

A study of the narratives of adults who grew up with seriously mentally distressed parents

Zoë Cowie

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Abstract

Despite the advancement of knowledge and understanding about the experiences of mental health service users which has been attained over the last decade or so, most of the 'carer' literature in the UK and worldwide, relates to parental or spousal experience. There is also a growing body of work which is addressing the experiences of young carers. In the UK however there is a complete absence of research into the experiences of adult children of parents with severe mental distress. Worldwide there are just a few examples. This study was therefore designed to help break the silence.

Seven participants, who identified themselves as having a seriously mentally ill parent, were recruited for this study. Each person was interviewed with no pre-set agenda. Participants were asked to tell their stories in any way they wished.

With an underpinning social constructionist philosophy the resulting narratives were analysed using the 'holistic content' dimension of the framework offered by Lieblich et al (1998). This means that the stories can be seen as saying something depending upon where in the narrative they were presented.

The findings are discussed using the metaphor of the 'rollercoaster' which was used with some regularity in the narratives. The themes which first emerged are presented in "Hold on tight the ride is about to begin". This theme is primarily about the shock, role changes and silence which surrounds the family. As the stories progress, "The Ride" begins, and details various traumas and losses, with particular attention paid to relational trauma. The final part of the discussion; "It's stopped for a moment" offers insights into the reflections and meaning made by the participants in the intermittent spaces when the ride had slowed sufficiently to allow time to think, before it resumed its repetitive circular motion.

The findings and discussion of this research form a platform in the UK, which does not currently exist, but which, it is hoped, will provoke discussion and arouse interest.

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My acknowledgements would not be complete without due thanks to my sister Lisa; we have travelled a long way together, our lives running an odd parallel. Your love has held me strong for years.

And lastly to my dear friend Bec; thank you for all these years of friendship. It has meant more than you will ever know.

Glossary

AOSMDP ...Adults of Seriously Mentally Distressed Parents

AMS... Adult Mental Health Services

APA...American Psychiatric Association

CAMHS...Child and Adolescent Mental Health Services

COPSMD...Children of Parents with Serious Mental Distress

DH...Department of Health

DSM...Diagnostic Statistical Manual

ICD...International Classification of Disorders

NHS...National Health Service

NICE...National Institute for Health and Care Excellence

NMC...Nursing and Midwifery Council

RCP...Royal College of Psychiatrists

RIO... (NHS patient identification system)

SCIE...social Care Institute of Excellence

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Chapter 1

Introduction

The research aim

Serious mental health problems have profound repercussions for the individual affected, and the ripples are also felt by those close to them. There is a growing recognition that the loved ones of mental health service users often have to embark on their own journey of recovery as a result (Shepherd et al 2008).

Little is known about the lived experience of children who grow up in families with parents who have serious mental distress. These children tend to be referred to as 'invisible' and 'silent' (Gopfert et al 2004a and b, Foster 2006, 2010, Misrachi 2012). Less still is known about those children once they have grown up. This study explores some retrospective narratives from adults who grew up with a seriously mentally ill parent, and articulates their journeys into adulthood along with the consequences which they feel their early lives have had upon their ability to find meaning and personal value as adults. Hearing the stories of the participants and their thoughts about how the experience has shaped their identities will therefore add to the scant literature informing the knowledge base upon which services are currently designed and delivered and with which clinicians practice.

Organisation of thesis

This thesis is structured to be consistent with the methodology which underpins it. The methodology of a study is the general research strategy, i.e. the alignment of the research question with the way the research is carried out and analysed, underpinned with a coherent philosophy. This thesis is therefore designed as an evolving story. It has been organised to show the progression of time throughout the participants' lives, which is crucial to understanding the experience.

Chapter one introduces the reader to me, the narrator and my rationale for

undertaking this research. This is followed by a brief review of the topic and a broad overview of the context along with the reason why this study is important now.

Chapter two explores the literature which frames this study, thus building a case for the way this research was undertaken, so that it contributes to the literature base in its own unique way. The literature review has been constructed using various professional perspectives ranging from early psychiatric and psychological studies through to more recent qualitative work from nursing and social work in particular.

Chapter three provides a more in- depth exploration of narrative inquiry followed by the design and undertaking of this particular research along with the philosophical underpinnings which have guided its development. This chapter gives the reader a clearer picture of the design of the study, the method of recruitment and the ethical issues which were considered. The process of interviewing the participants, the transcription of their narratives and the analysis strategy is also found here.

Chapter four presents a short story written for each of the participants, and a brief overview of the findings is also provided.

Chapter five is divided into three parts each representing an aspect of the findings along with relevant discussion. The chapter is titled 'the rollercoaster' and the reason for this will have become evident from the preceding chapter. The first part of the discussion relates to the experience of finding oneself on a rollercoaster, unable to get off and trying to assimilate the changes. The second part of the discussion relates to the ride of the rollercoaster as it turns and takes the person by surprise each time. The third part of the discussion shares the participants' reflections as the rollercoaster slows down and emotional equilibrium is regained for a short while.

Chapter six presents the conclusions of this work, along with implications for practice and ideas identified for further research. A few personal reflections on the writing of this research are also offered.

Font

For ease of reading, the main text is written in Calibri. Direct quotes from the participants of this research are written in *Segoe Print*.

Confidentiality

In order not to breach confidentiality all the participants' names, the names of their family members and any other identifying detail have been changed.

Language

In order that I do not alienate the reader by use of clumsy terminology, I turn here to clarify the meaning of the use of language in this study. It is acknowledged that use of the term 'illness' in the context of a Mental Health condition is not entirely accurate. Illness is generally defined by the presence of pathology or a pathological process. It is something about which the person complains. Neither of these conditions is routinely met in serious mental health conditions making use of the term illness unreliable. The term illness is however still used by other authors and has been referred to by some of the participants. On these occasions, the use is replicated here.

My own use of the term illness was consistent with my initial nurse training but has been influenced by others more recently to be harmonious with the recovery model in current use in mental health, and also as my understanding of the nature of mental health problems has evolved during study for this thesis. Therefore in order to reach and make meaningful to the majority of readers, the use of the term 'distress' has been adopted throughout this thesis.

The use of the acronym AOSMDP (Adults of Parents with Serious Mental Distress) is also clumsy and jars somewhat with the flow of reading. It is difficult to find a meaningful term for this group which is acceptable to all, because the term 'illness' is still in common parlance across parts of the globe. Using the word 'distress' is also problematic, for two reasons; Firstly not everyone with a psychosis is distressed by it.

Secondly it does not distinguish between everyday upsets and a more serious problem. For clarity then, this study is about the grown up children of parents who were, and are still sometimes distressed by inner psychic phenomenon. This group is henceforth referred to as AOSMDP.

Introduction to me, the narrator

Throughout the thesis it will become evident how closely involved I am, both as the researcher, and also an adult with lived experience of growing up with a seriously mentally distressed mother. This stance as researcher is both helpful, and filled with risk of accusations of bias. Elements of reflection and reflexivity are therefore included to help the reader to follow my thinking and decision- making along the way. As this is deemed a crucial component of the methodology I have used, I have elaborated on the theme of reflexivity in chapter three. With the disclosure of a little about my own story, I hope you will be able to appreciate this journey not just as an academic read, but also rich with the heartfelt passion of personal experience.

It was difficult to let go of the sense that I was making it all up; Was it me? Was this really happening? These are questions that I asked myself repeatedly over the years. There is much about my life that feels vague. I have never been sure who I really am. I have tried hard to find my 'self' through all manners of routes, from spirituality to art, travel and therapy. I never married or had a family of my own, partly because I was not sure if I would end up distressed like my mother and partly because if you don't know yourself, how can you know what you want? I am not sure whether the stories I was told about my personal and family history are true. I have a sense that they are not entirely based in reality, which further destabilises my foundations. I am someone who is happy in my own company and does not make small talk easily. It seems just too trivial. Years of nightmares has made me serious and more introverted than I used to be.

At some level from the age of about five or six, I knew my mother was not always 'with me'. Although I had no frame of reference for mental distress, I could see it in her eyes.

As a child, I knew Mum would not deliberately hurt me in any way, but that look in her eyes frightened me, I found it difficult to trust her because I could not always 'read' her.

My father left the family home when I was five, leaving Mum to raise me and my two siblings alone. I was very aware how she struggled and worried about money. When Mum was distressed she could not be there for me and my world was therefore intermittently lonely. I became independent because I had to be.

The memories I have add patches of deep colour contrast to my growing up years and early adulthood, some very dark patches when Mum was particularly distressed and some areas of lightness and frivolity when she was less burdened.

We were forbidden to speak about her 'business' outside of our home. "What the eye doesn't see, the heart doesn't grieve over" was my mother's mantra, and she resolutely stuck to it. I learned early on that life was easier for me if I too could not see and hear what was in front of me. I became a child whose needs and at times, very being, was unrecognised by either my mother or myself. I was lost and silent.

As the years went by, I began to question Mums' health more and more and eventually found my way into mental health nursing as a career. At this point I was still unaware that Mum was living with a psychosis and much of what she did and said was based in a delusional world which only she could inhabit. She was an exceptionally competent woman who was generally able to keep her distress internally hidden. This meant she did not come into contact with services until I was in my thirties when I had to request a Mental Health Act assessment as it became clear how desperate she had become. The deterioration in her health was still only evident to my siblings and me. One of my main concerns was that of making others aware, so that we did not have to bear this alone. We had kept silent for years as she wished, but I was no longer willing to keep it to myself. I wanted my own life, and this meant breaking my silence. Despite feeling guilty and disloyal, the assessment did achieve Mum being finally offered some support. Attending appointments with her was helpful to her but fruitless for me because she did not want her confidentiality breached so open dialogue was never

achieved.

I was however not given an official diagnosis for my Mum until I was about 45. I am convinced that Mum thought she was protecting me from the chaos in her mind, but it simply left me filling the void with my own interpretations.

For some years I searched the literature for knowledge to help me understand, but found nothing which resonated deeply with me. Everything I read was about the possibility and chances of me developing mental health problems of my own. Another tranche of information related to social outcomes which I might anticipate in my life such as poverty and unemployment.

Interminable phone calls between my sister and I helped us piece together the fragments of our experience, attempting to tame it with words, but at times failing. “There are no words” became our mantra. Search as I did, I could find nothing on why I had no language to describe or make sense of my experience. I wasn’t sure if this feeling was unique to me and my sister, or whether other people who had grown up with parents who had serious mental distress experienced a similar frustration.

My mother developed dementia as I undertook this project. She died as I was reaching the end. Perhaps it was the safety of knowing that that I need no longer feel guilty or disloyal for exploring the perspective of the adult child, rather than the service user, which enabled me to undertake this study. This thesis was part of my recovery.

Serious mental distress

I have conceptualised serious mental distress as that which is “long lasting and severely interferes with a person’s ability to participate in life activities” (Waldock 2010 p6).

With the exception of drug induced, a psychosis tends to be long lasting (two or more years) and generally interfere with a persons’ ability to participate fully in life.

The psychoses are often diagnostic criteria of schizophrenia, bipolar disorder and delusional disorder. Other conditions giving rise to serious mental distress are severe depression and personality disorder. Serious mental distress is characterised by

disturbances in a person's thoughts, behaviours and mood, whether they are psychotic or not. These disturbances may be brief or long term and there is a general consensus that conditions are influenced by levels of stress (Zubin and Spring 1977).

The original conception of this study was to focus upon the adult children of parents who had a psychotic disorder, mainly because I considered that there were issues specific to this type of condition. However my thoughts have evolved since then. I have become less concerned with the particular diagnostic category which I now regard as less significant than anticipated. The participant's stories revealed more important issues. These findings reinforce the opinion of Seeman (2004) who suggests that the duration and severity of the condition is more important in determining the outcomes for children, (and adults) than the diagnosis. Furthermore, some authors have stated that the social ramifications such as unemployment, poverty and family breakdown leave the family at more risk than the diagnosis (Rutter and Quinton 1984; Bannerman 2009). Devlin and O'Brien (1999) have succinctly articulated three distinct but interactional components which they suggest contribute to the onset or exacerbation of parental mental distress. 1) The stresses of coping with the symptoms of mental distress make parenting more of a challenge. 2) The integral stresses associated with parenting may in turn increase symptoms, particularly if that parent is a lone parent or if a child is particularly demanding. 3) Social adversity associated with mental distress brings stresses of its own.

In order to tailor services in mental health age related interventions have been explored across the life cycle. This is important because schizophrenia is known to take a different course depending on gender. A typical male presentation is worse in the first decade from onset, whereas for women, the condition tends to be mild in the first two decades (apart from postpartum illness) and typically increases in severity from the menopause onwards (Stromwall and Robinson 1998, Seeman 2004). This disparity has implications for parenthood as it is more likely that a woman will have already had a family before a serious mental distress becomes obvious.

The impact of serious mental distress is unique to the family concerned, depending upon who is distressed, how old they are; the presentation of the distress and the social context of the family. The number of variables renders it impossible to generalise across the stories of the participants, and this is not what this study aimed to do. The aim of this research was to explore both the unique elements of life for the offspring and those which were found in common. The lack of qualitative research in this area denotes that exploratory work is appropriate. This research conceptualised serious mental distress, as either displaying psychotic phenomena, or alternatively identified by the participant as being long lasting and with a significant impact.

It is worth highlighting here that this research is not about blaming parents or their families. Parenting is challenging enough, without the addition of mental health problems. Neither does having mental health issues assume a person is ineffective as a parent, or necessarily has poor parenting skills. However the child's needs and the adult child's needs and experiences must not be fused or confused with those of the parent. It is important to recognise that there is an impact upon children, which deserves to be understood in its own right. There is a paucity of work published about the impact of growing up with parental mental distress. This area of knowledge stands in stark contrast to the growing body of literature from the service user perspective. There is another body of work which addresses the impact on the family and/ or carers. This work however tends to assume that the carer is either a spouse or an adult caring for a child.

Underpinning philosophy

It is expected that qualitative researchers make explicit their personal and philosophical standpoint so that the motivations which dictate subsequent choices and decisions throughout the study are clear to the reader. Gergen and Gergen (2008) advise that early commitment to a paradigm is a prerequisite of research for this reason. Each researcher will have their own perspective on the nature of existence (ontology) and it is this which will influence their choice of theory about the nature of

knowledge (epistemology) (Howell 2013). Both Hammersley (2004) and Silverman (2011) however, advise new researchers to be cautious and guard against becoming entrenched in a paradigm, which they suggest can lead to becoming unable to countenance any other perspective. This advice does seem sensible although for the purpose of a researcher's clarity there comes a point when committing to a paradigm is necessary so that the methods chosen to undertake the research can be assessed as having coherence with the underpinning philosophy.

The following extract has been taken from my research diary;

The Monday morning "what did you do over the weekend?" office catch up led to me briefly recounting Victor Frankl's (1992) '*Man's Search for Meaning*', which I had read whilst remaining in bed for the entirety of one very rainy day. One of my colleagues suggested that "a story of the holocaust should be read with some caution regarding its truth" because he said, "trauma is likely to alter ones' perception and memory".

I did not respond, but jotted down the sentence in order to return to it later when I had the space to give thought to why it had made me uncomfortable. This statement of my colleagues became a pivotal moment in the identification of my personal world view. It occurred to me that my view of reality is like a rainbow. We could both see a rainbow from the window, but I would see mine and you would see yours. For me it is subjective truth which is of interest.

As a mental health nurse my role is about interpreting a patient's perception. If I tell a person something which is misperceived, my role is to communicate more effectively, not deny their perception. My commitment to this ontology runs deep; I grew up with someone whose reality was not always the same as mine, but which was no less real to her nevertheless, and on these occasions we had to negotiate when determining a reality which was acceptable to both of us.

This study was therefore underpinned with constructionism as its philosophy. This means that reality and knowledge of the world is seen as socially constructed through

experience and interaction with others. There is no single reality because truth is constructed, not found. There is no fixed self; self is understood to be relational and contextually dependent (Holloway and Freshwater 2007a). Because the self is understood to be relational, it stands that I am not claiming that the stories in this research represent the participants as fixed entities who would tell the same stories in a similar manner, were I to re-interview them today. The stories told by the participants were from a perspective constructed on that day, at that time and with me, and as such represent the truth only of that moment (Darlington and Scott 2002).

The embodied sense of personal and social meaning which derives from constructionism provides the subjective sense of self which is responsive in relation to others, which means that it is the very act of self-revelation with another person which makes us conscious of ourselves. The narratives obtained in these interviews are not representations of identities, but constitutive of identities (Bruner 1990; Bakhurst and Shanker 2001).

Epistemologically, constructionism depends on the idea that there are various ways of knowing which are always contextually dependent, and language (verbal and non-verbal) is seen as the tool which mediates that understanding (Butler- Kisber 2010; Denzin and Lincoln 2013 a).

The social construction of mental distress

In order to understand the social construction of mental distress there is a need to detail how understanding of mental health conditions has evolved from early metaphysical and theological explanations, through to more recent scientific understanding, which is commonly held as positivism. Positivism in mental health is seen as reductionist because of the disease framework it is situated within, which means that problems of living and responses to adverse social experiences become overly medicalised (Tew 2011). Walker (2006) adds that the adoption of Medicine as a framework led to the introduction of diagnosis and treatment for these problems. Wittgenstein (1889-1951) believed that problems of the mind and reality were not a

scientific concern and should be considered through language. He is still considered a leader of the post- modern perspective. The post- modernists believe that there are no certain truths, only interpretations. Underpinning this is the acknowledgement that relationships and communication rather than medicine, are better suited to the interpretation of experience (Walker 2006). Berger and Luckmann (1966 p37) state it thus;

“Others have a perspective on this common world that is not identical to mine.....my now does not fully overlap with theirs.....I know that there is an ongoing correspondence between my meanings and their meanings in this world”

According to Horwitz (2012) the current DSM definitions confuse problematic but natural human responses to stress with mental illness. Yet diagnostic conceptions of mental health are entrenched across professions and the public. In contrast, a social constructionist model of knowledge recognises the social meanings attached to symptoms. The roots of these meanings are founded in cultural assumptions which place the meaning in its historical social setting. This means that Western notions of normality and pathology cannot be universally replicated across the globe and throughout time. It is this contextual aspect which is missing in a positivistic approach. This idea is easily understood with the use of homosexuality as an example because of its historical conceptualisation as a mental illness.

The objective and scientific language used to create the categories of diagnosis is stigmatising and exclusive. This is problematic and has caused me much consternation. Unlike a true constructionist, I believe that the DSM does create a pragmatic way of distinguishing the type of resources which are most useful for categories of people in need. There has to be a system of judgement outside of cultural and social construction. This stance does not deny the existence of symptoms of mental health problems because these arise despite and outside of a social construction. A pure constructionist would have no way of critiquing a conceptualisation of mental health

because of the lack of criterion against which to distinguish mental health problems from other socially disordered states (Walker 2006).

The postmodern drive in the UK can be seen in the Governmental papers on health inequality; the Black Report (1980), the Acheson Enquiry (1998) and subsequently the Marmot Review (2010). The aim of these reports was to explore the root causes of ill health such as poor housing, poverty and unemployment. These reports summarise the data on health inequality in terms of socio-economic status, geographic, ethnic and gender variables. All three reports emphasise that health inequalities are the result of multi causal factors. The Black Report primarily focussed upon factors relating to the early years and motherhood, whilst the Acheson Enquiry and the Marmot Review adopted more of a life course stance and from that the Marmot Review identified that it is the cumulative effects of disadvantage and deprivation through life which produces social patterns of disease and ill health. The emphasis upon social determinants has grown with each of the reports, although the Marmot Review was written and has incorporated some of the psychosocial explanations which are popular in mental health service provision at the moment such as isolation, control and empowerment, which again slightly understates the context and time of the research. This has the effect of deflecting attention from the causes of disempowerment and lack of choice. Focus upon a person's psychosocial experience deflects from the underlying issues of the causes of the low self- esteem and stress in the first place (Bamra et al 2011).

The reports do however raise important areas to discuss such as opportunities to create resilience through the environment throughout the life span. Much of this is centred on the creation of sustainable housing in health communities.

Why now?

In the 1980's the population of the asylums began to drop as understanding grew about institutionalisation and its cost to society, as well as the individual. It remains unclear whether the rise of the welfare state was promoted by the cost of institutional

care or whether the emergence of a new moral philosophy which valued human rights and 'least restrictive care' was responsible (Jones 2002). The new philosophy however underpinned the provision of health and social care in the United Kingdom and has evolved in tandem with pharmaceutical and psychotherapeutic progress, resulting in a shift in policy from institutional to community based care. Shorter stays in hospital have contributed to increased numbers of people living in the community with a serious mental health problem. As a result, the role of the family as care givers has had to adapt in line with society's changing expectations, making the topic of study a relatively recent phenomenon (Mind 2012).

Amendments to the Mental Health Act (1983) (amended in 2007) afforded more coercive powers to the psychiatrist, perhaps reflecting some doubt regarding the practicality of such a liberal philosophy within the context of limited resources for community care (Jones 2002). Doubt about the longer term implications for society was voiced as far back as 1966;

“What remains uncertain is the price that has to be paid for keeping the patient out of hospital in terms of the effect on the health of other members of the family. If the cost of keeping a parent in the community; is the development of psychiatric disorder in the children, then it may be too high” (Rutter 1966 p 108).

Parenthood for people who were seriously mentally ill was uncommon before de-institutionalisation, largely because it was traditionally assumed that people with psychosis were less fertile due to the effects of the psychosis itself, and the neuroleptic medication they were treated with. Naturally there was also less privacy for relationships in hospital. Parenthood and mental health are therefore only recently becoming a priority area for policy and research (Caton et al 1998; Devlin and O'Brien 1999; Howard 2000). The adults interviewed for this research are from this new generation of individuals who were raised with parental mental distress largely being treated and cared for at home within the family.

There have been numerous studies which have articulated the raised incidence of mental health problems in the offspring of parents with serious mental distress. The rate of the general population who are diagnosed with a condition such as schizophrenia is around one percent (National Health Service (NHS) 2012; Royal College of Psychiatrists (RCP) 2012; National Institute for Health and Care Excellence (NICE) 2014). This rate increases to 13% life time prevalence for schizophrenia in a first degree relative (such as a child) (National Health Service Genetics and Genomics Education Centre 2015).

Why should we care?

Mahatma Gandhi is reported to have once said, 'The measure of a civilization is how it treats its weakest members.' There is a moral responsibility to care about children who are living in circumstances which are not conducive to well-being. Personal vulnerability is however sometimes challenged by attending to the suffering of others and this may raise feelings of discomfort. The easiest thing to do is to deny that reality, so that the discomfort is no longer remembered. Facing this complex problem, which has the potential to be, at first glance, expensive to treat and manage, takes courage. The cost to society may be greater if we don't. This is a group who has thus far, remained silent and unheard; their ability to camouflage themselves also prevents them from readily seeking help (Graovac 2014). Survival is not enough. The unreached potential of this group is a loss for each individual, and a cost to wider society. AOSMDP are also parents and potential parents, and this has implications for the transmission of vulnerability to the next generation (Lombardo and Motta 2008).

There is a cost of life itself for some children. Reder and Duncan (1999) found that 44% of child homicides in the United Kingdom were perpetrated by parents with mental distress. In the UK each year there are 200-300 deaths of children from abuse and neglect (Wilczynski 1994). These children are generally already known about, i.e., who have usually come to the attention of social services long before they become statistics, which raises the possibility that these children are just a fraction of those

who may be vulnerable.

There is also a cost to the well-being of each individual who has grown up with a seriously mentally distressed parent. Studies on the impact on AOSMDP have shown greater levels of social dysfunction, lower self-esteem, and greater levels of anxiety and depression (Manjula and Raguram 2009; Devlin and O'Brien 1999; Dunn 1993; Bannerman 2009; Somers 2007). The cost of these effects, to the individuals, means that there are a group of people who are unhappy and unfulfilled, and as yet, largely unrecognised as being so.

A further hidden cost is the cost to the health of society. Families with serious mental distress are one of the most marginalised in society, readily becoming socially isolated due to the poverty, stigma, and relationship breakdown which often accompanies mental health problems (The Social Exclusion Task Force 2007). Breakdown of the family structure commonly leaves the family headed by one parent. This is usually the mother due to the later age of onset of serious mental distress in women, and the fact that children generally stay with their mother in the event of family breakdown (Dunn 1993). The risk to children in this situation is that they are then more likely to lose their extended family, which may in turn, also contribute to the social isolation experienced by these families which are more likely to become fractured and separated. The implications for society should also be considered in terms of lost work days and lost potential. The World Health Organisation (2012) estimate that 33.5 % of the worldwide burden of disease in middle income countries; is attributable to mental disorders. Given the increased risk of mental distress in the offspring of adults with serious mental distress, understanding the experience of this group becomes an imperative.

An area of research which is fast gathering pace is the link between physical and mental health. The ACE (adverse childhood experiences) project by Anda and Felitti (2003) was a courageous example of this. ACE was a decade long study from the USA in which 17,000 people participated. The findings demonstrated a link between many physical conditions in adulthood, including heart disease and cancer, to adverse

childhood experiences. The study provided a checklist of experiences such as sexual abuse, violence, parental substance abuse, parental incarceration, parental divorce and parental mental illness. The prevalence of physical health conditions is shown to have a direct correlation with the number of ACEs scored. It was also found, that those individuals scoring four or more ACE markers, were twelve times more likely to have attempted suicide than the general population. The correlation which has been identified between mental health and physical health suggests that it is highly likely, that the cost in terms of burden to society is vastly underestimated.

Statistics and data collection

According to Dearden and Becker (2004), at least 60% of women with serious mental distress, live with children under the age of 16. It has been determined that there are about 175,000 children living with a family member with mental distress (Palazidou 2015). These children will often find themselves willingly or unwillingly in the role of a carer. Additionally Dearden and Becker (2004) also suggest that between 50 to 90% of parents on a children's social workers case load, suffers from mental health and/or addiction problems. They add that it is likely that a large proportion of children in the care system also have parents with similar difficulties. Dearden and Becker (2004) were amongst the first in the UK to try and establish the number of young carers, and what kind of care they are providing. The participants were identified via specialist young carers' projects throughout the UK. It was found that 29% of the young carers reported caring for someone with a mental distress, and 82% identified themselves as providing emotional support and supervision (which was defined as observing emotional state and trying to cheer the person up). The report also offers that 56% of young carers are living in lone parent families. Again, given that the participants were recruited from young carers projects, raises the prospect that this too is a figure a long way short of reality.

Precise numbers of young children living with mentally distressed parents are unclear because the systematic collection of data regarding inpatient parental status is still at

an early stage. Until very recently, estimates of prevalence depended on secondary data, such as census surveys. Children who are living with seriously mentally distressed parents have now become a priority to identify and support. The Department of Health (DH) (2009) stipulated that adult services must develop a systematic process for identifying patients who are also parents, and assess their parenting skills as a matter of course. The implementation of this good practice is however still variable due to local anomalies with the RIO system, which is the electronic recording system in adult mental health care services. A deeper look at current policy can be found in the literature review.

Under-reporting

The number of children who are reported to be caring for parents with mental distress is likely to be a conservative estimation for a number of reasons. This group of children is very well camouflaged and may not readily reach the threshold for services because they are just too resilient (arguably superficially). Mental health services in the UK are designed upon a risk based model which does not allow for the assessment of a quality of life, but only reacts when a person is actively at risk which means that there will be many more child carers who are yet unknown and do not receive services.

Jones (2002) makes an interesting, if somewhat over simplified observation regarding the origins of stigma and shame associated with mental distress which he suspects is a derivative of the Lunacy Act 1845 which demanded that counties provided asylums to offer rest and recuperation, within a family- like environment. The thought was that madness could be contained and possibly cured in an environment which replicated a solid family unit. This thinking gave rise to the assumption that it was the absence of a good family, which caused the distress in the first place, and thus the link between the dysfunctional family and madness was made. Stigma and shame still exist to this day and prevent open acknowledgement and discussion. Service users, in turn have been found to resist disclosure of parenthood, making it likely that official figures will remain somewhat under reported (SCIE 2008a).

The nature of psychosis frequently leaves the person who is psychotic preoccupied by and believing as real, their hallucinations and/or delusions. This means that the person who has a psychosis will often not recognise that their experiences are not shared by others. As a consequence, there may be frequent disagreements about the level of care or treatment which may be helpful. This makes caring for the mentally ill person particularly challenging, and the possibility of risk to any child living in the home, has to be considered. If the parent is single it may mean that there is no other adult aware of the situation. It is therefore possible that unless the person's behaviour brings them into contact with services, the child may be living with a parent who has psychosis possibly unbeknownst to themselves or others, and thus more likely to be responsive to the fears and anxieties related to their parents' psychosis as well as their own (Bannerman 2009). This dynamic is compounded by the evidence that children brought up in families with parental mental distress do not establish ties to their extended family to the same extent, partially due to stigma and partially due to the fact that relationships become difficult for the person suffering severe mental distress (Somers 2007). Therefore, for the parent who is psychotic and unaware, the involvement of services is sometimes experienced with suspicion and fear, which may in turn lead to avoidance or resentment, thus isolating the family further.

The parent who is aware of their distress is more likely to seek and accept support and help for themselves and their children. There is however evidence that some parents resist involvement from services due to the fear of having their family separated (Boursnell 2007; Howard 2000) which has unfortunately created a climate in which it has become more difficult for a person to ask for help with parenting issues.

In order for a parent to be able to ask for support, it is necessary that they must acknowledge personal vulnerability and need, which of course may bring forth an associated sense of guilt and or shame about parenting skills. For a person who has severe mental distress, the distraction, company and support of a child may be helpful and consequently acceptance that the child's well-being is at risk is a thought that may

be too much to countenance. For these reasons, assessment of the welfare of a child growing up with a mentally distressed parent should be sensitive and thorough. Practice and research needs to reflect the sensitivity by hearing what the child and the parent say, together and apart.

Chapter 2

Literature Review

Introduction

The literature consulted in order to position this research was disparate due to its various conceptual sources. There was a need to search the literature from a variety of professional perspectives, as well as the service user/ carer perspective. For that reason the literature discussed here is from psychiatric, psychological, social work and nursing perspectives. In the UK these professionals work either in children's, adults or older peoples services. There is very little overlap and this is considered in more detail further into the literature review. The literature for this review stems from professionals working for child and adolescent mental health services (CAMHS) or adult mental health services (AMHS). The research from the service user and carer perspective is also divided by these age boundaries which reflect the separate policy and service provision for children, adults and older people. There is very little research which derives from a family perspective or considers both the child and adult in research.

Because of the disparate origins of the literature consulted for this review, I have presented it neither in a chronological fashion, nor with a distinction between professional backgrounds, but more simply relating to the type of work which is being consulted. The review is divided into three sections. Other authors (Foster 2010, Misrachi 2012) have used the term 'waves' of research output, which creates a good framework for the literature, which I have 'borrowed'.

The first wave of literature is the outcome- based research which has been identified for COPSMD and AOSMDP. This work is largely of a psychiatric background, although not exclusively. In this section of the review, I have also considered attachment theory. It is outside of the scope of this research to investigate attachment in any meaningful depth, but it is relevant, so there is an overview to create a flow of ideas. Linking to

attachment theory are ideas about inter-subjectivity/ socialisation and parentification which are also briefly discussed.

The second wave of research in this review starts with a discussion about the risk/resilience construct which informs the primary discourse underpinning children's services and has emerged as a result of dissatisfaction with the deficit model stemming from outcome- based research. Again, it was not perceived that this wave of literature is directly relevant to this study, so it has been incorporated briefly so that a reader might be able to follow the progression of research through to the current qualitative momentum.

The second wave research also considers the contribution about carers which proliferated in the 1980's, mainly centered upon the burden/coping construct. More recently attempts have been made to tease out the elements of caring and exactly what that means. Some of this work is also included in this literature review in order to illuminate findings which are relevant for AOSMDP.

Finally, in this section of the review I have also explored current UK policy which is relevant both for children and adults who are family and or carers. Some of the inherent issues and contradictions are illuminated.

In the third and final wave in this review, are the findings from research which has been attained using the perspectives of the carers and service users themselves. I have reviewed this qualitative work in more depth, both in the review and in the discussion chapter, as it is these studies amongst which my own is located. For this reason the strategy used for identifying relevant literature is shown at the start of the third wave of literature consulted. Most of this research stems from nursing and social work. It is the most recent contribution to the knowledge base, influenced by the rising awareness of the service user and carer perspective in mental health services.

Outcome- Based Research

Much of the work on the impact of parental mental distress has been conducted from

a psychiatric and psychological perspective. It is therefore mainly of an empirical nature and stems from a positivistic philosophy which largely views mental distress from a pathological perspective. The risks and deficits for children growing up with parental mental distress have been identified as partially deriving from genetic risk, along with environmental risks stemming from the social consequences of living with severe mental distress.

Some of the research from the 1970's and 1980's centres on the children of parents with a specific mental illness diagnosis, reflecting societal inclination to give precedence to the medical model.

In the early 1970's the psychiatrist Bleuler conducted one of the first longitudinal studies on the outcomes for children of parents with schizophrenia, following 184 children over 23 years. This time frame allowed for the children to become young adults. His research found that internalised shame, loyalty to parents and fear, often led to the participants remaining silent about their suffering. He also noted that these children had often become separated from their parents when they were hospitalised and this had led to instances of living with wider family or foster carers (Bleuler 1972).

Other well-known work comes from Rutter (1966; 1972) and Rutter and Quinton (1984) who studied 137 families over four years with two control groups. The findings from this study pointed to approximately a third of children who were deemed to be well, a third who had developed a transient problem in childhood, and a third who had developed a more persistent problem. These estimated numbers of children raised by a mentally ill parent who will develop a disorder during childhood and adolescence have been supported more recently by Cowling et al (1995, 2004) whose work suggests that the development of distress in this group varies between 25- 50%. They continue that for those children who are raised by a parent with a psychotic disorder, the lifetime prevalence of developing a psychosis themselves has been put between 5-14%.

The study by Rutter and Quinton (1984) also attempted to identify some of the

underlying mechanisms of transmission. The researchers argued that the genetic basis of transmission is not well enough understood to be considered evidence- based, particularly since their study explored symptoms developed in childhood rather than later on in adulthood. They did however consider that the impact of the distress was important in cases particularly when the parental symptomology such as delusions or hallucinations involved the child or where the child was neglected for pathological reasons.

The third area which was explored in the Rutter and Quinton (1984) study was the environmental impact, which was considerably worse for those families in which marital discord, poor housing and poverty was present, and these social issues clearly correlated to increased risk for childhood mental distress. These findings have been repeatedly consistent with the later work relating to social inequalities the most recent of which is the Marmot review (2010). The other significant finding in this study was that when the parents' level of distress increased, approximately a third of their spouses also became distressed. This was attributed to the stress of living with mental distress as well as what has been termed 'assortative mating ', (Kalsched 2013) whereby a vulnerable person is more likely to select a partner who also has mental health vulnerabilities.

From a psychological perspective Stern (1985) discusses the concept of 'self-coherence' in adults with psychosis. Problems of self- coherence relate to psychosis exclusively. The person with a psychosis, he argues, no longer has a sense of wholeness with physical and psychical boundaries. Wholeness is distorted and may lead to experiences of fusion or merger with the other. In a spousal relationship this can lead to both partners sharing pathology or 'folie à deux'. If the adult with a psychosis is a parent, then it becomes possible that the child may become engulfed in the parental pathology and incorporated into the delusional system. If there is no other adult available to support the child and mitigate this risk, in rare cases a folie à deux may develop between parent and child (Hall 2004). The challenge for the child is to

distinguish between the parent's version of reality and the evidence, and this awareness may then help the child to differentiate their own reality from others, which in turn affords some protection.

The consequences of mental distress leave the family at a greater risk of further potential pitfalls which relate to the dynamics of the relationship affected by mental distress. These include negativity about the child including rejection, neglect and emotional unavailability, inability to maintain boundaries, give support and love, distorted and confusing communications, ongoing hostility and criticism and inconsistent and inappropriate expectations (RCP 2002). The dissolution of psychic boundaries, inadequate supervision and emotional unavailability may lead to a lack of protection available to the child thus also exposing them to a greater risk of abuse from within and outside of the family (Devlin and O'Brien 1999; RCP 2002). The Royal College of Psychiatrists state;

"The mechanisms involved in the emergence of disorders and problems in parents and children will include some or all of the following: genetic factors, the quality of the child's early attachments, rearing environment and parenting, life events, family discord, the nature of the psychiatric disorder and its associated manifestations; and social and economic factors" (RCP 2002 p8).

More recently Mowbray and Mowbray (2006) and Mowbray et al (2006) articulated a concern that due to the peak age of onset of severe mental distress being in the twenties for men and for women, slightly later, the outcome measurements of psychiatric disorder for children of parents with mental distress could not be seen as complete. Their studies therefore recruited adult children, rather than young children. The adult child and their parent were interviewed for the Mowbray et al (2006) study. The findings were largely consistent with other studies and determined that approximately a third of the adult children had not finished high school, a third had psychological problems, and they surmised that many had relationship difficulties. This was on the basis that only one in nine was in a committed relationship, despite the

average age being just 22; which seems a little premature to make the claim that these individuals had relationship difficulties. 38% of the adult children were already parents themselves. This work was a small scale quantitative study which measured the outcomes for adult children of mentally ill parents.

There is no doubt that AOSMDP are disadvantaged and that growing up with a mentally distressed parent presents the developing child with a number of hazards (Falkov 2009; Gopfert et al 2004b). Higher rates of mental distress, higher rates of substance abuse, lower self-esteem, relationship difficulties and lower rates of academic achievement are all found in a greater percentage than the general population (Falkov 2009; O'Connell 2008).

Subsequent to some of the work on potential risk and outcomes, has been a body of research exploring the care and support of the child. This work has identified and addressed ways of helping children understand and articulate the experience of living with a mentally distressed parent (Gopfert et al 2004b). This body of work also includes the assessment of children in crisis, child caring and service developments to support children coping with distress (Cowling 2004). Prior to exploring this work, it is important to consider first the contributions from psychological theory.

Socio-political factors

The Department of Health (DH) (2004) issued the 'Ten essential shared capabilities' which are socially oriented capabilities at the core of practice. The fourth capability is 'Challenging inequality' which relates to addressing the causes and consequences of stigma, discrimination, social inequality and exclusion. The origins of the social approach of this document has been based upon the work by the inequality reviews such as the Black report (1980) and Acheson enquiry (1998) followed more recently by the Marmot review (2010). All three reports clearly state that health inequalities are a result of societal differences and inequalities which are multi causal.

Perceived social injustice has a higher prevalence of mental distress than poverty per

se. Disadvantages stemming from poverty, social exclusion, stigma, unemployment, and poor living conditions in poor neighbourhoods are all now well known to be linked to poor physical and mental health (Tew 2011). Mental wellbeing is not just an expression of inner lives; it is also about the quality of social relationships, connections, and the ability to experience fairness, inclusion, respect and opportunity.

Pilgrim (2008) writes that the poverty is accompanied by losses stemming from a variety of sources which include loss of finance, loss of daily structure and for some; loss of face which further influences the wellbeing of the person.

Research in Finland has found that the effects of an adverse environment are much greater than the genetic influence as a contributory factor of serious mental distress. The combination of both was found to be particularly pernicious (Tienari et al 2004).

Presently there is much discussion about cultural and social capital. 'Cultural capital' means the persons cultural locality; the neighbourhood, the school and social and familial expectations. 'Social capital' is the network of connections which support a person in adult life (social cohesion). The discussions and debates are around how cultural and social capital relate to the way in which people consciously and unconsciously maintain or alter their social position, well-being and quality of life. The argument is, that if a person comes from a poor background (commonly seen in people with mental distress) the personal identity is moulded by social and family expectations including schooling and future employment. This means that most people develop a sense of 'knowing their place' which then becomes their cultural capital. Pilgrim (2008) argues that a person's cultural capital does not prescribe their social capital; but it does predict it. It seems that what he means is that it is very hard to shake off early deprivations.

Mental health care is seeing a long overdue shift towards a more social approach but this demands values in partnership and empowerment based upon the recognition

that inequality stems from difficulties and deprivations in the persons background or family of origin, leading to problems in living. Mental health care provision in the UK has some way to go before this becomes anything more than tokenistic. Unfortunately the psychosocial movement in mental health care has deflected the focus of attention from the socio-political to internal explanations of distress. This has meant that the underlying causes of the disempowerment and lack of choice which drives decision making are much ignored (Tew 2011).

Attachment

Developmental theory posits that children have a number of vital needs which must be met in order to grow into healthy, well-adjusted adults. These include love and protection, stimulation, opportunity for social interaction, an effective learning environment, physical and emotional sustenance and a secure attachment.

Attachment to a care giver is the long term reciprocal emotional bond viewed as a fundamental start to adult life (Howe 2011).

Bowlby (1998 a,) was a children's psychiatrist who initially became intrigued with the emotional bond between a child and their care giver. He began his research on the effects of separation, deprivation and loss around the time of the Second World War, noticing that prolonged separation from a caregiver was often followed by an emotional bluntness, thus the link from early deprivation to subsequent mental distress was thus made. After the war, Bowlby joined forces with Mary Ainsworth and together they proposed the theory of attachment. Despite the subsequent criticism of Bowlby's work, it is still a foundational element of psychological study.

Attachment theory relates to the behaviour shown by a human being when they are hurt, frightened or separated from their loved one. It is not a relationship theory but a theory which attempts to explain the differences in a person's care seeking behaviour i.e. the innate sociability of the infant in order to elicit care giving behaviour from an adult. Babies who can elicit care giving behaviour from an adult obviously stand a greater chance of survival. Sociability is at the heart of a person's drive towards

others. It is found in all humans to some degree with a direct correlation between friendliness and the ability to form attachments (Howe 2011).

Bowlby thought that every caregiver has times when they are tired or distracted and that it was not the mismatch of communication which was crucial, but the sensitivity with which those ruptures were later repaired. Children then learn how best to protect themselves from anxiety when they cannot rely on the consistency of their caregivers availability and responsiveness. It is the constancy of interaction with the caregiver which allows the baby to develop their internal cognitive schema, which forms the basis of future attachments, ability to cope with stress and the regulation of emotion. The style or quality of an attachment continues to evolve during childhood and adolescence in relation to subsequent styles of relationship. The adult intimate relationship (rather than friendship) is considered to display the characteristics of the early attachment style (Weiss 1991). Despite the constantly evolving nature of the primary attachment style, it is still understood to be a cornerstone for the individual's later emotional development. Securely attached babies have also been shown to demonstrate higher levels of self-esteem and self actualisation in adulthood, and it is thought that delay or disruption to the attachment often has far reaching detrimental subsequent effects on the individuals' sense of wellbeing (Rutter 1972; Bowlby 1979; Holmes 1993).

There are three main styles of insecurely attached infants and these are described as ambivalent, avoidant (or anxious) and disorganised. Avoidant styles of attachment are those in which children fail to cry or protest during caregiver absence, and fail to greet the care giver on reunion. Ambivalently attached children cry on separation, but are not easily consoled on reunion. Disorganised attachment is characterised by children who are overwhelmed with distress when their caregiver does not respond.

Bowlby (1979) maintained that any kind of emotional disorder will impact on the persons' capacity to emotionally bond with their children. Anxious and ambivalent styles of relating have been observed in greater numbers in mothers with mental

distress and a disorganised style of attachment is most often observed in children of parents with alcohol/substance misuse and depression.

Evacuation policy work completed by Bowlby during the Second World War predicted rising levels of mental distress amongst those children who were separated from their mothers during these years. Unfortunately for researchers, the timing of the increase in community psychiatry clashed, making patterns more difficult to identify. However the current political climate makes it important to recognise, because a secure attachment creates a resiliency into adulthood which increases the threshold for vulnerability. Conversely an insecure attachment in childhood lowers the threshold for vulnerability (Bowlby 1979; Rutter 1972; Holmes 1993).

One of the criticisms of attachment theory is that the research was primarily confined to twentieth century Europe. Because culture is passed on through the process of socialisation, most especially child rearing practices, it is important to compare European findings with those further afield so that the effects of attachment can be differentiated from cultural influences. So far cross -cultural research has generally supported attachment theory, which points to the conclusion that aspects of attachment are innate rather than culturally determined. However an attachment should not be considered inevitable or universal but dependent upon cultural and environmental conditions (Diamond and Marrone 2003; Parkes et al 1993).

Socialisation

The early attachment of the child and caregiver is influenced later by processes of socialisation, whereby an individual is taught to adapt to a new context or culture. In order to 'fit in' the individual has to learn the behaviours, skills, values and morals of the culture (Maccoby 2007). This process of socialisation occurs in families, schools and employment for example. The most significant primary socialisation is assumed to occur within the family context, whilst the child is growing up, and is thought to be the bedrock of the individuals' ability to self-regulate their behaviour and emotions, thus enabling participation in reciprocal relationships.

The process of socialisation is thought to be 'relational'; i.e. the young child's sense of trust and security along with other personality characteristics are directly influenced by the quality of parental care. The child develops ways of relating to the parent which elicit the required care or interaction. Close emotional attachment in which warmth, security and reciprocity underpin the motivation to respond to parental influence. The emotional tone, content and style of these interactions are then introjected by the child and develop into an internal working model of relationships which is carried forward and modified further along the developmental trajectory (Malekpour 2007).

Children also imitate their loved ones, so if a parent is open and secure with others, the child will grow up imitating this behaviour. Alternatively if the parent is wary or anxious amongst other people the child will learn this behaviour. Social behaviours are also learned through the process of role modelling. If a parent is controlling, it is more likely that the child will become controlling with their own peers. Whilst growing up, the child internalizes the world of the significant other, usually a parent. The internalisation process will include the attitudes, roles and values of the parent, so that when a parent is unwell it is likely that the child who is socialised to offer care in the event of ill-health will automatically adopt this role. This is perfectly natural and harmless in the short term. The 'normal' role of the child within a family is largely culturally determined and this has relevance when considering the role of the young carer. As such, caution should be exercised when assessing families from other cultures where the structure of the family, the values and expectations of children, are unknown or where the culture prioritises family relations above individualism.

Young carers

It has been estimated that in the UK there are 50,000 children who are deemed to be looking after an ill or disabled family member (Becker 2012). The young carer is defined as someone who is under the age of eighteen, and involved in developmentally inappropriate tasks of either a nature or extent that restricts experiences and opportunities which are crucial to their development. Despite the vast body of

research on adult caring there is surprisingly little qualitative work published on the impact of young caring.

Aldridge (2015b) suggests that it cannot be assumed that every child living at home with a mentally unwell parent is a carer. Caring, she says is just one outcome. This is where the language of 'young carer' becomes problematic because living with someone with a serious mental distress has ramifications, whether the child carries out domestic duties or not. Caring 'for' and caring 'about,' both affect the carer.

Aldridge and Becker (2003) and Aldridge (2006, 2015a and b) have tackled the subject of young carers in the UK. Whilst their work has provided a spring board for other researchers to add to, it is limited by its rather literal understanding of caring, particularly with regards to mental distress. In 2010 Aldridge completed a study involving vulnerable children in a photographic representation of "what really matters to you" The use of photography, whilst innovative, may be seen as focused upon the tangible and visible; skewing the understanding of young caring to the domestic, or at least measureable, which may be considered a simplistic interpretation. As pointed out by Misrachi (2012p 128) Aldridge appears to have accepted the plight of young carers rather uncritically, as also demonstrated by her assertion that caring for needy parents can be good for children(Aldridge 2006 p81).

Unfortunately the media's representation of the young carer as noble and self-sacrificing is unhelpful and the awards which are given out to children who care, making them into little hero's serves only to add a moral compulsion to the role. Despite this, advances in media reporting and initiatives such as 'child line', have ensured that children's welfare, safety and rights now generally assume a higher profile in the minds of the general public.

Philosophical change was made apparent with the introduction of The Children Act (1989) (now updated to Children's Act 2004 and the Children and Families Act 2014). This legislation marked a turning point in the UK regarding the care and treatment of children. The welfare of the child was its central principle and the underpinning

philosophy of the legal framework was that children are generally best cared for within their own families wherever possible (SCIE 2008a and b). This philosophy has undoubtedly impacted the numbers of children who live with a parent with mental health problems rather than being provided for by social services (Weir 2004).

In the UK in 2004, the Social Care Institute of Excellence (SCIE) and the National Institute for Clinical Excellence together initiated the Parental Mental Health and Child Welfare Network. The aim of the network is to share and disseminate research, information and best practice examples in order to assist in the development of national guidance and professional development. SCIE were subsequently commissioned to undertake a report for the Department of Health. The project brief was a series of literature, policy and practice reviews which culminated in the publication of 'Think child, think parent, think family' (SCIE 2009). This document lays a foundation stone for future policy, practice guidance and research to be built upon. It advocated an early intervention, whole family approach as being best practice. Since then, interest in parenting has grown, and government initiatives such as Sure Start emerged and highlighted the deficit of support available to families in need, in particular those where there is parental mental distress (Barnado's 2011).

The Children and Families Act (2014) also now demonstrates a more explicit focus on parenting. Whole family assessments are advocated rather than the carer as an individual. New duties to identify young carers are now mandatory as are responsibilities for strengthening family resilience. The assessment of young carers now also has categories such as education, employment and aspirations. The idea of offering family assessments can be seen as a step toward the whole family approach advocated by SCIE (2009). In 2014 the Department of Health issued "Closing the Gap" which also addresses the need to support parents who have serious mental distress. Time will tell whether these notions go far enough.

Despite the changes in policy regarding the status of the child and recognition of the carer, children who are brought up with parents who have serious mental distress,

with the exception of those who fulfil the criteria for child protection intervention, have remained for the most part invisible and unheard. There are a number of reasons why the development of UK policy has been problematic and slow. Firstly, the 1990's saw increasing specialisation in mental health care which may have inadvertently contributed to a deepening split between the Child and Adolescent, and Adult Mental Health Services (CAMHS and AMHS). AMHS primary focus is the individual and pays a lack of attention to the individual as a parent; in turn, clinicians from CAMHS have tended to pay insufficient attention to the parental mental distress. Separate legal frameworks have produced separate guidance on policy and practice which has prevented the two services from developing a robust interface (Falkov 2004). The training package 'Crossing Bridges' (Falkov 1998) was designed in order to address this issue, by increasing collaboration and communication between services involved in working with families where there is a parent with mental distress. Unfortunately, despite being commissioned by the Department of Health, its implementation was not centrally coordinated and there was no systematic evaluation strategy (Diggins 2009). The Royal College of Psychiatrists (2002) advocated for sessions of 'family psychiatry' which would bridge CAMHS and AMHS. They also recommended that all psychiatrists in training should experience a CAMHS placement. Additionally, professionals working in front line adult mental health services have been recorded as saying that, not only do they feel unqualified to work with and talk to children, but also that it can pose a conflict of interest regarding the therapeutic relationship with the adult, which is built upon trust. Anxiety about breaching a persons' confidentiality is frequently cited as a reason for not talking to a patients relatives (Devlin and O'Brien 1999).

There have been recent attempts to pull together the work which has been done on COSPMD and AOSMDP, so that a clearer way forward may be identified. Progress has been most obvious in Australia, and as a result children of parental mental distress been identified as a priority group for governmental attention (Singleton 2007). The COPMI website is a rich reservoir of policy and guidance for clinicians/ parents and children, as well as a link to a fast growing database of research and examples of local

practice initiatives. Unfortunately this initiative has recently faced some funding concerns, which have meant that its survival is now under threat.

In clinical practice, (in some areas in the UK) CAMHS are already supporting children identified as having a parent with a severe mental distress. There have been some innovative groups run for example, which aim to provide the children with a network of contacts in order to reduce isolation and help the children to articulate what they are experiencing. Referral is generally via AMHS i.e. when an adult is admitted to hospital their parental status is now recorded so that the child or children can be referred to the local young carers' service, and then onwards if deemed necessary. This does not happen with enough regularity, partly because there is still a lack of awareness about the implications for children, and also lack of communication regarding the existence of the services. It appears then that unless a service has a statutory responsibility to refer, development and maintenance of other services are no one's responsibility or financial priority; therefore recognition of the needs of the child who has a parent with mental distress is still vague and services scarce (Devlin and O'Brien 1999).

If children are already in contact with social services they may be offered a transition service so that they are not on their own from the age of eighteen. The children picked up by these services it could be argued are the lucky ones. The threshold for admission to hospital is high which means that there must be many, many more children who never come into contact with services at all. These children either have to meet the criteria for adult mental health services themselves, or alternatively identify themselves as a carer in order to receive a care assessment in their own right.

Identification of oneself as a carer in mental health is emotionally loaded and is neither easy nor helpful, for the child or young adult. The complex dynamics in these families may make separation of the young adult from their parent very difficult and acceptance of the role of carer may actually make this adolescent /young adult task much harder. It would also necessitate a complete abandonment of any denial which

the family may be using as a coping method. Therefore, early identification of oneself as a carer could be perceived as likely to thwart any potential opportunities for growth and individuation. The use of the term 'young carer' should be used with the utmost caution for children living with parental severe mental distress. Use of the terminology in this context highlights severe deficits in the parent's care package.

Parentification

Parentification is a term initially coined by Boszormenyi-Nagy and Spark (1973) and used to describe the role reversal which is sometimes seen when a child takes on a caring role. It is prompted by a parental figure who expects the child to fulfil a parental role in the family system. The parental role which is subsequently adopted by the child may include caregiving or gratification of parental aggressive, sexual, or dependency needs (Earley and Cushway 2002). According to Jurkovic (1997) the cross generational styles of relating are a result of the parent who seeks to compensate for their own losses in childhood. Jurkovic adds that a parentified child will show the consequences both in the short term, and the long term once they reach adulthood. Like the measurement of the impact of trauma, the full effects may only be evident at a later stage. From a sociological viewpoint, a role is frequently related to an identity; so that if the role of parent or child is altered, the identity of that person is also affected (O'Brien 2011). Aldridge and Becker (2003) contest that most children are able to distinguish between their care giving roles and their role as a child within the family, and therefore do not see themselves as parenting their parent. It is perhaps the subtlety of emotional care that makes the visibility and measurement out of reach to researchers and possibly also the child concerned who is *unable to see* themselves as parenting the parent.

One of the outcomes resulting from the lack of ability to perceive and manage the child's emotional state, is that the child learns to give up their own needs which cannot be heard by the parent, i.e. the child by default, has to abandon their childhood status and developmental needs. A pattern of giving up one's own needs is then established

and may continue into adulthood. Problematic adult relationships are a legacy of this childhood pattern of compulsive care giving (Chase 1999). Chase adds that, childhood defenses against the stronger narcissistic demands of the adult associated with parentification, include denial and avoidance. The child is therefore blindly self-sacrifices their own developmental needs. Unfortunately, as the child becomes parentified and adopts adult roles, their isolation from peer groups may intensify. Finney and Falkov (2009) concur, and add that children may also become very conscious and sensitive to reactions regarding their parents' appearance and behaviour and may avoid asking school friends home as a result, thus compounding this isolating experience.

Risk/resilience construct

Research on the impact and the psychosocial outcomes of mental distress on family members has been becoming more frequent since the 1960's. The majority of the studies relate to identifying and mitigating risk. However, latterly there has been dissatisfaction with deficit, or risk based models, and this has led to an attempt to balance risks against any moderating or protective factors i.e. the identification of features which allow the child to thrive despite significant adversity. Both risks and protective factors can be construed as cumulative, i.e. the more protective factors which are found in a child's life the greater the likelihood of resilience and vice versa. The risk/ resilience construct is situated within a larger discourse regarding childhood and risk i.e. A child's physical and psychological vulnerability renders them in need of protection during the critical development period of the formative years (McConnell Gladstone et al 2006). The term 'risk', in this context is therefore relative to environmental and personality traits such as the age and developmental stage of the child involved when the parent becomes distressed rather than specific to children who have special needs such as mental or physical disability. The term has been adapted from medicine, whereby particular risks are identified in an attempt to predict vulnerability and subsequent outcomes (Howard et al 1999). Resilience is also an

intangible concept, which may be transient depending on the specific environmental context and developmental stage of the individual.

Adoption of the term 'risk' in social care and mental health care has allowed for identification of individuals and groups who may benefit from specific intervention, and thus appropriate allocation of resources. It does also pose some problems; risk status is generally determined by objective factors which are measurable and quantifiable. This leaves the withdrawn and sad child who is posing no problems at school and still achieving reasonable grades, at risk of being overlooked. Risk factors may be subject to ideological drives such as values relating to the 'normal' culture, family structure, appearance etc. The 'at risk status' also identifies the individual as vulnerable which can, not only lead to stigma, but also to the offering of interventions which aim to change children rather than support them (Howard et al 1999).

Furthermore, the problem with using risk as criteria for resources is that opportunity for early intervention is often missed when a person does not reach a level which warrants intervention until they have reached a level of risk (Hetherington et al 2002).

The study of what makes a child resilient has shown a number of factors to be significant, such as a high IQ, personal qualities such as humour, self- esteem and problem solving skills, warm relationships with parents, peers and teachers, involvement in activities out- side of school and low levels of parental discord (Heriot 2009; Foster 2006). Also considered important, is having an internal locus of control which relates to the ability to feel master of one's own destiny rather than a victim of life (Rutter 1984). Rutter (1985) added that having one mentally well parent may also be a protective factor, although he also stressed that the impact of resilient features must be regarded with some caution, as they can be misleading. They can only ever be estimated, due to the inherent variables and complexity of life and cannot therefore be measured either individually, or in multiples.

Initially the body of work used to describe resilience used the term 'invulnerability' to research potential protective factors (Anthony and Cohler 1987). Labelling of children

using terms such as 'resilient' 'invulnerable' or in one instance 'superkids' (Kauffman et al 1979) is risky in itself, and has the potential to allow society to dismiss children as coping, and thus absolved from having to ask poignant questions, find resources or even care (Mordoch and Hall 2008). Interestingly, in novels, rarely would anyone be found to be invulnerable. The descriptive terms of resilience and invulnerability would be perceived as antithetical to the human condition. In contrast to this, medicine draws upon reductionist language which fails to convey the complexity of humanness.

Based upon these ideas of risks and resilience, much work has been produced from a practice standpoint i.e. books and journal papers which are not necessarily research but have presented ways of helping children understand and articulate the experience of living with a mentally unwell parent, assessment of children in crisis and service development to support children coping with distress (Cowling 1999, Gopfert et al 2004). Attachment theory and developmental theory underpin this kind of work. More recently there has been research underpinned by postmodern methodologies which have attempted to elicit the child's perspective on their caring role and perceptions of the terms resilience and vulnerability. This is a welcome addition to the existing work and adds another relevant dimension to the discourse.

Much of the work on the impact of parental mental distress has been conducted from a psychiatric and psychological perspective. This means that practice guidelines are focused upon the individual, largely neglectful of their context and relationships. Research conducted in the social sciences which does consider relationships, tend to focus on the study of the adult /child relationship and there remains a gap in the study of adult/adult relationship.

Carer research

A steep rise in the amount of research into the impact of caring, and its consequences for the informal carer ensued after the advent of the Carer (recognition and services Act (1995) which precipitated an increase in studies about carer burden and coping in particular. The main discourse about care and the majority of current policy on

informal care provision is centered upon the notions of burden and task (Henderson 2001, Stickley and Freshwater 2002). This may be representative of the medical bias found in health care which tends to prioritise empirical research and pathology.

The emotional aspects of caring are grossly underreported. It is the invisibility of this aspect of care which renders it out of reach to quantitative research (Henderson 2001). The recovery movement in mental health care has stimulated research into service user and carer perspectives. Much of this research tends to adopt a qualitative approach which attempts to hear the thoughts and understand the experiences of those on whom the research is focused. This perspective has identified that service users and carers tend to be less concerned with symptoms and tasks and more concerned with conceptual notions such as hope, self-esteem, relationship and identity (Bonney and Stickley 2008).

Coping methods employed by family and carers of people with mental distress is another area which has not been researched well. However, Kinsella and Anderson (1996) conducted a retrospective study on the coping strategies used by offspring and siblings of those who have serious mental distress. They found most of the adults in their study using mechanisms such as escape, isolation, acquiring information, and spirituality to help. There however, appears to be a paucity of literature regarding the helpfulness of statutory service provision and web based support in relation to the carers or relatives of people with mental distress.

Chambers et al (2001) studied the support needs and coping strategies of a group of adult carers for people with dementia, and found that the carers frequently cited their emotional needs as being particularly difficult to bear. It seems that the problem is that of teasing out the difference between 'caring for' and 'caring about'. Bobinac et al (2011) provide a useful approach to the discussion on caring with their work on 'separating family and care-giving effects'. They have attempted to distinguish between the emotional burden of caring (care giving effects) and the personal impact on one's self (family effects). The family effects include grief and distress at the plight

of the loved one. Guilt could also be seen as fitting the 'family effects category' and has been documented and related to how much care one is able or unable to give without becoming depleted (Braine and Wray 2016).

Use of the term 'carer' is problematic in itself. It is a term which has grown since the introduction of the Carers (Recognition and Services) Act 1995 (Department of Health 1995) and has become common parlance to depict both statutory and informal/family carers. There is a great deal of concern about its use, particularly in the field of mental health, where to be 'cared for' may be perceived as inherently disempowering or dependent. A study by Henderson (2001) found that some carers were ambivalent about identifying themselves with the term carer, and instead argued that they cared about, and/ or performed tasks for their relative as a natural part of their relationship. The title of their paper is a quote from one of the participants "He's not my carer – He's my husband". This quote highlights how adoption of the term 'carer' can be seen to undermine or somehow diminish the relationship role. With this in mind, the term 'Young carer' becomes even more problematic, because if adoption of the term is seen to diminish the role of the family member, then childhood naturally becomes foreshortened in favour of role.

In the UK in 2006 there was a campaign to give the word 'carer' a protected status as a statement of value in recognition of the financial savings for the government (Lloyd 2006). Interestingly in other European countries the word carer is not used, the preference is to use 'family' or 'relative' (Braine and Wray 2016).

The relationship between the service user and the carer has been explored by Yeates (2007) and was shown to be fraught with ambivalence, stemming from a number of conflicts such as the dependence of the service user which was resented by both parties. The language of 'carer' and 'cared for' exacerbates this and are terms for which both parties have expressed disliking (Henderson 2001). It may be that it is the ambivalence associated with the role of carer which causes the person to want to escape and isolate themselves as a coping method (Kinsella and Anderson 1996).

Lack of choice was articulated by carers in the study by Arksey and Glendinning (2007) who suggest that it is the lack of appropriate alternatives which impel the caring role, which is often assumed with resentment that caring will inevitably curtail the carers own life. Yeates (2007) agrees, and says that the implications of commitment and dependence which stem from the language of 'carer' are filled with responsibility and a sense of entrapment. When these hidden notions of caring are appreciated, it becomes unsurprising that AOSMDP are a group who remain hidden.

Tensions were also shown to arise when the carer and service user disagreed regarding the uptake of statutory support, which is a more likely outcome of caring for someone with a mental distress due to differences in the perceptions of need. The change in the dynamics of the relationship from cared for to carer, may also bring envy particularly as the care giver sees care being given to their loved one but who is not entitled to statutory care of their own by virtue of their wellness. This is at the root of the sense of abandonment which Yeates (2007) argues exists, and is at the bottom of the resentment and ambivalence in care giving. The ambivalence is added to by the stigma of having a relative with mental distress (Jones 2002, 2004).

In order to advance purported goals of social inclusion and antidiscrimination, the inherent ambivalence within the role needs to be recognised and validated. Policy chooses to see the dyad of carer and service user as a partnership, when in reality there is a sense of abandonment within the relationship (Yeates 2007). Abandonment was also found by Jones (2002, 2004), who found that caring for someone with mental distress is characterised by grief, stress and fear, and it is these aspects of caring which have remained shrouded by the attention on task and burden.

There are valid arguments against the use of the term 'carer' by the very people for whom this concept has aimed to make life easier. Henderson (2001) rightly points out that that unless there is clarification and agreement at service, policy planning and ethical levels, empirical research such as identifying numbers of carers and uptake of carer support services, cannot be carried out with any validity, and will have profound

implications for the uptake of carer support services across the country. Until such time as the word is replaced with a more acceptable term whose definition is shared by the public, policy and practice, the subject will remain confused.

Legislation which is based upon an incomplete grasp of what caring actually entails is unsustainable, sentimental and cannot with honesty purport to be based upon the notion of choice, partnership and the pursuit of one's own life goals. It appears that there is some reluctance to engage with the more gritty aspects of caring such as the ambivalence and resentment of dependence. Carer policy is, as a result naïve and services appear to be confused about whose needs are actually being addressed.

Recent service developments have shown a proliferation of carers groups and family work offered within adult mental health services. New dedicated carer liaison roles have been created in some areas, and their role is to provide support and psychoeducation in order to enable the carer to feel more supported in their caring role, which in turn allows the patients care to be optimised (Devlin and O'Brien 1999). Identifying these developments as services for carers may therefore be somewhat misleading as services designed truly for carers remain limited.

Carer policy

The importance of mental health and wellbeing is beginning to filter into public consciousness due to various media campaigns such as 'Time to Talk'. Various television personalities have been brave enough to speak openly about their mental health problems, and this has played a part in the reduction of stigma thus enabling a more open discussion than ever before. In tandem, Governmental policy in the UK has been updated to include an increased awareness of carers and particularly young carers, and with this in mind the following paragraphs aim to elucidate how this has aided understanding of the role and impact of caring for an unwell family member.

Since the 1960's, in tandem with the developing welfare state and associated increase in care being provided in the community, discussion of informal care has become

increasingly evident in the literature. Formal care is that which is provided by paid employees; Informal care is assumed to exist naturally in the community, provided by family and friends.

There is considerable debate, and little agreement about the definition and role of an informal caregiver. Current policy shows some inherent inconsistencies and conflicting information, upon which current services are being designed. The term 'carer' has become part of everyday language in today's health and social care environments and contemporary research. Its use has become commonplace since the late 1970's when the feminist literature which was being written at that time, began to highlight the role of women in the family, and the caring responsibility which fell largely on their shoulders. Before this time, there was no reference to informal caring in society.

In 1995, the Department of Health published the Carers (recognition and services) Act (1995), and for the first time, carers became the object of governmental policy. This meant that carers became entitled to their own assessment for support, providing they were delivering "regular and substantial care" to their loved one.

More recently the Care Act (2014) has made the assessment of a carer easier to attain, with the amended wording "When the carer appears to have such needs." Undoubtedly this amendment will reach far greater numbers of adults providing care for their mentally ill family members and is much welcomed. The Care Act (2014) states that the assessment must include;

“(A) whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care. (B) whether the carer is willing, and is likely to continue to be willing, to do so”

It continues that the carer must have identified elements in their life, which they are unable to fulfil, such as a desire for more social time, or meeting other family needs. The provision of carer support is dependent upon whether it "could contribute to the achievement of those outcomes" (Para 10.5).

The willingness to care is therefore assumed unless a person deliberately opts out via a carer assessment. In practice however, the role of the informal carer is often perceived as being without much choice. It has been established that there are strong notions of expectation, duty and obligation to taking on a caring role, and that it is often in the absence of a viable alternative that it is adopted, which undermines the ideology of partnership and choice for carers. It appears that both practice and policy neglect the complexity of the care giving dynamic and tend to see the two elements as inherently harmonious. There is evidently also some confusion about whether the carer is a provider or a consumer.

A further complication for families of people with serious mental distress is the Mental Health Act (1983) (amended in 2007) which affords decision making rights to the 'nearest relative'. The review of the MHA in 2007 extended this right to civil relationships. The nearest relative role can be assumed to have controlling, or at least monitoring functions. The underlying principle here would appear to be that the term 'relative' and the term carer are not synonymous. However the development of the discourse of informal caring has persistently used the terms interchangeably. This is an important area to consider because of the number of families which are led by a single parent, thus often leaving the nearest relative likely to be an adult child. In turn, there are obvious practical difficulties if the adult child exercises their right to be excluded from care duties. Therefore notion of 'choice and partnership' in caring, is flawed so long as the carer is seen as a resource for the state. Leaving cost implications aside, this would not be as problematic, if the nearest relative had to 'opt in' rather than 'opt out' of the role.

Uptake of the role of carer has been shown to be inherently laden with contradictions and risks to the AOSMDP which is further complicated by legislation which may enhance the sense of entrapment discussed by Yeates (2007). The sense of entrapment is discussed further in the discussion chapter.

Review of qualitative work

Over the last two decades there has been an attempt to add to the literature base a new perspective, that of the lived experience of the COPSMD or AOSMDP. This work has stemmed from various disciplines, mainly nursing, social work and counselling, and has primarily adopted qualitative methodologies. This is a welcome addition to the existing research and adds further insights to the discourse. However, as yet, this area still stands in some contrast to the plethora of studies on service user experience. It seems qualitative research with children is slightly more plentiful than studies examining the adult child/ parent relationship. Indeed in 2006 Mowbray et al found just seven quantitative studies and three qualitative studies had been conducted. Since then, the momentum has gathered pace although it is arguably still a much under-researched area.

There is a little lay literature primarily from the USA and Australia, which offers some insights into this topic, see for example; Brown and Roberts (1989), Wasow (2000), Nathiel (2007). The following literature review however, concentrates upon peer reviewed studies and theses which have explored the subjective experiences of adults who grew up with parental mental distress. The studies included in this review have adopted a range of methodologies and demonstrate a variable focus upon the subject which has facilitated a deeper understanding of several facets of the adults lived experience.

The aim of the following literature review is to examine the extent, range and nature of the qualitative research already undertaken relating to the adults lived experience of parental mental distress. There is some debate regarding how much the literature should be investigated prior to a qualitative study, with the argument that the nature of qualitative work is inductive and that reading other similar research is likely to leave the researcher with some bias (Chenail et al 2010). However, studying at a doctoral level also means that there is an expectation that there will be a contribution to new knowledge (Bournemouth University 2012). Relevant research has therefore been

identified to include in this review, thus pinpointing approaches to and aspects of the topic which have thus far been neglected.

The following method was used;

The research question utilised was “what is known from existing qualitative literature regarding the experiences of adult offspring of parents with mental distress? “

The aim was to identify as comprehensively as possible, the qualitative primary studies (published and unpublished) which were suitable for answering the central question.

In order to achieve this, the following four distinct sources of literature were searched;

1) Electronic databases

2) Reference lists

3) Use of two existing networks which maintain relevant electronic resources.

4) Google scholar

The start date of 1990 was selected because the topic under investigation is a relatively new phenomenon both from the societal viewpoint of de-institutionalisation, and also the philosophical viewpoint of postmodern inspired research which means research which explores the experience of people. English language was also set as a review criterion. Whilst the date and language limits above were selected for practical reasons, it is recognised that papers of value may have been missed.

1) Electronic databases

Librarian support was elicited particularly to help guide the related terms which were appropriate to search as well as guidance on which databases to search. There is considerable ambiguity relating to the term ‘adult children of parents’ which was replaced with ‘offspring’ and ‘sons’ and/ or ‘daughters’. The same applied also to the term ‘mental illness’ which was replaced with ‘mental health problem’ and ‘psychosis’ as well as the names of various illness’s such as ‘schizophrenia’, psychosis and bipolar

disorder. The range of language which had to be substituted for the search, illustrates some of the philosophical tensions with regards to current mental health provision in the UK. Research on children who grew up with parents with alcohol and drug abuse difficulties was excluded and grey literature was also excluded.

Google scholar was searched in addition to the database search which was primarily conducted using Ebsco host. Ebsco can access databases including the BNI (British Nursing Index), CINAHL (Cumulative Index to Nursing and Allied Health Literature), psychINFO (psychological abstracts), Medline and Social Care Online. ProQuest was also searched for theses. Truncation was utilised with the words parent *, child* and psych*.

2) Reference lists

Reference lists of journal articles which were found to be particularly appropriate (mainly those used in this review) were scanned for studies which may have been missed from the electronic search. This strategy found several missed studies and was also found to be judicious in terms of time. Many of the references used in this thesis were obtained by this method.

3) Use of two existing networks

The searching of two networks revealed a wealth of information from relevant research to related policy. Unfortunately many of the links were broken which meant searching for the identified literature electronically. It did however help me to recognise when I was beginning to reach a point of saturation. The first of these networks was The UK group 'Parental Mental Health and Child Welfare Network'. <http://www.pmhcnw.org.uk> and the second was the sister web site in Australia 'Children of Parents with Mental Illness'. <http://www.copmi.net.au>

Since the start of this project both web sites have met funding crises and the UK site is no longer maintained.

This review was not intended as a systematic review of the literature, rather its aim was to illuminate the findings which recurred in papers relating to adults of mentally distressed parents in order to position my own research amongst other research of the same topic, highlight the contribution to new knowledge, and ultimately to justify the study.

From the literature search defined above, a total of thirteen papers were reviewed. A further six theses and one meta- synthesis was also consulted. Barbour and Barbour (2001) suggested that application of checklists for critique can be counterproductive in qualitative research because the nature of the paper can incorporate such diverse descriptions and broad ranging arguments that they do not readily fit pre-determined checklists. Dixon-Woods et al (2004 p 224) concur with this and state that;

“A study may be judged to have followed appropriate procedures but suffer from poor interpretations and offer little insight into the phenomenon. A second study may be less transparent in terms of methodological procedures but offer compelling, vivid and insightful narrative grounded in the data”

The quality appraisal for this review was therefore based upon suggestions by Dixon Woods et al (2004 p224). “Is this qualitative and supported by quotes? Is it relevant? And are the aims clear?” My own appraisal of the documents may also be included.

Of the thirteen papers the majority were semi structured interviews. I found two grounded theory based research, and one phenomenology. I found no other studies using narrative inquiry. The themes in these studies reveal the painful and unpredictable lives of the participants. I have synthesized the main themes from the papers identified into three major categories; the community, the family, and the personal. These findings are presented here, and discussed in relation to relevant findings from COPSMD research, some theory, and the earlier outcome based research.

Literature Review Papers

No	Author and Date	Title	Method	Sample group	Findings	Critical Review
1	Dunn 1993 USA	Growing up with a psychotic mother	Semi structured interview with thematic content analysis Self- selected sample	9 AOSMDP 21-41	Abuse and Neglect Isolation Guilt and Loyalty Grievances with Mental Health services Supports	No ethical approval detailed Mothers with psychosis only 18 had presented with mothers and two with fathers who were psychotic so the study was limited to those with mothers.
2	Maunu and Stein 2010 USA	Coping with the personal loss of having a parent with mental illness: Young adults' narrative accounts of spiritual struggle and strength.	Semi structured interviews and thematic analysis. How is the personal loss described? How do participants describe their faith journeys? How do people describe the impact of having PMI?	9 ACOPMI 18-22	Loss of role Loss of future Loss of routine Loss of self Loss of relationships	No ethical approval detailed Inclusion criteria; A psychiatric diagnosis. Recruitment at a college which may have led to a more educated group of participants with something in their lives described as spiritual and sacred.
3	Polkki, P. Ervast SA and Hupponen M 2004 Sweden	Coping and Resilience of children of a mentally ill	1 ACOPMI Written narratives analysed using NUD*ist 1 COPMI- Interviews	COPMI x 6 9-11 ACOPMI x 17	ACOPMI Experience and feelings at time of onset Family roles and parenthood	No ethical approval detailed Methodology unclear Report structure is

		parent	coded using grounded theory		Coping and resilience Social support and help COPMI Family and parenthood Mental illness of parent Fear and worry Stress reactions Coping with daily life Social supports	not clear and results discussed together ? flawed method due to competition status of narratives
4	Foster 2010 Australia	You'd think this roller coaster was never going to stop	Interpretive Phenomenological Analysis	10 AOSMDP	Uncertainty Struggling to connect Being responsible Seeking balance	
5	Knuttson- Medin et al 2007 Sweden	Experiences in a group of grown up children of mentally ill parents	Questionnaire and qualitative questions Manifest content analysis Experiences and opinions about services studied.	36 participants 19-38	Lack of support Difficulty understanding Lack of interest in children Worry Responsibility Role reversal Links with services Relief on treatment Wanted greater information	
6	Kinsella and Anderson 1996 USA	Coping skills, strengths and needs as perceived by	Semi Structured interview and questionnaire Thematic Analysis	10 ACOPMI 10 siblings	Coping skills Self- control/ Self -isolation Constructive Escape/ Spiritual faith/Blocking(quote)/	Lack of differentiation between findings of ACOPMI and siblings.

		adult offspring and siblings of people with mental illness: a retrospective study.			Internalising/ Seeking support/Objectifying the illness/ Acquiring information/ Self- censoring behaviour Strengths Independence and self –reliance/ Ability to create or accomplish Empathy/Resilience/Assertiveness Spiritual life perspective Needs Information/ Attention to emotions/ inclusion in treatment process/validation	All ten ACOPSMI went into therapy
7	Ali 2011 Sweden	Daily life for young adults who care for a person with mental illness: a qualitative study	Semi structured interviews	12 between 16-25	Showing concern (readiness) Providing support (unconditional action) Sacrificing good relationships with confrontation Management attention seeking/secretcy/self- harm	No differentiation between findings of groups caring for parent/sibling/friend.
8	Marsh and Dickens 1993 a USA	Troubled Journey	Survey Structured and open ended questions. Themes data coded	ACOPMI and siblings x 60	Subjective and Objective burden Developmental risks Familial consequences(loss of relationships in quest to self -preserve) Education and Career	Siblings and ACOPMI data combined
9	Marsh, Appleby, Dickens, Owens and Young 1993 b	Anguished Voices: Impact of Mental Illness on Siblings and	Survey Structured and open ended questions. Themes	ACOPMI and siblings x 75	Personal legacy Interpersonal legacy Intimacy, commitment and sexuality	Siblings and ACOPMI data combined

	USA	children.	data coded		Marriage and Childrearing Caregiving responsibilities Coping/adaptation and resilience Ongoing responsibility for parent/sibling	
10	Duncan and Browning 2009 New Zealand	Adult attachment in children raised by parents with schizophrenia	Semi structured interviews Content analysis	23 participants from 24-61	Adulthood; intimacy/trust and vulnerability Themes of absence Intrusive psychotic phenomena or withdrawn and absent Grief loss of mother Shut down emotionally/trust Lack of social support	4 men 19 women
11	McCormack, L., White, S and Cuenca. J., 2016 Australia	A Fractured Journey of Growth: Making meaning of a 'broken' childhood and parental mental ill health	Interpretive Phenomenology	7 ACOPMI	Who Cares, nobody cares, Trauma and Betrayal, Transferring the distress, Ducking, weaving and staying safe, Growing myself up and transforming a broken childhood.	6 women and 1 man
12	Rose, L, Mallinson, K and Walton –Moss, B. 2002 USA	A grounded theory of families responding to mental illness	Semi structured interviews Grounded theory	AOSMDP 29 participants in 17 families 4 AOSMDP	Pursuing normalcy Confronting ambiguity- Keeping watch/ losing trust/being consumed by the illness /making	Doesn't differentiate findings to relationship

					sense/seeking control/containing losses/managing grief/adopting possibilities Resolving responsibilities/affirming hope/maintaining stability and relationships.	
13	Murphy, Peters, Wilkes and Jackson 2015 Australia	Childhood parental mental illness: living with fear	Narrative Inquiry	13 AOSMDP	Living in a secret world Living with fear and mistrust Living with stigma and secrecy Loss of me and my parent Finding myself/a journey of recovery	
	Theses/other					
1	Harstone 2009 Unpublished Master's thesis Canada	Experiences of adult offspring of parents with mental illness	Grounded theory	6 ACOPMI 27-63 retrospective reflecting on childhood	Growing up with MI Family life Childhood experiences Transition to adulthood Experiences of adults Making meaning Wishes of children	
2	Camden Pratt 2002 Unpublished PhD Australia	Daughters of Persephone	Feminist research informed by Post-modern perspectives.		Presented as a play	Findings presented as a play so not easily summarised. Daughters of

			Focus Groups Grounded theory and content analysis			mothers only
3	Foster, K., 2006 Unpublished PhD Australia	A narrative inquiry into the experiences of adult children of parents with serious mental illness.	Narrative, phenomenology, Auto-ethnography	10 adults 8 women and 2 men.	Uncertainty Struggling to connect Being responsible Seeking balance	
4	Smith, S. 2003. Unpublished PhD, USA.	Adult Offspring of Parents with Schizophrenia: New Opportunities for Clinician-Family Alliance.	Phenomenology	11 AOSMDP	Age when illness onset Age when parent diagnosed Age across the course of PMI Caregiving for parent Caregiving for own children Caregiver burden Cohort effects	

5	Misrachi, S. 2012 Unpublished Master's Thesis. Australia	Lives Unseen: Unacknowledged Trauma of Non-Disordered, Competent Adult Children of Parents with a Severe Mental Illness (AOSMDP).	Literature review			
6	Graovac, R., 2014. Unpublished Master's thesis. UK	Bringing Hidden Voices to the Forefront: Adult Children of Parents with Schizophrenia and /or Psychosis and their Experiences of Counselling and Psychotherapy.				
7	Murphy, Peters, Jackson and Wilkes 2011 Australia	A Qualitative meta-synthesis of adult children of parents with mental illness	Literature review		Fear Stigma Loss of self and parent Recovery.	

Community

The stigma commonly associated with mental distress has been remarked upon for many years now. Underpinning stigma is shame, which has the potential to silence a person by making the mental distress a shameful secret. This means it becomes harder for the family to enjoy their friends and neighbours because of a sense of feeling different or ashamed. Feeling 'different' implies a sense of alienation from other members of the community (Dunn 1993). In turn those friends and neighbours will also keep their distance, thus compounding the families' isolation further. Marsh et al (1993 b) included a quote from one of their participants which expresses this idea with simplicity.

"My family and I withdrew; from each other, from our extended family and from our neighbours"(p25).

In the study by Dunn (1993) there is a quote by one of the participants who said

"Everybody pretended like nothing was going on" (p180)

These quotes show how each family member retreated into themselves unable to speak about the fear and confusion which they find they are living with.

The participants in the Marsh et al (1993b) study also spoke about the feeling that there was no point telling anyone, because no one could possibly understand anyway. The studies by Dunn (1993) and O'Connell (2008) found there was a reluctance to invite friends home, due to either the shame about the family, or fear about the unpredictable nature of their home life. Envy of friend's families was also found, making friendships harder still (Knuttsen Medin 2007; Pölkki et al 2004). Secunda (1997) describes how neighbours and friends tend to eventually detach themselves and expect less from the family. Consequently the family not only loses their local connections by withdrawing, but eventually the community also turns away.

In the rationale for her methodology Misrachi (2012) stated that empirical research is

inappropriate for some topics; by implication with reference to her own work on AOSMDP. This, along with other factors, influenced her decision to complete a trauma informed literature review, as opposed to research. Her literature review has pulled together some far ranging studies, and this has been helpful. However the inclusion of a caveat for some topics of research (into adult lives) may be falling into the trap of avoidance for other reasons, thus further silencing AOSMDP. If a participant is willing and understands the research process, surely the benefits outweigh misplaced protectionism which colludes with society's denial? Indeed there are reasons why people have a desire to tell their story, which may also be quite healing. Three of the participants of this study expressly stated that were participating to assist knowledge production in an area which they had already discovered, has little to offer.

Family

It has been recorded by some authors that the family may find that lack of communication helps to maintain the status quo (Pölkki et al 2004; Foster 2010; Dunn 1993; Duncan and Browning 2009) which is considered to be important for a number of reasons. Families with a parent who has serious mental distress often fear the break-up of their family unit should social services become aware of them. This fear is flamed by the media with sensational stories which unfortunately makes early interventions less likely, the family being left to their own devices, until such time as the level of risk is too great to ignore. Sometimes the root of the silence may be the parents misguided attempt to "protect their offspring" from their distress. In these cases the children will be deterred from asking direct questions, and as a result be excluded from any discussion about seeking help or care planning.

Out of the research included here, five overtly discussed abuse. In most instances this was physical and emotional abuse, although reference to sexual abuse was also found. In the study by Dunn (1993) abuse was so prevalent she adopted the term abuse and neglect as one of her thematic categories. Out of the ten participants in the study by Foster (2010) eight participants discussed abuse and/ or neglect. In the UK, the Royal

College of Psychiatry (2011) advise that all psychiatrists should be aware of the possibility of abuse or neglect of children where there is parental mental distress.

Abuse may be a direct result of the pathology of the parent, which results in the child becoming embroiled, or on the receiving end, of the parent's delusions. Abuse may also result from stressed and/or complex relational patterns. Neglect is harder to measure, and does not limit itself to the physical. Preoccupation with the content of the psychosis is common, and can often be seen as part of the distress itself, particularly when the person is unaware that they have a mental health problem. Neglect of self and others, is often the result. More commonly referred to in the literature, and found with some regularity, is a strange sense of absence of one or both parents. This is sometimes referred to as a 'sense of abandonment' (Duncan and Browning 2009, Dunn 1993, Foster 2010, Harstone and Charles 2012). One of the participants in the study by Duncan and Browning (2009p81) is quoted as saying

"She would be in another world and you couldn't get through to her. In a sense you don't have a mother....So it was like living with a ghost".

The emotional absence of the parent who is not unwell has also been documented. It has been found, that on some occasions the other parent will leave as the home becomes stressful, often choosing to work away from the area, or work longer hours. In many cases it seems the parent will turn to alcohol in an attempt to cope (Dunn 1993, O'Connell 2008). This finding corresponds with the research by Rutter and Quinton (1984) whereby a third of partners became unwell themselves.

Psychic boundaries, which become distorted in psychosis, lead to confusion about the sense of the self. It is when the sense of self is distorted, that the person is rendered unable to accurately perceive the child's emotional state. It is the lack of attunement (Stern 1985) and mirroring, which detrimentally affects the child's sense of self. The child needs mirroring by the adult in order to know themselves, and their own emotions. Along with the neglect which may ensue if the parent cannot perceive the child's needs, there is often an intrusive quality to the dynamic. The intrusiveness of a

parent has been commented on in the research. It lies at the heart of enmeshment whereby the family can no longer recognise each other's boundaries and this can affect the relationship lifelong. The child has to learn how to keep themselves safe by creating a distance when their parent becomes intrusive. The study by Mordoch and Hall (2008) is much cited and shows how the child has to learn to 'keep the distance and maintain the frame' i.e. keeping an attachment strong enough to sustain connection, whilst at the same time keeping enough distance, to avoid engulfment or abuse when the distressed person is driven by narcissistic needs which impinge on the child. Sadly this drives some children to feel the need to leave the home, or stay out of reach of the parent by some other means. It becomes a lifelong task for these children to balance the needs of their parent with their own desire for autonomy and a life of their own.

One of the participants in the study by Harstone and Charles (2012) stated

"I knew that when my Mom was hugging me, and I would let her cuddle me...it was about making her feel good about being a parent, it wasn't about my feelings" (p19)

And later in life, a participant from the study by Marsh et al (1993a) stated

"Mom still wants me to move home" (p16)

In Dunn's (1993) study it has been detailed that guilt and loyalty had been a strong theme. The participants described the sense of loyalty and love for the parental connection, but also guilt when they had to retreat in order to preserve their own sanity.

The constant vigilance which is needed to be able to predict slight changes in the parent's mood or dependency needs is described as exhausting, and children have been documented to leave the parental home when feeling overwhelmed (Mordoch and Hall 2008). Keeping watch, monitoring and keeping alert to changes, allows the child or adult child to measure how much contact they feel able to have. Harstone

and Charles (2012) explained that two of the participants of their study, moved as far away as possible, so that they could maintain the connection on their own terms. This sense of vigilance also occurs in the studies by Ali et al (2011); Duncan and Browning (2009); Pölkki et al (2004) and Rose et al (2002).

The role of young carers includes taking responsibilities which a child would not normally be expected to take. Quotes from participants which indicate a level of responsibility often include the phrase “I grew up too fast”. This sentiment has been found in most of the studies which are being reviewed here. In some cases participants took on physical care work including housework and dispensing medication. In others, the responsibility for monitoring parental mental health was more subtle and the children described feeling worried about leaving a parent, whilst attending school, or indeed worried about returning from school and what they might face on their return (Marsh et al 1993 a and b; Rose et al 2002; Knutsson –Medin et al 2007; O’Connell 2008; Foster 2010; Ali et al 2011 and Harstone and Charles 2012). A participant in the Harstone and Charles (2012) study described it as feeling;

“It is more that you become like this pseudo adult, you don’t have any rights like getting to say what you want, but you have all the burdens, at least you feel you do, I felt some pride about being able to do stuff, but I think it allowed things to continue though” (p21).

This particular quote shows clearly how, although the child might relish the responsibility; on another level it is felt to be burdensome. This dynamic can quickly lead to parentification as it becomes a desired outcome for both parties, which may be difficult to stop. Eventually the child can find themselves staying at home because they are afraid that the parent will not be able to cope without them. To live with this level of fear and a feeling that one has to protect the adult, is too much for a child, and is a sign that the child may have become parentified. One of the participants from Harstone and Charles (2012) study also stated;

“I wish they had taken me from my family and I had never seen them again”
(p18)

The study by Ali et al (2012) obtained narratives from 12 young carers, some of whom were looking after a family member, and some a friend. The results are not separated although they suggest that

“Supporting a friend was considered as large a personal responsibility as supporting a family member” (p1)

The researchers do not make clear how they arrived at their claim, or how they measured their participant’s level of responsibility. It does however appear to be at odds with the claim by Marsh et al (1993a) who state

“That as a group, children are more vulnerable to the consequences of caring for a close relative” (p16)

Personal

As previously discussed, the child’s ‘self’ may be unrecognised by parent who is mentally unwell. It therefore becomes more likely that their needs will not be met, and will remain unseen. Over a period of time as the child grows up, they are therefore at risk of not recognising their own sense of self, and therefore their own needs. The lack of sense of self effectively silences the person who is unable to ask for what they need, or express themselves emotionally. This of course has implications for the long term wellbeing of AOSMDP. In the literature it has been noted that there are a number of sequele commonly found. The first of these is the long term impact on the mental health of the AOSMDP. Fosters’ (2010) study found 7 out of 10 participants had struggled with anger, anxiety, and most commonly, depression. O’Connell’s’ (2008) study found 50% of her participants complaining of depression. Pölkki et al (2004) also found a large number of their participants suffered with mental health problems, although in this case, given that the data was found in narratives written for a competition, it is unclear how reliable these findings are. A creative method perhaps,

but 'winning' may have given rise to embellishments.

Another finding in these studies is what Marsh et al (1993 b) call 'emotional anesthesia' which they describe as a shutting down of the emotional life of the AOSMDP. This was also found by Duncan and Browning (2009) and Kinsella and Anderson (1996). Kinsella and Anderson (1996) found a general emotional constriction which they felt was a result of dissociative states, over monitoring of the self and also drugs and alcohol abuse. Lack of trust is generally understood to be behind these mechanisms of avoidance (Duncan and Browning 2009).

Lack of trust, both of self, and others, can lead to long term problems in relationships and has been found with regularity in the AOSMDP research. Marsh et al (1993 b) found that fear of rejection, trying to please others, and fear of abandonment, all played a part in the trust issues of this group. The study by Duncan and Browning (2009) had a specific focus upon the adult attachment patterns of children raised by parents with schizophrenia. The researchers interviewed 23 adults from the age of 24-61, and although many of the participants were married, many also expressed an inability to trust or commit to another. Several of the participants stated how they looked for partners who somehow replicated the attachment they had with their distressed parent. For instance, one participant expressed that her relationships failed when the partners "wanted too much from me"(p 83), and another reported that she was often attracted to people who were "Extremely funny and a little bit on the crazy side."(p82).

The authors discuss their findings and state that;

"The abnormal and unpredictable become normal and predictable" (p83),

With such conditions in adult relationships, secure attachments become very hard to establish.

Perhaps because secure attachments are hard to find, some participants in the qualitative literature have clearly found school a sanctuary. There appears to be a high

level of academic achievement found in these studies. It is unclear whether this reflects the nature of a person who might agree to participation in research, or whether this is a wider finding which requires further investigation. It however contradicts the outcomes based research which determines that lower rates of academic achievement are all found in a greater percentage than the general population (Falkov 2009). In the study by Marsh et al (1993 a) it was found that 86.2 % had completed college. Knuttson Medin et al (2007) also found that the participants were 'well-adjusted in terms of education and employment'. O'Connell (2008) also found a higher than expected level of educational attainment. She discusses the possible reasons for this as being either a way of exerting control in otherwise chaotic lives, or a form of escape in order to avoid the mentally distressed parent. Certainly other participants have stated that they joined after school clubs or escaped into music or art as a coping mechanism (Kinsella and Anderson 1996). It seems likely that it is a combination of both. There is another theme found in Fosters' (2010) study which relates to 'knowing and not knowing'; so driven by a thirst for information and understanding, participants may have explored their interests to a level which exceeds average.

The quest for information it seems, begins with an attempt to understand what is going on in their family life. The participants in the study by Ali et al (2011) were still quite young (16-25) and were reported to use the internet to help them understand what their friends or family were experiencing. Kinsella and Anderson (1996) considered that acquiring information helped participants to reduce their sense of helplessness which then increased the level of predictability which helped them to objectify the distress, and therefore separate the effects of the distress from the personhood of their parent. Knuttson Medin et al (2007) also found a search for information to be an important issue, and Foster (2010) used the theme "Being uncertain" to describe the sense of not knowing which she found. The 'not knowing' in her study was about the child (or adult) not having a frame of reference of mental health problems, and therefore being less able to sufficiently objectify it. Objectification and confronting the ambiguity (Rose 2002) of the problem is a strategy which may help the child (or adult) to be able to

preserve the attachment.

It is tempting to correlate levels of high academic achievement and employment with resilience. Foster (2010) however argues that the participants in her study expressed that people sometimes misperceive them as resilient and competent, and that this was because of a resistance to ask for support, based upon pseudo independence and perhaps lack of trust. Harstone and Charles (2012) support this assertion with the idea that sometimes the motivation underpinning study can be misinterpreted as competence.

Many of the participants within these studies have stated that a positive outcome of their experience is 'independence' (addressed further at the end of this section and also in the discussion chapter). It seems however, that when independence is equated with strength, the consequent avoidance of intimacy and inability to trust others is at risk of being downplayed.

The final theme which must be considered here is loss and grief. Marsh et al (1993 a) expressed the thought that there is much evidence for the presence of "chronic sorrow" in the lives of AOSMDP, and include the quote from one of the participants of their study

"It's like someone close dies- but there's no closure. It's never over" (p20)

A few years later in 2002, the grounded theory study by Rose et al (2002p 11) found that participants went through a process in order to 'pursue normalcy', and this meant that they first had to confront the ambiguity of diagnosis in order to make sense of behaviors. They then 'sought control' so that losses and grief could be contained, and finally, they had to adopt a stance of possibilities and realities, so that hope could be reaffirmed, relationships redefined, and, stability and growth attained. The authors argue that the grief stems from different levels of loss, which include personal, family and societal. Loss of the pre distressed family relationships was felt to be the key focus of the grief at this point.

Ali et al (2011p 4) recognise the sorrow which follows when a friend, sibling or parent experiences a change in their mental health, although their portrayal of this grief as “upset by that experience, (and) also angered and disappointed by the consequences” I suspect falls a long way short of most people’s experience of grief.

The study by Maunu and Stein (2010) had personal loss, and the role of religion and spirituality as its central aim of inquiry. The authors of this study found that the grief and loss stemmed from five main sources. 1) loss of social roles 2) loss of former relationships, 3) loss of sense of self, 4) loss of normal routine, 5) loss of a sense of future. They stated that the young people interviewed, varied in the frequency with which they described these losses. Some of the participants described all five categories and some just one.

The loss of a sense of future was also found by Foster (2010) in relation to the choices people had to make about having children. The participants in her study disclosed that they had to consider not only the genetic potential for their offspring, but also the possibility that they themselves might become distressed parents.

Unsurprisingly a large proportion of the participants in these qualitative studies had sought therapy and many of them also mentioned the role of ‘validation’ and ‘being seen’ which they felt was missing from their childhoods. Even by American standards, the amount of participants seeking therapy is huge. Eight out the nine participants in Dunns’ (1993) study sought therapy and Kinsella and Anderson (1996) stated that all ten of the participants in their study, had sought help. It seems likely that unresolved grief may have been at the heart of their distress. UK comparisons are not available due to the lack of research in this area.

On a more positive note, some participants offered a view of themselves as having acquired values and skills which they were proud of, as a result of their lives. Empathy and compassion have been cited as particular strengths of AOSMDP (Marsh et al 1993 b; Kinsella and Anderson 1996). The constant watching for changes in mood and behaviour, perhaps enhances skills of observation and empathy, and it is likely that

having to separate the personhood from the distress also enhances compassion.

Creativity, tolerance and personal values which are not concerned with status have also been cited (Marsh et al 1993 a). Finally, self-reliance and independence have been found with regularity in all of the studies. It has been seen as a healthy and adaptive consequence for AOSMDP. If however vulnerability is seen as a prerequisite for the development and maintenance of relationships, it could be argued that the ability to be vulnerable in relationships is a strength, and that excessive independence and self-reliance, are therefore a strategy of avoidance. The following quote was taken from one of the participants of the study of Duncan and Browning (2009).

“I actually struggle to have deeper relationships...I just don’t really know how to interact or how to be vulnerable” (p 83).

This literature review has presented work from the three waves of research which has been completed on adults who grew up with mentally distressed parents. It has looked to various professions for their contributions, and world- wide studies have been consulted for the qualitative work. Much of the work here has been conducted using questionnaires and pre-determined questions, particularly relating to a specific idea such as Knuttson Medin et al (2007) whose focus was largely on experiences of services. The problem is, such specific lines of question cannot capture what it is the AOSMDP feels is most important to address.

My own study will therefore add to the scant literature base, with its focus upon the adult’s experience of their lives over the course of their life span. As yet there is no qualitative which has been published in the UK.

Information on the methodological approach may be found in the following chapter.

Chapter 3

Methodology

Introduction

This chapter offers a rationale for the methodology selected for this research, and explains how this was guided by my own personal world view. The steps taken to complete the research, including the method of analysis are also detailed here.

Because of the nature of a narrative research project, special consideration is given to the ethical use of narrative. I have started this chapter with the aims of the research and the research questions which directed the choices and decisions subsequently taken.

The research aim

The aim of this study is to explore how adults understand and explain the experience of having grown up with a seriously mentally distressed parent, and what impact they think the experience has had on their own life.

The steps taken to achieve this aim are to answer the following questions;

- a) How do individuals describe the experience of having a seriously mentally distressed parent?
- b) What effects on their lives and sense of self are described by individuals?
- c) What sense can individuals make of their lives lived with a seriously mentally distressed parent?

Underpinning philosophy

It is expected that qualitative researchers make explicit their personal and philosophical standpoint so that the motivations which dictate subsequent choices and decisions throughout the study are clear to the reader. Gergen and Gergen (2008) advise that early commitment to a paradigm is a prerequisite of research for this reason. Each researcher will have their own perspective on the nature of existence (ontology) and it is this which will influence their choice of theory about the nature of knowledge (epistemology) (Howell 2013). Both Hammersley (2004) and Silverman (2011) however, advise new researchers to be cautious and guard against becoming entrenched in a paradigm, which they suggest can lead to becoming unable to countenance any other perspective. This advice does seem sensible although for the purpose of a researcher's clarity there comes a point when committing to a paradigm is necessary so that the methods chosen to undertake the research can be assessed as having coherence with the underpinning philosophy.

Reflexivity

Qualitative research demands a level of reflexivity by the researcher in order to highlight awareness of personal identity within the research process. According to Finlay (2002 p 210) reflexivity is the "project of examining how the researcher and inter subjective elements impinge on, and even transform research". She also argues that reflexivity is now a defining feature of qualitative research, better able to present the postmodern world than authoritative texts.

The knowledge which is co-created through a situational and interactional event such as an interview cannot be entirely objective. I undoubtedly influenced the participants, and they influenced me. As such, my interactions and interpretations were part of the process which cannot be dismissed or bracketed out. Both parties are subject to transferential influences, in which both the teller and the researcher are responding

consciously and unconsciously to influences from other relationships (Merrill and West 2009). I have no doubt that my personal experience of being an AOSMDP will have had an impact throughout the research on both a conscious and unconscious level, for me and for the participants. Not only can I fail to be removed from the interviews, but I also cannot be removed from the interpretation and the writing up, because every piece of my written work bears my symbolic signature in the way the work is constructed and communicated.

Following each interview I used the dictaphone to record my first impressions of the participant and their story. I repeated this after the transcription phase to aid immediate reflection. The rationale for this was to capture reflexive thoughts and ideas which were still fresh and accessible and add another layer of meaning to the interpretive process. My reflexive and reflective comments therefore contribute to the research by acknowledging my part in the construction of the narratives, the interpretations and conveyance of them.

Hofmann and Barker (2017) distinguish between reflection, which they say is a sustained exploration of one's role in the research, and reflexivity, which is a critical self-aware evaluation of the impact of oneself, on the research and vice versa. As Foster et al (2006) say; it is *not* an excuse for wallowing in subjectivity and narcissism.

The reflection and reflexivity in this particular study was crucial, due to not only my being an AOSMDP, but also the nature of the study, which has included an exploration of relational trauma. Teasing out the 'me- other' influences were therefore arguably even more important.

In research the terms used are insider / outsider. Insider knowledge is that gleaned by experience, and outsider knowledge is that learned professionally in the classroom and books. Both modes of knowledge acquisition have strengths and weaknesses.

One of the benefits of insider knowledge for a study such as this is the motivation for the selection of the topic. Topics which are neglected are neglected for a reason such as their complexity, inaccessibility or ignorance that the problem even exists.

Researchers with lived experience who are tenacious enough to explore it are therefore able to push the boundaries of current knowledge. They might also be able to understand and respond to nuanced reactions with empathy. The choices made by participants may also have made more sense to me as an AOSMDP myself.

The danger of insider knowledge is the risk of imposing my own values, biases and perceptions. There is also a danger of over identification with the participants which might have had implications for my own health because the interviews also brought my own experiences into sharp relief. This was particularly important when participants were discussing stories containing concepts (such as parentification or relational trauma) rather than contextual detail, because although I felt I knew what the participant was trying to convey, I had to be careful not to assume, so that collusion might be avoided or meaning taken for granted. I am fortunately very comfortable with silence and did not respond verbally when I felt that might be an issue. Naturally my nods and other non- verbal signals may have given away more than I intended, but where the topic of conversation was resonating with me, I attempted to either simply nod to indicate they should continue, or ask for clarification. I also found that I had to temporarily suspend some of my reactions in order to be able to function with some criticality. Keeping personal reactions at bay until I am in a safe space is something with which I am very familiar. Not only from my own early experience but also that of being an experienced mental health nurse and therapist. When my concentration is held by the story of the other, my own experience is not foremost until later.

Maintaining an emotional distance which allowed me to be critically detached was easier said than done. I *did* identify with the participants, some more than others. Some of their stories were so familiar, it was uncanny and unsettling. Most of the women were of a similar age and I warmed to them, but more than that, even when from a distinctly different background, some of their stories resonated with me at a deep level which I found difficult to articulate. It was this navigation of balance

between empathy and over identification which was an ever present and ongoing task (Hofman and Barker 2017).

The issue of self -disclosure was considered in depth. One of the supervisory team prompted me to ask some searching questions about this and I eventually decided not to disclose my own story until after the interviews. I am pleased that I did not. In Meg's story she had a tendency to overuse "y'know?" and I wondered whether her difficulty, or lack of trust that someone might understand had influenced this. She seemed at pains to check my ongoing understanding of her meaning. So I was able to gain another layer of interpretation *because* I had not disclosed.

Likewise Cathy became cautious at her disclosure, at one point when I had asked her about her relationship with her husband. It may have been that she wondered at the relevance, but the impact, was that she moved on, ignoring my question and leaving me in no doubt that I was not to probe further. Perhaps if she had known my own story she might have answered, but the fact that she did not, is part of the findings. She had a reluctance to let me into this area of her life which was meaningful.

Narrative inquiry

For a study underpinned by constructionism, the obvious choice of a method was the narrative interview, whereby the participants and I could co-create meaning and mutual understanding. The participants intended meaning would then be negotiated between us; like a fabric where the weave is formed by the warp and weft between me, the participant, the language, the context and the mode of telling.

There are many qualitative approaches which use interviews as their method, and I found myself considering and then discounting them for various reasons until I found what I was looking for. I became increasingly aware that a narrative inquiry would offer the best fit for this study. It seemed most important to me to find a mode of research

which incorporated a reflection on time. Like any long relationship, the parent/child relationship will evolve and mature as time goes by. I therefore wanted something which would provide more than a snap shot insight, and which could capture the longevity and change which I wanted to explore. A retrospective study which explored the stories within narratives from interviews was ultimately decided upon. Stories are not a traditional mode of inquiry in nursing research (although they are, of course part of clinical practice). The ideas and values inherent in narrative inquiry felt right for the study, and for me.

What I did not imagine and could not have anticipated however, was the complete lack of a map by which to orientate myself in the landscape of all things narrative. At times I felt completely lost and actually a little scared that I might have taken on too much. The problem is that narrative inquiry means different things to different people. It is a diverse intellectual landscape, the attraction of which allows the researcher to be creative; the downside is that there is no map to guide the novice through the myriad of meanings.

As a research methodology, narrative inquiry can be traced back to the sociology department of the Chicago School in the 1920's and 1930's when interest in personal histories and cultures was beginning to emerge. In the 1940's and 1950's narrative work plummeted as quantitative studies became favoured. More recently, research in health and social care has seen a reemergence of narrative inquiry, perhaps prompted by the emphasis on the humanisation and recovery agendas; see for instance Hinshaw (2008) or Grant et al (2011).

Scholars tend to use the terms narrative, narrative inquiry, narrative analysis, analysis of narratives and stories, interchangeably, although each has a slightly different meaning and focus. For some, narrative is the essence of life itself, for example Bruner (1990) or Polkinghorne (1995). For others, it is an analytic tool i.e. a way of assessing the congruence between the tellers, the story and the history, for example Wengraf (2001). Some authors see 'narrative' as a paradigm whereby the participant's story is

eschewed in favour of truth constructed between the story teller and the listener, for example Charon (2006). At the other end of this continuum the narrative is viewed objectively as a unit to be analysed in terms of its syntax or meaning, by literary techniques such as stanzas or the breakdown of the component parts of a story, for example Labov and Waletzky (1997).

Given the myriad of meanings of the term narrative inquiry, it is apparent that there can be no specific process of analytic strategy (Kelly and Howie 2007). The method adopted to analyse a narrative will of course be influenced by how the researcher perceives narrative. The multiplicity of usage of the term necessitates that the researcher makes clear the meaning and remit in relation to their work. Having already discussed my personal ontological perspective it befalls me now to explain a little more about my conceptualisation of the term 'narrative'.

What is a narrative?

The word 'narrative' originates from the Latin 'gnarus' meaning 'knowing' (Holloway and Freshwater 2007 a, & b), and reflects the longevity of an ancient art of communication. Human beings have told stories as a mode of communication to pass on familial and societal history, values, guidance and meaning, intra and inter generationally for centuries. My own understanding has been influenced by the work of the psychoanalyst Stern (1985) who explained that the making of a narrative is not the same as thinking or talking, because it involves personal decision making in a sequence usually with a beginning, middle and end.

The terms 'narrative' and 'story' are often used interchangeably although there is a clear difference between them. Frank (1995, 2000) offers the following distinction between the two; one does not tell a narrative, a story is told. So for the purpose of this study, I have assumed the whole transcription of the interview to be the narrative, which is composed of many stories which are linked together to create one overall plot. The plot is the "emotional experience that preoccupies the teller, the insight, the wisdom, the thing that one has come to say" (Gornick 2001p13). It is the sequencing of

the events and their relationship to one another i.e. how one event leads onto the next in a temporal dimension, which provides the plot of the story (Polkinghorne 1995).

Narrative and time

According to Husserl, (Crossley 2000) an event in the present is only perceived and incorporated into a person's frame of reference against the backdrop of the past and the future. Much like a piece of music, the note is not encountered as an isolated event. It only takes on meaning when heard as part of a sequence, meaning, in relation to what has preceded it, and in anticipation of what will succeed it. The experience is akin to the plot structure of narrative. In a narrative the story takes on meaning in relation to the past and affords meaning to the future; the present being the connection between the two.

Ricoeur thought that that "time becomes human to the extent that it is articulated through a narrative mode" (Ricoeur 1984 p85). In this sense, composing a story involves threading together a series of events so that they make sense in relation to one another (Ricoeur 1991 p121). This means that memories of the past influence what is happening in the present in anticipation of what might happen in the future. This is an important notion for narrative work of any kind. Predicting antecedents and possible consequences will influence the way a person goes about their life.

The interviews of this study aimed to elicit the life stories of the participants in relation to their parent, which they wove together to form a coherent whole. The stories set mostly in their past, will have influenced their present in relation to the predicted future. Each person is in the middle of their story and cannot predict how it will end. When trauma strikes, the person has to work out how to accommodate the change in direction, to rethink their aims and start a new story. This is the element of time which I have tried to capture in this thesis; the broken life stories which have had to be rewritten by each participant.

Narrative and nursing

One of the roles of the mental health nurse is the facilitation of stories which can then be honored, and the individual's thoughts and feelings validated. Holloway and Freshwater (2007b) argue that this helps to create a distance from the experience of vulnerability. It is a dialogic process whereby the role of teller and listener is equally important (Frank 2000). The context which enables individuals to begin composing their story is the therapeutic relationship. Within the safety of a therapeutic relationship an individual can 'play' with stories and this is seen to offer a way to make sense of deep seated insecurities emerging from a less predictable life course, which may have disrupted and threatened the individuals' sense of self, their relationships and the meaning of their experiences (Merrill and West 2009). Much of the work of the mental health nurse can therefore be described as listening to and telling stories (Foster 2006). Bruner (1990) says that whenever a person encounters an exception to ordinary experience and is asked about it, they will almost always tell you a story that contains the reasons. The human propensity to interpret the causes of misfortune drives a need to create a narrative which reconstructs the imagined biography. This then repairs any ruptures between body, self and world (Riessman 2008). The reconstruction of an imagined biography 'makes sense' and 'gives meaning', and this may in turn, facilitate the development of an identity which has more coherence, thus empowering the story teller (Mishler 1996; Andrews et al 1998).

I am fortunate to have been given the opportunity to study something so personally meaningful and, notwithstanding ethics approval, in any way I choose. Despite the advantage of nursing research from a variety of perspectives, the politics of research funding generally favours particular approaches. Research deliverables are frequently counted in reductionist terms which include; cost effectiveness and the ability to have an immediate (quantifiable) and measurable impact. Decisions regarding funding are therefore often made by groups which have positivist views regarding what constitutes validity (Cheek 2000; Denzin and Lincoln 2013 b). The kind of qualitative narrative

research in this study does not readily tick those boxes and I am aware that the University funding this PhD has afforded me an unusual opportunity. Benner (1994) argues that this kind of research helps to distinguish nursing from medicine, which contributes to making nursing expertise more easily recognisable and visible which in turn, has the potential to encourage a nursing approach which is based upon wellbeing both for the individual and for society (Merrill and West 2009). Narrative research emphasizes working closely with personal truth and core values of both researcher and participant, and this aims to restore the experiencing person to the centre of the inquiry and is akin to humanistic and holistic patient care (Holloway and Freshwater 2007a). The synergies between story- telling and mental health nursing are evident, and may help to mitigate any criticism of the use of stories as a methodology (Merrill and West 2009).

The benefits of using narrative inquiry in a study such as this are that it helps to challenge negative labelling or dismissiveness of the group under review. It seeks to give the group a 'voice' and be heard by others via later publications and conferences. This raises the groups profile in socio- political terms.

On an individual level listening to a person's experience can in itself provide some kind of validation of that experience (Merrill and West 2009). The experience of mental distress has been characterised as partially stemming from having an incoherent story, hence some theorists and therapists deem that psychotherapy is an exercise in story repair (Polkinghorne 1988, Crossley 2000). In mental health care there is a growing recognition that narrative therapies help a person to re-story their lives and create an alternative ending of that story.

Stories

First person stories represent a person's lived experience and the way in which that person constructs their world. There is a dynamic interplay between the teller, the listener, their history, their inner and outer worlds, and the connections between them and others which personal stories educate (Merrill and West 2009). Personal stories are

by their very nature person-centred and subjective and therefore ideally suited to the study of identity and subjectivity. Butler- Kisber (2010) adds that stories are also embodied, i.e. integrate the physical and psychological dimensions of knowing. Stories can therefore capture the complexity of humanness and appreciate the social, spiritual, and interpretive aspects of that person. The ability of the story to show this complexity makes narrative inquiry helpful when more familiar scientific approaches to research would not be able to do so.

The defining feature of a story is that of sequence, so for the purpose of this study, I made use of a simple method of identifying the stories within each narrative. I drew upon Denzin and Lincolns (2013b) conceptualisation of stories as passages which;

- Have a beginning middle and end
- Are set In the past
- Are sequential
- Have a plot
- Make sense to the narrator

The size of the stories collected was variable. Some of the stories are very short, and some are longer depending on the narrator's style of communication and my own recognition and understanding of the inherent meaning. In accordance with the guidance from Mishler (1996) who states that what falls outside of the storied account is felt to be general discursive material, I excluded some elements of description and static structure around the stories. This has prioritised the component of the data which was intended to convey the meaning. Sometimes however, the surrounding discursive material contributed to the richness of the context or has shaped my interpretation in some way, on these occasions it has been included.

Inclusion criteria

One of the inclusion criteria for participation in this study was the imperative that the individual should have grown up with a parent who had a serious mental distress. This was primarily because my interest lies in populations for whom the nature of reality is distorted. In due course this was also felt to be too rigid and as such, disregarded as it became evident that some participants were unclear about their parent's diagnosis or even symptoms. For this reason, the decision was made to forgo any preconceived ideas and allow the participants perception of what constituted 'serious' mental distress to dictate their inclusion. It was however made explicit that people with a primary drug or alcohol problem would be excluded. This is because Dayton (2012) has already completed some research into the experiences of family members of people with primary substance abuse problems and this is not my area of expertise.

It was also made explicit that the parent could be alive or deceased, and the adult child may or may not be their natural child. The significant aspect was deemed to be the fact that the child had grown up for a period of time with a mentally distressed parent.

A final criterion for inclusion to the study was the relatively late age of thirty which was given. The rationale for this decision was partially that if a study is going to explore retrospective stories, then the individual needs to have had a decade or so of adult life in order to have experiences upon which to draw. Another factor which contributed to this decision about age was my own experience, which has taken me more than twenty years to be able to not just articulate, but also see and appreciate with a degree of clarity. In her discussion on the narration of sensitive topics Hyden (2008) says that the significance of 'having been through a lot 'and' known about' is that of reflection and giving meaning to an experience. Without the cognitive processing that can accompany an experience, rendering it meaningful, i.e. knowing about it, it is difficult to discuss the experience. At the time this study was conceived I am not sure that I had consciously grasped that, but at some level it did influence the decision regarding age. As will be seen in the following pages, one of the participants was slightly younger than 30 but

particularly wanted to engage with the study. I agreed to this, although it is interesting how different her narrative appears compared to the others. I return to this in due course.

Ensuring credibility

Life story research has stimulated much academic debate regarding its validity as a research method. The nature and role of memory and truth has been questioned in an attempt to validate the accuracy of a story. Qualitative epistemology however maintains that there is more than one truth and that the “dualism of valid or invalid does not allow for an alternative perspective” (Koro-Ljungberg 2006). His argument is that within a constructionist study knowledge is a co-created process and that the term validity does not reflect a process, but refers to an outcome. Likewise credibility within a qualitative research study refers to an evaluation of its trustworthiness. There is some ongoing dialogue to determine what research is worthy of a person’s trust. Kvale (2007) suggests an ongoing process of checking for sources of potential bias throughout the interviews and during analysis and this, he states ensures that research is as credible as it can be. He adds that seeking feedback from participants also enhances credibility because it affords an interpretive buttress that what is perceived, accurately reflects the participants’ meaning.

My interpretations are based upon the co- constructed latent and manifest meaning which was negotiated in the interviews. My reflexive thoughts are shown in order to make the process of the interpretive role transparent which should lead to knowledge which is intrinsically credible. Throughout the interviews, I was careful to clarify the participants’ meaning of stories at the time. In some cases, the meaning of their narrative was unclear and of course given my own history I had to be particularly careful not to make assumptions. Additionally on some occasions my recorder had failed to capture some detail, so in line with the advice given by Kvale (2007) in those instances the participant was contacted for clarification. I had email or phone communication with five of the participants following the interviews. I was unable to

contact two of the participants. Participants who lived nearer, and who wished to, I met again and as such, was able to give them their written story and a little feedback on my progress with the results. It was somewhat reassuring when participants validated my ideas. No-one expressed any disagreement regarding my interpretations of their meaning.

No attempt is made to generalise this narrative work. Each of the participants told a very different story and I would not want to undermine a participant's individuality by reducing the narratives to a series of categories. The ideas identified in the stories may however be transferable and this is best assessed by their resonance with the stories and lives of other people (Koro-Ljungberg 2006).

Ethics

Ethics concerns the morality of human conduct and this includes the preservation of dignity, wellbeing and safety, which should be inherent throughout all ethical research (King and Horrocks 2010). The Research Governance Framework for Health and Social Care (DH 2005) sets out the ethical requirements and standards which should inform all research projects relating to health. This includes all research conducted by charities, universities and health and social care systems where the research may have an impact on the qualities of a service. The research proposal for this study was therefore subject to scrutiny by Bournemouth University ethics committee See Appendix 1. The participant information sheet is included as Appendix 2.

Narrative Inquiry raises particular ethical issues which are mentioned here because they fall outside the consideration of the forms used by the ethics review committee which uses positivistic language and concepts. Smythe and Murray (2000) suggest that the consent for narrative work should be a 'process consent' meaning that continued consent is a mutually negotiated ongoing process, which serves to avert anyone left regretting their level of disclosure, which is unpredictable in narrative work. Josselson (2007) suggests that this kind of consent is more akin to the ethics of care than standard research ethics. Because this study was by its very nature personal and

sensitive, I was very mindful of this notion and whilst a consent form (Appendix 3) was signed by each participant prior to the interview, I also took care to ensure that on-going consent was not assumed, and checked with each participant at intervals that they were happy to continue relating their story.

Confidentiality is difficult to ensure in narrative work because a life story may be recognisable by its uniqueness. It was stressed to each of the participants that although a pseudonym would be used to present the stories, and that all identifying locations would be disguised, it remained a truth that it is virtually impossible to ensure complete anonymity. Due to the study having been advertised locally in the newspaper, it seemed important that confidentiality was discussed in detail particularly with those who were recruited from the local area. One participant remarked on her concern about this before it was raised in the interview, so I was able to reassure her that I would keep her as anonymous as I could, and she agreed to continue with the interview with the expressed notion that she doubted anyone from her place of work would read a PhD, or any resultant articles which may ensue.

Ethical dilemmas also occurred during the interviews. The subject area was likely to be very sensitive, and although I am a nurse, I was not nursing, and therefore felt a degree of anxiety that I might leave someone distressed and not 'be there' for them afterwards. Whether this relates to me personally is unclear, perhaps it stems from both my own psychopathology and also that of a concerned human being, not wanting to be the cause of distress. At the same time, I knew that the research should not evade difficult areas; the emotional life of the participants is part of their experience. It became clear that I had to draw upon my skills in lessening the intensity of the discussion if either a participant had indicated, or I felt that the conversation was becoming too uncomfortable thereby touching upon the fringes of being unethical (Josselson 2007). An ethos of pragmatism ultimately directed the completion of the research. After each of the interviews I made sure the participant was feeling as 'contained' as possible. Each participant was also given a list, which detailed sources of

support which they might access at a later date should they feel the need (Appendix 4). Because some of the participants were not local, a reference to self- help and internet sources were included on this. The importance of acceptance of help to address anything which should subsequently arise was stressed at each interview. It seems relevant here to state that I was immensely grateful for the level of disclosure which demanded such courage by the participants.

During the analysis and writing up phase I had further ethical decisions to consider, not least who the story belongs to. If the interviewee is a 'participant', should the participant have full access to what was written about them? Should they also have the opportunity to feedback on the findings and comment or edit any of the work? Hollway and Jefferson (2000) discuss whether it is more ethical to give full access to the findings in research, or whether in fact it is likely to be more harmful to present the participant with the stark findings of the data analysis. And whose truth is being displayed in the final thesis, that of the participant or that of the researcher? The stories are undoubtedly the participants, but the data belongs to the researcher. For this reason a core story was created for each participant. These have been included as the next chapter.

Discussion about the findings of this study and the core stories therefore use the participants' own language to highlight relevant points. Quotations from the participants are used throughout. This should assist the reader to follow how I have arrived at the conclusions and interpretations. Reflexivity required Using the participants' own language also allowed me to do justice to the stories, which had been entrusted to me with such courage. It is not easy to discuss ones vulnerability and I could not bear the thought that the participant might be left feeling that I had not entirely understood their meaning or misrepresented them in any way (Smythe and Murray, 2000). Using the participants own words to underscore interpretive meaning also affords a more humanised appreciation of the stories which would not be possible in the third person.

Recruitment

The sampling strategy for this study was purposive and opportunistic which means that recruitment was directly targeted towards anyone who had the lived experience of being an adult who grew up with a seriously mentally distressed parent (Berg 2004; Creswell 2007). The method of recruitment evolved over course of the study. My intention was to avoid recruitment from local carers centres, because I was keen to target a population who may or may not consider themselves as a carer. The likelihood of there being individuals who fulfilled the criteria for my study, without necessarily ever having sought help or support from local services either as a patient or as a carer, was assumed to be high.

However recruitment of participants was more difficult than expected, and has therefore limited the amount of participants I was able to interview. Fortunately large numbers of participants are not expected in this kind of qualitative study, which aims to reach a depth of analysis which would not be possible with a large number of participants. As there is no attempt to generalise findings, the number of participants was not considered so problematic as to be likely to thwart this study; but one which I have had to work around by being as creative with my sampling strategy as I possibly could. The final number of participants of this study was seven.

The first round of recruitment for participants was via the newspaper I was left somewhat deflated following the inclusion of my advertisement which had been amended to suit the editorial space available, cropping the heading and misspelling my name (Appendix 5). Due to circumstances outside of my control, it also went in the paper the week following New Year which was unfortunate timing, and led to just one person making contact. Financial considerations, and anxiety about whether the newspaper would crop crucial elements which had been reviewed by the ethics approval committee, made me cautious about a second advertisement. I then amended the advertisement for email presentation to the local Health Care Trust and University website. This method heralded a further two participants. A blog was

created and reached many countries across the world, particularly Australia. One person contacted me via the blog, although the logistics of timing the interview unfortunately deterred this person from continuing.

Submission of the advertisement to the Parental Mental Health and Child Welfare Network website generated some interest, and from this I was able to find a further three participants. This was interesting because it is a professional network which is not particularly well known, but one which was evidently attracting the interest of people (not necessarily health professionals) whose lives have been touched by mental distress themselves.

The problems I have had recruiting participants may have been partially logistical in terms of my not being able to get the word 'out there' but may also be due to the nature of the study. It is hard to speak about familial mental distress, and lack of people coming forward may have been a reflection of this difficulty.

It is of course a truism that participants who are willing to be interviewed and make contact with the researcher in order to be involved, will have a reason for doing so. The participant may wish to share their experience with others for altruistic reasons, or for an opportunity to be heard. This may have been relevant for the participants of this study who by nature of being an AOPMD may not have previously had anyone to tell their story to. This is partially why the interviews were conducted as flexibly as possible. The participants were then able to direct the interview and discuss whatever they felt to be relevant. I was careful also to allow as much time as was felt needed so that however much someone wanted to say could be accommodated. It did occur to me that individuals who were too traumatised or personally distressed may not come forward. This means that this study is likely to have appealed only to those who were sufficiently confident to be able to speak about themselves and their vulnerabilities.

It was interesting how all seven participants were women. And all but one grew up with a mentally distressed mother. However, the person who grew up with a mentally distressed father also had a mother who was vulnerable. The gender of the participants

may be representative of the higher percentage of women found in caring roles, both formal and informal (Braine and Wray 2016). It may also be indicative of both the desire to participate in the research process, and the kind of research this is. Telling ones story is not an easy task and it may be that participation in this kind of sensitive research may hold greater appeal for women. Further discussion about this can be found in Chapter 5.

Interviews

The style of the interview is recognised as being more or less facilitative of a narrative. Too many questions can render a person feeling threatened if they are unable to provide answers which they perceive the interviewer to be looking for (Hyden 2008). This is likely to provide limited and curtailed responses. However, it is also argued that unstructured interviews or asking something too general may leave people floundering (Benner 1994) and that rather than affording a greater sense of control over the process, it may actually be a more coercive form of control which forces people to speak (Hammersley and Atkinson 1995). This of course would in turn influence the participants' response.

Reflecting upon this dilemma led to the adoption of a middle path. I did not want the participants to leave feeling that they had not had the opportunity to share what it was they wanted to say, or the knowledge they wished to convey. At the same time, it seemed important that they were given some direction so that anxiety would not silence them.

This approach led to a request to the participant to tell me their story albeit with some prompts. These prompts included "Talk me through how you first became aware of your parents' mental distress" and "How did life change for you then?" "Tell me more about that" or "Could you give me an example". For some participants this was sufficient, although others needed more. Riessman (1993) suggests the optimum would be about 5-7 broad questions as icebreakers relating to the study objectives. I did not follow this advice, given the understanding that Freud and many gestalt

therapists believe that the observation of free behaviour reveals the essence of the communication (gestalt) being expressed. The idea here is that the more free the behaviour from external influence, the more completely the internal dynamic can be expressed and understood (Wengraf 2001).

The participants all reached the end of their interview in their own time, allowing for them to create the end of their story as they wished. Given that I had no prompt list for the questions and opened the interviews with a broad “tell me your story” I think it is possible that participants were unsure of exactly what I wanted. Some asked me for guidance and in these cases I responded by suggesting they tell me what they thought was important for me to know. Naturally the unconscious dynamics of our relationship in the interview may have influenced the participant’s choice of what to tell me. It may be that they saw me as a mother figure, or rescuer, and this of course raises the question about what they felt they might share. To a greater or lesser extent each participant was not heard by their own mother so they may either have ‘softened’ their story to protect me, or because they were unused to hearing their own story, or alternatively given me their story and their experience of trauma with some gusto to ensure they were heard.

I was careful to try and establish a sense of rapport by making some small talk and providing coffee where I could, but found some participants struggled to know where to start. Once the interview had got going, it was easier to facilitate the story telling with my questions and reflections in response to the interviewees’ train of thought.

As the interviews progressed, my style altered to become more interactional in light of the growing understanding that the process is dialogic, i.e. there needs to be some kind of a relationship between myself and the participant, in order for stories to be attained. As I read more about constructionism, it occurred to me that I could afford to be more interactive without derailing the interview. The latter interviews as a result, became more and more like a focused conversation, and I became less and less concerned about intervening when I felt I wanted to. On reflection, I feel that

Riessman's (1993) advice is particularly relevant for sensitive interviews. I had assumed that interviewing would be relatively straightforward given my therapeutic background. The therapeutic interview is however quite different, because the practitioners primary aim is the development of the therapeutic relationship. The researcher does not have the luxury of this time, and a good enough rapport has to be achieved with some urgency. The interviews were carried out in a public place of the participants' choice and varied between fifty minutes and two hours depending on how much the participant wanted to say.

Providing coffee and a congenial atmosphere allowed me to re-enforce the importance of the participant's story, so that any assumptions of special expertise or unrealistic expectations of me might be mitigated. The inclusion of my professional status on the information form made this particularly important. I did not disclose to the participants prior to the interviews, my own experience of having grown up with a very distressed mother. I felt this would have altered the participant narratives to reflect an unconscious sense of knowing which could be assumptive. I also wanted to avoid the participants being mindful of my sensitivities, or trying to protect me, whilst telling me their stories. In the interest of honesty I shared the origin of the study's personal significance after the interviews.

Face to face interviews did allow me some measure of non-verbal communications thus enabling me to have some insight to the participants' emotional state which guided me to respond as necessary. The exception to this was the interview conducted by SKYPE which is discussed in more detail below. Where participants stalled and I intervened was considered in detail using the transcription, because it was not always clear whether it was participant anxiety or my own, when breaking the silence at times.

Reflecting upon the process of interviewing also made me aware how distracting using a dictaphone had been. Perhaps some people would not find it burdensome, but I found my concentration wandered at times. I found myself anxious that the batteries might fail or that I would inadvertently delete the interview later in my bag! It may be

that practice would help here, although of course my focus on the dictaphone might have masked anxiety about the content of the interview.

Although I used a reflective diary, debriefing was not always possible. I used my formal academic supervision where it was scheduled, but did not telephone my supervisors for support between sessions. Both of my supervisors had given me a contact number which I chose not to use. My own story clearly plays a part here. I found the interviews more difficult than I had anticipated. Despite hearing many traumatic stories in my nursing career, the focus on parents who were distressed made powerful impressions on me. I suspect it was the intensity of the interviews on this chosen subject which touched me so closely. I went home directly afterwards in order to allow myself to cogitate. I also felt utterly exhausted after each interview and needed to be alone. Part of the reason I did not contact my supervisors is that I was aware they lived some distance and are very busy people. I felt unable to ring them whilst they were at work and did not wish to intrude in their personal lives by ringing them later. I therefore kept the experience to myself as I do not like asking others for emotional help. There are a number of reasons for this; 1) I do not trust easily that anyone really has my best interest in mind. 2) By acknowledging that I wish to speak to someone I have a sense that I am making myself vulnerable. Almost as though saying it out loud makes it feel more real and throws light on my vulnerability. This of course emphasised and resonated with the isolation and aloneness which was found in the stories. I felt unworthy of reaching out, as if I could not burden anyone else with concerns which I should be able to manage myself. Of course I am aware at one level that this is nonsense, it is an area I still need to work on.

SKYPE

One interview was conducted by SKYPE. The participant wanted to be involved in this study but the distance meant that face to face interview was impractical. Given the nature of the study I had some reservations about this which I shared with the participant, who assured me that she wanted to continue her involvement. One of the

concerns which arose for me was the lack of ability to control the environment, and indeed the participants' doorbell went twice which then started her dog barking! She and I found this interrupted the flow of the interview and it took both of us a while to resume where we left off.

The other issue with skype which was problematic for such a sensitive interview was the poor quality of our web cams, and slight time delay speaking to each other. It felt very difficult to 'read' her face, and at times establish contact and meaning between us. The camera was unable to pick up minor eye contact changes, or flushes of skin, which would normally enable me to measure a person's emotional state, and adjust my interaction accordingly. Because the camera was focused on the face, minor shifts of body language were also unavailable for me to see. Whilst skype is useful to researchers in terms of its ability to reach a wider audience, it should be used with some caution with a qualitative study of a sensitive nature.

Transcription

All of the participants' narratives were transcribed in full by me. All of the inflections of voice, 'ers and ums' were kept in totality, to assist with my recall when I came to analyse the narratives. In actuality the inflections of voice and nuances of language gave me so much insight to the participants' meaning; I came to realise that without them the narrative is flat. It was the hesitations, the stutters and the silences, which gave meaning to the stories and allowed me to identify each plot. In the transcription of Meg's narrative for instance, I noticed she had two distinct laughs. One was a deep belly laugh, and the other was a nervous giggle. It occurred to me that had I not transcribed myself, this was the sort of important information which might have been missed. Despite the laborious nature of transcription, I was able to glean so much more information which would not have been identified by use of software or sending the recordings to a transcriber. When transcribing, I could immerse myself back into the interview, and replay it, capturing moments which I had previously missed.

Data analysis

Most forms of narrative inquiry tend not have an exclusive set of procedures to follow, nor a clearly articulated analytic strategy. There is also no specific underpinning theory. The theory drawn upon to analyse a narrative is dependent upon the researcher's question, personal preference, and unconscious processes, which all play a part in determining the choices made. As such there is a wealth of literature detailing various approaches to narrative analysis, and it is left to the researcher to select the most appropriate for their study (Kelly and Howie 2007).

In terms of the analysis, academic debate centres on the strength of the interpretative role employed which must be neither too strong, nor too weak. It is argued that if the interpretative role of the analyst is too strong, the analysis will demonstrate insufficient links to the empirical data, leading to a romanticism of the story more suited to celebrity or media type interviews. Alternatively, if the interpretive role of the researcher is too weak, there is likely to be a lack of attention paid to the social context and interaction within the data (Atkinson 1997). For this reason, researchers must therefore be able to describe and defend the interpretive framework being used to analyse the narratives (Riley and Hawe 2005)

Although narrative inquiry does not have a standard method of analysis, approaches to the analysis fall broadly into two main categories. Scholars tend to refer to these categories using different terminology, however; one analyses the structural features of the text, and the other analyses the themes found in the text (Elliot 2005, Andrews et al 2008).

The decision-making relating to the analytic strategy caused me much consternation. The search to identify an analytic technique which could target what I wanted to explore, took months. Throughout this time, I engaged with various theories and ideas. At times I did not believe that I would succeed in finding my way. Transcriptions sat on the screen of my computer until my eyes blurred, and fatigue drove me to close the computer once again. I vaguely regretted not doing something which software might

have helped with. My stubbornness and/or tenacity eventually prevailed, when I finally accepted that narrative analysis is essentially a way of organising the texts to try and make sense of the long and sometimes meandering stories presented at the interviews. From my own life experience, I had detected a kind of process which I wanted to capture, although I was not sure what the steps or stages of that process were. Insights of a thematic nature would add to the sparse literature base, but would be limited by their lack of ability to appreciate the temporal dimension of the narratives. Splitting the texts into themes, categories or codes, was therefore something I wanted to avoid. The need was to find a way of keeping the story as together as possible, so that the stories did not become disembodied from the teller.

The approach first considered, was that of using a life course framework such as that proposed by Dollard (1949). Some researchers have cited the usefulness of a life course approach in the study of the impact of mental distress on families, due to its ability to recognise the interdependence of family members (Cook et al 1997; Stromwall & Robinson 1998). Stein and Wemmerus (2001) suggest, that age related norms of behaviour such as leaving home, getting married, having children, can be used as a gauge, against which a person's life course can be assessed. If a person fulfils the expectations of their age group at roughly the same time as others of the same age, they are deemed less likely to suffer from stress and lowered self -esteem. Elements of culture, gender and social status, are therefore important in this kind of analysis. The initial appeal of using a life-course framework was that it might be able to provide some rich contextual detail to help structure and re-present the findings, in a way which would make sense to the reader. Initially therefore, this study had been aiming to use 'childhood, adolescence, adulthood' etc. However initial attempts to analyse using this kind of a framework, were in due course abandoned. It was difficult to show the life paths of the participants who were a) of very different ages, and b) whose parents were at different stages of their distress as it evolved over years. This method therefore failed to show the evolving process, because of the amount of variables in each narrative.

Because the concepts of identity and meaning making are central to this study, it became clear that there was a need to find a way of expressing the gestalt or plot of the stories, which prioritised the representation of time, rather than themes. Riessman (1993) suggests that the sequential and structural features that characterise a narrative are key to a narrative analysis. The role of the plot is emphasised by Polkinghorne (1995) as a way of holding the story together. He argues that it is the plot which recognises the contribution of the events which are narrated to the development of the story, and the position in which the story tellers find themselves at the end. The understanding derived from this, was that for the study to work there was a need to prioritise the plot or thread of the story over the context and extraneous detail.

The model described by Lieblich et al (1998) offers a way to keep the narratives intact. They use the terms 'content' and 'form' to depict one continuum, but they add another continuum by relating each of the above categories, to that of 'categorical' and 'holistic'. The diagram shown depicts this framework. Each section of the framework spotlights particular aspects of the data which may be used to analyse in a variety of studies, dependent upon the researcher preference and the study aims.

Categorical Content Parts of the story Beginnings/Endings Distinct wording A section of the narrative or a theme is analysed	Categorical Form Narrative coherence How the story is told
Holistic Content Entirety of story Meaning of story content	Holistic Form Scene /plot/character Style/genre of narrative Turning points Story trajectory

Lieblich et al (1998)

The narratives in this study were therefore analysed primarily using the holistic content dimension of the framework, which because of its ability to keep the data intact, maintains the gestalt, when presenting the stories. This approach suits work which aims to explore identity and meaning, because of its flexibility, which allows the study to unfold in its own way.

Because of my interest in meaning-making, some of the elements of the categorical content dimension of the framework were also used. These elements were chosen for their particular relevance to the study, where they helped clarify meaning. The main elements which were utilised included metaphor, overused words, contradictions and slips. This allowed for a deeper consideration of the narratives, where the participant

omitted detail or relayed only partial detail, due to their inaccessibility to speech (Riessman 1993). These details were not seen as problematic as such, but part of the findings. Additionally, where some of the narrative data is hard to comprehend, underlying emotional threads are detectable which moved the narrative on to the next story.

Eventually, I found a visual representation of the dilemma which was causing such a block to this work. Much like choosing a lens for my camera, I needed to find the best way of extracting the detail I wanted to explore, by blurring the rest. By blurring the information which is not directly relevant to my question, the viewers' focus is drawn to the detail which is. It was not a macro lens I wanted, but a wide angle lens, which would show the breadth of the experience, along with a shallow depth of field (depth of focus) which would highlight the emotional journey rather than confuse the image with contextual detail.

Holstein and Gubrium (2007) suggest that this is a way of using an interpretive framework to explore biographic *work*. The *work* is how the person represents their life course, and how it is transformed by the meaning making process. This option allows use of a constructivist framework which is not dependent upon chronological sequence, but relies upon the meaning- making process of the individual.

Chapter 4

Participant stories

Emden (1998) posits that core story creation is essentially a means of reducing the full length narratives to a shorter story. This process she argues must retain the essential plot or essence of the narrator. Kelly and Howie (2007p 141) add that “the core story is not a story verified by the participant, but rather a construct that gives meaning and understanding to the narrative data” This proved to be more difficult than I had anticipated. I struggled to achieve stories which were engagingly written whilst maintaining the participants’ nuances of expression and voice. I wanted to convey the essence of each participant and their story. I first tried writing these short stories in my own voice, using the third person, however they sounded bland and cold. My next attempt, in the first person was closer, but still sounded like me. My own tone of voice is quite serious. My syntax is distinct to me and made me realise that I had to distance myself so the participants’ voices could emerge. My degree of empathy for each of the participants had to be sufficient to facilitate an insight into the dilemmas and motivations the participants had shown me, whilst it was up to me to show the complexity of each person so that the stories could breathe, or as Gornick (2001) simply puts, “Get the narrator and you've got the piece” p163.

In order to adopt the persona of each person, it became necessary to immerse myself in their story, and allow myself to really feel them through their language. I had to somehow identify with each person’s defences, and their traumas and losses, as it was these which were so illuminating. For a period of time I sank to a dark place myself, where the depth of these stories were felt and experienced viscerally. I knew I had to face this darkness in order to tell of it. My own story interwoven throughout this time had also to process the failing health and eventual death of my own mother. I did not want for my own story to be told here, but had to face my own confusion, my own mixed feelings about my life, in order to sift through what was mine and what was not. Facing the traumas and losses of the participants with as much courage as I could

muster, led me to realise that *this* was their story. Firstly I had to acknowledge what the feelings were, and then let them guide me into the experience. The crazy, frightening and sad dark place I had been to, was what I needed show, because everything else was superficial and did not tell the whole truth.

The stories revealed uncertainty and self-consciousness in these wise, funny and brave women. Women for whom life has been, and in some cases, still is painful at times. These women's stories sometimes resonated so closely with my own story, that I could sense the familiarity in-between the lines. The struggle here was that the greater the resonations, the greater the danger of romanticism fueled by identification with a madness, shared between those who have this lived experience. Part of the confusion I had to work through was the familiarity of the stories. Where did my own interpretive meaning begin and end? Where did it overlap with the participant's narratives? Riley and Howe (2005) suggest that this dilemma is natural in a narrative analysis, because of the depth of engagement with the stories which the researcher must achieve. They argue that it is the depth of engagement which may provoke a blurring of the interpretive boundaries. When this happens the researcher is at risk of the interpretive role becoming too strong without sufficient links back to the data (Atkinson 1997).

As a way of addressing these concerns I opted to use as much of the participants' own language as I could, because that gives so many clues to the reader about who they are. Their own words bring the story alive, their tone of voice, and their view of the world, their rhythm of speech and dialect giving personality to each story. The stories each person had chosen to narrate, the meaning they had intended, what they saw or didn't see, could then be told with honesty. As advised by Holloway and Freshwater (2007) I was very conscious of my responsibility to convey the meaning as accurately as I could, so that the stories are deemed credible and the narrators trustworthy. Bruner (1990) however claims that narratives are not verifiable and not necessarily wholly truthful accounts, but rather a flow of plausible events and dramatic versions of experience. For this reason, I was careful to use myself only to clarify meaning or

propel the story forward. By this, I mean that I relied on myself to reconstruct sentences which had to be shortened, so that I could keep the story flowing whilst keeping to a predetermined word count.

Anna's story

How did we get into such a muddle, and a mess? How did it all go so wrong? I look back now I can see all five of the kids are definitely all scarred for what they've seen over the years what with my mum and dad, and also perhaps me and my marriage as well.

It's only you in life who can do it. You are the one who's got to make the decisions. That's the only answer. That's the only battle; is to do it. Anti-depressants and alcohol and drugs just put a surface on it. At the end of the day it's still you who's got to do it. I am the one who has to keep going and get myself out of this. It's down to me.

We never did find out what triggered it. It was so strange. She had had a horrendous life as a child. She told us her dad had been an alcoholic, and lost everything when she was born. They were virtually in the workhouse in those days. They were like begging on the streets.

You look at people and you don't know what is round the corner, people can change overnight like my mum did. Never got anyone involved with it, just put up with her really, and tried to cope as best as we could. You look back and think *whoah!* Just absolute roller coaster!

I am 67 now and I think why didn't I ask her a question? But she never used to answer, she would never talk about anything, you could start talking and she just wouldn't give you answers or never ever mentioned what she'd done or felt. Just never discussed it, she didn't want much communication.

People don't know, on the outside I am the life and soul. But that is just a front because inside that is not how I am feeling, I just put on this outward thing. I used to be angry. I've never fallen out with my brothers over anything apart from my mum,

because it was all on my shoulders. Yeah they used to come and visit but then they would go away! They had their lives. It was all down to me. I was the only one here caring for her really. And she was just an absolute living nightmare.

When Mum went into the care home the pressure was taken off me. We only saw her on visiting days, and we had certain days we could bring her home which we did. I am glad we did have her; my youngest one saw her as quite a nice little nan really. We never thought we'd get her back. The day before she died we'd had her round on the Sunday.

Once she barricaded herself in the room when she fell out with me. I couldn't not go and see her but she wouldn't let me in. I used to knock on the door and she used to ignore it. She was stuck. She'd gone. I used to think twice even like having a holiday or not. I couldn't move away. No way, I could even think about doing it. Most of the time I was thinking; "What is she doing now? How is she coping?" When we did move it was only one road away from her. I was always in easy access. Soon as I met my husband and got married, all through our marriage until dad died and then mum died, he had to deal with not only me and the children; he also had my parents on tow.

He turned violent though; he started to drink a lot which I didn't know about. I lived in a fear. I don't know why I had 5 children really; I should have stopped at one but I didn't. No one knew what was going on in doors.

Even giving birth and in hospital for 10 days she was on my mind. My dad had been diagnosed by then and he was dying. She wouldn't look after him. I had him round my house, in one of the babies' bedrooms and of course I had to go 'round and see her all the time. She wouldn't even come 'round and see him. I was racing round sorting her out, sorting my dad out, sorting my own family out. So what with trying to cope with a new baby and a little toddler of 2 and a half, I had mum round the corner and dad upstairs in bed! When the hospital said he was coming out she said "I'm not looking after him". I said "Well what we gonna do then?" That's when he came 'round and lived with us. Ohh I've just lived off my nerves all my life really.

As she got older and all her family was dying, she got lonelier, lonelier and lonelier and of course I think the loneliness brought more and more depression on. She didn't have hobbies, she had no interests; she didn't ever go out. Her life was just looking after us and I think once we all left, it went worse on her. I said we've got to get help but dad would do nothing about it.

As a kid, I'd lay in bed waiting for Dad to come home, then the rowing would start, the constant screaming, the battles 'n' smashing stuff, she used to break stuff up and when she started being horrible to him and fighting with him and arguing with him, I think yeah a lot of it turned to hate. I know when she was admitted the first time to the hospital one part of me wanted her to die, because I thought well you know, it would make my life easier, it will make my Dads' life easier.

None of this started till I was 14; Up till I was 14 my mum was lovely and normal. I'd had such a nice little childhood, with a happy mum and dad. My parents were a loving couple you know they used to kiss and she used to stand at the gate and we used to wave him off to work.

Now all my friends now are celebrating their golden weddings, I look at them and I think what did I do so wrong? They say "I cannot believe you are still around with a smile on your face" But you do though, you've got no alternative. They tell me to write a book; I could write a book and name it 'a battle' couldn't I?

Meg's Story

I guess I have always, I don't remember *becoming* aware of it, I just know it as being part of who she was forever, she was always very good at telling me about it, being honest, you know it was never hidden, it was just part of her. I just grew up knowing that that was my mum. She's got great insight always, so I guess I never really knew of anything different.

I had to care for my mum and do things around the house and I guess take on a lot more responsibility than people that I was growing up with. You know they, When I'd

look onto their families they'd have the 2.4 classic family; with both parents working, siblings, nice house, cars and all that. No responsibility really, they just had to decide what to wear that day! And sometimes I'd go to school when my mum had taken an overdose the day before. I'd be really stressed, that was very *different!*

I worry about Mum, where I guess people with parents without mental health problems don't *worry* about their parents in that way. They don't worry about having to come home, has she had a bad day? Has she taken some pills? Is she going to be alright tonight? Is she gonna get poorly? Is the medication gonna be enough? Is she gonna relapse? Is she gonna go into hospital? Will I get taken away by social services?

I think my mum took care of all my *needs*, she could cook and get my washing done and make sure I had what I needed for school and the main thing she gave me is a lot of *love* and respect and helped me grow up. My mum was good at giving me a really stable home and my grandparents were very good. I think she did a really good job. I have a lot of respect for my mum. I really do. I think it is a big challenge to cope with every day; you know like being in a wheelchair *and* having a mental health problem.

She was really poorly when I was born and in hospital for a *long* time. I think we were in a mother and baby unit for a while so I think my dad kind of brought me up for the first 4 months on his own then I went into a mother and baby unit. And then we came home together... Yeah. My relationship with her now is good. She has been very open with me about her history. If she fully relapsed and needed hospital she would be a *massive* risk to herself. Like huge. She jumped out of a window, that's how she ended up in a wheelchair. She also tried to drown herself and set fire to herself; *I think* when I was born and she was in hospital, but luckily they found her.

Ultimately I guess if I really think about it, the worry is that my mum is going to get unwell and that she probably won't live through another relapse. Sometimes they talk about reducing her medication and she's like, "I don't want anything altered" She is so scared about changing anything. She really doesn't want to get unwell and she will say "I wouldn't survive it"

A lot of her friends are the people I grew up with and have mental health problems of their own. Mum used to host a schizophrenia support group at our house, for as long... all the way through my childhood. They used to meet once a month. They saw her as a person to come to, so I would have people in my house that were unwell. You know? people sleeping on my sofa sometimes. Most of the people that she met are the people I grew up around have mental health problems. Like one person she has kept in touch with was the Rethink worker that used to come and she is one of my mum's closest friends now.

She has taken lots of overdoses and once I was 15 and she took an overdose, I was very *angry* with her. I had a lot of anger, a lot of "*Well what about me? Hang on a minute*" But when she has taken overdoses it's been in the context of stresses and it's not been an attempt on her life, it's more been a way of being desperate and needing help. She'll say you know? "I feel really suicidal today; I am really struggling" we just talk through it really; I don't think she would do anything.

Sometimes though it can be *agghhhhh!* When you come home to a voicemail message saying "can you ring me when you have finished work, I need" and then you are on the phone for half an hour/ forty minutes to your mum and it can be.... I am open with her though. If I say to her, I can't cope with it at the moment, I can't....you know? It's *too* much," then she will, she will back off usually and ring someone else. But it doesn't always work!

When I was going to do Uni, I really thought about whether I should or not put myself through that, and not flip the switch. That's how I've always talked to my mum about it. Potentially the switch is there you know and I have *got* to make sure I don't turn it on. My mum was always very good at sitting me down from an early age and talking to me about drugs, and like, don't do them! Don't do anything that might potentially give you this horrible illness. And the reason I said no to drugs was because I knew that potentially it could make *me* unwell. But actually I've moved house and I've done Uni and actually work in a really stressful job! And I am alright! But I definitely do worry.

Will I get it? Won't I get it? Definitely and I think about having children, I worry about giving it to my kids. And I have to think about who I have children with, do they have a family history of mental health problems? It would be good if I had children to be with somebody without that in their history at all and then the chances would be a lot less. But actually the person that I live with has bipolar! What are the chances? You know the statistics would just be ridiculous! And I can't live, I can't spend my whole childhood looking after my mum and then having that, spending my adult, later life looking after my child, it would drive me crazy! I just think oh no, it could be me one day.

Cathy's Story

I remember her being very odd, as it were. I very rarely had friends come for tea. I felt very embarrassed and I don't think at the time I could really put my finger on *why* I felt embarrassed. Anyway there was this *horrendous* row between my parents. I was about 12. It was about quarter to eleven. My mother was shouting at my father saying all sorts of things, saying she was going to leave him. It was very traumatic, and the doctor came and they were in the room talking and I went to bed. The next day after school dad said "Oh mum's not here, she is not very well and she's had to go off to hospital in an ambulance" I didn't understand what was happening.

And suddenly she was *gone*, out of my life; she was gone. We had to go and visit her. And I have very vivid memories of going to door of the psychiatric unit and a woman standing there with her legs all scarred, at the door and a cigarette filter hanging out of her mouth. It had a huge impact on me. I can remember like it was yesterday.

I guess she was having outpatient appointments and things until I was about 16 and doing my 'o' levels. I was at private college, which was fine with me because home life was really very cold and I really felt there was nothing there for me. I had become quite introvert from that. I wanted to get her attention but she would never acknowledge, or you know she just didn't really have time for me. That sense of abandonment has never left me.

And one day dad went off to work, he used to come home at lunch time from the farm, to have his lunch and she'd gone. She stopped taking her medication. She lived in hostels for the next two years because she had the voices that told her she wasn't allowed to buy anywhere. Eventually dad got her back and she moved back in.

At 21 I moved back home but she couldn't stand it. She couldn't stand me being there and asked me to leave. She just couldn't bear me in the house. My brother however landed on his feet, he was marvelous, everything he did, marvelous! They built a house for my brother and his wife on the farm and I was asked to leave.

We had a row before my wedding and she shouted at me and I shouted back, and she slapped me around the face and I said "don't come to my wedding" So she didn't. And then we didn't have contact for I guess it was about two or three years. In that time I had two children but we divorced. He left me completely penniless with the children. I had worked throughout, kept everything going; continued my study. Basically he just lied, he squandered all the money. I was in every night with the children doing my studying, and he was nowhere to be seen. I didn't know anything about it until the bailiffs were at the door. I decided to fight for everything.

Anyway she got sectioned about 16/17 years ago. When she came home she was on meds and it was amazing. It was like having my mum back from when the best memories I could ever imagine. She was warm, caring it was just great. It was amazing. It was like having a rejuvenation of my mother, it was fantastic. You know the voices were under control we could go for coffee, we'd go shopping you know? The future looked bright. It was amazing. It was just lovely. She would phone me, it was a normal relationship.

And then she started to get side effects from the medication, you know jittering of the leg, dry mouth. I'd had her for a couple of years back with me when it started to go a bit awry, started to drift a bit. The voices started coming back in. The CMHT said "well you know she deserves to have a chance off the meds". I knew what was going to happen straight away. And by the November I was phoning the consultant saying "you

really need to do something here”.

I’d done so much, I decorated the outside of the bungalow, I decorated the inside. All her money had gone; I got her onto her benefits, her pensions. I had smoke detectors fitted in the bungalow; made sure she had enough money to pay for her oil and petrol so I knew she could get her groceries in. I tried so hard to get her love but I never really got it. It’s almost like she gets possessed by these incredibly dark thoughts of *me...oh my god*. I can’t bring myself to talk, use the words that she says because they are *horrendous*. I asked her “Why are you like this? Why are you saying these things to me? Why? I just wish you wouldn’t push me away, I love you and I wish you wouldn’t do this to me you know cos it just soul destroys me”

Within the family it was always agreed that my brother would have the farm and I would inherit their houses. It was a very old fashioned family thing that he would work with my father and that that her property would come to me. But my brother told me she is thinking of changing her will. I am someone who had a life at private school, big house, ponies, two holidays a year, skiing in the south of France, you name it. And I have nothing. I have lost the lot.

I haven’t been to the bungalow it’s got to be for two years, and you know my daughter said to me “Mum I know you care for nana but I think you have to let it go, because it’s just too much” but I still phone her and still makes sure she is okay and make contact with the CPN and everything. It still hurts as much as it did. How my life could have been different. How it should have been. But it has just *torn* our family apart. They just destroyed me.

I don’t know about the future. I will continue with my mum, I will always be there; only to get kicked down again but to come back up, that won’t stop, I will always be there. Because I can’t abandon her, I am not that sort of person I just can’t do it. I can’t walk away. Maybe just maybe, I have a glimmer of hope that one day....

Jo's Story

There was always a sense that something terrible was about to happen. To start with, I had no term of reference that made sense to me. My older brothers and sisters were at University and work, and my Dad was useless really. There were people around, but it was kind of me who was there with her all the time as she became more and more ill.

She was very beautiful, a very good looking woman, very much the kind of 50's housewife. All her brood of children would go off to church all dressed well, with gloves and hats and that kind of thing. But she physically became really, really, really ill looking, so she neglected her hair. She used to have her hair permed like the queen, you know? But it got greasy and long, she got really sunken eyes and got really, really thin and she wasn't sleeping. She would wake me up in the middle of the night. She would get really worried about things. She would come into my room and say 'oh my goodness, look, this is happening'. So I was as tired as she was.

I remember writing her a letter saying "Mum I think you ought to go to the Doctors" She wouldn't go though, she had no insight, she has never ever had any insight, so anything that has gone wrong all through my life has all been our fault, and she is blameless, and that, I find that, really difficult actually.

One day I was at home with the three children, I call them the children because I was looking after them, but they were my younger brothers and sisters, anyway Dad said you have to take the children out of the house. So we bundled them out, and as we were going up the drive we saw the ambulance with its lights flashing. She was screaming, she was screaming at my dad saying "if you love me don't let them do this to me"

After that I stayed with the nuns for a week and I slept night and day for a week. Nobody talked to me about it. Nobody talked to me about what had happened. I told one of the nuns and I can remember her laughing and I know she probably did that in

order to make me feel not so worried about it but because she laughed it made me feel, you know that I was making too much of a fuss. That really it was silly and that I should forget about it really.

I never did as well in my A levels as I had hoped. I think it's the thing about things being spoilt because of my mum being ill. She was ill during my A levels, she was ill during my finals. There's that sense of being quite powerless to fulfil your potential because you've always got your hands full looking after the others.

Just before she was sectioned I had been for an interview at Oxford, and I was offered a place so there was this kind of disjuncture between someone coming from a family which is completely chaotic or am I this scholar? I don't know; there is an unreality about it; because the two things are surprising. So I've always had that, psychiatric hospital versus Oxford University; they don't kind of marry up. When I went to Oxford there was always this sense that there were things I had to...pretend about or not admit to. I went into therapy after I graduated, that was really very good for me because it was the first time that someone had said 'so what were *you* thinking then?' What happened to *you*? And that was a real eye opener. It has always been about her.

Obviously a lot has happened over the years because my mum has not been well ever since. Basically the pattern has been that every 4 years she gets sectioned. We got to the stage where we were trying to get court of protection for her so that she didn't sell the house she has just sold. We wanted to get her finances on an even keel. She was going to go to court against us, so we would have incurred charges because she imagines that we are trying to get her money from her. She hasn't got very much money left! We helped her sell her house because she couldn't afford it, and helped her set up in a new house. We sold the family house it was a terrible mess, got her a nice little house in the same area, 2 bedrooms, garden. My brother would go down and buy her fish and chips, give her money for the week, put a little bit by. We bought curtains and blinds and carpets. It was a new build house so there was nothing

she needed to worry about in terms of comfort. But then she gets ill, goes into hospital, and that's the thing, the hospital never told us they had taken her off her medication, so we were doing all this, getting her into a nice stable situation and they said "Oh you seem quite well, we will take you off your medication" and nobody told us! We didn't know and then gradually she got more and more ill. Eventually she was sectioned again. But by then she had sold the house..... I think that was the turning point really. We put so much effort into that house and she was in bed and breakfast for a long time before she found somewhere new to live. We've all been well intentioned, it's, I don't know, it's been to no avail really.

That's always been my problem, what the mental health services say to us is that she has a mental illness and it is her human right to suffer the consequences of that illness. However she doesn't have insight into her illness. Those things for me don't tally.

A number of years ago I decided, that it was taking me too long to recover from seeing her because I'd just be so exhausted so I made the decision, I was looking after my children and I couldn't look after her as well. And anyway whatever I did didn't make any difference but I had to protect myself, so I made the decision I couldn't have any contact with her. I've kind of had to work out where I want to be in relation to her, because I feel that I have given an awful lot in terms of trying to make it better. So she's an elderly woman who is quite vulnerable, so part of me thinks oh I am really horrible, but what can I do? I have a responsibility now for my own life. I will have to be stricter about it. In order to have my own life; I have got to not see her at all.

Emma's story

I feel very unjust talking about them really because they are both dead, so this is all filtered through my memory, and of course your children never see you for who you are, they have only known you since they have been alive. So I never knew my mum when she was growing up and what type of person she was. So whatever I might say may not be true.

And the family stories my father told, by the time he was telling us, I remember I'd lost any trust in what he said. Other stuff that he'd said and done undermined any sort of factual basis to it, so the stories have left us my sister and I uncertain as to what was the reality.

But anyway growing up in that household it was very, looking back now it was an intense atmosphere where my father dominated, because it was of that generation where men were dominant, and he clearly was the shape of the household.

My father had a fairly high powered job in television at the time and the story goes that he had a couple of nervous breakdowns and that in the end he couldn't cope with having a high powered, high stress job so he did what one might see as a fairly classic, escape to the country, sort of thing. He bought a village shop, took his mother with us so Granny lived in the flat beside the shop and we had the flat above the shop. I dream about that house a lot. An immense amount, it was a very old place, a bit creepy and my mother had this thing about there being a poltergeist there, and I still dream about the poltergeist in that house, bizarrely. And when we go through the village, it still gives me shivers whenever we go past it. I think possibly there's some emotional stuff going on, there is obviously fear of the ghost but there is also all the emotional stuff because there were some heated moments in that house. I think I was about 8 when we moved down, and I think I was about 10 when Dad got ill but I am not sure, I can't remember if I was at primary school or not to be honest.

If there is a sick person in the house, it becomes a strong element of the family dynamic; it's like another family member. I always think looking back on it, I think he had to be sick to get out of, he was unhappy, very unhappy where he was, so he had to be sick to get out of it. The sickness got him off the responsibilities. He could then live on benefits and everything without having to worry about a job and that legitimized his role of being a man still.

He was sexually inappropriate with people and was more open with us than he should have been and had social services known about that now, I am not sure if we would

have been taken into care. They certainly they weren't parenting to a standard. I mean I would go to school in not a very good state, things like having great mats in my hair. Then again parenting is different these days as well.

Mum wasn't a home maker, mum wasn't entirely responsible herself. Not that she was irresponsible, she didn't drink or anything like that and when we were babies we were easy but as soon as we got to be young children with more challenging needs then we were difficult. She didn't do things like cook or anything like that. My mother was very vague, it was impossible to pin her down on anything really. Mother's a ghost. Her personality was translucent. She was not very solid or there. She didn't have relationships with us. When we got married and I had the children, my mother was absent from all of that. She kind of floated in at some point to see the baby. She couldn't drive and was she was scared; she was very scared of everything. She was scared of the world. She was absent emotionally.

We weren't a family big on talking; certainly in my house emotions weren't shared properly, we weren't emotionally literate because it was too frightening, too scary. Dad was quite violent at times because of the drinking, he wasn't a nice drunk. I don't remember him hitting me particularly but I know he used to drag my sister around a bit. She would stand up to him. She is still quite feisty now.

Whereas I get depressed, I will do anything to avoid confrontation. If it gets bad, I do go to the Doctor and get the treatment. I get the internal monologue we all suffer from and I have to drown that out because it gets too strong at times. Stuff which is fairly classic and to be honest with you, I don't think I am an unusual woman for this at all. I think there are an awful lot of people out there who feel fairly crap really.

I am very shaky as a person. I don't know who I am and what I am doing and what it is all about. I don't know who or what. I don't have that golden well to draw on. The self-efficacy, I don't have any inner confidence. I think that's when you've had unconditional love; it gives you inner confidence because you know you are loved. Your place, your legitimacy in the world, that you are a positive member of society. I

think my identity is like a ghost that I walk around but I am invisible, or only slightly visible to people. I don't have that big golden pot inside me to draw on, of resilience. My self-esteem is paper thin. I know I can do things and I am a functioning adult and I hold down a job and I've always worked and blah, blah, blah but it is paper thin and I am very frightened of stuff. Not tangible stuff, but I am frightened of being alone, of ending up like my mother. So I don't know, I've pop psychologised myself I think.

Sue's Story

Basically the first time I became aware my mum had mental illness was when she took a massive overdose which was around the time I was 11. She was in a coma, and dad got us from school which was quite shocking as I wasn't aware she was having difficulties.

One of nurses in the hospital spoke to me and my younger and said "I want to let you know that basically your mum is in a very deep sleep." I just wanted to scream don't be so patronising! I know what a coma is... I didn't say that but I remember thinking 'she is not just in a deep sleep! She was in the infirmary in intensive care; she was on all the life support and everything.

Both sets of grandparents had died and we had no extended family at all in any close vicinity. I was very upset and wanted to talk about it whereas my brother just wanted to watch the television. I guess the question is that if we had had somebody outside of the family who we could have talked to, would we have been able to talk about that stuff?

And then it's kind of weird because I don't really remember much for a period after that, it's like completely sort of blank. I used to get my brother and dad up in the morning, basically took on the responsibility and it was very much the sense of if I don't keep things running here we could end up in care because dad won't be able to cope so I just kind of did it by default.

My dad wanted us to see her every day and took us pretty much most days after

school. I was quite angry really because there was no choice about visiting, he insisted. Going to a mental hospital was a totally scary experience as a child. People talking to themselves, it was just, there was no, we were given no support at all, absolutely nothing! I meant they might do it differently now.

Sometimes if she was too bad, we would stay in the car. There would be periods where she would be on a locked ward, she had ECT and when I was about 15 she had a frontal lobotomy which was a very difficult period as that was also around the time I was doing my GSE's so, it was all quite stressful Basically she lived in the hospital until I was about 19 and only came back home for like a weekend or something sometimes.

I actually had quite a lot of health problems in my teens; I developed a continuous headache and continuous stomach problems. Looking back it is quite clear to me that it is to do with all the stress that was going on but nobody had picked up on that. The GP was offering me tests and investigations and things but there seemed to be no link. He never mentioned my mum!

I am guessing that other people go through this as well you know? I am hugely empathetic towards her and also incredibly angry at her as well and certainly in the first few weeks I remember thinking I hope she dies, because if she dies then we have got almost like a clean slate..... we can start again. For years I felt hugely guilty for having ever thought that.

Some things were so traumatic , I would have flashbacks around it, like when mum was home one time in the kitchen and seeing her holding a knife to her wrists and being frozen, and then walking out and thinking should I have said something? Should I have done something?

I think my dad was desperately trying to maintain normality but it was almost like he was in denial that we might actually be feeling something. I am sure that is because he had so much to cope with himself that he just didn't have anything left to be able to support us really.

Mum came out of hospital when I was about 19 and she's largely been out since then, she goes for respite regularly and she has had some stints back in. She took another overdose when I was in my late twenties and she was in another coma. One of my biggest regrets is that we didn't have a mother daughter relationship; we didn't do the shopping for clothes together having our nails painted together or that sort of thing. That is still quite a big loss. Huge in fact...

Then I met my husband, during the first few years we were together I was very insecure and actually he was great because he kind of realised what was going on and instead of running from this crazy woman he stuck with me. It's almost like me and my brother has kind of been trying to find some normality elsewhere. I don't have children; I never had any kind of maternal instinct. Actually another thing I came to the conclusion of is that I do not want to put a child through what I went through and I know that I am not stable enough to be able to cope with a child. I know just how much anger I have..

I have started to not take on these responsibility to try and make things right, I said I am not doing that anymore. It is not that I don't care but I have got to look after myself. One of my strengths is being intellectual and analytical but that can become a defence mechanism. What I went through was traumatic and still is, because I think I down play it and then wonder why I am so insecure! It should be pretty bloody obvious!

It feels like a death might have been easier because there is an end point. It would be a period of grieving, then start making life afresh whereas this is like within a week my life could be turned up- side down. I've had the phone call at work to say mum has taken a massive overdose. So it is not unreasonable for me to actually just accept that at any time everything could be just thrown up in the air, I live with a constant sense ...Of dread or anticipation or whatever... that is very wearing.

They are both getting frail now so there is the whole issue around what happens as my parents get older. I am going through this place of actually I don't want to be

responsible for them so I am kind of feeling the not wanting to and the guilt of not wanting to. Will there be pressure on me to go down there and do stuff? She might go into one of the respite places who have people who live there permanently and then what happens to Dad? It has become more complicated but I have no energy left to give to them.

Martha's Story

I was about 5 when she went to hospital. I don't remember much about it. I do remember holding onto the front gate thinking I am not going to ask for help, I am on my own. I remember her being pregnant with my sister and leaving the house and not saying goodbye. I don't remember anything after that, but I remember when she came back that I wouldn't let her go anywhere. I wouldn't let her go.

No one told me in the family, I don't think I knew what was wrong because no one told me. As a child I didn't kind of know where to go with it, there was quite a lot of confusion? I don't think there was anything out there when I was a child at all. There was no one to talk to. There were no school counsellors or anything.

I think I would have been about 14 and she had another breakdown and again there was no explanation or anything. I don't think Dad understood because my parents are refugees from a small village so they were quite uneducated in terms of mental illness. Dad took a step back and I became the parent looking after my mum while he went to work. I took a lot of responsibility I guess. I think then it got quite confusing and if I look back then I think I was developing depression at the time. I wouldn't go out, I wasn't sleeping well, I had a lot of anxieties about falling asleep and not waking up and I remember not being able to tell anyone. I couldn't tell my mum, she was unwell and by then my dad had closed down and he was no longer emotionally aware andyeah so.

I used to go to all the meetings at the hospital and that and everybody let me go on my own which was kind of bizarre, when I look back now it was a bit of a responsibility. I

remember leaving school and I was treated as her carer. I had no idea what was going on. I just thought it was a breakdown and my family just said it was the menopause and that was their interpretation of it all.

When she came home her behavior was quite odd and her thoughts were quite disordered so she couldn't even speak English. She wasn't speaking her mother tongue either; she was speaking her own kind of language which was really bizarre. She would try and run out of the house but was a danger to herself and would run into the road, she tried to run away. So I had to stop her leaving. I didn't go to school then, I had time off and I think my auntie used to come over and watch her so there were bits where I did go to school. I think it was around the time of my exams and I didn't manage to achieve anything. I think I confused myself. I remember that I thought people were not helping me. I wondered where to go to find help; I didn't know where to go. Dad was going to work, he just said "your mum is unwell and I don't know what is wrong". He took a very backseat approach.

I was about 19 I was just floating around. I didn't know what to do, I think I was unemployed. I was feeling quite down still but I became a carer for my mum; I could start predicting her behaviour. Any little behaviour I could start predicting when she would become unwell. Then I would become quite anxious. But my main role was to look after her and forget about myself.

I was about 21 and she became ill again and then when she went into hospital and the psychiatric nurse for the first time asked me "I am just worried about you and where do you go for help?" I think that was the first time anyone had thought about me and how I was. I think what happened was that because someone acknowledged me, I became more depressed myself and I think I had suicidal thoughts and that was the first time I thought well gosh maybe I am not quite well myself.

After that I started having some counselling, where I went for 3 years. That was quite hard for me, because initially I thought that the way I felt had nothing to do with my family.... I know!! I don't know whether that was because I wanted to defend my mum

but that was the start of the journey really to where I started to look at my sense of self.

I think initially it was really hard for me I had such abandonment issues, my poor husband! I had a really strong fear of being abandoned. I think I was plagued by a lack of self-esteem and a sense of vulnerability. That is sort of related to not being validated as a child I think.

She was well for the next 18 years but then 7 years ago she stopped taking her medication without telling anyone and got very, very ill in a matter of months. She was hospitalised for 8 months. They couldn't find the medication that worked for her and now her condition has become treatment-resistant. She can't leave the house; the voices are quite persecutory.... I live some way away so it is a lot of work. I go to all her appointments with the psychiatrist. I feel very stressed and quite burnt out. When I go to my mums' she is still quite thought-disordered so it is kind of trying not to distress the children as well. I wonder how it impacts the children; like forgetting birthdays and things.

I wouldn't so I wouldn't say I had been neglected or emotionally abused or anything. I wouldn't say that. From school I remember not wanting to talk or come forward; I think it may be about being seen. At home I felt I could not put my needs forward so I felt quite uncomfortable when I had to do it and even now I feel uncomfortable when I have to stand in front of a group or do a presentation. I have so much anxiety. Something about being visible I think.

I have come to peace with most of it now but have quite a lot of anger with my mum for not taking her medications. I feel that it should have been my time now, and she has taken that away. She made a conscious decision and a plan that she would come off her meds. I don't think she remembers, she is so psychotic, she can't think about anyone else.

Chapter 5

Findings

The practical steps taken to analyse these stories are now offered. Throughout the transcription phase I had already begun to develop some ideas about what each person had been trying to convey. I tried to have an open mind and so I carefully listened repeatedly to the tapes until I began to make sense of them. Following the advice of Lieblich et al (1998) I then read the transcripts of each participant with the aim of trying to identify the 'self' which each participant had brought to the interview.

Particular attention was paid to evaluative comments such as "it was awful" and the opening and closing of each smaller story which gave me various impressions about the meanings. Trauma and loss were apparent in each of the narratives, so using both Robinett (2007) and Lieblich et al (1998) I adopted more of a 'categorical content approach' for this section. This meant identifying use of specific language such as; adverbials, such as *suddenly*, mental verbs, such as *I thought*, *I noticed*, transitions between first, second and third person speech and intensifiers, such as *really*, *very* or *like*. I also listened for contradictions, metaphors and slips of the tongue.

The next phase saw me noting key phrases, concepts and themes which occurred to me for each participant's story. In time they began to overlap with one another until I had reached a stage whereby similar ideas were occurring in each narrative. At this point I used those specific ideas and developed them into 'foci' of content and decided to follow them as they evolved throughout each of the narratives. To do this I used coloured markers, to help identify each focus in each transcript.

In due course I noticed that the foci I had chosen fell naturally into the same order in each of the narratives. This led to me developing the overarching metaphor of the Rollercoaster journey.

Dowling (2011) writes that Ricoeur introduced the idea of reciprocity between time

and structure. Ricoeur (1991) argued that we make sense of our lives through narrative, but that narrative is not always linear. He added that the other way we experience time is phenomenologically, and this is experienced in terms of the past, present and future. The foci of the discussion (a ride on a rollercoaster) to some extent represent this phenomenological experience of time. The first concept being what happened in the beginning, the onset or what happened in the past. Then the participants moved on to discuss day to day experiences, some in the present. The last foci centres on the meaning making attempts each person has made. For some whose mothers have died, this was more reflective, for others whose mothers are still alive it often incorporated fears and hopes for the future.

The main findings from the narratives are briefly presented here, in three sections representing each stage of the rollercoaster which are the chosen foci. This summarises the main themes of each focus so that the reader can read the discussion with a greater sense of direction. The discussion chapter includes many stories which were chosen from each of the narratives, as they were those in which the focus was clearly evident.

This chapter also includes some of my own thoughts and reflections following the interviews. A brief overview of the findings is then given followed by the discussion.

“Wow, Cathy’s mum could have been mine! Perhaps we are sisters! I am shocked at the similarities of her story. Her mother had exactly the same delusion as mine! Mum was clearly more settled than hers, and less spiteful but the desire to escape abroad was also true for me. The revered brother was also so reminiscent” (Post interview reflections 19/5/12)

“That was spooky.... How alike we are, we even looked similar! Jo’s struggle with her mother’s intrusiveness is shockingly similar to my own. Culturally we are worlds apart, but our stories are not. I really felt I understood her frustration when trying to help her mother settle knowing that it will all apart again” (Post interview reflections) 25/3/13)

These are two excerpts from my research diary which show just how shocked I was that some of the participants in this study shared such similar stories to me. Both Cathy and Jo in particular had experiences which I could relate to. My shock at the similarities sent me on my own rollercoaster and contributed to my need to defer the research for a while until I had processed what was going on. This gave me a long period of introspection without the demand of deadlines.

It seems that I had inadvertently recruited women, some of whom who were so similar to me that it was actually quite disconcerting. Stories resonated with my personal experience throughout. Perhaps this had been an unconscious desire; I had not consciously set out to find people like me, although arguably I do feel a connection when I meet other people who have a parent with serious mental health problems. For me the prime reason for conducting this research was to be heard. I wanted to raise the profile of adults who were struggling in a position like my own a few years ago. Anna and Meg are not close to me in age but the other women are in the same, or an adjacent decade. Culturally, we are all white European. All but one has a high level of education. All but one has worked, or is working in health care.

This was not by design as I had wanted an even split of the sexes. I was however mindful that the advertisement did reach the local Trust by email and that it was likely that I might recruit women because of this, simply due to the split between men and women working in the Trust. It was however a surprise that no men approached me to be included. Checking other papers (those in the literature review) it seems that this phenomenon is not unusual. So what lies behind this?

Drawing upon the feminist literature, Chesler (1972) discusses the uneven availability of mothering afforded to babies. Chesler argues that 'The Madonna' always comforts her son, never her daughter. The son is revered and divine. It is interesting how all of the participants who have a brother (including myself) noticed this phenomenon. In each case there were clear differences in the relationships between the sons and daughters with their parents. This difference appeared to suggest that men are

encouraged to seek a life outside the home environment, which may in turn facilitate greater independence and separation from the family of origin and might explain why fewer men feel the entrapment which motivates them to participate in research such as this.

Friedan (2010) first wrote about the different roles and expectations of men and women in 1963 (reprinted 2010) when she argued that the 1950's created a generation of women who felt empty and dissatisfied by the expectation that her role would be to marry and take care of her husband. This generation of women lived for and through others. Friedan describes this as a problem of identity, the core of which is the stunting of personal growth. She attributes this to our culture which does not encourage women to accept or gratify their basic need to grow and fulfil their potential as human beings. This book led to the women's liberation movement. Is it coincidence that the participants and me, have/ had mothers who were of this generation? Could it be that very intelligent mothers in particular became frustrated? This generation of women had seen their mothers cope throughout the world wars, perhaps this left them wanting for the recognition of worth and value to society with which their mothers were credited. I do not propose to answer these questions, simply raise them.

I am only too aware that my own mother experienced these frustrations. She was envious of her brothers who were able to establish a career whilst she was sent to learn Pitman shorthand with the expectation of becoming a secretary. This was a woman who adored literature and poetry and very much wanted to study.

Something is wrong

The interviews started, not with the reflections of childhood as might be anticipated, but with the *awareness* of something which felt wrong. Even with the most apparently sudden change (Sue), there was an acknowledgement of a growing awareness that something was wrong, prior to the crisis. I have included more of Sue's thoughts about this, later in the discussion. Both Jo and Cathy articulated the difficulty faced by young children, who know there is something wrong but do not have language or experience, to be able to frame mental distress. Anna and Jo identified the tangible aspects of their

mothers' deteriorating health, the neglected self-care and of loss of weight, were mentioned by both of them. Their attempts to communicate the problem then failed, or left them thinking they were imagining it, or worrying unnecessarily. Interestingly Megs' story is the only one in which the unfolding mental distress did not feature. Meg's mother was distressed pre and postnatally, and received services as young mother. Meg therefore grew up knowing that her mother had been distressed, and also had the support of statutory services, and her grandparents, as a child. This appears to have mitigated the element of shock at the unfolding distress, and changing family roles, which are found in the other stories.

Most of the participants recalled the changing relationships and roles in their families. Anna, Jo and Sue, took on caring roles for their siblings. In both Anna and Jo's story, it fell to them to encourage their mothers to seek help, or indeed sought help on their behalf. Both the participants were just teenagers at the time. Anna and Sue both voiced how they felt impelled to take over a care role in order to avoid going into care, or in Anna's case, to avoid her parents hurting one another. The onset of mental distress in these stories brought chaos and much confusion to all of the members of the families. Anna, Emma, Sue, Martha and Jo all expressed both compassion, and anger for the parent who was well, but was unable to support their children adequately. In some cases, the father was drinking too much or working so hard that they avoided seeing and coping with the unfolding catastrophe at home.

The all-pervading silence surrounding the participants, during the crisis befalling their family is evident in each of the stories, again with the exception of Meg. It appears that the silence is experienced sometimes at the individual level, within the family itself, and also at the community level. Martha, Anna, Sue, and Cathy explicitly mentioned denial as part of the family coping strategy, and this is explored further in the discussion. Jo makes use of a self-dismissiveness reflected by the regularity of her use of the word 'anyway' which moves the story quickly onwards. Others, like Cathy and Emma, were ambivalent about the process of the interview and tentative about

speaking, even though they wanted to participate. A sense of loyalty to their parents and perhaps, shame permeated their stories and this dynamic underpins the silence with which they battle. It is interesting how the courage I needed to take on this study, thereby allowing others to know my own history, and break my own silence, has resonated with this.

Trauma and loss

Once the interviews got going, most of the participants then settled into telling me their stories with less hesitancy. The traumas and losses then tumbled out like a dam which had been broken. Ruptured and damaged connections and losses were apparent in all of them. From Martha's desperately sad thought, as a child of five, that she was now alone, to Cathy's ongoing search for her mother to this day. Two of the participants (Sue and Anna) expressed a desire for the death of their mothers, which might then have put an end to their tortured situation, and allowed them to move on.

The taboo nature of sexual abuse in some families is also considered, and whilst Emma courageously hinted at it in her family, I have deliberately left it to the reader to interpret for themselves whether they consider this might have been evident in others.

Some traumas are included in the discussion chapter. It will become evident that the participants as children, and adults were, and still are, trying to cope with traumas directly associated with their parent's distress, and also traumas associated with the relationship. These have been discussed further in some detail and are referred to as relational trauma. Relational trauma appears to lie at the heart of the experience of the AOSMDP.

Whilst the participant has been preoccupied with monitoring and adjusting distance, *associated losses become clear*. The losses include not only the parent, but also a way of life, and hopes and expectations the participants had for their futures. The losses are also discussed in some detail and links made to some of the elements of unacknowledged loss or disenfranchised grief.

Making sense

Finally, it seemed that the interviews all had a period of more gentle reflection towards the end. I noted that I had even recorded this aspect of the changing nature of the interview, particularly in Anna's interview, where I noticed that she became more reflective and collaborative after the initial surge of traumatic stories. It was as though once the trauma had been heard she could move on in a calmer frame of mind which may be an expression of the therapeutic value of the interview (Hollway and Jefferson 2000).

This section of the discussion is therefore mainly about the meaning- making attempts of the participants. From understandings about the nature of mental distress, through to particular coping strategies which are employed by the participants.

Attention has also been paid to the impact of trauma on a narrative, and the effects on a persons' identity. Self –reliance is a key finding, as is the desperate need for validation of the traumas and losses which have been experienced.

Anxiety about parenthood was also found, both in terms of raising young, and also about the possibility of inheriting a severe mental distress oneself. The consequences for adult health and intergenerational transmission are discussed in this section.

Personal recovery was not discussed in detail by the participants although some alluded to a recovery journey and Meg's interview ended with her considering the future, as did Sue's, Jo's and Martha's. Sue in particular is clearly anxious about the effect of her ageing parents, and the expectations she may face to care for them.

For Anna and Emma, the story of their parents' mental distress is over. Both of them have however, sadly identified mental health problems in the younger members of their families. Other participants' stories are still ongoing, and one can only hope for the recovery of the families in due course and that mental health services can alleviate the worst of the impact.

The Rollercoaster

This discussion is about my interpretations of some of the latent and the manifest meaning of the participants' stories and attempts to highlight some of the shared experiences and similarities found in these narratives. This discussion displays the critical tensions between the families' actions, the context and the meaning for the participants at the time. Kalsched (2013) uses the image of two worlds to explore meaning. The first world has an eye which faces outwards; what can be seen and is tangible. From this perspective, some of the more sociological elements relating to the family and community are considered. The second world is that of the eye which faces inwards to the private self and the deeper who and why. This less familiar territory enlivens the outer world discussions with depth and gives them meaning. This relies on the assumption that for every self-other relational moment there is also an inner event and that in order to show meaning the writer should attempt to weave together both worlds (Kalsched 2013). With this in mind, this discussion has drawn upon work from several disciplines including social work, psychology, family therapy, psychotherapy and nursing. This enables the discussion to move from a singular to a more holistic view which is necessary with such an under researched topic.

The discussion is presented in three sections using titles which reflect an aspect of the rollercoaster experience with which most people will be familiar and a metaphor referred to by three of the participants.

The use of this metaphor was cautiously considered. The participants' often painful stories deserve respect and use of the metaphor may be seen as flippant because a rollercoaster is meant to be fun and frivolous. It is also a very haggard expression which is frequently used to tell of somebody's difficult emotional journey; for example in lighthearted entertainment shows. Carpenter (2008) cautions researchers to be aware of the potential to trivialise the data, or try and make the data fit a metaphor, and this was in my mind in my deliberations. Miles and Huberman (1994) however, encourage researchers to use metaphor in their thinking and writing, stating that the use of

metaphor goes beyond that of using words alone. They argue that whilst not adding to a description, metaphor can add a depth and illuminate meaning. This research has used the metaphor of the rollercoaster to contribute to the analysis and discuss the findings which has also avoided a separation between the method and the interpretations which Sandelowski (1991) argues would be anti-narrative. Using the metaphor has facilitated a sorting of the data into meaningful concepts which provides a coherence between each section. The metaphor has therefore provided a plot through which each story is woven.

Three of the participants of this study used the metaphor of the rollercoaster in their narratives. In Anna's story it was used it as a final sentence which made it feel like a full stop used to draw attention to the meaning of the whole story. The paper written by Foster (2010) from her PhD "Narratives of adult children of mentally ill parents" was entitled 'You'd think this rollercoaster was never going to stop'. Further reference has been made to 'Rollercoasters' in the work by Maunu and Stein (2010) and again by McCormack et al (2016) in their studies on the same topic.

Interestingly towards the end of this research, I discovered that I was not the first scholar to use this metaphor to describe an emotional journey. Koos (1947) wrote about family crisis and stress, and the model of recovery which he later described has been referred to as the 'rollercoaster'.

The metaphor is particularly useful because of its ability to show the progression through time in the lives of the participants, not through chronological age, but through the emotional journey the participants have taken. The background context of the participants' culture and era of mental health service provision have been deliberately dulled, and are left out of focus, thus drawing attention and fore fronting the emotional journey which each participant has visited to a greater or lesser extent. Using the rollercoaster metaphor facilitated flexibility with time as there are no limits or boundaries to say at what age someone moved from one stage to the next. It also allowed for movement back and forth, and up and down between the stages, which

echoes the experiences of some of the participants as they manage their waning and resurging hope between lulls and crises as demonstrated in the following quote;

"Within a week my life could be turned up – side down. I've had the phone call at work to say mum has taken a massive overdose. So it is not unreasonable for me to actually just accept that at any time everything could be just thrown up in the air, I live with a constant sense ...Of dread or anticipation or whatever... that is very wearing"(Sue).

The rollercoaster repeatedly turns, and each stage of the cycle may be visited again and again, usually, though not necessarily in the same sequence. The stages of the discussion are called 'Hold on tight the ride is about to begin'; 'The ride'; and 'It's stopped for a moment'.

The first stage of the discussion 'Hold on tight,' is about the realisation that life had changed and felt different. This occurred either as a sudden shock or as a gradual increasing awareness which brought with it, changes in the family atmosphere and dynamics.

The second stage, 'The ride', relates to the ongoing stresses which are articulated by the participants, unique to each individual, but still clearly embedded in each story. Once a person is on a rollercoaster, it is impossible to get off without it stopping, and the losses caused by staying on the rollercoaster are also discussed.

The final stage, 'It's stopped for a moment', details how each participant is learns to live on the rollercoaster and the meaning they have constructed from the experience.

Whist reflecting upon the interviews, I found that on each occasion the participant followed a similar path in the telling of their story and I travelled this path with them. This seemed relevant. The start of each story related to the awareness of mental distress and sometimes the shock of finding their lives turned upside down. At times I struggled to stay tuned and found myself losing concentration as I tried to balance

'being in the moment' and making sense of what was being said. I couldn't keep up and eventually I decided to give up trying to make sense at the time, and left that to the transcription phase. This freed me to participate more fully in the rest of the interviews.

As each interview progressed, we settled into a dialogue and following the stories became easier as I allowed myself to become gripped with compassion and awe. The stories were telling me one horror after another and I was at times disturbed and perplexed. My reactions seemed to parallel those expressed by the participants. I tried to keep the feelings at a distance, at least until I had got home safely. The stories also made me feel angry at the powerlessness expressed by the participants struggle to be seen by services, and people who did not recognise them. Each interview also left me feeling very tired.

Following each of the stories detailing various trauma and losses each person appeared to enter a period of calm when the interview itself became more reflective and collaborative. At this point most participants told me how they had begun to make sense of their lives, some more so than others. Some participants then chose to look towards the future, some with hope and some with dread.

My experience of interviewing and my reactions informed the data analysis and added to the case for the use of the metaphor. The resonance was therefore used to recognise the dynamic influence between me and each of the participants. Mirrored feelings experienced in relation to in-depth, sensitive interviews has been discussed by Beale et al (2004) who analysed the impact of in-depth interviews on the interviewer, and call their paper the Roller Coaster Ride!

Hold on tight the ride is about to begin...

Each of the participants started their story by paying attention to *how* and *when* the distress started. In some cases the onset of the distress was sudden, dramatic and shocking, but for other participants it was a slowly evolving sense of becoming aware

that family life no longer felt the same. Like any chronic illness, mental distress tends to develop slowly over a period of time. Most mental distress is also episodic in nature making each person's experience of the onset and course of the mental distress, unique. At first there may be small incidents, worrying signs, or just a vague sense that something is not right. It is most often the changes in a person's behaviour which are first noticed by people. This means that unless there is an already identified underlying problem, a *normal* response would be to think that the behaviour is a reaction to something that has been said or done, to upset that person. Avoidance of the topics which cause distress; or confrontation, thus becomes the only obvious options. Each member of the family has to endure a growing awareness until the pretense of normal functioning is unable to be sustained any longer. This process may be just a few weeks, or may last decades, until finally, the family will be in no further doubt that there is a significant problem. Relationships may become fraught as normal social functioning ceases and the parent who is no longer able to maintain their role becomes the focus of the family life. In this study two of the participants' parents became distressed whilst they were babies or small children, whilst the others appeared to have been adolescents before the distress became obvious. It is notoriously difficult to pinpoint the start of mental health problems and as such, distress may predate the story told.

Any kind of change in the family structure and dynamics will demand that adjustments are made by each family member so that the unit continues to function. As the distressed family member loses the capacity to undertake the tasks associated with their role, the family must find another way to cope. Of course, it is hard to know what comes first; deteriorating relationships or symptoms of distress. Whichever way around, the ripples of the distress are felt by the whole family as each individual family member attempts to cope with the consequences in their own way. Each of the participants in this study grew up as a child within a family in which there were one or both parents who suffered serious mental distress. One of the participants had both parents with a diagnosed mental illness (Meg), another participant's story involved the distress of both parents, although neither was officially diagnosed (Emma). In all but

one case, it is the mother who is experiencing symptoms of distress, leaving only one participant whose father became psychotic (Emma).

Interestingly the well parent of each of the other participants was often described as either absent or subsequently playing a minimal role in the family, either physically and/ or emotionally. Some participants stated that alcohol was a contributory factor in the presentation of the well parent whilst others stated that denial and avoidance probably underlined their well parents' emotional absence. All of the participants in some way, referred to the absence of the second parent. Below are comments from each participant about the parent who was not unwell. These show how distress in the family affects the dynamics between the parental couple, as well as consequences for the child.

"Dad always did shift work, so he always come home late at night. I used to lay in bed even as a teenager and I wouldn't drop off to sleep until I heard the moped. I wouldn't go to sleep until I heard that moped come in the gate. Then I'd think "oh my dad's home now". But he wouldn't do anything about it. I said we've got to get help "(Anna).

"My father was quite reserved, quite cold and not really affectionate at all. My mum was the one I sort of reached to, to get that affection. And suddenly she was gone, out of my life; you know she was gone" (Cathy).

"Mum wasn't a home maker, and she wasn't entirely responsible herself. Not that she was irresponsible, she didn't drink or anything like that, but she just didn't take responsibility for stuff and I think when we were babies we were easy, but as soon as we got to be young children with more challenging needs then we were difficult. She didn't do things like cook or anything like that. My mother was very vague, it was impossible to pin her

down on anything really” (Emma).

“My older brothers and sisters were at University and work and were kind of aware of it. and my Dad was useless really. He was kind of travelling a lot for work plus he was struggling with his own issues, alcoholism” (Jo).

“I remember when my dad overdosed about the same time as my mum did actually; when I was about 14 or 15. He rang my mum, but he couldn’t get through because my mum was on the phone. So he phoned my mobile. “I want to speak to your mum but can’t get through”. I said “are you alright?” He told me he’d taken loads of tablets. So I ran and said “mum get off the phone, get off the phone” And my dad rang through and spoke to my mum” (Meg)

“Dad went to work and just carried on. He just said “your mum is unwell and I don’t know what is wrong”. He took a very backseat approach. I don’t know whether it is because I am a girl, or culturally; you do things at quite a young age, like house- keeping, while the men go to work. It is quite defined roles so I think after that there was a pattern. I think I was quite kind of angry with him for leaving me and letting me deal with it
“(Martha)

“I think my dad was desperately trying to maintain normality and trying to keep things ticking over, but it was almost like he was in denial that we might actually be feeling the effects on us. I am sure that is because he had so much to cope with himself that he just didn’t have anything left to be able to support us really “(Sue)

In two of the participants' families, parental separation or divorce followed the onset of the mental distress, leaving either the well, or the unwell parent to raise the children alone. In one case the participant was eventually sent to boarding school and in the other the participant was raised alone by the parent who had been significantly unwell. This participant was also an only child living with her mother whilst all of the other participants in this study had one or more sibling.

There have been surprisingly few attempts to study family groups where there is a parent with serious mental distress although in 2016 a study in Denmark (Ranning et al 2016) found that nuclear families were twice to three times more likely to separate when a parent was mentally distressed, and that the children were more likely to end up living either with their mother, or away from both parents. This study has found more of the participants being raised by a father than the research described above.

The role of fathers in families has not been studied to the same degree as the role of mothers. The asymmetry is replicated in work stemming from social work, psychology and psychiatry. Day Sclater (2000) posits that this is a result of an ideology which considers the mothers influence as being more important to the child's development. Concern about current divorce rates in the UK and the growing rates of father- absence from children's lives is precipitating a resurgence of research in this area. The role of fathers tends to be as providers of help and support for mothers, rather than primary attachment figures. The consequence of this dynamic is that the scope of the role of fatherhood is then perceived as negotiable, perhaps optional, and dependent upon the mother's cooperation. Day Sclater argues that this means that fatherhood is linked to the status of husband, and therefore difficult to sustain once an adult relationship has broken down.

It is striking how in each of the participants' narratives the role of the father did not offer much emotional support to the children. This may indicate that mental distress in a mother is a particularly challenging scenario for the child.

In each of the participant's narratives it can be seen that the onset of mental distress

brings a change in the structure of the relationships in the household. Changes may be obvious between couples or between parent and child stress levels increase as shown in the following quotes;

“She changed from a lovely little quiet mum to someone that was rowing, shouting and screaming; rowing with my dad, fighting;” (Anna).

“I hit puberty very early at 9, but we had a lot of conversations leading up to that, where she was actually bringing in a lot of her stuff, her fears, and from then on there was a feeling that the relationship changed a bit, in the sense that she was no longer coping with me. I had really bad PMS and really; really dark, dark days and I remember mum saying “you are making life difficult for me.” Something was changing for her that would mean that she wasn't able to cope with my problems, my distress. I can see that I was desperate.... I remember lying in bed at night thinking ‘if only somebody would love me’. Because my dad wasn't really able to be there emotionally so I was just desperate” (Sue)

Alternatively, relationships between other members of the family may be affected;

“It is very different with my dad. We don't get on like me and my mum do. There have been several periods throughout the last 10 years or so where me and my dad haven't spoken for a couple of months at a time, usually due to the dynamics between me, him and his parents and I try and be in the middle of them. And they clash and usually it's me trying to get them to be friends and get on! Then they both turn on me and I get shunned for 6 months at a time for trying to help. So that happens, you know, has

happened enough times to make it a regular occurrence. Where do I stand?"

(Meg)

"Mother blamed Granny for making dad into such an odd person, Granny blamed mother because mother was never good enough for him" (Emma).

The parents of both Meg and Cathy separated whilst they were young. In the United Kingdom it has been shown that single parents have a higher rate of mental distress than their married counterparts or single adults, and that their children have twice the rate of mental distress (Meltzer et al 2000). At the same time, it has been shown that women who are not involved in child care have the lowest prevalence for all the common mental health disorders (Targosz et al 2003). It is widely accepted that the stresses of raising children along with financial pressures, and possible difficulties with employment and childcare all contribute to the development and or maintenance of mental distress. Relationship breakdown may be between the marital couple or a wider extended family breakdown as in the following quote;

"She wrote to all the family. She sent them the most horrendous letters, they told us after, and she took all the photographs. She cut every bit, we had photographs with all these people missing off it, she chopped people up, she'd cut all the photographs out of people's faces of people she'd fallen out with. She cut them all out. She fell out with everybody that loved her. Everybody that came into our house she rowed with. She fell out with all the relatives over the years. Even the night before I got married, she had a blazing row with me and my husband to be and I thought, "is she gonna come to the wedding?" None of the relatives from (town) came because she'd fallen out with all them previously so they didn't turn up" (Anna).

Parentification is a term which has been used to describe what happens when the role

of the parent and child start to become interchanged (Jurkovic 1997). The risks for a child to become parentified may be increased as the wider family network falls apart and the child is left in a position where they have no choice, but to take responsibility. Aldridge and Becker (2003) argue that caring for a parent who is having difficulty coping, is a natural response for a child and does not necessarily lead to parentification. This viewpoint becomes questionable where there is serious mental distress developing, because of the resultant impact upon the dynamics of all of the family members. Measurement by behaviour, such as the regularity of caring duties undertaken, becomes inadequate. More recently Aldridge (2010) has asked children of mentally distressed parents to photograph their caring responsibilities, reflecting her concern with the domestic and tangible aspects of caring. Bleuler (1972) commented that some children will develop task skills as a way of coping with their distress, and how these skills can be advantageous in later life. It is with the utmost care that statements concerning the benefits of skill acquisition should be made, because of the tendency to assume that these children have developed resilience, where in reality; it may be at the cost of the development of healthy interpersonal ways of coping with personal distress.

It is widely agreed that parentification will have consequences for the child's psychological adjustment. The child who is parentified will feel compelled to take inappropriate responsibility, sometimes due to their parents inability to parent, and sometimes because their parent is needy and/or dependent. Feeling impelled to do more for the parent, is central to the process of parentification (Aldridge and Becker 2003; Göpfert et al 2004).

Martha articulates the process in the following passage. She also clearly links becoming a carer with her eventual choice of profession.

"I think I was just floating around, didn't know what to do, I think I was unemployed. I was feeling quite down still and not really knowing where to

go with it. I think I became a carer for my mum; I could start predicting her behavior. Any little behavior I could start predicting when she would become unwell. My main role was to look after her and forget about myself. I am a bit muddled after 19 as to what happened but I had this idea, I don't know where it came from, but I wanted to be a counsellor" (Martha)

Developmentally, a child's egocentricity will leave them open to interpreting events and experiences from their own perspective, which brings the potential to assume that any parental distress will be attributed to their own behaviour. This adds to a sense of responsibility as the child tries to make the parent feel better, by behaving well or doing chores for example. The risk is that the child will learn to give up their own needs in order to prioritise those of the adult. Long term, this dynamic can be seen to lead to adoption of compulsive caring in adulthood along with an inability to know the self or identify one's own needs (Jurkovic 1997). In order not to further burden their parent, and perhaps no longer feeling they have a right to be cared for, the child learns not to share what is going on for them. Past experience has shown them that sharing their feelings and needs gets them nowhere, so they effectively silence themselves (Dayton 2012). By silencing themselves and not seeking help when they need it, it becomes clear why this group of individuals remain unseen. In this study it is clear that several of the participants adopted parentified roles. The clearest example is found in Anna's story.

"Every time I'd go out and leave them, I wanted to be there, I thought at least if I'm here they won't kill each other, because you thought the rows would come to, you know..., one day; one would do something to the other one. And this is how it went on. As well as having her and my dad, I had my brother to bring up, because he was still young and at school. The very day I'd been to the doctors to see about her, she'd been to the doctors

herself, seen the doctor, and that was a very rare thing. I can't remember what she'd been for now. I said to him um "I've come to see you about my mum", obviously he knew us, and he said "Well I've seen her this morning". I said "You've seen her?" He said "yes she came" I said "oh right, what did you think?" "Oh" he said, "she was alright" I said "ALRIGHT?" I said "do you know what we are having to live with at home?" and I told him lots of things and he said "oh dear me" he said "well, You know she came in here, I couldn't see it", She just said what she was here for and obviously whatever he prescribed or whatever he didn't prescribe and off she went! So he said "I'll have the psychiatrist sent down to her" which he did have."

Anna was clearly torn between going out to live her own life and the knowledge that her parents may harm each other if she is out of the house. She then feels she has no choice but to take the responsibility to prevent her parents coming to harm. Later, as she speaks about the visit to the GP, it is interesting how the tense shifts back and forth and she relives the experience as herself and the GP, as the memory came alive for her and led to the past and the present becoming interwoven. According to Robinett (2007) this happens when the person is hyper aroused due to the memory which has become intrusive. This may be a good example of the alternating pattern (hyperarousal leading to intrusive images, in turn with the constriction or numbing withdrawal and emotional detachment) described by Herman (1997). Despite Anna's psychological arousal at this point, much of her narrative left me stunned at the apparent indifference to the horror of her story. On one level, she knew that she was disconnected, and this did not resolve until she moved into the final stages of the interview as she became more reflective. Various intense details were recollected, but the regular use of names, without the detail of the relationship, and her generalisations, indicated difficulty finding language thus displaying the psychological tension between the desire to remember, and the desire to forget.

This was reflected in my own understanding of her narrative, which was tiring to listen to because my concentration was expended in trying to piece together the story. This is the 'disruption of the plot' referred to by Robinett (2007).

Elements of role reversal are also noticed in the stories of Jo, Sue and Martha.

"Me and my mum were bringing up the younger children. I kind of slipped into that pattern. There were people around, but it was kind of me who was there with her all the time. I remember writing her a letter saying 'Mum I think you ought to go to the Doctors'. It was hard for me to work out what was going on. It was obvious that she was ill. She would get very, very anxious and worried that things were happening or about to happen. There was a sense that something terrible was about to happen. She was becoming very paranoid and deluded. To start with, I had no term of reference that made sense to me" (Jo)

"And all the time I was taking care of the house. I used to get my brother and dad up in the morning. I can't believe I did that now! I basically took on the responsibility and it was very much the sense of "if I don't keep things running here we could end up in care because dad won't be able to cope". So I just kind of did it by default" (Sue)

"I would have been about 14 and she had another breakdown and again there was no explanation or anything; no one told me. I used to go to all the meetings at the hospital and everybody let me go on my own, which was kind of bizarre when I look back now, it was a bit of a responsibility; I must have been 14 or so. I knew something was wrong I think. But

whether that's to do with my memory? I just thought it was a breakdown and my family just said it was the menopause. She would try and run out of the house and would run into the road; she tried to run away. I didn't go to school then, I had time off and I just, I think my aunty used to come over and watch her so there were bits where I did go to school. I think it was around the time of my exams and I didn't manage to achieve anything. I think I confused myself. If I go back to when I was quite young, no one told me in the family; I don't think I knew what was wrong because no one told me. As a child I didn't kind of know where to go with it, there was quite a lot of confusion? My Dad took a step back and I became the parent looking after my mum while he went to work. I took a lot of responsibility I guess. I think then it got quite confusing and if I look back I think I was developing depression at the time. He was around, but I don't think he kind of understood'' (Martha).

Added to the role reversal it would appear that Anna, Jo and Martha were also all assessing risk. Deciding when to seek help is a task which befell both Anna and Jo. Despite not having any knowledge of mental distress, they both took responsibility to encourage their mothers to seek help in the absence of an adult doing so. Risk is an element of caring for someone with mental distress which becomes overlooked, when the spotlight is too task-focused. Assessing the level of risk is arguably the most onerous of burdens for a child. Seeking help for a parent who does not believe they need it, places an intolerable level of stress on the relationship. If the parent is then admitted to hospital, the experience could be expected to be even more traumatic for the child and raise anxiety about not only about the capacity of the relationship to withstand the challenge but also in terms of resultant self-blame due to the child's age. Anna and Jo had responsibilities far beyond their years precipitated by the

emotional collapse of both parents prior to and subsequent to service intervention. Foster (2006) used phenomenology for her study and one of the themes she identified was 'being responsible.' This study certainly reflects this finding.

Sheehy (2001) argues that the parentified child is at risk of developing a burdensome fantasy of omnipotence. She explains that the child develops a belief that their wishes and needs are too dangerous, and that others will not be able to be sufficiently supportive or robust enough to emotionally hold her. This is at the core of the parentified child's experience and Sheehy believes that it is this which retards creativity, because it stifles fantasy and the ability to play constructively and destructively (Sheehy 2001). The fantasy of being too needy to approach another for help may also contribute to the difficulties AOSMDP have asking for help. Sheehy (2001) continues by saying that it may be too high an expectation for these children to be given time and space to 'play'. The parentified child may not know *how* to play and that the development of policy to support parentified children may need to consider other ways of engaging them. Given the levels of responsibility these participants were holding, this seems to be a point worthy of further thought. Interventions to help children may be misguided.

Parentification can also affect sibling relationships. Jurkovic (1997) argues that as the younger naturally look to the elder siblings for support and guidance; the elder sibling will not only feel the responsibility of the parental role, but also possibly resentment, which may accompany younger child care. Despite this, it has also been found that children who have a close sibling relationship are more able to question their parent's reality, so in this respect afford a degree of safety for each other (Beardslee and Podorefsky 1998; Maybery et al 2005; Göpfert et al 2004).

Anna's story tells how abandoned she felt by not only her parents but also her brothers who were able to move away in search of work. There is a note of resentment towards her brothers in the following story;

“Because; I think; I was a girl, it all sort of fell on my shoulders because girls and women seem to cope more than the boys don’t they? Women are stronger; the boys did their own thing. I’ve never fallen out with my brothers over anything, apart from a couple of times over my mum and anger with them because it was all, it was all on my shoulders. Yeah they used to come and visit; but then they would go away and then, you know? They had their lives mmmh” (Anna).

Anna was the middle child in the family and her adopted care role raises discussion about the rights of men to work, which (Sheehy 2001) argues women still have some way to go to replicate. In the UK however it has been found that women account for 58% of unpaid carers and men 42%. These figures are shown about caring in general, so show the percentage which includes spouses caring for those with dementia (Braine and Wray 2016). Almost exactly the same figures are shown for young carers with 56% girls and 44% boys. Of these young carers 56% live in a single parent house hold and 29% care for a parent with a mental distress (Dearden and Becker 2004).

A further aspect of changes to sibling roles which has not been articulated well in previous AOSMDP research is the ‘splitting’ of the siblings, which may also affect the relationships between them. This phenomenon is described by (Dayton 2012 p 31) although her work is about children of an alcoholic parent. She describes that “Parents may co-opt one child as a surrogate partner and distance the other”. Two of the participant narratives in this study clearly demonstrate this phenomenon. The bad child is seen as being one who will argue and assert themselves, which leads to rejection; whilst the good child is seen as more amenable but is then more likely to be intruded upon and engulfed in parental pathology. Jo attempted to explain how this dynamic worked in her family where each of the 7 children were assigned either role. Fortunately for Jo this does not appear to have led to resentment between the siblings.

“I think the thing is in my family she had some children who she thought were naughty and some that were good. My problem is that I was good because I helped with the children, I was very placid and I did as I was told, I was good at school. So I was good and aligned with her, whereas my older brother he was naughty, he was bad, he left home at 16 etcetera, so it has been easier for him in some ways to not give his address, to not have her involved. He knows, he knew from quite early on how damaging she was, where it is hard for me to work that out. But I think being bad really just means sticking up for yourself!” (Jo)

It is also an element in Cathy’s story which has led to ongoing resentment and semi estrangement between the siblings.

“My brother, ((sarcastically)) marvelous, everything he did, marvelous! They built a house for my brother and I was asked to leave! So that had quite an impact as you can imagine. It’s always been like that and it’s got worse and worse and worse” (Cathy)

This dynamic resonated; I had never heard anyone describe this before. In my own story, the good/bad child in my family altered every few weeks or months. My sister and I developed our own language for it. We would only realise that the dynamic had shifted focus, when it became obvious the roles had switched, so our ‘in favour/ out of favour’ language allowed us to continue to communicate, where it might otherwise have broken down. Strangely I have found discussion of this phenomenon hard to find in other professional literature.

Five of the participants of this study indicated that there was a level of shock which accompanied the development of their parent’s mental distress. For some this stems from a defined incident such as hospitalisation which led to shock, for others it seems

that the shock stems from both the changing family dynamics and the change in the presentation of their parent. Rose et al (2002) also found that the participants of their study experienced shock, confusion and fear early on in their relative's mental health problems. This was largely attributed to the sense that life was no longer normal and predictable which led to a sense of unreality. The participants in their study included various other familial relationships and although there were four AOSMDP, their experience is not discussed separately. They also noted that shock accompanied the attribution of a diagnosis later in their relative's period of distress.

Five mothers of the participants of this study were admitted to a psychiatric hospital whilst they were young. Two (Anna and Jo) witnessed this event, which both experienced as traumatic. For Jo the experience was still painful as she recalled that particular day with me thirty years later in the interview for this study. Jo was just about to sit her 'A' levels at the time.

"So there was an ambulance outside and 3 men and my mum knew as soon as she saw them coming, she knew something terrible was going to happen, she tried to escape. And these 3 typical burly men came down the corridor and made sure she stayed where she was. One of them was a psychiatrist. There was a family down the road a bit who we sort of knew from church and my dad said you have to take the children to that family. So he said to me "take the children out of the house". So we bundled them out, and as we were going up the drive we saw the ambulance with its lights flashing..... She was screaming; she was screaming at my dad and saying 'if you love me don't let them do this to me' so it was really kind of traumatic really. So it's that bit that kind of stays with me, it was kind of not knowing what was going on with her" (Jo).

Jo continues with her story by explaining what happened next;

“Anyway..... I think, what happened after that was that I kind of had a physical and emotional collapse really. Then a nun said ‘why don’t you come and live with me? I remember going on the bus with my overnight bag and turning up at the nun’s house. So I went and stayed with the nuns for a week. They gave me a little room and I just slept. I slept night and day for a week; I remember them waking me up and giving me food and then me going to sleep again. Literally for a whole week and then I remember thinking, I must go into school’” (Jo).

Herman (1997) argues that witnesses to trauma are also subject to the consequences, which by virtue of being a child may be worse for the witness than the victim. It is a particularly stressful event for anyone involved in a detention against the will of the patient. It has been found however, that children who later visit their mother in a psychiatric hospital generally perceive their parent’s hospitalisation in a positive light, and suggest that it brought relief (Garley et al, 1997). It is unclear however whether the children in their study witnessed the procedure of their parent being detained or whether they were shielded from this. Anna at fourteen also saw her mother detained and also had to cope with having been the one who orchestrated this.

“The psychiatrist saw her, the psychiatrist then said to my dad; despite me asking for help the psychiatrist answered to dad! “You know she is going to have to be certified and go in to hospital“. So all that was arranged, that was horrendous waiting for that to happen in the morning. You had to have police and doctors and there was a big lot of people came to the outside the house, I was over the road in my friends flat watching it. She looked out the window and saw this going on in the road so she closed every

window, locked every door, barricaded furniture. So watching that was like an absolute nightmare, she was screaming and shouting” (Anna)

In some of the participants narratives the shock and realisation was a slower process. The slow creeping onset of the crisis in Cathy’s family took four years. There was no sudden insight into what was happening, but Cathy recalls a strange atmosphere whereby her mother used to upset her by saying ‘nasty things’. There is also a sense of a cloaked assault portrayed in the following recollection of her father’s explanation when her mother was taken to hospital. Despite the lack of memory regarding her age, Cathy is remarkably precise about the time of the argument which indicates that the memory is still alive, as is the snapshot of visiting her mother in the hospital.

*“As a child, my childhood memories, everything was very **difficult**. Mum just wasn’t normal you know? I suppose it’s from about 8 years old that I remember her being very odd, as it were. I very rarely had friends come for tea or you know.... I felt very embarrassed and I don’t think at the time I could really put my finger on why I felt embarrassed, at that point she was just strange in behaving. There was this **horrendous** row between my parents. I was about 12 I think. It was very late, about quarter to eleven. My mother was shouting at my father saying all sorts of things, saying she was going to leave him. It was very traumatic, and the doctor came and they were in the room talking. Then she came up and said she was sorry she had upset me. So anyway I went off to school. The next day, came home and my dad was there. He said “oh mums not here, she is not very well and she’s had to go off to hospital in an ambulance” and I was “well what do you mean?” I didn’t understand what was happening. He said “well she did leave you a note but it wasn’t very nice so I destroyed it” (Cathy)*

Cathy now moves on to telling the story about the visit to hospital.

*“I can’t remember if it was that night or the next night, we had to go and visit her. And I have very vivid memories of going to the door of the psychiatric unit. It was next to a very large psychiatric hospital and I have memories of a woman standing there with her legs all scarred, at the door, with a cigarette end in her mouth, you know it was not a whole cigarette it was just a filter, and as we went up the stairs the sort of chaoticness of this ward as a child of 11, 12, had a **huge** impact on me. I can remember it like it was yesterday. I couldn’t understand why she was there. And as we came away that night I remember saying to my father, “I just want mummy to come home, why does she have to be there? She seems fine”. Anyway she stayed in; she was sectioned and given medication, she looked dreadful. And then she came home (heavy sigh) and I can’t really remember much when she came home” (Cathy)*

Sue also spoke about the shock in the family following her mother’s hospitalisation.

“Basically the first time I became aware my mum had mental illness was when she took a massive overdose which was around the time I was 11. She was in a coma so dad got us from school and he said that something awful had happened and then we went straight up to the hospital. So obviously that was quite a lot of shock because I wasn’t aware at the time that there were any problems” (Sue)

Sue also remembers her first visits to hospital;

“Going to a mental hospital was totally scary experience as a child. Even on

an open ward you know at the age of 12, seeing people walking up and down the corridor banging their heads against the wall or screaming, people talking to themselves; it was just... there was no, I mean they might do it differently now but there was no space for us to go to where we could just chat. We had to be in the open public area. What I don't know is if support was offered to us and my Dad turned it down or whether there was nothing offered at all "(Sue)

The lack of privacy which is described by Sue is echoed in other studies which have thankfully precipitated a greater awareness of the needs of the child when visiting a family member in a mental health facility (Garley et al 1997; Maybery et al 2005; Polkki et al 2004).

Martha was a small child when her mother was hospitalised and her story shows the aftereffects she experienced following her mother's admission.

"When I was 5 my mum went into hospital for quite a long time, I can't remember for how long but I think it was about 5 months. That was the earliest time I remember her being unwell. I don't remember visiting her or anything. I don't remember much about it. I remember her being pregnant with my sister and her leaving the house and not saying goodbye. I don't remember anything after that; but I remember when she came back that I wouldn't let her go anywhere. I wouldn't let her go" (Martha)

There is a very different quality in Meg's narrative. Meg's mother had been distressed following childbirth and as a result services were engaged with the family at a much earlier point.

It would be naïve to suggest that Meg's experience was easier but it does raise some

important ideas which will be explored further later in the discussion.

“She was really poorly when I was born, and in hospital for a long time. I think my dad brought me up for the first 4 months on his own, then I went into a mother and baby unit. And then we came home together.... I guess I have always, I don’t remember becoming aware of it; I just know it as being part of who she was forever. She was always very good at telling me about it, being honest, you know it was never hidden; it was just part of her. I just grew up knowing that that was my mum. I guess I never really knew anything different. It wasn’t like a big secret you know where you get sat down when you’re 18 and told actually you know you’ve got this” It was just part of my experience as a child, all the way through. I hope you’ll appreciate me saying, it is just normal “(Meg).

It is the lack of awareness that accompanies a psychosis which makes the child’s comprehension more difficult. The complex task of distinguishing one’s own reality is important in the development of personal identity (Stern 1985), and it is shown here how the child attempts to make sense of the situation. In all three examples, trust is the casualty.

“He never did anything in half measures; he always had to be off or on so everything was heartfelt and strong, and powerful and everything. He would then tell us these stories about how it was love at first sight; (with his wife) it was all terribly passionate. But by the time he was telling us those stories I remember I’d lost any trust in what he said. I’d got to the age where I realized that he was an unreliable narrator, to use a literary term. Other stuff that he’d said and done undermined any sort of factual basis to

it, so the stories have left us; my sister and I uncertain as to what was the reality” (Emma)

“I remember one time, I had to go to the shops to get some food and I was taking my little brother and she said to me “what do you think you are doing? Why do you think you are taking him? Where do you think you are taking him?” It was really sort of scary and accusative; it was like I was someone else, and I was doing something awful, whereas all we wanted to do was go to the shops to get some food” (Jo)

“I remember at 5 holding onto the front gate thinking I can’t rely on anyone else, whether I picked up unconsciously that my mum couldn’t do it? (Martha)

There are studies which have referred to the developing distress, in terms of the child’s difficulty understanding; for example those of Knutsson Medin et al (2007) and Kinsella and Anderson (1996). Though not explicitly using the term *shock*, for some participants, it was a sudden shocking experience; for others it was a slow dawning realisation that the family felt different in some way. Children living in a family, in which mental distress is developing, have no frame of reference by which to understand their experience. Jo explicitly spoke about this lack of a frame of reference, and stated that although she did not understand mental distress, she still knew something was very wrong. All of the participants of this study with the exception of Meg expressed the desire for more knowledge and understanding. Sue, Jo and Martha all complained about the frustration of not knowing, and the confusion that they felt as a result of this. The period of confusion and not understanding is echoed by Foster (2006, 2012) whose study on the same topic identifies four phenomenological themes, one of which she has called ‘Being Uncertain’. This section of her study has a subsection called ‘knowing something is not right’ in which her participants expressed

similar confusions and fears. Although an adult may have a frame of reference, or language for mental distress, it should not be assumed that this eliminates the fear and confusion.

According to Falkov (2004) the nature and extent of the child's understanding is suspected of having a direct correlation to their eventual healthy adaptation. He argues that it is the power which comes with knowledge, which may be a protective factor in the later transmission of distress to the next generation.

Fear was detectable in at least four of the seven participant's stories in this study. The fear accompanied the onset of parental distress and the struggle to understand what was happening. This finding also echo's some of the research on COPSMD (Aldridge and Becker 2003; Caton et al 1998; Garley et al 1997, Maybery et al 2005) and indicates that it may be far more than a simple explanation which is needed.

Three of the participants of this study stated that they wanted to participate in this study due to the lack of information and support available for AOSMDP. Each one of them had researched books and the internet for help and support, and in each case the person expressed that if they could contribute to a wider understanding, it would be worth participating.

The shock and fear and confusion around the developing distress are compounded by the shock of the changing dynamics within the family. As the family is now in crisis, the child's internal world may also be in chaos.

In order that the findings of this study are understood, there needs to be a brief presentation of the background literature. By giving the reader some theory, the findings can be appreciated at a deeper level and in context.

When a baby is born the loving care it receives is the foundation of basic trust in the world. The pre-verbal elements of basic trust are built upon familiarity, confidence and love (Janoff Bulman 1992). Erikson (1980) adds to this with his idea that basic trust is the fundamental pre-requisite of mental vitality, and that this stems from the

recognition of a mutually fulfilling relationship between baby and mother. Upon this basic trust each baby will develop core assumptions which will guide the rest of its life. According to Parkes (1971, 1988) these assumptions form the basis of our internal worlds which help to keep us feeling generally safe. Whilst we still experience misfortunes and setbacks in our external worlds we tend to believe that inside, in 'our world' we are safe. These assumptions are so familiar to us, they are barely even recognised. When we are wounded or those we love are wounded, the danger suddenly becomes very close, very powerful and very personal. It threatens the very core of our being, putting our identity and even our internal experience of existence at risk. These beliefs constitute the bedrock of our cognitive- emotional worlds (assumptive worlds) (Parkes 1971, 1988) and fall into three distinct areas.

- 1) The world is benevolent
- 2) The world is meaningful
- 3) The self is worthy

The idea of the assumptive world stems from social psychology and relates to the schemas and meanings that operate in our psyches. When we have a new experience it is either interpreted to fit our existing schema or our schema must be altered to accommodate the new learning.

Epstein's (1991) addition to this discourse brings the idea of meaning being central to the assumptive world. He considers that the essence of a personality is the individual's theory of self and world, so the assumptive world then becomes meaningful. Although coming from a different perspective and using different language, Bowlby's (1988) 'working models' are a similar construct.

In 1992 Janoff –Bulman added to growing theory with her contribution of what happens when someone experiences a traumatic challenge to their assumptive world, and it shatters. Her work is now used extensively in the assessment of trauma survivors and aims to elicit their perceptions in the three main assumptive areas; the

benevolence of the world and people; meaningfulness in terms of justice, control and non-randomness, and self-worth, or one's own goodness and luck. These areas, she states are the specific sites which are damaged most in psychological trauma.

The loss of the assumptive world is a theory which presents a way of trying to understand changes in psychosocial reality "From the wound of loss that is present in change; In other words the concept of loss of the assumptive world is a theory about grief" (Kauffman 2002 p2).

The study of trauma has a curious undulating path of intermittent amnesia. Herman (1997 p8.) writes that "Periods of active investigation have alternated with periods of oblivion "Unspeakable atrocities are banished from consciousness. They are too awful to utter. At the same time, it is common folklore that truths will always come out eventually and denial can only work for a limited time. This is behind the notion that traumatised people veer between knowing and not knowing, which Herman calls the 'dialectic of trauma'. Mental health professionals tend to refer to the state of amnesia as denial or dissociation. There is a push/ pull dynamic of sharing trauma and secrecy both at the societal level as well as the personal level. It appears that the atrocities of September 11 2001 have awoken a renewed interest in trauma and its aftermath, and this has been shown at a societal level with the attention paid to more recent child abuse scandals, through to research which has now begun to filter into mainstream psychiatry, such as the study by Read et al (2005) which explores the links between childhood trauma and psychosis. The 'not knowing' is also part of the trauma process.

Bowlby (1988) wrote about the nature of disavowal, explaining that when a mother constantly denies her own experience or behaviour, the child has to learn to disown their own experience in order to stay close and safe. Disowning one's own experience compromises the integrity of the psyche as pieces become fragmented and temporarily forgotten. Loshak (2013) discussed how the nature of serious mental distress often leads to a process of disavowal, partially through the trauma of the condition and partially through the stigma associated with it. This can happen to the individual, the

family, and at a community level (Kauffman 2002). Psychosis is therefore frequently denied by the person who it affects. This is particularly important to understand in relation to the AOSMDP who may learn to disown aspects of their identity for example, anger or personal needs, because it is just too risky to allow them to enter the relationship for fear of losing any remaining tenuous connection between parent and child.

‘Not knowing’ features in the participant’s stories and those of their families and adds weight to the evidence of the experience being traumatic for the family. Not knowing has its source in various theories the language of which may change depending upon the profession’s perspective from which it has been written. The participants in this study have referred to the state of ‘not knowing’ either in relation to themselves or in relation to their well parent. For some of the adults, it seems alcohol helped them to maintain their ‘not knowing’ and avoid thinking about what was happening to their family. In the following excerpts this can be seen as the participants attempt to put it into language.

“My Dad would do nothing about it. I think because we never saw him drunk but ‘e obviously had a drink problem as he died at 70 of cirrhosis of the liver. But I think because he was drinking all the time, it obliterated it from him, but I mean, it didn’t to us children. He didn’t sort anything out with doctors or anything. It was down to me, I don’t know we just carried on with it, I just don’t know. I had to get her help” (Anna)

“I knew stuff had happened but downplayed it; I think because mums illness was so huge, it was kind of easier to.” (Sue)

“Well you see I could have done more; if I had been braver I could have done more. There is lots of things I could have done if I had been braver, I don’t

know what those things would have been. Oh no, telling you my story; It's a story I am not sure I participated in it, but I saw it somewhere, maybe I watched it on the telly or something! "(Emma)

Both Martha and Jo spoke about how the dissolution of their 'not knowing' helped them on their recovery journeys.

"It was quite hard for me, because initially I thought that the way I felt had nothing to do with my family (laughs) I know!! Now I have made sense of my past because before I think I blocked things out, nothing was to do with my past. Now I can say "okay that is because of that and that's Okay." I don't know whether that was because I wanted to defend my mum. I think what happened was that at 21, because someone acknowledged me, and that was the start of the journey really to where I started to look at my sense of self." (Martha)

"That was the first time that someone had said 'so what were you thinking then?' What happened to you? And that was a real eye opener. It has always been about her" (Jo)

These two stories from Martha and Jo demonstrate how having someone to acknowledge the pain and thus far unspoken trauma can move the shock into consciousness so that it may be dealt with, and potentially become an area for growth (Dayton 2012).

Kinsella and Anderson (1996) have discussed denial, in terms of their participants who described mentally escaping their environment in order to obtain some relief from the pressures of living with a mentally ill parent. Dunn (1993) incorporates denial into her theme of isolation, and cites one of her participants as saying "the family pretended

like nothing was going on". The reference to denial is however fairly scant in the academic literature about AOSMDP. It is however considered in some of the lay literature (Wasow 2000; Nathiel 2007). Wasow (2000) refers to denial as part of the process of coping with the uncertainty of what is happening. From the grief literature Stroebe and Schut (1999) posit that denial is part of grieving, and is a dynamic process that reflects both the realisation of the loss and the continued fight against the reality of the loss.

From a psychological perspective, dissociation is a term commonly referred to as forming part of a similar pattern of not recognising and not seeing and not knowing. Children learn to dissociate in order to avoid frightening, overwhelming or unpredictable situations; most commonly neglect or abuse. In these circumstances, the mind functions to preserve self- continuity by the creation of dissociative state (Bromberg 2011). Simeon et al (2001) noted that the genetic transmission of the tendency to dissociate is estimated to be zero. This indicates that dissociation is an environmentally induced state, which is an unconscious attempt to cope with circumstances and which, if continually used, may become an unhealthy pattern.

The underlying mechanism for dissociation is similar whether the trauma is relational (as is the case with the AOSMDP in this study), or life-threatening. It has been found though that despite similarities in terms of the process of dissociation, the way memories are encoded has been found to be both quantitatively and qualitatively different. Sands (2007) explains that a person's dream is a voice from a dissociated part of the patients self that they are not quite ready to acknowledge. In this respect it serves the same purpose as that of denial, although arguably at a more unconscious level.

This may hold true of the repetitive dream which was complained about by Emma who alludes to the source of the dream but is as yet unable to pinpoint the meaning.

"I dream about that house a lot. An immense amount because it was a very

old place, a bit creepy and my mother had this thing about there being a poltergeist there and I still dream about the poltergeist in that house, and when we go through the village it's bizarre I don't know why I dream about it so much but we drive past it regularly on the way to my Mother In Law who lives in the village nearby and it gives me the shivers whenever we go past it. I think possibly there's some emotional stuff going on, there is obviously fear of the ghost but there is also all the emotional stuff because there were some heated moments in that house (Emma)''

Bromberg (2011) writes that, dissociated aspects of the self carry a terrible cost such as the loss of capacity for conflict, for inter-subjectivity and for mentalisation. He argues that the person who has been traumatised does not feel at a deep level that anyone can understand, imagine their distress or resonate with their internal world. This assumption, she writes, makes inter- subjectivity impossible. Sands (2007) adds that the dissociative individual needs to know that the other has somehow 'lived' a similar experience both emotionally and cognitively in order to be able to truly empathise and that this is the basis of the desire for validation commonly seen in trauma survivors. Several of the participants in this study have mentioned validation and I return to this later in the discussion.

Naturally it is impossible to imagine how each of the participants in this study has experienced their lives. This study asked for the participants' story and they have chosen to relate to me what they feel was important to say. Each person's personal resilience, memory and current social context influenced what they chose to say, which may be different tomorrow or next week. This is their personal construction of the experiences they have had which they wanted to relay to me and these should be respected as their truth. It may be that the imagined difference between those who have suffered and those who have not, is at the root of the victim identity.

Bromberg (2011) also explains that when a person is overwhelmed or dissociates due to fear, the linear experience of time is distorted which produces an associated amnesia for perceptual memory of trauma but which leaves both bodily and affective memory intact. The result of this is that the person's perception of the future and the present becomes frozen. The frozen elements then become models of the past. "So instead of being able to say 'this is what happened to me' the person will now say 'this is what happens to me'" (Bromberg 2011 p 4).

One of the problems in families where denial exists, is that it becomes not just defensive or protective, but malignant. When this happens it isn't simply the distress which is disavowed, denial becomes the *modus operandi*. This is potentially more problematic than the distress. Not speaking one's mind leads to suffering in silence which can crush the core self. Secunda (1997 p161) writes about the silence that covers families in crisis and says that "the reluctance to accept that the loved person has a mental illness is a normal part of mourning".

Breaking the silence is therefore vital for people to remain in touch with their own beliefs, needs and feelings. Herman (1997) discusses captivity and says that when neither resistance nor escape is possible the human system of self-defence becomes overwhelmed, and loses the sense that it has a self at all. If and when that person manages to escape they may be hindered by complex Post Traumatic Stress Disorder (PTSD). Under these circumstances the person may eventually become emotionally constricted by becoming powerless, or resort to numbing through drugs, and a disconnection of the mind and body may be a result. Some people may avoid any attachments because intimacy is felt to be so threatening that emotional detachment becomes so second nature.

In her master's thesis on adults who have mentally ill parents Harstone (2010) found considerable silence, some of which she believed was due to denial.

In this research apart from one narrative, (Meg's) it seems the others were all, to some degree unable to have a conversation about what was happening. Secrecy was found

in each of the participant's narratives to a greater or lesser extent and it contributed to their accounts of the breakdown in communication between family members. From a pastoral perspective, Swinton (2001) writes that when a family has experienced an unusual loss, or the relevant attributes of that person's role cease to be operative, so for a mother for example, to no longer be available to care for and protect her children, the loss is surrounded by silence. He writes that the silence is self-imposed by the family as a result of their discomfort and can endure for years leaving the community unable to help. The communal silence is then reflected back to the family and contributes to the shame which they already struggle with.

"If I was worried about school or friends I wouldn't tell her because she couldn't hold it, she would start crying so I think that is why I hold things in. I tried to tell my mum you know, 'when you were ill it did affect me' but she 'no I can't hear this', so I kind of left it. It is 7 years now since mum became treatment resistant and no one has asked me how I am. I think the loss, the losses throughout life, like 7 years ago I lost my mum but the psychiatrist has never asked me how I am doing, or whether I need anything" (Martha).

Shame and stigma are often considered in tandem. Etymologically, shame means both exposure and cover at the same time. So the person who is ashamed feels exposed to the eyes of another, and will attempt to hide themselves as a result. Helplessness and powerlessness underlie the feelings of shame and inadequacy (Doka 1989). Stigma is a term which has been long related to the experience of mental distress and Jones (2002) considers it at the heart of the existence of the very concept of mental distress. Goffman (1963) first wrote about the feeling of humiliation which colours the identity following the internalisation of stigma. He elaborated on this idea by stating that the effects are not confined to those with the perceived difference, but also their loved ones. This effect he called 'courtesy stigma'. 'Stigma by association' was more recently

explored by Östman and Kjellin (2002) although they have approached the topic with the assumption that 'burden' equates to the same thing. The instrument they used to measure the stigma by association, was the tool developed by Schene et al (1994) which was a tool for measuring burden. The questions included "Has the persons mental illness led to any mental health problems of your own? And, "Are there times when you think that the ill person would be better off dead?" The findings of this study are that 83% of the relatives interviewed experienced a burden in one or more of the assessed psychological factors of stigma by association. Similarly, Corrigan and Miller (2004) in their study on familial stigma found that children were fearful of contamination by the distress of their parents, and this too has been considered evidence of stigma

The problem with this loose conceptualisation of stigma, is that it undermines the very real fear, despair and pain experienced by family members who are witnessing the suffering of their relative. Fear of inheriting this awful condition, is not stigma. Burden is not stigma. If a pet was suffering, and it needed to be euthanised, no one would call that stigma. It would be perceived as a painful recognition that the loved pet is now suffering so much, it would be kinder to let it go. This is not to say that stigma and stigma by association does not exist, but that stigma must be clearly defined to capture the experience of difference and discrimination, or it becomes easy to overlook the grief, loss and pain of having serious mental distress either oneself or in the family.

Stigma has been explored by scholars mainly from this sociological perspective but is also relevant from a psychological perspective, where it has its origins in shame. Shame is an emotion based upon fear which is underpinned by the feeling of being unworthy and unlovable. The feeling brings threats to the integrity of the self which is perceived as being deficient and bad. This in turn leads to an attempt to conceal the flawed self (or family) from others. Vulnerability and fear of being found out, exposed or humiliated further prevent a person from reaching out to others. By shutting themselves down, a distance is created from their own internal painful state and also

from others. Developmentally shame occurs in the second year of life (Erikson 1980) and constitutes the conflict between autonomy versus shame and doubt. More recently shame has been seen as a veil which covers the hidden self in people who have suffered neglect or abuse (Herman 1997, Schimmenti 2012).

Shame experienced by a child is a result of early developmental loss either real or perceived. It is thought that it may stem from loss or other threats to the child's basic sense of security. Feelings of shame either cause the child to react with anger or withdraw. This is seen at the personal, familial and societal level in the participants' stories.

Meg who works in mental health and is the youngest of the participants stated it thus; (Meg uses her voice volume to add to understanding and I have kept the original transcription notes intact to show her decreasing volume as shame enters her voice)

"Everyone's very professional and I don't mind people knowing about my mum and who she is you know and that she is with that CMHT at all but I guess it's um, you don't shout it from the roof tops either, Yeah you kind of keep it on the down..... "(Meg)

Meg continued with her idea about feeling different which Murphy et al (2015) argues demonstrates stigma.

"A lot of people I've grown up with; I've been friends with them since 9/ 10 years old. They are the people I compare myself to sometimes; you know, the worry that they have had and the childhood they have had in comparison to mine. In that way I had to be very grown up and had to be quite mature. I had to take on a lot more responsibility than people that I was growing up with. You know when I'd look onto their families they'd have the 2.4 classic family; with both parents working, siblings, nice house,

cars and all that. No responsibility really, they just had to decide what to wear that day!" (Meg)

Sue relates the abuse she received as a child from other children and how she chose not to tell her father in order to protect him, but also questions whether she would have told anyone else, had she had the opportunity.

"There was a boy who lived on my street and when my dad was away was basically shouting "your mums a looney" blah blah. I remember running into the house screaming and balling my eyes out. I won't have told my Dad that and my brother won't have told my dad that. So there is also something about, there are experiences the child has that they will hold themselves because they want to protect the parent. I guess the question is that if we had had somebody outside of the family who we could have talked to would we have been able to talk about that stuff?"(Sue)

Speaking about her mother's hospitalisation Sue recalled,

"Then it's kind of weird because I don't really remember much for a period after that, it's like completely sort of blank. I just remember odd little things like being sent to stay with various friends for a few days or whatever. I was very upset and wanted to talk about it whereas my brother just wanted to watch the television" (Sue).

Martha also recalled the difficulty she had knowing who to tell

"I don't think there was anything out there when I was a child at all. There was no one to talk to; at that time there was no school counsellors or; there wasn't a carers' centre either I don't think. What I remember kind of well

was that people were not helping me. I would call the doctor and we waited quite a long time for someone to come in and assess her so I remember that being quite significant. Wondering where to go to find help, I didn't know where to go. The responsibility was on me quite a bit" (Martha).

Following her mother's hospitalisation, Jo also recalled the lack of communication from the community and how this left her in need of validation for her experience of watching her mother's detainment.

"Nobody talked to me about it. Nobody talked to me about what had happened. For some reason I am not angry with my dad; I am angry with the nuns, that wouldn't talk to me about it. I can remember one time telling her this and the nun laughing and I know she probably did that in order to make me not get so worried about it but, just that thing of her laughing; made me feel, you know that I was making too much of a fuss. That really it was silly and that I should forget about it really. So it was that kind of sense of not validating my experience" (Jo).

Anna also spoke about the stigma she felt and the silence this brought with it.

"I always felt, I felt oh she's my mother and like walking down the road to go to school and I'd think oh if I put me head down I wonder if they would see me coming. Get on the bus and there'd be someone on the bus who lived near me; I didn't want to talk to the neighbours cos I didn't want to hear what she's been saying to them or what she's been calling them. We felt ashamed of telling people. Even when I was at school, everything I'd do I was just frightened that you were going to come home what you would see,

if she went out with you, if it would trigger off when you was out. If friends come round you'd think "oh please God don't start rowing "(Anna)

Schizophrenia in particular is sadly still feared and taboo. Covert bias and prejudice still underpin society's acceptance of this distress. Despite the recent explosion of literature from the service user perspective (for example Grant et al 2011, Hinshaw 2008) and the service user/carer recovery groups; schizophrenia is still a long way from acceptance.

The trauma and loss which is evident in the participant's stories is compounded by stigma, shame and silence. These dynamics have their roots in denial and repression, and contribute an important element to the families' experience of feeling isolated. The silent withdrawal into shame, lends itself to an opportunity for nurses, social workers and other professionals to intervene and break the silence at this point, so that each member of the family can begin their own recovery journey.

Issues surrounding confidentiality have been discussed in the AOSMDP literature for some time. The exclusion of family members is sometimes at the distressed person's request which prevents open dialogue and adds to the maintenance of secrecy with the result that families are rendered helpless and unable to gain support for themselves. It has been purported that sometimes this is in the mistaken belief that children will become upset speaking about their parents distress, so the parent tries to avoid burdening them (Cowling 2004). Other reports discuss the fear of parents who are anxious that children may be removed and that open acknowledgement will bring further unwanted surveillance upon the family which is not entirely without foundation. Adult mental health services in the UK have been much slower than the CAMHS services at investing in family centred practice wherein families are seen as systems rather than individuals with no context (Cooklin and Gorell Barnes 2004). Various reasons have been given for this including that therapeutic relationships are based upon trust. The level and depth of trust is a complex and delicate area to confidently assess in order to establish whether it is sufficient to enable the identified

person to confide and share any concerns about parenting which may cause them to feel vulnerable. It is perhaps particularly difficult for the person who is unable to see that their reality may be preventing them from being able to acknowledge any impact on their child.

More recently Murphy et al (2015) have discussed the navigation of stigma by AOSMDP and this study relates the need to maintain secrecy to stigma. It is hoped that the quotes used above might encourage caution about this assumption due to the hidden nature of trauma following shock or grief.

The Ride

The second part of this discussion also utilises the structure offered by Kalshed (2013) whereby external and obvious trauma and losses are considered first, followed by the internal and less obvious trauma and losses which have been experienced by the participants.

As can be seen in 'Hold on Tight,' the entire family structure is tested by the onset of severe mental distress and may break down as a result. As the parent with the mental health problem becomes less emotionally available, the other parent may struggle to keep the family home running, provide childcare and go to work. The demands of a dual parent/carer role along with processing feelings which have arisen as a result of a partner's distress may lead to difficulties coping or possible exit from the family structure entirely. The consequent lack of protection available to the child may expose them to a greater risk of abuse from within and outside of the family (Devlin and O'Brien 1999; Royal College of Psychiatrists (RCP) 2002). Further pitfalls which have been identified by the RCP (2002) relate to the dynamics of the relationships affected by mental distress and may include negativity about the child including rejection, neglect, inability to give support and love, distorted and confusing communications, ongoing hostility and criticism and inconsistent and inappropriate expectations. Crastnopol (2015), a psychoanalytic psychotherapist from the USA, writes that sometimes it is hard to identify her clients' past trauma but that careful

investigation nearly always reveals many incidences of micro-traumas such as the rejection and confusing communications, which combine and leave the person dealing with consequences of a cumulative trauma. According to Fonagy and Target (1995) cumulative traumas such as neglect have an effect on a child's mind which is indistinguishable from violence.

None of the participants of this study disclosed being on the receiving end of any violence although Anna witnessed regular domestic abuse between her parents and Emma's story shows that her father physically and possibly sexually abused his family. This is a common outcome in families where the mothers become emotionally unavailable by virtue of mental distress. Ruppert (2011) explains that the child in their search for connection, will often turn towards their father for emotional intimacy, and that given the propensity for a vulnerable woman to find a vulnerable man, the child is then at risk of becoming entangled in the fathers' early trauma as he takes advantage of the child's approach for connection. Emma explains how her family was affected by her father's developing psychosis.

"Certainly in my house emotions weren't shared properly, we weren't emotionally literate because it was too frightening, too scary. Dad was quite violent at times because of the drinking, he wasn't a nice drunk, he was a sentimental drunk but also he could get a bit nasty. I don't remember him hitting me particularly but I know he used to drag my sister around a bit"
(Emma).

Further on in Emma's narrative she returns to the topic

"One day Mother said; she had been watching a programme on child abuse and ..."that's what your dad used to do to you", I thought oh that's interesting isn't it? But of course it wasn't really known in those days so that was quite insightful. My sister and my mother and I were going to talk

about it all, but I don't think it would have served any purpose it would have only got us all wound up. He was really into pornography, he wasn't the worst man in the world; he was just not a happy man. And he was a man of his generation too. He was sexually inappropriate with people and was more open with us than was really appropriate. He never really laid a finger on me but he would just do things that were very inappropriate in front of us. And he would do things to my mother in front of us which should not have been done in front of children. And then he would get other men in to do things to mother that should certainly not have been shown in front of children. I remember that yeah, oh yeah'' (Emma).

Emma continues this theme with her unsurprising response as a teenager.

''We weren't a family big on talking I used to stay out all night as a teenager and they either had no idea or didn't care, my parents, and I don't know which is which'' (Emma).

The themes which emerged from the retrospective study by Dunn (1993) included abuse and neglect which she found in all of the participants narratives. One of the difficulties with Dunn's work is one of insufficient information because she uses 'maternal withdrawal' as one of the criteria for neglect. It remains unclear however whether there was anyone else involved in providing any care for the participants in her study. She also appears to have determined that children who have provided care for their psychotic parents are, by virtue of this, neglected. Without more detail regarding the family set up it is hard to contest this.

The neglect found in this study was evidenced by some of the participants' quotes which I have included below. Three of the participants stated that social services were involved in their family, they thought because they were neglected. Others also spoke

about neglect whether or not social services were involved.

“My sister says that when we were small the social workers came out because we were neglected but I have no memory of that at all. Certainly they weren’t parenting to a standard, I mean I would go to school in not a very good state, I do remember that but I was blamed for that, things like having great mats in my hair. I was blamed for that, because I screamed so much. So rather than taking it in hand and having my hair cut or anything like that....” (Emma)

“I had a friend whose mum shopped in Marks and Spencer’s and I am still friendly with her to this day. I used to think why can’t,... I used to love going up there because it was homely and she’d been to Mark’s’ and we had cakes. We never had none of that. She stopped buying food. We only had absolute basics” (Anna)

In Martha’s story the neglect is experienced when she felt vulnerable and frightened and found there was no one she could turn to;

“I wouldn’t go out, I wasn’t sleeping well; I had a lot of anxieties about falling asleep and not waking up; just being left, abandonment. I remember not being able to tell anyone. I couldn’t tell my mum because she was unwell and then my dad had closed down and he was not emotionally aware and yeah so... There were lots of issues with not being able to sleep. I remember thinking; what happens to people when they die? Where will I go? Lots about death; Lots of anxiety about those sorts of things. And I remember that going on for quite a long time. I am guessing from about 8 all the way

through to teenager” (Martha).

The neglect experienced by these participants is evident and indisputable in the above quotes. This neglect derives from maternal deprivation which in some cases is compounded by paternal deprivation or absence. What may be less obvious is the trauma associated with the mental distress itself. The following quotes show how the participant’s lives have been traumatised directly by the distress.

“There is lots of incidents, some of which I have had to work through in EMDR in therapy because they were so traumatic I would have flashbacks around it; things like when mum was home one time walking in the kitchen and seeing her holding a knife to her wrists and being frozen and then walking out and thinking should I have said something? Should I have done something? We would have to hide things like medication and then seeing her one time going to the cupboard and finding paracetamol that my Dad had hidden and having to go and tell my dad that I had seen her take it so he could go and get it off her, seeing her hysterical and trying to calm her down. One Christmas we had to have plastic cutlery and paper plates because we couldn’t have the risk of proper knives and things that she might have used to cut herself. Another Christmas actually she didn’t come home, she was on a locked ward and we went to visit her in the locked ward on Christmas day. Hating it just not wanting to be there, “This is not how Christmas day should be” (Sue)

Witnessing a loved one becoming ill and displaying inexplicable symptoms is also painful as Anna explains.

“We saw her the following Sunday and oh:: it was heartbreaking. After she

had all the electrical treatment she went in like a zombie stage. She was just sat there. She went from being very loud to being very quiet, I don't know what was worse because it was horrible seeing her sitting there taking no interest in life what so ever, she went from one extreme to the other which was absolutely horrendous. That happened a few times in her life'' (Anna).

The inexplicability of psychosis is particularly troublesome. The thesis by Camden Pratt (2002) which is titled using Greek mythology "Daughters of Persephone" describes Persephone's regular decent into the underworld, leaving her family behind in an entirely different landscape. The underworld is so distinct, that it bears no resemblance to the world from which she is regularly taken. In the myth, Zeus, Persephone's father, aids his brother Hades, king of the underworld, to abduct the young Persephone. Hades has fallen in love with Persephone and wants her to be queen of the underworld, where death, rape and destruction rule the day. For a while Persephone wanders lost, frightened and confused, but in time she becomes Hades' wife. Demeter is Persephone's mother, the Greek goddess of the earth (agriculture) who brings blossom, light and warmth to the earth in preparation for the spring and subsequent harvest. When Demeter learns that her daughter is missing, she is devastated and abandons her role as goddess of the earth. The earth becomes barren. To re-establish harmony in the world, Zeus needs Demeter to return to her divine responsibilities so he orders Hades to return Persephone to her family. Hades does care for his wife and so tricks her into eating a pomegranate seed that binds her to him forever and ensures she returns to him for half of every year. Persephone makes her escape and Demeter is overjoyed to see her daughter returning and in her joy she returns spring to the world. Every year now when Persephone is recalled to the underworld her mother again grieves and the earth knows only winter. Spring returns when Persephone reappears. Camden Pratt (2002) has utilised this myth to illuminate the experience of the loss of a loved one into a world of psychosis. The loss is then re-experienced every time she

goes. The pull to go with her is strong and each of her daughters must resist that.

Bolen (1984) explores this dynamic in depth through the goddess Demeter. Demeter was the archetypal super mother but as she saw the end of her mother role on the horizon, lost her meaning in life and became depressed. She became obsessed by the loss and her own growth became stilted. She experienced Persephone's growing autonomy as a personal loss.

Bolen continues that Demeter women see themselves as good mothers. From the offspring perspective however she is either superbly able or terrible and all consuming. When her adult children resent her she becomes deeply wounded and confused. If something happens to her child she will feel forever guilty and responsible. She may become overprotective and over controlling. Sometimes the daughter becomes bound to her for life. The daughter who chooses estrangement often does so after attempts to make her feel guilty and manipulated. Demeter thinks she always knows best and will attempt to take over. She needs to be needed and grows anxious if the other person becomes competent.

Persephone does not have a close relationship with her father who may have been dissuaded by the exclusive relationship with Demeter. He may have left or been uninvolved. As Persephone ages she may be dogged by depression. She may stay defeated by her captivity and chose to reside in her own underworld. This feeling of entrapment gives rise to resentment and a victim identity. Persephone may also retreat into the world of madness.

Herman (1997) discusses captivity and states that when neither resistance nor escape is possible, the human system of self-defence becomes overwhelmed, and loses the sense that it has a self at all. Perhaps this underlies the process of folie à deux'.

Swinton (2001) describes the experience of being with someone who has psychosis using the analogy of entering into a landscape which crosses a cultural boundary, like

being in another country. He continues by saying that

“there is an urgent need to find and learn a new language and a new frame of meaning in order to effectively communicate without misunderstandings, like trying to connect with someone whose cultural context is entirely different from one’s own” (Swinton 2001 p142.)

The experience of being with someone who is psychotic is therefore sometimes frightening as normal expectations of culture and meaning, and as will be shown in Martha’s story, even language no longer necessarily apply. Below some participants describe difficulties they had as a result of having a parent who was suffering from a psychosis.

“Her behavior was quite odd and her thoughts were quite disordered so she couldn’t even speak English. I can speak (mother’s native language) but she wasn’t even speaking that, she was speaking her own kind of language, it was really bizarre” (Martha)

“She took delight in coming to where I was working and told everybody that my child was through my father, shouted it around, I had no contact with her. And then we made contact again, she contacted me but I was very wary” (Cathy)

“She would wake us up in the middle of the night; there was a sense of ‘you can’t do that because something terrible is going to happen’. I remember one time, I had to go to the shops to get some food and I was taking my little brother. And she said to me what do you think you are doing? Where do you think you are taking him? It was really sort of scary and accusative; it was like I was someone else and was doing something awful.

Whereas all we wanted to do was go to the shops to get some food. And one day she had this sort of vision, it's a bit difficult to explain but she, in our living room there were some bookshelves, low bookshelves with a glass front so if you were laying on the sofa you could see the glass and see some things reflected in the glass because there were books behind and she had said she was lying in bed and had felt this burn on her back and it had been an alien, she knew it was an alien because she could see him reflected in the glass and she had woken up and asked me to look at her back because she thought it was burnt "(Jo)

"Then she went missing. I get a phone call in the middle of the day from this woman and she said she was in Australia and she said "I've got a lady sat in my front garden" she said. She said "I've looked in her handbag and found this address book" and I thought; I am here in England she is in Australia, what can I do? It was absolutely horrendous; my brother went and found her and brought her back to England" (Anna)

Some of the events in the above stories happened when the participants were children so making sense of these occasions would have been quite a challenge. Some of the events however happened later when the participants were adults, highlighting the ongoing stressful episodic nature of mental distress which gives rise to the 'rollercoaster effect'. Cathy's story below shows how this happens.

"She came home and she was on meds it was amazing. It was like having my mum back from when the best memories I could ever imagine. She was warm, caring it was just great. It was amazing. It was like having a rejuvenation of my mother, it was fantastic. You know the voices were

under control, we could go for coffee, we'd go shopping you know? The future looked bright. It was amazing. It was just lovely. She would phone me, it was a normal relationship. I had her for a couple of years back with me. The voices never went completely but they weren't so aggressive or really causing her pain, or to interrupt a conversation. I had decorated the bungalow, all her money had gone and I got her onto her benefits, her pensions, had smoke detectors fitted in the bungalow, all the normal essentials that she would need you know for normal living. Making sure that she had enough money to pay for her oil and she had a car so that she had her groceries in that she was eating ok.When you want someone's love, you do a lot for them, but I never really got it..... Then she started to get side effects from the medication and because of that she wouldn't take the tablets. Then she started to drift a bit. The voices started coming back in. Then "I've had some readings you know" and the Community Mental Health Team said "well you know she deserves to have a chance off the meds". I knew what was going to happen straight away. By November, December time I was phoning the consultant saying "you really need to do something here". So then Christmas came and went with no card, and I knew, I knew" (Cathy)

This is familiar pattern to people who have loved ones who are seriously mentally distressed. Jo and Martha have offered similar stories to describe the tenuous relationship which is repeatedly tested. Cathy goes on to describe what happens when her mother is distressed;

"It's almost like she gets possessed by these incredibly dark thoughts of me

and everybody else, oh my god. I can't bring myself to talk, use the words that she says because they are horrendous. She's told me I've got the plague and I've got leprosy. Yeah, oh yeah, yeah It's not very nice is it? ((Cringing)) When I went to the hospital, I took her in some juice as she hadn't drunk and I went to give, "don't kiss me, don't come near me" ((mimicking mother)) so she reject, the pushing away, straight away again. So I visited her again (sighs) and it gets to the point where she won't even touch what I've touched. Visited her and again the complete rejection of "Don't come near me" I said to her "Why are you like this? Why are you saying these things to me? Why? ""Oh cos I've had readings of you" anyway I just said to her "I just wish you wouldn't push me away, I love you and I wish you wouldn't do this to me, it just soul destroys me" (Cathy).

Anna also stated how lovely it was to have her mother well again, albeit knowing that relapse was likely at some point.

"The hospital did wonders with her, they got her back, you know, to sort of talking and then it was decided she couldn't go home to her home anymore, she'd have to go into a care home sort of place. And they did, for six years we had my mum back, I had a mum again that I'd known as a little girl you know?" (Anna)

Jo also spoke about her mother's relapsing distress which causes so much stress to the family.

"There is always so much sorting out to do. Everything is always a mess, financial mess, physical mess. We helped her sell her house because she

couldn't afford it, so we helped her set up in a new house. We got her a nice little house in the same area, 2 bedrooms, and garden. My brother would go down to town, buy her fish and chips, give her money for the week, put a little bit by, we bought curtains and blinds and carpets; there is nothing she needed to worry about in terms of comfort. And yet she gets ill, goes into hospital, and that's the thing, the hospital never told us they had taken her off her medication, so we were doing all this, getting her into a nice stable situation and because of client confidentiality they said "oh you seem quite well, we will take you off your medication" and nobody told us, so we didn't know and then gradually she got more and more ill;..... sectioned. She goes to a tribunal and they said "oh you don't have to take medication if you don't want to; you can choose to make ill - advised financial decisions if you want; off you go" and since then she's been going downhill; absolutely downhill. She sold the house. I think that was the turning point really. We put so much effort into that house and we used to go and visit her, we'd go and see mum, go on the pier, go on the beach. Then she moved to some strange place. She was in bed and breakfast for a long time before she found somewhere she was going to live, so since then, I mean the effort we put in to maintain her, we've all been well intentioned, it's, I don't know, it's been to no avail really" (Jo)

Jo continues her story with the pattern which has now become established;

"Basically the pattern has been that every 4 years she gets sectioned. She sold the house and moved to another house nearby, sold that and moved on again, and each time she moves she loses money and makes inappropriate

decisions and she is in danger now of becoming homeless. Because all the money that was in the family house has gone, and there's nothing we have been able to do about it even through Power of Attorney. All the legal stuff we've looked into; we've battled for years. And it's just a nightmare really. So now she has sold, bear in mind she had a 2 bed roomed house with a garden; she has now got about 50 thousand pounds left. She sold the last flat and she is living in a B&B somewhere'' (Jo).

The stories Cathy and Jo in particular show how hard they have tried to help so that their mother's lives are as normal as can be. Both of these women describe their parents coming off their medication and how this precipitates a further breakdown. Both of these women also describe the warnings they gave to services which were felt to be unheeded.

In addition to the obvious stresses and crises, highs and lows, endured by the participants in the preceding stories, there is also a horizontal trauma effect. This means that the relationship is also increasingly traumatised. There is a need to set the scene with some theory before showing the effects in the participant stories.

Problems of self-coherence relate to psychosis exclusively. A person's experience is as if there is no longer a sense of wholeness with physical and psychical boundaries. Wholeness becomes distorted and the dissolution of psychic boundaries can lead to the experience of fusion or merger with the other (Stern 1985). The challenge for a child who has a parent with psychosis is twofold. One; is that they have to learn to distinguish between the parent's version of reality and the evidence. From a family therapy background, Day (2009p 141) writes;

“Values, ideologies and schema about the safety of the world include the nature of reality and this is part of the system of family functioning into which the child is socialised”.

For example, the nature of reality was not questioned by Jo in the previous story when she was asked to examine her mother's back for burns, even though she knew she would find nothing. And two; is that they have to also navigate an appropriate closeness so that connection is maintained but at a safe enough distance to avoid becoming engulfed into the parental pathology. This is an extremely complex task for the child by virtue of the attachment. Ruppert (2008 p52) explains that

“A child's love for its mother is “indestructible” because the more the child senses the danger of rejection; the more he clings to her”.

Overuse of denial as coping mechanism can leave an individual at risk of failing to resist the pathology and in extreme cases a folie à deux may occur (Anthony 1970). Folie à deux is a shared psychosis more commonly associated with marital couples. It is a condition which is more likely to arise in the child if the parent is single (or the other parent is unavailable) because the child is therefore exposed to psychotic phenomena, and is likely to have no other reality with which to compare and mediate their understanding. Children who are exposed to parental psychosis are known to be vulnerable to poor adjustment longer term, and there appears to be an increased risk the younger the child at the time of exposure (Falkov 2004, Hall 2004).

The mothers of Cathy, Jo, Meg, Marta and Anna and Emma's father, all experienced psychotic features which are by nature usually inherently inexplicable to others. Although there is no evidence to suggest the extreme condition of folie à deux in this study, both Jo and Cathy are certainly embroiled in their mothers' pathology. This is shown by their previous stories which demonstrate how their mothers' paranoia became focused upon them. However Anna's story included a tale of her younger brother who was still being bathed and dressed by their mother at the age of twelve. This demonstrates how the youngster was 'going along with' the madness, and could have been at further risk. The discussion by Anthony (1986) adds that the process of folie à deux is likely to start with subtle but nevertheless dysfunctional motivations particularly involving younger or more submissive children.

Five of the AOSMDP in this study have remained in their parent's lives as much as they feel able without feeling overwhelmed or engulfed by the pathology. This has been a difficult balance to achieve at times and necessitates constant assessment both of their parent's health and their own health, wellbeing, willingness and availability. Like a dance in which there are two people who have difficulty assessing the position of each other, and so sometimes pull away too far, but who also sometimes comes too close, and step on each other's toes. Therefore if the AOSMDP is feeling overwhelmed or impinged upon, the need to withdraw to protect personal boundaries to regain inner space and use it to recuperate, is vital for wellbeing. If their parent is overly needy i.e. wanting to be too close, and the AOSMDP is readily available, they may find they do not exist for their parent as a whole person, but only as a function. Maintaining a balance which suits both people between getting too close or too far away is something over which both have little control, because the very perception of too close or too far away is so deeply subjective. This dynamic is played out in every normal relationship, but is undoubtedly more difficult when one person's needs and wants differ from the other. Some people use anger or criticism to create more distance, because they cannot stand the feelings which being close provokes. The closeness which both wants becomes dangerous for one of them. There is little time for fun as the constant monitoring to avoid being hurt takes priority.

Usher(2017), writing about the mother /daughter relationship, posits that if the mother struggles with a lack of self- awareness she may not have enough of a sense of self to allow her child to grow away from her. She may then feel threatened and abandoned by her daughters growing independence. This causes her to cling harder, as she senses the forthcoming separation. Ruppert (2008p 123) adds that it is;

“Often attempts by the child to leave the family home that threaten the family equilibrium and awaken old fears of separation in the mother, while the child feels guilty about leaving the adult to their fate”.

Such muddling of emotions; needs, and thoughts can be so tormenting that total

separation can seem like the only solution. In the end the person who is turned to has become the person who the AOSMDP must get away from. This may contribute to the later onset of schizophrenia commonly found in women as opposed to men who generally develop symptoms at a younger age. Indeed Johnstone (2000) argues that, commonly the first schizophrenic breakdown is precipitated by the threat of separation of a child from a parent (usually the mother); hence when the AOSMDP is a young adult and struggling to establish their identity and separateness from their family. It is the expression of sexuality and anger which are experienced as so threatening to the relationship which has until then been described as unusually close and connected. It is after many years of being a good child that the child rebels and if the adult's whole identity is tied up in the child the prospect of separation is intolerable. Each side becomes involved in a desperate struggle for self-preservation. It is clearly a very complex issue and unsurprisingly, qualitative research on the experience of relational trauma which did not manifest as abuse, or in particular, incest, was difficult to find.

Johnstone continues by adding that this is not a conscious process and is not in conflict with love. It just emerges as confused and contradictory statements. The child is then torn between the overt and the covert messages. If the child wins, the parent will have to face up to the accusation of possessiveness but if the parent wins, the child will breakdown. This, she argues, is the point at which the problem will be located in either the parent or the child.

Each time the AOSMDP's parent becomes unwell, the connection between them is again tested and has to be renegotiated. In time the connection may be renewed albeit with less of their parents 'self' to reconnect with as the distress takes its toll. The AOSMDP may then become increasingly guarded as trust is repeatedly undermined. Day (2009 p 58) says that "stability is an illusion". It is staying on the Rollercoaster without being sick, that is the key.

In the COPMI literature, nearness and distance is a theme which is most clearly discussed by Mordoch and Hall (2008) who discovered that the child learns to 'find the

rhythm and maintain the frame'. This was a grounded theory study based upon symbolic interactionism, and it found that children monitor their parent's emotional state whilst at the same time adjusting their behaviour to match, thus finding the rhythm of the 'dance'. Secondly the child also learns to preserve and gauge an appropriate distance which maintains the frame, and keeps them safe from being engulfed in the parental pathology. Holding the parent at a safe distance they learn how to keep safe whilst maintaining the connection which sustains them. The balance between the two is constantly moving and they argue, must be negotiated with care by the child. They added that despite their seemingly opposing qualities, the two aspects are actually intricately intertwined.

Kinsella and Anderson (1996) studied the coping skills, strengths and needs of AOSMDP and found that adults described 'constructive escape' which as children had included outside school activities for example. This conceptualisation is similar to that of Meadus and Johnson (2000) who described the 'detachment' in adolescents who had a depressed parent, as coping. Maybery et al (2005) also articulated the avoidance and distancing activities of children with a parent with mental distress as a coping mechanism. They however add the caveat that used long term; it could be seen as an unhealthy coping mechanism. What is meant by 'long term' is unclear. Yet children tend also to state that they find their parent's hospitalisation made them anxious and distressed (Mordoch and Hall 2008). Murphy et al (2011) comment on this as an interesting dichotomy, in terms of children who find separation difficult, but who themselves create the distance. Children who resist being engulfed by parental mental distress and who manage to forge their own lives are deemed the least vulnerable (Anthony 1985). It should not be assumed however that children, who are least vulnerable, are therefore resilient. These children may grow up with little or no connections at all.

At least four of the participants in this research appear to be wrestling with issues to do with nearness and distance from their parent. This is a finding which has also not

been well articulated in previous AOSMDP research. Some scholars have explored one or other of these aspects, nearness or distance but rarely have they been seen as related. Sometimes a similar kind of experience is depicted using different language; Foster (2006) for instance uses the themes of 'struggling to connect' and 'seeking control' in her phenomenological research and these constructs of her participants experience represent a similar idea. Struggling to connect, being the desire for closeness; and seeking control, the desire for distance. 'Parental absence' has been found in much of the literature (Knutsson- Medin et al 2007; Duncan and Browning 2009; Marsh et al 1993a), and again points to a similar idea of emotional distance. In Megs' story which follows it is evident that she and her mother are in constant negotiation about how close they are.

"She will be a bit smothering while we are away and you know "stay with me" and we don't go out. "Sit with me" when we are with family. We don't see them very often. The connections she has with her brothers and her dad are fragile I guess and she wants the reassurance of having me there a lot of the time. Usually while we are away I will sort of have her as a captive audience and get the confidence to say "I am not being rude but please stop ringing me every day, I haven't got anything to say you know every day I've got nothing to report!" "I've just been asleep or at work!" Or "don't ring me I haven't got anything to say!" and she's like "Oh, you're not talking, why aren't you talking? you're quiet" and I am like "well I spoke to you yesterday and nothing has changed" so yeah, that's a good way to put it really It's like, it can be quite intense, she will be phoning me regularly because she is unwell and I'm "agghhhhh!"

She can usually just take some extra medication and go to bed for a couple

of hours and it kind of passes but she will phone me if she is really struggling. She does talk about being suicidal when she's having like breakthrough symptoms. She'll say you know" I feel really suicidal today; I am really struggling". But we just talk through it really. When you have a busy day at work and then you get home to a voicemail message saying "can you ring me when you have finished work, I need...." and then you are on the phone for half an hour, forty minutes to your mum who is struggling. At one time she was phoning me every day, I was just like; "mum you are driving me crazy!" "It isn't normal for someone to speak to their mum every day!" And then she'd text you and if you didn't text her back within 5 minutes you'd have another one saying "Hello? Are you going to answer my text?" Sometimes I think she has a lack of understanding that I have a life and I am doing other things. I tell her, I say "mum you are drowning me a little bit" and "you are you know overwhelming me", "please back off a bit" and we kind of have to negotiate sometimes. And I say "give me a text, but appreciate that I might take a little time to reply" "And ring me every third day or something" She's like "Okay, okay"; she will do that for a little while. But she will forget and start ringing me every day again. I am like "mum really... Just back off a bit" Sometimes she doesn't retain it, at least when you do talk to her about it she listens and she does take it on board. I don't think she likes it. Sometimes she will get a bit angry about it and then the next day she will say "I know you are right, I've thought about it and I know you are right, I do ring you too much and I am sorry" And I say to my mum, "Mum I am just feeling a bit

overwhelmed with it at the moment, you know, stressed, like work's really busy and I'm, I'm struggling to cope with your symptoms as well" and she is really receptive to that" (Meg)

Meg has spoken about how she has to repeatedly reinforce the boundaries between her and her mother. Her mother will telephone and text so that it occasionally becomes intrusive and Meg becomes frustrated that it then impacts her life. At the same time she has to monitor her mother's health in case she needs to respond in a hurry. So she is constantly monitoring and adjusting her behaviour towards her mother. Feeling emotionally smothered also creates ambivalence and Usher (2017) believes this is at the heart of the desire to withdraw. She suggests that the ambivalence is tantamount to 'merge or murder'. The findings in this study are more suggestive of the desire for some respite, to survival against being engulfed by psychosis. In Jo's story which follows, her experience appears to be much closer to that of exhaustion and survival and this would echo some of the children in the study by Mordoch and Hall (2008) who stated that maintaining the relationship had become too 'emotionally draining'. It seems clear that the nearness and distance dilemma is one which continues throughout the lifetime.

"A number of years ago I decided to go and see her, but it would take me about 3 days to recover because I'd just be so exhausted. I made the decision I was looking after my children and I couldn't look after her as well. And anyway whatever I did didn't make any difference; so I had to protect myself. So I made the decision I couldn't have any contact with her. But I've been doing what I can in terms of the legal advice and stuff like that. But so it's that I have kind of worked out where I want to be in relation to her, because I feel that I have given an awful lot in terms of trying to make it better.

My mum is always so easy to impress. I got into Oxford, not her, but she has now moved to Oxford and she goes to the college where I used to go and talks to them 'oh my daughter used to come here'. She will talk to the porters and it's that sort of things I can't control, her intrusiveness. And she is always sending me big pictures of paintings of the outside of the college. It is like she is stalking me, it is like that. And then the other day she sent me a card, my husband says I should probably just not read anything (from her) but every now and then I do and she sent me a card saying we are..... she called me her 'other half' You're my other half she said, which I just find really creepy. It's not been that easy to not have contact with her because she will turn up at my house. If she knows where my children go to school for example, she would ring the school. It's just too much. I just can't deal with that level of intrusion. So she's an elderly woman who is quite vulnerable, so part of me thinks "oh I am really horrible. Because I am not helping in any way" but what can I do? I am stuck I can't do anything; its survival" (Jo)

In Jo's story she feels so intruded upon she used the word 'stalked' to describe the experience. Her mother's card to her expressed how close and intimate she felt they are as it described Jo as her 'other half'. However Jo does *not* feel close to her mother, she feels she has to maintain some support and connection in order that her mother's life is as comfortable as possible but Jo is actually now quite estranged from her mother and chooses to no longer visit. This finding contradicts Kuipers et al (2006) assertion that over involved relationships are symmetrical. Ironically their book on family work demonstrates the asymmetry of the problem, as it is written almost exclusively from the perspective of a parent who is coping with a child; just two paragraphs are given to the AOSMDP. AOSMDP are again hidden and forgotten.

The experience of feeling stalked and unable to escape could be seen as having similarities to the experience of hostages who are attached to their keeper (Stockholm syndrome). Adorjan et al (2012) say that the term was first used in 1973 to describe a pathological response in kidnapping or hostage taking situations. It is now used much more widely, in relation to domestic violence, trafficking, cults, etc. It is the power imbalance which is at the core of the condition, which leads to false emotional bonds. The victims' need for survival is stronger than the impulse to hate the person who has created the dilemma. The hostage is kept in a pathological relational system and left doubting their subjectivity and even reality. The keeper believes that the separate subjectivity of the hostage is a threat to their literal or metaphorical survival and must therefore be controlled. Shaw (2014) considers that this is an effect of the deep rooted narcissism which is found in relational trauma. The origins of this stem from guilt or fear about separation leading to intolerance for loss of relationship which means there is a consequent tendency to hold onto the child (Usher 2017). Barber and Buehler (1996) writing from a family therapy perspective, state that family cohesion is a measure of supportive interaction, but enmeshment is a measure of psychological control. The control inhibits the individuation process, and development of autonomy. McCormack et al (2016) in their research on AOSMDP, have described it as a process of ducking, weaving and staying safe.

Dunn (1993) found a theme she called 'Guilt and Loyalty' in which she described the participants as feeling they needed to maintain contact with their parent even though they knew it was not good for them largely driven by deep seated guilt that they had caused or contributed to their parents distress. Usher (2017) considers that this stems from a person's guilt about being born and consequent indebtedness which is the result of the gift of life. She continues that children who hate, or are burdened by guilt, are likely to be adults who feel responsible for the care of their parents, and who are children of parents who cannot let go. Fear and guilt she argues, only arise in those who have unresolved separation issues because breaking free is felt to be disloyal. Guilt has been found in the following extracts from the participants of this

study. How much this has influenced the relationship as adults is unclear.

"I don't know about the future. I will continue with my mum, I will always be there. Only to get kicked down again but to come back up, that won't stop, I will always be there. Because I can't abandon her, I am not that sort of person I just can't do it. I can't walk away. Maybe just hoping that; that glimmer of hope one day" (Cathy).

"I think a lot of it was as we all grew up, and then my dad died, my brother in Australia, the other brother was (working elsewhere) I was the only one here caring for her really. All her family was dying, she got lonelier, lonelier and lonelier and of course I think the loneliness brought more and more depression on. She didn't have no hobbies, she had no interests, she didn't ever go out. Her life was just looking after us and I think once we all grew up it went worse on her". (Anna).

"There was no way I could have her living with me the amount of children I had. I wouldn't have had the room and eventually when it was taken out of my hands. Somebody else made that decision. The pressure was taken off me" (Anna).

"We nursed mother through her illness and became very close doing that, cleaning out the flat and stuff so we both ended up being very solid citizens. That was tricky for me; I do remember I felt really mean after, but I said I am prepared to do this but I want you to know that you're aware I am doing this for you and you did bloody nothing for me. It was really mean wasn't it? Yeah I felt really awful afterwards" (Emma)

“I hit puberty very early at nine but um, we had a lot of conversations leading up to that, she was actually bringing in a lot of her stuff , her fear as well and from then on there was a feeling that the relationship changed a bit and um in the sense that she was no longer coping with me because actually I had really bad PMS and really really dark, dark days and remember being nine or ten and just feeling everything was really dark um, er, and balling my eyes out, I remember mum saying ‘you are making life difficult for me’ “(Sue).

“I have tried to get my dad to consider the Power Of Attorney forms just in case, just to have them ready but he just walked out the room because he couldn’t cope with the thought, it immediately sent him into a huge anxiety state you know so it is kind of like, I am powerless, powerless to do anything. But also I am going through this place of actually I don’t want to be responsible for them so I am kind of feeling the not wanting to and the guilt of not wanting to” (Sue)

Returning to COPSMD research; in the study by Mordoch and Hall (2008) they found children who said they no longer wanted to invest in the relationship with their parents, because they felt they had reached the end of their endurance, and that their connection was putting them at risk. If the child is unable to separate and develop individuality, depression is the only alternative as they remain closely entwined with the parent. This is the child who will not challenge the parent and is non- competitive. Sheehy (2014) considers that the depression is in service of the attachment. One of the young carers in the study by Ali et al (2011p5) articulates this dilemma in the statement that they “sacrificed a good relationship with (their parent) because they were mostly the ones who confronted (their parent about their illness)”.

Ruppert (2008, 2011) writes that the entangled and enmeshed relationships which characterise the lives of AOSMDP are part of the picture of relational trauma. This suggests that the findings of the study by Mordoch and Hall (2008) may also be relevant to adults and indeed the nearness/distance dilemma has been found in several narratives in this study. Ruppert (2008 p118) states that;

“Bonding and trauma are directly connected and splits hinder the development of healthy stable partnerships making loving parent child relationships impossible”

The inclusion of the word ‘love’ is interesting, and has been carefully deliberately avoided by Misrachi (2012) with whom I concur; love may, or may not be part of the relationship.

The course of psychosis in women often becomes progressively worse with age, each subsequent breakdown provides less and less of an opportunity for a full recovery. AOSMDP therefore may experience a gradual pulling away of the connection, much like a broken zip in which both sides gradually tear apart and cannot be completely reunited. Whether love is destroyed in the process, is questionable.

Several of the participants of this study expressed anger with one or both parents. Although anger is a perfectly normal emotion to have in any relationship, this anger stems directly from the distress and as such, is an additional feature to cope with. The following stories acknowledge this anger.

“I used to be angry really. I’ve never fallen out with my brothers over anything, apart from a couple of times over my mum because it was all on my shoulders. Yes they used to come and visit but then they would go away and then you know... I know they couldn’t do anything. One was in (another town) one was in Australia. They had their lives. But I couldn’t move away. No way, I could even think about doing it. I used to think twice even like

having a holiday or not. A lot of the time I hated her. I was always more; praps, cos I was a girl; they say that a girl is a daddy's girl, I don't know if it's true, and when she started being horrible to him and fighting with him and arguing with him, I think yeah a lot of it turned to hate. One part of me wanted her to die, because I thought well you know, it would make my life easier, it will make my Dads life easier" (Anna)

"I also have quite a lot of anger with my mum for not taking her medications, because I feel that it should have been my time now, but she has taken that away and it is not because of her illness, although it is, but she made a conscious decision and a plan that she would come off her meds. Another thing is this kind of genetic thing; I was so worried; I waited so long to have children, and the thought of passing it onto my children. I went to my GP; he said "you and your husband have different genes so it will probably be all right" And so I had my son, and three years later she stopped her meds, so it's loaded isn't it?" (Martha)

"I only remember her taking an overdose once when I was about 14 or 15. I was very angry with her; I had a lot of anger; and a lot of "well what about me? Hang on a minute! I think she'd done it more times when I was younger but I hadn't really been aware of it at the time. I was lucky that my dad; although my parents had split up, my dad never lived more than 10 minutes' drive away but I guess if I hadn't had another parent, it would have been more likely that the care services would have got involved. I think there have been quite a few incidences of overdosing" (Meg).

“I used to put all my anger onto the professionals; some of it has now gone towards my dad because you know I think my dad could have done more in terms of finding us support but also despite his stuff there is something about taking responsibility as a parent as well” (Sue).

“I don’t have the emotional maturity to own my own emotions. So anger is something I can’t deal with appropriately, it comes out as frustrated rages rather than as properly thought through. So I don’t know, I’ve pop psychologied myself I think. I am not emotionally unintelligent, I recognize them, but I don’t express them correctly and I bottle things up” (Emma).

Two of the participants in this study spoke about how they wished for the death of their mother (in one story of Anna’s above). The other story is shown later in this discussion. This of course is the ultimate taboo. Hatred of mother was also found in the study by Dunn (1993). Desire for the end of despair, appears to be at the root of these feelings.

Before moving on to an exploration of the grief that accompanies trauma, it is worth including how trauma is conceptualised in health care.

According to the American diagnostic manual, the DSM 5 (American Psychiatric Association 2016), there are two types of trauma. Type I Trauma is the outcome of a single traumatic episode, usually environmental or accidental, such as an earthquake or car accident. The victim will sometimes go on to develop symptoms of Post-Traumatic Stress Disorder (PTSD) and may occasionally need trauma related therapy to process intrusive images, memories or anxiety.

Type II trauma is the result of an accumulation of traumas, for instance if someone is repeatedly abused. It is usually relational i.e. caused by another human being. Betrayal or relational traumas may also be considered complex trauma, and also involve

abandonment by the primary care giver. Intrusion and Avoidance are both listed as diagnostic criteria under the category of PTSD. There are other criteria which need to be met in order for the diagnosis to be made, and this study is not about diagnosing anyone, it might however warrant further investigation.

The ICD 10 (WHO 2016) does not explicitly determine between types of trauma. The preference in the UK is for language which draws upon stress theories. There is however a category which addresses PTSD brought about by long or short exposure to an event or situation which is deemed threatening or catastrophic. This heralds persistent symptoms particularly when re-exposed to a trigger. Symptoms should occur within six months of the end of the period of stress.

There is now a rapidly growing understanding regarding the causal relationship between trauma and mental health problems, including mood disorders and psychotic disorders. There are several models of the relationship between psychosis and trauma.

In the UK, Read et al (2004) and more recently Hammersley et al (2008) are the authors most commonly referred to. In this study, I chose to draw most heavily upon the work of Ruppert (2008, 2011) who is a German psychologist, mainly because of his ability to think about how traumas become multigenerational. All of the recent models however attempt to rebalance the overemphasis on the biological contributory factors which have predominated for many years. According to Bentall (2003) and the work by Read et al (2004) there are a number of environmental factors which leave a person vulnerable to psychosis. These include childhood abuse, smoking, cannabis, poverty and living in a city.

The link between trauma and psychosis was of course first made by Freud, although this was later reneged. Medical, legal and political professions were still in denial about the prevalence and significance of the problem. It has recently (in the last decade or so) become a topic which is fast gaining credibility and it is now clear that there is an overlap between post traumatic and psychotic phenomena. It is also now clear that

psychotic phenomena are not indications of illness but are understandable responses by the person concerned to deal with overwhelming and extreme experiences.

Much of the research so far has concentrated upon trauma from physical and sexual abuse in childhood. It is however also becoming evident that neglect and emotional abuse also have potential to cause psychosis in later life and are a causal factor in the development of schizophrenia (Read et al 2005). It is also true that many individuals progress through life without developing obvious signs of mental health problems despite severe childhood trauma and this is prompting further work on resilience (Manning and Stickley 2009).

Whilst some of the participants of this study have undoubtedly endured severe stress and trauma, whether they would meet the criteria for PTSD in the UK is unclear. It seems more likely that in the USA, AOSMDP might be seen as group for whom trauma therapies are a treatment option.

In common with other research (Marsh et al 1993b; Rose et al 2002; Smith 2003), this study found much loss and expressions of grief in the participant's narratives.

Interestingly from the COPSMD research, grief is largely absent. It is unclear whether this is because researchers have not asked sufficiently searching questions, or whether it is because it may be too early in the life of child living with parental mental distress, to be able to recognise loss and grief.

I have found just one research study which focusses specifically upon loss in the lives of AOSMDP and that is by Maunu and Stein (2010). Their work is a research study on nine young adults aged from 18-30, and specifically explores loss in relation to 'spiritual struggle and strength.' The study finds that the greater the amount of loss in life; the greater the spiritual struggle. The study is limited in some respects; as the loss is only explored as far as its consequences for one's spiritual journey. Seven of the participants parents are said to have had depression; the other two, bipolar disorder. There is however such a wide range of experience of depression, the impact discussed,

could be misleading. Maunu and Stein (2010) however, found that the losses associated with having a parent with mental distress were wide ranging and not necessarily obvious. They found that the greater the amount of losses corresponded with an increasing level of spiritual struggle, which sometimes impacted the ability to find meaning in their grief. Meaning and its relation to grief is explored further later in the discussion.

Kuipers et al (2006) agree that grief and loss are common emotions in families with long term mental distress; they however articulate just two types of loss. One is loss of the person who was known, and two is loss of the hopes and aspirations held for the afflicted person. This perspective is limited by its inability to see other losses including hopes and aspirations in relation to relationship, and self, rather than for just the individual who is unwell. The complexity of the loss is however discussed by Jones (2002, 2004). These works clearly point to the non- finite loss, experienced by families who revisit their loss, as various life points are reached. So for example, when a person gets married or a baby is born, it highlights the loss. The study by Jones drew upon narratives from thirty four participants, although just one was an adult child.

The doctoral study by Smith (2003 p 127) explored how the experience of being an AOSMDP is considered to have affected the ability to care for the parent. Interestingly she has recognised the loss which is felt by AOSMDP, and accompanied by forms of grief for which she adds, there is no remittance. She ends the study on the following note;

“Bereavement may linger from earliest childhood to the end of the lifetime of a parent who is present, yet not present. Adults whose parents develop Alzheimer's dementia have been said to experience ‘the long bereavement’. By this token (AOSMDP) whose loss of a parent begins far earlier-may be said to experience the longest bereavement”

The losses experienced by the participants of this study are also wide ranging and also

not always very obvious. They have been conveyed here under various headings in order to explore the losses from different angles.

As the child or adult child withdraws from the parent in order to protect themselves they are then faced with the increasingly felt loss of their parent. Not only does the COPSMD and AOSMDP lose the individual, but also, the one person who is supposed to be able to love them unconditionally. To be 'known' by a parent, who can detect fear, sadness and rage, is the love which a parent can bestow. This is the price paid for the withdrawal from the parent, so it easy to see how difficult separation must be. The price of conformity is also high, loss of an authentic sense of self, which is dealt with here in due course. The following stories from the participants of this study convey various sentiments about loss and grief .The traumatic loss is felt by Cathy who describes the impact upon her life, and how that has left her grieving. Note how carefully she differentiates this experience from depression.

"I think one way it has affected me was I never really got that love from my mother that I wanted to have. There was always that feeling of being left, that abandonment that's never left me. It's been tough, really tough. I've had a lot of pain. A lot of pain...; not depression; a feeling of pain inside. I know that she is unwell and I know that. I know she will never be well. But it has just torn our family apart. You know crucified me. I still makes sure she is ok and make contact with the CPN and everything but it still hurts as much as it did. It's Heartache; complete disruption; loss of so much"
(Cathy).

"She never told me about periods, she never told me about birth control, nothing. Never talked, didn't tell me; never, ever asked me if I wanted a bra, cos she never wore a bra. Everyone else wore a bra at school, and I was

thinking, *please* can I have one? I *want* one. Never discussed anything like that. I don't know how I got this, saved up this money but I did and I went up to Woolworths in XX and that was our only sort of shop and I didn't know that bras came in the size you are. I just picked up this bra, one of these torpedo ones with cotton in the lines they had in the old days. I bought this bra and I got it home and put it on but of course it was massive and I thought; I didn't even know they come in sizes! Cos that's how well thick really! Anyway I remember, I had to get some cotton and I puckered it all in so like it fitted me. But I couldn't wash it because I didn't want her to know that I had a bra. I can remember it getting dirtier and dirtier and thinking now how am I gonna wash this? She didn't do my washing for me or anything. And that was like all through my teenage days. Girls coming to school all with their mums and I used to **YEARN** for my mum to come up the school with me. Whereas all the other girls, my mates said "we've been down the shops," and they got measured up for theirs. Like when I started my periods. I never forget that was a Monday. I was going to a church thing in the evening. She had never mentioned anything like that; I mean I didn't know what words to say to tell her that I'd started. You know, I thought, "what do I say to her?" (Anna).

"We didn't do the shopping for clothes together, having our nails painted together or that sort of thing. That is still quite a big loss; huge. That is kind of what I was missing I felt very much, things have been said about me upsetting mum, causing problems so yeah I've been taking on the guilt of causing the problems. One of my biggest regrets is that we didn't have a

mother daughter relationship “(Sue).

“Mother was a ghost. Her personality was translucent. She was not very solid or there, she didn’t have relationships with us. So for example my mother in law is a mother, what I would call a mother. She is involved, she’s interested; she asks questions, even though she is in her 80’s. My Mother in law has always been interested and she was the one who came when I had the children, she came and helped me out and all the rest of it. And when we got married she was the one, my mother was absent from all of that”
(Emma).

All of the participants (with the exception of Meg) spoke about the loss they felt with regard to the relationship they should have had with their parent. Anna depicts the loss with clarity in her story about the bra. A girl learns about femininity from her mother, and what it is to be a woman, and Anna’s story shows clearly how she struggled as a teenager without a mother figure. Her expression ‘I used to **Yearn** for my mum to come up to the school even utilises the language offered by Parkes (1972) in which he states that the person will ‘yearn’ for the lost relationship.

Emma compared the role of the mother (who she felt she never really had) with how different her mother in law is, as she shows an interest in both her and her children. Jo, Martha and Anna also spoke about the lack of a fully present grandmother for their children and how sad that was, particularly when it came to Christmas and birthdays. This corresponds with the findings from the research by Jones (2002) who says that life events and celebrations can reawaken a sense of loss. Sue spoke about how death would have been easier because there is an end point. This supports the notion which Misrachi (2012) is proposing in her thesis, that the grief is disenfranchised, i.e. unseen and invalidated.

“In the first few weeks I remember thinking I hope she dies, because if she

dies then we have got almost like a clean slate....., we can start again. For years I felt hugely guilty for having ever thought that. Over the years I have come to terms with the fact that that was a child's way of trying to find some kind of hope or way out of the situation” (Sue).

“She used to talk to herself all the time. I couldn't not go and see her, but she wouldn't let me in. I used to knock on the door and she used to ignore it. She was stuck. She'd gone” (Anna).

The early demise of childhood was felt by all of the participants in this study and has already been discussed under the heading ‘family dynamics’ in which parentification was considered. The loss associated with this idea relates to the loss of a carefree childhood; sometimes expressed as growing up too fast. Meg mentioned that she thought that she had grown up quickly and this tallies with participants in Fosters’ (2006) study who stated that they also felt they had grown up too quickly. Responsibility and stress curtail the innocence and playfulness which should accompany the child through their early years and into adolescence.

Four of the participants in this study refer to a sense of loss regarding how they perceive their lives should have been. Previously discussed was the idea of the assumptive world (Kauffman 2002) and what happens when this is challenged. The assumed trajectory of our lives is determined by our early experiences which give rise to our assumptive worlds. When these assumptions are not borne out, there is a loss to the meaning of the life which had been anticipated. In the narratives in this study it can be seen how this is portrayed.

“All my friends now are all celebrating their golden weddings and that. I look at them and I think what did I do so....where did I go? My life, was it me? They've still got mums and dads praps alive, and it's all such a loving

family and I think why was ours terrible from the age of 14 right the way through to even now?" (Anna).

"I definitely do worry. Or have done like when I was younger, Will I get it? Won't I get it? Definitely, and I think about my children, having children, I think about it. It skipped a generation with my mum didn't it so; I worry about giving it to my kids. And I have to think about who I have children with, do they have a family history of mental health problems? Like, it would be good if I had children to be with somebody without that in their history at all and then the chances would be a lot less but actually the person that I live with has bipolar! And his mum's got depression so I think well we can't have children! Like 3 of their grandparents are poorly, what are the chances? You know the statistics would just be ridiculous!" (Meg).

"You know it had always been a given that her property would come to me (and the business to her brother) cos I've had, not what he's had. The life of both children at private school, big house, ponies, two holidays a year, skiing in the south of France, you name it. And I have nothing. I lost the lot "(Cathy).

"I recognise it is quite a big challenge to my husband's values and expectations about how life would be as well, but realistically I cannot really work. My energy levels are so erratic that it is best for me not to have commitments to other people. I am pretty convinced that the fibromyalgia is a result of the early trauma and the patterns of behaviour that has set up. I studied psychotherapy but I decided that being a psychotherapist is

about the last thing I should be doing as the course was really, really hard for me physically” (Sue).

Todres et al (2009 p5) writes that health care often adopts a snapshot approach to understanding a person and that the temporal dimension of a past and a future is overlooked. They add that “to be human is to be connected to a sense of continuity” The familiarity of a life trajectory guards against randomness, and so provides a sense of stability and coherence. Continuity is crucial for psychological well-being and personal integration, and underpins the assumptive world, so that the person can predict the likely future based upon their past. The sense of predictability and coherence is challenged when life is so radically disrupted. The participants in this study have all experienced biographical disruption, which for some has led to the asking of existential questions such as who am I now? Where do I fit in?

The disruption of the empathic connection between mother and child contributes to the internal experience of trauma. The result of the empathic bond rupture is incapacity to sustain a connection with the self-i.e., the child then becomes lost itself (Bloom 2000). It is because of this trauma/loss dynamic that the two concepts are viewed as interrelated and cannot be easily disentangled (Herman 1997). Kalsched (2013) writes from a Jungian perspective, that trauma is a spiritual crisis, which brings an interruption to identity. The lost part of the psyche becomes regressed, but the part which is still visible continues to grow, giving rise to the perceived early maturation identified earlier. The true self becomes hidden, and the false self becomes the care taker (Winnicott 1965). The false self describes someone who is attuned to messages from the outside, rather than trusting in, or having much sense of their own inner direction. Emptiness, futility, loneliness and impoverishment, all stem from the loss of a sense of self. It is experienced as a loss of solid ground inside oneself. Without this solid ground it makes it impossible to trust and love oneself, because it is difficult to know what one’s own thoughts, feelings or needs might be. It is therefore a risk that the person will only be able to function in accordance with others’ needs and desires.

Sometimes this may lead to a clinging to another identity, whether that is at work, as a risk taker, or sometimes a victim.

The traumatised and grieving lost self are thought to reside in the body causing psychosomatic distress. If the lost self is the true self and vitality is associated with the essence of self; then it stands that there is a loss of vitality which accompanies the loss of self.

The loss of self which is found in these stories is not well documented by other studies. The process may begin as a baby when the lack of attunement from mother does not allow for a secure sense of self to develop (Stern 1985). If a child is then parentified the process continues with little chance of mitigation. The prediction of a mother's needs and behaviours is likely to be followed by the adjustment of the child's own behaviour (Mordoch and Hall 2008) and is at the heart of parentification, as the child learns to monitor the other rather than experience their own subjectivity. This then leads to the non- recognition of the self or the needs of the self. By not being seen by others, the child then loses confidence in their own separateness, subjectivity, reality and sometimes existence. Emma has given a clear example of this in her description of her 'self'.

"I am very shaky as a person. I think my identity is like a ghost that I walk around, but I am invisible, or only slightly visible to people, I am very shaky as a person. I don't know who I am and what I am doing, and what it is all about, and I don't know who or what. I don't have that golden well to draw on, of self-efficacy. I don't have any inner confidence. I know I can do things and I am a functioning adult and I hold down a job and I've always worked and blah, blah, blah but it is paper thin, and I am very frightened of stuff. "(Emma)

If one loses one's self, then what face is shown to the world? Winnicott's (1965) false

self is the alternative. The person must adopt a mask in order to hide the true but frightened self. The vulnerability and neediness, of the frightened self, may cause them some shame (Dayton 2012; Herman 1997; Ruppert 2008, 2011). A split between the way someone feels on the inside and the way they appear on the outside is maintained at the considerable cost of increasing meaninglessness and decreasing choices. The internal world of ones thoughts and feelings is no longer felt to be legitimate. This is the basis of the invalidation which is described later in the chapter. Anna spoke about her false self and how the mask prevents anyone knowing the real her.

“On the outside I am very, I am the life and soul. But that is just a front because inside that is not how I am feeling. I just put on this outward thing”
(Anna)

From the lay literature on AOSMDP Wasow (2000 p 127) writes that it is “grief without end”. It has been found here though, that it is not only ‘without end’ but also largely unrecognised. Doka (1989) has written about the concept of disenfranchised grief and states that loss can be disenfranchised in two ways. Either the loss is not recognised, for example the loss felt by mourners who were ex partners or divorcees of the deceased person; or the person is disenfranchised, for example a child or an elderly person with dementia whose ability to grieve is questioned. The disenfranchised loss gives way to grief which cannot be openly acknowledged, socially validated or publically mourned. When death is recognised, society gives it a status; the funeral validates the grief and legitimises the sadness. Neighbours and friends send condolences, and time is given for compassionate leave from work. When the grief is disenfranchised, helplessness and shame are the result and may create a detachment and alienation from the self as the person struggles to give words to the experience in order to validate it.

Doka adds that when someone’s grief is disenfranchised in childhood (for example evacuees or AOSMDP) there is a greater risk of self- disenfranchisement in adulthood.

This means that the person does not allow themselves to feel the grief, and so the grief simply continues to persist at a deeper level. When a new loss occurs, it then contributes to the repetition of the pattern and reinforces it. This may be of particular importance for the British given our commonly cited cultural virtue of stoicism.

Doka (1989) continues by saying that the inability to express grief also leaves the person with a deep sense of shame. The person is ashamed at the exposure of their vulnerable or real self because it is not recognised by others, and it is this, which gives rise to self-consciousness and a feeling of exposure.

The term 'disenfranchised' has more recently been contested by Attig (2004) who suggests that the word is inaccurate, in that to disenfranchise something relates to rights, and disenfranchisement of grief is not about rights, but recognition. He states that disenfranchisement of grief is essentially an empathic failure, whereby society fails to see the devastation of a griever whose life is thrown off course, leaving all meaningful connections undermined or lost completely. In the case of the AOSMDP the empathic failure to recognise the grief, serves to compound the empathic failure which caused it.

Grief is a central argument of the work by Misrachi (2012). Her work is a master's thesis which proposes that the concept of disenfranchised grief is recognised in relation to AOSMDP, particularly by policy -makers and counsellors. Her work is a thorough literature review and although it does not add to the empirical evidence base, she has composed a convincing argument.

The concept of ambiguous loss (Boss 1999) has been added to the grief literature and depicts a similar idea. Boss writes that when grief is unclear, it prevents closure and lies at the root of much distress. She continues that the ambiguity of a loss which occurs when the person is still present (most obviously in dementia) contributes to the effect in which the person is lost, but has occasional flashes of return, which raise and then diminish hope again and again. This effect is traumatic, but unlike typical Post Traumatic Stress Disorder (PTSD), stays in the present rather than an expression of the

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past, so true grieving is frozen. Two of the participants of this study considered how life might look if their parent actually died and wondered if it might have been easier. Perhaps this is an expression of the desperate desire for closure which accompanies the ambiguous or disenfranchised loss of an AOSMDP. The process of grief is marked by the vacillation between yearning that which is lost, and wanting to move on to find new meaning without the lost person. This is a normal expression of grief but as Boss (1999) articulates, frozen for the AOSMDP, by the reminder that the loved one is still present.

Jones (2002, 2004) argues that hidden grief is further complicated by ambivalence, which accompanies the ambiguity. He says the ambivalence stems from feelings and conflicting emotions of the family who are attached and committed to their loved one, whilst at the same time may also be angry, disappointed and grieving for the person they were. This complicated loss he says, makes it more difficult for the family to find meaning in their grief.

The term 'chronic sorrow' (Roos 2002) has been used to describe the grief associated with long term loss. Chronic sorrow originates from the literature about caring for people with Alzheimer's disease, and other organic based diseases. Roos (2002) argues that chronic sorrow changes the persons' perception of the world; the world as it was previously understood, no longer exists. This gives rise to a feeling of betrayal and alienation from a world which was once familiar. Whilst this is not inaccurate for AOSMDP, it perhaps does not capture the sense of the ambiguity which accompanies mental distress which the work by Boss (1999), does.

Weller (2015) has developed a framework for understanding the grief which is experienced by all of us by virtue of being human. He suggests that there is also a grief which relates to our ancestors. By this, he means that we carry around with us the pains and sorrow of our deceased families. Undigested grief from the past is carried through the generations and despite the young now living in an increasingly globalised society, they still carry that grief. It is this; he argues which is the cause of much

malaise and hatred in the world today. Although coming from a clearly more spiritual perspective than most of the authors, his thinking does harmonise with the knowledge that grief and loss and trauma have an intergenerational component. This is explored further in the following section.

In common with Marsh et al (1993a) and Misrachi (2012) this study has found that psychic loss and the grieving process, is at the core of the experience of being an AOSMDP and it is this which contributes to the emotional roller coaster.

It's stopped for a moment

Being an AOSMDP gives rise to profound loss. Some of the stories in the preceding section of this discussion also demonstrate complex or relational trauma. This section of the discussion moves into the consideration of the effects of this trauma and loss. Most participants included these thoughts towards the end of their interviews as their stories slowed and became more reflective and collaborative with myself. It was as though the urgency to convey the trauma had not allowed for much thinking space until afterwards. This tallies with the work of Frank (1995), who argues that trauma narratives are hard to hear, because they tend to follow an 'and then' style. From time to time, some of the participants paused and wondered at the meaning of their own story. This was most obvious towards the tail end of the interviews where occasionally I would be invited in to comment either using my mental health nursing expertise, or to offer my thoughts about whether the story was unique, or resonated with other participant's stories. It was as if I was being asked if I could help make sense of their experiences by offering my thinking, so that they might feel less isolated by the extraordinary lives they have led. Grief is a meaning- making experience, and this study has found that it is still a vital process, even if the grief is hidden.

Within this section of the discussion, I have considered a range of topics worthy of further consideration due to the frequency in the narratives. I have drawn upon both the content of the narratives, and also a little from the form of the narrative construction, which I felt added to the discussion. Whist this is not a thesis based upon

narrative form (linguistic analysis) the overuse of particular words and slips of the tongue are both meaningful and interesting and as such it would have been neglectful to omit them.

Physical and psychological wellbeing have been linked to the ability to make meaning in life. It is hard however to explain what it is. Frankl (1963) argued that if a person can find meaning in their suffering, then they will find a way to bear it. Without meaning, a person loses hope and the transformation of personal tragedy into finding meaning, is to find a way to triumph. If the circumstances of a life are not changeable then the person has to change. In order to do so, painful moral and ethical questions must be asked such as “Why me?” “Am I being punished?” “Are my parents blameless?” “Am I obliged to care for them?” “What do I do with my sadness and rage?” “Can any good come from this?” Cognitively the basic assumptions about life’s meaning, its benevolence, justice and sense of destiny are all likely to be questioned in an attempt to create meaning. At a very deep level this may include the person’s religion which may be questioned (Maunu and Stein 2010) or alternatively take on greater significance. In the front of the book by Frankl (1963) is a preface by Allport (p 9) and this states that

“Man’s concern and distress over the worth of his life is an existential crisis not a disease”.

Meaning is crucial to coping and recovery, yet hopes, expectations and experience are rarely considered in psychiatry (Bonney and Stickley, 2008). Johnstone (2000) considers that personal meaning is the first and biggest casualty of the medical model. She takes this further still, and argues that human distress and confusions can take the form of schizophrenia. Writing from a theological perspective Swinton (2001) adds that an increased emphasis on spirituality would offer meaning, care and understanding, which would in some way balance the current quest for explanation and cure. Asking a person questions related to their values helps to elicit meaning. Questions like ‘What keeps this person going?’ facilitate an entering into the experience of the other and

being willing to 'be with' that person on their life journey, understanding rather than explaining. Spirituality and moral questions in psychiatry are sometimes deemed pathological or at best extraneous. Walker (2013 p 67) poses some interesting thoughts relating to death, grieving and meaning. He asks whether grief in itself has become dehumanised as the pace of life gets ever faster. This was a response to grief now having been incorporated into the DSM.

It is the psyche or the self, which is the dynamic life force which keeps the person growing and adapting to life changes. This motivates the search for meaning, which can synthesize the whole personality, integrating the psyche and the soma thus vitalising and permeating every dimension of the person (Swinton 2001).

Frank (1995) suggests that constructing meaning is done by employing various strategies including the construction of life stories which provide meaning when the bad can be transformed to good (redemption stories). To give an example I have included the quote here from Cathy about her participation in this study.

"I dunno why but I just decided the other day to have another look, there is nothing written. I was really quite surprised when I looked there seems to be nothing. There's lots if you are a parent of a mentally ill child, and stuff out there if you are the sibling, um there is stuff out there if your parent is an alcoholic or abuses drugs but.... but there seems to be this massive gap. I just can't believe it! Surely there must be lots of ...people who are mentally ill who have got children. There is barely anything. I rather hoped that things had moved on since I was a child, because there was no support what so ever.. so". (Cathy)

Cathy was not alone in her expression about the paucity of help which has been available for her and clearly linked this with her decision to participate in this research. This way she finds a meaning for herself by her contribution to help others.

According to Frankl (1963) the human being can discover the meaning of their lives through three different ways;

- 1) Creating work
- 2) By experiencing something or encountering someone
- 3) By the attitude shown towards suffering.

The language of the interviews is briefly considered here along with Frankl's (1963) ideas about meaning making by the strategies he suggested.

Metaphor and other literary alliterations are particularly useful in the exploration of meaning. The use of mythical or other imagery can help to convey the intended meaning.

Anna used the term 'battle' liberally throughout her story; Seventeen times in an interview which lasted 90 minutes. Jo also utilised the 'battle' metaphor. The metaphors of 'war' or 'battle' have appeared previously in research associated with AOSMDP (Misrachi 2012). Holloway and Freshwater (2007 B) discuss the use of 'battle metaphor' in storytelling and write that often people with chronic pain or illness describe it as a constant battle or fight for survival of the self. It has also been argued that finding the metaphor 'battle' in a narrative tends to depict a 'chaos narrative' (Frank 1995). The metaphor relates to Anna's internal as well as external world. She has battled to survive, to care for her parents, to keep her marriage together and to raise her children in the face of overwhelming odds and, as will become evident, this has cost her dearly. Frank (1995) suggests that chaos narratives do not lend themselves to empathic relations of care. This is because they are so hard to hear. This is not to say that Anna would not have benefitted from treatment and services, but does raise the possibility that she may not have been able to formulate her own needs sufficiently to ask for help.

Part of what is so difficult following trauma is the inability to find coherence and

meaning in a dimension that is beyond comprehension. Stress, guilt and depression are the result. The meaning making following trauma is sometimes called post traumatic growth. It is the essence of recovery. The recovery model which is currently in vogue in mental health deliberately avoids use of medical and psychiatric language and as such is essentially seen as a meaning making process. It does not assume that the person returns to a prior level of functioning but that they make the best of who they have become.

The ability to find meaning in recovery is similar to the final stage depicted in various models of grief. I show two below to demonstrate my meaning;

1. Kübler Ross (1970) Denial, Anger, Bargaining, Depression and Acceptance.
2. Rando (1993) Recognise, React, Recollect, Relinquish, Readjust, Reinvest.

It is the adjustment to the new environment and new self which is being created; finding new meaning in life, or emotionally relocating.

The difficulty for AOSMDP is the disenfranchisement of their grief (Doka 1989; Misrachi 2012). There is no funeral, there are no cards, and the person being grieved is still present. So if the grief is unacknowledged by the family's denial, the danger is that that the AOSMDP will disenfranchise them self and remain unaware of their grief. This is where the grief becomes frozen (Boss 1999). In some cases it may be that a family dealing with long term mental distress can eventually reach a point of 'acceptance', which may be quite liberating, and facilitative of reinvestment in one's own journey of healing. However the presence disenfranchisement and denial may thwart this process, making acceptance impossible. Additionally whilst trying to adapt to the losses encountered, the trauma is ongoing and may be so for many years. This makes reaching a point of sufficient calm which might enable the meaning making process to evolve, compromised.

Because psychiatry is an inexact science there is a reluctance to diagnose serious mental distress quickly, as the picture can change so rapidly. It is also argued that the

diagnosis of schizophrenia is particularly controversial given the evidence that social factors contribute to the distress. Some mental health colleagues may therefore disagree with the emphasis on diagnosis. However in some cases a diagnosis can help the family to seek information and support. The attribution of disturbed behaviour to a diagnosis can also help lessen guilt and blame within the family. Diagnosis has also been shown to help with being able to separate the symptoms from the person, thus keeping relations intact (Jones 2002, 2004). This does not diminish the associated shock however. The following discussion collates some of the expressions from the participants' narratives which relate to the way in which they start to make sense of their stories. I have first chosen those extractions which best demonstrate the participants understanding or meaning- making attempts in relation to mental distress. Despite my expectation that the medical model would be the primary source of knowledge and understanding, I was surprised by the range of other perspectives offered.

"Someone in the hospital said she had paranoid schizophrenia. That was really shocking because I didn't know" (Jo).

Cathy's experience of being told her mother's diagnosis it seems was not particularly helpful until perhaps much later in her life. She describes the attempts to see her mother despite her diagnosis.

"I knew she was mentally ill but no more than that. My dad had some leaflets on schizophrenia. I had no idea what that was, split personality, that's what people used to say. I had no idea really. Yeah it was incredibly hard and it's only been in the last 10 years that I've gained the insight to understanding of what is wrong with her". So I can try anyway to detach myself; but it doesn't really work that well. There is still the rejection" (Cathy).

Being diagnosed with an illness however brings the family another dynamic, as the normal responses of resentment and anger may become inhibited and excused on the ground of illness. Martha describes here how her family was unaware of the cause of her mother's problems and the surrounding confusion.

"They told me she had schizophrenia, before then I had no idea what was going on, I just thought it was a breakdown and my family just said it was the menopause and that was their interpretation of it all "(Martha).

Sue tells her story about the understanding in her family and how she has later been able to question more deeply how things came to be. She starts by offering her father's medical construction, and then moves on to her own psychological understanding followed by the impact of religion and finally to a systems- based construction.

"I go through phases of being sympathetic towards my father and then angry because what he used to say was "it's a biochemical imbalance" that something had gone wrong in her brain, and of course I accepted that but as you get older you start thinking well that might be, but I am guessing that something might have triggered that! Over the years I thought there's got to be more to it. In a way it almost felt like it was dad's way of coping with it himself; you know it's a medical thing, somethings gone wrong in the brain.

My mum is from a very catholic family so of course that has huge connotations for suicide. She is not actually a catholic herself because my dad led her astray after they got married! I am sure there would have been issues of catholic guilt...which is part of why she became ill. I am pretty certain there would have been some of that in there. I am sure that has

compounded her guilt subsequently and within the extended family there may have been some stuff about that. I am aware of the catholic context as well, behind and underneath.

What has been really interesting is that since my dad became ill actually I've had more of a relationship with my mum. He had a breakdown about 4 years ago and basically for this last four years has spent most of his time in bed with anxiety and depression. He is still my mum's carer but my mum is also his carer. There does seem to be a little bit of a see saw effect sometimes with my mum and Dad, as one gets better the other one gets worse so we will see. Quite frankly over the last 4 years, they have been bloody awful because they haven't seen as I can see it as a system. They are supportive of my mum but they haven't seen that they also need to support my dad. And in turn that is affecting my Mum. How could they not think that actually not helping my Dad is not going to help my mum's situation; to treat them as a unit, I found it incredible, absolutely incredible" (Sue).

Anna also tackles this complex issue with a range of explanations from interpersonal connections to past trauma to biomedical conceptualisations. None of her attempts seem to entirely suffice. Interestingly she finally considers her mother's sense of psychic safety which is quite a sophisticated understanding.

"Now at the age I am now I think why didn't I ask her a question? But she never used to answer. She would never talk about anything, you could start talking and she just wouldn't give you answers or never ever mentioned all what she'd done or felt. Never... just never discussed it. Now there's books and help and the television and documentaries on everything isn't there?

But there just didn't seem to be, and for years we just muddled on through it. Never got anyone involved with it, just put up with her really, and tried to cope as best as we could" (Anna)

"She had had a horrendous life as a child she'd told us her dad had been an alcoholic and lost everything when she was born. She had nothing as a child. They were virtually in the workhouse in those days. They were like begging on the streets and all that" (Anna)

"I am looking at them and thinking obviously (my husband) and I's genes weren't very good together. My Mum and Dads weren't; and we battled, they are battling, and now the grandchildren are battling, and I find that sad. Do you think it's hereditary? Do you think it is in our genes or is it circumstances in life that affects you or? If you get married to someone and you are in love when you get married and it all runs nice, if there is not many problems you wouldn't start arguing and violence and all this would you?" (Anna)

"I cannot sit still and I cannot do nothing. I am always busy, go places, do things, just to keep going. The God send was going to work after bringing a family up. I started work and I had seventeen good years. It was the only thing I think that really kept me sane, by going out into the world, seeing what was out there, which my mum never did" (Anna)

"We would go and visit her and bring her home every Sunday to our house for Sunday dinner. But you know she turned out to be a lovely little old lady from the wild woman she was, quite a nice little Nan really, she was

very sweet and loving. That was quite nice, the last 6 years really. She mellowed and all the staff, she just got on with them, perhaps she felt safe then in those last six years'' (Anna)

Emma discusses a sociological understanding of her father's distress perhaps reflecting her professional background.

"I always felt, looking back on it, you know the sick role business? I think he had to be sick to get out of; he was unhappy, very unhappy where he was so he had to be sick to get out of it; got him off the responsibilities. He could then live on benefits and everything without having to worry about a job. And that legitimized his role of being a man still. I try to be understanding about it because they were only people. They had their own foibles and childcare perhaps wasn't particularly well known. Certainly mum didn't have any role models "(Emma).

Jo articulates the confusion in her mind about the tension between the right to be treated in the least restrictive manner (MHA 2007) and the right to treatment, the balance of which is reflective of the current societal mental health philosophy which has become arguably more liberal.

"That's always been my problem, what the mental health services say to us is that she has a mental illness and it is her human right to suffer the consequences of that illness. However she doesn't have insight into her illness. And those things for me don't tally. In about 2004 she was sectioned. She appealed against her section and they found in her favour; if you could call it her favour. So she was discharged after four weeks, really unwell. She didn't have time for the medication to have an effect'' (Jo).

Some of the participants spoke about their education and career. I had not asked for this information. Interestingly the level of education in this group of participants was exceptional. One participant has a PhD, a further three have a Master's degree and two have a Bachelor's degree. This level of education does not reflect previous findings and the unfulfilled potential which has been previously commented upon (Falkov 2009; O'Connell 2008; Marsh et al, 1993 a and b). It may be that educated people are more likely to come forward for research but even allowing for this, it does seem significant. McCormack et al (2016) also found a high level of educational success in their research and suggested that it may have been a result of recognition that for the participants in their study, education was a way out of their childhood despair. My own thoughts concur with this as if, perhaps there were more connections or a greater sense of being known at school than at home. Kauffman et al (1979) argues that poor performance or alternatively, super achievement at the expense of a personal life, was frequently the result.

In terms of career, six out of the seven participants are professionals. All of the professional group; bar one are in direct health care, the other one is a professional in a health care administrative role. The recruitment for this study did include an email to the local Trust although only two responded from this. Three participants contacted me via online networks. Both the education and chosen career of the participants may reflect a desire for career which might facilitate a meaning making experience. Certainly two participants mentioned this in their interviews. If knowledge is power, then perhaps the search for information both through education and work, is a way of trying to make sense of personal experience. The following quotes show how education and work are meaningful in the AOSMDP's lives.

"I was a very good student; school for me was my safe place. I loved being at school. I am good academically so I wasn't really acting up or doing anything that might require intervention. I was a good girl yeah so! "(Sue)

"I got sent to private college and that was fine with me because home life was really very cold and I really felt there was nothing there for me. I really enjoyed college and I would get jobs in the holidays rather than go home. I was bottom of the class when I got there, there was all this going on with my mother and everything was horrendous and um it was noted that I was bottom of the class but I wanted to be better so I worked my way to become top of the class and stayed there. And my 'o' levels I studied incredibly to the extreme" (Cathy)

"The reason I became a mental health nurse is because of my mum, definitely and that's another reason why I am really grateful for the experiences I've had because I love my job and I am really grateful that I had those experiences and it pushed me into mental health nursing" (Meg)

"I was offered a place at Oxford so there was this kind of disjuncture between someone coming from a family which is completely chaotic, or am I this scholar? I don't know; there is an unreality about it. The two things are surprising because obviously I was quite bright so I've always had that; psychiatric hospital versus Oxford University, they don't kind of marry up. So when I went to Oxford there was always this sense that there were things I had to...pretend about or not admit to. I was offered a place unconditionally on the basis of the interview. I was very good at English but because my A levels had been quite messed up; I never did as well in my A levels as I had hoped. She was ill during my A levels, she was ill during my finals. There's that sense of being quite powerless to fulfil your potential because you've always got your hands full looking after the others. I think

the thing is there is this disjuncture between what we were capable of, what our parents aspired to in some ways but what they themselves kind of undermined “(Jo)

“It’s interesting because I have been quite open about it growing up with friends and stuff I kind of get used to telling it, so it becomes quite normalised as a story, and of course one of my strengths is being intellectual and analytical but that can become a defense mechanism. It’s interesting doing the course and going through therapy again and being reminded that what I went through was traumatic and still is, because I think I down play it and then wonder why I am so insecure! It should be pretty bloody obvious!” (Sue)

In terms of choice of profession this research has a similarity with the findings of the research by Secunda (1997). In her study 26 % of participants were found to be working in the arts and 31% helping professions. Secunda (1997) thought that the arts serve as way of being heard and making sense of life. AOSMDP who were in the helping professions she considered were also making meaning for themselves by bringing an acute sensitivity to helping others. Being able to read cues was a skill of particular note. Interestingly, three of the participants in this study were writing academically, and another was writing poetry and a novel.

In this study, as has already been discussed some of the participants believed they grew up too quickly. In some research this independence has been seen as a healthy coping mechanism which leaves the child feeling grown up and capable (Maunu and Stein 2010; Kinsella and Anderson 1996). The danger is that it may become too easy or convenient to overlook the

“Deep weariness that others cannot understand and which stems from the grief

hiding beneath a veneer of capability” (Bannerman 2009 p 172).

Society can then excuse itself from inquiring further because the COPSMD and AOSMDP are demonstrating seemingly resilient behaviour. Ruppert (2011) however states that resilient people rely on social contact, so it is possible that a lack of healthy connections due to fear of dependency or enmeshment contribute to the commonly referred to independence or self- reliance, which AOSMDP often cite as part of their legacy (Duncan and Browning 2009; Marsh et al 19993a & 1993b; Kinsella and Anderson 1996). Self -sufficiency is based in lack of trust; the person who has no connections with others may also have no connections with self.

In the following story it is clear how Anna is avoiding the reminder of her traumas. She also speaks about the catastrophic psychic trauma which destroyed her faith in the world and her trust in others. The one lesson for her children is ‘you cannot rely on anyone’

“I now I hate rows. I hate when anything comes on telly that’s violent or rows. All the soaps, my friends thrive on them but I hate them, because I’ve seen it all. I don’t need to be reminded. They haven’t seen it you see. To them it’s a laugh and I say, “ no if you are living with someone like that and things are going on, it’s not a laugh to me” I can’t watch anything that’s films that have got any violence in or anything, because I’ve seen so much of it over my life.

I tell my kids at the end of the day it’s still you who’s got to do it isn’t it? I try to tell them that, it’s only you in life who can do it. You are the one who’s got to make the decisions you know? It’s a sad life really, you look back think “how did we get into such a muddle, and a mess? And then I think “we are still here and we’ve come through it” (Anna)

Cathy also considers the impact of independent behaviour on her relationships whilst recognising that it is she herself who has chosen this.

“You’ve just got to get on with it. There’s been no one there to say it’s all going to be Ok. And I have a bad habit and this is probably why; part of my upbringing but I seem to go into relationships; may be my wish to always work hard and provide for my children means that somebody else comes second. I have a partner but it’s very difficult, you know, you’ve been through so much and their life has been fantastic with their parents. They have no concept. I have detached myself from my parents. I don’t need to be destroyed by them any longer as a grown adult. I no longer try to reach out to Dad because; I just don’t want to get hurt again ((sighs)). But I can’t forget. He didn’t help me get where I am. Neither of them did. They just destroyed me “(Cathy)

Martha also included her independence in her narrative and relates it to not being seen. This is the regressed self who is vulnerable which was discussed previously.

“I think that is another thing that is a difficulty now is that I am self-reliant and I don’t ask for help until I am quite desperate. From school I remember not wanting to talk and not wanting to come forward and that. I think it may be about being seen. At home I felt I could not put my needs forward, so I felt quite uncomfortable when I had to do it and sort of even now I feel uncomfortable when I have to stand in front of a group or do a presentation, I have so much anxiety. Something about being visible, it is just a guess” (Martha)

Sue also discusses her independence, although she relates to not being heard.

“It is just kind of fortunate that I have got the kind of personality that has gone right what can I do about it for myself? No one else is going to help me so you know; I’ll pay for my own therapy! Whereas I am sure for other people that is not an option they either can't do it financially or just in such a place they wouldn't think to do that. I have not trusted my own inner voice so that's something I have been working on, to hear it and to trust it. I think that is a lot to with not being heard, not being able to be heard when I was growing up” (Sue).

In terms of current attachment the participant’s marital status was as follows: Four participants were married. Two were divorced and two were in long term relationships. Anna disclosed that her marriage had been abusive. Interestingly none of the participants chose to speak much about their partners or children. Some gave brief outlines, particularly children’s ages. Perhaps they did not think their family lives were relevant to this study or may be that they had too much to say about their early lives that current family set up took less priority.

The last two quotes depict a sense of not being seen and not being heard, both of which have been previously found in the AOSMDP literature (Kinsella and Anderson 1996). The prolonged experience of non- recognition may degenerate into dissociation of that aspect of the self which is seen as valueless or even despised. The disavowed parts of the self, can lead to mistrust of personal reality and an inability to process one’s own emotional states, to reflect on them and own them. The child’s own need for loving recognition becomes shame ridden (Bromberg 2006).

The essence of validation is the process of substantiation or confirmation. An invalidating environment is also found in the narcissistic family in which the needs of the parent system take priority over the needs of the children. The children then struggle to identify their own needs and feelings and as a result, express a need for

constant validation. This dynamic has been expressed using mythology in that Narcissus represents the parent system and echo is the child who tries to gain approval by becoming a reactive reflection of her parents' needs, thus never developing the ability to find her own voice. Echo can only reflect the words of others as it is their primary job to meet parental needs. It becomes easier not to have needs or feelings at all than not to have them expressed or validated (Donaldson-Pressman and Pressman 1994). If a child is not recognised, it is possible that they will grow up not recognising themselves. The following quotes from the participants of this study all allude to or directly refer to this sense of not being validated.

"If there are vulnerable children in the household of course it is going to impact on them. I guess there is something about as a child not having your emotions validated and if you don't get that as a child how you learn to do that as an adult? I remember the day I got my A level results and how devastated I was because I wasn't going to go to the University I had chosen. I can remember I remember sitting on the sofa reading a book and then throwing it on the floor as I was frustrated and upset and my father getting angry with me you know? "It's not the end of the world" and all that. Whereas for me; it was the end of the world. There was no acknowledgement that this was a really important decision for me

“(Emma)

"One thing that came out of that which was really good was that I got into therapy. And that was really very good for me because that was the first time that someone had said 'so what were you thinking then?' What happened to you? And that was a real eye opener. It has always been about her. In some ways people might say 'oh social work, what a rubbish

job to go into given that you have so much scope in your own family! 'But in some ways I am drawn to it because its people who talk about emotions and have more of a language of that kind of thing so in some ways it is quite..... ..affirming' (Jo).

Speaking about her childhood Martha commented

"You know my main role was to look after her and forget about myself. I think also lack of self -esteem and I think that sense of vulnerability that is sort of related to not being validated as a child. (My sister and I) are really close; we talk about lots of things, our experiences. Having my sister has helped me make sense of things and validate each other's experiences. When I was about 21, she became ill again. And then when she went into hospital and the psychiatric nurse for the first time asked me "I am just worried about you and where do you go for help?" I think that was the first time anyone had thought about me and how I was. So it was quite a long time coming" (Martha).

"Not having any say in things, not having a voice, so one of my big things is in therapy this time around has been about the fact I have not trusted my own inner voice so that's something I have been working on, to hear it and to trust it. I think that is a lot to with not being heard, not being able to be heard when I was growing up. Yeah" (Sue)

Jo, Emma, Sue and Martha all discussed the lack of validation in their lives for the experiences they had as children. If there is/was no other to validate the experience, then they are at risk of doubting their own truth. Doubting that something 'really did happen' is a painful state and leads to further isolation and denial as the individual is

left terrifyingly alone and alienated. The traumatised individual needs to see that someone else 'gets it' in order to reconnect from a 'zone of annihilation' characterised by solitude (Bromberg 2011). If a child does not have herself mirrored and reflected back to her, then it becomes impossible for her to know herself and her feelings. It follows that when the child is not mirrored by their primary attachment figure; they are not recognised or validated as a separate being. Development of the self is thus inhibited (Stern 1985). Lack of validation has been found in other AOSMDP work; for example (Gladstone 2010; Kinsella and Anderson 1996) and also gives weight to the traumatic appraisal of the experience. Jones (2002 p 155) states that "The family feel themselves to be involved in a fight over whose voice is heard, whose language is used, whose interests and whose understanding inform the narrative we have about mental illness?" It is possible to add to this, whose needs take precedence? And perhaps even whose lives are most important?

With a family of such complex dynamics, where children may struggle to be seen, heard and validated as separate individuals, it is going to be very difficult for the child (or adult) to not only know themselves but also as a consequence, to live their own life.

Jo and Sue explain how this feels for them;

"It's that intrusiveness that I have tried all my life to keep at bay and then further along being more strict about it and actually in order to have my own life I have got to not see her at all. But I am not even allowed to do that because she still turns up, like she did recently "(Jo).

"I feel like I am coming around and this big heavy black weight is in front of me and every day I am worried about them, thinking about them. I have started to not take on the responsibility to try and make things right which I am trying to do. I said I am not doing that anymore. I have actually just sort of said to them because of my own health I am not going to be able to

support them in the way they might need emotionally and physically. It is not that I don't care but I have got to look after myself. So I am just starting to put some boundaries in place. But it is still quite early days; what I find is if I go and visit my mum, go and see her face to face, that kind of reignites the compassion in me. Then I have to try and remind myself that I need to be compassionate to myself "(Sue).

The links between chronic stress and long term mental health have been articulated by Zubin and Spring (1977). When stress becomes chronic, there is a likely consequence for health. Trauma and grief which is unacknowledged will also find a way to express itself through the body (Van der Kolk 1994).

Emma discusses the impact on her own mental health using her lovely metaphor of the big golden pot to describe where she sees resilience as being held. Sue takes this further and clearly links her physical health condition to her early life.

"I have periods of deep depression, so I get treated for that, every now and then. If it gets too bad, I do go to the Doctor for it. Get the treatment. You know the internal monologue we all suffer from? I have to drown that out because it gets too strong at times. There are times when I can't tolerate silence because otherwise I hear my internal too loudly. The usual, you're crap, you're rubbish, kind of thing, you're worthless. All that sort of stuff which is fairly classic isn't it? And to be honest with you, I don't think I am an unusual woman for this at all. Because I think there's an awful lot of people out there who feel fairly crap really. A lot of us women, our age feel a bit run out don't we? I don't have that big golden pot inside me to draw on, of resilience. My self-esteem is paper thin" (Emma)

"I don't have children, I never wanted children. I never had any kind of feeling maternal instinct. I've gone through kind of 'am I sure I don't want them?' Actually another thing I came to the conclusion of is that I do not want to put a child through what I went through and I know that I am not stable enough to be able to cope with a child. What with my fibromyalgia and the tiredness, that has just shown me that actually children would have been probably about the worst thing I could have done. And of course I have lived in fear of being ill like my mum. So each time I have a breakdown you know that fear of, is this genetic, am I going to end up like her and may be the fibromyalgia is a way of my body preventing that from happening you know it has kind of forced me to start looking after myself. I actually had quite a lot of health problems in my mid-teens. I developed a continuous headache and continuous stomach problems. Looking back it is quite clear to me that it is to do with all the stress that was going on but nobody had picked up on that. The GP was offering me tests and investigations and things but there seemed to be no link" (Sue)

For the past thirty years mental health services have been witnessing the repercussions of childhoods which were blighted by adverse experiences (Anda 2003). Adverse experiences are common and it could be argued that most people do not reach adulthood without some kind of adverse experience. The study conducted by Anda (2003) however is one of the first which has linked serious adverse experience in childhood to the development of Post-Traumatic Stress Disorder (PTSD). This study was a collaborative venture undertaken by The Centre for Disease Control Prevention and Kaiser Permanente which is a managed care consortium in California. Together they identified ten risk factors which are considered 'toxic stresses. These include the following; Childhood abuse; emotional, physical and sexual abuse, emotional or

physical neglect; including parental mental distress. The physiologic responses to childhood adverse experience or chronic stresses may include insomnia, headache, impaired appetite, loss of energy, indigestion, palpitations, and changes in immune and endocrine systems (Sadock et al 2015).

Van der Kolk (1994) entitled his book “The body keeps the score” and this poses his argument that the body will in some way, at some time, respond to the trauma and losses it has endured. Miller (2005 p 124) wrote that

“As long as the pain born of those injuries is denied, there will be someone paying the price in terms of sanity and health, either the former victim or his/her children”.

Awareness of the role of trauma on the development of mental distress has led to increased focus upon the diagnosis of PTSD. It is now considered that when a person is unable to get away from a highly stressful situation, or their survival instinct to run is thwarted, the potential to develop PTSD is increased (DSM V, 2016). AOSMDP are therefore a group who are at risk of the development of PTSD by virtue of growing up with a parent who is seriously mentally unwell. Further complicating the risk profile is the silence which surrounds mental distress. Moving away cannot ensure that the individual separates from their parent because the separation is internal or psychic, rather than being about how close one lives to the other. Some sense of control however, might be gleaned with some physical distance.

Before concluding the discussion, it remains to be said that there is now a growing understanding about the inter-generational effects of trauma and some of the participants spoke about their fears of inheriting a condition as well as passing it on.

“A mother who has suffered trauma will inevitably pass her traumatic experience onto her child in some form, because the human psyche is a multi-generational phenomenon” (Ruppert 2005 P 25).

Ruppert states that fathers can also pass trauma to a child, albeit in a slightly different

way which may account for the comment by Harstone (2010 p 39)

“There is something uniquely challenging in the experience of having a mother with mental illness”.

Anna spoke about how mental distress has taken a toll through four generations of her family.

“I think I could have gone the same way, because it's in me, it's in my children as well which is sad; I've got 5 children; they have all got, in different ways, mental issues of some sort. They have, you know, succumbed to it and also now it is also in the grandchildren in quite a way. Their mum has taken to drink and drugs so they were brought up dreadfully by her. She's suffered in a big way. So I think it affected the children when they were growing up. They are definitely all scarred for what they've seen over the years what with my mum and dad and also perhaps me and my marriage as well. All my children have all had to watch this and see me cope with all this as well through their childhood. I've had hell with them cos they've taken to drink and drugs and violence and fighting. Of course they all remember it” (Anna)

Emma also spoke about the wider ramifications within her family

“My mother's sister is childless, my mother's brother married a woman with manic depression or bipolar or schizophrenia, she has been in and out of institutional care with it. She had two daughters who have really struggled with life and had major mental health issues. My sister's youngest son has poor mental health. He is different and tragically my sister feels

very guilty. She suffers terribly from anxiety’’ (Emma).

All of the participants in some way referred to this intergenerational threat. Some spoke about their fear of developing serious mental distress and some spoke about the concern of passing it on to their own children or the impact upon their own parenting behaviour. This has been found in other research, for example Marsh et al (1993b)

“I thought if I can make it past 44 without doing what she did that would be ok. That’s been the main thing really. At 44, it was kind of at the back of my mind. In terms of being ill, I’ve never thought I would be ill so that I see aliens and all that kind of thing. I’ve always thought that because I know what she does wrong, I am aware of how negative she can be that I am aware of that in myself. I think it was going into therapy that enabled me to have the children. I don’t think I would have felt able to.., So what is going well is my daughter’ who is 17, has just been offered a place at Cambridge and I am not mad!” (Jo)

“I was so worried; I waited so long to have children, and the thought of passing it onto my children..... It was only my GP; he said you and your husband have different genes so it will probably be all right “(Martha)

Despite the reassurance offered by a GP, many AOSMDP chose not to have children. This has been attributed to inability to maintain connections (Marsh et al 1993 a & b) although it seems the fear of developing, and the possibility of passing on mental distress may also underlie the decision making. Meg, the youngest of the participants of this study raised this worry explicitly and also considered the mental health of any partner and how this may raise her risks.

“We have it (schizophrenia) in our family which is another worry, yeah.

When I was gonna do Uni, I really thought about whether I should or not put myself through that, and not flip the switch. Potentially the switch is there you know and I have got to make sure I don't turn it on. My mum was always very good at sitting me down from an early age and talking to me about drugs, and like, "don't do them. Don't do anything that's going to potentially give you this horrible illness". Obviously stress can be another trigger can't it? I never did any drugs for that reason, and I would always be very strong with my friends and if it was offered something. I just said "I don't want it". And I had the confidence to say "no". Ok I am nearly out of the danger zone now, and actually I've moved house and you know I've done Uni and actually work in a really stressful job! And I am alright! I can do it, so I think I am alright, I think. But I definitely do worry. Or have done, like when I was younger, Will I get it? Won't I get it? Definitely and I think about my children, having children, I think about ((sigh)) It skipped a generation with my mum didn't it so, I worry about giving it to my kids. And I have to think about who I have children with, do they have a family history of mental health problems? Like, it would be good if I had children to be with somebody without that in their history at all and then the chances would be a lot less. But actually the person that I live with has bipolar! and his mum's got depression so. I think well we can't have children! "(Meg)

Trauma is a narrative disruption which disconnects the plot or the life trajectory. Van der Kolk & and Van der Hart (1995) discuss how the experience of psychological trauma becomes speechless, as it cannot be organised on a linguistic level, and thus becomes inaccessible to language. They suggest that this is why traumatised

individuals often turn instinctively to poetry, art or writing as they face the problem of reconstruction of their narratives.

According to Kosenko and Laboy (2014), personal growth is inversely related to depression, PTSD, and psychological distress. This means that recovery is a difficult journey whilst still suffering.

After grief and trauma, the cognitive response is to try and keep the loved one present. Carrying on internal dialogue with the lost person (or self) heals the hiatus, so that recovery can begin. The construction of a narrative about the meaning of one's life is an important step in recovery. A person needs to experience subjectivity in the present and understand its links to the past, in order to create a future. Hope is not just cultural, it is central to wellbeing (Sheehy 2014). The past, the present and future anticipated stories, give life meaning. Experiences need to be framed into a logical, coherent and integrated system (Neimeyer 2002, 2005; Kalsched 2013) so that hope for the future can be built upon solid ground over time. A secure foundation therefore provides autonomous choice in the future. Sheehy (2001p 203) writes

“Culturally society has been led to believe that the future will be better than the past. The promise of a bright future provides meaning for the present. Mourning the potential of a better future means mourning the process of creating hope and anticipation”

Loss of expectations and anticipation for the future has been found in this work (see The Ride) and this makes the connections to future much more tenuous.

Polkinghorne (1995) says that it is relationships and connections, through which our sense of ourselves is made and adjusted as time goes by. The feature of time is therefore characteristic of the order of meaning and sequence (Crossley 2000). Narrative competence is compromised when major parts of the self and life remain hidden. This may account for the difficulty in recruitment for this study, and indeed any study of trauma. One must reframe the past to make sense of the present and provide

orientation for the future.

The following few stories show how the participants anticipate the future. There is some hope but there is also some concern.

"I don't know about the future. I will continue with my mum, I will always be there. Only to get kicked down again but to come back up, that won't stop, I will always be there. Because I can't abandon her, I am not that sort of person I just can't do it. I can't walk away. Maybe just hoping that; that glimmer of hope one day.....very doubtful, very doubtful" (Cathy)

"Also knowing that actually I can't either you know if I am going to stay sane then actually I can't offer them much support but then it is a case of what is going to happen? Will there be pressure on me to go down there and do stuff? I am hoping, obviously mum is very hooked into the mental health services down there and probably what would happen if she needed to go into a home she would just go into one of the respite places who have people who live there permanently and then what happens to Dad? I think that is another complication as you become an older adult child of a mentally ill parent. It has become more complicated and it has become more complicated at the same time as me recognising my need to step back and look after myself more. The challenge is massive in a way. I feel a huge amount of guilt around having to say I am not going to be able to support you because I feel the weight of society's expectation. You have to look after your elderly parents. I guess I would say to society "I've already done that looking after my parents and it's burnt me out. I have no energy left to give to them. The irony is that my parents always said that they didn't

want us to look after them. They had to look after their parents when they were old but I am not sure if my parents get that I've already done it. They kind of forget that physically I did that for a long time and mentally I've done it for even longer. Things are changing a little bit so all I can hope is that they will do all they can to support them. There is a lot of hoping going on!" (Sue)

Anna, Cathy and Jo all provided a loving poignant sketch of their mothers *before* the distress became evident. Each of them remembered with tenderness who their mother had been and what life was like for the family before their worlds were shattered. It may not be simply a case of "refusing to speak" about what their parent is like now and an insistence on "harking back to past good memories" (Kuipers, et al 2006p 64) but an attempt to heal personal trauma that underlies the telling of life before the distress became obvious. The attitude expressed by Kuipers et al (2006) can be seen as representative of the criticism that adult mental health is individualistic and does not adequately address the family. This is an important point because this book is written about family work.

Bowlby (1988) suggests that people who have experienced a traumatic loss will attempt to capture that which is held dearly, as a link to a sense of a secure base. Traumatic loss disrupts the continuity of our self- narratives so that our construction of a personal identity is interrupted. The memories of the mothers of the participants *before* they became distressed were offered as a way of reconnecting their sense of continuity of identity, constructively with me. This process underscores a deep and profound need to restore the basic assumptions with which we were born from 'meaninglessness' or fragmentation, to their pre-trauma state of 'meaning' or integration, thus providing renewed coherence and stability. The restoration of a coherent narrative provides the possibility of turning from a passive victim into a story teller with the wisdom of experience. If trauma can be seen as a narrative fracture, it

makes perfect sense that several of the participants in this study spoke about life before their parent became distressed.

"It didn't start till I was 14. Up till I was 14 my mum was lovely and normal. She changed...." Up till I was 14, you know I had the most wonderful life; they were a loving couple you know they used to kiss. She used to stand at the gate, and we used to wave him off to work. So you know, I suppose then at 14 to suddenly see this lady turn into something, if I'd have had her from word go as a baby, I'd have been used to her, but to suddenly see it happen then. I'd had such a nice little childhood, with a happy mum and dad. We went on holidays and did things. In those days we were quite comfortably well off, nicely dressed. We were rich. My friends used to say "oh we used to be jealous of you when you was a little girl cos you always had lovely clothes at Easter and Christmas" (Anna).

"When I look back it was incredibly sad, my mum was a very attractive woman. She was the belle of the ball you know? There was always something going on in the house; we had dinner parties every weekend. I've got a cine of her when she was younger, when I was younger with my grandmother. She was lovely, she really was lovely."(Cathy)

"She was also a grammar school girl and she got a scholarship to the catholic girl's school. Then she met my dad at 19. They were these grammar school kids with a real sense of culture and education in inverted commas. Together they were, she was very pretty, dressed well and that kind of thing, so they had a lot going for them. She was a 50's housewife and she did a lot of reading, she was reading at home and getting us to do

our spellings, when she was more stable. She was very beautiful, a very good looking woman, and she was very much the kind of 50's housewife; all her brood of children, big catholic family, would go off to church, all dressed well, with gloves and hats and that kind of thing. But she became really, really, really ill looking, so she neglected her hair; she used to have her hair permed like the queen, but it got greasy and long, she got really sunken eyes and got really really thin and she wasn't sleeping'' (Jo).

Chapter 6

Conclusions and Recommendations

When I started this piece of research, I started it as a meaning -making exercise for myself. With honesty I can say that the acquisition of an award was secondary to the opportunity to try and make sense of my own past. Like a redemptive narrative (Frank 1995), I also wanted to try and use the experience I have had, and create something positive out of it. I wanted to investigate my own experience, and that of others, so that I might contribute to knowledge, at the same time as create some dialogue about the very real issues which AOSMDP have to deal with, not just for me, but also for others like me, who struggle to find the language needed to express the experience. Perhaps the need for validation of my own grief lies behind this desire.

The focus on the temporal dimension of the narratives, has offered a unique insight to the experience of growing up with parental serious mental distress. As I scribbled down the words that struck me from each section of the narratives, onto flip chart on the kitchen table, I was struck suddenly by how familiar they were to me, in terms of the theories of grief I learned as a student nurse. From the crisis which brought shock, confusion and disorientation through to trauma, loss and grief, followed in some cases by attempts to create meaning and move on. It became obvious to me that this was what I wanted to show.

Writing the thesis brought several issues to a head for me. One was that I needed to acknowledge my own trauma and grief before I could begin to write about it. This took some time and left me shocked that I had not fully appreciated this beforehand. It seemed I was suddenly faced with the thought that actually this is at the *heart* of it rather than simply an aspect of it, i.e. Trauma, loss and grief are central to the meaning of being an AOSMDP.

Like any other model of grief however; the stages are not necessarily sequential. I visited each stage repeatedly over forty years before I came to see it for myself.

It seems to me that along with each participant, I had managed to have some respite and attended to meaning making to a greater or lesser extent before finding myself facing yet another crisis.

The journey of this piece of research has therefore taken me by surprise. Like the journey of an AOSMDP, it was filled with highs and lows and stops and starts. Sometimes I felt on a roll, other times I ground to a halt and needed to put it aside for a while to process what I was discovering.

The final chapter of this thesis draws together the conclusions and recommendations based on the findings of this work.

This chapter integrates the key ideas and suggests some of their possible implications. Recommendations are made for practice, policy and further research, although practice and policy have been discussed together because of the amount of overlap. The limitations of this research are then discussed in terms of both its scope and the personal confines which are more complex for me as a person with lived experience of growing up with a seriously mentally distressed mother. Lastly the contribution to knowledge of this thesis is argued and is followed by some reflections on my personal learning.

What have I shown?

The purpose of this research was to explore the experience of the participants and the impact it had on their lives. The investigation was into the impact participants thought the experience had, or is having on their own lives. The stimulus for this idea was the notion expressed by Shepherd et al (2008) that loved ones of service users who have severe mental distress often have to embark on their own journey of recovery. This made me think about my own life and I wondered how far this related to my own experience. Through years of searching for personal understanding, I knew that there was little published about the experiences of ACOSPMI. So little is known about the lived experiences of adults who grew up, and are perhaps still living with a seriously

mentally distressed parent, that they are commonly referred to as 'invisible' or 'silent'. The intention of this research was therefore to address this gap in knowledge. It seemed to me that the most logical place to start was by asking what it was that people wanted to say about their experiences. Again, from my own experience I knew that being an AOSMDP is likely to persist indefinitely. For this reason I decided that capturing the element of time would be crucial because a snapshot approach would not be able to tell the whole story. Narrative inquiry was therefore selected as the most appropriate methodology.

The findings of this research have been presented to replicate the fairground ride of the 'rollercoaster'. AOSMDP in Foster's (2010) research used this metaphor and three of the participants of this study also referred to their experience using the metaphor 'rollercoaster'. The rollercoaster ride starts either suddenly or as a slow climb and heralds a family crisis as the family realises that its equilibrium is being challenged. Role changes ensue as the family attempts to redress the balance. As the spousal relationship is tested, children may take roles of responsibility far beyond their years. This may be either to protect the parental relationship from further stress or an attempt to step into the gap by trying to support their parents and siblings. Family breakdown is an ever-present threat. Shrouding the family chaos may be a sense of shame and confusion which silences the family members. This may be caused partially by lack of information, but also at a deeper level of stigma and a traumatic inability to speak about what might be going on in the family. This is particularly important for children whose un-well parent is not yet receiving services and children who are being raised in a single parent family. These children are at risk of having their childhoods foreclosed by levels of responsibility for assessing risk and attaining services, which an adult would find daunting.

Many traumas have been spoken about in these stories, some which are the direct result of the distress, such as witnessing the loved one's health deteriorate, and various social ramifications such as poverty and housing issues. Some of the traumas

are however not easy to see, as the family members either move away from the crisis, like a centrifugal force, or cling harder to each other. This is the relational trauma which underpins families in crisis, and has been shown to be a component of several of the participants' narratives. The nearness and distance from each other has to be constantly assessed and renegotiated as time passes. This study shows clearly how relational trauma is experienced as a deep psychic on-going attempt to maintain an appropriate distance; neither too close; which is shown to suffocate, or too distant; which leaves the family member feeling estranged. Siblings in the family may hold opposite positions, which may leave sibling relationships also at risk due to resentment of the others' position. The constant monitoring of safety, both at an internal and an external level, leads to loss in other areas of life; like being on a moving rollercoaster unable to get down and enjoy the rest of the fairground.

The loss associated with being an AOSMDP has been shown to be felt on many levels. Loss of the distressed parent is just one aspect of the sometimes overwhelming losses which are endured. In many cases, loss of the well parent may also ensue. All the participants of this research spoke of some degree of loss of both parents. Sometimes the well parent will leave the family home. Denial, particularly through alcohol, may become an additional problem.

Other losses spoken about in this research include loss of a sense of self, loss of potential, and loss of the roots of security which others may take for granted. Curtailed freedom, dreams, hopes and expectations for self and others in the family are all found in this study. Some authors have described these unacknowledged losses as ambiguous or disenfranchised.

The inability to understand the family dynamics as they evolve and the consequences of serious mental distress leaves the son or daughter also at risk of being emotionally hurt by the parents' inexplicable rejection or neediness. Much of this trauma goes unnoticed, denied or unspoken even within the family. This means the child's feelings and experiences may be left invalidated or unseen. If this continues, the child is at

risk of growing up not knowing who they are or what they feel, and it is often not until later that this becomes evident. Loss of self has been expressed in several ways by the participants of this research. Three participants used the word 'validation' (loss of) to describe the lack of emotional language in the family. Six of the seven participants described their emotions as dismissed in a variety of ways. A secure sense of personal identity is therefore hard to achieve. It may take many years, and some AOSMDP find their way into therapy as an adult, which indicates that felt needs have not been addressed. In this study four of the participants have sought help. It seems that the AOSPMMD has to fight hard to emerge from their early lives unscathed and as such may battle against the development of a victim identity. This is an ongoing fight which may last many years and which some people appear to have managed with more success than others. Ones' natural mental health trajectory has been shown to be largely a result of cultural capital and the early lives of the AOSPMMD have been shown to be riddled with deprivations of one kind or another. The lack of cultural capital influences the amount of social capital as an adult and it is this which maintains well-being. It follows then that the development of a victim identity whilst not prescribed, is possible. This sense of victimhood has been identifiable in some of the stories herein.

Many AOSMDP work in the caring professions, or creative pursuits which enable some healing to take place through finding voice and identity with others, or creatively through language or the arts. It is as though AOSMDP have dual identities. They are in limbo, suspended between two worlds, their internal life known only by them, and the external reality of distress which demands so much from them. This is like the mythological experience articulated by Camden Pratt (2002) earlier in this thesis. It is not the level of stress which is most destructive, it is the inescapability. The dual lives are an attempt to define one's own life, rather than have it defined by mental distress and adopt another's identity.

What does it mean?

If a family member's recovery journey is seen to incorporate healing from trauma and loss, recovery becomes a meaning making process. Grief is a possible outcome of the trauma and loss, but not inevitable. The longer a person maintains denial and dissociation, the less they will be able to grieve for their loss, hence the delay in development of loss awareness. Simple acknowledgement of the underlying grief of relatives has been shown to be helpful.

This study has shown that personal recovery and healing may be facilitated by further attention to meaning and understanding in mental health services, rather than a quest for explanation and cure. If meaning making were given the same status as problem solving, it might lead to a more compassionate work force. It seems relevant here to raise the possibility that all psychiatric disorders have trauma of one kind or another at their root, and recovery should therefore include a much greater attention to trauma and loss. Additionally, it raises the question whether the depression which is complained about by carers and families, may in fact be an expression of grief.

Type ii trauma symptoms are a result of repetitive and cumulative exposure to trauma (DSM V 2016). There can be no doubt that AOSMDP are a group who are at risk of these symptoms. The consequences of unrecognised trauma and grief are that the body will eventually tell the trauma story itself. Additionally, the trauma may be passed from generation to generation. All of the participants of this research commented either upon the possibility of becoming mentally distressed themselves or passing it to children.

Recommendations for practice

Because of the linguistic hiatus commonly found following trauma, it may not be possible for long standing unresolved grief to be resolved through verbal means alone. Greater availability of narrative therapies including art, story and enactment may help to integrate the verbal and non-verbal aspects of traumatic experience. These

therapies are often more widely available in CAMHS but could make a significant difference for service users who are adults suffering the consequences of multiple trauma.

If AOSMDP were more widely considered as a group for whom complex trauma is significant, it may be easier for primary care staff to identify the symptoms associated with it. This may in turn lead to AOSMDP being more widely offered trauma informed therapies. This may indicate that front line professionals such as GP's may be a good group to target.

There has been some attempt to raise awareness at a policy level, and the collection of data regarding parenthood status is now a standard in adult mental health services. Data collection is however pointless unless it is used. A robust system of referral to family services should be prioritised. Five of the participants in this study recall their desperate search for support and information in order to try and make sense of the situation. Identification and referral to a family service would help facilitate this. It has been shown previously that children do not always tell school teachers they are living with parental mental distress. Identification of oneself as a carer is problematic. Schools therefore have a role to play in the identification of these children. Young carers' links, health visitors and school nurses, all need to avoid using the term 'carer' and simply ask "do you live with someone who is mentally distressed?"

Much more support for the partner in families in which there is severe mental distress, might help prevent further family breakdown and supporting the partner as part of a system, will in turn benefit the children. In this research, it was unclear how secure the spousal relationships were before the distress took hold. It is however clear that the onset of distress drove changes in each of the participants' parents' lives.

Emotional support for young female parents is also indicated so that the women can be helped to develop their own identity, which is outside of parenthood. A stronger identity with aims and goals of one's own may help mitigate the sense of isolation which is found to accompany many mothers and which contributes the desperate

clinging found in relational trauma. This of course is the aim of the recovery movement, which facilitates the development of personal life goals.

One of the most obvious findings of this research is the distress of *all* members of the family. Individualistic styles of intervention which are common in adult mental health services cannot help the whole family to regain its balance during a crisis. If patient is a parent of young children, a whole family approach needs to be adopted. A systems-based approach in these families has been advocated for some time but it seems policy has some way to go to catch up.

The promotion of mental health and wellbeing across the life span and between generations requires a broader approach to assessment and treatment, and an incorporation of a preventative and relational lens. Greater focus in nursing on health and wellbeing might facilitate nurses to be more widely involved in creation of policy and services which reach out to the families of those in need. Services to address homelessness and employment are now commonplace but comparatively few resources have been allocated to supporting parents who have mental distress. There have been intermittent attempts to drive forward early intervention programmes such as *Sure Start* although the sustainability of these has been dependent upon the Government priorities. This is a shame because early intervention can prevent the exacerbation of distress and family fragmentation (Heatherington et al 2002).

The study by Heatherington et al (2002) demonstrates how early intervention is culturally led and they suggest, that contributes to the lack of progress in the UK to become more early intervention focused. They attribute this lack of willing to engage early as part of the British culture which values 'minding your own business.' This particularly piece of research was both multi professional and multicultural using small groups of professionals from around the world to discuss how they would manage a three part scenario in which the mother develops symptoms which indicate that she is becoming increasingly distressed. The uniqueness of this study lies in its comparison

between various professionals in various countries, and how different the outcomes are depending upon how this situation is managed. This indicates that further interdisciplinary and multicultural studies can create powerful learning.

All health practitioners, particularly those in primary care, need to feel able to ask searching questions, rather than waiting for people to come forward for help themselves. Practitioners need to pay less attention to the fear of being perceived as intrusive and unwelcome and need to feel comfortable with a more powerful 'state' intervention role in family life. Culturally this will demand quite a shift, particularly for those practitioners who are less confident, and this raises important ideas for education, including greater use of placements in a CAMHS. This would help students who are the care coordinators of the future, to feel more confident to speak to children in both in-patient units, and when visiting unwell parents in the community. Open discussion would mitigate the tendency for secrecy and silence to dominate the family.

Four of the participants of this research discussed how powerless they felt when their parents chose to stop their medication regimes. Each story tells of the participant's distress as their parents' mental health deteriorated, and as a consequence, their relationship also. The participants also articulated how at times, they felt alone with the burden of the risk in their families, sometimes as children. Early intervention services might have been able to help. Service users' right to 'treatment' is out of balance with their right to 'liberty'. Perhaps intervention at an early stage to help with childcare and daily stresses would be more acceptable to people than waiting until that person is desperately distressed and needs treatment.

The age remit for Early Intervention Teams (EIS) in the UK is generally 18-34, so these teams are in a prime position to offer family support. The majority of EIS teams are informed by a behavioural paradigm and many are 'Thorn' trained practitioners, some of whom offer 'family work.' It is not described as 'family therapy' but 'family work' as they do not view the family as in need of treatment, but aim to help the family cope

better with the identified patient. The stress/ vulnerability model employed by Thorn argues that stress only triggers the breakdown, which has a medical basis. Conceptual clarity and personal meaning are lost by declining to address the aetiology, rather than risking the protest which might ensue from the medical profession. The idea here is that if the EIS services adopted a wider remit, and were trained in systemic family therapy, rather than family work, the plight of family members would be addressed at the same time as the service user (Johnstone 2000). The family would need to be open to this kind of intervention and it is possible that it might not be so well received in the UK, or indeed so well evaluated. It is however an area which needs further research.

The social constructionist approach favoured in Scandinavian countries may offer an alternative. 'Open Dialogue' is a standard care whole service approach in Lapland which was developed by Seikkula et al (2003, 2006). It is based upon there being regular network meetings for the clients to which family, friends and loved ones are invited. The regular team comprises of family therapists who work closely with the family network to find a shared language for experiences. The enmeshment of members of the family requires a delicate and sensitive approach to untangle and separate the individual members, so that each person is free to live a life of their own.

Usher (2017) discusses how the aim of treatment of relational trauma, is to separate the enmeshment. So far, Open Dialogue has shown positive findings which need to be researched further. Open dialogue and other narrative approaches both stress the importance of making space for hearing people's experience breaking silences and asking questions of the family. Listening and tolerating uncertainty are crucial especially in the early stages of a crisis when family members are feeling hopeless and helpless (Jackson and Fox 2014). It is engagement with stressful or adverse conditions which creates family resilience. The avoidance shown in some of the stories in this thesis does not. I concur with Braine and Wray (2016) who state that the application of the concept of resilience to families rather than individually, is most appropriate given that adversity affects the whole family.

Recommendations for research

Relational trauma reactions are delayed by the processes of denial, dissociation, secrecy and shame, and therefore tend to take a long time to surface. The delay of grief reactions and the difficulty with which they are recognised has implications for research being conducted with younger age groups. Whilst not wishing to prolong the epistemic injustice (Carel and Györfy 2014) of youth, adult retrospective studies have the advantage of the wisdom and insight that comes with age, and are still comparatively under represented. More research with AOSMDP may help to clarify some of the issues raised in this study and are arguably a more reliable way of assessing the impact of these experiences than studies carried out in childhood. Relational trauma needs to be explored further.

The relationships between recovery, grief and post traumatic growth is still unclear and this needs attention. It seems likely that they share similarities which have yet to be appreciated. Each concept articulates a process which is ever evolving and adjusting to life circumstances. All three have 'stages' which may, or may not be linear. There appears to be a lack of research into complicated or disenfranchised grief, and mental health knowledge and understanding would benefit from more research in this area.

Another area which warrants attention is how far resilience equates to wellbeing. Aldridge and Becker (2003) state that caring for a parent with mental distress can lead to positive outcomes such as resilience and independence. These concepts have been equated with wellbeing. However, in order to be connected to others, which can be assumed to be the primary drive of a human being; a person needs to be able to be vulnerable. Shame, is the fear of disconnection due to an assumed lack of worthiness for connection. In order to be connected a human being has to allow themselves to be vulnerable. Resilience should therefore not be assessed on the basis of work, educational achievement or capability alone, but also upon the ability to connect with others. All but one of the participants in this research discussed how little connection they had with their distressed parent, and sometimes also with their well parent. The

connections were intermittent, but arguably still tenuous. Some of the more poignant quotes were included to demonstrate that the self-reliance often stems from having no one to turn to. This is not a positive outcome for a child or an adult. Skills based research such as coping and resilience competencies may be seen as superficial for this group in particular. Misrachi (2012) adds that they are likely to obscure trauma and that it is better to use the term wellbeing as this has a subjective component. The lack of wellbeing despite apparent resilience was also remarked upon by Marsh et al (1998) who discussed that, adults who lived with a parent with mental distress described outward confidence and competence, which they felt hid an inner turmoil and chaos. If resilience is to be useful at all, it should be perceived as a lifelong process of adaptation and recovery. Further research for AOSMDP using wellbeing as a framework would avoid having to use the contested term of resilience for this group.

There is much potential for further research with AOSMDP. Wellbeing, resilience and self-reliance all need further analysis and understanding due to the AOSMDP's ability to hide their vulnerability, yet who so often seek therapy. Further exploration is also indicated to help identify the most useful ways of addressing the relational trauma and loss which are evident in their stories.

Contributions to knowledge

As far as I am aware, this is the first study in the UK which has explored the experience of being an AOSMDP. It is recognised that there is a small amount of research from other countries which has used phenomenology, grounded theory or questionnaire type methodologies. I believe this is the first to have used narrative inquiry.

This research has identified that trauma; loss and possibly grief, may be part of the recovery journey of adult children of parents with severe mental distress. This is the first UK study to show this. Trauma and loss have been found in other studies mainly from Australia, but have not been previously identified as a central theme to the lived experience. This finding may offer new ways to conceptualise the problems brought to therapists and counsellors. This work has also added new understandings about the

lived experience of relational trauma and enmeshment in the lives of AOSMDP. I was unable to find any previous research on this.

Limitations of this research

One of the limitations of this research is the small scale on which it has been conducted. This obviously means that the findings cannot be assumed attributable to all AOSMDP. The recruitment of participants was difficult and this has also resulted in a limited cultural perspective. Where cultures prioritise communality rather than individuality, it makes the findings perhaps less transferable.

The age and sex of participants and their parents was spread across three decades of Mental Health Care and there has been significant progress in the understanding and treatment of mental distress within this time. This is perhaps most relevant for the inclusion of stigma in this study but also perhaps the availability of community service provision for families with a distressed member. One might hope that children facing these difficulties may be better supported now than the participants were as children.

Completing research such as this alongside having personal experience of the topic has also arguably led to some limitations. Perhaps my personal experience has influenced not only the interviews, but also the interpretation of the data. I have made every attempt to keep bias at bay although I do not doubt that I have blind spots which may be obvious to others. Use of many quotes to show my findings, has hopefully allayed any accusations of bias.

What have I learned?

Using my own experience to guide a topic of investigation was not something I had considered when I decided to undertake further study. Trying to decide what 'my niche' might be, led me down many blind alleys before I eventually settled on a topic I felt I already knew well. I knew it would take some courage, but once I had considered the idea, nothing else would do. I knew from personal experience of searching the internet over many years, that there was little written. Starting from such an obvious

gap in the literature was both an advantage and a disadvantage. It meant that at the same time as having little to guide me, I could design the research with some degree of freedom and creativity.

Because of my own experience, I was sensitive to the warnings of friends and the potential judgement of others. Unfortunately during the first year of this research I had several changes of supervisor. On one level this meant I had the opportunity to think this research through with various academics. On another level because of the nature of the study, I felt a deep need to be secure with my supervisory team because I knew I would need support. Fortunately, once my supervisory team was established, I could not have asked for more.

It seemed logical for me to approach the topic from the participant's perspective. Having worked for many years in mental health, I had a sense of my personal philosophical leanings, although I would not have been able to articulate it to others. I also considered, that by allowing the participants as much control as possible over what they wanted to say, helped to moderate the very real potential for bias afforded by my own experience. For this reason, I had no prepared questions or conscious preconceived ideas about what I might find.

The level of trauma and loss hit me hard. I was shocked and shaken by each participant's story. I had not been as prepared as I had thought. In order for me to write the stories, I had to face my own mixed feelings. This meant firstly I had to acknowledge what the feelings were, and then let them guide me into the experience. I then realised they *were* the experience. This was both a revelation and a relief. I could step back from the stories with this in mind and see them from further away. My first attempts at writing reflected this vacillation between nearness and distance. I found it difficult at times, to use either first or third person. The research journey was mine, I also have my own experience, but I was telling the stories of someone else. The muddle and confusion almost mirrored what I was trying to say. In the end, I tried not to tidy up the writing too much. There was almost a conscious attempt to allow the

reader to become a little lost in the trauma before finding their way back.

Focusing this research on the AOSMDP also fulfilled a felt poverty of my own self. My much loved mother was a powerful woman whose needs, certainly in much of her later life, took precedence over my own. My own voice was quiet and being a nurse meant that my role was to help others. This research has been an opportunity for me to hear my own voice and raise my own ideas to consciousness. This was my turn to speak. Hearing my voice however brought another struggle which was that I faced becoming visible. By writing I am committing my thoughts to paper and here my words may be witnessed and judged by others. It also demands a level of faith in the legitimacy of what I know. As I have a fragile sense of self, writing brings with it a sense of exposure I am not familiar with. I am reminded of Nelson Mandela's' inaugural speech "We are less afraid of our darkness than our light ". I cannot write without being seen and heard. Each time I aimed to send work for approval, procrastination crept in until kind words from my sister encouraged me to click 'send'.

Overall the transformative impact of the research on me has been tremendous.

It was a journey which I undertook to learn more about, and I had not anticipated that I would be so challenged but also so changed by it. Meeting the participants and hearing their stories, was extraordinary and they resonated with me, I am now changed by that. I now understand the trauma and loss which I have experienced and can validate my experience with compassion through this knowledge.

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Appendix 1

Ethics approval



School of Health and Social Care

Research Governance Review Group

Feedback to student and supervisors

Student: Zoe Cowie

Title; Sons and daughters of madness: narratives of journeys through the lives of the offspring of seriously mentally ill parents

Re-review report prepared by: Martin Hind.

Date: 28.10.11

Dear Zoe

Thank you for re-submitting your revised proposal and associated documents in relation to the points raised in your initial report dated 28.08.11.

You have adequately addressed all issues raised; either by way of your advised amendments or, in the case of '*age selection criteria*' and '*eligibility of parents*' through your re-articulation of your original rationale.

Your study is now fully approved to proceed and thank you for taking the time to make these amendments.

Please do not hesitate to contact Martin Hind at RG2@bournemouth.ac.uk if you have

any queries, or need further clarification in relation to the feedback on your study proposal. On behalf of the Research Governance Review Group I wish you well with your study.

A handwritten signature in black ink, appearing to read 'Lee Ann Fenge', with a stylized, cursive script.

Yours sincerely

Dr. Lee Ann Fenge

Chair of School Postgraduate Committee

Appendix 2 Participant Information Sheet

Thank you for showing an interest in my study, please take the time to read the information below.

An investigation into the experiences of adults who have a mentally ill parent

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask any questions you may have about anything that may not be clear to you.

The researcher

My name is Zoe Cowie and I am a Registered Nurse and Bournemouth University doctoral research student.

What is the purpose of the study?

Mental health problems have a profound effect not only on the sufferer but also on those close to them. Relatives must re-evaluate their lives and find new sources of meaning and personal value both for themselves and their relationship. There is some literature in the UK concerning the impact upon a parent of a mentally ill son or daughter and some from a spouse or sibling perspective. What there is from the perspective of offspring, almost exclusively concerns young children. When a child turns eighteen, it appears that research into their experience grinds to a halt.

Shepherd et al (2008) on behalf of The Sainsbury Centre for Mental Health; recognised the recovery journey of the families of those who have mental illness and recommended that mental health services should also facilitate the recovery of the carers and/or close family. In order for mental health services to be able to facilitate any recovery, the stories of these adults need to be heard. Learning more from adult children of parents with mental illness may help professionals to recognise the

implications for family members and in turn, influence their practice.

Would I be suitable to take part?

You have responded to my advertisement in the newspaper to indicate that you would like to know more about this study. If you grew up with a parent who suffered with a mental illness which had symptoms such as hallucinations or delusions e.g.; schizophrenia, manic depression or delusional disorder, are aged 30 or above and would like to be involved in this study, I would very much like to hear what you have to say.

What do I have to do?

I will be offering interviews to approximately twenty people who would like to participate in this study. In the first instance we can arrange a suitable time and date to meet. This appointment will be for a maximum of two hours, either on Bournemouth University premises or at a public place of your choice. Travel expenses will be reimbursed. I will be asking you to tell me anything you wish to, regarding your life since you left home. I do not have a list of prepared questions in the belief that each individual's experience will be unique. It is your perspective on your life I am interested in hearing. I may ask to see you again for a subsequent interview at a later date. I would like to tape record the interviews so that I am able to type them up accurately later. At any point in the process you would be free to withdraw from the study and any personal information you have disclosed would be deleted.

Afterwards you can have a copy of the typed interview if you wish. I will also write a report about the study for the participants.

What are the possible disadvantages?

Telling your story may be very powerful and it is possible that it may cause you some emotional discomfort. Reflecting on your memories may bring them to the surface for you. I will be providing a list of support you may access should you be left

worried or preoccupied by your experience.

What are the possible benefits of taking part?

Sometimes people have found that telling their story is helpful. Having someone to listen to your experience may help you to make sense of it yourself. You may never have had the opportunity for someone to listen to your story before and this too may help you feel that someone is interested in your experience.

I hope the study will be read by professionals and other groups who provide services to support families of the mentally ill so that any struggles and dilemmas can be further understood and appreciated.

Will my taking part in this study be kept confidential?

Please be assured that anything you say will be held securely and in confidence with me and my academic supervisors. All of the information will be anonymised in the collection, storage and analysis of the material. Your identity in my written work will also be protected and specific details like names and locations will be disguised.

What will happen to the results of the research study?

The results will be incorporated into my thesis and hopefully published in journal articles. The intention is to also write a paper which can be presented at conferences about mental health. Your confidentiality will be maintained at all times.

Who has reviewed the study?

This study has been reviewed by the Bournemouth University Research Ethics Committee.

Your decision

It is entirely up to you to decide whether or not to take part in the research. If you do decide to take part, please contact me to arrange a suitable time to meet. I will ask

you to sign a consent form when we meet. Once you have signed the consent form, you can still change your mind and withdraw from the project at any time.

If you have any concerns about how the research is conducted you should contact one of my academic supervisors;

Professor Immy Holloway; R105, Royal London House, Christchurch Rd,
Bournemouth, BH ihollowa@bournemouth.ac.uk or 0117 9264088.

Dr Ciaran Newell (consultant mental health nurse); c/o Kimmeridge Court, 69 Haven
Rd, Canford Cliffs, Poole, BH ciaran.newell@dhft.nhs.uk or phone 01202 492147

Thank you for taking time to read this information sheet. If you are happy to participate in this study, or would like any more information or clarification about the study please don't hesitate to contact me on zcowie@bournemouth.ac.uk or 01202 967345

Reference

Shepherd, G, Boardman, J. and Slade, M. 2008. *Making recovery a reality*. London: Sainsbury Centre for Mental Health.

Appendix 3 Consent form

An investigation into the experiences of adult children who grew up with a mentally ill parent

This study is concerned with how the adult understands and explains the experience of having grown up with a mentally ill parent and how that understanding and explanation has evolved over the lifetime.

Ms Zoe Cowie; Professional Doctorate student.

Contact Details; Email; zcowie@bournemouth.ac.uk. Tel; 01202 967345

- I have read the Participant Information Sheet and had a chance to ask questions.
- I give consent to having an audio recording of myself whilst being interviewed by the researcher.
- I understand that I will not be identified in the study and any information given will be anonymised.
- I am not required to answer any specific questions if I chose not to and have the option to withdraw at any time from the interview or study and the tape destroyed.
- The researcher will retain the tape for a period of two years and then it will be destroyed. The tape will be destroyed in accordance with the Data Protection Act (1998) and the Records Management Code of Practice (2000).
- I agree to take part in the study.

Signature of

Participant.....Date.....

Signature of

Researcher.....Date.....

Data Protection Act (1998) from <http://www.dataprotection.gov.uk/dpr/dpdoc.nsf>

[Accessed 12 Sep 2012]

Record Management Code of Practice (2000) from

<http://www.justice.gov.uk/guidance/docs/foi-section-46-code-of-practice.pdf>.

[Accessed 12 Sep 2012]

Appendix 4 Information for study participants

- **Your G/P** is your first option to contact should become concerned about anything which relates to your own health such as becoming preoccupied with worries or uncomfortable memories relating to your experiences. If you are feeling depressed or anxious your G/P can offer advice and other sources of support such as counselling.
- **East Dorset Mental Health Carers Forum.** This forum website offers a range of local support groups and meetings you may wish to access. The groups are based at a variety of locations across the county and the contact details are listed under each group. Phone number: 01202 481730. www.edmhcf.org.uk
- **The Princess Royal Trust.** This link provides a list of regional groups (although none in Dorset). It does however provide a range of helpful resources such as information on legal and welfare advice. It also offers blogs and discussion forums for carers. www.carers.org
- Marsh,D.,and Dickens, R.,1998. How to cope with mental illness in your family: a self -care guide for siblings, offspring and parents. New York: Penguin Putnam.

This is a very good book offering some words of wisdom and comfort for families of the mentally ill who are on their own recovery journey. It is available from Amazon.co.uk

Appendix 5 Advertisement for Newspaper

Research into the experiences of adults who have a mentally ill parent

One in four of us will experience a mental health problem throughout the course of our lives. There is a growing recognition that families shoulder much of the burden of caring about and for their suffering relative. Little is known however about how the children of mentally unwell parents grow up and what sense they are able to make of their lives. Registered Nurse and Bournemouth University Doctoral student Zoe Cowie is conducting a study to investigate how these adult children feel the experience has shaped their identity. Zoe is looking for volunteers to help with her research into the subject.

She says “There is so little known about the adult child of a mentally ill parent and how much they are able to recover and make sense of their lives. It is important to society that their voices are heard”

“I believe that there is much to be learned about the topic and feel that my research will extend knowledge not only in the academic world but also potentially in mental health care provision in the future”

Zoe is investigating these experiences through interviews where she hopes people will share their journey of growing older with a mentally ill parent. She believes that the individuals will all have a unique tale to tell and as such will allow the participants to tell their story in their own way.

If you grew up with a parent who suffered with a mental illness which included symptoms such as hallucinations or delusions, are aged 30 + and would like to take part in Zoe’s research, please contact her at Bournemouth University on 01202 967345 or write to Zoe Cowie, B412, Bournemouth House, Bournemouth University, 17 Christchurch Rd Bournemouth BH1 3LH / zcowie@bournemouth.ac.uk.

All communications will be treated in complete confidence and contact will not mean

that you are committing to take part at this stage. You will be sent more information before making any decision and will be able to withdraw from the study at any stage should you wish.