or make sense of it. Many spoke of focusing on the physical symptoms and/or causes of their parent's behaviour, which felt more tangible than psychological explanations. In this vein, participants spoke of using hospital admissions as an indication of illness and later on rating the severity of the illness by the response of the mental health services. Freya, Sophia and Natalie rated this by whether their parent had been sectioned or not. Roman describes knowing his mum was 'bad' when the doctors visited or when the police brought her home.

The recurrent theme within existing literature regarding the difficulties children have in making sense of their parent's illness was reflected across the majority of these interviews. Very few remember anyone speaking to them or fully explaining their parent's mental illness. This lack of accessible information is reflected in the fact that half of the participants were still unclear of their parent's diagnosis as adults. This includes two participants who have gone on to work professionally in the field of mental health care. For those who did know the diagnosis, many questioned how well it fitted their parent and did not find it useful. One participant, Natalie, spoke of actively avoiding learning about her father's diagnosis as she feared it would colour her impression of him and interfere with their relationship. This lack of information and lack of assistance in making sense of their parent's illness is further discussed in terms of service intervention in chapter twelve.

Ill parent behaviour

Within the narratives the participants described a range of behaviours associated with their parent's mental ill health that, using psychiatric terminology, could be categorised as acute or chronic behaviour. Acute behaviours are associated with manic or psychotic illnesses. Participants described acute behaviours such as hallucinations, delusions, grandiose beliefs, paranoia, pressure of speech, chaotic/impulsive behaviour, disinhibition, overspending and going missing. Chronic behaviours reported related to depression and anxiety. These included: staying in bed/sleeping a lot, self-neglect and being emotionally labile, for example emotionally withdrawn, flat, tearful and distressed and not being 'present' or involved in family life.

I chose to refer to this as behaviour instead of symptoms, as it is the experience of the participants witnessing the phenomena as a behaviour which is being considered within this study. This perspective differs from the internal sensation of illness that might have been described by the person with the mental ill health themselves or the observation of symptoms described by a mental health professional.

Natalie, Seb, Caroline and Lucy described their parents as going through phases during which they presented with either acute or chronic behaviours. Interestingly all four stated that they found the 'depressed' version of their parent easier to deal with. However the participants who experienced their parents as being continuously 'depressed' and emotionally withdrawn felt that this caused significant long-term damage to their relationship with their parent, more so than the participants who witnessed their parents having time-limited psychotic or manic episodes. These appear to be understood as a break in their relationship with their parent as opposed to an indication of the quality of their relationship with their parent as a whole.

In terms of the emotional and physical impact on the children, the experience of chronic self-neglect as described by Georgina and Emily was also extremely difficult to manage:

She'd sit in her big fluffy greying, should be white, dressing gown and just... she just used to have blood on the back of her all the time, it was just horrible to see your mum like that. Erm, so I used to like,

even like physically wash her and...and all this sort of thing, so I'd...I would come home from school about quarter past seven and find mum like that and then... I'd sort of got mum washed and dressed and erm fed her because she wouldn't have eaten, wouldn't have eaten properly. - Georgina

This self-neglect was also punctuated by episodes of self-harm which the sisters also had to tend to and which in Emily's case had a long term effect:

Emily got home and found mum in the bath having cut her feet and there was blood everywhere apparently and my poor sister had to deal with that. And erm, obviously the guilt that I wasn't there (crying) but mum knew Emily was coming home on her own, she knew and she still did it...after the incident where Emily found her having cut her feet in the bath. Which she then tried to pass off as getting the dead skin off her heels, which it was evident that that isn't what she was doing. And that's when Emily's self-harm started more, I think she had been doing it beforehand but she used to cut the top of her thighs. – Georgina

Six other participants spoke of their parent's self-harming behaviour, which included cutting, banging their head and deliberately burning themselves on the cooker. Six participants also spoke of bearing witness to their parent's suicide attempts. These predominately appeared to be through an overdose of medication, although other methods were also used. Jess spoke of her mum making multiple attempts to end her life; including running out into traffic. Ethan described his mother attempting to drown herself in the sea. Karen spoke at length about her father taking his own life and the impact that this continues to have upon her. Two participants also spoke candidly about attempts they have made to end their own lives. While neither seemed to attribute this to their childhood experiences, both used methods remarkably similar to those they had witnessed their parents use.

One of the behaviours that participants described as being most difficult to cope with (in some cases even more than the self-harm or suicide attempts) was the emotional

un-containment and over disclosure of their parents. For 14 of the participants this related to the expression of their suicidal ideation. Caroline recalls being in the car with her dad aged nine, and the fear she felt as he told her that he often felt he wished he could drive the car over the cliff edge that they were passing. Sophia recalls, at age seven, her mum leaving notes saying how much she hated herself and wanted to die. Sophia, in turn, would write back to her and draw her pictures telling her how lovely she was. The devastating impact of hearing her mum voice her suicidal feelings and the on-going impact of this was clear in Jenny's narrative:

I didn't realise I was this messed up from it all. Like I thought I was fine but like I'm not fine I've still got these images of her like of her telling me she wants to die and that's so hard to hear from your mum (tearful) sorry. I didn't mean to get . My mum telling me she wants to die. I would never get that thought out of my head so I will, it will never change. – Jenny

Suicidal ideation was not the only disclosure that the participants described as difficult for them to emotionally process as children. Several participants also described that while they were still young (under 10 years old) their parents would tell them about sexual abuse they had suffered in the past. These disclosures would often involve other adults within the participant's life which would result in them feeling confused and unsure about the security of the relationships around them:

The most difficult thing was that she would tell us everything, she has no filter and she erm when I was...I think I was about 16 because I was at college, she told me that she was going to get my dad kneecapped and she told me that erm my dad anally raped her and told me all these things which I couldn't cope with at all. But I never know what to believe because she made up lies about me and [Georgina] as well erm, which obviously I know aren't true. - Emily

Regardless of the content none of the participants spoke about feeling able to talk to anyone else about what their parents had said. They described not wanting to get their parents in to trouble, break their confidence or that they simply did not feel able

to repeat what they had heard. All of them felt that they had been too young to hear such things and felt that the boundaries between parent and child were detrimentally blurred.

Eight of the participants spoke about their parents' behaviour as being childlike and manipulative. Georgina spoke of her mum liking to "act the victim" and take on the "sick role". Whereas Jess described her mum as liking to "push her buttons":

I think like some of the actions were done like deliberately to upset me because like, I think it's weird but I think she was getting a kick out of knowing that somebody cared about her, so to see me really upset because she done something to really hurt herself, I think almost in a weird way showed her that somebody cared about her so that that would be her way almost like a little child being naughty because they wanted mum's attention or something that kind of thing... No matter what you'd say she just get herself more and more wound up until and then it would almost be like this game like ohhh are you going to walk out Jess because you know what I'll do if you walk out, kind of things like that. It was this game that used to get played and for me it was like I don't even know what to do, because I don't want to stay because I'm probably going to get hurt but if I leave she's going to do something to hurt herself so it was almost like I thought, oh well I'd rather get hurt than her hurt herself. – Jess

When considering their parent's behaviour, most participants were clear in their positioning it as part of their parent's mental ill health and therefore beyond the parent's control or their subsequent reproach. Roman felt that it was his role to learn about his mum's illness and change his behaviour accordingly:

It's an illness. Now there's not a lot of control in a mental illness. There's only so much blame and stuff that can be thrown around. – Roman

Whereas his sister Sophia reflected upon what she felt was the difference between her mum's mental ill health and her personality:

If I am like emotional or too understanding then she tries to start to manipulate to like try and get you to do things for her and that sort of stuff. Some of it's a bit erm I know some of it is her personality she's quite selfish in nature and I can't justify that as a mental health thing, to me that's a personality thing. - Sophia

Seb, Karen and Georgina also ascribed some of their parent's behaviour and subsequent strain on their relationship to their parent's personality as well as their illness. Within her narrative Lucy describes the conflicting emotions she feels now that her mother has "recovered" from her illness, as she feels that her mother is unable or unwilling to acknowledge, or take account of the difficulties Lucy and her brother encountered throughout their childhood as a result of her illness:

She won't recognise what she's done because she doesn't remember, or if she does remember, oh but I was ill, so it's not my fault. It's like, like being ill absolves her of all responsibility of being a parent or being...you know, and that's what I find most difficult now. - Lucy

This placement of responsibility within mental ill health and the associated behaviour will be discussed later in the chapter when we examine the impact of the behaviour of a parent with mental ill health on the child's sense of acquiescence.

Managing parent's risk of self-harm and suicide

Nine of the participants felt that while their lives were impacted by, and they had to take account of their parent's mental illness, they were not required as children to provide any substantial amount of care for their parents. Of these participants Vivienne, Karen, Natalie and Seb explained that this has changed as they grew older, and that as adults they feel more obliged to provide care for and respond to their parent's ill health.

Eleven of the participants described themselves as having substantial caring roles and responsibilities as children. With Jess, Terry and Alicia moving in with their parents specifically to provide care. For Jess and Alicia it was a result of a breakdown in their mother's relationship. For Terry his step in to the role of care was a particular dramatic

turning point. His mother had been in psychiatric hospital from his birth. During this time he had lived with his grandparents and at his mother's behest had only visited four times throughout his childhood. She was discharged from hospital when he was 10 years old but not considered well enough to live alone. As such Terry was asked to live with his mum and provide care for her. While he did not initially want to take on this role he felt he had no choice to accept out of a sense of duty to his grandparents:

She came home and it was sort of discussed erm would you go and live with your mum at some point and I felt a duty to them I think, but I didn't want to. I didn't want to very much. Erm when she came home she was very erm, she was quite lively I suppose, erm, I think she might have been a bit manic. – Terry

The practical care that the participants provided ranged from managing medication, being responsible for the household chores, cooking meals to performing personal care tasks. Some participants spoke of the care they had to provide increasing as community mental health resources decreased and admission to hospital became less regular. For Sophia this caused concern as she felt that her brother was being asked to provide care that was beyond his capabilities:

You can't get help now and when you do it comes in the form of drugs.. [Roman] administering drugs to my mum is really bad. When she gets too manic he can decide when to calm her down and [Roman] I don't think he's the right person to do that he's very much ... if you say he's got Asperger's yeah so for example the other day when she was really bad the crisis team came in and they said to [Roman] it was his responsibility to make sure mum takes her drugs. Like my mum don't like to take them and [Roman] has Asperger's so you just told him it's his responsibility to make sure she takes her drugs. So basically he's trying to physically force these fucking drugs down her throat because she won't take them and as far as he knows he's going to get in trouble now unless she takes these drugs and I have to be like what you doing? – Sophia

The majority of participants described providing a significant amount of emotional support for their parents, this included comforting them, providing reassurance and attempting to reduce their parent's sense of isolation and loneliness. What marked this above the emotional support that would be expected in any close and loving relationship, was that it was often perceived as one sided. Sophia spoke as having to 'enter her mum's world' in the manner one might see a mother doing with a child when engaging in play:

I used to be able to sit with her for hours when she wasn't feeling well and just chat to her and you know she'd maybe look at the raindrops or something and I could just completely get involved in her ... story or her whatever, like play along with her. – Sophia

For Ethan the emotional support he provided was undefined and as such all-encompassing. While he strongly identified as his mother's carer, it was clear that the absence of any clear understanding or boundaries of what care she might need, meant that there was little chance for Ethan to manage his caring role in a manner that would allow him opportunity to consider or meet his own needs:

I said that I'd always make her happy and that, I said I'd look after her from...from the start all the way to the end. She's still...still there, you know. I used to have to be in all the time for her and that a lot of the times. School didn't like it. She would have ...wouldn't have had a good day at all cos she usually...I usually asked her about her day, she used to say...say it was alright if I wasn't there she told me she always gets lonely in the house and that. – Ethan

A final powerful theme that came through the participants' reflection on the emotional support they offered to their parents was the sense of responsibility which was attached to it:

There were the massive levels of responsibility on me, definitely and I...I can't remember if that was put on me or self-perceived responsibility, I can't remember. I felt a hundred per cent responsible

for keeping mum emotionally stable, erm and if she wasn't it was my fault. – Georgina

Aside from the physical, practical and emotional support that the participants provided for their parents, over half of the participants (12) spoke of having to physically intervene in order to keep their parents safe. For six individuals this meant managing their parent's deliberate self-harm and for eight responding to suicidal attempts. This does not include participants who described their parents expressing suicidal ideation without physically acting on it.

Roman, Mike and Alicia spoke about their parent's commitment to them not to self-harm as they were aware how much it would worry them. However for the six participants who do recall their parents as self-harming they described their general behaviour as impulsive and egocentric. Indeed for Jess, Holly and Terry they recalled incidents when they had to physically intervene to prevent their parents harming themselves further. As Holly recollected an episode when she was 12 years old, it is interesting to see that the level of agitation that she was accustomed to dealing with, was formally assessed as 'high risk' for the adults who became involved:

I've had to stop her from punching the wall, sort of stuff ... there was only one occasion when she did do it erm and her best friend was there as well and erm we had to call an ambulance out for her because we couldn't do anything with her, and erm and they ended up sending police and stuff as well because they didn't know if she was a risk to anybody and she wasn't, she was a risk to herself but she wasn't a risk to anybody else. – Holly

Furthermore the physicality of the intervention that was required from Jess, not only put her at significant risk of physical harm but also carried with it psychological trauma:

There was my mum there with this like pot of pills, and she just looked at me with like this massive smile on her face and just poured them into her mouth and like started like swallowing them and stuff, and erm it was horrible because like I had to like hold her throat tight

and try to get them out of her mouth and stuff. These actions you just like do naturally and at the time you just get in there and do what you need to do, sort of to look after that person and stop them doing stuff like that but afterwards, this stuff, you just think afterwards like wow that that was heavy and yeah it's a weird way of sort of I mean even now I don't like the fact that I know what it feels like to strangle someone and I know only because of the incident. When she was drunk it was especially when she was drunk she used to, basically she'd, like I said earlier about running in front of cars and stuff and I'd sort of try and stop her leaving the house because I knew she was going to do stuff like that but so she'd just sort of smack me or something like or pull me out of the way that kind of thing, she just end up whacking me. - Jess

Six of the participants spoke of witnessing their mother's attempts at suicide. Whether it was a singular event as with three of the participants, or a regular occurrence, as with Jess, Lucy and Alicia. Each painted a vivid portrayal of this within their narrative. This in itself was indicative of the level of trauma and the resonance that the memory held for each individual. Two participants, Karen and Vivienne spoke of dealing with their father's suicide attempts but that they did not physically witness the act. The two fathers made their attempts away from the family home. This mirrors the proposition that while females are more likely to attempt suicide, men are more likely to successfully complete the act (McLaren, 2011). In this study only one parent took their life and this was a father.

For the participants who witnessed their parent's suicidal behaviour, as with their understanding of the illness, many recalled most clearly the physical aspects of incident. For example Freya recalls being most worried about the fact that her mum had 'wet herself' as the paramedics put her in the ambulance. Many also spoke of discovering their parent on their return from school and for Jess, Ethan and Lucy feeling intrinsically implicated in the trigger for the suicide attempt:

Like it became quite common for us to come home and find that, you know, mummy was lying on the sofa having taken an overdose so we had to...oh ring up the ambulance again and get her stomach pumped and...I remember er, I mean, I must have been about 9 at the time, so I don't remember a lot of it, my brother was 11, erm but I do have this vivid image of my mum lying on the kitchen floor and being 9 years old and walking in and finding her like, ...like...you know vomiting and crying and saying she wanted to kill herself. Erm, and saying that she'd taken an overdose and it was cos she loved us too much or she couldn't cope with, I don't know, we were always like drawn into her overdosing, like she couldn't cope because we were, you know like she couldn't cope with being a parent. And she loved she loves us so much that she wanted to kill herself. Erm, and erm yeah I've got this really strong image of the ambulance people being there and just being like, so is it your mum and the two of you and we were like, yeah. And I think shortly after that social services got involved. – Lucy

While many participants spoke about not knowing what they would come home to after a school day, and that this uncertainty would cause a sense of trepidation and prevent them from inviting friends home. Jess, Lucy, Alicia, Terry, and Jenny described feeling acutely anxious while they were at school, as they feared for their mother's safety. As such this impacted greatly on their school experience, often unable to concentrate and as Jess describes still feeling responsible for her mother's safety:

I felt like it was my responsibility and if I let her out my sight a lot of time she would try and hurt herself. So I felt like if she was in my sight I could stop her you know like physically stop her from like doing something erm and then when I was at school I was quite well a lot of the time I would like to leave lessons to go to the loo but actually it was to give a call to try and find out where she is and you know erm you know and whether she was all right that kind of thing and if I couldn't get an answer calling the hospital. - Jess

This sense of anxiety continued for some beyond their school years. Alicia and Holly explained that they had got jobs specifically because their shifts would mean that they would not have to leave their mothers alone for more than an hour or two. While Jenny describes the fear she holds every time she is away from her mother, and her need to check in with her mother regularly to reduce her own anxiety:

That's my biggest fear I get a phone call saying she's gone. That's my biggest fear in everything because I don't know what's going to happen. I don't know what's going to happen the next day I phone my mum a lot more just checking in on her seeing if she's alright but I don't want to just go are you okay I just try and make up a bit more conversation not just go yeah, because she's probably just thinking leave me alone but I just need to know really that's she's alright. –
Jenny

For Jess this sense of responsibility also extended from checking in on her mother, to being about to make complex risk assessments for both her mother and herself. Within her narrative she recalled overhearing girls at school talking about their evening plans of getting together, watching a movie and trying a new hairstyle on each other. In stark contrast Jess went on to describe her routine, once she got home from school:

Like I'd get back and it would be assess the situation. Was she drunk, like if she was in was she drunk, what kind of mood was she in? Acting as if things were normal, as if you're not walking into a ticking time bomb just kind of going yeah, alright how's your day been, kind of trying to be normal and then you'd like, I'd assess you know how she was. But then that was the thing, if she wasn't in it would be like right I've got to try and work out where she is now, so then it would be a case of erm running round the local area to places she would normally sort of frequent and if she wasn't there call the hospital and stuff. Erm so it would be kind of you'd yeah I'd be really anxious if I'd walk in the door and she wasn't there. But if she was there it would be a case of right okay can I see any drinks bottles, can I see any pills

bottles. So you kind of just taking in the environment as you walk in and what chaos, like her shoes are there so what does that mean that kind of thing. Makes you quite perceptive I guess. I know if I was really lucky she might just sit there and be a bit tearful and just talk to me about stuff, and erm I'd encourage her to maybe go for a walk with me or we'd do something like paint nails or do something like that, or I'd make some tea for her. But if she wasn't in that kind of mood then it was a case of okay, it was a case of right I'll er get some padding on just in case, just things like that, just to be ready and move sharp objects and stuff like that. – Jess

This anticipation of crisis, sense of responsibility, continual attempts to assess risk and pre-empt need, meant that many of the participants described their childhoods as being shaped by a constant watchfulness. This prevented them from attending to their own social, emotional and developmental needs. This was both psychologically and physically present for them and there was often no respite. Roman described not allowing himself to go to sleep until he knew his mother was deeply asleep:

I don't get a lot of sleep because you never know what you'll wake up to ... like sometimes you'll think ah it seems alright I'll just doze off then you wake up she's not here all the doors are open, everything's a mess and it's like it's only been a few hours, how does someone do that? It amazes me but you know you always have to be on the lookout and just ... yeah just make sure everything's going on okay, a lot of monitoring yeah but when you don't have a lot of time. -

Roman

In the same vein Jess recalled that she would only feel able to relax when her mother had 'passed out' and that in fact this was the only time she was able to reflect on what had been happening and become aware of her own physical reaction to it:

If my mum got drunk and then passed out and it would almost be like relief you know like thank goodness you know, because if she's passed out and she's asleep there's not really any harm she can do,

you know the worst she can do is fall off the sofa you know ... so erm that's kind of time when it's like. I wouldn't be able to sleep until late because of all the adrenaline of what been going on earlier and that kind of stuff and I'd sort of sit there and I remember just sitting in my room and sort of thinking oh thank goodness it's okay. – Jess

The weight of carrying the anticipation of crisis for many of the participants extended past the acute phases of their parent's illness. For Jess she described feeling more accustomed to how to respond to a crisis, while she found periods of calm unnerving:

I couldn't see any pattern of what would trigger it, she might just have a couple of days when she was not like 100%, but she was just calmer. But then often that to me would indicate that she was probably going to try and do something, but not a loud big bang sort of situation high drama bit, that she was actually going to probably try to do something big, elsewhere, so for me I could never really switch off. – Jess

This was also the case for Terry who went on to describe how he feels that this sense of having to be watchful and the anticipation of crisis has over shadowed his life from the age of ten and continues throughout his adult life:

I'm not really ambitious I think. I could have been but er not with...I think going through that, all that turmoil and that...that does something to you. Cos you're always waiting for something to go wrong, you just can't dedicate yourself to something else 100%. I think that's what it is. - Terry

Managing risk of harm to self

As discussed, the long term impact of managing their parent's mental ill health and associated behaviours was evident to varying degrees for all the individuals who participated in the research. However fifteen of the participants described episodes within their narratives, during which they were themselves exposed to an undesirable level of risk.

For many, the risk was associated directly with the symptoms and associated behaviours stemming from their parent's mental illness. This harm would ensue either as the child attempted to respond to and manage their parent's chaotic behaviour, or when the child became involved or included in the parent's delusional beliefs. Freya, Vivienne, Natalie and Caroline described trying to make sense of their parent's beliefs, whether they were true and, if the family were indeed at risk as their mothers told them. This was borne out of the child's point of view which would generally accept their parent's truth without question and lack of understanding of what mental ill health was or, specifically, the symptoms of psychosis or paranoia. Freya explained that her father underestimated how much she was aware of as a child. As such he attempted to shield Freya and her brother from hearing discussions about her mother's mental ill health during the day, without realising that her mother would go into Freya's bedroom and wake her at night. Being shielded from the conversations during the day meant that Freya did not have the awareness of mental ill health to enable her to build a cogent understanding what her mum was saying to her at night:

I wasn't quite aware that she was going through maybe like a period of psychosis at that time, you know she wasn't in touch with reality, you know she was talking about these people coming to get her. Then she just started saying that the little buggers, whoever they were. She thought someone was trying to kill her and things like that. I think I was maybe...the reason why I'm not really remembering it is maybe I was quite...they were trying to protect me from it but then (pause) at night when my dad was asleep, you know, she'd wake me up and you know try and she used to say that we were like connected, like we had a connection and...and we understood each other she'd tell me I had to stop them, don't let them kill me she'd say over and over again. – Freya

For Vivienne, her mother would believe that she had to protect herself from her daughter and as such this would place Vivienne in circumstances within which she was physically vulnerable:

She was getting really, really delusional erm thinking that me and my dad were plotting against her, erm she was hallucinating, like people shouting in the street and people saying things ... There was one day when she didn't want me in the flat and she like locked me out on the balcony, it was like 32 degrees heat I think, it was awful. – Vivienne

Lucy spoke of particularly high risk situations when her mother involved her and her younger brother in her suicidal behaviour. The first time this happened Lucy was nine years old:

Other traumatic things, erm, m...my mum took us out in the car and said she was gonna to drive off a cliff, cos she...if she was gonna kill herself then she was gonna kill us too because she loves us so much. She used to always tell us how much she loved us as a sort of guilt trip almost. – Lucy

A strong theme that ran through the majority of the narratives was also that relapses of the parents' mental ill health or instability were triggered by key life events for the children, which in turn would negatively impact on the child's ability to negotiate the stresses they faced:

She'll be stressed out because [Roman's] got his A levels and she cares but then she'll just get ill which is obviously a lot more stressful than just having to manage doing your A levels. – Sophia

As illustrated by Sophia, this was primarily related in the narratives to education, but for Holly and Lucy these life events also involved the death of their fathers. The connection also continued for many of the participants into their early adult lives:

He was getting overwhelmed by the amount of stuff. So he erm attempted suicide, er I was so angry with him, I was so angry with him because I just thought...you know, I'm...I'm eight month's pregnant, like how selfish of you. – Vivienne

Participants also described being left at risk of harm when their parents were admitted to hospital, especially when there was a limited support network for them at home.

Jess described her mum being in hospital for several weeks. During this time she was alone at home with no access to money and therefore no electricity. She fed herself by rationing out her free school packed lunch and despite visiting her mother regularly neither the hospital nor her school realised she was living alone.

Experiences of abuse

For some of the participants, the risk ran deeper than isolated episodes of behaviour driven by mental illness. When describing their relationship with their mentally ill parent, five of the participants described their mother as being emotionally abusive, two of the five also identified physical abuse in terms of physical violence and fabricated illness. Many of the participants also described feeling as though their parents, for whatever reason, were neglectful. Sophia recalls going to spend the weekends with her mother when she was five years old and then being left home alone with her younger brother.

She'd like go out and like leave me at home and I'd get really sad I didn't know where she was and she'd take ages to come back ... like she'd have emotional bad days like some days she'd be really short and like other days I'd like she'd be fine I mean she's got a really vicious tongue really. – Sophia

Sexual abuse was also disclosed by four of the participants, three of these identified a family member (not the mentally ill parent), one spoke of multiple assaults from other adults and one spoke of several incidences of abuse which occurred both within the family and outside. In terms of the experience of growing up with a parent with a mental illness, the common aspect in these disclosures was the parent's inability to recognise what was happening or to be able to respond in a protective manner.

Vivienne described being sexually abused by her step-father and felt that he specifically targeted her mother because of her mental illness, rendering both Vivienne and her mother vulnerable. The lack of protectiveness was further highlighted for Vivienne as after the abuse came to light her mother chose to remain in a relationship with her step-father:

I definitely think that he targeted my mum because she was a vulnerable person, he was...well (er) very sort of strange, very strange man, very manipulative, very Machiavellian. Erm he abused me from sort of the ages of like eight to about 11 or 12. I think my mum knew but I just don't think she like would believe it. He used to sort of manipulate her a lot ...he managed to convince my mum that she'd hallucinated ...I think he very...he very much erm played on my mum's sort of vulnerability erm and really manipulated that,... As I say I don't know if that's because of the way that my mum is or whether she knew but wouldn't allow herself to believe it or...or what erm. But as I say then she made the decision to continue the relationship erm and I just (long pause) I can only assume really it's just because she felt like she couldn't sort of function without him because he'd manipulated her that much that...because you wouldn't want to share a bed with someone who had done that to your child erm. So yeah as I say I...I hated her, I hated her and I didn't speak to her for months and months and months, erm and then after they separated and everything I...I still didn't sort of reconcile with her for...for quite a long time really. - Vivienne

Monica described being raped in the months following her mother's sudden manifestations of illness. The guilt that Monica attributed to herself in her belief that she has caused her mother's illness and the sense she had of being separated from her family as a result, meant that she did not feel able to confide in them about the attack. She also wove her rape experience in with her experience of her mother's mental illness, constructing for herself a perception that the adult world, which she was now forced to inhabit, was a dark place within which such experiences were normal and acceptable. This, combined with her family's focus on her mother, meant that Monica found herself attempting to negotiate this 'dark adult world' with no supervision or support, placing herself in situations within which she was at great risk of further exploitation and abuse:

After that it was a series of assaults in parks because I'd go out at night and walk round and erm the like gangs of young lads and erm, nothing hugely, I mean, I say nothing serious, it is serious if it happened to a nine year old now, I would be up in arms as much as anyone else. But at the time to me it didn't feel serious, erm it, I kind of interpreted well I'm a grown-up and this is what grown-ups do and this is how it happened. And I turned all of those things that happened to me during that time into, this is where I get my attention, this is where I get my affection, this is where I get all the love that I'm missing, that I had solidly for seven, eight years without question, that suddenly disappeared and it wasn't there anymore. So this is my alternative now, so I kind of turned away from trying to make...integrate myself back into the family erm and began like a relationship with the outside world where my body was erm a mechanism for getting attention and affection. Erm and also during that time though I never, there was just, when I think about it now it's awful, but at the time it felt like erm this is what the world is like.

- Monica

While not everybody experienced the traumatic experiences that Monica described, 13 of the participants recalled being specifically aware that they had very little structure or boundaries within their home life, that there was little or no supervision of what they were doing. Many commented that they considered themselves fortunate that they did not get themselves into more trouble than they had. While at times this sense of freedom appeared to have been appreciated and presented a much needed escape as from the pressures they felt at home, many of the participants also expressed a desire for closer parental supervision, feeling its absence indicated a lack of interest leaving them feeling uncared for and at times unsafe:

As a young child I was allowed out after school with no curfew, I could have literally stayed out all night and she wouldn't have noticed. Erm, and that used to really irritate me, I used to hate that actually and as a...you think as a child...me as a child would be, oh

this is great, but I just used to be like...everyone else's parents would be really worried about them, my mum couldn't care less, so that annoyed me. – Caroline

Acquiescence

Despite the disproportionate levels of adversity and stress that the majority of participants spoke of, adversity that in many cases was not counterbalanced by additional support or protective factors, many appeared, on the surface, to negotiate their childhoods remarkably well. By and large they did not come to the attention of health or social care services, and no one spoke about coming to the attention of the police. Only Emily showed a level of emotional disturbance that triggered the involvement of Child and Adolescence Mental Health Services and only Ethan left school with no qualifications. Indeed Jess, Lucy, Terry and Vivienne, who had particularly difficult home lives, described themselves as model pupils, quiet, conscientious and keen to please.

Across the narratives there was a sense that the participants were skilled in keeping themselves and subsequently their parents under the radar of scrutiny. Those whose parent's mental ill health was known to services appeared to have been viewed as quietly competent and resilient. However, immersing myself in these narratives, in the sense they had of their parents illness, the subsequent impact it had upon their lives and the associated adversity they faced, I would question for many of these participants, whether their version of themselves, as presented to the outside world was an illustration of a resilient ability to successfully adapt to the demands of their lives in the face of adversity. Alternatively, perhaps they established coping mechanisms based upon their need to 'fit in' and as such developed a psychological model of acquiescence which came at a personal loss.

The definition of acquiescence is a reluctant and passive acceptance of (or submission to) something without protest. This sense of acquiescence was deeply embedded in the majority of the narratives in this study and appeared to be founded in the participant's understanding of their parent's illness and their own role within it. This understanding of both illness and self is categorised into six elements which form a

model of acquiescence. Figure 8 (below) represents this as a cycle wherein each element relates to, overlaps with and reinforces each other.

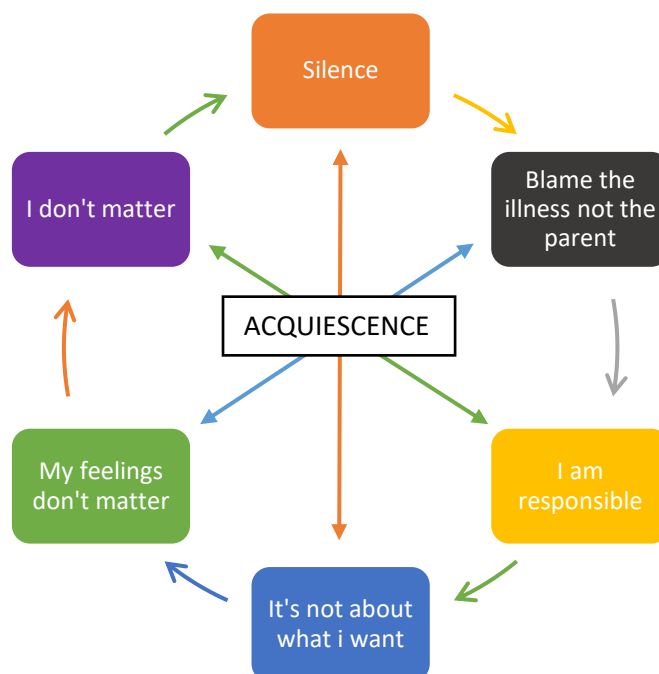


Figure 8 – Model of Acquiescence

Silence

The first and potentially the most consistent facet of the model of acquiescence is the inability to express or communicate what was happening. This was often attributed to the participant recalling as a child that initially they did not realise there was anything different about their experiences at home or relationship with their parents. As they began to notice differences between themselves and their friends, they faced the double bind of not having sufficient understanding or language with which to express themselves whilst also being at an age when ‘fitting in’ with peers was a priority. Jenny expressed her fear that she was not normal and describes her attempts to disguise this:

I just tried to keep it a secret. I wanted to be like I was normal. I just wanted to be normal like a normal kid, – Jenny

Seb went on to explain that he had felt that he would have been singled out and potentially bullied if he had spoken about his father's behaviour:

Because I didn't want to kind of be singled out in anyway which that I could well have done, because I wouldn't have known how to express it maybe. So it's kind of like, well my dad just cries all the time, which I knew wasn't sort of normal. So I didn't really have anyone that I could talk to. – Seb

This lack of communication was also often present within the family, either based within an attempt to protect or shield the child from the illness or a manifestation of the strained or fractured family dynamic:

So everyone got really angry with everyone and no one really spoke to each other and if they did it was always quite just like, I don't know, my sister was really angry all the time. – Emily

In terms of communicating with the outside world, further barriers were present. Karen spoke about her family's perspective that mental ill health was taboo and as such her father's illness was shameful which contributed to a rigid family rule of not talking openly about illness, relationships or emotions. Jess and Terry were anxious that if they spoke out they would be taken into care. Roman describes wanting to protect his mother and feeling that speaking about his experiences was disrespectful to her, and Emily spoke of having to protect her father's reputation within the community:

I was told I wasn't allowed to tell anyone at school because my dad was the headmaster of our school and it was a...a really hushed...it was like it was a...a really, really bad thing. Erm, and again with the hindsight I'm not really sure why it was so hushed, it was like it was this dirty secret. But I think it's because my dad was a headmaster so he didn't want the other kids to know about his private life. Erm, and my mum erm whenever she had a...a suicide attempt I wasn't allowed to tell anybody. – Emily

Blame the illness not the parent

Several of the participants spoke about their parent's mental ill health as if it was a separate entity to their parents, with some trying to pick up what was behaviour driven by the illness and what was their parent's personality. For many of the participants, they viewed their parent's illness not only as unpredictable but also beyond their parent's control:

It's an illness there's not a lot of control in a mental illness there's only so much blame and stuff that can be thrown around. - Roman

They therefore felt that they could not blame their parents for the difficulties associated with their behaviour or hold them responsible for not meeting their needs as a child. This was also reflected in them having lower expectation of their parents meeting their needs, and indeed seeing their peers as being unreasonable, demanding and ungrateful by comparison.

This reduction of expectation and responsibility was not afforded to themselves. Indeed they ascribed high levels of responsibility to themselves and self-criticism if they felt they had not been good enough:

I've never been like a bad child because I've always had to be the responsible one, I've always, you know, made sure the cats have been fed and ...I'm not saying I did all the cleaning and stuff and I was this domestic goddess but I certainly had an awful lot of responsibility during my adolescent years for the housework, for you know like making sure my mum was okay and all of that. And yeah suddenly like she was starting to try and be a mum again and I couldn't cope with that. – Lucy

This also meant there was difficulty in the relationship adjusting as the roles changed and the parent child boundaries and expectations of each other shifted.

I am responsible

Participants recalled feeling extremely high levels of responsibility for their parents and their younger siblings. Some of this was directly asked of them, however a great deal was self-perceived due to their response to their experiences. Georgina recalls feeling “100% responsible” for her mother’s emotional stability and this being reinforced by the professionals involved, who would ask what she had done if her mother was distressed. She described never being able to ask the community mental health workers for help, as she worried they would blame her for upsetting her mother. Equally, her mother would portray herself as feeling bullied and manipulated by her care co-ordinator which would mean that Georgina felt that she had to protect her mother from service intervention, keeping them at arm’s length. Natalie also spoke about her father’s pathological fear of services and her own subsequent mistrust. Natalie’s sense of responsibility was deepened further by her father’s sole trust in her:

When my dad’s psy...man...manic or psychotic erm he’s very trusting of me and I don’t know why, like no one else in my family, like he’s convinced they’re all against him. But with me he will listen to me. -

Natalie

This sense of responsibility continued for many of the participants beyond childhood and into their early adulthood, as they felt that it would be unreasonable to ask anyone else to take on responsibility for their parent. Yet through the nature of their position within the family as they describe it, they had no choice. This was illustrated by Terry who was clear that not only could he not ask his grandparents for help or support in caring for his mother, but that he also had a duty to actively protect them from the implications of her behaviour. However as her son, he saw himself as part of a unit he couldn’t escape. He described having to sleep on the floor next to his mother’s bed from the age of 10 to the age of 17 years, as his mother did not like to be alone at nights, and feeling trapped and hopeless within his relationship with her, yet not attempting to escape it as it was his role and as such his responsibility:

Because I never thought that I would escape that unit, I thought this is my life and I...I used to get quite frightened about that, that that

would be, my future would be just looking after her and certainly because I thought she'd never come to terms with me being gay, how am I ever going to have a relationship? And I thought I'm gonna be like Mrs Merton and Malcolm or some ...something like on the telly you know, I thought that is me, I'm stuck in that and whether I like it or not. – Terry

This sense of not being able to escape the responsibility towards their ill parent was also expressed by Jenny who continues to live with and care for her mother and foresees no point in the future when her responsibility towards her mother will reduce:

I do get angry inside but I can't, I can't, can't do anything about it, it's not going to solve anything, it's not going to do anything about it, I just have to get on with it and deal with it. I've dealt with it for 19 years like I can deal with it for the rest. – Jenny

Holly, Alicia and Natalie spoke of not realising the impact that the care they provided for their parents had upon them until they were asked to reflect upon it and their ability to engage with education and peer relationships:

I think you really start to realise that actually you are caring for somebody... you don't really look at the impacts it has on you unless it you're asked to if that makes sense. I didn't look on that as an impact until somebody asked me a few months later how's it impacted on your sort of your uni experience and it was only then that I thought actually it did massively impact on my uni experience it put me behind and I think obviously it's not mum's fault, but had I not had everything that was going on at home that I did maybe I would have done better, like my outcome would have been better at uni erm I always hate to say things like that as I feel like I'm bitching about her and yeah I guess, I guess you don't really realise about it until you ask it I guess you go onto auto you just carry on. - Holly

However, it is clear that for Holly, as well as others, the consideration of the impact their parents' mental ill health has had upon them is uncomfortable. This is reflective of the participants not asking for help, as it carries a sense that they are blaming, betraying or holding their parent responsible. For others, such as Jess and Jenny, they proposed that reflection on their own feelings and the impact upon their lives would have been overwhelming:

Because a lot of it was about being there for her, and not my feelings didn't really matter erm because I suppose in those situations those type of situations if you tap into I hang on a minute how do I feel about this I wouldn't have had enough strength to keep going to look after her really. - Jess

The final aspect of the sense of responsibility is the sense of failure that Jess, Robyn, Emily and Lucy described when they perceived their parent's relapses and ill behaviour as an indication that they were not doing enough, or at times were not good enough.

It's not about what I want

For the majority of the participants who felt a strong sense of responsibility towards their parents this was combined with the acceptance that their parent's needs had to come before their own. Indeed fourteen of the participants spoke of regularly feeling that they had to put their own needs aside to be able to respond to and maintain their parent's emotional stability and physical safety. This sense of relinquishing their own needs was further reinforced for seven of the participants who expressed feeling that they were part of the cause of their parent's illness. For Jess she saw part of the trigger of her mother's illness as her own experiences of sexual abuse, and Monica held herself entirely responsible for 'infecting' her mother with the illness. The other five, Vivienne, Ethan, Jenny, Terry, Sophia and Lucy described their mother's illness as originating from the time of their birth or through the pressures of motherhood. During her interview Jenny became extremely tearful while she spoke of the manner in which she saw her role in her mother's mental illness:

She had post-natal depression with me. I know it's something stupid but I feel like I caused it like it's my fault. Cause I'm alive it's my fault

that's she's like this. Like I shouldn't be here because it's causing her, her I don't know her to be the way she is, so I should change. - Jenny

Mike, Seb, Freya and Monica also spoke about the pressures that their well parent faced and their minimisation of their own needs in order not to burden their well parent further. There was also a strong sense of wanting to keep the peace in order to try to avoid a worsening of their parent's behaviour, for Jess these meant making herself as unobtrusive as possible. It is only in recent years through therapy that Jess has been able to challenge that:

I'm starting to understand what is my stuff and what is someone else's stuff which is a really new thing as well erm and just being visible because a lot of the time when I was looking after mum I was invisible really. It was more about I needed to just do whatever she wanted to do and it didn't matter about me. – Jess

My feelings don't matter

The tendency to put aside their own needs was at times a conscious act and was keenly felt by participants, for example when Jenny missed her own birthday celebration with friends to go home to support her mother who was distressed and suicidal:

I was the one picking her up on my birthday like it's my birthday can I not enjoy this day you know, no I can't. Probably that sounds selfish on my behalf because like could I just have one day, one day? - Jenny

However on many occasions it seemed as though the participants and those around them were not actually aware of their needs. This relates to the focus on the parent's mental ill health and the primacy of this ill health within the family dynamic.

Consequently, the child's needs and feelings could go unrecognised. Also linking back to the concept of silence, Natalie, Seb, Jess, Lucy, Terry and Roman spoke of how they were able to discuss their parent's illness openly within the family. Each showed a sensitive understanding of their parent's needs and feelings, yet also stated that they could not talk about their own feelings within the family:

We're able to sit down as a family and talk about all the things that we were able to talk about. Like I say kind of you know from having a...an unwell dad to death to suicide to whatever came up, there's no taboo subject in our family and that was because my mum was willing to talk about it with us... We had no secrets as such, like yeah we're quite open about some things, but I don't know if it's the Britishness that we don't really talk about our feelings ... Certainly I think from my point of view I didn't want to ever show that I'm kind of upset or struggling or whatever because I didn't want to make things worse for them. Because I think that if I did I'd feel quite guilty or would have done... I don't think he would have liked it to be honest, I don't know if it would have made things more difficult in hindsight because he was, you know pretty unwell. To be honest with you I think like me crying a bit wouldn't have sent him further down into a spiral of depression, but I guess as like a seven, eight, nine year old you don't really know that. - Seb

For Jess the surrender of her own needs and feelings was also entwined with her desire to protect her siblings, a need to protect which became fundamental in her formation of identity (discussed further in Chapter Ten).

Well I'd rather deal with it than have somebody else deal with this I suppose, and if I can maintain as much of a normal childhood for them and they enjoy it and they play and all that other stuff, that's really important to me you know. I'd love to be in that situation but I'm not so you know if I can maintain someone else's, so they don't have to be in a situation then you know. - Jess

I don't matter.

As seen in the last quote of Jess', the relinquishment of their own needs and feelings could be associated with a child's motivation to protect those around them, friends, siblings or indeed their parent as they saw their illness as central and untouchable. This, combined with the lack of opportunities to discuss their own feelings, their role in

meeting others' emotional and physical needs without reflecting upon their own, and the lack of awareness or recognition from others, contributes to a sense that they do not matter. This process is illustrated in Figure 9.



Figure 9 – Modification of child's emotional need in response to parental mental ill health

This was particularly pertinent for Jess, Vivienne, Karen and Monica who spoke of experiencing sexual abuse from others and being unprotected and overlooked. For them this contributed to the perception of the world being an unsafe place, and that to assert themselves within it might render them in an even more insecure position. For Vivienne, the abuse from her step father became normal within the spectrum of all of the other adversities at home, and she feared that after she had been disbelieved by her mother, if she told anyone else, she might have lost the little respite they gave her:

I just felt like I couldn't tell her again because she hadn't believed me in the first place. And then things just sort of became like normal, like it was just normal and then when I would go and see my...like stay with my grandparents I would...I...there was always kind of hope

there that I wouldn't have to go back. So I thought, and like I thought if I said something it might rock the boat and I might not be able to stay with them or...so I just kind of...just kept it to myself really. -

Vivienne

For Jess, the abuse she experienced from multiple perpetrators compounded her sense of not being wanted or of little worth. The role she had in caring for her mother, while in itself abusive, gave her a sense of belonging and purpose, and as such she took it on without complaint or thought for herself:

I know that from a very young age I wasn't wanted and you know to the point where there were attempts to get rid of me sort of thing and I think because I knew I wasn't wanted it was kind of just keep myself to myself and if I wasn't any trouble then at least I'm not in the way kind of thing, because that's how I felt and I guess what motivated it, and then especially when mum got really ill or when mum when really downhill it was ah okay well just do this then and focus on her and try and make her feel better. - Jess

Summary

Participants recalled becoming aware of their parent's mental ill health in a variety of ways, such as a sudden critical incident or a gradual realisation. Their age and the manner in which they became aware of their parent's mental ill health was significant in terms of how they made sense of it, and their role within it. Another significant factor was the behaviour they saw in their parents which they attributed to the mental illness.

The behaviour which was highly emotional, unpredictable and risky was the most difficult for the participants to manage. However chronic detached or emotionally flat behaviour has long term negative connotations for participants. They spoke about the high levels of perceived responsibility and sophisticated strategies that they had to develop in keep both their parents and themselves safe. These strategies served to

both minimise the distress and/or potential triggers for the parent and to protect the family from the intervention from services which they feared as being negative and stigmatising.

For a large number of participants the way they managed this burden psychologically was through a process of beliefs and behaviours which have been built into a model of acquiescence. Within this model the primary concern is the parent's mental ill health and the management of the associated behaviours. In response to this the child sees themselves as being responsible for and secondary to the mental ill health, it is about what the parents need not about what the child might need or want. They do not have an expectation that their needs would or should be met, and do not feel justified to express anger about this as it is not the parent's fault but rather a consequence of the mental ill health which is beyond anyone's control or reproach. This lack of regard for self can be exacerbated by the sense of personal blame the child takes for the mental ill health and the parent's subsequent distress. It is also mirrored for the child in the apparent lack of regard or protection that some children received from others.

Chapter Ten

Identity

Introduction

This chapter will examine the theme of how participants' adult identity, self-concept and self-esteem were shaped by the experience of growing up with a parent with mental ill health. This includes the way in which they saw themselves in relation to others and the perception they have regarding their own strengths and vulnerabilities. Their identity can be intertwined with their ongoing relationship with their parents and for some this was influential in how they felt about key transformative stages of their lives, such as becoming a parent themselves.

Identity and the perception of role

Within all of the interviews, participants spoke either directly or indirectly about their identity and how they saw themselves in relation to their family, peers and the world around them. In considering this theme, the distinction between how they perceived themselves as children and how they reflected upon themselves as adults were at times difficult to unpick. These will be discussed further in chapter eleven. One aspect of identity which was clearly rooted in childhood was the sense of being marked out as different due to their parent's mental ill health and their desire to appear "normal". The majority of participants spoke of the efforts they made as children to 'fit in' with their peers and the subsequent steps they took to hide their home life. For those who spoke about their view of what constituted a normal family, it was not necessarily a belief or wish that their family could change that was expressed, but merely the desire to maintain the appearance of normality:

I tried to seem like we were normal, you know like, you see these families and you want. Well I want a mum like that, I want a dad like that. – Jenny

For some of the participants, they felt the care tasks that they had to perform which marked them out as different were most difficult to manage. For example Georgina, who provided emotional, physical and personal care support for her mother, described the chore that she disliked the most as being the collection of her family's dinners from the school kitchen. This was because she could be seen by her peers and they would know that her mother did not cook for them in the evening. For Vivienne it was her peers' reaction to her mother's hospital admission which caused her to begin to feel different and separate to them:

It had obviously got out somehow that my mum was in hospital or, I remember one of the kids saying, oh (sings) [Vivienne's] mum's in the loony bin. And I think that was sort of the first time when I kind of felt like different. - Vivienne

Within her narrative, Sophia spoke very positively about how her mother's mental ill health was "framed" as normal and as such she felt she was not concerned about stigma or difference. She recalls inviting her friends to her home and feeling able to speak to her friends about her mother's behaviour with openness and confidence. However at one point in her interview there was a suggestion that her mother's illness had more of an emotional impact than she allows herself to consider, and that there had been a sense for her that this might not be the average experience for most children:

I don't remember how much it got me down when I was younger, I remember I cried everyday as a child, I knew that and I remember thinking I wonder if everyone cries everyday. – Sophia

As would be expected, for many of the participants there were other aspects of their identity that contributed to their sense of difference. For Sophia and Roman it was their ethnicity, for Terry his emerging sexuality and for Natalie the fact that she lived with her father as opposed to her mother. Mike defines growing up as one of six children in social housing as having a greater impact on his sense of difference than his parent's mental illness:

Because we were in a council house and some of our mates had, like parents, like had, like proper jobs and had like a car and that kind of stuff or had money for school dinners and all that kind of stuff, it seemed bizarre that I didn't have any of those bits and bobs, erm not normal. And as a kid you want to be normal, you felt a little bit of an outsider for having the wrong jacket, wrong rugby shirt to play in, wrong kit, wrong, being a fleabag or whatever, do you know what I mean, you try and be normal and fit in. – Mike

A further aspect that some participants described as marking them out as different from their peers was the level of maturity they had to develop in order to respond to and cope with their parent's mental illness. Nine of the participants described feeling that this diminished their childhood and made it difficult for them to relate to their peers. This is portrayed throughout the young carers literature (Aldridge and Becker, 2003). Caroline also spoke of feeling that she had to be independent of her parents and that she was not able to turn to them for support during her middle childhood and adolescence:

It also made me quite independent from a young age because I felt like I couldn't rely on them ... I need to do everything for myself, and yeah I don't want to burden them, I don't want to rely on them. – Caroline

Lucy also described having to negotiate puberty by herself, buying her first bra alone and using her inheritance from her father to pay her mother's rent at the age of 10. She felt that this marked her out even as physically different to other children her age, recalling a conversation she had had with a childhood friend:

I think I had to grow up, and people used to say I was 11 going on 30, he said you've always looked old, you always had dark eyes, you were always very serious and I think it's cos I had to be, you know I had, I had a lot of weight on me, I had a lot of responsibility at that age. – Lucy

As described in chapter nine, Monica's perceived transition to the adult world was triggered by the combination of the traumatic manifestation of her mother's illness and her own experience of sexual assault. This resulted in her developing an identity of herself as an adult and a narrative about the world around her which was deeply maladaptive. While viewing herself as equipped, capable and resilient, this did not carry with it the tenets of resilience such as positive adaptation (Rutter *et al.*, 2008).

I felt different, but kind of in a good way, like I was more emotionally mature than them, I'd just experienced more things that tend to happen to adults, I wasn't more emotionally mature at all, I actually really wasn't. I was the one who was flailing around inside but and I had this kind of erm cartoon pastiche image of what an adult is and I was acting according to that image. – Monica

She describes this identity continuing through her childhood and into adulthood preventing her from reflecting on her own needs or accessing the appropriate psychological support:

I went to see counsellors, but nobody ever got through, there was probably a lot of kind of impression management on my behalf. Like wanting desperately to tell them how suicidal I was and how dark and bloody the world was and how scary it was, but at the same time I also have this thing, like going back to being nine where I am the grown up and I have to be responsible and I have to be good and take care of myself, so they're kind of two things in conflict the whole time. – Monica

Terry also spoke about not being able to access support for himself which he attributed in part to his sense of himself as somebody who 'coped' and therefore could not complain. As with Monica he recalls how this continued into his late teenage years where he could not express his suicidal feelings:

It was all right but I wasn't, I wasn't unhappy really, I wasn't very happy, I was just coping, coping, but I wouldn't tell other people about it. - Terry

Terry's description of his identity as being someone that copes without complaint was not an indication of strength for him but rather a representation of his submissive identity:

I was bullied a bit at that time, I had access to mother's money and was erm sort of doing the bills and one of the boys at school bullied me and got me to give him some money. I remember that, and I was keen to do it because I wanted to be liked I suppose. Erm, so I was very submissive in that respect. - Terry

Karen also remembered herself as being submissive with no sense of power or agency in her life:

I was passive and I put up with it and a huge amount of awful stuff, things would happen to me, I didn't make them happen you know, I didn't sort of have that locus of control, I was sort of, things just happened to me. – Karen

This identity of submission and the subsequent inability to acknowledge, express or assert their own needs was often reinforced within their relationship with their parent with the mental illness. This was especially so when the parent appeared not to be able to reflect on their child's needs or indeed when the parent's own needs were often more primary and overwhelming for the child:

A lot of the time when I was looking after mum I was invisible really it was more about I needed to just do whatever she wanted to do and it didn't matter about me... it took me a long time to understand what I like doing and to be visible again. - Jess

Seven of the participants spoke of feeling that they were to blame for their parent's mental ill health and the adversity that they faced and as such attributed to themselves a high expectation of submission and low levels of agency. For four of them this was based on the narrative of their mother's mental ill health which appeared to begin at the point of their birth. Jess, Monica and Lucy attributed blame to themselves as they attempted to make sense of traumatic experiences, often with

very little information with which to reach a rational conclusion. For many years Lucy believed she was responsible for her diabetic father's death because she had given him chocolate. It was in fact only when she was 25 years old that she learnt he had committed suicide:

I had the belief that I was responsible for my dad dying and also my mum being ill. Awful for a 10 year old really to be feeling. I've got a really strong memory of me being in bunk beds with my brother on holiday, so I must have been about nine or 10 and it just going round my head that like, my dad's dead and my mum's in hospital and you know like, it's my fault My dad's dead and it's my fault, my mum's in hospital and it's all my fault. – Lucy

For Monica, this perceived responsibility extended to the sense that in some way she deserved the appalling things that happened to her, and that they were a confirmation that she was a bad person:

I took some of the responsibility and the blame for the assaults and the rape on myself as though there was something that I'd done wrong and I had to keep it a secret from people because it was bad. Although I kind of had no agency really in that because I was too young to have any, influence on other people's decisions in that way at that age. – Monica

Terry and Georgina also spoke of the sense they had of themselves as a bad person being directly attributed to their mother's mental illness. For Georgina, this was reinforced by the way that her mother spoke about her and co-constructed their intertwining narratives.

[Mum would tell people] that I used to pick on her all the time and that I was a lazy, horrible teenager and that she couldn't bear the thought of living in the same house as us. I was just a teenager, I was being a normal, probably a little bit angst-y teenager. – Georgina

For Terry, this was bound up in feelings of frustration that he had, yet was not able to express. He described an episode during which his mum had taken multiple overdoses and became distressed each time he tried to leave her alone at home. Feeling overwhelmed by this Terry remembers that he “went to school hoping she would”. This image of himself as a person who had hoped his mother would take an overdose jarred with his identity of the ‘good boy’ who coped and would cause him to question his own self-worth.

Robyn, Sophia, Caroline, Georgina and Lucy also described the lack of emotional warmth and the avoidant parenting they received caused them to feel rejected and unworthy:

She’s never really liked me. I think being a parent and having mental health must be difficult because you don’t really know if you’re coming or going a lot of the time. But it did mean in terms of experiences of us together like I always felt like I was trying to please her or trying to get her to like me or love me. My mum’s not very good at showing love. – Sophia

This desire for their parent’s love and connection ran through their childhood and into their adult years. Yet when reflecting upon it they appeared to turn more readily to their own shortcomings than attributing any responsibility to the parent. This is also reflective of their understanding of the illness as discussed in chapter nine within which the illness has a primacy and renders the parent beyond reproach:

Even when you’re older, you know you want your parent’s love and acceptance, you want their support and when you don’t get that you do take it to heart, you think oh, well what...what’s wrong with me. – Robyn

The sense that the neglect of their emotional needs was attributed to a lack of deservedness in themselves was also generalised to their sense of self-worth as a person, and would prompt the children to try harder to please their parent and the other adults around them rather than challenge them:

I think I have always struggled with not feeling worthy enough to have a good mum. What have I ever done to not deserve a good mum? Yeah, it's okay, hah, and I guess it's that whole thing which I've heard before about kind of being a kid and thinking well if I'm good enough, if I just try harder you'll be happier and then getting to the point of realising that actually that's not gonna kind of, it's not going to change, you can never do enough hence why I just felt exhausted all the time, exhausted emotionally and physically. –

Georgina

With the perceived level of inadequacy and the subsequent dampening of their own needs, many of the participants described themselves as needing to be good. This served the purpose of not exacerbating their parent's difficulties and keeping their family and themselves under the radar of social scrutiny:

I've never been like a bad child because I've always had to be the responsible one. – Lucy

For Monica and Terry this desire not to be perceived as demanding or problematic was also rooted in their insecurity about their position within their family and the fear that they would be rejected:

I guess it is that I couldn't be who I was when I was nine because I had to be quiet and responsible and keep myself to myself and not offend them. Because I'd already almost killed my mum, I thought I had killed her, you know, I'd killed her identity but I thought I'd, I was very close to kind of killing her as a human being and it was my fault. So I had to be good, quiet, and I am kind of good really, and I am kind of quiet really as a person, but I had to be this artificially constructed good and quiet and responsible person who didn't demand much from other people, erm, in order to, in my head, in order to be allowed to stay in that house where I was safe and secure. Because the streets and the outside world at that time was full of murder and assault and fire and death and stuff like that. – Monica

For many of the other participants the motivation to be good also had more complex roots, which involved the multiple difficulties and differences they had within their lives, from their parent's mental ill health to other experiences of abuse, social disadvantage, gender, culture and ethnicity. As such being good not only represented a lack of self-esteem with which they felt justified to assert themselves, but also a fear of adding stress to an already weak family system and not wanting to appear different or vulnerable in front of their peers.

The manner in which Vivienne struggles within her interview to identify why she felt she had to conduct herself in such a non-confrontational manner throughout her childhood, is representative of the complexity beneath this identity. It is also indicative that it is an expectation that many of the participants imposed upon themselves as children, rather than being directed by an adult:

I always had to sort of hold it all together and present this kind of, I think I don't know, I mean obviously with the abuse I think, you know, again there's like self-blame and things like that and with my mum's mental health problems, I think, I think probably, you know, not wanting to sort of be different from my peers maybe, that could of possibly been a factor. I don't know why I felt like that, I've never really thought about it, but I, I think I did, I think I just kind of thought like, you know, you've got to hold it all together. - Vivienne

This need to be good, not cause difficulties and hold it all together is reflective of the "impression management" that Monica discussed in terms of having to present herself as an adult, and continued for many of the participants through to their adult lives. Another facet of this was where the participants drew their sense of self-worth and achievement from. For Lucy this was clearly defined as judging herself through how she believed other people felt about her, as opposed to an internal sense of worth. This was also present for Terry, Vivienne and Lucy who described measuring themselves in terms of their educational attainment. Indeed Lucy described herself and her brother as 'throwing themselves into education' not only as a form of respite but also as a way of rebelling against their mother:

I always did my work and stuff, you know I wasn't a tearaway. I had no reason to be a tearaway cos I...I didn't have to rebel against anything because there were no rules, you know there was no, there was no structure or nothing that I could rebel against. I probably rebelled in an opposite way in that I was so conscientious. – Lucy

Rebellion to assert their sense of self was discussed by several of the participants. For Caroline, Monica and Georgina they felt that it went largely unnoticed by their parents because of their general lack of awareness of them, or interest in them. However for Jess, Lucy and Seb they spoke of performing what they perceived to be rebellious acts, but were always careful to conceal them in order to avoid the potential consequences, which they imagined would be beyond the expectation of general teenage rebellion:

I was quietly rebellious as well because I'd like I say, I didn't want to kind of upset people but I think I kind of wanted to be noticed a little bit, so I was very quietly rebellious. So I did stuff that was a bit naughty but would never get caught for, but I don't know if that makes any sense at all, but I got a sense of, I got some sense of something from it... I don't know I've kind of taken a more alternative path as well. So like the stuff I've listened to and the kind of subcultures that I'm involved in are a little bit more underground, so like the music I listen to and like the...you know everyone's got a tattoo, I've got quite a lot of tattoos so I'm like a tattooed person as opposed to someone who's got a tattoo. - Seb

Vivienne, for whom both parents had mental health problems, found the lack of boundaries imposed by her father an indication of his acceptance and trust in her, as opposed to a lack of interest in her. While she did not live with her father until her teenage years, she felt able to draw upon the loving and emotionally connected relationship they had, and she described this as a protective factor. She felt able to explore the world around her secure in the knowledge that she was loved and lovable, able to turn to her father if she needed support, which was representative as a safe haven or secure base (Walsh *et al.*, 2009):

I could go out on Friday and come back on Monday and that would be okay as long as I'd been in touch a couple of times over a weekend, and that he kind of knew I was still alive, then he was very much just kind of, just do what you like really. Which again at the time I thought was great and like in a lot of respects I got into a lot less trouble than my friends did, because they would often lie and hide things from their parents and sneak around. And then when they got themselves into sticky situations they kind of didn't feel like they didn't have anywhere to go or couldn't say. Whereas for me, if I got myself into a sticky situation I could always ring my dad and, you know it would be fine. – Vivienne

Caroline also described both her mother and father having mental illness, and again while she predominately lived with her mother, it was the warmth and unconditional love that she feels that she received from her father that protected her from internalising the high levels of criticism and emotional rejection which she felt defined her relationship with her mother:

I think I maybe thought it was her problem, and I certainly do now, I don't...even as a teenager I never felt like that kind of complex, oh my God, you know it's my fault and my mum doesn't love me. I did think, well you're just a shit mum and that's your problem, I'm gonna go and get on with my life. So obviously it's affected me in ways that I probably don't even know, but I don't feel like I'm damaged or like it's affected me massively and that I sit there and think about it all the time, I don't. I have just kind of accepted it and got on with it. Erm, I think yeah I think as I got older I kind of more and more realised that it's not me, it's her, which is good. – Caroline

A more common theme across the interviews was that of identifying themselves as protector rather than protected. This included striving within their relationship with their mentally ill parent to protect them from their illness. Robyn, Emily, Sophia and

Lucy spoke of believing they could ameliorate their parent's symptoms and distress by adjusting their own behaviour and trying harder:

I am going to make sure you know how much you are loved, so that you can start to feel better about yourself and get happy. – Sophia

Natalie, Georgina, Lucy and Sophia also spoke about feeling that they had to protect their parents from the judgements and interference from other family members and mental health services. For Sophia she experiences this protective role as distancing her from her mother and brother, only being invited into their relationship when there is a crisis:

I'm the "fixer" because I'm like I'm the changer and we need to do this if we want this to work, which they are fine with at crisis I'm the one that they call first and I come in and then I put all back together and then it's like go away. – Sophia

Jess also spoke about her role as her mother's protector, differentiating her from her siblings. This manifested both physically in the fact that Jess alone chose to move in with her mother to provide care for her while her siblings remained living with their father, and also psychologically as Jess sought to also protect her siblings from the implications of their mother's mental health by hiding it as much as possible:

For me it was it was a lot of pressure because I was trying to appear like a normal sort of young girl, didn't want to be seen like there was something going on when my siblings came over to stay. I had to hide the whole thing from them because in my mind, I didn't want them to lose their childhood and I didn't want them to know sort of all the horrible stuff that was happening with mum. – Jess

Jess, in particular, extended this protective role to others as well, seemingly developing her identity and sense of worth and purpose around her ability to provide care and protection to others. This psychological need or compulsion to care for others is present in several of the narratives as they discuss their adult identity and roles and will be discussed in Chapter eleven:

Whenever we moved cos we moved so much I always made a point to make friends with the people who were being bullied because I figured I'm probably not going to be here very long and it sucks that someone is, you know getting called names and stuff, so you know if I can stand with them and say you know stop calling them names I think their cool then that's fine for me because I don't mind if it gets directed at me as long as that you know it gives them a break. – Jess

Young Carers

Of the twenty participants within the study only eight discussed the concept of being a young carer. Holly, Alicia, Jenny and Ethan were recruited from a Young Adult Carers Group and Natalie described having been involved in another young carers programme. Sophia and Terry described becoming aware of young carers once they themselves had become adults and the dawning realisation that that they themselves had been young carers. Terry also describes himself as a carer for his mother now, describing slipping back into a care role which he feels is deeply ingrained and inescapable. Georgina and Emily spoke of being told about a carers support group being run at their school but not wishing to engage with it as they saw school as respite for them:

Why would I want to be associated with all that, I don't want to go to a young person's group, why would I want to sit around and talk about my ill parent when I can just smoke dope and...and ignore it? – Georgina

Natalie, who intermittently engaged with her young carers programme as a child and went on to volunteer for it as a young adult, described feeling that she never fully fitted in with the group while also feeling that she was also very different to her peers at school. Her lack of confidence with the group and her uncertainty of her credentials as a carer were borne out of her difficulty in quantifying the care tasks that she performed for her father, and the fact that while her experience of his illness involved episodes of acute psychosis these were interspersed with periods of relative stability:

I remember going there and being like, well I don't really need to be here as much as these other people, like these other people clearly have parents that are very unwell. Because we would talk about it in...in the...in a thing, in the [programme] and I remember thinking that's not really me, but then at school I wasn't really part of the real parents club either, so like, I don't know if that make, like I don't know, obviously I didn't see it as a club but if we're going to say it like that. There was the very sick parents and the normal parents and I didn't feel like I belonged to either of those, if that makes sense. – Natalie

For Jenny, Holly, Alicia and Ethan who are currently members of a Young Adult Carers group they described the support that they received from the group as invaluable. For Jenny, a new member, it was helping her reflect on whether her own anxieties are related to her caring role with her mother, and consider ways she might ask for support from others. Holly and Alicia (who chose to be interviewed together) developed a close friendship with each other as they became aware of each other's role as a young carer during secondary school. This friendship has endured into their adult years and they both cited it as the thing that made their caring experiences tolerable. Ethan joined the Young Adults Carers Group a year ago and describes it has having a transformative affect in his life, enabling him to identify as a carer. He takes a great deal of pride in this role, feeling that it has elevated his status and given his life purpose:

If you're a carer I said you do it 24 hours a day. You don't realise you're doing it, that's the way of life, of doing it. I said if you were in my shoes, I said you'd understand. I said it takes years to become, sort of you can never become the perfect carer. You just always try the best, the best to do things. And that, that's the way I've always tried to do it... So she's now had to believe me, she hasn't got it [this other illness]. I said I'm your carer I should know, I said I should know what, what you're like. – Ethan

This sense of acknowledgment and recognition was clearly extremely valuable for Ethan, Holly and Alicia but also seemed to carry with it an acceptance that they are ‘carers’ and that role would be indefinite. Holly, Alicia and Jenny spoke about hoping that in the future they would be able step away from their role as carers and concentrate on their own ambitions to develop their careers and start a family, but at the time of the interview could not envision a time that they would be able to make that move. They also felt that as ‘identified’ carers others had great expectations upon them to manage their parent’s mental illness. These included their parents themselves, their wider family and mental health services.

Memories

In reflecting upon their childhood and themselves as children one recurrent theme presented itself in many of the interviews. This was of memory, specifically difficulties in accessing memories which appeared to link to autobiographical memory and identity. Many of the participants described their memories as hazy or as Seb called them “snippets”. This appeared to be more prevalent in memories pertaining solely to themselves, as within these same interviews they were able to recall incidents relating to their parent’s mental illness, such as psychosis or suicidal behaviour with vivid and often visceral detail. The power of these hazy memories was also illustrated in Lucy and Emily’s interviews within which they spoke of having no clear memories of their childhood preceding the initial episode of their mother’s illness. For Emily her memories are further obscured by her sense that she was never fully able to see or understand what was happening:

But all of my memories of that, are sort of I’m always outside the door or something, I’m always sort of like, aside from it, so I sort of always knew what was going on but from a sort of half in perspective. – Emily

Karen, Georgina, Seb, Vivienne and Freya speak specifically of their lack of memories as representing a coping mechanism. Karen and Seb define this as “compartmentalisation” and Seb takes this further, feeling that his lack of memories in

certain areas may represent a response to trauma, causing him to question the validity of the memories he does have:

I kind of think back and wonder if the memories that I've got are real or if it's stories that I've heard about my childhood, if that makes sense. So it's pretty vague a lot of it. It wasn't like traumatic but maybe to a certain degree it might have been. So I've compartmentalised some of those memories to not have to think about them, is what I've reflected upon now. I don't know if buried is the right word but I've certainly compartmentalised those memories so I don't have to think too much about them I would say. And that's kind of...yeah, how I probably managed it at the time, I think, just to kind of well yeah bury it a bit. – Seb

For Freya the sense of burying memories in order to psychologically protect herself was powerfully illustrated through her description of a metaphysical brick wall:

For a long time I felt like I had a big brick wall at the back of my head and whenever I used to get upset about things, like I used to not think about anything and not really get upset. But if I ever did get upset, it felt like little bricks would come out and I'd remember little things about what had happened and then I'd get really, really upset cos I'd blocked these things out. And for ages I felt like there was something there that I just couldn't remember. But whenever I used to get stressed or really upset as, you know things would start to come back, you know like about how mum had been in the past when I was younger, and there was, it just felt like there was something there that I just could not remember at all. So it was a bit of a weird feeling like I had a big, I could like almost physically feel it, like there was all this stuff behind a wall, but I couldn't remember or I couldn't unlock what it was really. – Freya

Interestingly, while both Seb and Freya clearly portray aspects of their memory recall which would be indicative of trauma (McCormack, White and Cuenca, 2017), they also

describe their childhoods as being relatively happy and protected. Indeed from a professional mental health gaze there is little indication of high risk or concern within either of their narratives. This would suggest that it is the way that they have understood their parent's mental ill health as children and their own role within it, which has been experienced as traumatic as opposed to the event itself. This disparity between the professional assessment of risk and/or harm and the child's own sense of jeopardy is discussed further in chapter twelve in relation to Jenny's perception of risk and her mother's suicidal ideation.

Another example of memories being obscured was portrayed in participants' recollections of visiting their parents in psychiatric hospital. Of the seven people who spoke about visiting their parents as young children, Freya, Seb, Sophia, Terry, Vivienne and Emily describe the hospital environment, the grounds, nursing staff and in Seb's case playing table tennis with the other patients, however each of them struggle to remember their parent there. The only participant who spoke about remembering his parents in hospital was Mike:

When I was little as well, I can remember going up to these big hospitals, I can remember going into these places. I can remember my mum would have made us a teddy or something or made us a chair or whatever was in vogue at the time, you know a little stool and that kind of stuff. And that, that's interesting because you kind of feel that's not, I don't know if that's normal for a child, but it was kind of a bit more normal for us to go up there. – Mike

Perhaps these positive memories were aided by the fact that he would visit the hospital with all of his siblings, which he identified as a strongly protective factor for him. Furthermore both his mother and father had regular admissions to hospital so he had become accustomed to it, and his mother would make them gifts, thus maintaining for Mike a sense of maternal love and connection.

Summary

Many of the participants described their childhood identities as having been constructed in response to their parent's mental ill health rather than through a period

of exploration (Marcia, 2002). This was either to disguise the specific circumstances and differences in their family life that they felt would set them apart from their peers, or in an attempt to present the best version of themselves to manage their parent's illness and the expectations of others. This was described as impression management rather than a true representation of identity, which can be linked to Goffman's presentation of self (Goffman, 1963). Several participants based their identity and self-worth around their protective role towards their parents and the care they provided to them which gave them purpose, place and significance.

Some recognised this as a specific role, such as young carer, while many others were not aware of this term until their adulthood. This lack of clarity was attributed to both, the term not being widely used during their childhood and because the level of care that they provided was not adequately recognised.

For many of the participants speaking about their identity, a powerful theme which was present within their narratives was around the impact on their childhood memories, specifically in terms of memories being distorted or lost altogether. Some participants reflected that this was indicative of the kind of psychological protective processes associated with experiences of trauma.

Chapter Eleven

Impact as an adult

Introduction

This chapter will focus on the impact that participants felt that their childhood experiences had had upon their adult lives. This ranges from the sense that they made of their experiences, including the strengths and vulnerabilities they feel it had bestowed upon them. While speaking as adults, the participants still remain a child of a parent with mental ill health and for the majority, their caring responsibility and concern continues. Strategies and boundaries employed to manage this are discussed and the adjustments to these strategies are examined in the light of key events such as the participant becoming a parent themselves.

Redemption stories

Redemption stories are a narrative motif which is highly cherished within Western society. They refer to a story arc of difficulties being confronted, overcome and turned into a positive, transforming adversity into an advantage and ultimately seeking to use the advantage for the benefit of others (McAdams, 2006a). It may be the repeated use of this narrative trope or retelling of a specific redemptive story which helps distil the meaning of a key experience or turning point and refine the construction of a personal identity (Brandon, Philip and Clifton, 2017).

In the parts of the narratives during which the participants considered the longer-term effects of their childhood experiences, many of them either minimised the negative aspects, “it’s not ideal but its fine” (Roman), or presented the risk as either manageable or acceptable. Monica reflected on the significant level of physical and emotional risk she was exposed to a child, and while still presenting it as an acceptable level of risk for herself, she could also conceive how she would view this risk very differently if it were related to another child:

I say nothing serious, it is serious if it happened to a nine year old now I would be up in arms as much as anyone else. But at the time to me it didn't feel serious. - Monica

This disparity between the acceptance of risk for themselves and others was a recurring motif across the interviews highlighted the distorted perception of risk, rights and self-esteem for the children growing up with a parent with mental ill health. This reflected a lack of a sense of entitlement to a 'normal', happy childhood that they had expressed as children.

Participants also minimised the difficulties they had experienced and interpreted them as a necessary aspect of their adult identity. Mike described his childhood experiences as being "written through him" and "giving his life more colour". In a similar vein Jenny, who spoke of her childhood relationship with her mother as traumatic and debilitating, also saw it as defining her sense of self: "I can't change it and I wouldn't want to because it wouldn't, I wouldn't be the person I am today" (Jenny). Within her interview, Sophia went further to consider the positive skills that she was able to develop as a result of her mother's mental illness. Interestingly though, she also reflected on how her life had changed and how she felt that these experiences, which had once aided her development, now held her back. This links in to the need participants described, in terms of feeling trapped within their continued caring role and their desire, to create a distance for themselves. This was exemplified by Sophia who at 25 reflected that as a child she drew strength and learning from the 'bohemian' lifestyle she felt arose from her mother mental ill health, however as a young adult she now felt that she was unable to 'get on' with her own life, as her time is often dictated by responding to her mother's mental health needs:

I think it is the best thing that's ever happened to me like I wouldn't change it, I wouldn't change my mum. I'd change her now I'd have the exact same upbringing and then I'd press a button when I got to 25 so she could get better and I could get on with my life. – Sophia

This theme of the continuing impact and care responsibility that participants carry into their adult lives will be discussed further later in the chapter.

Swiss Army Knife

For some of the participants their redemption stories were used to build upon what the participants saw as the defining attributes for themselves. Within these stories they claimed the skills they had developed in response to their childhood experience, were an advantage to them within their adult lives. Either in terms of bestowing them with an extra level of maturity or independence, or equipping them to support others in need. A powerful image of this is drawn from Jess' narrative in which she likens herself, figuratively, to a Swiss Army Knife:

I feel like I'm super equipped now ... it's almost like a Swiss Army Knife type of thing, that in one sense that it wasn't ideal and it wasn't brilliant and I didn't particularly enjoy it but another sense it equipped me to help others and it's made me stronger as a person, and I'd rather it happen to me than someone else. - Jess

It could be argued however that for Jess her Swiss Army Knife analogy is also a mechanism for her to make sense of and give purpose to the trauma, neglect and abuse she had faced as a child. As with many other participants she also carried forward this sense of enhanced skills in to her adult career, which appeared to have been chosen, shaped and informed by her childhood experiences. As discussed within the methodology, twelve of the twenty participants were working within health and social care jobs, with five of them having studied psychology and three going on to qualify as Registered Mental Health Nurses. Lucy recalled, "my whole life I've been training to work with people with mental health problems". However her choice of career was not solely driven by the utilisation of her specific skill set, but also by her own needs in terms of addressing her unresolved feelings regarding her mother's mental illness. Her work gave her the opportunity to almost re-experience her role within the illness in a contained and manageable way:

It gives me a sense of like fulfilment I suppose and I always felt really frustrated and guilty that I wasn't doing enough for my mum when she was ill. All I've known is like dealing with my mum who is always really distressed and it's so much easier to work in mental health

because you get respite, you get a break, whereas during those years I didn't, it was all the time, it was unrelenting and I suppose I didn't even realise at that time how much of a responsibility it was... you know there are difficult parts of my job, yeah, but if I compare it to how it was for me and what I had to cope with at that age, like not only like being with someone 24 hours a day and having to like monitor them when they were at their worst, erm but also having that emotional attachment, like so you really care, you know when, I mean I care about the people I work with if they're suicidal, but they're not my mum. – Lucy

Freya also described giving up her career in marketing to work on a telephone support line, explaining that she used her supervision and training to reflect on her relationship with her own mother and that her work on the support line enables her to feel that she can distance herself from her mother's on-going needs:

[My supervisor asks] Why you do the job? and I think a lot of it is to do with, you know being that empath and being that person for my mum and just filling that role now with something else...and I think I do the job cos I feel like I need to do it rather than, is it actually what I want to do? Probably not but it works well for me now. – Freya

Vivienne studied psychology at university and felt that it helped her to reflect on and respond to her parents in a much more balanced manner. This was also the case for Georgina who described her knowledge and expertise as protective:

I do remember actually telling her that I'd become an RMN [registered mental health nurse] and feeling, and feeling empowered that I could protect myself from her a little bit more. – Georgina

Outside of the work environment, participants also felt their adult identities had been affected on a personal level. For Jess, Vivienne and Natalie they spoke explicitly about the effect they felt their parents' mental ill health had upon their personality and both the responsiveness and responsibility they felt towards others:

I think that's definitely in my nature because as soon as I see someone upset I want to respond to it, like I wanted to deal with it because in my relationship with my dad for example, or my mum...actually my mum too, it's the personal responsibility. Like if someone's left out of a conversation it makes me incredibly uncomfortable, like its weird. – Natalie

Relationships

Ten participants spoke of their current relationships in a manner which suggested that they did not feel that their childhood experiences had negatively impacted on their ability to enter into long term relationships. This said, many of the participants also spoke about the impact their experiences had had upon these relationships. Mike spoke about being initially reluctant to tell his (future) wife about his parent's mental illnesses for fear that she would be put off from building a relationship with him. Vivienne, Jess and Natalie spoke about their tendency to take a caretaking role within both their romantic relationships and friendships, and their inability to assert their own needs or requirements. This can be rooted back into their childhood development of acquiescence and the sense that their needs are unworthy or secondary to others, as discussed in Chapter nine:

It can be hard in like relationships because I give a lot more probably than I get back. The reason I broke up with my ex-boyfriend was because it was just way too one-sided and it was just, it became so clear that I just became really resentful and it was, I was just really not happy and I was just like I can't have another one-way relationship anymore. Because my dad, my relationship with my dad and my sister is very one way and erm I think I've become a bit too aware of the fact that all my relationships can be one way. – Natalie

Natalie goes on to describe how she feels that she needs to 'work on this' before she could consider beginning a family of her own. As she fears that the imbalance within their relationships would result in her resenting not only her partner but her children

as well. This could mirror the model of acquiescence, the reluctant submission to other's needs above her own.

A further barrier to addressing their own emotional needs was also present within Jess's and Terry's narrative, as they described having to keep their parent and their partners separate. For Terry this was due to his mother's reaction to and jealousy of his partners. For Jess the need to compartmentalise her life also included not being able to tell her partner about her experiences. For her, this mirrored the sense of discord and dishonesty she remembered feeling as a child when she had to hide her home life from her peers. As an adult she still feels compelled to shield others from the realities of her life:

Generally I have to watch what I say because some people have said to me like my ex-partner said it was just too much to hear, he couldn't deal with it, it was really upsetting for him to hear and that was quite hard actually because he didn't want to know anything after a while he said to me I don't want you to talk to me about it. –

Jess

Vivienne, Lucy and Emily recalled having discussions with their partners regarding their childhoods and their parents' mental illness. As part of the conversation they felt the need to plan how they might cope as a couple if they were to become unwell like their mothers:

I said to [my partner] when we got engaged, I think we should write a pre-nup in case I go mad and I'm horrible to you like my mum was. –

Emily

Robyn, whose father was mentally ill, recalls insisting that she and her husband attended couples counselling during their first pregnancy to address what kind of parents they would be. While attending such counselling might have been more culturally expected, with Robyn coming from America, she also saw that it was directly motivated by her fear that their family life and parental roles would repeat those of her childhood:

I've always kind of been ultra-sensitive to the point it does get on my husband's nerves that he can't have a down moment. You know if he plays on his phone, I'm like, there's your children interact with them. Because I had no interaction with my father growing up so I don't want them to grow up and think, oh my dad was always on his phone or he's always playing games. Which is not how my husband is... But, yeah you do get ultra-sensitive and it just makes you think I don't want that, I don't want my life to be like that. – Robyn

At the extreme end of the spectrum, Monica and Ethan spoke of not feeling that they could consider an adult relationship. Ethan presented himself as being so intertwined with his mother, other relationships had no significance for him and as such he had never tried to forge any. Whereas Monica described having several unsuccessful relationships in the past (both romantically and friendships) which, she felt, had failed because of the “psychological baggage” she carried from her childhood:

I've kind of come to the conclusion that the world is just made up of constructs and narratives that and the narrative and the constructs that I've put on the world have not been helpful for me and they've not worked for me and that's fine, it's okay. – Monica

Again, she repeats the mechanism of minimisation, defining it as not okay but acceptable for her. Jess reports using psychotherapy sessions to enable her to challenge some of the constructs she built as a result of her childhood experiences, and begin to form healthy reciprocal relationships. However, she still sees the impact that her childhood has upon this aspect of her adult life, “*It's still kind of has an echo effect I don't know if that will ever really 100% go*”.

Waiting for the interruption

During his interview, Terry reflected upon his academic ability at school and the potential he might have had. He described feeling as though this potential had been curtailed due to his experiences of his mother's illness and likened this to another friend he had, who had had similar experiences:

But I'm happy here and I'm settled and I think that's all I ever wanted was to be just settled, settled ordinary life... No chaos, or as little chaos as possible... I'm not really ambitious I think. I could have been but not with, I think going through that, all that turmoil and that, that does something to you. Cos you're always waiting for something to go wrong, you just can't dedicate yourself to something else 100%. I think that's what it is. – Terry

This sense of holding themselves back or waiting for interruption was present in many of the interviews. This was evident both practically, for example with Ethan, Jess, Seb and Monica whose educational achievement and choices were directly influenced by their parent's mental illness, and psychologically where participants described not pursuing ambitions or taking opportunities because they did not feel worthy or because they were concerned how their life choices might affect their parent's mental wellbeing. This was ever more so for the participants who were still providing substantial care for their parents. Both Holly and Alicia spoke of their time at university as being extremely stressful as they continued to be the primary carers for their mothers. They never felt able to engage in what they perceived as being the normal student life. They returned home every weekend to check on their mothers, and took time off from their course if their mother's mental health needs required it. Both described a sense of relief once their degrees were over so that they could stop juggling the degree and the care role. Both have returned home and have no clear idea when they will be able to use their degrees to pursue their careers further. Sophia also described failing years at university and being dismissed from jobs as she has been unable to find the balance between working and her caring responsibility for her mother:

She ruins everything like I always have to break, like stop things or do things later do you know what I mean? It's like whenever I'm busy or have got lots of work to do she'll go into crisis and I'm so fed up of using her as an excuse, like I'm not using her as an excuse but her actually being an excuse do you know what I mean? I just, I want, I want to break free from that now, I just want to be me I really don't

want to have to walk with this baggage like I don't want to be that person whose always got to go off to sort out her mum, I just really don't. Like, I want to be like everyone else now do you know what I mean? Like I want to be, like I don't want to come across as like a liability. – Sophia

Natalie, who was currently a student at university, spoke of the anxiety she feels each time she thinks about how her father might be at home, but also of the psychological impact that she feels that her childhood experiences have had upon her, specifically around her anxiety and her need to be in control of her environment, always striving to keep a sense of calm:

I think it's made me quite anxious like as a person and like around uni stuff I get quite, like if something changes or like if something gets affected that's not in my control it really like makes me really anxious... It's almost like loads of things like spilling out and I have to like just kind of try and keep them in. – Natalie

This anxiety that Natalie describes having had in the past has been extremely debilitating for her, causing her to self-harm and avoid all social situations. She kept this to herself for some years, fearing that it would upset her father and cause a relapse of the psychotic phase of his illness. However, since speaking about her anxiety and receiving therapy herself, she has come to realise that much of her anxiety and need for control was related back to the unpredictability of her father's psychosis.

Watching themselves

Of the twenty participants, seven identified themselves as having their own mental health issues which had required a range of interventions from medication and therapy to hospitalisation following a suicide attempt. Within these seven participants, five cited their childhood experiences as being at their root of their own difficulties. While thirteen of the participants reported no concerns about their own mental health, nine of them described at times feeling worried that they were genetically more likely to become mentally ill and felt the need to monitor their mental health closely. Therefore, while on the surface the participants within the research did not

appear to experience mental health issues above and beyond what might be expected of the general population, a much higher awareness of their own mental health was expressed. This awareness manifested itself in constant self-monitoring, avoidance of stress and a particularly cautious approach to life:

I worry that like, oh if I overshare, will I like go off the rails like my mum did, you know. You're always checking your own self for like your own mental health and I'm so acutely aware of it, that it's exhausting. You know like I'm aware if there's any signs, any, any like erm, any like, you know like it's if someone were to tell me that I'm just like my mum, that would be devastating for me. – Lucy

For Vivienne, Seb, Emily, Georgina, Mike and Robyn, the genetic heritability of mental illness was prominent in their minds, urging them to adjust their lifestyles to avoid potential triggers and to discuss future risks and plans with their partners:

I often worry about my mental health and, you know because these, these things do have sort of quite a strong genetic component and stuff. My mum was older than me when she had her first episode and you know and I've, it's something I've sort of discussed with my partner. – Vivienne

Sophia recalls being particularly anxious as she approached the age her mother had been when she first became unwell. Since that time Sophia has used the 'positive framing' that she had described her family using when speaking about her mother's mental ill health to re-evaluate her risks of becoming unwell, balancing her thoughts around genetic inheritability and learnt behaviour and employing a further redemptive angle to challenge her fear of mental illness:

You've always got that fear of is it going to happen to me and like I had that really bad being 24, because that's when my mum first got sectioned when she was 24 sort of thing, erm and at the time I was really very scared...I don't know if I was mentally ill or not I don't think I am but, I know that I am emotional or emotion-full I've got a lot of emotions, I get up days and down days and I think a lot of that

is learnt behaviour really... as for the fear of getting ill I don't have that fear anymore, I don't think I'd even know if it did, my mum looks like she's having a great time especially when she's high. - Sophia

Both Robyn and Mike also discussed their additional fear of the genetic inheritability of mental illness. Mike spoke about his fear that his parents' illness would have "skipped a generation". This was also the fear for Robyn who specifically spoke of the genetic inheritability of schizophrenia. With this at the forefront of her mind, not only does she monitor her own mental wellbeing, but she also watches her children closely, to the point that she may be at risk of pathologising what could be normal adolescent development or behaviour. The gendered nature of parenting and responsibility which was discussed in the Family Dynamics chapter is also revisited in her sense of responsibility regarding her children's mental health. While she concedes that her husband also has a family history of mental illness, she feels that she, as the mother, would be more responsible if one of her children were to develop a mental illness themselves:

I want a stable family for my kids like that, a normal family. But then it also makes you very nervous, because I know like erm mental illnesses, it does come in families. I have two boys, my other son is, and he's actually going through emotional wellbeing therapy, so he had a very tough summer. So I always have that in the back of my head that, you know when I look at them it breaks my heart to think that I could do, they, they might be, turn out to be schizophrenic and there's absolutely nothing that I can do, that's just in the genes... But what do you do not have children because you might, you know? You have to live your life and just really pray I guess and hope that everything's okay with them... my husband has mental health issues on his side as well, so we don't know where it's coming from but I think I do take, you do take that personally as a mother, like oh it's me, I've done something. – Robyn

Continuing to care

The majority of the participants described their care role continuing into their adult life, with five providing 24 hour care at home with their parents and a further ten stating that although they no longer live with their parents they still very much feel responsible and 'on call'. Of those that remained within the home providing care, Holly, Alicia and Jenny voiced that they felt they had no choice in this matter and each spent time in their interview considering how their lives could be different:

If I had the choice I would be at uni now and I'd be doing my teaching degree I reckon and it my life would be completely different if I wasn't caring. – Holly

However neither Holly, Alicia nor Jenny were able to take these considerations to the point when they felt able to predict when they might be achievable. Indeed for all of the participants that continued to care for their parents, there was little hope for their parent's recovery. Freya, Vivienne and Sophia predicted that their mother's illness would worsen with age:

She's not going to get better she's never going to get better, and I think that more than likely she's going to get worse because people get worse as they get older and she is always going to be a burden and she's not going to go anywhere. I'm always going to feel responsible, erm and I as much as I say I'm having a break I'm never going to have a actually break mentally... do you know what I mean so it's like having grown up children you never gave birth to. – Sophia

This sense of seeing your parent as the perpetual child, links into the concept of parentification as explored in chapter one.

Creating space in-between

With this continued sense of care responsibility, boundaries are a concept that presented as very important to most of the participants. These boundaries enabled them to continue to provide care for their parents without feeling overwhelmed or engulfed. The shape and strength of the boundaries set appeared to change as the

participants life changed, specifically through key life points such as adolescence, early adulthood, marriage and becoming a parent. For many of the participants, they described setting boundaries between themselves and their parents as a conscious decision to move away from an acquiescent state to one in which they begin to prioritise their own needs:

Some of the things that she would have done before that would have got a real rise out of me, oh no what's going to happen and it would've it would have controlled my behaviour. Now it would be like don't play that game with me. I'm not I'm not interested in engaging with it, that it's your choice. I want to have a healthy life and I've given you a lot of my years. – Jess

However this transition and management of boundaries is no simple feat and is often tested by fluctuations in their parent's mental illness, external supports or pressures and their own sense of being emotionally robust:

I find our relationship really difficult to manage, mine and my mums, like I find it really difficult to set boundaries and maintain boundaries with her and I feel like it's always two steps forward and one step back. – Vivienne

Several of the participants described needing to create a physical distance between themselves and their parents in order to maintain the boundaries between them. Lucy recalled a saying "happiness is a family 200 miles away", while Vivienne reflected on the practical difficulties she faced supporting her mother who lived abroad, balanced with the benefit she finds that physical distance has for their relationship:

I really wouldn't want her to move back to England to be honest because our relationship is a lot better and a lot easier to manage now that we're in separate countries. – Vivienne

In considering distance, there was a distinction made between physical distance and psychological distance for the participants. While Vivienne's mother lived in a different country, it was still Vivienne who was alerted when she had a relapse of her

mental ill health and Vivienne who felt it was her responsibility to travel to her mother and support her through the acute phases of her illness. Freya described that although she no longer lived geographically close to her mother it was not until she became pregnant herself that she could psychologically distance herself:

I think the distance helps me, to be far away from it then I can't physically be responsible for her because I'm not there, so it's like the physic...physically not been...of not being there but also I think I was still mentally there for a while. But now I feel a bit more disconnected and I have to...I feel like I have to be. – Freya

Becoming a parent

The implications and impact of becoming a parent was a powerful (and yet unexpected) theme, which emerged from seventeen of the interviews. The presence of it in each participant's narrative was not just related to their experience of becoming a parent, but also their hopes and fears, the preparation they felt they had to do or the reasons they felt that the option of parenthood had been removed for them. Whatever the focal point, this theme was a significant part of their narratives and was deeply interwoven with their personal sense of identity. As Freya began to discuss this in her consideration of physical and psychological distance, she went on to unpack the significance becoming a mother had upon the dramatic shift in her relationship with her own mother and her sense of self:

I think having a baby and having a child has helped to disconnect me from her, you know, because I feel like, I know, you could say I'm replacing mum with my child and my husband, but I can't, I feel like my family is them, then it's the, then it's my family you know. It's my husband and my child and then it's my family, so from that point that you're pregnant you're responsible for them and I knew that I couldn't allow myself to get too stressed by the situation because it wouldn't just impact me, my child, it would impact somebody else. So I think that helped me to be removed from her. - Freya

Several of the participants spoke about their desire to have children, however, they felt that this was impeded or delayed by their experiences of their parents' mental illness. This could be for practical reasons, such as Alicia's who lives with her mother and only feels that it is safe to leave her mother alone for two - three hours at a time:

It sounds really silly but I'm now 21 and I I've always since I've been little, always by the time I was 21 wanted to be married and have kids by the time I was 21...I'm 21 now I haven't been in a relationship for 5, for nearly 5 years. I don't, I don't have the time to go out and meet people or and you know it's not, it's a process isn't it you know and meeting somebody getting married having children it takes time and like and that's not, I don't think I'm going to have kids until I'm about 30 at this rate. – Alicia

Sophia, Jess, Lucy, Natalie and Emily described psychological reasons, feeling they had to work on themselves before they could consider becoming a parent:

I want to have kids and I want to have a happy healthy family, and I know at the moment there's a lot in my life that hasn't been healthy and I need to be able to get to the point where I know that actually I can, I know what's a healthy environment and I can create a healthy environment and all that kind of stuff. – Jess

For each of these young women the 'work' that they felt they had to do related to the development of skills they felt they had missed due to their childhood experiences. These ranged from emotional regulation, how to have balanced reciprocal relationships and how to 'be a mum'. For Monica, Lucy and Emily this work felt insurmountable and the additional fear that they were similar to their mothers, either through genetics or personality meant that they felt unable to have their own children:

I was like I'm not having children, because I was so worried about not, about turning into that type of mum. – Emily

Monica and Emily were adamant that they could not imagine a point in their future where they could consider having children of their own. Lucy described the painful

conflict of emotions she experiences when considering becoming a parent. She described herself as wanting to have children, as does her husband. However, despite being married for several years she has not reached a point where she feels emotionally ready to become a mother. This has resulted in considerable strain within her marriage and continues to be a difficulty for them. It was noticeable that throughout her interview Lucy had spoken in a manner which would be construed as angry, her speech was rapid, loud and assertive in tone. However as soon as the issue of becoming a parent came into her narrative, Lucy's voice 'cracked' - she became very quiet, tentative and tearful. She took care to tell me that she was not trying to use the interview as therapy and I felt compelled to respond to her in a reassuring manner, which had not been required throughout the rest of the interview. This idea of the interview representing a therapeutic or cathartic experience and the subsequent response of the researcher specifically with Lucy and sharing information has been explored previously in the methodology chapter.

For those who had children, there was a need to consider and plan how they would manage the care they had previously given their parents against their new responsibilities to their own children. Vivienne illustrated this as she reflected on her mother's cycle of psychosis, which compels Vivienne to travel to a European country to stay with her and spend a month or two physically managing the symptoms of her illness and subsequent risk. There have been occasions on the past that Vivienne herself has been at physical risk of harm as she has become the focus of her mother's delusions and paranoia, consequentially she is clear that she could not take her infant daughter with her. Yet she is reluctant to leave her daughter for such an extended period and is unsure how her husband would manage to provide full childcare in her absence. Given her mother's established cycle the next phase of her psychosis would occur when Vivienne's daughter is one year old. On a practical, rational level Vivienne has discussed this with her husband and come to the conclusion that she cannot leave her family in order to respond to her mother's illness. However, on an emotional level, she fears that her mother will not be able to engage with any alternative forms of help, with disastrous and potentially fatal consequences:

I've always felt like I was kind of having to look after them really and as I say I just, now I've got a child of my own I just don't want to do that anymore. Like I really just want to sort of focus on [my baby] and our life together, and my partner's not particularly impressed with it all either. Like last time my mum was ill, I was like I need to go out there and he was just like, just don't... I feel guilt all the time with my mum, and I don't know why because I've got no reason to be beholden to her, and I don't owe her anything. But she's just got a way of like manipulating me. So it's all very well me saying, I'm not going to go over there anymore if she's ill again. But I don't know if when it came down to it I would actually not, I certainly wouldn't bring [my baby] with me, she'd be, you know I'd have her stay here with her dad, but, I don't know, it, it's, it's difficult to say. – Vivienne

While not as dramatic, this need to plan for periods of ill health and manage the competing needs of their parents and children was prevalent for four of the seven participants who had children of their own. There was also a great deal of consideration and negotiation given to how the participant and their partner would manage the relationship between their child and its grandparent. For Georgina, Vivienne, Freya and Seb this meant setting rules about how their parents could behave around their children, limiting contact and ensuring that they are not left alone together:

His reaction to lots of things just seems a bit emotionally dysregulated. So that's something that we've talked about and I don't know how to put it to my dad, that we don't really want him solely looking after our child at any point, and my wife in particular only wants him around our son if either of us are there as well. Which I, I'm, I'm not sure about that yet, still as long as my mum's there I'm kind of happy, but she doesn't want just the two of them there. So yeah that's, it's quite a different dynamic again and like I can totally see where she's coming from and I'm with her all the way. – Seb

This need to manage and control the relationship adds a level of anxiety for Georgina when she considers her mother's emotional un-containment and the damage she feels this has done to her sister and herself. This anxiety is not going to go away, indeed she envisions as time goes on it will get worse as her control of her son's relationships with others will diminish. She fears she may find it harder to manage his contact with his grandmother and therefore protect him from potential harm:

I'd never leave him with her. No way, no way. Not because I don't think she could cope with him, but because of any potential emotional damage she could do to him. I'm sure she would be very good with him because she is very good with babies but I want to watch her all the time... I do worry about like when he wants to have a relationship with mum, one that I can't control, you know that there'll be times when she could, she'll talk to him and he'll be able to actually respond and I, I just, I do worry about that. – Georgina

The potential for intergenerational harm is also a prime consideration for Seb and his wife who, as soon as she became pregnant began to make significant changes to their relationship with Seb's father and agreed on strict restriction on the relationship they will allow him to have with their son, in an effort to circumnavigate what they feel to be the 'ripple effect':

That has an impact on the next generation as well, because obviously the impact it's had on me which my wife is seeing how I've, you know who I am and she knows where that's come from and I think she's happy with me. But you know in terms of like erm, yeah just wanting something different for...for our as well, so it's kind of...it has the...the ripple effect doesn't it. – Seb

Robyn felt that she had to take this a step further by ceasing all contact with her father when she became pregnant with her first child:

But after a while I just had to for my own I think mental wellbeing and just cut him off. So we don't speak, he doesn't know anything about the children, he's never met the children, he's never seen the

children erm just because erm I feel like children need consistency and they have one gran, grandfather that more or less gives that to them. They don't understand how I cannot speak to my father, the thought of them not speaking to their dad they just can't even think about that and I just said you know sometimes people aren't good for you even if they're your family. - Robyn

On an individual level there was also a strong current of personal introspection and determination about what kind of parent they wished to be. This was highlighted across multiple narratives as they spoke about their need to be a different kind of parent. Seb spoke of his desire to be “present and involved, which is the opposite of the memories of my dad” and Lucy was adamant that she “wants her children to grow up differently”. This sense of parenting differently meant that many of the participants spoke about consciously defining their own parenting style rather than relying on instincts and memories of their own experiences of being parented:

I think when you grow up like that and you see what you, you see what you don't want your child's life to be like... I try to do things differently, I've completely towed my own sort of parenthood you know and, I don't, I haven't copied anyone, because I don't feel there was anyone I wanted to copy...I just want to shelter them in a way that I wasn't sheltered. – Robyn

Not only did this at times challenge their redemption story of their experiences giving them strengths and resilience but it also made them reflect on their parent's behaviour and the subsequent impact it had on their relationship from a different more detached and critical perspective:

Having become a mum I just, I don't understand how she can behave how she does, I've always wanted to be a mum, always wanted to be a mum. I think having had a bit of a crap one, I've just always wanted to, I don't know, I've always had a lot of love that I haven't been able to channel, I don't know. I just want to be the best I can be

for him and I know every parent feels like that, or should, because it certainly didn't feel that mum felt like that. – Georgina

This strength of conviction about what is acceptable for their own children and the steps taken in order to protect them from potential harm is particularly interesting and poignant when juxtaposed with what they not only experienced throughout their own childhood, but accepted, internalised and acquiesced to, minimising it as “not ideal but it’s fine” (Roman). Clearly, when it comes to the next generation they are striving for the something better.

Summary

This chapter explored how participants understood the manner in which their parent’s mental ill health had impacted upon them in the longer term. While many spoke of adversity, neglect and at times abuse, many appeared to minimise the effect that it had had upon them, which reflected a stance that might be taken from the model of acquiescence. However others took it further and presented it as a redemption narrative stating that they wouldn’t change anything. It made them the way they are and even drew benefit from it, specifically that they were more equipped to help others.

Half of the participants were in committed relationships and while they saw that their childhood experiences had some impact upon them, which ranged in significance and complexity, it had not prevented them from making a meaningful connection with another. Others felt that their experiences either physically or psychologically prevented them from forming adult relationships.

Another tangible impact identified by participants was that of opportunity and potential during their childhood and into their adult lives, while only one of the participants could be defined as living in a precarious manner (with no paid employment or permanent address) several could be considered to be professionals. The majority of participants described feeling they had been held back or were compelled to hold themselves back to provide a base from which they could respond to the next episode of parental mental illness.

The sense of holding back also arose from an insecurity in the robustness of their own mental health. While there was not a significant number of participants who reported having mental health problems, a high number of participants who described themselves as being excessively worried about their mental health, having to constantly monitor and check themselves and avoid situations they fear might trigger mental illness. For one participant this anxiety and fear of mental illness extended to her children in a way that she recognised was, at times, detrimental to everyone.

Of course as children grow up, the relationship with their parent endured as did, in many cases, their parent's mental illness. As such the majority of participants described still providing a substantial level of care to their parents, which was a role and responsibility they could not foresee coming to an end. Several participants responded to this by putting in place firm boundaries, and in many cases managing these boundaries by moving to another geographical area, thus placing a physical distance between them and their parents.

These boundaries became key again for participants who had or were expecting their own children. It was striking that not only did they have to reflect on what kind of parent and family they wanted to be, they also had to set terms and conditions in order to feel able to manage their ongoing relationship with their parent, and plan how they would orchestrate the relationship between their child and its grandparent. For many, this was about establishing with their parent that they were no longer their primary concern. For one of the participants this extended as far as ceasing all contact with her father as her children were born. Their focus was on protecting the child from the emotions they themselves had experienced. They couldn't protect themselves but were determined to protect their children. However, for some it forced them again to reflect on how their parents could have been uncaring and harmful in ways that their mental ill health did not fully explain.

Chapter Twelve

Service intervention

Introduction

Across the board there was a significant level of criticism levied against services. This could be broken down into themes of missed opportunities, barriers to recognition and communication and a sense of disconnect that was felt by the children in terms of their relationship to their parent's needs and the professional intervention.

An interface (or lack of interface) between health and social care services and families ran through all the interviews. The perception of the availability, responsiveness and professionalism of services was often interwoven with the participants' understanding of their parent's mental illness, its severity, its societal construction and indeed a reflection of their own culpability and self-worth. This chapter will explore the key points within the narratives during which this interface (or lack of) was most powerfully felt.

By developing an understanding of the participants' perspectives on service intervention, we can explore the dichotomy that most of the participants described in terms of being involved but not included. Finally the only direct question I asked the participants within the interview was at the end of their narrative, when I enquired what could have helped. There was an overwhelming consensus amongst the participants which will be discussed at the end of the chapter in terms of what they felt was missing and what would have been helpful.

Children's interface with services

Children who grow up with a parent with severe and enduring mental ill health encounter health and social care professionals in a range of settings during their life.

As for most children, school is the primary place where children are observed by and interact with professionals. However with the complex needs of their parents, the participants within this study also had contact with professionals from secondary (or specialist) services such as community mental health teams, nursing staff within psychiatric hospitals, children's services and child and adolescent mental health services. Despite this layering of professionals who touched upon the child's life, many of the participants described feeling overlooked by services, and that opportunities to realise and respond to the child's specific needs were missed.

While two of the participants spoke about the school that they attended together in glowing terms, stating that the staff went 'above and beyond' to support them with their caring responsibilities, most spoke about school staff as being largely unaware of the circumstances of their home life. They described wanting to keep their school as distinct and separate from home, defining it as a refuge, a place they could feel normal and escape the care tasks they faced at home. They also spoke of not wanting their home life to be exposed at school for fear of being teased or ostracised by their peers. However, participants also spoke of times when the care they were providing for their parent directly impacted on their school performance but this not being recognised by the school:

I got taken out of class one day because I'd been sat there dozing off and I was just I was really tired I'd been up the night before looking after my mum and they took me aside and they said erm we've got concerns we think you might be doing drugs ... I just said to them no I'm just tired, I'm just really really tired I don't get to go to sleep at night and they sent me back to class and stuff, but erm it was just amazing I don't know I don't know how people didn't pick up on it. Now looking at it because there were things like I didn't attend for two weeks, I just consistently didn't attend erm but I think I possibly got away with it because when I was in school I was attentive ... I wasn't kicking up a fuss or being really naughty or anything I just, If they gave me homework I'd do it. – Jess

Again because he wasn't presenting in a manner which would have obviously suggested a significant level of emotional distress, Terry's increasing difficulties in managing his home and school life were not attended to:

I think I just held it together as a kid and I think because I presented as quite sort of ... sort of intelligent, quite sort of happy, quite well adjusted, had lots of friends. I think the assumption was that I was just dealing with it. – Terry

These missed opportunities to pick up on potential emotional disturbances, or looking further into the child's experience of their parent's mental ill health also occurred within the home. Participants spoke about professionals such as doctors, nurses and social workers coming to the house but rarely speaking to them. Some parents would ensure appointments would happen during the school day or at a community clinic. This could have been perceived by professionals as their patient proactively engaging with their care and attempting to limit the impact of their needs on the children. However, for some participants it meant that they were not seen or considered and their parents could present in a very different manner than how they were at home. For two of the participants, child protection services were involved but once they withdrew, the support the child received also ceased. This was also the case with mental health services, where Holly described services flocking in at periods of crisis but soon drifting away when the issue became complex or chronic, leaving her feeling abandoned and trapped within the situation:

You try so much to try and help them, but all of a sudden nothing works anymore because you've tried everything and that hasn't helped, I think then when it gets to that stage that everyone goes 'Right I can't deal with this' and they have the option to walk away, I don't. – Holly

Several of the participants spoke about visiting their parents while they were in psychiatric hospital and finding the environment intimidating. None of the participants recalled being spoken to in depth by the nursing staff or having any form of family therapy offered. While the opportunity was missed to help the child build an

understanding of their parent's mental health needs, the child's own needs were also ignored. In one powerful example, Jess described herself aged 13 taking the bus to visit her mother in hospital every day after school for three weeks, at no point did any professional speak to her for long enough to realise that all this time she was living alone, with no access to money for the electricity meter or food other than her school 'dinner disc'.

In seeking to understand how these opportunities were missed in so many cases, it is important to consider it from the standpoint of the professional services and the child themselves.

In terms of the services, a primary factor may have been the focus of mental health services as being patient centred. This derives from the individualist nature of the medical model of mental illness which is the dominant ideology of health services. The holistic assessment of the patient as a parent is often omitted, and consideration of the children is not viewed to be part of mental health services remit. This was reflected in how the participants felt that they had been largely invisible to services. A restricted focus on the patient, and the separation between health, social care and education can also lead to the assumption that the child's needs are being addressed elsewhere. This was considered in a study by Alan Cooklin (2010) which interviewed health and social care professionals directly and proposed that children of parents with serious mental ill health fall between the gap, being everyone's and yet no one's responsibility. This is echoed in Jess' sense of being surrounded by 'serious bystanders':

Whoa hang on a minute at what point was somebody going to do something like, it was it serious bystanders like ohh somebody else is probably dealing with this one leave it or I don't know, absolutely bizarre. – Jess

Professionals can also be hesitant to look too closely at the child's experience, reluctant to appear that they are reinforcing the stigma levied against parents with mental illness, or interfering with their privacy as a family. Equally they could be concerned about 'opening a can of worms' they feel ill-equipped to deal with. Nevertheless, without suggesting that there are child protection concerns as a matter

of course for children who grow up with a parent with mental ill health, there is often a need for additional support, a point that Sophia felt strongly about within her narrative:

There are certain things that were missing, that could have made it easier, I think, I just don't think you should be left to your own devices, because you're not capable you're not competent as a parent, erm not to say you can't have your kids, like we were never in danger, nothing was ever going to happen to us, okay we wouldn't, it was better than being in care I'm not even trying to say it wouldn't be, do you know what I mean, I know I always knew that our mum loved us like I'm not saying that erm but if they there was a little bit more help, a little bit more support around helping you do children things and being a child erm I think that would have been helpful. – Sophia

However, there was also in several narratives an implication that service intervention should be avoided, for fear that it would result in the family being separated. This is mirrored in Jess's sense that she 'got away with' hiding her highly risky home life by not 'kicking up a fuss' or being 'naughty'. This fear of negative or punitive service intervention is commented on in research examining the experience of parents with mental ill health (Montgomery, 2005; Jeffery *et al.*, 2013). This in turn can reinforce the fear for the child.

Barriers to communication

When considering further barriers to communication originating from the child, participants spoke about not having the words during the formative years of their childhood, nor the ability to fully express their experiences (Cossar *et al.*, 2013). Many spoke of not realising it was not 'normal' initially until they began to spend time at their friends' homes and compared them with their own. However as the realisation of difference developed so did the awareness of associated stigma. The majority of participants discussed their need as children and adolescents to appear normal and to fit in with their peers.

Many of the participants minimised the difficulties they had faced - *“it’s not ideal but okay”* (Roman) - and it was apparent they had done this for much of their childhood. They explained that they felt that they could not speak to friends, as they believed peers would not be able to relate to what they were saying, that it might be upsetting for others to hear and/or it might result in them being teased. They also kept their parent’s illness secret as a way of protecting their parent from stigma, and felt that expressing their needs and difficulties regarding their parent’s mental ill health would cause their parents to feel guilty. This guilt would in turn exacerbate their parent’s distress and consequently make things harder for them.

The reluctance to reflect on and communicate their own needs is also a coping strategy, since thinking about their own needs would make their care tasks feel overwhelming. Also the fear of intergenerational transmission of mental ill health and the strong desire to not be like their parent meant that they actively avoided addressing their own mental health needs or talking about their feelings.

Jess, Terry, Natalie, Georgina and Sophia spoke about being prevented from speaking openly to services, because they never had opportunity to talk without their parent present and that speaking to services about their own needs or contradicting the parent’s beliefs and/or demands would have been seen as a betrayal:

There’s that expectation I know from the ill person that you’re going to be their advocate and if you don’t get the result they want, they’re not happy and you haven’t shouted loud enough. – Terry

Despite the barriers to communication it was clear that the position of and relationship with the child was often integral to the manifestation of the parent’s mental ill health and subsequent engagement with services. Ten of the participants grew up in a single parent household. However, of the other ten who had another parent present within the household, four spoke of the other parent being predominately occupied by work with the major share of the emotional and physical care resting at the participant’s feet. Equally, given the severity of their mental illness, it was surprising to discover how many parents did not have ongoing support from mental health services, a factor

potentially influenced by the amount of ongoing care and support that the children provided.

Provision of care

As discussed in previous chapters, the range of care tasks performed by the participants was extensive, from physical care to emotional containment and crisis management. At the point when services did enter the equation, older children, (those approximately nine years and above), took on tasks within the care plan, such as managing medication, monitoring mood and encouraging daily structure. Lucy recalls a care co-ordinator suggesting that she and her brother took her mother breakfast in bed in order to encourage her to get up before they went to school. She remembers that they did this every morning for four years *“like a bedroom waiting service”* (Lucy).

Some of these care task appeared to be directly detrimental to the child’s own needs, such as Terry aged 10 moving in with his mother after she was discharged from the hospital she had continually been in since his birth and being required by her to sleep on her bedroom floor until he was 15; or Natalie aged 15 spending the night with her father on the balcony of their flat while he was acutely psychotic and driven to defend their home from invaders. At times participants described how professionals directly requested some of these tasks, for example Roman being asked to manage his mum’s medication concordance:

The crisis team came in and they said to [Roman] it was his responsibility to make sure mum takes her drugs, like my mum don’t like to take them and [Roman] has Asperger’s so you just told him it’s his responsibility to make sure she takes her drugs so basically he’s trying to force these fucking drugs down her throat because she won’t take them and as far as he knows he’s going to get in trouble. -

Sophia

Along with the numerous occasions where participants described feeling that there was an expectation from services that they would provide a level of care for their parent, they were also often used as source of information. However, it was felt that the flow of information was largely one way as they were rarely given information

regarding their parent's mental illness, invited to meetings, or made privy to aftercare arrangements. It seemed that on some occasions this lack of inclusion and information would be based on a notion that it would not be age-appropriate to involve the children with care discussions. However, as Lucy described, this concept of what is age-appropriate is skewed when the child is already physically involved with the illness and necessary care:

People thinking oh we won't tell them because we don't want to burden them when we were too ... we were really fucking burdened already, like we were burdened with all the responsibility of living alone with our mother, and I ... I think people were like, oh they're too young, we don't want to involve them in mum's treatment cos...cos they're young and they won't understand, well you know, we don't ... but then we're left with not understanding but having to deal with it, so we were too young to go to the carers group or to you know, to ... you know come along and be in...involved in my mum's discharged planning meeting, sure of course we were too young for that, but we weren't too young to actually have to look after her all those years afterwards. So the implications of all those decisions that were being made had such a profound effect on us, but these decisions were completely out of our control. – Lucy

This resulted in her feeling sidelined and unsupported throughout the process yet left with a great deal of responsibility:

As a young person I wasn't involved in my mum's treatment I ... I would have liked a manual, I would have liked some sort of information about mental health and what depression was and most importantly I would have liked something, a manual that had told me that it wasn't my fault that's what I would have liked or just someone to do that because through my mum's mental health treatment I was totally side lined because... because I was seen as too young to be in be involved in her care ... well I was too young to be involved in her

care but I wasn't too young to be involved in looking after her when she got home... so I had all this responsibility but no control, no ... I had no say in my mum's treatment. - Lucy

Even as the children grew older they continued to feel excluded from the care planning process. At 19 years old Holly describes how this lack of information hinders her role as a carer and as such had a negative impact on her mother's recovery:

I rang them a few times and said look I'm her carer, I need to know what's going on and I need to know what you've said and what you've done so I can put things in place for her when she comes home... I feel like me helping her is hindered when things like that are going on, because they don't, they don't help you they don't help you understand what's going on and how you can help them when they get home. – Holly

This lack of inclusion also meant that professionals' decisions were often made upon a snapshot assessment of the parent, and the expertise of the child who saw them around the clock was missed:

Because at the end of the day I am an expert on it, like maybe not because I'm his child, but because I'm the person who's seen him for the past few weeks being...like more and more out of control. And whether I'm 15 or 25, at what point do I get credibility for really knowing what's going on and knowing what he needs. Because they want to ask me all these questions about his medication and they want to ask me all these questions about his behaviour, that like are quite complex stuff, and to be honest I didn't know the medication stuff but I definitely knew all the other stuff. But then when they...they come to decision making I'm not allowed to say what's best for him ... I thought it was hypocritical that the crisis team was like asking all these questions but not actually listening. – Natalie

In terms of the emotional wellbeing and resilience of the child, a key factor was also the understanding of risk and vulnerability, both for themselves but primarily for their

parents. Within the heart of this disconnect between (child and adult) carers and professionals there lay a miscommunication and lack of understanding of each other's assessment of risk. This was illustrated by the crisis team deciding that Natalie's father did not require a hospital admission while Natalie and her sister did not feel they could safely manage his psychosis at home. This was also evident in Holly's narrative, when the social worker did not seem to acknowledge that Holly's anxiety surrounding her mother's suicidal ideation was exacerbated by her father's death the year before, *"I've already lost one parent, I know it might not happen but there is always a risk and that terrifies me"* (Holly).

An example that made me reflect directly on my own practice and training was that of Jenny. Jenny spoke about her mother who was chronically depressed, rarely able to get out of bed, often tearful and emotionally needy. Jenny described a single incident that occurred when she was 12 years old, during which her mother was emotionally distressed and kept telling Jenny that she wanted to die, that she wanted to take an overdose. Her mother did not make an attempt to end her life, nor had she ever done so in the past. However she had regularly told Jenny a story of how she had been close to committing suicide when Jenny was a baby. that she had had tablets in her hand and was only distracted when Jenny's brother (then a toddler) had called to her for a drink. As a professional working for an acute mental health crisis team, trained in suicide risk management and accustomed to situations of significant risk and high expressed emotion, I suspect I would not have considered Jenny's mother to have been at a significant risk of suicide or deliberate self-harm. However, listening to the rawness of Jenny's account I could see that not only did she not have the same perspective on the situation as I had as a professional, but also that she was a child who was frightened for her mother and who had ascertained from her mother a story of her previous attempt that it was her responsibility to prevent any future suicide attempts by being there. As Jenny spoke about her fears regarding her mother's risk of suicide she demonstrated indicators of Post-Traumatic Stress herself:

I've still got these images of her telling me she wants to die ... I would never get that thought out of my head so it will never change so ... I can't leave because, I always remember her, that day my mum telling

*me she wants to die, so I need to be there, because I can't move,
because I can't leave so I can't carry on with my life. – Jenny*

The experiences of children and their interface with mental health services are drawn together in the following illustration in Figure 10.

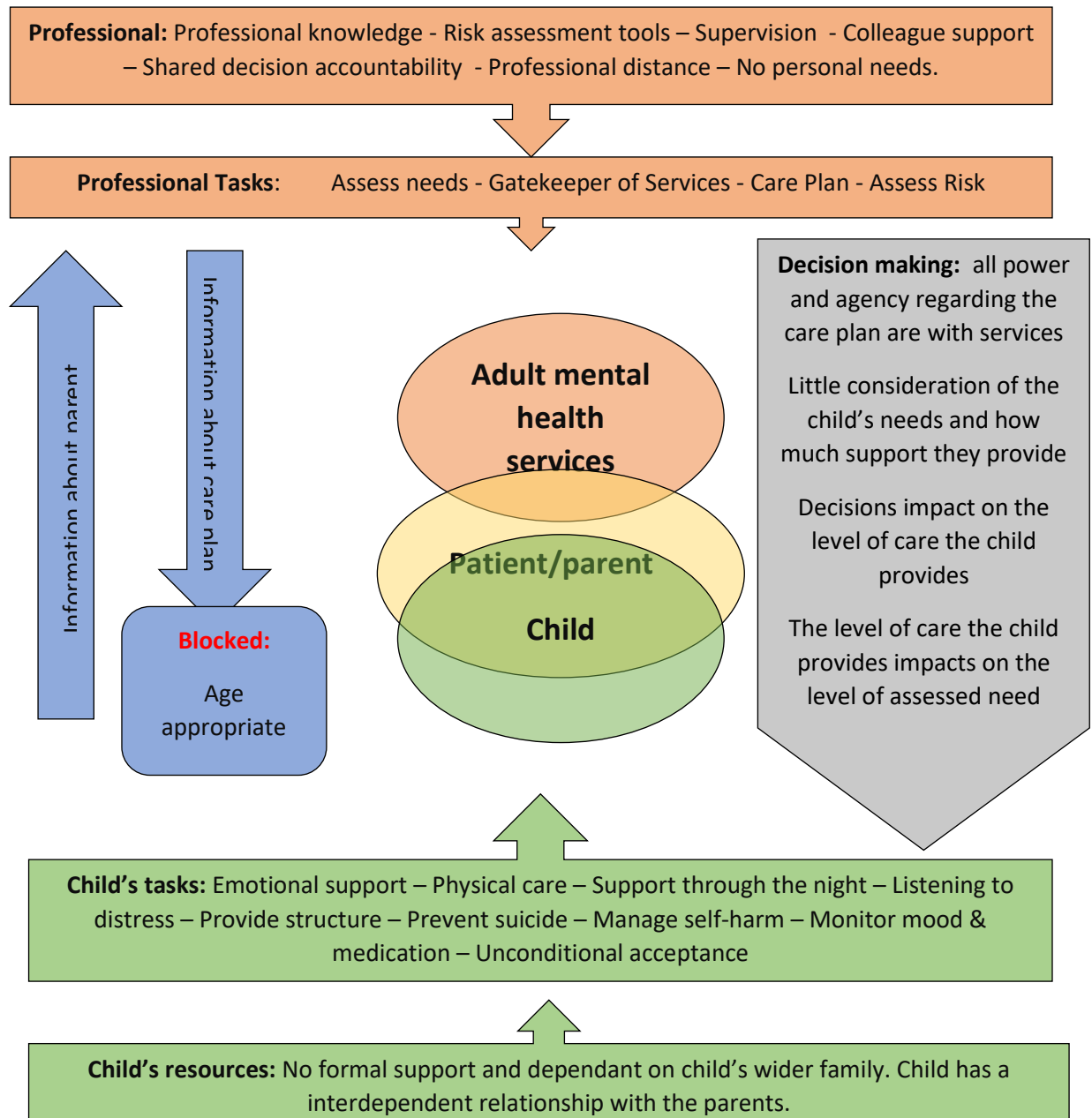


Figure 10 – Interface of the provision of care to a parent with mental ill health between the child and mental health services

The child and the services both touch upon the parent, although not on each other, and the overlay between the child and the parent is much greater. The mental health professionals' tasks focus around the assessment of need and provision of services, and within this role they are backed up by a wealth of professional knowledge and collegial support. In contrast, the child provides a wide range of support for the parent with very little formal support or understanding of how or why it is necessary. With the almost total overlay with the parent, the child also has little opportunity to create a sense of distance from the parent's mental health needs and at times has to subjugate their own needs, which would ordinarily be met by the parent. Participants often described being asked to give information to services regarding their parent's mental state, behaviour and/or medication concordance. Yet this flow of information was predominately one way as they were considered too young to be involved in discussions regarding their parent's mental ill health and associated risks, or such conversations were kept within the bounds of patient confidentiality. Finally, in terms of decision making, the power lay firmly with the mental health professionals and it seemed there was little appreciation of the needs of the child, the amount of support they were providing and the impact the decision made about the parent would have had on the child. In several interviews the participants described their parents being discharged from services or declining services, and it struck me, with my insider knowledge that this would not have been possible without the high level of daily support that the parent was receiving from their child (or children).

This sense of being excluded from the care planning process and the issues discussed within the model, is not new or unique to children of parents with mental illness. Many other family members who take on the care role for spouses or adult children have described feeling unsupported and without the relevant knowledge to enable them to cope with their caring role in an effective and safe manner. Indeed, this tendency of mental health services to focus on the individual needs of the person with the illness is often seen as person centred, empowering and protecting the rights of the patient. However, difficulties present when there is little appreciation of their social relationships, which can be rooted within the biomedical approach. This places the difficulties as internal to the individual, and is combined with a lack of holistic

training received by mental health professionals and the legislative processes which prioritise individual assessments and the protection of personal confidentiality (Glasby and Tew, 2015). This is further exacerbated when the person holding the care role is under 18 years old.

Social policy from both health and social care has sought to address this disconnect between carers, children and services. Primarily this has been delivered through the Department of Health care programme approach (CPA) guidelines (Department of Health, 2008) and in the Think Family initiative led by the Cabinet Office Social Exclusion Unit (Cabinet Office, 2007). Both of these policy initiatives would have been in force while 15 of my participants were under 18. However there was no indication from any of their interviews that they had had a perceptible influence of their relationship with mental health services. This echoes Glasby and Tew's (2015) recent findings that the achievements of these policies were modest, held back by the significant organisational barriers in terms of the different approaches of the respective agencies, lack of communication and differing priorities. While further steps have been taken with Part 5 of the Children and Families Act 2014 (Legislation.gov.uk, 2014a), whereby each young person would be entitled to a Carers Assessment as a matter of course. Yet this is still dependant on the point of need being identified by the frontline professionals and the resources being available to them to respond in a proactive manner, again mirroring the assertion that for any improvement to be made there must be a strong commitment from both the bottom and the top of the agencies involved (Glasby and Tew, 2015).

What could have helped?

Given that it was clear from the collective narratives that experiences of mental health services had been largely difficult, and with the insider stance of hoping that this study could in some way add to the understanding of how practice could be improved, I asked a single question at the end of each interview when the participant had drawn their narrative to a close. This question was simply 'what could have helped?' and the response was overwhelming in its level of consensus. My initial thought when preparing to embark on this study was that I could assist children growing up with a parent with severe and enduring mental ill health by creating age appropriate

accessible information written for children explaining specific mental disorders. However out of the 20 people I spoke to, only two of the participants felt that learning about mental disorder would have helped them. Furthermore, as Lucy explained she did not want this to enable her to become an expert in mental disorders, but rather to enable her to make better sense of her experiences with her mum and her own role and identity within it:

I would have liked a manual, I would have liked some sort of information about mental health and what depression was and most importantly I would have liked something, a manual that told me that it wasn't my fault, that's what I would have liked, or just someone to do that. – Lucy

Others were even more adamant that they did not want to be taught about mental disorder and by implication how to become a better carer, but rather for someone to ask them how they experienced their parent's specific difficulties and help them make sense of it from that point of reference: *"I didn't want to learn about Schizophrenia I just wanted to understand my dad"* (Natalie).

With both approaches it was clear that individuals desired a relationship with an independent, interested adult within which they could speak freely, be that with a social worker, mental health nurse or teacher. They wanted a safe space in which they could talk about how they experience their parent's illness. It was important to them that there should be a recognition of all they do and acknowledgement of their expertise within the situation. They felt it would have been beneficial to be able to reflect on their parent's illness, their role, responsibility and accountability:

I think I could have done with somebody just somebody I could have just opened up to and gone 'ahhh d'you know what it was tough today' and to know that it wasn't going to be horrendous, the world wasn't going to end through me saying what I felt erm and just somebody to give me a cuddle and a genuine cuddle not you know anything sexual just purely 'you're okay, YOU are okay, you're okay,

well done for getting through today I know it must have been tough.

– Jess

The key message about what participants felt would have been helpful from services did not point towards dramatic interventions or complex (or expensive) resources. Instead it was about a transformation of the relationship between services and children who grow up with a parent with a mental illness. As illustrated in Figure 11, these can be broken down in to ways in which professionals interact with children growing up with a parent with mental ill health and the manner in which the children experience their relationship with services. They wanted to become visible and to be noticed by the professionals providing care and support to their parent. They wanted the care and the support they provided to be acknowledged both in terms of the impact that it had upon their lives and also the expertise that they held as a result. They wanted their families and themselves to be treated with respect and hoped for a reduction of stigma which would enable them to speak more openly about their specific circumstances and reach out for support when required. They wanted their needs for information to be considered and for it to be individualised to their own understanding not based on external models of age-appropriateness. Finally, they called to be not just involved in the provision of care but truly included in their process with their voices and needs written in to decisions made.



Figure 11 – Desired factors in professional interaction with children

Summary

It is clear within this chapter that children growing up with a parent with mental ill health face many of the same challenges that adult carers encounter. Specifically in terms of the disconnect between themselves and services, and being intrinsically involved in the provision of care yet at the same time not included in the decisions made either about the level of care needs or the role of mental health services in meeting those needs. However, with children and young people the likelihood of this disconnect and its impact upon themselves is increased exponentially. They are a largely hidden population and all too often overlooked by services. When they do come in to contact with services there are significant barriers to communication on both sides. While they provide a substantial amount of care for their parents this is difficult to quantify as are the needs they have themselves as children which are, generally at times, neglected.

Nevertheless when asked to reflect on what would have made things better for them as children, the overwhelming sense was not a radical intervention in their family life, it was not a complete removal of their care tasks, although for many it was clear that

respite would have been greatly appreciated. The predominate points that participants came up with was to feel included, to be noticed, acknowledged, respected and considered. This inclusion not only would have made their care tasks more manageable both on a physical and psychological level but would have also ameliorated many of the other issues that have been discussed in previous chapters such as attending school each day without constant worry.

Part IV

Discussion and recommendations

Chapter Thirteen

Discussion and implications for policy and practice

Introduction

The purpose of this discussion chapter is to draw together the themes and insights that have emerged through the findings of this study and consider them further in the light of the existing body of knowledge as explored within the review of the literature.

As previously discussed within the methodology, I feel that it is important to reiterate that this study is not designed to produce generalizable outcomes, however the insights drawn from the findings of this study can be of significant benefit due to the understanding that can be drawn from the narratives. Indeed the majority of the self-selecting group of participants involved within this study, came with an extraordinary story to tell. Many of these narratives conveyed memories of loss, trauma and neglect and spoke of an ongoing longing for a relationship with their parent that they felt they were never able to fully grasp. These narratives were so emotive, raw and powerful that it was with a sense of trepidation that I approached them. My concern was predominately in how I could present them in a sensitive and faithful manner, but also a large part of my concern was with the potential that my findings could be used against parents who experience severe and enduring mental ill health.

The stigma surrounding mental ill health is irrefutable, and the manner in which this has coloured the profession's perception of the abilities of parents with mental ill health in terms of media representation, societal assumptions and the parents own self-evaluation is widely evidenced as being negative and disabling. By presenting narratives of the difficulties participants experienced because of their parent's mental ill health, this study could be perceived as further evidencing and compounding the

existing stigma that families with parental mental ill health face. This, of course, could not be further from the aims and intentions of the study. The intention and motivation of the study is exploratory, seeking to shed light and increase understanding of experiences of children growing up with a parent with mental ill health, rather than to attribute causal factors, responsibility or blame. The narratives offered here are not presented as representative of all children growing up with a parent with mental ill health, indeed there is no way of knowing if they are a common experience or the exception to the rule. What we do know, however, is that even if these narratives are illustrative of a small number of individuals growing up with a parent with mental ill health, they are real and vital and deserve to be heard in their own right. To minimise these stories or to look away from them in search of more positive and affirming experiences, would be to further silence the voices that have been marginalised and denied time and time again. Moreover when we step back to consider the root of the difficulties participants faced and the factors that compounded them, it was rarely the symptoms of the parent's mental ill health in isolation, but rather a combination of fear, stigma and lack of understanding or resources. Thus any criticisms or recommendations drawn from this discussion chapter or study as a whole are not levied against the parents of the participants, or generally against parents with mental ill health. It would be unfeasible and unfair to do so, given that this study has not included a consideration of their own experiences and perceptions. Instead it is an acknowledgment of the impact experienced by the children and a consideration of how children in similar circumstances (and their families) can be better supported by social work and mental health workers as a profession and society as a whole.

As seen within the review of the literature, the field of enquiry surrounding parental mental ill health is relatively small with the specific perspectives of the children themselves only beginning to emerge in recent years. While I have been particularly inspired by the work of Elaine Mordoch, Jo Aldridge, Brenda Gladstone and Andrea Reupert in the field, I believe this study offers an original contribution to the knowledge of this subject. This is demonstrated through the strength of the narratives given, the illustration of the complex dynamic of vulnerability and resilience which can be associated with growing up with a parent with mental ill health and the manner in

which that vulnerability changes in its intensity and direction across the life course. It is this journey through the life course that will give structure to the discussion chapter as we move from early childhood, through to adolescence, early adulthood and into adult life. Whilst one would ordinarily expect these stages to be discussed separately, early childhood, mid childhood and adolescence are considered together. This reflects both the fluidity of participants' chronological narratives and that the roles and expectations they ascribed to themselves were often out of sync of what would have been a generally expected developmental stage. Finally implications and recommendations for policy and social work practice will be discussed.

Vulnerability and resilience

Within this study there are many different examples of vulnerability and resilience were evident within the participants' narratives, some of which are more easily identified and defined than others. In terms of vulnerability the examples that the participants described broadly fell into two camps. The first contained objective examples where harm had occurred while the second described a more subjective sense that the participant's potential had been restricted.

The first clearest type of vulnerability, was illustrated in examples where abuse had occurred. Five of the participants spoke of incidents of sexual and physical abuse. For the four participants who spoke of sexual abuse, this harm was not perpetrated by their mentally ill parent. However they felt that their parent had not been able to protect them against the abuse they suffered. Three of the participants explained that their parents had been aware of the abuse, but had been unwilling or unable to intervene. Vivienne believed that her abuser had specifically entered into a relationship with her mother because of her mother's own vulnerability and her potential to be manipulated, in order to gain access to her children. She also believed, along with Karen and Jess, that the knowledge of the abuse caused their parent significant distress and risked deterioration of their mental state. As such the participants described feeling that, as children, they had to protect their parents from the abuse that they themselves were suffering. It was this protectiveness towards the parents which lead Monica to make great efforts to hide the physical injuries she had sustained when she was raped at age nine. In addition she felt that she had caused her

mother's mental ill health and therefore had no right to add to the family's difficulties by asking for help.

Two of the participants did however, describe being abused by their mentally ill parent, receiving physical beatings when their parent was distressed and or intoxicated and being forced to collude in their parents fabricated or induced illness, taking medication they knew they did not need and using a wheelchair for months because their mother convinced them it would be physically dangerous for them to walk. While both of the participants were able to reflect that their mother's behaviour would constitute child abuse, they also both held the belief that it was connected with their mother's mental ill health and as such they could not hold her truly accountable. This also connects to an exacerbating facet of the participants' vulnerability as several individuals across the study, expressed that they had lower expectations of their own needs being met or safeguarded than they would have had for their peers. As Monica described, if she imagined another child going through what she had she would be appalled and outraged, but for her she felt it was acceptable and that it had been her responsibility to develop coping strategies rather than to expect her parents to protect her. This diminished sense of expectation and/or entitlement is indicative of low self-esteem and fits with a cognitive model of acquiescence which may have made the participants themselves more vulnerable to abuse and exploitation. For Jess and Monica this was evidenced by the fact that they both described three-four separate experiences of abuse by different perpetrators.

Moving away from the clearly identified incidents of abuse, six different participants spoke of feeling that they had been put at risk of harm as a direct result of their parent's mental illness. Four participants recall being left alone at home from a young age for lengthy periods of time. Three, spoke of not being able to sleep due to their parent's reversed sleep patterns and disturbed behaviour at night; for Terry this included being required to sleep on the floor in his mother's bedroom for five years from the age of 10. Three participants also described becoming physically involved in their parent's psychosis and delusions and suicidal behaviour, either spending nights sleeping on a balcony for Natalie, or fearing for their safety whilst driving with a parent who threatened to crash the car for Lucy and Caroline.

For many of the participants a sense of physical and emotional harm was drawn from their relationship and caring responsibilities towards their parents. As Juckovic (1997) argued in the extreme form of parentification, which is characterised by the excessive nature of the care, the primacy of the identity as carer and the associated guilt, self-blame and isolation which sets a child aside from their peers should in fact be defined as an abuse in itself. This is further compounded when the parent's individual difficulties mean they are not able to attune to the child's needs, or able to engage with the core elements of care, control and development within their parental role (Jones, 2001).

Over half the participants (12) while not reflecting on tangible experiences of abuse or harm did feel that their opportunities and subsequently their potential had been considerably restricted as a result of their parent's mental illness. This was commonly illustrated through their education and three of the participants remembered their grades falling and subsequently moving to lower academic sets at school after their parent became mentally ill. Two stated they had not been able to complete their A Levels because of their parent's periods of crisis, three attended university but had to leave their course to return home to continue to provide care for their parent and siblings. Finally, two of the participants were offered opportunities to attend prestigious academic institutions with scholarship funding, but did not feel able to take these up for fear it would leave their parents distressed and unsupported. Several participants also spoke of actively avoiding job opportunities, relationships and personal goals to circumnavigate any negative impact these may have had upon their parent. Many of the participants explained that this restriction has continued into their adult life, describing their lives as being on hold, or having to keep part of themselves back to ensure they would have the capacity needed to respond to their parent's ongoing mental health needs.

It is important to acknowledge that despite the adversity that some of the participants faced throughout their childhood and early adult life, none of them suggested that it would have been preferable for them to have been cared for outside of the family home and on the surface they all appeared to be well functioning successful adults. As illustrated in Figure 4 the majority were in paid employment with secure housing and

half identified themselves as being in a long term relationship. However across the interviews there was a consistent theme of vulnerability and at times precariousness, with their lives, as adults continuing to be impacted and/or restricted by their parent's mental illness.

However, running alongside this thread of vulnerability there was also a reoccurring motif of resilience, which as discussed in chapter three, is an interactive concept which refers to the relative resistance to risk and a process of overcoming stress and adversity. Conceptually resilience is very different to social competence and positive mental health (Rutter, 2006). An individual may be seen as highly competent or not showing signs of stress or distress and yet still be vulnerable, whereas the person seeking help could have a higher level of resilience. Equally, resilience is not a single quality, an individual could be resilient in the face of one demand but not another. Their level of resilience can also ebb and flow through the different stages of their lives in response to circumstances and context (Rutter, 1987). This fluidity between vulnerability and resilience could be seen across all of the participants within the study, and at the point that they gave their narrative they could be roughly plotted on a spectrum (Figure 12) between being vulnerable, or enmeshed and still largely defined by their parents mental illness, or resilient and self-determining, feeling they had the power and freedom to control their own lives.

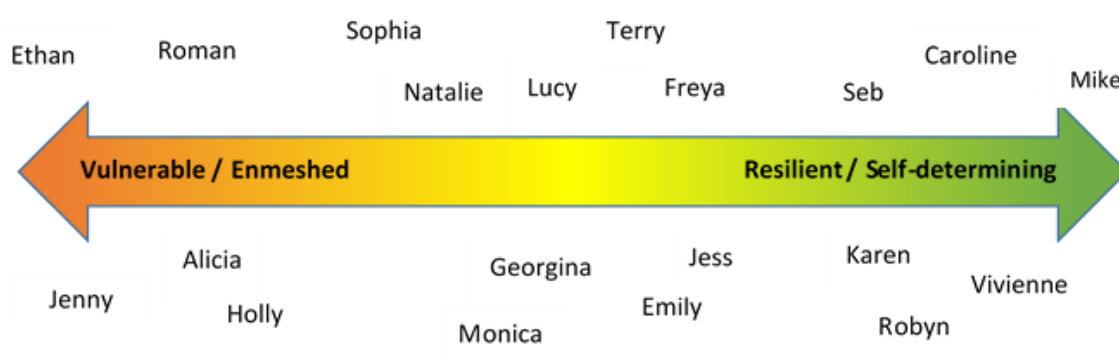


Figure 12: Spectrum between vulnerability and resilience

It is clear reflecting on the narratives of this study, that it was not the experience or severity of the parent's mental ill health which determined where on the spectrum the participants were placed. Rather, it was the sense of physical and psychological self-

determination that the participants attributed to themselves, combined with their ability to adapt flexibility to the stresses in their lives. Rutter (2006) states, key elements in resilience and successful coping are psychological adaptability, a sense of self-efficacy and the cognitive redefinition of an adverse experience. Some participants such as Lucy, Georgina and Monica saw creating a physical distance between themselves and their parents as psychologically protective, yet were still very emotionally tied to and impacted on by their parent's illness and their childhood experiences. Others also maintained a distance yet appeared to feel stuck, such as Terry who expressed the feeling that his life was still 'on hold', and who was fearful of doing anything that might disturb the equilibrium between himself and his mother. In contrast Jess, who had experienced an extraordinary amount of trauma, was with the help of a therapist, able to psychologically separate herself from her mother's mental illness. Similarly Vivienne and Caroline were able to continue to provide care and support to their mothers at times but saw themselves as separate, with their own needs valued in their own right. They demonstrated a level of fluidity, which enabled them to move along the spectrum, at times becoming more involved and providing care to their parents and then being able to move back, to step away and re-focus on their own needs.

Of most concern to me within the study were the young adult carers, Ethan, Holly, Alicia, Jenny and Roman, still living with and caring for their mentally ill parent. So it was unsurprising that they were enmeshed. However, there was also a sense of vulnerability as they all, for a variety of reasons, could see no end to their current caring commitment. For Ethan and Roman there were complicating factors; Ethan's identity was defined by being a carer, Roman's attachment to the family home meant that he saw caring for his mother as a way to avoid change. However Jenny, Holly and Alicia, all wanted to move away and build independent lives for themselves, but felt unable to do so because of how much their mothers depended on them and because of their perceived lack of alternative options. Each had older siblings who had moved away and were minimally involved in their parents care needs. Jenny felt responsible for her mother's illness and subsequently indebted to her, whereas Holly and Alicia felt constricted by more practical factors. Their mothers simply refused to consider

accepting care from other sources and as such had disengaged with mental health services, however both Holly and Alicia believed their mothers would be unsafe if left alone, and so felt they had 'no option to walk away' (Holly).

Early childhood, mid childhood and adolescence

Many of the participants described not being consciously aware of their parent's mental ill health within the early years of their childhood. It was what they had always been used to and they had few comparative opportunities until they began to interact with peers independently. Many described their childhood as being somewhat unrealistically idyllic and happy, recalling their parents in happier times. Examples include Emily, who described her mum as being her idealised version of motherhood 'creative', 'warm' and wearing 'flowery dresses' or Sophia who felt that as a young child she was able to 'enter mum's world' happily spending hours 'watching raindrops together'. However even with these happy memories, a theme repeated across several narratives was of the child from a young age entering the parent's world, focusing on the parent's happiness and strengthening their bond by adapting to the parent's needs. This adaptation and awareness of the parent's needs was represented much more prominently than participants' recollections of their parents entering their world or doing special things for them. This may of course be an unconscious influence of the research project itself, which may have led the participants to think of their contribution to and understanding of their relationship with their parents and their parent's mental illness, as opposed to recalling other significant events in their childhood such as birthdays or holidays. However in several narratives participants appeared to have a strong image of the person their parent was during those early years and even in four narratives, what kind of person their parent was long before they were born. Yet, they struggled to recall themselves as children, stating that they had gaps in their memory throughout their childhood, especially the early years up to age eight.

Regardless of whether this emotional sensitivity towards the parent was an illustration of the child's early emotional and developmental needs being overshadowed, or indicative of a close and sensitive bond, it could be argued that this early ability of the child to consciously or unconsciously read the parents emotional temperature and

respond to their needs, was to a large part, developed in response to the parent's mental illness. Indeed it is this early development of caregiving skills that opens up the possibility for other adults, such as the 'well parent' or grandparents to step back and allow the care, support and security to be provided to the mentally ill parent by the child. As Aldridge and Becker (2003) propose, this closeness can be a positive part of the a young carer's relationship with their parent. However as Byng-Hall (2002) described within his consideration of parentification, any positive effect can be cancelled out if the level of expectation is disproportionate to the child's developmental abilities, overwhelming the child's own needs and offering no reciprocity. What can on the surface be seen as adaptive, skilled and resilient behaviour in a child, may be more complex, with the child feeling a sense of abdication and abandonment from the other adults around them (Ostman, 2008; Petrowski and Stein, 2016). As Natalie described, the fact that her father would talk to or trust nobody but her, brought her pleasure, pride and security in the close and intimate nature of their bond. Yet at the same time she would on occasions feel overwhelmed and alone as she described not having any 'functioning adults' in her life who recognised her as a child and looked after her accordingly.

A lack of contact, acknowledgement and support from other adults could also leave the child vulnerable to developing maladaptive schemas of blame, guilt and low self-worth as they struggle to make sense of their parent's mental illness, their family functioning and their role both within the family and the wider world, with limited understanding or information.

In mid childhood and adolescence there appeared to be, for many, a more conscious step in to a caring role. The participants described this stage of their life as being when they became increasingly aware of their parent's mental ill health and the stigma that could be associated with it, not only for their parents but for themselves as well. They described just wanting to appear 'normal' to their peers, to stay under the radar and that they feared bullying if their 'secret' were to be exposed. This level of secrecy overlaid with the physical requirements of the care they provided for their parents began to separate them from their peer group. Several participants described not being able to invite friends to their home and as a consequence not receiving

reciprocal invitations to friends' homes. For Jess both her extraordinary experiences and the level of secrecy she had to maintain meant that she felt that she was set aside from her peers. Unable to connect or share a common understanding of the world around them, she was not able to build close friendships with others.

This awareness of difference and fear of stigma, coincides with an increased awareness of their parent's mental ill health, a recognition that combined an acknowledgement of the emotional needs and potential behaviour associated with their parent's mental illness, and for many an emerging mindfulness of the potential risks. This was especially poignant for the participants whose parents displayed self-harming and/or suicidal behaviour or ideation. With an increased awareness and subsequent concern for the parents, for some participants their caring responsibilities began to impede on other areas of their life, such as education. Participants described missing school or not being able to concentrate at school due to both tiredness and anxiety for their parent at home alone.

However, interestingly, despite five participants describing a definite drop in academic grades and/or failing subjects, none recalled school identifying potential problems at home. While I initially assumed, as I developed the concept of this study, that teachers would be best placed to notice the needs of children growing up with a parent with mental ill health, it quickly became apparent through the interview process that this was not at all the case. It appeared that by the time the children were in school (beyond primary school) they had become skilled at hiding their parent's mental illness, not drawing attention to themselves and indeed presenting themselves as resilient and competent. Participants described taking active steps to ensure their difficulties were not identified at school, they did not want to be seen as different from their peers, and they feared what would happen if professionals got involved. For many participants they also saw school as a refuge, a haven within which they did not have to talk about their parents or their home life. Therefore even for Jess, Monica, and Vivienne who were simultaneously caring for parents who were acutely distressed whilst also suffering sexual abuse themselves, they described themselves at school as quiet, conscientious and competent, the 'perfect student'.

This lack of indicative behaviour or symptoms of distress, speaks to the ability children can develop to mask their emotions (Aldridge, 2002; Cooklin, 2009; Gladstone *et al.*, 2011). For several participants it also spoke of the disconnect they expressed in terms of not understanding their own emotions. While many of the participants spoke at length about their parent's emotional state, the language they used to describe their own emotions as a child was much less expressive or definite. Seb recalled that he was not able to discuss how his father's mental ill health made him feel because he 'didn't have the language'. Jess also described not thinking about how she felt as a child because it would have been overwhelming for her, and that she had a strong sense that her feelings were trivial next to her mothers. She described herself as invisible as a child, and it felt that it was due to her invisibility to other people and to herself that she was not able to reflect on how she felt about her experiences, or meet her own needs. This lack of awareness also manifested itself physically, she described cooking meals for her mother each night, but that when her mother was in hospital Jess struggled to structure her time or look after herself because she could not identify what she wanted or needed. Her skills of caring for her mother were highly developed and sophisticated, to the point that anyone looking in would commend her on her level of maturity and competence. However by never feeling that she had been cared for by others, Jess had no understanding of self-care. As skilled as she had become at placing her mother's needs and wants before her own, she was not able to connect with what she wanted herself when she had opportunity to do so.

This lack of connection with their own needs is reflective of McCormack, White and Cuenca's (2017) portrayal of the caretaker child who minimises their own needs and expectations in favour of their mentally ill parent in order to protect themselves and their families. This has the potential to lead to a hypervigilance and a compulsion to meet the emotional needs of others. There is also a sense of vulnerability which manifests in participants describing how they feel that they have to care for others in order to remain in control, safe and valued in a relationship. Terry, Natalie, Jess and Monica all reflected on their tendency within adult relationships to take the caring and submissive role. They feared that if they were not actively looking after a partner or friend, or if they allowed their own needs to become too demanding they would be

rejected and abandoned. Sophia described this cycle of rejection within her relationship with her mother and brother, describing herself as the 'fixer'. She would be called in during periods of crisis and then dismissed and ignored when the situation had resolved and she was no longer useful.

For many of the participants the fear, secrecy and isolation they experienced in their early childhood also carries through the life course making it difficult for them to trust others enough to expose their inner thoughts and feelings. Again this links back to the false appearance of resilience and the model of acquiescence. Winnicott (1964) referred to the physical embodiment of this, as the 'walking wounded' where individuals who are outwardly successful have a sense of emptiness on the inside. This reminded me once more of the apparent success of my participants. It would be all too easy to conclude that there was little impact from their childhood experiences of parental mental illness, given that they were all succeeding in key areas of their lives. But as soon as their narratives were given voice it became apparent that there had indeed been significant impact that for many was ongoing, as was their framework of acquiescence and their finely crafted ability to 'put on a brave face'. From the study findings this can be taken a step further, in consideration of the emergence of the wounded healer (Valdez, Chavez and Woulfe, 2013) where the need to care for others extended beyond their parents, forming the basis of their adult identities.

Early adulthood

For many of the participants this compulsion to care for others as described within the concept of the caretaker child continued in to their early adult life. This appeared to some degree to lead individuals into caring professions. As discussed within the methodology this tendency could be attributed to a certain extent to recruitment bias since many of the participants were drawn from the health and social care field. However several participants reflected that their childhood experiences of parental mental ill health had drawn them into working in the care field. In three cases participants felt that they trained in mental health nursing, not only to use the skills they had developed throughout their childhood to help others, but also to make sense of their experiences and equip them with additional protection against the harm they feel their parent's mental ill health had caused them. The six individuals who worked

within the wider mental health field, described using their work identity in order to reflect on and reconceptualise their childhood experiences and their parents' mental illness. As such they had developed a sense of separation between themselves and their parent and used the professional skills they had developed at work to set and maintain these boundaries.

Working in a caring capacity also enabled some participants to displace or manage the feelings of guilt or loss about their own parents. Karen described her training as enabling her to work through her emotions. Lucy described finding pleasure in the positive effect she can have with patients as a mental health nurse which she never felt she was able to achieve with her own mother, and Freya describes working for a counselling service as atonement for the guilt she feels for not being able to continue to emotionally support her own mother.

While the use of these skills can be a positive feature of a redemptive narrative, as with Jess who described herself as being equipped with a 'Swiss Army Knife' of abilities, it can also be indicative of a foreclosed identity (Erikson, 1959; Marcia, 2002) within which the participant was not able to engage with the exploration expected within adolescence. This was particularly relevant for the four young adult carers who took part in the study. All four spoke of how they had found being identified as a young adult carer positive and supportive. They particularly valued having the opportunity to meet other carers, and felt that they were more able to demand acknowledgement and respect from their parent's mental health care team. Interestingly though, all four participants saw being a young adult carer as their primary identity and function. For Ethan his identity as carer was held with great pride, he felt it gave his life value and purpose, and had actively rejected friendships and an opportunity to complete an apprenticeship because he felt it would dilute his potential to be the 'best carer he could be'.

Jenny, Holly and Alicia, however, they felt that being identified as a young adult carer both supported and restricted them. They all lived alone with their parents and had specifically chosen employment that would offer the flexibility to fit around their caring responsibilities. They felt that the care they provided was valued and they spoke about their mothers with warmth, love and compassion. They did not question

whether they should be providing care for their mothers, but equally none of the three could foresee their care role coming to an end and spoke with some regret that they would not be able to pursue their own hopes and dreams as a result. They also felt that their parent's care team relied on them as the carer. Holly and Alicia struggled to continue to care for their mothers while they were at university because they were away from home three-four days a week. During this time the local mental health service attempted to put in place packages of care to meet their mother's social care needs. However for both girls as soon as they completed their degrees these care arrangements were cancelled as their mothers and the care team agreed the assessed needs could be met once more by Holly and Alicia. Thus two years since completing their degrees neither Holly nor Alicia had completed the subsequent teaching training that they had originally hoped to do, and both ruefully recalled their time at university as a 'selfish waste of time', fraught with difficulty with no real purpose or reward.

Adult life

As the ages of the participants in the study ranged from 19-54 with the mean age being 31, it would be difficult to say with confidence what issues may arise as individuals approach middle age and beyond. However several of the participants projected themselves into the future within their narratives. For some, their parent's mental ill health had 'settled' and while they continued to experience chronic and enduring difficulties there were fewer periods of acute relapse and risk. However, for others the high intensity of their parent's needs and subsequent risks persisted. These participants generally saw little hope in recovery, indeed Sophia, Seb and Georgina predicted that their parents would 'get worse with age'. They envisaged themselves as always having to provide care, and described feeling that they did not have a parent in the traditional sense of someone they could look to for care, support and guidance. Indeed it could be said for Sophia that in her 20s the role of the parentified child becomes solidified as she describes her mother as "like having a grown up child you never gave birth to".

The majority of the participants also continued to feel an emotional discord or disconnection with their parent. This was exacerbated by their still being locked within an aspect of acquiescence where they did not feel they could truly address or resolve

their painful memories of childhood. Unable to fully blame the illness or hold the parent responsible, participants described not being able to reflect on their childhood with their parents. This prevented them from reaching for a deeper shared understanding of their memories. Furthermore they had to continue to subjugate their needs and mask their emotions as they feared that any expression of sadness, frustration or regret might appear selfish or accusatory.

A further theme that I had not anticipated as I prepared for the study, nor have I found reference to in the review of literature, is the level of anxiety that was present for participants in their adult life as they consider the possibility of becoming parents themselves. As discussed in chapter eleven, several of the participants felt that having a parent with mental ill health significantly influenced their decision whether or not to have children of their own. While a few of the participants spoke of the genetic inheritability of certain mental disorders, this was not the primary concern expressed. Instead it was about their fear that they had not had a parental role model which could equip them to be a parent themselves. Some worried that because of their lack of understanding of what a 'healthy' parent/child relationship looked like, they might inadvertently harm their children in the way they had been harmed themselves. Jess described having a lot of work to do before she could begin to consider becoming a mother, because she felt she did not know what a healthy environment and relationship was for a child to grow up in and as such did not feel able to create one for a child of her own. Many were concerned with how they could balance their parental responsibilities with their caring responsibilities and to that end, Seb, Georgina, Vivienne and Freya saw becoming a parent as a trigger for distancing themselves from their own parents and putting in place clear boundaries which demonstrated that they intended to prioritise their children over their parents. Seb, Georgina and Vivienne also felt that they had to maintain boundaries in order to safeguard their children against what Seb defined as the 'ripple effect' of their grandparent's mental illness. For Robyn this fear of intergenerational harm was so great she became estranged from her father when she fell pregnant with her first child. Each of the participants with children recalled having extraordinary discussions with their partner about how they would manage both their anxiety around parenting and the relationship their child would

have with their grandparent. Seb and his wife had negotiated a contact agreement stating that his father was not allowed to be with their son unless one of them was present. Emily had offered to sign a pre-nup with her fiancée agreeing to give him full custody of their children should she 'turn out like mum' and Lucy described the considerable strain that had been placed on her marriage by her desire to have children and simultaneous terror of becoming a mother.

Summary

A key insight drawn from this study is that regardless of the age of the participant they remain the child of their parent with mental ill health and as such continue to have the same complex emotional connection. The needs of the child shift and change both in response to the progression of their parents mental ill health and their own emotional and social development. However, in some cases these needs remain hidden behind a skilfully crafted veneer of resilience which is built upon a model of acquiescence. This encompasses the belief that their needs are secondary to others, that they do not matter and cannot make demands of others, that asking for help is risky and finally that they are responsible for holding things together. Findings from the study showed that the ability to step out of the role of child of a parent with mental ill health and reflect upon themselves as autonomous and independent is key for an individual's personal well-being and fulfilment, reflected in an overarching theme within which participants spoke of attempting to create and maintain a distance between their parents and themselves, both physically and psychologically. To do this the participants were not asking for a reimagining of their childhoods or an eradication of their parent's mental illness. Their experiences had made them the people that they were and, on the whole, they loved and valued their families in their entirety. The findings and analysis suggest they required their vulnerability to be recognised, for their needs to be acknowledged and their model of acquiescence to be challenged. It is with this in mind that I conclude this thesis with a consideration of policy and practice recommendations that could offer this support.

Implications for policy and practice

As discussed in the introduction to the study, the needs of children growing up with a parent with mental ill health are reflected in a wide range of policies from differing social policy areas such as mental health, carers and children in need (Aldridge and Becker, 2003). However the plethora of policy guidance produced largely under the previous Conservative and Liberal Democrat coalition government can be difficult to interpret and unclear as to whether it is still resourced and implemented within service provision.

From the findings of this study it is demonstrated that a further obstacle in meeting the needs of these children and their families is the fear of intrusive service intervention and stigmatisation. Participants referred to actively attempting to 'stay under the radar' of teachers and social workers, presenting as competent and resilient to avoid being identified. The needs of the participants in this study also changed significantly across their life course reflecting changes in both their parents' mental illnesses, their own social and cognitive development and their social circumstances. Intervention needs to be flexible and responsive to their individual needs. An illustration of the way in which needs change and support would be required to adapt is given in Figure 12.

The findings also demonstrate that many children growing up with a parent with mental ill health do not present with symptoms of mental distress themselves and as such may not be picked up by targeted mental health programmes within the school system. All of the participants however provided a substantial amount of care for their mentally ill parent.

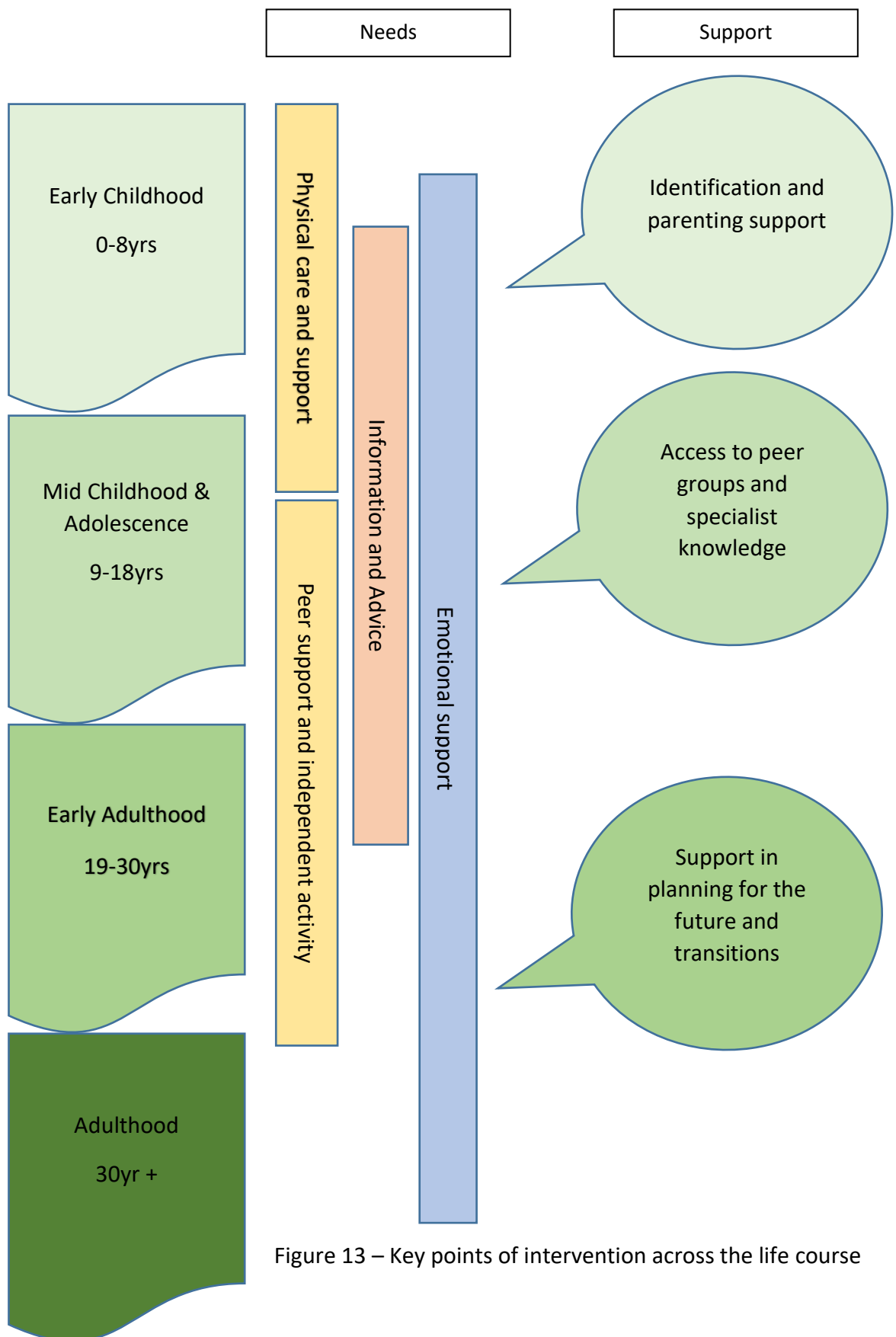


Figure 13 – Key points of intervention across the life course

Early childhood

As illustrated in Figure 13, in the early years of children's lives their overriding need is that of physical care and the emotional warmth provided by their parent. Therefore, the key priority of services would be to recognise the child's potential vulnerability and to provide instrumental support to the parent and wider family. This could be provided by the inter-agency collaboration of health visitors, children social workers and adult mental health workers, with disabled parent protocols being used to support the parents fulfil their role.

Mid childhood and adolescence

As the child gets older they begin to become more aware of their parent's mental ill health and associated care needs. It is at this point that they may develop a framework of acquiescence, take on greater caring responsibilities and feel separated from their social world and peers. Exemplified by the yellow, orange and blue banners, their needs are layered at this age. They continue to require physical care and support from the adults around them, whilst also needing to build relationships with their peers and engage in independent activities outside of the family home. In order to make sense of their parent's mental ill health they require information and advice regarding the care they provide. They also require emotional support to enable them to explore their feelings about their parent's mental ill health in a manner and environment that feels safe and non-judgemental. This will also reduce the fear and stigma they may perceive as a result of their parent's ill health.

Intervention can be put in place through mental health teams and or/schools as the child's needs as a carer are recognised and communicated. This would involve professionals always asking about children in the household, being flexible with visiting times to ensure that children have an opportunity to speak to a professional and not assuming that children are not performing care tasks because there is another adult in the house. Carers' assessments should be undertaken even if the child does not consider themselves to be a carer.

Peer support and training for young people about mental health and their own mental well-being is required. For many this may be membership of a young carers group

where they can relax, have fun and realise they are not alone. But as illustrated within this study, not all children might want to go to a young carers group. Hence the support offered to a child should be personalised to them. It could be putting care for the parent in place to free the child up to play a team sport and providing age appropriate resources and access to a mental health professional to answer questions that would be most useful. It is also important that the child's needs are considered and their voice heard within the planning and delivery of mental health care for their parents.

Early adulthood

Peer support and independent activity is still key for this age group as is information, advice and emotional support. Opportunities need to be factored in which give the young person space within which to explore their own identity, dreams and aspirations. It is at this point that the transition assessment embedded within the Care Act 2014 would be required, not only in considering future needs as a carer but whether the young person wishes to continue to provide care. Putting in place plans and services for the parent enables the young carer to step away and follow their own goals. This consideration of future aspiration, goals and next steps could also be incorporated into young adult carers groups.

Adulthood

For some individuals, such as those who participated within this study, emotional support is still required to reflect on some of the experiences they have had throughout their childhood and how it has affected them as adults. For some this could be particularly key at significant life stages such as becoming a parent, divorce, providing physical care for aging parents or bereavement. While these adults would have access to carers support groups it was interesting that none of the participants within the study were linked in with such a group. However, several of the participants had felt that it would have been helpful to them as adults to be able to discuss their concerns with others at specific points in their lives. While not indicated in the model of proposed intervention as it would be a service the adults would seek out themselves

as opposed to being provided by professionals, such support could be offered online, through telephone helplines, GPs or primary mental health services.

Current initiatives and provision in the UK

As discussed in the introduction, the Care Act 2014 reforms the manner in which care and support needs are met for adults, it also includes requirements for Young Carers with the intention that these will link across to the provisions within the Children and Families Act 2014. Additionally the Care Act 2014 recognises the interconnectedness and interdependence between family members (Falkov, 2015) requiring local authorities to adopt a whole family approach, coordinating support around the person and their family while considering the impact of the care needs of the adult on the wider family system, including the children (Department of Health, 2015)

Whole family working is not a new concept within social work and social welfare, however in practice it is often elusive, as it attempts to bridge gaps between separate services, each with distinct boundaries, priorities and financial pressures. This is despite the 'No Wrong Doors' principle agreed between the Directors of Children's and Adult Social Services (Directors of Children's and Adult Social Services, 2015) as set out in the key principles of Think Family (Cabinet Office, 2007) Further promoted in Think Child, Think Parent, Think Family pilots which sought to integrate family support where both children's and mental health services were involved (Social Care Institute for Excellence, 2011; Tew *et al.*, 2015). Despite the widening recognition that family approaches are key to supporting both vulnerable parents and their children they often hindered when faced with the different ideological perspectives of children's and adult services, this is further exacerbated by fiercely guarded service boundaries, a 'production line model of intervention' disparate computer systems and risk averse organisational approaches to accountability (Tew *et al.*, 2015). As such the barriers and challenges faced by organisations distract from the most effective and humanistic way to meet the needs of children, parents and families.

Indeed the Children's Commissioner's recent review of support provided to young carers (following the Care Act 2014) found that despite the wide acknowledgement of need, there was still much to achieve in terms of how those needs were identified,

assessed and addressed. Indeed the report states that four out of five young carers are not receiving support and of the 5,958 children and young people assessed as not needing support in their own right, 94% also did not receive a young carers assessment. Furthermore the report found that not all local authorities are taking the necessary steps to identify the need of young carers in their area (Children's Commissioner, 2016). Illustrated by the consideration of needs across the life course in the study, it is also clear that the age of the child is also key in terms of the support they received. While the majority of young carers support is directed towards children aged 10-15 years old (55.9%). This reduces dramatically to 13.9% for 16-17 years and 8% for 18+ years (Children's Commissioner, 2016). I would argue that the needs of children growing up with a parent with a mental illness remains significant into their late teens and early adulthood. As such support must be accessible, flexible and available to be revisited at individual points across the life course.

While there is a small body of highly valuable resources currently available specifically for children growing up with a parental with mental ill health across the UK. Much more needs to be done to increase resources and accessibility for children and young people growing up with a parent with mental ill health. Examples of good practice can be seen in projects such as Kidstime, a charity in London, which runs workshops for children and their parents, providing an environment where children can learn more about their parent's mental ill health, its causes and treatment. Their aim is to enable children to manage their caring role in a way that builds resilience and reduces their risk of developing mental health problems of their own (*Kidstime Foundation, 2018*). Another example of positive working can be found within the Gloucestershire Young Carers group which provides direct support to young carers in partnership with other agencies. Services includes; group support, specialist targeted support and assessment and support planning (which includes child focused tools such as 'safe sorted and supported' crisis plan). This group also work with young carers to offer support and training to professionals and commissioners, raising the profile of young carers needs and allowing the children and young people themselves to have a voice (*Gloucestershire Young Carers, no date*).

The effectiveness of such targeted support was reviewed by NSPCC who ran a four year evaluative study of a programme called Family SMILES (Simplifying Mental Illness plus Life Enhancement Skills). Based on the Australian SMILES programme, the programme offered eight weekly group sessions to children, six individual sessions with their parents and a final joint session within which child and parent could reflect on the programme together. The aim of the programme was to; improve children's self-esteem and resilience, help parents understand the impact their mental ill health has upon their child and finally develop protective parenting skills (Margolis and Fernandes, 2017). Evaluating the programme the NSPCC found small but significantly important improvements in the emotional well-being of the children involved and statistically significant improvements in the parent's protective parenting (Margolis and Fernandes, 2017). However they also found that their programme aim to bridge the gap between child and adult mental health services was somewhat compromised. This was attributed to their decision to allow a small number of children in to the programme despite their parents not receiving secondary mental health services (Margolis and Fernandes, 2017) meaning that they could not fully evaluate the impact that their programme had in drawing children and adult services closer together. While this was clearly problematic for the research project, it is important to remain conscious of the fact that many children will be providing care for a parent with mental ill health who chooses not to receive statutory services themselves and their needs are still valid and significant.

Findings from my study endorse the claim that children growing up with (and caring for) a parent with mental ill health are often silenced and hidden, regardless of whether their family is receiving statutory health and social care or not. As such it is crucial that mechanisms are developed to identify all children and ensure that they have access to the support they are entitled to. There is currently no clear route to how this could happen, however it would seem practical that schools could be key to the identification, given that they are a universal provision for all children in the UK. Weal (2015) proposes that the use of a 'children's vulnerability audit tool' could be an opportunity to further the objectives of the Troubled Families programme (Department for Communities and Local Government, 2016b).

While education is a universal service for children and it could be argued that the majority of teachers within primary education settings know the children in their class very well (Weal, 2015). There could however, be limitations to this method of identification when considered in the light of this study. Firstly the majority of participants who discussed their time at school described it as a 'safe haven', a place to seek respite from their parents mental ill health. Therefore they were adept at hiding what was happening at home for them. They did not want school to be a place to talk about their parents needs and may have felt that it had lost its safety if assessments and potential referrals were made there. While this could be minimised by assessing all children in the school in a sensitive and confidential manner, this would be a time consuming process and one for which teachers did not feel sufficiently equipped. A second limitation may be around the age of the child when the assessment is made. As seen within the study children's awareness of or exposure to their parents mental ill health can happen at any point throughout their childhood, while a teacher may know the children well in a reception class (Weal, 2015) the same may not be true in secondary school. As such the assessment would need to be conducted at various points along the child's pathway through education, with potential more self-assessment/reporting required as the child matures.

It is also apparent from the findings of this particular study that children growing up with a parent with mental ill health, may experience traumatic events. Furthermore their lack of voice as children and potential psychological dissonance or acquiescence could mean that trauma remains unresolved, continuing to echo and impact on them throughout their life course. At times a barrier to addressing and overcoming this trauma is the love and protectiveness they feel towards their parents, who may not have been able to mitigate the manifestation of their own distress or recognise the impact of it. However as Rutter (1987, 1996, 2015) asserts individuals are able to mitigate the impact of early adversity and develop resilience throughout their life course. Indeed there is evidence that turning points in adulthood such a significant positive relationship or engagement with a therapeutic process could disrupt a previously maladaptive trajectory (Maughan and Collishaw, 2015; Rutter, 2015). As such support needs to be available for a child who has grown up with a parent with

mental ill health throughout their life course. Services that they are able to access at a time they feel able, which feel safe and non-judgemental whilst working with the individual in a strengths based, person centred manner.

Summary

In essence as described in the introduction of this study, there is a raft of policy which could be utilised to support children growing up with mental ill health. However each child's family dynamic is different, their relationship with their parent and the world around them is unique and the manner in which they experience and make sense of their parent's mental ill health is deeply personal. Professionals need to be able to recognise the needs of these children, young people and adults and offer support, driven by research and policy in a flexible and adaptive manner. Support should reflect and adjust to meet the needs of the individual at different stages of their life course, and their level of vulnerability or resilience at that point. Most crucially any support or provision must be co-constructed with the individual and be meaningful to them, as opposed to being bureaucratically applied or tokenistic.

The final word

It is important to me in the last words of this thesis to pay tribute to the narratives that were gifted so generously to me during this study. They were so powerful, moving and coherent I feel I can do nothing else but to give the final word to their narrators. The participants predominately came with unresolved and unheard stories to be told. This was not because they wanted sympathy or judgement to be levied against their parents, they didn't wish that their childhoods could have been radically different or for professionals to have stepped in and taken control. They brought to the interviews dignity, compassion, love and pride in their families. They also brought with them the hope that by sharing their stories they might somehow alter the experiences of future children growing up with a parent with mental ill health. Not by eradicating the illness, or replacing the parent but simply by making the child visible; for them to be noticed and valued, for their needs to be acknowledged, for someone to reassure them, 'I know this is difficult, you're doing well, it's not your fault'. They wanted the care they gave to their parent and the love they hold for their family to be respected, for their voice, opinion and concerns to be considered, and finally to be included, truly included not silenced and hidden.

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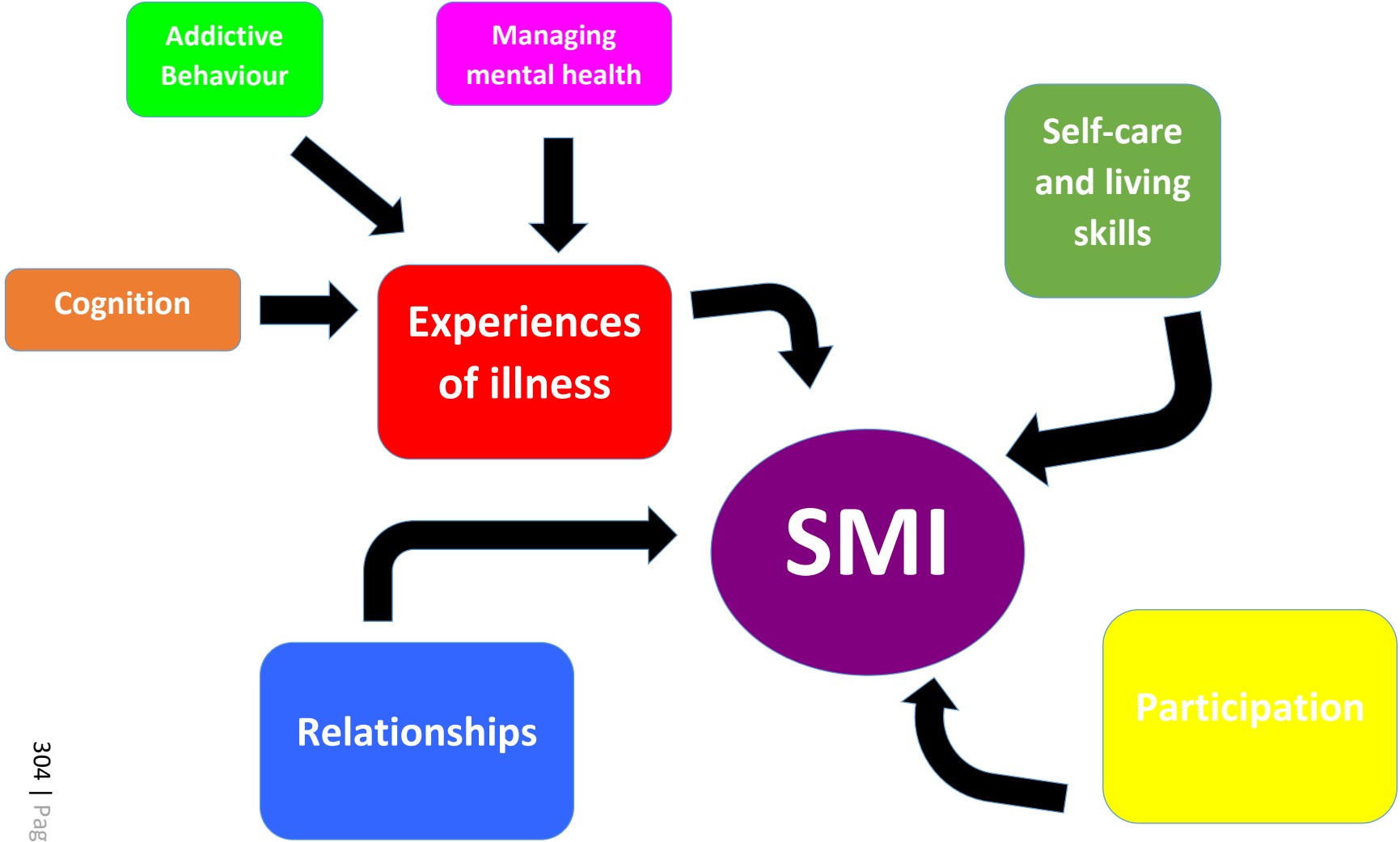
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Appendices

WHODAS 2.0	HoNOS	CPA	MH Recovery Star
Understanding and communicating	Behaviour	Risk	Managing mental health
Getting around	Self-injury	Relapse history	Self-care
Self-care	Problem – drink or drug taking	Self-neglect non/concordance	Social networks
Getting along with others	Cognitive problems	Vulnerability	Work
Life skills	Physical illness – disability	Distress/instability	Relationships
Participation	Hallucinations and delusions	Substance misuse	Addictive behaviours
	Depressed mood	Multiple service provision	Responsibility
	Relationships	MHA	Identity and self esteem
	Activities of daily living	Reliance on carer or caring responsibilities	Trust and hope
	Living conditions	Disadvantage	
	Occupations and activities		

	Cognition			Addictive Behaviour
	ADLS			Other disadvantages
	Relationships			Participation
	Managing MH			Other



Appendix 3 – Participant screening tool.

	1-never 2-sometimes 3-occasionally 4-mostly 5-always	N/A	1	2	3	4	5
Experiences of illness	Did you parent have a diagnosis?						
	Did you parent have a professional other than their GP to support them?						
	Did you parent ever have to go away because of their illness.						
	When did they first become ill						
	How long were they ill for						
Self-care and life skills	Was your parent able to go to work or look after the family home						
	Was your parent able to take you to school or attend school functions						
	Was your parent able to look after their own self care needs – eating washing etc						
	Did your parent manage the household finance's						
	Did your parent provide physical care for you and your siblings – cooking your food, cleaning your clothes, bathing you.						
	Did you parent look after you if you were unwell.						
Participation	Did you parent have work or interests outside of the family home						
	Was your parent able to attend your school events						
Relationships	Was you parent married or in a close stable relationship						
	Did you feel that your relationship with your parent to be loving and secure						
	Was your parent able to comfort you and support you in times of need.						
	Were you ever aware that other people viewed your parent differently						
	Were you ever aware that your parent was different to the parents of your friends.						

Behaviour	Did your parent ever have thought of harming themselves or ending their own life.						
	Could you predict how you parent would respond to things						
	Did your parent ever behaviour in a bizarre or excitable manner (outside of what would be consider normal)						
	Were their times when your parent would spend a long time in bed, or on their own (outside of what would be consider normal)						
	Were there times when your parent was very anxious or tearful						
	Did your parent ever misuse drugs (both prescribed and non-prescribed) and alcohol						
	Were there periods when you parent appeared to be well.						

Disadvantage	Did you parent have any physical illness or disabilities						
	Did your parent misuse drugs or alcohol						
	Did you have specific financial worries						
	Was your home warm, safe and stable.						

Ethical Approval Form for Research 2013 version

School of Social Work Research Ethics Committee

All staff and students (including research staff) must obtain approval from an appropriate Ethics Committee before undertaking research involving human participants; this includes piloting. This form is for staff and students applying for ethics approval from the School of Social Work Research Ethics Committee. Information on the Committee and links to ethical guidelines are available on the School Ethics web pages (<http://www.uea.ac.uk/socialwork/research/ethics>) In completing this form, it is expected that applicants will refer to the UEA ethics policy and the ethical guidelines suggested on the school ethics pages (eg ESRC, BPS, JUC-SWEC) and will follow best practice as suggested by these guidelines.

1. Principal Investigator(s)Kate Blake-Holmes.....

Proposed start dateMay 2015.....

Proposed funding source (if applicable)N/A.....

2. The Project

2.1 Title

Growing up with a parent with a mental ill : making sense of the experience through the reflection of adult offspring.

Please attach a **brief** outline of your proposal that summarises your aims, sample and methods. This should include details of how you will recruit your sample and what exactly participants will be asked to do. Data collection instruments (where available) should be appended. Where interviews, focus groups or other activities/experiments or interventions are planned an outline of the content of these should also be appended. Where the development of your research materials/strategy is not yet complete but you need ethics approval to proceed, the committee can discuss with you how these other plans can be reviewed and approved at a later date.

3. Informed Consent and Briefing

3.1 Informed Consent and Briefing

Please explain your strategy in relation to gaining informed consent from participants. Points to consider include:

- Are there any ethical issues in relation to recruiting your sample for example unequal relationships between the gatekeepers and potential participants?

With the focus of the study on a specific experience (mental illness) it is appropriate to use snowball sampling, which will seek to recruit participants through recommendations. Such recommendations tend to be made by the initial participants, and as such the access to participants snowballs from the original core members.

However this study deviates somewhat from the original premise of snowball sampling, in that there is no identified evidence to suggest that this group of people have an explicitly shared identity or physical cohesion, such as a club. Thus it is expected that many of the recommendations may be made by people who have not experienced the phenomena themselves. This proposition has been backed up during my time planning and when discussing my research where, I have encountered numerous people who have recalled experiences of relatives or friends who they feel would be interested in participating.

As such I propose to recruit participants through the utilization of my personal social network, and also to ask friends to share an information poster on a social networking site (Facebook & Twitter) to widen the recruitment pool (please see attached screen grab) While such sites have obvious sample limitations regarding who has access to them, this would be balanced with word of mouth recommendations and potential promotion of the study at related events, such as mental health awareness events and conferences. I have also designed a postcard that

could be given to individuals who feel they might be interested or know somebody who could be (Please see attached).

I propose that participants may be interested in this study for two reasons. Firstly to have the opportunity to add to the research knowledge and understanding relating to children growing up in similar circumstances, and secondly research surrounding families and carers repeatedly reports that they often feel ignored and silenced. Indeed my own professional experiences bears testament that families all have a story to tell and are keen to be heard. As such the invitation to speak openly and freely to an active and interested listener may in itself be a motivating factor for a participant.

In terms of the practicalities of recruitment, there are 3 core routes, 1) Participants can recruit themselves through responding to the postcard or Facebook site. 2) Participants may learn about the study directly from me at a (mental health awareness) event, I will ensure I have postcards and/or information leaflets to provide them if they show an interest in taking part or 3) Participants may be recommended by friends, however after the initial recommendation, I will give the “friend/referrer” a copy of the postcard to pass to the potential participant. Therefore they can contact me without any pressure. The referrers will have no further role in the process and therefore not be considered gate keepers.

- What information (and in what form) will be given to participants about the study?

Additional information will be given within 48 hours of contact being made either by phone or email. I will discuss the study, what is expected of them and any questions they may have during the initial contact, I will also send a copy of the participant information leaflet if appropriate.

At this point either they or I may decide that it is not appropriate to carry on with process. If this is my decision, it could be for a variety of reasons as defined in my inclusion/exclusion criteria.

Inclusion criteria would be;

- Having been cared for by a parent who experienced a serious mental illness for a year or more – a short term mental health problem would impact very differently upon a child.

- Any diagnosis – this study intends to focus on the manifestation of an illness and the child’s experience as opposed to specific diagnostic labeling.
- Any gender.
- Any culture.
- A specific age range 25 - 45. The dramatic changes in the treatment of mental illness over the past 30+ years will mean that different generations will have had starkly different experiences.

Exclusion criteria would include;

- Lack of mental capacity to give informed consent to the study.
- Psychological fragility affecting the individual’s ability to participate safely. This would include their perceived risks and the level of support they could identify from themselves.
- Geographic Limits. Within the UK and dependent on the constraints of the study and resources.

If I feel it is not appropriate to include them in the study, I will carefully and sensitively explain my reasoning to them, and I will offer to send a sheet of the local support groups if they wish.

Information and consent to the study will be reviewed before the interview begins to ensure they have not changed their mind and to answer any questions. Please see attached information sheet

- How will consent be recorded?

Consent will be fully discussed, upon first contact and before the interview and will be recorded on a consent sheet. This will be continually reviewed throughout the interview as an on going process. Please see attached consent sheet

- What are participants consenting to in terms of uses of the data (for example will you make it clear that the data may be used in publications or for further secondary analysis?)

Use of data will be described in the information sheet, participants will be made aware that it could be used in publications but would be completely

anonymous. Data will be stored and managed in accordance with the Data Protection Act 1998.

- What rights will participants have to withdraw from the study during or after data collection?

Participants will have full rights to withdraw from the study before the interview, during the interview and to withdraw their data for up to two weeks following the interview. If requested all of their data will be disregarded from the study and destroyed. As all data collection is based upon individual interviews this will not compromise any other data collected

- For participants under the age of 18, please detail if and how you will obtain consent from parents or guardians, and explain how the assent/consent of the child/young person will be obtained

All participants will be over 18 and will have capacity to give informed consent.

- Is consent required from any other persons for example gatekeepers such as teachers or social workers?

No gatekeepers are involved

- If you do not plan to gain consent from participants, clear justification for this must be made.

Consent will be gained

- Will you be offering participants any reward/incentive?

As an acknowledgment of the time that the participants are offering to take part in the study, they will each be offered a £20 Love to Shop gift voucher which can be redeemed in a wide variety of stores across the UK.

It is not expected that the participants will be financially disadvantaged by their participation. Therefore where possible I will travel to them and fit in around their schedules. If they do incur small costs for travel or refreshments I will offer recompense.

Copies of information and consent forms attached.

3.2 Withholding of Information from Participants

Do you plan to withhold any information from participants about the nature or purpose of your study?
NO

If YES, describe your reasons for this and your plans for debriefing participants at the end of the study.

3.3 Information for Participants on Completing the Study

Do you plan to give participants more information about your research and/or findings after they have taken part? YES

If YES, how will this information be given and what will it include? (give details or attach the information sheet)?

A brief summary of the findings will be produced and sent to the participants at the end of the study. Participants will be given the opportunity to decline this.

If NO, why won't participants be given further information?

4. Confidentiality, Anonymity and Data Storage

4.1 Will the data be gathered anonymously? No

Any identifying information would be removed from the data, and if it necessary to be kept while the data is being analyzed would be kept separately from the anonymised data. Any identifying data will be destroyed as soon as possible. Pseudonyms will be used.

If NO, how will you protect the identity of your participants and ensure that any personal information you receive will be kept confidential?

4.2 How will you ensure the secure storage of data both on and off site?

Data (including recordings) will be transferred and carried on an encrypted memory stick and transferred to a password protected computer within 3 working days. These will additionally be stored in a locked cabinet both on the university campus and at home.

Any third party who might be recruited for transcription purposes will be required to agree to confidentiality and secure management of the data.

4.3 What are your plans for archiving or destroying the data after completion of the research?

A copy of the data will be kept on a password-protected computer after the completion of the study; this will be retained while there is a possibility that the data may be reanalyzed for future work.

All identifying information will be removed from data before archiving.

This archived data would only be used by myself and would not be shared with a 3rd party as it would be impossible to request permission from the participants at this point.

Identifying information should be removed from all data and, if necessary, replaced by ID numbers or pseudonyms. Data should be stored securely (e.g., in a locked filing cabinet, password protected files).

5. Risk assessment: Protection of Participants

What risks and/or inconveniences might participants experience and what steps will you take to minimize these?

Be aware that interview questions or questionnaire items might raise issues that are sensitive for individual participants or may create anxiety. Explain what steps you will take to minimise this or to help participants, for example by providing information on relevant support groups or centres in your information sheet.

Where relevant, you should detail how you plan to deal with any situations where you may uncover evidence of a risk of serious harm to the participant or another person.

During the initial sampling, a discussion about the risk would be conducted to ascertain the likelihood of any harm coming to the participant by entering the study. This discussion and consideration of risk will be based upon my professional experience and knowledge of working with adults with severe and enduring mental illness and risk assessment/management. Given the sensitive nature of the topic a participant could be affected by memories and/or emotions they recall. Together with the participant I will explore how they feel it may affect

them, what the risks could be and what kind of coping strategies and support they may have in place.

A list of local resources offering emotional support would be offered at the end of each interview (please see attached). This information of local resources will be given to all participants, in case they should need it at a later date, or do not wish to disclose to me that they have found the process unsettling.

During the interview the level of comfort for the participant will be continually reviewed. If it were felt that the participant was becoming distressed, the topic could be changed or the process paused or terminated. This could be requested by the participant or by myself in line with my duty to be mindful of the wellbeing of the participant and the impact of my research.

As an experienced Mental Health Social Worker I feel I am well placed to discuss sensitive topics with vulnerable people, and that this experience and knowledge will enable me to conduct the interview in a calm and sensitive manner.

No physical risk of harm is expected to be present, but I will ensure that the physical environment in which the interview takes place is appropriate and mutually agreed. It is expected that this will predominately be in the participants' own home.

As discussed within the realms of confidentiality, if the participant discloses any information about significant harm to themselves or others I may be duty bound to take the concern and information further. Where possible I would discuss my concerns with the participant and inform

them of the action I intended to take as a result. The only reason for this discussion not taking place would be if I had reasonable believe that it may significantly raise the risk for either the participant, myself or a third person.

Harm to participant by another	I will give information about how to access appropriate help, through the local authority safeguarding procedures, police or 3 rd sector organisation such as a women's refuge
Harm to another – adult or child	I would have a discussion/make a referral to the Norfolk Multi Agency Safeguarding Hub (MASH) 0344 800 8020. If I felt I required specialist police advice I would contact the duty detective sergeant of the MASH 01603 276151. If the harm was immediate and significant I would contact the police on either 101 or 999.
For interviews conducted outside of Norfolk, I would ensure I was aware of the appropriate numbers and procedures to report concerns before embarking on the interview. This information is readily available on all Local Authority websites	

As a researcher there could be an inherent power imbalance, in that it is my study and I am asking them to expose themselves by recalling private memories and emotions. Given the nature of the discussion of mental health this could be further exacerbated by my professional status as an Approved Mental Health Professional. For the purposes of the research I will identify myself as a PhD researcher, which is my role in this context. While I will not conceal my professional registration if directly asked, I will make it clear that I do not represent the local authority or NHS Trust in this instance and therefore am not able to have any direct influence on their situation or that of their parents.

6. Risk assessment: Protection of Researcher

Does involvement in the research put you at risk of physical or psychological harm, distress or discomfort greater than that encountered in your everyday life?

YES

If YES, describe the nature of the risk and the steps you will take to minimise it. Again the location that the interview takes place in will be carefully considered if it is felt necessary to ensure safety the interview will be conducted in a neutral venue. I will have a mobile phone with me at all times and an individual (Mr Colin Blake-Holmes) will be aware of the time and location of the interviews should I require assistance or do not make contact within the agreed period of time, we will have agreed what steps Colin should take such a situation arise. As a Social Worker with many years of experience of lone working within the community I am confident

of my skills in assessing and managing potential risks, both with individuals and environments.

As a researcher I may find that I am emotionally affected by the content of the interview and would use my supervisor to 'debrief' as needed.

7. Other Permissions and Clearances

7.1 Is ethical clearance required from any other ethics committee?

NO

If YES, please give the name and address of the organisation:

.....

.....

Has such ethical clearance been obtained yet?

YES/NO

If YES, attach a copy of the ethical approval letter

7.2 Will your research involve working with children or vulnerable adults?

NO

If YES, have you obtained an enhanced disclosure certificate from the Criminal Records Bureau (CRB)?

YES/NO

DECLARATION OF PRINCIPAL INVESTIGATOR

I am satisfied that all ethical issues raised have been identified and that satisfactory procedures are in place to meet the standards set out in the UEA ethics policy and to adhere to ethical best practice.

Signature **Date** ..10-3-15.....

DECLARATION OF THE SUPERVISOR (for research students only)

I have reviewed and discussed with the student their ethics application and am satisfied that all ethical issues raised have been identified and that satisfactory procedures are in place to meet the standards set out in the UEA ethics policy and to adhere to ethical best practice.

Signature **Date**



Ethics Application
Pre-pilot interview

Rationale

With a focus on the individual experience of growing up with a parent with a mental illness, I am proposing to analyse my data using Biographical Narrative analysis. In order to do this I need to collect data that enables the participants to frame and communicate their own life story without influence from myself. How they choose to tell the story can be as significant as what they say.

Within Wengraf's (2004) Biographical Narrative Interpretative Methodology, a specific form of interviewing is required. This Single Question Aimed at Inducing Narrative (SQUIN) technique seeks to uncover what the participant wants to say as oppose to what the research wants to hear. This interview will contain two sections, the first section begins with a single question which is designed to elicit the life story of the individual as he or she chooses to tell it. During their account no further questions will be asked, the researcher actively listens and makes brief notes on key aspects. In the second section, the researcher can ask for further detail on their notes. These points can only be on issues that the participant raised within their own account and must be asked in the order that the participant presented them to preserve the integrity of the narrative structure.

Because this interview technique is so specific and integral to the subsequent analysis, it is important that it is done correctly. I am aware that it is vastly different to the assessment techniques I have developed over my years of being a social worker and as such would value the opportunity to practice the interview technique before I began my study in earnest.

Interview Plan

This interview will not be focused on or specific to mental health. I will begin the interview with

I am interested in individuals' childhood experiences and how they feel they influence them as adults. I wonder if you could tell me your story, take as much time as you need for this and start wherever you wish. I will just listen, I won't interrupt and I may take a couple of notes about things I would like to ask you more about later. As I say take as much time as you'd like.

So could you tell me your life story, the events and experiences that you feel have been important to you up until now.

Sample

I would like to recruit my sample from the 3rd year BA social work students. I have selected this cohort of students as, after a single session on the 31st March I will not be involved in any more teaching with them nor will I be involved in any of the assessment of their work. Therefore, there would be no conflict in roles and boundaries.

Risks

As with any recall of childhood and/or life experiences painful memories could emerge. However given the interview technique, no probing questions will be asked and therefore they are free to omit any memories they would like from the narrative. This leaves the participant in greater control and reduces anxieties regarding what will be asked of them.

I will discuss this risk with the participant and ask them to reflect on what support they may have available to them, for example, friends, family, academic advisor, Dean of Students. I will encourage the students not to participate if they feel there is any expectation that this experience could be unsettling or detrimental to their wellbeing or studies.

Interviews would take place on the university campus in a private room or in the student's accommodation if appropriate.

Consent

Full consent will be sought and the attached form completed. Consent will be reviewed throughout the interview.

Data Management.

Interviews will be recorded, and field notes made. Interviews will not be transcribed but may be shared with supervisory team to review my learning needs. This will only happen with permission from the participant. Field notes will be anonymised within 3 working days of the interview occurring. Sound files of the interview will be kept on the university central store and will be deleted within 12 months.

Information for Participants

Narrative Interviewing Skills

The project is about

My name is Kate Blake-Holmes, I am a PhD researcher with the School of Social Work. I am intending to conduct a piece of research that seeks to explore the experiences of individuals who have grown up with parents with a severe and enduring mental illness.

In order to do this I plan to use the Biographical Narrative Interpretive method. For this method of analysis to be applied, the participants need to have been able to frame and communicate their own life story without influence from myself. How they choose to tell their story can be as significant as what they say. Within Wengraf's Biographical Narrative Interpretive Methodology, a specific form of interviewing is required. This Single Question Aimed at Inducing Narrative (SQUIN) technique seeks to uncover what the participant wants to say as opposed to what the research wants to hear.

In order for my interviews (and subsequent analysis) to be robust and valid I would like to practice this specific interview technique. As this not intended to be used within the body of my research, there is no criteria attached to who I can interview.

What do I have to do?

I would like to practise this technique by asking you to tell me the story of your childhood and how you feel it affects you as an adult. You can tell me as much or as little as you like, and I will not ask any questions about anything you have not already raised. The interview would be recorded digitally and could take up to 2 hours.

What are the benefits of participating in the study?

I would really appreciate any help you could give me in developing my research skills and I hope it would be an interesting experience for you in terms of gaining insight into what it is like to be a research participant. To thank you for your time I could also offer you a £20 love to shop voucher.

Are there any risks for me if I agree to participate?

Depending on what your childhood was like, you might remember things that could be upsetting. However with this interview technique, no probing questions will be asked and therefore you are free to omit any memories you would like from the narrative. This leaves you in complete control of the direction of the interview. If you felt that there was a possibility that the interview would trigger unsettling memories I would ask you not to put yourself forward as your stability and ability to continue with your studies must be your priority in this instance.

If during the interview you felt it was becoming uncomfortable we could stop it straight away.

I will not be delivering any further teaching or be involved in evaluating your academic work so no bias could be formed following the interview.

What if I decide to change my mind and withdraw from the study?

You can decide to withdraw from this process at any point. If you change your mind after the interview, you just need to let me know that you wish to withdraw within 1 week and the interview will be deleted. You do not have to give any reason for this.

What happens to the information that is collected?

All of the information that I collect will only ever be used by me, to reflect on my interview technique. It will not be transcribed and will be deleted within 3 months of the interview. The audio files will be kept securely on an encrypted memory stick. The only people I will discuss the interviews with would be my supervisors Prof Marian Brandon and Prof Gill Scholfield. It maybe useful within our supervision to listen to extracts of the interviews to reflect on my technique. I would not reveal your name or details, however if you are concerned that either Marian or Gill could identify you by voice you have the right to ask that your interview not be used for this purpose. The only time I would break confidentiality, would be if you told me about an illegal act that was placing yourself or others at high risk of harm.

If you have any questions or are interested in taking part;

Please feel free to contact myself Kate.blake-holmes@uea.ac.uk



- **Have you grown up with a parent with a mental illness?**
- **What was it like?**
- **How does it affect you as an adult now?**

Children and families of adults with mental illness, often feel like their voices are not heard. Your story could help us learn how to support these children and their families better.



If you would be willing to be a part of this research and tell me your story, please contact me for more information on

07746 934423 or
kate.blake-holmes@uea.ac.uk



Appendix 7 – Project Facebook page

The screenshot shows the Facebook page for 'Growing up with a parent with a mental illness'. The page is managed by Kate, as indicated by the profile picture and name in the top right. The page header includes the name 'Growing up with a parent with a mental illness' and a search bar. Below the header, there are navigation tabs: Page, Inbox, Notifications, Insights, Publishing Tools, Admin Feed, Settings, and Help. The main content area features a post from January 27, 2016, where the page owner shares their PhD research at the University of East Anglia. The post has 68 people reached and a 'Boost Unavailable' button. Below the post, there are comments from Emma Ward and Kristen Smith Allen, both dated January 29, 2016. The right sidebar contains 'Page Tips' such as 'Help People Take Action' and 'Try Posting a Short Video'. At the bottom right, there is a 'Community' section showing 31 likes and 31 follows. A 'Chat (18)' button is visible in the bottom right corner.

facebook.com/kate.blakeholmes.research

Growing up with a parent with a mental illness

Kate Home

Page Inbox Notifications Insights Publishing Tools Admin Feed Settings Help

Like Follow Share

Growing up with a parent with a mental illness January 27, 2016 ·

I am doing a PhD with the School of Social Work at the University of East Anglia. I would love to speak with anyone (over the age of 18) who grew up with a parent with a mental illness and might be happy to met with me to tell me your story.

68 people reached Boost Unavailable

Share

1 Top Comments

Emma Ward Hi Kate, I'm a researcher in SWK too (work with Birgit in EFB 1.21). I grew up with depression and alcoholism in my family so think your research is important. Would you be happy for me to share around my FB networks? Message · January 29, 2016 at 7:28pm

Growing up with a parent with a mental illness That would be great Emma thank you. January 29, 2016 at 7:41pm View more replies

Kristen Smith Allen Hi. I grew up in a house with my father who is schizophrenic. I am happy to meet with you. Please PM me Message · January 29, 2016 at 1:32pm View 1 more comment

Growing up with a parent with a mental illness January 29, 2016 ·

Page Tips See All

Help People Take Action Add a Button to the top of your Page.

Try Posting a Short Video Videos help engage people in News Feed and on your Page.

How to Create Effective Posts Short, visual posts created for the right audience are more successful.

See All Page Tips 4

95% response rate, 2-days response time Respond faster to turn on the badge

31 likes 0 this week Orphan Holmes and 14 other friends

31 follows

See Pages Feed Posts from Pages you've liked as your Page

31 people like this and 31 people follow this Orphan Holmes and 14 other friends

Community See All

31 people like this

31 people follow this

Chat (18)






If you have any questions or concerns about the study.

Please feel free to contact myself, Kate Blake-Holmes or my supervision Professor Marian Brandon.

Kate.blake-holmes@uea.ac.uk
07746 934423
M.Brandon@uea.ac.uk

School of Social Work
01603 591 515


If you have a complaint

If you do not feel able to discuss this with myself or Marian please contact Professor Gillian Schofield Head of the School of Social Work.

G.Schofield@uea.ac.uk
01603 593 561

UEA
University of East Anglia

crcf Centre for Research on Children & Families



Growing up with a parent with a mental illness: making sense of the experience.



Kate Blake-Holmes

UEA
University of East Anglia

crcf Centre for Research on Children & Families

Information for Participants

What is the study about?

I am interested in what it might be like to grow up with a parent with a mental illness. Were there any things that helped, were there any things that were difficult? Do you think it still affects you now that you have grown up, if so how?

What do I have to do?

I would like to come and talk to you about your experience, and for you to tell me your story. You can tell me as much or as little as you like. The interview would be audio recorded and may take up to 2 hours.

Are there any risks for me if I agree to participate?

Depending on what your experience was like, you might remember things that could be upsetting. If this happens we could change the topic, take a break or stop the interview.

What happens to the information that is collected?

The information that I collect will be used for my PhD study and possible follow up publications. I will use false names and make sure that nothing within the information could be linked back to you.

Will anything I say be passed on?

This would only happen if you told me about an illegal act that was placing yourself or others at a high risk of harm. I would tell you if this were the case.

Will the study cost me anything?

No, I will travel to you, and I am happy to meet whenever it is convenient to you. You will not have to take time off work or any other commitments.

What are the benefits of participating in the study?

Often, children and grown up carers or relatives, feel like their voices are not listened to. Your participation would help me to build an understanding about what it feels like for children and carers. It is hoped that if we understand more, we can try to support children and their families in better ways.

I will produce a short summary explaining my findings, a copy of this would be sent to you, if you wanted one.

To thank you for your time you will be offered a £20 Love to Shop voucher, which can be redeemed in a variety of stores.

What do I do want to take part?

Please email me, kate.blake-holmes@uea.ac.uk or call me on 07746 934423 and we can talk about the study some more.

What if I agree then change my mind at a later date?

You can decide to withdraw from the study at any point. If you change your mind after the interview, you just need to let me know that you wish to withdraw your information within 2 weeks of the interview.

Appendix 9 – Consent form



Consent Form

Title of Research Project

Growing up with a parent with a mental illness: making sense of the experience through the reflection of adult offspring.

Name of Researcher

Kate Blake-Holmes

Contact details of researcher.

School of Social Work, University of East Anglia, Norwich, Norfolk, NR4 7TJ. 07746 934 423
Kate.Blake-Holmes@uea.ac.uk

1. I confirm I have read and understood the information sheet for the above study and I have had the opportunity to ask questions. YES / NO
2. I understand that my participation is voluntary and that I am free to stop the interview at any time, without having to give a reason. YES / NO
3. I understand that the interview will be audio recorded. YES / NO
4. I understand that all the information I give will be treated confidentially, under the Data Protection Act 1998. YES / NO
5. I understand that if I disclose any information which leads to concerns regarding the safety of a vulnerable adult or child this will be reported to the local safeguarding services. YES / NO
6. After the interview I can choose to withdraw my interview and information within 2 weeks. YES / NO
7. I agree to take part in the above study. YES / NO

Name of research Participant

Date

Signature

Name of researcher

Date

Signature

Jess Coding Index

Dad – other parent

- Perception of dads power
- Dad relationship with mum
- Dad impact on mums MH
- No help from dad
- Dad relationship with siblings
- Dad relationship with me
- Not related to me
- Dad abuser
- Dad twists stories
- Dad driving force of family
- Now- no contact

Relationship with mum

- Didn't look to mum for care
- Mum not responsible
- Mum tried sometimes
- Mum unable to relate/support
- Happy when mum happy
- Focus on mum
- Mums positive actions
- Not normal mother/daughter relationship
- Still worry now
- Needs space from mum now

Relationships now

- Now – Reciprocal with others
- Now- mum no more games
- Now – mum professionals response to MH
- Now – has echo effect
- Now – plans distance from mum

Family

- What is family
- Importance of family
- Poor marital relationship
- Domestic violence
- Family divided
- Early relationship with siblings
- Difference between siblings
- Birth order
- Caring for siblings
- Siblings unaware
- Now – limited contact with siblings

School

- Academic ability affected
- Poor attendance
- Parents not involved
- School structure and controlling
- School didn't notice
- School only interested in their agenda
- Education interrupted
- Got away with it – good behaviour
- Desire to learn

Peers

- Social development stopped by caring
- Choose friends to protect
- No close friend groups
- Can't identify with friends
- Hid self from friends
- Couldn't take friends home
- Friendships not reciprocal
- Imaginary friend – diary
- Attacked by friend
- Now – older friends – parental figures

Abuse

- Physical abuse mum
- Dealing with abuse
- Links with sibling
- Abuse dad
- Relationship 22 yr
- Friend rape

III parent behaviour

- MH services
- Alcohol use
- Anger/violence
- Self-harm
- Manipulative behaviour.

Care tasks

- Practical tasks
- Searching for mum
- Crisis
- Emotional support

Watchful

- Hard to relax
- High alert

Impact of care tasks

- Invisible guilt
- Constant care needs
- Couldn't be child
- Poor self-care
- Poor sleep

Protect Others

- Protecting as motivation
- Protect siblings childhood
- Deflect bullying on to self
- Rather it happen to me than someone else
- Apologetic for others upset
- Protect mums image
- Rather mum hurt me than herself.

Silence/secrets

- Hid from siblings
- Threat of separation
- Now – people find it hard to hear
- Only tell what's relevant
- Use diary as confident.

Alone

- Alone & alienated
- Only attention is reprimand
- No interest in me
- My feelings didn't matter
- People not aware
- Nobody asked

Adult tasks

- Prevent suicide /DSH
- Role reversal
- Balance mums needs with siblings
- Adult interaction with MH services
- Managing mums relationships

No support

- All focus on unwell one
- Request for help refused
- Nobody asked if I was okay
- Was like serious bystanders
- 22 yr there but exploitative

Responsible

- Couldn't be child too responsible
- Have to be close to keep her safe
- Felt responsible for mums behaviour
- Carry worry to school
- That's when it started
- A lot of pressure

Being a child

- Couldn't be a child
- Sibling had different childhood
- Wasn't wanted/no affection
- Early memory –eager to please
- Adult conversations

Normal

- Perception of world skewwhiff
- Trying to appear normal
- Okay I'm the weird one.

Impact of care tasks

- Lasted a long time
- Guilt and trapped
- Couldn't worry about myself
- Would have loved to have a childhood.

Awareness of Mental illness

- Became aware in critical moment
- Not aware in younger childhood
- Illness concealed by other parent.

Assessing risk

- Anticipate aggression
- Assess situation
- Assess environment
- Emotional impact

Self-awareness

- Aware of others but not self
- Couldn't identify own needs
- Engage with therapy
- Therapy – space to talk
- Becoming visible
- Own poor mental health
- Physical symptoms of poor mental health
- Trigger own mental distress
- Didn't understand happiness
- Build emotional intelligence
- Learning what I like
- Learn about health relationships
- Thinking of children

Understanding of mums Mental Health

- Mums mental health needs
- Mums illness in early childhood
- Trying to understand root of mums illness
- Mums illness triggered by marriage breakdown
- Feel responsible for mums illness (abuse)

Making sense

- Trying to make sense as child.
- Trying to make sense as adult

Sense of self

- Early sense of self
- Time to challenge beliefs about self
- Self-development
- Now- positive attributes
- Experiences conflict with sense of self.

Framing the experience

- Not ideal (minimizing)
- Thank goodness it's okay
- Too risky to reflect.
- You get used to it.

Helping others

- Swiss army knife
- Motivation of life
- Care giving experiences

Memory

- Early memories unclear
- Large black spots

Critical point as adult

- Accessing help for self

Move as adult – leaving home

- Leave and return
- Struggled when left home
- Redefine relationship when return home
- Difficulties leaving ill parent
- Planning the right time to go.

Moving as child

- No consistent reason for moving
- Stressful home environment
- Moved a lot

Romantic relationship

- Intense relationships
- Controlling relationship
- Alienate friends and family
- Chose mum over relationship

Child play

- Importance of space to play
- My time to play now

What I want now

- Will need long term therapy
- Time for me
- Plans to travel
- Thinking about becoming a parent
- Enjoys calmness
- Adult life brighter because of difficult childhood.
- Don't want to end up like ill parent.

What would have helped?

- To feel cared about
- To be noticed
- To develop emotional intelligence
- A chance to talk
- Encouragement & acknowledgement

Makes me who I am

- Childlike now
- Finds simple pleasures
- Wouldn't be me without it
- Will be there for others
- Helps me help others
- Makes me perceptive
- Makes me stronger.

Honesty

- I'm nice & honest
- Importance to be open
- Felt deceitful as child
- It's part of me
- Need people to understand me.

Timeline and participant/research analysis

Jess

<p>0 – was one of triplets, other 2 lost pre-birth Domestic Violence</p> <p>Pre-school – knew she wasn't wanted as a toddler. "just able to walk" remembers slamming herself into walls and wishing she was dead</p>	<p>Participant Analysis - evidence of not being wanted</p> <p>Participant Analysis - felt very separate to the rest of her siblings but did not know why, black sheep of the family. Attempted to be either pleasing or invisible to avoid further rejection. In adulthood Jess understands this as being a result of her having a different biological father and perceives this as being more acceptable/understandable.</p> <p>Researcher Analysis – this level of disturbed behaviour in a child so young indicates an extremely disorder attachment, which would leave Jess vulnerable to future abuse and exploitation. When Jess reflects on this it is interesting that while she describes it as being wrong she also feels it is justified given the nature of her relationship with her father as a non-biological parent.</p> <p><u>Theme – inhibited development of emotional intelligence.</u></p>
<p>Earlier childhood – youngest brother diagnosed with life limiting condition. Family moved in order to spend more time with him.</p>	<p>Participant Analysis – the family's closeness enables them to band around her brother and draw together for comfort.</p> <p>Researcher Analysis – while this does indicate a closeness of the family, it also suggests a insular and slight separation between the family and the outside world that they can move and</p>

	<p>'drop out to do this' The other children stopping school to be with family and brother suggest that their needs as entirely linked with the family and not the outside peer/education world. This also represented another period for Jess where you put yourself on hold to care for another and the uncertainty that something bad could happen. The potential to lose a sibling at such a young age brings the fragility of life into closer focus than it might be for other children of her age group.</p>
<p>Early childhood – Aware of mum being on and off tearful</p>	<p>Participant Analysis was largely unaware of mums weakness or strength, dad was the primary figure Researcher Analysis - this did not feel as though dad was managing mums mental health but rather that her mental health needs were suppressed within the confines of a controlling/abusive relationship.</p>
<p>8 yrs old – abused by dads friend, "lent out" "did what he wanted"</p>	<p>Participant Analysis - describes large blacks, memories of abuse did not fully begin to emerge until early 20's. Jess alludes to dad functioning with in a paedophile ring, and not directly involved, although she states that he watched. Jess did not feel that her mother was involved in the abuse but was maybe partially aware, Jess attributes the guilt of this that triggers mums mental distress and at times feels that makes her partially responsible for her mum's illness.</p>
<p>childhood/adolescence – large black spots in memory</p>	<p>Researcher analysis – this experience of abuse will clearly have significant long term impact on Jess' life and perception of the world around her and as such needs to be considered with the analysis of this narrative. However it is interesting how she does not express anger regarding the abuse that was perpetrated against her, instead she frames it in terms of the themes of</p>

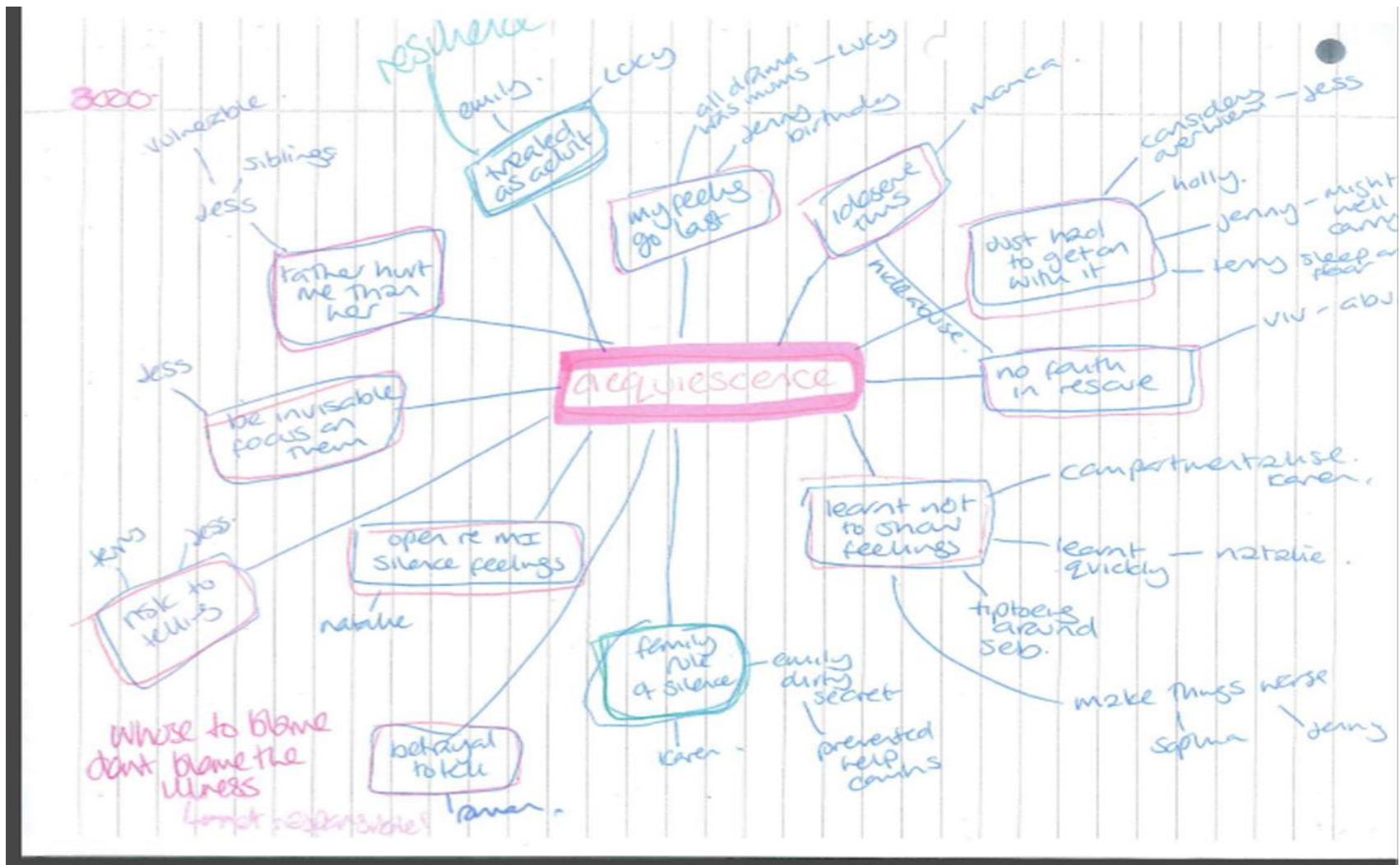
	<p><u>Protecting others</u> – expressing gratitude that it happened to her and not her siblings</p> <p><u>Responsibility / guilt</u> - while not attending to the emotional impact the abuse had upon her she believes that it caused her mum distress and triggered her mental illness.</p>
<p>Mid childhood – not wanted only attention when in trouble.</p> <p>mid to late childhood - Father phoned and woke Jess during a sleep over to berate her and tell her she was an embarrassment to the family</p>	<p>Participant’s analysis - Jess had strong memories of not being wanted or fitting in. Only attention given was negative, if in trouble.</p>
<p>adolescence – moved a lot, at least 15 different schools</p>	<p>Researcher analysis. The positioning within the family and experiences of abuse left Jess increasingly vulnerable. Feeling alienated and needing to please to avoid further rejection.</p>
<p>adolescence – A star student / scholarship to private schools</p>	<p>Participant’s analysis – no consistent reason for the moves, no family involvement, mainly sudden moves at dad’s request.</p>
<p>adolescence – A star student / scholarship to private schools</p>	<p>Researcher analysis – kept the family alienated and insular, hard to form friendships or reflect on yourself in relation to others.</p>
<p>12 yrs old – Father Sam and Edith move to Norwich, Mum Jess and Henry join them later</p>	<p>Researcher Analysis Jess enjoyed learning and obtaining positive recognition for herself outside of the family home.</p>
<p>13 yrs old - mum and dad separated</p>	<p>Participant’s analysis - home environment becomes fractured and mum begins to consider leaving the marriage, dad attributes this to her poor mental health. Jess is involved in the discussions about whether the marriage should end.</p>
<p>13yrs old - became aware of mums mental illness</p>	
<p>13 yrs old - In relationship with 22 yr old man – relationship set up by father</p>	<p>Participant analysis Jess considers this a long-term relationship and is sexually active. However she remembers that this was physically</p>

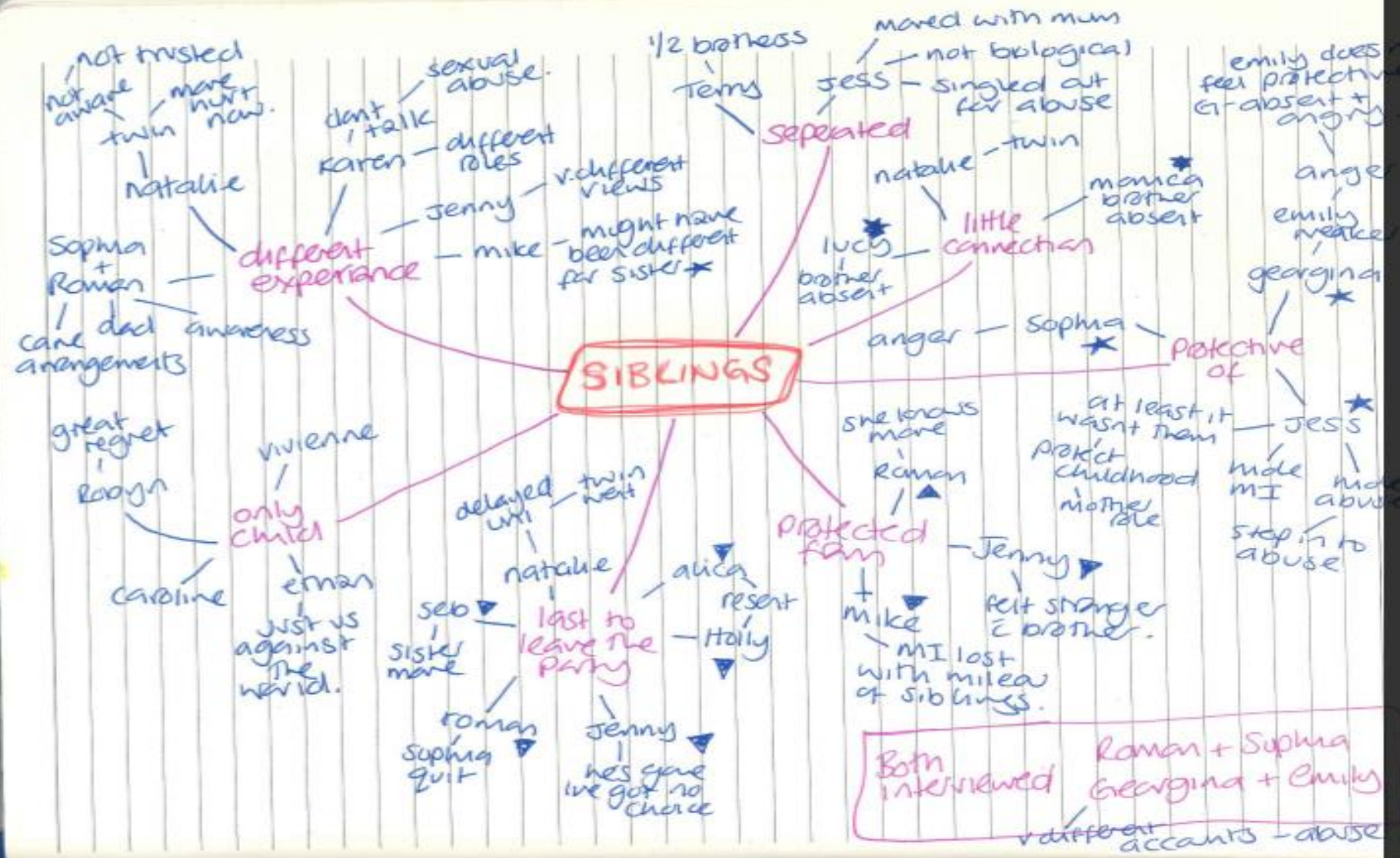
<p>13 yrs old – mums suicide attempt – Jess searches house for mum’s body.</p> <p>13 yrs old - moved in with mum to care for her.</p> <p>Mid-teens – school attendance dropped, leaving lessons to telephone mum.</p> <p>15 yrs old - mum admitted to psychiatric hospital, Jess living alone and visiting ward alone.</p> <p>18 yrs old - Threaten with school exclusion in 2nd yr of A Levels for poor attendance</p>	<p>painful for her and believes that the relationship was set up by her father.</p> <p>Researcher analysis. She continues with the relationship as she nothing to judge it against, and also finds it a source of support and distraction from her parents.</p> <p>Participant analysis breakdown in mums mental health, and turning point for Jess. Jess moves out of family home to live with mum. Strong memories of walking into a suicide scene and searching for mum’s body, dad sat outside and offered no assistance or support.</p> <p>Researcher analysis <u>Critical point</u> jess took on caring role and responsibility for mum</p> <p>Researcher analysis <u>carrying worry to school</u></p> <p>Participant analysis - Jess felt ill equipped to be living alone, unsure where money would come from, how long mum would be in hospital. She was unable to express her concerns for fear of separation and further deterioration in mum’s mental health.</p> <p>Researcher’s analysis - jess was so used to focusing on mothers care needs she felt lost without them and even in her interaction on the ward she was the expert in her mother’s needs and behaviour despite having little empirical knowledge to base that on. While Jess probably gave the impression of being adult and competent, this was a facade.</p>
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<p>Late teens - Moved in with boyfriend. V controlling, not allowed to see friends and family. Gained 3 dress sizes – left and returned to mum after 6 months when partner began to exclude mum.</p>	<p>Participant analysis moved in with boyfriend, was an intense controlling relationship, Jess unsure how to manage this. In the end the relationship ended as the boyfriend tried to stop Jess seeing her mum, Jess could not tolerate this due to the risk to her mum and her responsibility to continue to provide support.</p> <p>Researcher analysis Jess recreating controlling abusive relationship. Was only aware through reflection of what it would mean to her mum and the physical effects on her.</p>
<p>Early 20's - graduated (art?) got job in Greece ad a nanny ++ health issues, couldn't maintain strength +++ low mood, returned home to mum after 2 months.</p>	<p>Participant's analysis felt her mum was stable enough for Jess to pursue an opportunity for herself. This was unsuccessful.</p> <p>Researcher analysis Jess struggles when away from her mum, in potentially the same way that mum struggled when stepping away from a controlling relationship. Jess has very little insight into her own mental health needs, instead focusing on physical manifestations.</p>
<p>Early 20's - mum began seeing therapist</p>	<p>Participants analysis things starting to calm down and improve</p>
<p>21 yrs old - lived with mum for a year</p>	
<p>22 yrs old - drugged and raped by friend.</p>	<p>Participant's analysis attack happened out of the blue. Jess finds this particularly distressing as it was a person she trusted, Jess attempts to deal with it physically, but mum intervenes regarding reporting to the police and accessing psychological support</p> <p>Researcher analysis Jess shocked by this as the person was considered a friend and trusted as oppose to being accepted and expected with regards to the abuse throughout her childhood.</p> <p><u>Critical moment for Jess. First</u></p>

<p>22 yrs old - Jess began seeing mums therapist.</p> <p>23yrs old- didn't know what happiness was, began to explore black spots in memory.</p> <p>24yrs old -began remembering/ addressing abuse.</p> <p>24yrs old - reported abuse and 22 year old boyfriend to police.</p> <p>24yrs old - mum tells Jess Liam is not her biological father</p> <p>25 yrs old - told siblings about abuse</p> <p>25 yrs old – moved out from mums</p> <p>26 yrs old - tries to maintain boundaries with mum</p> <p>future plans – Jess has future plans to go travelling for a year when she is 27 and hopes one day to have a family of her own.</p>	<p>documented moment where mum was protective and focused on Jess needs.</p> <p>Researcher analysis – first opportunity when someone attended to Jess' emotional needs. This enable Jess to begin to address the abuse of her childhood, and her relationship with her mother.</p> <p>Family secrets exposed re dad not biological and jess reveals to siblings about abuse and mums mental illness.</p>
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Appendix 13 – support information for participants

Services that offer advice and support – Bristol

	What they offer	When they are available	Contact
Carers UK	Help and Advice Online forum	Mon-Fri 10am-4pm Anytime	0808 808 77 77 www.carersuk.org/forum
Saneline	Helpline Caller care – they will call you to offer support over an agreed length of time.	7 days a week 6pm – 11pm	0845 767 6000
The Samaritans	Help line Face to face support (drop in)	Anytime 7 days a week 8am – 9pm	0117 983 100 37 St Nicholas St Bristol, BS1 1TP
Bristol Mind	Carers support service Advice, resources, counselling & befrienders	Mon – Fri 9am – 5pm	0117 980 0370
Bristol Carers Support	Individual support, carers groups and advice	Mon – Fri 9am – 5pm	0117 965 2200

Frank	Information and advice about drugs Helpline	Any time	www.talktofrank.com 0300 123 6600
Changes Bristol	Weekly Mutual Peer Support Groups for people in mental distress –open access	varies	0117 941 1123
Lift Psychology in Bristol (NHS)	Support and treatment for mild to moderate mental health problems.	Mon – Fri 9am – 4.30pm	Lawrence Weston Clinic Ridingleaze BS110QE 0117 982 3209