Family Stories about Mental Health Difficulties: An Intergenerational Perspective.

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CONTENTS

ABSTRACT

Background and aims: While individual family members' experiences of living with mental health difficulties have been widely researched few attempts have been made to understand how families talk about and make sense of their experiences together. Systemic theory highlights the importance of beliefs in shaping how families respond to difficult experiences and acknowledges that these beliefs may be passed down through generations of the family. However, little is known or understood about how this process happens. The aim of this research project is to explore families' stories about mental health difficulties and to consider how family members' views, ideas, and beliefs about mental health may shape and be shaped by intergenerational narratives. By understanding the process of creating shared narratives and the content that emerges we can gain further insight into families' experiences of mental health difficulties, with the aim of informing clinical practice and improving the support offered to families by mental health services.

Methodology: A qualitative approach was used in this project. A purposive sample of three families where one adult member was accessing mental health services was recruited. Each family was interviewed on two separate occasions and interviews were audio-recorded and transcribed. Narrative Analysis was used to analyse the transcripts with a focus on the content of the interviews and the processes involved in jointly narrating their experiences.

Analysis and findings: To preserve the unique experiences of *each* family their stories are presented in turn before considering the findings that connect all three. Each family section begins with the context of the interview and a consideration of '*who's in the family',* before moving on to the main themes, which varied for each family, and ending with '*interviewer reflections'.* Particular attention was paid to the influence of family interactions on identity construction, sense-making and storytelling. Consideration was also given to the researcher's influence on the co-construction of the interviews and the influence of the wider socio-cultural context. The combined analysis of all three families is divided into two sections: '*The legacy of a label'* and '*What happens when we talk'.* The first of these sections considers how the intergenerational narrative 'it is not okay to talk about mental health difficulties' has impacted on families experiences and how stigmatising discourses are maintained within the families through relational interactions. The second section explores the complex processes involved when families talk and considers some of the factors that influence their interactions: construction of their preferred identity; their positioning by each other but also by their

involvement with this research and by social and cultural discourses; issues of power; the state of their family relationships; and intergenerational beliefs about mental health difficulties. The findings are discussed with reference to the clinical implications, strengths and limitations of the methodology and directions for future research, along with personal reflections.

CHAPTER 1: INTRODUCTION, RESEARCHER'S STANCE
AND LITERATURE REVIEW

INTRODUCTION

> Because all families are unique they each have their own distinctive stories, stories that express the lives of their individual members, but are also something more than simply the sum of those individual lives (Pratt and Fiese, 2004, p.1).

The aim of this research project is to explore families' stories about mental health difficulties and to consider how family members' views, ideas, and beliefs about mental health may shape and be shaped by intergenerational narratives[1]. Through this research I hope to develop some understanding of how these narratives may influence family members' 'lived' experiences of mental health difficulties.

Polkinghorne (1988) writes of people's use of narratives to understand and make sense of the human world. It is my view that like the families that I am writing about, I too make sense of my experiences and the world around me through stories (listened to and told). It would be reasonable to assume therefore that my interest in, knowledge about and theoretical approaches to this topic are inextricably linked with my personal and professional experiences. My aim in the first part of this *Introduction* is to give you, the reader, "narrative knowledge" (Polkinghorne, 1988) which you may use to understand how this project has developed and why I have made certain choices that have influenced the direction of the research. I begin by sharing with you the background to how and why my interest in this topic developed before moving on to the next stage in my journey; establishing a clear theoretical rationale. In the final part of this *Introduction* I will review the existing literature in this topic area before outlining how this project attempts to contribute to an emerging area of research.

My stories

My interest in this research area is undoubtedly rooted in my personal experiences of family mental health difficulties and my later professional experiences of studying psychology and working in mental health services.

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[1] In this research I have used the term 'intergenerational narratives' to refer to stories that have been passed down between generations of the family. By this I mean accounts of events which a person from one generation of the family has told to a person from a different generation and which communicate certain beliefs and values.

My relationship with mental health difficulties began at a young age when they became a regular 'unwelcome guest' in our family home: always visiting unannounced and uninvited; wreaking havoc throughout their stay; stubbornly refusing to leave when we had had enough; and leaving behind stained carpets and broken furniture. Each time they would bring a rucksack full of memories, but not the kind that you would enjoy spending hours reminiscing over, ones that everyone wished could be forgotten or better still undone. The visits became so regular for a time that it was like having a lodger rather than a guest and, being curious by nature (or so I am told), I wanted to know everything about this lodger.

My parents shared with me what they knew and I came to understand mental health difficulties as extreme distress triggered by stressful life events and rooted in past experiences. My choice of career is an indication of how curious I became about mental distress and it is unsurprising that studying for my doctorate has raised as many questions as it has provided answers.

An important aspect of my clinical training at the University of Hertfordshire (UH) has been the use of experiential exercises to encourage reflective practice. On various occasions this has included the use of genograms (McGoldrick, Gerson and Shellenberger, 1999) to think about different aspects of our family history. During these sessions I began to see how certain beliefs persisted across generations of my family and I could see how these beliefs went on to influence family members' responses to future events. In systemic teaching we learned more about intergenerational patterns (McGoldrick et al., 1999) and I became increasingly aware of them in my clinical work.

My personal and clinical experiences have contributed to my view that it is essential to consider people's families when working with them in the context of mental health difficulties. To me it does not make clinical or even common sense to entirely separate service provision into age defined groups. Using genograms in a professional context has shown me how relevant family contexts are to mental health difficulties and how the stories families tell play a significant role in how they understand and make meaning out of their experiences.

I have also seen how beliefs and understanding about mental health difficulties are shaped by societal discourses and how these may be kept alive by passing from one generation to the next in families (McGoldrick et al., 1999). Discourses of shame and stigma around mental health are still prevalent in our society (Corker et al., 2013) and families' experience of living

with mental health difficulties may be significantly influenced by these wider contextual factors.

> If we take the time to understand how members of society use culture to interpret and represent their own and other's lives, we stand to diversify what it means to become who and what we are. In the process, we glean a more culturally nuanced and narratively active understanding (Gubrium, as cited in Phoenix, 2008, p.65).

In the next section I give details of the epistemological position from which I have approached this research. I begin this section by outlining my understanding of social constructionism (Gergen, 1985), the philosophical stance which has informed all aspects of this research. I then give an overview of two theories informed by this perspective that provide the theoretical underpinnings for this research, systemic and narrative theories. In my view these theories provide a useful framework for understanding the processes by which people come to make sense of, experience and influence their world.

MY EPISTEMOLOGICAL POSITION

Prior to training as a Clinical Psychologist I always believed that to understand people you must understand their social context and have insight into their (his)story. This belief has been strengthened through my clinical training at UH which holds central a philosophy of social constructionism and emphasises the importance of understanding people and their difficulties within a social context (UH Handbook, 2012). I now recognise that my own beliefs gave me the freedom to be curious about social constructionism (Gergen, 1985) and eventually to feel aligned to this philosophy. Viewing this topic through a social constructionist lens (Hoffman, 1990) shapes all aspects of the project from the language I use to communicate to the perspective from which I have critiqued the existing literature, the methodological choices I have made and the implications of this for analysis of the data and the discussions that follow.

Social Constructionism

> Social constructionist inquiry is principally concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live (Gergen, 1985, p.1).

Gergen (1985) summarises the key concepts of the social constructionist movement, which assumes that the process of understanding described above takes place through social interactions and is subject to constant negotiation and significant change over time.

Social interactions can take many forms and in constructing their understanding of the world people often draw from a range of sources including: previous experience, existing knowledge, publically available information, first-hand accounts and family and friends views. From a social constructionist perspective it is impossible to separate our knowledge and understanding of the world from our social and cultural context because we are born into a world where the categories and conceptual frameworks that form the basis of our understanding already exist (Burr, 2010).

Berger and Luckman (as cited in Burr, 2010, p.13) summarise the social constructionist perspective that "human beings together create and sustain all social phenomena through social practices" which changes language from a tool to describe things to a form of action which has meaning and the power to create and change things. Postmodern Systemic and Narrative Theories have their roots in social constructionism (Dallos and Draper, 2005; Murrray, 2008) and provide theoretical frameworks that describe social processes and the ways in which people construct their worlds.

Theoretical underpinnings informed by social constructionism

Systemic Theory

> The family is the primary and, except in rare instances, most powerful system to
> which we humans ever belong (McGoldrick et al., 1999, p.7).

The interpersonal nature of problems is central to systemic theory (Dallos and Draper, 2005), a perspective that represents a stark contrast to the psychiatric understanding of mental health difficulties that identifies a problem as diagnosable within a person and treats them accordingly. Systemic theory assumes that when an individual presents in distress they are representative of the family's current struggle with adaptation to their wider context at a particular point in time (Dallos and Draper, 2005). This idea assumes that there is an interdependence within families that connects individual members functioning, a process that Watzlawick et al. (as cited in Dallos and Draper, 2005) termed 'circularities', whereby each person is seen as influencing the other, often leading to a repetitive pattern of interactions (Bateson, as cited in Dallos and Draper, 2005). These patterns can be seen at various levels within the system and may cross generational boundaries or may involve whole family responses to the influence of wider systems.

Dallos and Draper (2005) trace early systemic ideas back to two key theories: Norbert Weiner's Theory of Cybernetics in 1948 (Weiner, 1965); and Ludwig von Bertalanffy's

General System Theory in 1950 (Bertalanffy, 1950). Since then, systemic theories have continued to evolve and during what is known as the third phase there was a move towards social constructionist ideas. This brought with it a recognition of the central role of language in family life and the development of problems, and an awareness of the social and cultural contexts shaping families' and therapists' beliefs. In this respect, Systemic Theory is similar to the families it theorises about in that it has been shaped by, and has adapted to, its social and cultural context. In the 1980s Carter and McGoldrick took Duvall's (as cited in Dallos and Draper, 2005) family life cycle model from the 1970s and updated it with the addition of intergenerational traditions; describing how patterns of relating and functioning are passed down the generations including attitudes, beliefs, values, taboos, and expectations.

In systemic practice the Milan School (Palazolli et al., as cited in Dallos and Draper, 2005) developed the idea that family members' beliefs play an important role in influencing what behaviours are possible for people (Vetere and Dallos, 2003). It is recognised that these beliefs may have evolved over generations and intergenerational patterns often form an important part of systemic hypotheses (Vetere and Dallos, 2003). Genograms are widely used in mental health assessments to develop an understanding of how family systems are organised and to begin to explore some of these intergenerational patterns. McGoldrick and Walsh (as cited in Rolland, 1989) describe how patterns of coping and adaptation are 'transmitted across generations' as family beliefs and catastrophic expectations. This information is seen to provide a useful insight into how a family adapts and copes when difficulties arise and as a result it may be a useful indicator of how mental health difficulties may impact on the family.

Despite this recognition of intergenerational patterns and beliefs about mental health problems little is known about how this process happens and what role family stories may play in influencing the experience of mental health difficulties. It is my view that Narrative Theory (e.g. Murray, 2000; Sarbin, 1986) has something to offer in helping us to understand the ways in which interactions and flow of knowledge, beliefs, values and experiences happen within a family but also in wider social relationships.

> Each member of a family has their own personal stories of their joint journey together and the web of stories, their intersection and weaving together constitute family life (Dallos and Draper, 2005, p.10).

Narrative Theory in Psychology

The study of narratives has its roots in the literary field (Riessman, 2008) but many of the social sciences now take a keen interest in exploring the importance of narrative in everyday life. While this has brought a depth and richness to the study of narratives it has also created uncertainty and at times confusion over how narratives should be defined. For the purposes of this research I have drawn from Narrative Theory in psychology for my definition of narratives:

Polkinghorne (1988) defines narratives as "organizational schemes expressed in story form". Riessman (2008) expands on this definition by describing how the speaker uses the story form to give meaning to events by carefully selecting and organising events into a sequence. A process which also involves "attributing agency to the characters in the narrative and inferring causal links between the events." Murray (2008, p.113).

While it is useful to be clear about what is meant when using the term narratives perhaps of greater interest are the psychological theories on the function and use of narratives in everyday life. The 'narrative turn' (Murray, 2008; Riessman, 2002; Kreiswirth, 1992) is a phrase that has become widely used to describe the period when the human sciences became interested in the study of narrative. Psychology was one of the disciplines included in this and Murray (2008) identifies a book edited by Theodore Sarbin (1986) *Narrative Psychology: The Storied Nature of Human Conduct* as the first key text in the development of Narrative Theory in Psychology. Murray (2008) summarises the position Sarbin took on the importance of narratives: "Narratives are not just ways of seeing the world; we actively construct the world through narratives and we also live through the stories told by others and by ourselves – they have ontological status (p.112)."

This view of narratives as part of the essence of being is shared by Bruner (1990), who viewed personal narratives as a way of constructing reality and making sense of life experiences by connecting people, events and feelings. This meaning-making process is considered to be a central function of narratives which helps people in bringing order to disorder (Murray, 2008).

When considering the meaning-making function of narratives it is important to acknowledge that "narrative accounts are not emitted in a vacuum" (Murray, 2008, p.116). By their nature narratives are socially constructed and therefore dynamic, the (told) narrative and the meaning may change over time and according to the audience. As Riessman (2008) suggests narratives

are "composed for particular audiences at moments in history, and they draw on taken-for-granted discourses and values circulating in a particular culture (p.3)."

Josselson and Lieblich (1993) make the point that in telling stories we are constantly drawing on previous knowledge and experience, much of which has been derived from the stories of others. This process begins when children are socialised into the ways of the world by their families, through the art of storytelling, and in listening to these stories they also learn how to narrate their own lives (Pratt and Fiese, 2004).

> According to narrative theory (e.g., Murray, 1999; Sarbin, 1986) we are born into an already storied world and we live our lives through the creation and exchange of narratives (Murray, 2008, p.113).

In recognising the role of families in socialising children we can begin to see how stories may connect the generations in a family and how the beliefs, values and understanding of the world may pass from one generation to the next (Fiese et al., 1999; Bamberg 2004).

Coherence has been given a very powerful status in the study of narrative to the extent that some researchers view the development of a coherent account as the central function of narrative and vital to human sense-making. In recent years questions have been raised about the importance of coherence and Hyvarinen, Hyden, Saarenheimo and Tamboukou (2010) in an introduction to their book *Beyond Narrative Coherence* provide a useful summary of the history of the concept and more recent indications that the idealisation of coherence has restricted the lens through which narratives are viewed and in some cases has meant that researchers have overlooked or dismissed data which did not conform to the ideals of how a narrative should be.

SETTING THE CONTEXT: WHY FAMILIES?

> Excellent children's services and excellent adult services are not enough in isolation. To transform life chances and break the cycle of disadvantage, services must go further. They must 'think family' (Cabinet Office, 2008, p.4).

In 2007 a government initiative called 'Think Family' was developed in response to the findings of the Social Exclusion Task Force's review of families at risk. The Task Force produced two reports which give details of their review and recommendations: 'Reaching Out: Think Family' (Cabinet Office, 2007); and 'Think Family: Improving the life chances of families at risk.' (Cabinet Office, 2008).

The review was based on analysis of data from the Families and Children Study, a longitudinal survey commissioned by the Department for Work and Pensions to look at the social circumstances of families with dependent children. Within the two reports the Task Force identified that 140,000 families were experiencing entrenched problems (including mental health difficulties) that were at times being passed from generation to generation. It was identified that the support these families were receiving was often poorly co-ordinated and failed to take account of wider family problems.

In the 2007 Report the Task Force identified the impact mental health issues can have across the generations in families and recognised that the current structures of separate adult and children's mental health services can leave services under-resourced to consider the needs of the whole family. In the 2008 Report they outlined how services at every level should be considering the needs of the whole family and, where appropriate, sharing information, completing joint assessments, and working together to ensure that service provision considers the needs of the whole family not just the 'identified patient'.

In addition to the 'Think Family' initiative the importance of families is recognised by the National Institute for Health and Clinical Excellence (NICE) who recommend family therapy and family based interventions in a number of clinical guidelines. In 2012 the Association for Family Therapy (AFT, 2012) produced a document that provides a summary of all the NICE recommendations that include family based intervention. Twelve clinical guidelines for mental health and behavioural conditions were identified as recommending family interventions and a further twelve were being drafted which make reference to family based intervention.

LITERATURE REVIEW

Over the past 20 months I have systematically reviewed the literature using key terms relevant to this study. Full details of the search strategy are included in Appendix A, p.100.

Illness Narratives

While it is beyond the scope of this research to review the extensive literature on illness narratives, it is useful to consider why this field has developed and what we might learn from it for researching people's experiences of mental health difficulties.

> The call to narrative within medicine has been a call to humanise the practice of clinicians, and even society as a whole, by looking beyond the disease or the narrowly

construed clinical case to see the "patient as person", one who experiences the disease and inhabits complex social worlds (Mattingly, 2004, p.73).

In the 1980s Kleinmann began using narrative research to demonstrate that treatment in physical health care settings was more effective if the patient's narrative was understood by the treating clinician. Medical treatments and recovery from illness are generally dependent on attendance at appointments, compliance with medication regimes, and/or making lifestyle changes all of which require a motivated self. And yet the sense of self is frequently perturbed by the illness experience (Charon, 2004) and the life issues it raises: hopes and expectations for the future; unfulfilled ambitions; questions about mortality; and loss and grief. Charon (2011) highlights the dilemma that "therapy for illness is probably not effective without the true achievement of human contact" (p.37) and yet this is seldom achievable within the structure of medicine. In talking of the importance of human contact Charon (2011) is connecting with Kleinmann's (1988) ideas about the need to understand each individual's unique illness experience to treat them effectively.

Kirkpatrick (2008) describes how people use narratives to find meaning in and make sense of illness experiences within the context of their lives. Mattingly (2004, p.73) writes that for some people when they experience chronic illness their personal identity becomes "intimately tied to the pain, uncertainty and stigma that come with an afflicted body" (Mattingly, 2004, p.73).

This links to a paper that Weingarten (2013) has written about her work in helping couples live with chronic illness. She talks about the process of socially constructing the self through interactions with others and highlights how in chronic illness the number of people the self is negotiated with can gradually decrease. Weingarten (2013, p.87) warns of the "potential for a distorting hall of mirrors" to be created, thereby disrupting the 'self'-narrative. In reading about Weingarten's work I was drawn to thinking about some of the people I have worked with and the relevance of these ideas about disruption to the 'self'-narrative for people living with mental health difficulties.

Ii is important to consider how social and cultural discourses may impact on people's responses to illness and that this may vary significantly depending on the illness. For example, the stigma associated with lung cancer, prostate cancer and breast cancer has been shown to impact on people's ability to adjust to the condition (Else-Quest, LoConte, Schiller and Hyde, 2009). Stigma is often associated with feelings of shame and can lead to a reduction in social

interaction and disruption to the self-narrative. As will be discussed later in this literature review, the stigma associated with mental health difficulties can have a similar impact on the disruption of the self-narrative.

Family Narratives

Pratt and Fiese (2004) in their book *Family Stories and the Life Course: Across Time and Generations* produce a useful introduction to the different ways in which researchers have approached family narratives. They identify three different uses of narratives in research: method, medium and meaning-making. Method refers to the earliest use of family narratives as a method of exploring relationship qualities or family dynamics. The narratives in this instance being regarded as a source of information relating to these topics rather than an active part of the process. Medium refers to the study of narratives as an important part of the process of socialisation and the "practicing" of family life. Finally, meaning-making refers to the study of narratives for understanding how stories are used by individuals and families to make sense of their experiences but also to develop a sense of self and personal identity.

Following the narrative turn and a rise in the interest in personal narratives a group of family researchers, who named themselves the Family Narrative Consortium (FNC), came together over their interest in how narratives may be used by families to make sense of their social world, regulate their social interactions and to share representations of relationships with children (Fiese et al., 1999). They were also interested in how "the process of interpreting family behaviour may be carried across generations, providing links between the family of origin and current family functioning" (Fiese and Sameroff, 1999, p.2). The research group focused on narrative form and were trying to develop a "multidimensional coding scheme that would allow for the reliable coding of family narratives" (Fiese and Sameroff, 1999, p.4). This was an important piece of research which attempted to develop a formal structure for investigating family narratives. While many of their findings were inconclusive they did demonstrate that Narrative Coherence and Narrative Interaction (See Fiese and Sameroff, 1999, pp.7-16 for detailed descriptions of each of these dimensions) had reasonable internal validity and that further research was warranted.

Intergenerational family stories have been cited as playing an important role in various aspects of children's and families' development. Researchers have written about the various functions of stories in family development: teaching behaviour and values (Koenig Kellas, 2005); helping children learn to become narrators (Pratt and Fiese, 2004); aiding in the creation of a

personal identity by helping family members to integrate lived experience with meaning-making processes (Fivush, Bohanek and Duke, 2005; Pratt and Fiese, 2004); helping to create family identities and a family culture (Koenig Kellas, 2005); and carrying messages so children and adults learn from them (Pratt and Fiese, 2004).

Kellas and Trees (2006) identify how families develop a "shared system of beliefs for understanding their environment" (p.53) and that the stress triggered by difficult life events can disrupt this and offer them a chance to construct new beliefs. In relation to mental health difficulties families' beliefs and explanations are typically formulated from previous experience and wider societal discourses, including professional and popular understandings of mental illnesses: medical, individualistic and interpersonal theories. These explanations subsequently guide families' responses in terms of reaction, actions and attempted solutions. Dominant family beliefs may be passed through narratives from one generation to the next and may be crucial for understanding how behaviour is understood and how 'normal' behaviour can become pathologised into an illness narrative.

Families and mental health difficulties

For some people, whether they are seen by mental health services and receive treatment is initially dictated by how the people around them respond to their distress (Goldberg and Huxley, as cited in Dallos, Neale and Strouthos, 1997). Walsh (2003, p.3) highlights the importance of the family when a person is presenting with mental health issues in reminding us that "serious crises and persistent adversity have an impact on the whole family" and the potential to "derail the functioning of a family system", while family processes also have the potential to "mediate the recovery of all members and the family unit".

Families' responses to distress are influenced by a wide range of factors one of which is likely to be their prior experiences of mental health difficulties, which may be told as stories across the generations. Dallos et al. (1997) cite three factors that they consider to be significant in influencing how a family respond to and understand mental health difficulties: cultural shared beliefs and narratives; emotional processes and attachments; and interpersonal processes. I will now expand on each factor.

Culturally shared beliefs and narratives form part of families' explanations and are based on their "internalisations of competing professional and popular conceptions of mental illness" (Dallos et al., 1997, pp.374-375) be they individualistic, interpersonal or medical. Each explanation leads to different actions: an individualistic view may lead to families searching

for an explanation or blaming the person and seeing them as "weak or inadequate" (p.375); an interpersonal explanation may lead to family members feeling guilty and becoming distressed themselves; and a medical explanation may position family members as carers and the person labelled as ill may be seen as "sick, incapable and not-responsible (Johnstone, 1992; Kleinman, 1988)" (p.375).

In talking about emotional processes and attachments Dallos et al. (1997, p.376) refer to cognitive theories and their notion that intense emotion leads to distraction by internal sensations, which negatively impacts on the person's ability to think. They go on to describe how the level of emotion in families may relate to attachment patterns from the parents childhood which contribute to beliefs and expectations about relationships.

Finally, with respect to interpersonal processes Dallos et al. (1997) describe a pattern in which a family member is distressed or unwell and in an attempt to help them family members inadvertently make the problem worse by making the person feel 'inadequate' or a 'burden on others'. These feelings of helplessness can lead to further distress and as the person becomes worse rather than better this leaves family members frustrated. Dallos et al. (1997) go on to describe how eventually the person becomes differentiated from the rest of the family and becomes rigidly assigned to the "deviant [or ill] position" (p.177).

Dallos et al. (1997) conducted a study in which they compare interviews with a group of people from a clinical population where difficulties have evolved into serious problems with those of a non-clinical population where difficulties have not been pathologised. The researchers were surprised to find that both the clinical and non-clinical groups had experienced problems of a similar severity and four of the eight non-clinical participants had received some form of psychiatric assistance or counselling. Dallos et al. (1997) considered this finding in connection with mental health literature and concluded that "most, if not all of us experience some difficulties in our lives which constitute a crisis and which, 'but for fortune', could lead us into more serious 'mental illness'"(p.394). Fortune in this respect refers to the personal, interpersonal and societal factors that may conscript people into pathological identities or offset the escalation of problems. Dallos et al. (1997) identified that support, positive relationships and the ability to "contemplate positive, validating and constructive conversations and interactions with others" (p.395) were all factors that could help to prevent problems from escalating. Conversely, rigid explanations for the problem, the involvement of psychiatric services at an early stage, reduction in constructive interaction and

designation of their inner thoughts as 'deviant, odd or mad' were all factors that led to long-term involvement with mental health services.

While the authors (Dallos et al., 1997) acknowledge the many limitations of this study the findings are very interesting for considering why some people's difficulties come to be pathologised while others are coped with in the course of their everyday lives. There are significant clinical implications of this study in terms of the potential for services to collude with 'pathologising practices' rather than supporting their discovery of alternative narratives.

It is frequently acknowledged that considering how individuals are influenced by and influence whole family processes is a significant challenge (Fiese and Pratt, 2004), but one that is very relevant in understanding how families construct, experience and learn to cope with mental health difficulties.

The perspective of the family on the experience of mental health difficulties has become a more widely researched topic in the last fifteen years. Qualitative research methods have been used to explore people's experiences of living with and/or caring for a relative with mental health problems. These studies have generally focused on the experience of individual family members that share a common perspective or role: person with the mental health problem (Gaillard, Shattell and Thomas, 2009); carer (Askey, Holmshaw, Gamble and Gray, 2009; Ayres, 2000; Baronet, 1999; Rowe, 2012; Stern, Doolan, Staples, Szmukler and Eisler, 1999); child (See Tunnard, 2004 for a comprehensive review of parental mental health literature, see also; Knutssion-Medin, Edlund and Ramklint, 2007; Maunu and Stein, 2010; Mordoch and Hall, 2008; Stallard, Norman, Huline-Dickens, Salter and Cribb, 2004; Van Parys and Rober, 2012); or parent (Eakes, 1995; Howard, 1997) rather than on the family as a whole. All the studies highlight the long-term implications of mental illness for people's lives and the significant emotional impact mental illness has on family members. They also capture experiences of adaptation, resilience and coping and provide useful insights into some of the factors that may help family members to adjust to such difficult circumstances. This is valuable research for understanding individual perspectives on the experience of living with someone with mental health difficulties but as Stern et al. (1999) acknowledge in their research of carer narratives: **"**To have a complete picture of the "ecology of stories" in which mental illness is inserted, it is essential to consider the narratives of the ill person as well as other family members" (p.12).

In conducting a study to look at children's experiences of dealing with depression Van Parys and Rober (2012) completed a thematic analysis of family interviews. On completion of their data analysis they felt that the findings did not do justice to the rich data and they wanted to find a way to "deepen" (p.7) their understanding. They used microanalysis to introduce a dialogical analysis to their research, which would allow them to "focus on the way talk among the family members and the interviewer was interactively produced" (p.7). Given the level of detail involved in the analytic technique they only completed the analysis on two conversations from two families. Having completed the analysis they describe how using microanalysis helped them "to move beyond the content of the children's accounts and gave [them] an explicative perspective on the interactional dynamics that evolve around children's aspirations to help and comfort the parent" (p.10).

Narratives in Mental Health

Roberts (2000) identifies the importance of narrative accounts alongside more quantitative evidence based knowledge in helping clinicians understand and respond to individual experiences. Pennebaker and Seagal (1999) identify that constructing coherent narratives that incorporate thoughts and feelings facilitates a sense of resolution and release from rumination on disturbing experiences. This is supported by research on trauma experiences which has shown that the development of a coherent narrative of traumatic experiences can be a protective factor in coping emotionally with the events (Herman, 1992 as cited in Hyden, 1997).

Family narratives about mental health difficulties

The experience of mental health difficulties can create intense emotion for everyone involved and meaning-making through narratives can be a way of working through these difficult emotions. Stern et al. (1999) emphasise that it is the possibility of making sense of difficult life experiences and integrating both positive and negative aspects of the experience that is necessary. In their research, Stern et al. (1999) found that carers who had transformed the experience of their relative having a serious mental illness into a meaningful event seemed to be coping more effectively with their role as carer. Those whose narrative accounts were 'chaotic and frozen' appeared to find it difficult to move forward with their lives and were experiencing higher degrees of carer stress and burden.

Mental health service support for families

Despite research demonstrating the emotional impact of mental health problems on all family members the involvement of families in mental health services is variable.

In Child and Adolescent Mental Health Services (CAMHS) parents and families are often included in interventions. Children's difficulties tend to be conceptualised as 'nested within multiple systems' and the approaches to assessment and treatment aim to address the systems relevant to the child's presenting problems (Carr, 1999). Daniel and Wren (2005) offer the opinion that including families in CAMHS made easier by the generally held view that adults should help children.

In Adult Mental Health Services families are less frequently involved and children tend to only be included under extreme circumstances when there are child protection concerns. Daniel and Wren (2005) give details of work they have conducted with families where an adult (parent) has a mental health problem and state that their motivation for involving children was "strong feelings about the lack of attention paid to children in adult mental health services".

In Adult Mental Health Services there has been an increased recognition in recent years of the burden and stress of the carer role. Research studies have shown that carer burden and stress is associated with an increased risk of relapse for service-users (Kavanagh, 1992; Kuipers, 1991) and in many services the assessment of carer needs has improved and more support has been made available.

Stallard, et al. (2004) conducted research looking at the effects of parental mental illness on children and in doing so identified that adult mental health service practitioners were often under too much pressure from large caseloads to think about the needs of children in addition to the needs of the identified patient. They concluded from their research that children and parents felt that the children needed more information about their parents' mental illness and that services should be more family focused. A finding supported by Beardslee, Gladstone, Wright and Cooper (2003), who demonstrated that increasing children's understanding about their parent's mental illness promoted resilience-related qualities.

Mental health discourses, the socio-cultural context

Discourses about mental health difficulties are dominated by stigmatising beliefs which lead to victimisation, unfair discrimination and social exclusion (WHO, 2002). The long history of

stigma associated with mental health difficulties is widely acknowledged, as is the detrimental impact that this has on the lives of people and their families. The World Health Organisation (WHO, 2009, p.6) identify that "the myths and misconceptions surrounding mental illness are the root cause of much of the discrimination and human rights violations experienced by people with mental disabilities on a daily basis".

> Stigma is a powerful phenomenon inextricably linked to the value placed on varying social identities. It is a social construction that involves at least two fundamental components: (1) the recognition of difference based on some distinguishing characteristic or "mark"; and (2) a consequent devaluation of a person. […] Stigmatized individuals are regarded as flawed, compromised and somehow less than fully human (Dovidio, Major and Crocker, 2000, p.3).

Goffman (as cited in Stuart, 2008) writing in the 1960s described the stigma related to mental illness as "one of the most deeply discrediting and socially damaging of all stigmas, such that people with mental illnesses start out with rights and relationships, but end up with little of either" (p185). In a review of the literature on stigma in mental illness Hayward and Bright (as cited in Crisp, Gelder, Rix, Melzer and Olwen, 2000) identified key beliefs about people with mental illness that contribute to stigma: "being dangerous, being unpredictable, being difficult to talk with, having only themselves to blame, being able to pull themselves together, having a poor outcome and responding poorly to treatment" (p.4).

Statistics on the prevalence of mental health difficulties in the UK indicate that one in four adults will experience mental health issues in any one year and one in six are experiencing a mental health issue at any given time (Office for National Statistics, as cited by Mental Health Foundation, 2007). These statistics indicate that the majority of adults in the UK will either have experienced mental health difficulties themselves or will have a close friend or family member that has. And yet in 2008 a survey conducted by the Time to Change[2] campaign found that 87% of mental health service users reported a negative impact of stigma or discrimination on their lives. The findings also revealed that the majority of people with

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[2] The Time to Change campaign was launched in 2007 by two leading UK mental health charities; Rethink and Mind. It is a campaign that has been funded by the Department of Health, Big Lottery and Comic Relief with the aim of reducing mental health stigma and discrimination. The campaign had a number of targets for the first four years which included a 5% improvement in public attitudes and a 5% reduction in discrimination. These targets were not met but there was a 3% reduction in discrimination and further funding has meant the campaign has continued into a second stage and will run until March 2015.

mental health issues reported experiencing some form of stigma and/or discrimination from their own family members.

While stigma towards people with mental health difficulties is well documented and researched there is limited understanding of stigma in families. When addressing this topic there is a need to consider the stigma and/or discrimination people experience from their family members but also how family members themselves may be subjected to stigma by association (Goffman, as cited in Karnieli-Miller, Perlick, Nelson, Mattias, Corrigan and Roe, 2013).

Research by Karnieli-Miller et al. (2013) identified that family members of people with mental health difficulties had been rejected, blamed or devalued when people learned about their family member's difficulties. In Corrigan and Miller's (2004) literature review on stigma they identified that the experiences of stigma are different depending on how the relationship to the family member is defined. They identified two key stereotypes that were applied to the different role relationships with family members: blame, and contamination. Parents were typically blamed for causing the mental illness, siblings and partners were blamed for not doing enough to help the person manage their illness, and children were viewed as contaminated by their parents illness.

In the research outlined above the emphasis is on the stigma experienced by family members and no mention is made of the stigma within families towards their relatives. Dallos et al. (1997) refer to stigmatisation from family members in which they see the person exclusively as sick and incapable, which can happen when a medical explanation is attached to their mental health difficulties.

Intergenerational narratives about mental illness are influenced by societal and cultural discourses and, given the prevalence of mental health stigma, are likely in most families to contain some stigmatising attitudes and beliefs about mental illness. These will impact on families' experiences of living with mental health difficulties.

Stories to be told and heard
Based on my review of existing research I have only found one study that has interviewed families' together about their experiences of mental health difficulties (Van Parys and Rober, 2012). While many studies have attempted to provide a perspective on individual family

members' experiences of mental health difficulties, none have attempted to analyse how the family members negotiate and construct a 'family narrative' about these experiences.

Parke and Buriel (as cited in Pratt and Fiese, 2004) suggest that "the 'whole family' level is crucial to conceptualise and understand" (p.7) and I am hoping my research will be one study among many that attempts to do this. I believe the process of creating shared narratives and the content of what emerges can provide us with further insight into how families experience mental health difficulties and what the implications of this might be for how services operate.

This study has four main research questions:

1) How are mental health issues talked about within the family?

2) What are the intergenerational narratives that seem relevant to how the family experience mental health difficulties and what influence do these narratives have on family beliefs and understanding about mental health difficulties?

3) What influence do intergenerational narratives have on family members' construction of individual and shared identities?

CHAPTER 2: METHODOLOGY

In this section I will provide an account of how the research was conducted. This will include the reasons for my methodological choices, some information about assessing the 'quality' of the research, the ethics process and the procedures and challenge of participant recruitment.

<u>METHODOLOGY</u>

Why Qualitative Research?

Elliott, Fischer and Rennie, (1999) identify that the "aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage and live through situations" (p.216). The discovery-oriented nature of my research and the focus on family experiences make it suited to qualitative methodology (Barker, Pistrang and Elliott, 2008). Thompson and Harper (2012) identify the importance of using qualitative methods in mental health research for developing our "understanding of experience and processes."

Why Narrative Analysis?

My focus on how families make sense of their experience of mental health issues and how this is affected by the intergenerational stories that are told made Narrative Analysis (NA) (Bamberg, 2006; Phoenix, 2008) an appropriate choice (Harper, 2012).

NA holds central the assumption that "telling stories is one of the significant ways individuals construct and express meaning" (Mishler, 1991, p.67). The family context is often an important arena where this process takes place and intergenerational stories that are passed between generations may play an instrumental role in shaping people's understanding of and beliefs about certain phenomena. Labov (1997) describes the discussion of narrative at a discourse level as a "hermeneutic study where continual engagement with the discourse as it was delivered gains entrance to the perspective of the speaker and the audience" (p.3). I hope that in using NA I will be able to gain insight into families' experiences of mental health and the ways in which intergenerational narratives have influenced those experiences.

In my view a narrative frame is appropriate for this research because the variety of approaches to analysis within the narrative field provides me, the researcher, with the opportunity to identify an analytical methodology that is specifically tailored to the data collected. The flexibility that NA offers in studying socially rather than individually oriented narratives will allow the data to be looked at on a number of levels: meaning-making (Murray, 2008);

narratives-in-interaction (Bamberg, 2006); social and cultural discourses (Phoenix, 2008); and creating a shared family identity (Gordon, 2007).

One aspect which is important in the analysis of family experiences is the flexibility of Narrative Research in studying socially rather than individually oriented narratives. This opens up the possibilities to include a focus on the co-construction of narratives in talk and what has become known as 'small stories', or 'narratives in interaction' (Bamberg, 2006).

Assessing the quality of the research

Walsh and Downe (2006) highlight how the different epistemological status of qualitative research makes transferral of standard quality criteria from quantitative methods (e.g., validity and reliability) inappropriate. To address the difficulties associated with evaluating the quality of qualitative research Walsh and Downe (2006) conducted a review of current frameworks and synthesised these to develop a checklist for qualitative research that is "useable in practice, as well as being adequately comprehensive" (p.110). I have chosen to use their criteria to demonstrate the quality of this research. (See Appendix B, p.101, for details of how this project meets these standards).

<u>DESIGN</u>

Sampling strategy

A purposive sampling strategy was used as it was necessary to recruit families with a 'lived experience' of mental health difficulties. Typically a sample size of five to eight participants is recommended for research using qualitative analysis, more than eight is considered practically unmanageable for conducting in-depth analysis (Wells, 2011). In this study the research participants were families and rather than interview five to eight families the decision was taken to interview three families on two occasions. Limiting the number of families to three meant that complex in-depth analyses would still be achievable.

Inclusion/exclusion criteria

The participants in this study were families where one adult member was accessing mental health services. Only families where all members of the generations attending the interviews were over sixteen years of age were invited to participate in the research. This decision was made for ethical reasons as it did not seem appropriate to invite a family to participate and then exclude children under the age of sixteen if their older siblings were participating.

Within this study, 'family' was left to the decision of the participant accessing services with the only stipulation being that to participate they would need to be interviewed along with one member of the family from a different generation to them.

Participant recruitment

Participants were recruited through two local NHS services commissioned to provide assessment and treatment for adults with mental health difficulties. The first service was chosen as a recruitment site because it is one of a limited number of local adult services that have a team of systemic psychotherapists working with families. It was felt that given the nature of the topic it may be appropriate to recruit families that had some experience of talking about mental health. The second service was added to the recruitment later in the study as it also engages families within the care process through systemic therapy and carer groups.

PROCEDURE

Recruitment procedure

Recruitment to the study was initially via four systemic psychotherapists at the first service. It had originally been agreed that recruitment would be from the waiting list and the therapists' caseloads. However, when recruitment began it transpired that the service had also agreed to participate in some research about family therapy and most of the families on their caseloads had already been recruited to this. The psychotherapists felt it was too soon to ask these families to participate in another project and so the recruitment was initially limited to eight people on the waiting list, one of which became the second family to participate. I visited this site on three other occasions and clinicians identified a further 14 families from the waiting list or their active caseloads, one of which agreed to participate. The clinicians were asked to give families an information sheet (see Appendix C, pp.102-104) and then leave them for a minimum of 48 hours to consider participation in the study before contacting them again.

While attempting to recruit from the first site I became aware of family involvement at another service in the area and being concerned about running out of families to recruit I took the decision to seek Research and Development Department approval for the second site. Two families were asked about participation by the clinician working with them and one of these became the third and final family to participate.

Recruitment difficulties

Recruitment at the first service began in August 2011 and after seeking approval to recruit through a second service the third family were finally interviewed in April 2013. Van Parys and Rober (2012) had similar difficulties in attempting to recruit families. They recruited over eighteen months and only fifteen of fifty-five families came forward, eight being eligible when exclusion criteria were applied. Given the stigma associated with mental health difficulties talking can be very difficult for families and this may have contributed to the difficulties with recruiting.

Interview procedure

When the study protocol was written, interviews were due to take place in a clinic room at the research site. However, the first participant requested that the interviews take place in their home due to mobility problems of a family member. After ethical approval was received for conducting interviews in the participant's home this went ahead (in accordance with local trust "lone worker" policy) and the rest of the participants chose this option for their interviews. At the start of the interview, participants were reminded that they would be interviewed together and that I would need to interview them a second time after a minimum of 7 days.

Narrative Interview Schedule

As this was an original research topic there was no specific interview schedule to follow and instead some prompt questions were developed to guide the interview process (See Appendix D, p.105). The questions were developed in consultation with my research supervisors and were piloted during a role-play with two trainees. Ideas for some of the questions came from McGoldrick, Gerson and Shellenberger's (1999) book on genograms.

I felt it was appropriate to use genograms at the start of the interviews to help families to consider their extended family when discussing their experiences. The second interview provided an opportunity to follow-up on any areas not covered in the first interview and to explore areas of interest emerging from the first.

Participant Debrief

After each interview was completed the researcher asked the participants how they were feeling and when necessary talked with the family and recommended where they could access support. Participants were given an opportunity to ask any questions about the research and they were given a debrief sheet (see Appendix G, p.112). The researchers contact details were

included on the debrief sheet and participants were encouraged to contact the researcher should they have any concerns or further questions. At this stage participants were also asked whether they would like a summary of the results once the project was complete and all three families expressed an interest in this.

Transcription

Verbatim transcripts of the first interview with each family were typed up in the week before they were seen again. During this process questions for the second interview were developed and included anything from the interview prompts that had not been covered or warranted further exploration. The second interviews were transcribed within two weeks of the interview. All interviews were transcribed by the chief researcher as this was considered to be an important phase in beginning the analysis and becoming familiar with the data. All audio files and written transcripts were stored in password protected files.

ETHICAL CONSIDERATIONS

Ethics approval

Ethical approval was granted for this research by the National Research Ethics Committee (See Appendix E, pp.106-110, for letters of ethical approval). The study was also then approved by the local R&D offices for each site

Informed consent

The participants in this study were given or sent an information sheet (see Appendix C, p.102-104) and given a minimum of 48 hours to think about whether they would like to participate. At the first family meeting they were offered another copy of the information sheet and each family member was asked to sign a consent form (see Appendix F, p.111). The consent form stated that each family member understood that their participation was voluntary and they had the right to withdraw from the study at any time.

Confidentiality

The information sheet informed participants that personal information would be changed to protect their anonymity and pseudonyms would be used. It was made clear to participants that the nature of the study meant there were limits to anonymisation and there would be a possibility that people who know the family well could identify them.

ANALYTIC PROCEDURE

In keeping with my adopted social constructionist epistemological stance the approach I have taken for examining the data is drawn from NA (Phoenix, 2008; Bamberg, 2006) and narrative-discursive psychology (Taylor, 2006; Reynolds and Taylor, 2005; Taylor and Littleton, 2006).

This account provides just one interpretation of the data collected for this research and this interpretation is influenced by my own stories and epistemological stance. I will reflect throughout on my own position in relation to the data to demonstrate my influence in the research process.

A key aspect of this research is the process that happens when families come together to talk about their experiences. The interview is immediately transformed from an individual telling to a joint telling of a shared experience, constructed in the context of an interviewer-interviewee relationship (Mishler, 1991). Kellas and Trees (2006) identify the significant differences between jointly and individually told stories and the impact this is likely to have on "the ways families create meaning, or come to conclusions about self and family, through narratives" (p.51). They distinguish between two types of joint storytelling: conversational storytelling in which the listener or recipient becomes a "co-author" to the story and influences the shape of the story through "questions, interruptions and displays of understanding" (p.52); and *shared* joint storytelling in which two or more related members collaborate in providing information for the construction of the story.

Discursive psychology represents a shift towards understanding talk as a representation of actions and practices in their social context (Taylor, 2006). It rejects the notion of talk as an expression of internal processes and instead focuses on what is happening now. This shift has been influential in the world of narrative research and the consequence has been the development of a 'second wave of narrative research' which focuses on small stories (Georgakopolou, as cited in Phoenix, 2008, p.64). Georgakopoulou (2006b, p.123) describes the term "small stories" as an umbrella term that covers all the "under-represented" narratives that do not conform to the "prototypical narrative" deemed to be "personal, past experience stories of non-shared events". The analysis of "small stories" was originally considered to be relevant to the narratives told in everyday interactions rather than an interview context and they were seen as a means of capturing important moments of talk which would be missed if looking for "fully-fledged stories." (Georgakopoulou, 2006b, p.123). However, more recently

their analysis has been recognised as useful for the study of narratives in interview contexts (Phoenix, 2008). Orientating to 'small stories' in interview research with families seems important because as they talk their conversations share features of everyday interactions.

The analysis of 'small stories' is concerned with how these narratives are performed and what they may be used for in the context of interactions e.g. identity performance (Bamberg, 2006). Stokoe and Edwards (2006, p57) talk about the interest being in "how stories are told, how they get embedded and are managed, turn-by-turn, in interaction – and *what* conversational actions are accomplished in their telling (e.g. complaining, justifying, flirting, testifying, etc.)." Talk is seen as social in that it may address anticipated disagreements and counter-arguments (Billig, as cited in Taylor, 2006) and it is typically constructed from meanings that exist within society and the wider cultural context (Taylor, 2006).

Bamberg (2006, p.140) refers to this as a focus on the "present of 'the telling moment'" and emphasises how the narrative must be understood as a reaction to the immediate past and the anticipated audience response. In this respect stories are "situated retellings" (Mishler, 1991, p.51) and any understanding of them must take into consideration the context within which they were created. For the purposes of this research context has been taken to refer to the local context of the interview and the wider societal and cultural context within which the research is situated. Phoenix (2008) in her chapter on *Analysing Narrative Contexts* has developed a methodology that assumes that the local context of the interview and wider societal contexts are 'inextricably linked'. The focus of the analysis is on what speakers orient to in their small story narratives, what is motivating the particular way of telling and the identities that are brought into being and reproduced in talk.

McAdams (as cited in Phoenix, 2008) identifies that repeated content often represents the narrator's worldview or ways of dealing with life and in doing so is thought to be communicating about either their identity or issues which pre-occupy them (Phoenix, 2008). I will therefore look for repeated analysis in this analysis when reading for interaction.

Taylor (2006, p.95) extends the work of Gergen (1985) on the social construction of meaning to the understanding of identity, which she describes as "an artefact of communal interchange". Taylor (2006) describes how talk is the site at which identities are constituted and they are derived from the discursive resources available in the wider social and cultural contexts. In families the discursive resources will include meanings passed down the generations, which may influence identity construction. Identity is considered to be "in part

conferred through positioning (Davies and Harre, 1990), and in part actively constructed, contested and negotiated by active speakers." (Taylor, 2006, p.95).

According to Reissman (2002) NA is an iterative process and therefore different levels of analysis may be used simultaneously. For the purposes of this research the analysis is focused on content, interaction, and context.

In conducting the analysis each set of family transcripts was read through four times while simultaneously listening to the audio recordings. Transcripts were initially read for content and tabs were used to mark themes down the sides of the transcript, with attention being paid to both "snippets of talk" (Georgakopoulou, 2006b) and story forms. Transcripts were then read with a focus on interaction and context.

Reading for content

To answer the first two research questions:

(1) what are the intergenerational narratives that seem relevant to how the family experience mental health difficulties; and

(2) what influence do intergenerational narratives have on family beliefs and understanding about mental health difficulties,

The transcripts were read to identify content related to the following areas: intergenerational stories about mental health difficulties; families lived experiences of mental health difficulties; and family members' beliefs and understanding of mental health difficulties.

Reading for interaction

To answer the third research question '*how are mental health difficulties talked about within the family*' the sections of transcript identified from reading for content were read to determine how families built their narratives and what performative work was being done. There were three aspects to interaction that were attended to: identity construction; conversational actions; and joint storytelling.

Identity construction: In reading for identity construction I was identifying times in the transcript when the family members used their stories to position each other in particular identities and times when the speaker was actively constructing, negotiating or contesting their identity (Taylor, 2006). I was also interested in how the family might construct a shared identity and so I read for times when they gave descriptions of their family (Tovares, 2010).

Conversational actions: This involved reading for what action was performed through interactions. I was looking for occasions when family members would justify, minimise, normalise etc.

Joint storytelling: This involved reading the transcripts to identity whether the family were engaging in joint or individual storytelling and whether this was conversational or shared joint storytelling (Kellas and Trees, 2006), the features of which are described in the *Analytic Procedure* section.

Reading for context

Reading for context has a number of components:

1. Co-construction: reading for how my questions or comments may be influencing the interview process and family storytelling (Mishler, 1991).

2. Researcher as audience: reading for times when the participants were narrating to me as researcher, psychologist, young female.

3. Wider context: Reading for information that connected the family to their wider social or cultural context and reading for the family narrating to audiences within the wider context (Andrews, 2007).

CHAPTER 3: FINDINGS AND DISCUSSION

In considering how best to set out this section I looked into what other narrative researchers have done and what is 'standard practice'. I discovered that while there is a 'traditional format' where findings are presented separately to discussion it is the responsibility of the researcher to determine what would make most sense for the reader (Wengraf, 2004). To ensure I could present the findings in a manner consistent with the interview data, I waited to see whether the impression I had formed of the structure during transcription would emerge during analysis. As anticipated, the data showed that the content and context were inextricably bound, with participants drawing from the wider societal and cultural contexts throughout. It therefore felt appropriate to maintain this structure in the write-up by combining the findings and discussion (Saukko, 2000).

In this section I have chosen to respect the unique experiences of *each* of the families I interviewed and will therefore present the findings from each in turn. When I have done this I will present the findings that connect all three families.

Again, a decision had to be made about whether to introduce the families, giving a brief summary of the key points that would help you to get to know them. I spent time considering what they shared with me in the interviews, how I experienced them as a family and as individuals and what they may want me to say in writing a summary about them. I came to realise that interviewing these families and listening repeatedly to their transcripts has shown me that there is a tremendous depth and complexity to who they are, as individuals and as a family unit, that could not be captured in the short summary this research project can offer. As an example let me use Mark. During the interview he was a son, father, brother, child, adult, friend, husband, godfather, man, person who has experienced trauma and I could go on. These labels tell us something about Mark's relationship to others and something the experiences that he may have had. But they tell us nothing of what it was like for him or what it means day to day, how it changes depending on where he is and who he is talking to. So instead I have chosen to only provide the context for the interviews, leaving you to get to know the families for yourself.

FAMILY 1: MARK AND LEONA

Setting the context
In setting up the interviews Mark was the family member that I recruited and so is immediately positioned as a member of the family that has accessed a mental health service.

Mark was aware that I was a Trainee Clinical Psychologist and he asked me about the work that I do and my reasons for choosing my career. Mark wanted his mother Leona to take part in the research and arranged for me to speak with her to set it up. Leona was initially reluctant as both her and Mark had told me of the difficulties they were having in their relationship and that this may make a joint interview difficult. Nevertheless she agreed and I interviewed them at their family home on both occasions.

Who's in the family?

We began the interview by thinking about "Who is in the family?" and constructing a family tree (genogram) together. During this process Mark told me that he was adopted and so "it gets complicated…for me and mother" and he felt it would not be appropriate to include his birth family on the genogram. After completing the genogram I asked the question "Can you tell me about your family's experiences of mental health difficulties?" and Mark responded by talking about his Aunt Jenny, his dad's brother's wife, who was not on the genogram. Leona responded by saying "you can't count her in the family, we talking about sisters and brothers" but Mark continued:

> Mark: […] she had a very, umm, say an influential role, umm, in my development, my personal development, umm, cause she's had mental health difficulties...
>
> Interviewer: Okay...
>
> Mark: ...and her daughter had mental health difficulties and her grandson had mental health difficulties and her granddaughter had mental health difficulties. […] I grew up with the responsibility quite often of having to look after her daughter with her problems […] and she was some seven or eight years older than me. And knowing what I knew about her mother, quite intimately, and the intimate information that my cousin (name) gave me […]. Ummm, errr, I didn't really have anyone to turn to for help when I needed it, because I get *SHUT DOWN* all the time. Umm (clears throat), so my Auntie did have a big impact on my mental wellbeing. I believe in some ways, although […] It's only until I hit nigh-on 50 I started to realise that the damage that was done a very long time ago.

The debate about whether Aunt Jenny should be considered a member of the family seemed significant to both Mark and Leona. Mark emphasised his reasons for wanting to call her family but Leona did not accept this, and later in the first interview and again in the second interview she disputes her inclusion in the family: "yeah but she's no relation really". During the interviews we learn more about Aunt Jenny's mental health difficulties including her

attempted suicide and I wonder whether Leona does not want Aunt Jenny to be 'family' because of this. Research on stigma presented in the *Introduction* shows that some family members conceal their relationship to relatives with mental health difficulties because of feelings of shame or fear of being blamed (Corrigan and Miller, 2004), or fear of social rejection due to stigma by association (Karnieli-Miller et al., 2013).

I'm talking to you

When considering the story above as a situated retelling (Mishler, 1991), we can see how Mark uses language which emphasises the importance of Aunt Jenny in his life: "influential", "close", "big impact", to perform an action (Stokoe and Edwards, 2006) of disputing his mother's view that she is not family.

In thinking about the reactions Mark may be anticipating from his audience in telling this story (Bamberg, 2006), I am aware that he may be trying to evoke different responses from myself and his mother and that the language has different meanings when considered relationally.

By giving me insight into his life story and providing the information I might need to understand him and to empathise with him, Mark may be using this story to signal how he wants to be understood (Bamberg, 2006). This is supported by the interaction that follows this story, in which I ask Mark a question about his awareness of other family members' mental health difficulties. Rather than answer the question, Mark returns to his story about Aunt Jenny and tells me about being "close" to her when "she attempted very serious suicide" and how he "tried to be strong as a young boy, but umm, you know, it sort of takes its toll on you".

However, considering Leona as the audience for this story brings a new relational context to the comments and her position as his mother seems significant. In referring to himself as a "young boy" and using the term "responsibility" Mark may be using a canonical narrative "children should be protected" to imply that his mother should not have let this happen. Mark makes this point more clearly when he states "I didn't really have anyone to turn to for help, because I get SHUT DOWN all the time." There is an angry tone to Mark's use of the words "shut down" and in moving from the past to the present tense his words connect his feelings about not being supported in the past to his current relationship with his mother. Fiese and Sameroff (1999) describe how "the ways in which family members describe each other often

include whether there is an expectation for reward and satisfaction or whether there is an expectation to be disappointed or even harmed" (p.5).

I'm not a bad mother

Throughout the interviews Mark refers to Leona's failures to live up to the requirements of motherhood. In response to these accusations Leona attempts to justify her parenting and deny his claims. For Leona there is a lot at stake because if she accepts Mark's account she has to take responsibility for not protecting him from the "damaging" experiences in childhood which may have contributed to his "mental wellbeing" issues. Dallos et al. (1997) describe the process whereby family members that feel responsible in some way for causing the difficulties may become mutually blaming, a pattern that we see emerging in the interviews between Mark and Leona.

Mark makes negative references to his mother's parenting throughout both interviews: "there are times when I know that mum could have made an effort, but she never came up the school or to any of those things." and "I'm very sorry but she hasn't been like most typical mums."

Mark directs these comments not only to me as the interviewer, but also to you as the reader. He uses dominant cultural narratives of motherhood to emphasise that his mother fell short of the desirable standards. Pope, Quinn and Wyer (as cited in Andrews, 2002, p.8) describe the dominant cultural narratives of motherhood and in doing so highlight the expectation on women that they be "entirely nurturant and provident" for their children.

Leona, in response, tells stories that reject Mark's positioning of her as a bad mother and instead she tries to re-position herself as a mother that did everything she could despite difficult circumstances:

> We loved him, we did everything we could, when he was about a year old […] we bought the café then and obviously we was busy job. We had a person come in there up in the flat, […] to look after him and then when he was over a year old we took him to the nursery, but I mean even when you have your own children you still take them to nursery.

Leona repeats the first words of this story in various forms throughout both interviews in talking to me and a wider audience to say that Mark was always looked after. Leona also uses this story to contextualise Mark's childhood and her life as a mother. By referring to her work in the café, Leona connects us to information she has provided earlier in the interview:

> […] And when we worked together we worked 18 hours a day […] Surprising we didn't give up, it used to be about five pounds left profit, but at the same time we work harder and we produce different things. And we, we run it for 35 years, it wasn't easy…

Leona is justifying why she may have been unavailable to take care of Mark herself, but she also combines this with statements that contradict Mark's perspective "we were always looking after him". Leona finishes her story by normalising her parenting "even when you have your own children you still take them to nursery", a strategy that she repeats throughout the interviews to defend her position as a mother.

I blame you…

In many of the stories Mark tells there is an implicit message that his mother is partly to blame for his difficulties and occasionally he makes this explicit: "and you've developed a dysfunctional family because you brought me up a dysfunctional person". Leona responds by constructing an alternative explanation for Mark's difficulties, firmly locating the blame with his birth family.

> When he was 14 we sent him back on his own and that's what made the worst thing in his life and ours of course. Because they kept saying 'oooh we didn't want to give you away.' Why did they then?

Leona repeatedly tells this story about Mark's birth family confusing him by saying they didn't want to give him away. In placing the blame with them Leona shifts it away from herself (and her husband) "they confused him…that's the whole problem, it's not us." McGoldrick et al. (1999) write about the relational pattern of triangles that can happen in families with adopted children and how adopted parents may "blame the biological parents for their difficulties (bad genes)".

This idea that someone must be to blame for Mark's mental health difficulties fits within the social context of stigma where people either locate blame with the individual (Hayward and Bright, as cited in Crisp et al., 2000), or the parents, the partner or the siblings (Corrigan and Miller, 2004).

In considering myself as the audience to Mark and Leona's construction of Leona as a mother who is to blame for Mark's difficulties I am aware that their accounts are influenced by what they know about me. My gender and my career are important because I may be a mother myself but also I may be a working mother. For Leona this represents an opportunity for her to

appeal to me, by emphasising the challenge of balancing childcare with the demands of work. For Mark my career being in psychology may be important because he can rely on my professional knowledge of motherhood to inform my opinion of Leona as a mother.

Making sense of "mental wellbeing" issues
In the following extract Mark uses a metaphor of a 'journey' to describe what mental health difficulties mean to him and in doing so gives us some insight into how he makes sense of the difficulties he has experienced:

> […] people start on a journey and they don't realise that umm, life is full of so many umm trials, tribulations and traumas, […] and it really depends what's been thrusted upon you through your life, and where you started from in life and what sort of childhood you had and ummm, how things have impacted on you when you've experienced horrendous bereavements and ummm, life traumas and umm, when shocks have occurred which you weren't anticipating in your life and […], if you've got very few people who actually understand and recognise that umm unfortunately the problems are starting to overwhelm you […] then unfortunately you might start to umm, umm, lose some of your rationality and then people start to think that oh that person is either going through some sort of mental breakdown […] and you will get labelled as opposed to anyone trying to find a solution […].

This story presents a psycho-social understanding of mental health difficulties and elements of this explanation are used throughout both interviews by Mark to explain his "wellbeing issues". Mark makes reference to the fact that no-one noticed what was happening to him and that if they had his problems may not have continued. This idea is supported by Dallos et al's, (1997) research which concluded that "parents or other relatives who are able to offer support can help to offset such an escalation of problems." (p.395).

Later in the interview Mark talks again about people not recognising that he was struggling to cope:

> Mark: […] I've always been known as quite an angry person, […] but you know I can tell when other people are disturbed but unfortunately other people around me, there was never anyone to actually see that I was being distu[rbed], there was something going on in my life that was disturbing me quite severely.
>
> Interviewer: It sounds as though you might be saying that anger might have been one of those things that was a way of expressing

> Mark: Yeah, it was like my sort of cry for help, you know, and umm I was expecting older people to actually understand it was a cry for help.

In describing his expression of anger as a 'cry for help' Mark indicates that at the time this was the emotion available to him for expressing his difficulties. Research on gender socialisation has shown that 'masculine' emotions like anger are often reinforced amongst boys (Chaplin, Cole, & Zahn-Waxler, as cited in Sullivan, 2011) and more 'feminine' emotions are often discouraged. Addis (2008) identifies that gender socialisation is a nuanced phenomenon and to understand its influence on whether someone presents with mental health issues or accesses services we must consider what social and cultural norms they were socialised into. .

When I ask Leona for her ideas about why people develop mental health difficulties she also gives an explanation that seems to be referring to Mark:

> Yes sometimes it's inherited, the tempers, and the way you want. Some of us, we don't like giving in. What we say, if you don't do what I say for instance and then, I snap. And I think that's what caused most of the troubles. Or a lot of people they like taking but they don't like giving.

Leona introduces the explanation that mental health difficulties could be inherited and she then refers to personality and attitude as the two main reasons why Mark has difficulties. Here Leona is drawing on a very individualistic understanding of mental health difficulties (Dallos et al., 1997), but later she reverts back to an interpersonal explanation when locating the blame with his birth family.

In the next part of the interview I ask Mark and Leona what their ideas are about why Aunt Jenny developed mental health difficulties. Leona attributes Aunt Jenny's difficulties to stubbornness and being unwilling to mix with people that she considers to be of a lower class. Leona says that "that's made her how she is now, ill. Because they couldn't have, they couldn't make any friends."

Mark expresses uncertainty about why Aunt Jenny developed mental health difficulties and he works through possible explanations. Firstly querying whether her father committed suicide:

> Mark: I believe that her dad committed suicide and when I sort of asked her

> Leona: No he didn't

> Mark: If I can just carry on a second mum […] all she said to me is my dad walked out of the house one day and never came back […] that's not the way most people would say how their father died

As Mark continues to debate whether this was the case he draws on his own experience to consider why her father might have committed suicide: "Maybe he was having a problem with their mum in their relationship. Maybe it was a husband and wife, matrimonial thing." Leona puts an end to Mark's wondering when she tells him that "Her father got killed, with, in an accident, he was driving an ambulance after he left the army."

Mark then moves on to consider alternative explanations for Aunt Jenny's difficulties including expressing an interest in Leona's opinion, but he is unsure whether grandiosity is a mental health difficulty:

> I'm not quite sure whether there's a medical condition, a mental condition, where a person could be going around like la-dee-dah, like lady of the manner, with a grandiose flair. Because to be honest with you my wife is a bit like that as well.

In a final attempt to make sense out of what happened to Aunt Jenny Mark moves on to wondering whether post-natal depression may have been the issue for her

> […] maybe she got post-natal depression, because the way that her life changed very rapidly. And then she had to then support the family home, out in the countryside, away from her sister and her mum, away from her family and everything, being quite isolated […] and maybe she got post-natal depression […] I don't know what the remedy is, but I do know once again my wife went through post-natal depression.

In trying to make sense of Aunt Jenny's difficulties we see Mark gradually working his way through possible explanations that are predominantly drawn from his own personal experience and the explanations he gives for his own mental health difficulties.

At other points in the interview Mark and Leona answer the question from a more general perspective and we see how intergenerational beliefs may be influencing their understanding of mental health difficulties.

"It is in the genes"
Leona introduces the idea that mental health issues may be inherited and Mark later refers back to his mum's comments stating that "sometimes it is in the genes, or sometimes we believe it is in the genes". His comments suggest an ambivalence or uncertainty about the

credibility of this explanation which may be related to his understanding of his own mental health difficulties which does not include an inherited aspect. Or it could be because he is asked this question by a mental health professional who he may think knows the answer.

Mark comments on how this belief has passed between the generations in the family when he says that without any expertise in this area he can "only believe or say or copy what [his] parents have told [him]". Mark goes on to provide us with what he considers to be strong evidence for this perspective from his wife's side of the family where two generations of the family and two siblings have mental health difficulties emphasising that it is "not me assuming it runs in families, that's the facts". In the final part of this section this perspective is presented once again when Mark explains that he wanted his family to attend therapy for his sons because one of them "may have inherited a bad gene".

The process seen here gives us some insight into how beliefs are maintained within families and passed from one generation to the next and why stigma may be so difficult to change. The idea that "it is in the genes" is a dominant societal discourse in relation to many physical and mental health difficulties. For example, during medical appointments people are often asked whether anyone in the family has certain conditions (e.g., diabetes or heart disease) and so we are used to thinking that if two members of the same family have shared difficulties it must be genetic. In this interview we can see that even once Mark's beliefs have shifted with respect to his own mental health difficulties he still reverts back to "it is in the genes" when he can see the pattern in someone else's family.

Dysfunction leads to dysfunction

This theme is apparent at the beginning of the first interview when Mark talks about Aunt Jenny's mental health difficulties and in doing so provides some background to the difficulties he has experienced. Mark uses the words 'pivotal' and 'influential' to communicate the significance of her role in his 'personal development'. As the story is coming to an end Mark clearly states that Aunt Jenny had a "damage[ing]" "impact on [his] wellbeing". The second time I interview the family this theme emerges again when Mark talks of how 'dysfunction' will pass on through the generations of the family. When talking about his son he says "he doesn't realise he's a by-product of two dysfunctional parents [...] and he will pass dysfunctional characteristics onto his children unfortunately".

This intergenerational narrative is a powerful one providing an almost inevitable fate for Mark's children, although Mark does suggest that the right intervention at the right time could prevent this.

Is talking a "no, no" because mental health difficulties are a "no, no"?
The first story that Leona tells in response to a question about her families experience of mental health problems is about her mother being in hospital "all the time" but she states explicitly "not with mental health", but instead for "six miscarriages". Leona continues to talk about loss and hardship experienced by her parents and grandparents and sums it up by saying "but they managed".

Once Leona has told a story about her childhood I ask if anyone in the family had mental health difficulties when she was younger and she says "not as far as I know, no." When I ask about Aunt Jenny's mental health issues Leona reminds me she is not a member of the family and in doing so silences any further questions on the subject. At the beginning of the second interview Leona clearly states her position that "I haven't got anybody in my family that I know, that have got mental health". Then again later on Leona says people in her family would not have talked about mental health issues and that actually there was "nobody else with mental illness".

Leona's response to these questions suggests that not only is talking about mental health difficulties unacceptable, but actually experiencing them is too. This may be an intergenerational belief in Leona's family which could be contributing to Mark's ambivalence about whether he has mental health difficulties.

Mark describes how he could never talk to his Aunt Jenny about her mental health "it would be a no, no, you would hit a brick wall, and you'd know seriously, *you don't go there"*. Then later when he uses his wife's family as an example of mental health being in the genes he describes how his wife was like his Aunt Jenny in that she did not want to talk about mental health issues in her family either. Mark emphasises this by telling the story of his wife keeping her brother's mental health issues a secret for 22 years of their marriage.

Systemic theory talks about how values, attitudes and beliefs about mental health are passed down between the generations of the family (e.g., Dallos and Draper, 2005). In Leona's family and Mark's wife's family we can see evidence that the taboo nature of mental health issues influences their actions. Mark speculates about why his wife does not want to talk

about mental health "she has like a phobia that people are going to find out" implying that she is concerned about stigma. For Mark's wife it is her father and siblings that have mental health difficulties and her desire to keep this secret may be related to the stigma about children being contaminated by their parents' illness (Corrigan and Miller, 2004).

Having identified an intergenerational narrative informed by social discourses that mental health difficulties are unacceptable and should not be disclosed or talked about, we can consider the impact of this narrative on how the family experience mental health issues.

"I don't think I'm mad"

Throughout the interview Mark's position in relation to mental health difficulties is constantly shifting between: 'I have had mental health difficulties'; 'I have never had mental health difficulties'; and 'I'm not sure either way'. It is analysis of Mark's fluid movement between these positions that brings to life the complexities involved in constructing his identity. As discussed earlier Mark begins the interview with a story that implies he has had mental health difficulties and that there are good reasons why. However, as the narrative progresses his ambivalence about being labelled as having mental health issues develops:

> Interviewer: Ok, so. I've obviously come to do the interviews with you both, well, because I contacted Mark through the service he has been seen at. So Mark, I'm just wondering, would you describe your difficulties as mental health difficulties? Is that a term you would use? Or is that a term that's familiar to you?

> Mark: Sorry, I'm just going to put the heating on. (long pause as Mark leaves the room to go to a cupboard in the hall) Ummm. It's getting dark. Umm, (Mark re-enters the room, sits down and clears his throat twice). Yes and no really, ummm, I dunno, and it's probably more on the yes side than the no, if I was being totally honest...

At this point Mark demonstrated his dilemma and was very hesitant in giving his answer. My question left him little choice and it is possible that my positioning of Mark pushed him towards answering 'yes'. When I first recognised my influence here I was shocked that as a social constructionist clinical psychologist I had made such an assumption and presented it to Mark with no real option but to agree. Considering the context of my question I realised that Mark had already told a story which suggested he had mental health difficulties and I had relied on this to assume he would be willing to align to this label. This is a mistake clinicians should be wary of because people may not always talk of their ambivalence, particularly if they are concerned it may jeopardise their access to care.

Once Mark has given his "more on the yes side than the no" answer he works hard to construct a preferred account of his mental health difficulties. Mark tells a series of small stories (Bamberg, 2006) which normalise, justify, and minimise his mental health difficulties while promoting his positive qualities that led him to be "open and honest" about his difficulties.

First Mark repeatedly normalises the experience:

> […] the mental health thing is something there, like your pulse, it's there the whole time, and you can have a good and bad day depending on, what stimulus have affected you […] I think we all have mental health issues from time to time […] I think anyone would have acted the same way, when put under that amount of pressure.

Secondly, Mark constructs his willingness to talk about his mental health as a positive demonstration that he is "open" and "believe(s) in being able to work at things to find a solution", a position which he contrasts with Aunt Jenny who would not talk about "mental health". Thirdly, he suggests that maybe he wouldn't have been accessing mental health services if people had supported him "where I got into the National Health Service set-up is because I didn't have anyone else to go to Louisa." And finally Mark provides a list of the reasons why he experienced "mental health issues":

> [...] everyone around me had lost people, no-one had lost as many people as I had lost and I have a lot of legal battles going on and I have work issues going on, […] and the pressure was full on and I had no-one to go to. […] I think anyone would have acted in the same way, when put under that amount of pressure.

Mark provides justification for the difficulties he experienced and normalises his response by indicating that no-one could have coped with this amount of pressure.

Later in the interview Mark talks about his consideration of doing a short course in counselling because he "think(s) that everyone is going to be subjected to some form of counselling in their lives." Mark then tells of his idea of providing counselling to a "niche market" in his field of work, 'construction and engineering'.

> Quite often the guys that we work with, ermmm bury it all inside them and a lot of guys are divorced and suffer from bereavements and the impact of what life is like and it is quite difficult if you feel that you can't go to mainstream counsellors because we're quite often not used to doing it.

In this section of the interview Mark gives extra weight to the normalisation of mental distress because he introduces the idea that everyone can benefit from some counselling, even the strong, masculine men that he works with in construction. By stating his membership of this group "my field" Mark is using himself as both an expert and as living proof that men working in that industry can benefit from counselling. In anticipation that the audience(s) may see him as an exception, Mark indicates that many of the men have experienced divorce or bereavement, just like him.

In this story Mark directly challenges the idea that people are either strong or vulnerable and indicates that most people are both, it is just that some people are "open" about it and others "bury it inside". The wider social and cultural context are important here because having accessed counsellors and mental health services Mark could feel like 'less of a man' than his colleagues but instead he positions himself both as 'one of the guys' and as someone that has something additional to offer.

Alongside constructing an account of mental difficulties that he would be willing to accept, Mark continues to maintain his ambivalence and then finally as the second interview comes to an end he rejects a 'label' of mental health difficulties: "I just keep things internally and people think you've got mental health issues. Well I don't think I've got mental health issues, I just think about things." This position is not surprising given Mark's concerns about being labelled with a mental health difficulty. The finality of this statement as the interviews are drawing to a close highlights to me the significance of Mark's social context. To consider aligning to a mental health label in the research context is one thing but to live with that label is quite another.

Is this a catch 22?

This is not the only difficult position Mark is in when considering whether to take on the identity of having a mental health problem. If Mark decides to reject this label he has "no-one to turn to for help". However, if he takes on the label he can access services for support but he has to cope with the social stigma, the dismissal of his opinions and his family distancing themselves from him: "well I know from my recent experience with mental health and the letters coming that my wife, my children umm didn't want anything to do with me".

In a number of the stories Mark narrates we can see how he has felt misunderstood and undermined when his mental health has been used as a reason to explain 'normal' behaviour. Gaillard, Shattell and Thomas (2009), in writing about mental health patients' experiences of

being misunderstood, identified the issues for many participants of having to self-censor their behaviour and conversations so that they could not be continually interpreted as a sign of their mental illness. In the study by Gaillard et al. (2009) participants described the feelings of frustration and resentment that this would lead to, which resonates with the experiences Mark describes.

Interviewer reflections

I was nervous about my first interview with Mark and Leona because they had both emphasised to me how difficult their relationship was. I was surprised by how respectfully they allowed each other to tell their stories and with a few exceptions they waited until each other had finished before disagreeing or offering a different perspective. The difficulties in their relationship were still evident during the interviews and at the end of the first interview I had to stop the recording during a heated argument. After this I spent time with Mark and Leona doing a debriefing as there was a lot of intense emotion. On my journey home I cried, tears of sadness at their stories and tears of guilt that my research may have contributed to the tension in their relationship. I spoke at length with my supervisor about this experience and the ethics of interviewing people under these circumstances. There was a similar level of tension in the second interview and so once again I spent some time debriefing them. Then when I left they both thanked me for the research and Leona hugged me and wept. Reflecting on this I was struck by how moving the interview experience was for all of us and I wonder about the therapeutic impact for Mark and Leona of telling their stories and feeling heard (Birch and Miller, 2000).

FAMILY 2: SALLY, CLAIRE AND JACK

Setting the context

I recruited Claire into the research through the psychotherapists at her team. She was keen to participate and invited her son and sister to join us. However, when I arrived for the first interview there was Claire and Sally but no Jack. Sally explained how they had gone for family therapy together and when talking about the past "he found a lot of it very, very upsetting", and was concerned this interview would be similar. Later in the interview I learned that Claire's son had been adopted out of the family when he was very young, so had not seen or heard much about what Claire had been through until he attended the therapy session.

Although my research protocol stated that I would be interviewing families with two generations of the family present, I felt it was inappropriate to exclude Sally and Claire from

the interviews. Jack's voice was present in his decision not to participate and Claire and Sally were still very interested in participating in the research and telling their stories. Ethically it seemed more appropriate to respect that than to exclude them. Following the first interview with them I spoke with my supervisor and she agreed with my decision. We also considered what had been talked about and felt the data was appropriate for the research and that the interview addressed the research questions, a decision that we confirmed with the Research Lead on the DClinPsy Programme.

Who's in the family?

We began by putting Claire, Sally and their brother on the family tree and when I asked about their positions Sally described herself as the oldest, with an older brother and Claire as 'the baby'. Initially I considered this to just be a reference to Claire as the youngest but revisiting this during analysis led me to see this statement differently. It is important to bear in mind the current context for Claire and Sally, in that Sally is still living with her sister following an eight month inpatient admission and is therefore being 'cared for' with respect to her mental health. As this research unfolds there are important implications of this for Claire and it is my sense that Claire's mental health difficulties and contact with services has meant that for the majority of her adult life she has been treated 'like a child' by both her family and mental health services. Gaillard, Shattell and Thomas (2009) write of people's experiences of being treated like a child and being assumed to not be capable of taking responsibility for themselves. In their research participants described the impact of this on their confidence and self-esteem. In the current research the impact of life experiences in childhood on Claire's self-worth are frequently referred to but being treated like a child by services and her family may also have maintained this.

Making sense of "mental problems"

When we were doing the genogram Sally and Claire began to talk about Claire's history of mental health difficulties. I asked a question about how it got noticed that Claire was having difficulties and rather than answering my question they told a story to explain why her difficulties developed:

> Sally: Well when Claire was about six we had a very strange neighbour, she was one of those sort of women that would just walk up and down with her dog. And she stopped Claire and she said to her, err 'you're not going to make anything of yourself, you're, you're just a loser in life'.

Claire: 'You're mad', no-one likes me she said.

Sally: 'You're mad, nobody likes your little suitcase'.

Claire: 'Everybody knows you're mad', that's it.

Sally: 'Everybody knows that you're mad' and she is six and it stayed with Claire you know, and her self-worth, and when she was growing up she was quite rebellious, she was going with men that she shouldn't be going with.

Claire: Does that normally happen when people? Does that, can that?

In this extract we can see Sally and Claire jointly narrating the story that they identify as the reason she developed mental health problems. Sally explains how this led to the problems Claire has had when she connects these events to Claire's "self-worth". Claire indicates uncertainty about this explanation for her difficulties and Sally then provides further evidence to persuade Claire "well because when you're a little child and an adult is telling you that." As this conversation continues we see Claire accepting Sally's explanation and then agreeing with the rest of the story:

Sally: See what is said to you when you're a small child it's damaging, well look at it.

Claire: It has, it really has, yeah

Sally: And it's affected your relationships with men, didn't it?

Claire: Yeah it has, yeah

Sally: You were going with all sorts of different funny odd bods what I call them...

Throughout the interviews Sally continues to make reference to this incident as an explanation for why Claire has been "ill": "but it really does stem back to what that lady said". In the second interview Claire again returns to her position of uncertainty as to whether this event can really explain and once again we see her persuaded by Sally to accept this explanation:

Claire: Can it happen, can it make you sort of do strange things in your adult life can it?

Sally: Of course it can, well of course it can because she because when you're small you look to adults.

Claire: Is that what you do? Yeah it is I suppose.

Having established a story which is used to make sense of Claire's difficulties we hear Sally reflecting back on childhood for evidence to strengthen this account. "But I still think Claire that it all stems back to that woman telling you, when you were six years of age. Because when she was a baby and that was my little sister she was fine." For a moment Sally seems to drift into a different story as she recounts her memories of Claire as a "smashing" little girl and an undertone to these happy memories is the sadness over what was lost (Lefley, as cited in Leith and Stein, 2012). But Sally returns to the topic to summarise her conclusions from these memories "but I do remember that Claire, and I do remember that we had problems just after that and I still believe that stems from it, I really really do believe that".

Sally's account of Claire's difficulties is rigidly adhered to throughout the interviews and she seems invested in this narrative when Claire raises questions about whether this could explain everything that has happened. As discussed in the *Introduction,* Dallos et al. (1997) describe how families internalise cultural conceptualisations of mental illness and in the interviews with Claire and Sally there is evidence that Sally draws on all three conceptualisations (individualistic, medical and interpersonal) but rejects an interpersonal explanation when it may lead to blame of the family. When Sally talks about her own brief period of depression we can see an individualistic perspective on mental health: "But the difference between me and Claire, I didn't let it get to me." There is a suggestion here that Claire is responsible for her difficulties because she let it get to her and the implication of this is that Claire is "weak or inadequate" unlike Sally who is strong: "I think it's different strengths of a person, I'm quite a strong person. I think it all depends how you are as a person."

While aspects of Sally's account demonstrate an individualistic understanding of 'mental illness' there are also times when she would appear to be subscribing to a more medical explanation particularly when referring to Claire's difficulties. "You see when I came here Claire was in terrible debt, you know, but it wasn't her fault, it's her illness." Johnstone (as cited in Dallos et al., 1997) identifies that a feature of medical explanations is the tendency to label the person as 'ill' and to excuse them of responsibilities. This explanation may be beneficial to both Sally and Claire because it allows Sally to actively take on the role of carer and Claire can escape having to deal with difficult responsibilities. I will discuss this in more detail in a later section, but one of the benefits to Sally of being in the carer role is that it allows her to label Claire as the one that is sick or ill in contrast to herself who can then be viewed as healthy (Dallos, as cited in Dallos et al., 1997).

At other moments during the interview Sally touches on an interpersonal explanation in talking about how her family responded to Claire's difficulties but the way in which she talks about this suggests that they may be associated with guilt or blame of the family which Sally wants to avoid:

> Interviewer: […] So you said that you didn't really want to, people didn't want to talk about mental health previously, what difference do you think that has made, if any?
>
> Sally: Umm, well I think it just, it helps to understand it and we talk about it.
>
> Claire: Well I found before I just went, they used to have day hospitals in the, do you remember? Just went to the day hospital for six weeks.
>
> Sally: Yes.
>
> Claire: And that was it, no-one talked about it you just went up there.
>
> Sally: No, you just went up there and but then the problem was still there so who do you talk to about it, you know.
>
> Claire: Yeah.
>
> Sally: We weren't really understanding about it, you know, and it was a problem that you wanted to talk about. But then we, we didn't know how to help you.

Sally excuses the family from responsibility by saying "we didn't know how to help". Sally reinforces this point as the conversation continues when she suggests: "you needed to speak to a professional and then you know there's only so much that we can listen to at home, what could we [do]".

Here Sally may be responding to the stigma associated with being a family member of someone with mental health difficulties (Corrigan and Miller, 2004). For the family and also the siblings there is a risk of being blamed for their family member's difficulties and this is something Sally seems to be working hard to avoid.

In the *Introduction* I explained how culturally shared beliefs are often passed down through the generations of the family (McGoldrick et al., 1999) and at the end of the first interview we can see evidence that this individualistic conceptualisation was passed from dad when I ask about their parents' understanding of mental health:

> Interviewer: Ermm, do you think your parents understood mental health in the same way?

Sally: Oh most definitely yes. Yes, well dad was.

Claire: I think dad was a little bit...

Sally: Ummm, dad was a little bit, he was the sort of person, he was a business man and he was, he never had a day off work. Ummm, pull yourself together sort of attitude.

Claire: He was a little bit less, I, I, I...

Sally: He was caring, I mean he cared didn't he, but enough was enough you know, he just sort of went...

In this account we see Sally and Claire suggesting that dad held a less compassionate view of Claire's difficulties and they go on to contrast this to how they and their mother saw things. However, the idea that Claire could "pull [herself] together" is very similar to Sally's view that she didn't let depression get to her. Both imply that it is the individual that is responsible for overcoming their difficulties and if they are unable to then it must mean something about them as a person.

Okay, so tell me again, why do you think people develop mental health problems?

Despite a strong explanation for why Claire has developed mental health difficulties when I ask them later in the interview about their understanding of why people [in general] develop mental health problems they have difficulty answering:

Interviewer: But how do you, what are your, what is your understanding of why people develop mental health difficulties, what would you

Sally: Urgghh well, the brain is such a complex…

Interviewer: That's quite a big question isn't it?

Sally: The brain is such a complex ummm, I really don't know

Claire: Is it how you worry about things, is it how you see life, is it how you worry, how you see life, is it?

Sally: It's how you worry, ummm.

In the third interview I ask the question again and Sally and Claire give a different explanation, but again it feels that they are working hard to construct an answer:

> Sally: Oh my god it could just happen to anybody. Ummm, first of all I was a little bit ignorant about it. Like before Claire was ill like I used to sort of think you know that there was sort of, it was in the genes and that they just sort of were raised like that, you know, like if a mother was a bit ummm, ummm, like with mental problems then it would come down to the family. But now uhh, I, I'm a strong believer that it could happen to anybody.
>
> Claire: Normally it happens to people that are quite bright.
>
> Sally: It seems to be, it seems to be, yes
>
> Claire: Overtax their brains is it?
>
> Sally: Yes that's what I was going to say.
>
> Claire: Does that normally happen? Because they sort of think, can that happen?
>
> Sally: They can overtax their brains yes.

Claire and Sally's uncertainty when answering a direct question about how they understand mental health difficulties may be because they see me as an 'expert' that knows the right answer, or it could also be to do with their sense making about mental health which draws from a number of possible explanations.

Sally describes how her understanding about mental health problems has changed over time: from a "quite ignorant" perspective of it being "in the genes" to a more educated understanding. Sally relates this change in her understanding to the difficulties Claire was having "I think it's really with Claire, I think going to meetings and sort of talking and looking at leaflets and just understanding." Sally also cites Claire's difficulties as one of the main reasons why she volunteered to work for the Samaritans.

It is interesting how Sally's explanation has become less clear as her understanding of mental health difficulties has changed and is no longer limited to a single explanation "in the genes". It is possible that this reflects how complex the issue of mental health difficulties is and how much our understanding is dependent on our understanding of the person the discourses available to us.

What is mad, what is sane?
In the first interview when I ask the question about their understanding of why people develop mental health difficulties Claire says "it could happen to anyone couldn't it?" and Sally raises the issue of "what is mad, what is sane". Sally uses herself as an example to illustrate this,

"Because what I do, I'm absolutely obsessed with cleaning, I've got a bit of an OCD, so really Claire could say I'm mad, so what is mad, what, what is it?" In the final interview Sally and Claire have a similar conversation:

> Sally: I mean you've got your routines don't you and I think for God's sake what's she doing that for and then I forget about, that I do similar things. So I think there's a very thin line between madness.
>
> Claire: Between madness and sane.
>
> Sally: Yes, yes definitely.

Sally makes clear that it can be difficult to distinguish between madness and sanity and that actually it can vary depending on where you are looking from. Sally's comments suggest that she may view madness as a social construction and in fact we may all, or none of us be mad. However, as the conversation continues this interpretation of Sally's comments seems less likely: "I've become, I've got a load more understanding and I, I think I can even tell people that are out in the street if they've had a problem. I don't know if it's the medication but they've got this sort of look in their eyes, that far away look in their eyes." Sally's comments here suggest that as her understanding has developed she has also learnt to identify where the line is between madness and sane. Sally's question about 'what is mad, what is sane' may have been an important part of her own identity construction because it allows her to say that certain experiences come within the spectrum of experiences that could happen to anyone and are not an indication that someone is 'mad', like her own experiences of depression and OCD.

This explanation is supported by Sally's reaction to Claire's question about whether Sally could be a throwback of a mad ancestor. Sally and Claire are talking about a Spanish Great Aunt from a number of generations ago who was in an asylum and there has been a suggestion in the family that Sally is a "throw back" of this Aunt. Initially Sally joins in and contributes information about being the only one in the family that is dark like this Spanish Aunt but as the story continues Sally gets upset with Claire:

> Claire: I'm just saying is it a throw back? Can people have, can sisters have?
>
> Sally: (Laughter) Yes Claire but don't go on, I'm not mad, I'm not.
>
> Claire: No you're not mad.
>
> Sally: I mean that's silly that is isn't it?

Despite questioning what madness is and suggesting it can happen to anyone Sally still reverts back to a position of not wanting to be labelled in this way. She describes how she reacted when she was first likened to this mad Spanish ancestor "we heard about it you know and I was getting all a bit upset, thinking am I, well am I going mad sort of thing, you know". The stigma associated with mental health difficulties means that even when people can contemplate the question of 'what is madness' there are still too many risks associated with being in that category.

I am not the only 'mad' one…am I?

The concept of madness is a very powerful one and as we hear about the events of Claire's life they are told from a framework of pathology. They are either described as positive but then interrupted by mental health difficulties "but unfortunately you [Claire] became ill didn't you", or they are described as negative and connected to her illness "and it's affected your relationships with men, hasn't it". Claire and Sally go on to talk about her two sons, one of which was fostered by her mother and the other was adopted out of the family as a consequence of her being "ill". Becker (as cited in Dallos, Neale and Strouthos, 1997) proposed the idea that "deviant identities" are created when the person is labelled as such and all behaviour becomes interpreted from this perspective. He went on to say that "Over time the person or 'patient' may come to accept and internalise these definitions" (p.371).

Claire never demonstrates that she disagrees with being positioned as "ill" but she shows a strong desire for other people to also be considered as having mental health problems. On four occasions Claire suggests that other family members (father, mother, brother and Sally herself) have "mental problems" and these are four of the rare occasions when Sally disagrees with Claire. On two occasions Sally says yes they did have mental health issues but "different" to you Claire and with respect to their brother Claire says no, he doesn't, "he's just set in his ways, that's quite normal, quite, quite normal."

Similarly, with their mother Sally initially seems to be in agreement with Claire but as they discuss it she gradually disputes Claire's claims:

> Interviewer: So you've kind of I suppose told me a bit about some of your experiences of mental health as a family and
>
> Sally: I think we've all experienced it, you know.
>
> Interviewer: And what about your parents, have they, did they have any.

Claire: Mum was a nervous woman wasn't she, quite nervous.

Sally: Yeah but very strong.

Claire: Yeah but very strong, quite strong. She used to suffer from her nerves.

Sally: Yes.

Claire: She was a strong, but she was quite strong though.

Sally: She was a quiet lady.

Claire: Quiet.

Sally: She thought didn't she...

Claire: She thought a lot...

Sally: No, I wouldn't have thought she was nervous at all Claire.

Claire: Yeah

Sally: I don't think so, I think she was quite strong.

Claire: She had ulcers when she was younger, didn't you know about that?

Sally: Ummm

Claire: Yeah she had them didn't she? Maybe she worried inside, I don't know, maybe she worried inside about things more.

Sally: All I know is that she was a very good mother, she brought us up.

Claire: Yeah she was a very good mother.

Sally: We always had a good home, we always had umm food on the table. We weren't rich but we got by, didn't we?

Claire: Yeah...

Sally: You know, dad worked hard and we were umm just a normal family growing up weren't we.

On this occasion there is a sense of desperation on Claire's part, wanting someone else to share this with her. Sally's response gives us an indication that she is trying to protect the family from being blamed for Claire's difficulties and her final statement in this conversation

supports this idea by placing the blame elsewhere "no it's just sad really how things have turned out. But it really does stem back to that lady, what she said."

For Claire this issue of whether she is the same as other people is a key narrative that she appears to be preoccupied by. Claire checks to see whether her behaviour is typical of someone that has had her experiences in life "does that normally happen when people?", and reminds us that one in four people experience mental health problems.

In addition to trying to normalise her difficulties Claire also works hard to develop an acceptable construction of people with mental health difficulties stating that they are "nice people" and that "normally it happens to people that are quite bright". The work that Claire is doing here is positioned against a wider societal discourse that stigmatises people with mental health difficulties (Hayward and Bright, as cited in Crisp, et al., 2000).

Who does the talking?
The content of the interviews with Claire and Sally was dominated by a life story account of Claire's mental health difficulties, which may be because she was still accessing mental health services for support and therefore stories about her mental health were always going to be more accessible during the interviews.

When I completed the first interview with Sally and Claire my impression was one of a collaborative interview in which both sisters worked together to produce an account. However, after transcribing I was struck by the dominance of Sally's perspective. Claire does actively participate in the process but many of her statements are confirmation of agreement with Sally's account "Yeah", "I know yeah, terrible". Sally does check in with Claire throughout this process using terms like "wasn't it", "won't he", "didn't it" to get confirmation of the stories she is telling but this is done with confidence, as though a confirmatory response is assumed.

Claire adds new information at times but she then uses a similar checking process to Sally by saying phrases like "wasn't it, didn't it, didn't you, weren't you." While the words used are very similar to Sally, listening to the audio file provides a different perspective and there is much more of a tentative tone to Claire's checking. This uncertainty invites Sally into a position of authority in which she is responsible for the 'final say' and as a consequence Claire's account is open to confirmation or dispute by Sally. On many occasions Sally confirms Claire's account but sometimes she disputes it and Claire ends up agreeing with the

view Sally presents. There are likely to be many factors that influence this process between Sally and Claire including the relational aspect of Sally being the older sister and Claire being "the baby". However I am also drawn to wondering about the social discourses which may influence Claire's opportunity to have a voice. Being labelled 'mentally ill' relieves people of responsibility for their actions but it also means losing credibility (Dallos et al., 1997). Georgakopoulou (2006a) describes how the way in which the story is co-constructed can reveal the dynamics of power relations.

Carer strong, cared for vulnerable

Early in the first interview the story of Claire's most recent inpatient admission leads to an account of how Sally came to stay with Claire "for a little while" when she was discharged but never intended to be there for a year. As the story develops so does Sally's position as a carer to Claire

> Sally: But because I've been with Claire for such a long time, I'm sort of like doing all the jobs and everything and Claire's, but I'm finding that I need a bit of a break now. I need, you know.
>
> Claire: Yeah I know, probably all the stress has been taken off me.

Even in this first account of being a carer we get a sense of the responsibility and burden associated with caring and this is repeated later in the interview: "But sometimes it does take its toll you know. I mean I suffer with Osteoporosis, you know, but I'm fine".

It feels difficult for Sally to hold this position of finding her caring responsibilities difficult and she uses the phrase "but I'm fine". This may be to re-assure Claire she can cope but also to maintain the identity she has developed for herself as the carer rather than the person being cared for. By placing herself in this position early in the interviews Sally is signalling how she would like to be understood (Bamberg, 2006). Her identity as a carer in the context of this mental health research becomes important later on when we speak of Sally's own experiences of mental health difficulties.

As the interviews develop this also becomes one of a collection of stories in which Sally is fulfilling the role of carer (or in some cases rescuer) to other people:

> I've got a daughter aswell, […] umm, she had a little girl about four years ago but she had terrible anti ermm, post-natal depression and she was coping okay a little bit at the beginning I mean me, I was doing, getting up for the night feeds and stuff.

As Sally continues this story we hear about her own depression in response to her daughter's baby being adopted but this story becomes one in which her caring role prevailed and she had to be strong "I had to be strong for, for my daughter, I had to."

Strength and vulnerability are linked with the positions of carer and cared for in Sally's account and we see how it is difficult for either her or Claire to move out of their respective positions. In the extract above she talks of her own depression but again counters the suggestion of vulnerability with a statement about "not let[ting] it get to her" and having to be strong to fulfil her duties as a carer. It is hard for Sally to be vulnerable when people need her, but also being vulnerable comes with the possibility of having her own mental health difficulties.

Intergenerational narratives about mental health

In the second interview Claire and Sally tell me how they had been speaking with their brother after the first interview and he told them about a Spanish woman in their family that had "mental problems". When we talk about this in the family we learn how they first came to hear about this woman:

> Sally: Right, well it was me really, umm because I became sort of ill and I've got a little bit of a temper, but not, not, I wouldn't kill anybody or anything like that.
>
> Claire: But you just go a bit
>
> Sally: But you just get a bit, umm, little bit unreasonable but that was when I was younger, I think I'm a little but more tolerant now.
>
> Claire: Yeah, little bit more tolerant.
>
> Sally: And mum, my mother said oh, you might be something to do with this Spanish ancestor of ours, umm, who went a bit mad, and she's very very dark, well I'm the only one that's very very dark

In this extract we hear an intergenerational narrative about "mental problems" being in the genes but there is no further evidence during the interview that Claire and Sally's beliefs are influenced by this narrative.

Experience of services

Claire has a long history of involvement with mental health services and we hear about her experiences and how services have changed in this time:

> Sally: So really we have learnt about it over time and we've gone through the ranks, we're seen it when it isn't so good, when they've just left you in a room and just let you wet the bed and stuff, up to now where...
>
> Claire: Looking after me.
>
> Sally: Really look after you.
>
> Claire: Looking after me yeah.
>
> Sally: I mean, you know some places they used to, the poor patients used to scream at night and they used to just look in and just walk away didn't they, just let them get on with it.

At the beginning of the first interview Sally tells us how this was one of the reasons why Jack had found the family therapy sessions so difficult: "umm you know when she was first initially ill, the way that you were treated, umm he couldn't bear, he just couldn't bear it".

In the interviews Claire and Sally contrast this experience to how Claire gets treated now in the services:

> Claire: They treat you like you're a something.
>
> Sally: Like a human being, you know. I think that's what it is, you are a human being, not just a person that's got a little bit of a problem 'oh I'll just dust them under the carpet, they're a problem.

While it is positive that services have changed so much we are also reminded of how recently people with mental health problems were treated in such an inhumane way. Many of the adults and older adults that are currently accessing services have experienced this treatment and while services have improved the societal stigma still remains (Time to Change, 2008).

Interview reflections

At the beginning of the interviews it felt as though Claire positioned me as an authority on mental health and she frequently checked with me whether her experiences were normal. As a researcher this was difficult to manage because I wanted to validate her perspective without offering opinions that would influence the research. As the interviews went on I realised she also checked with Sally and I wondered how her experience of being labelled with mental health difficulties from such a young age may have meant that other people's understanding of her may have become more valid than her own: "yeah I didn't go to, I went to a special

school. I don't know what you know, they used to call people maladjusted […] that's what they called me."

After the first interview with Claire and Sally I was struck by how collaborative their account was, with both sisters making a fairly equal contribution to co-constructing the stories (Mishler, 1991). It was not until I typed the transcripts that I realised how dominant Sally's voice was throughout the account and I wondered whether this was a consequence of Claire's long history in services or Sally's current position as carer due to a recent inpatient admission. Some comments by Sally about sounding like their mother also made me wonder how responsible Sally felt for looking after Claire since both their parents had passed away (Leith and Stein, 2012).

FAMILY 3: JANE, TIM AND PAUL

Setting the context

When I first recruited Jane to the study she had been keen to participate with her daughter, Sam, who has also experienced mental health difficulties. After explaining the study in more detail to Jane I emailed her the information sheet and gave her two days to consider participating and talk it over with her daughter. Jane said her daughter did not want to take part but that she thought her son, Paul, may be very interested. She just had not realised initially that he did not need to have had mental health issues himself to participate.

When I arrived at their house for the first interview Jane's husband, Tim, opened the door and spoke to me while Jane finished a cigarette. I asked Tim whether he would be joining us and he was unsure. I explained again what the research was about and said he was welcome to participate should he wish to. Tim agreed to stay and see whether it was relevant for him to be there. All of the family signed their consent forms and Tim ended up participating in both interviews.

Who's in the family?

Drawing out the family tree with Jane, Tim and Paul helped them to orientate to the extended family and when we began the interview with their family experiences of mental health difficulties Tim talked about the stories he had heard from his dad or uncle about a grandfather who had bowel cancer "and it got into his brain". Tim described how this grandfather reportedly did "strange stuff" like painting the bird bath in the night and jumping off a roof. Tim says it was "sort of" a mental health difficulty but "he wasn't ill because of

depression or anything like that it was more cancer related." Tim then moved on to talk about his mother:

> Tim: I know she used to self-harm a little bit didn't she?
>
> Jane: Yeah but you didn't know that did you until after she died.
>
> Tim: No, you told me.
>
> Jane: Yeah, that's because she told me.
>
> Tim: Umm, so she got anxious and she would
>
> Jane: It was tiny little scratches.
>
> Tim: Scratch
>
> Jane: At the top of her arm.
>
> Tim: Right
>
> Jane: It wasn't very often either. Normally she used to rip the shirt buttons off your dad's shirt but that's because she was angry.
>
> Tim: But umm you know she, she didn't really, she would be angry and she would be a little bit depressed I would say, during her life she was mainly having problems with my dad […].
>
> Interviewer: Yeah
>
> Tim: But she wouldn't do anything odd. It wasn't like, hang on 'hey, what's going on here?' It was more sort of crying and smashing up and
>
> Jane: Reactive wasn't it
>
> Tim: Reactive yeah

In this extract we hear about the difficulties Tim's mother had but was unable to talk about, to the extent that she kept it a secret from him until after she died. Her secrecy is an indication of how difficult it may have been to talk about distress and mental health difficulties in Tim's family and highlights a possible intergenerational family narrative, which I will return to later. The cultural context is important to consider here; stigma and shame about self-harm and mental health difficulties would have been even more prevalent than it is today. It is possible

that Tim's mother felt safe to share this information with Jane because she too has experienced mental health difficulties and has self-harmed at times in her life, and may therefore be less likely to hold stigmatising beliefs.

Towards the end of this extract we hear Tim saying that there were no obvious signs that she was anything more than depressed or angry. Tim seems to be anticipating that either myself or the wider audience might be judging him for not knowing about his mother's self-harm and so he is justifying why he did not know about it by suggesting it was not obvious.

The word "reactive" was also used again later in the interview to describe their daughter's mental health difficulties and the connotations of this are that it is in response to something difficult that has happened and may be easier to make sense of or understand. Again as the interviews unfold this explanation seems plausible and in the section "What the hell is going on?" (see below) I will explore this further.

When Tim finished talking about his family experiences Jane said "I don't know if I want to go into my side (laughter)". I got the sense that Jane was nervous about talking about her own mental health experiences and I wondered what it meant to her to take part in this research and to tell her story to me. I wondered how Jane might have constructed me and what her fears might be in telling me information that could be used to judge her as a person and as parent. Later in the interviews I learned about the stigma Jane has experienced from mental health professionals, a theme I will return to in the section on stigma. It is likely that this was contributing to her anxiety.

Jane began by talking about her paternal grandmother:

> Okay, my grandmother on my dad's side had depression, which is what my uncle told me. Obviously I didn't know at the time but she used to go for walks in the evening because back then it wasn't talked about, you know, it was you just get on with it.

Here Jane is also talking about hidden mental health difficulties and explains how people did not talk about it and were expected to just "get on with it." This suggests that the cultural context was one in which an individualistic view of mental health difficulties dominated (Dallos et al., 1997) and people were viewed as personally to blame for their difficulties and responsible for getting themselves back to health. We do also learn later in the interviews more about how mental health difficulties were talked about when Jane and Tim were children and we are reminded that fear of being committed to an asylum was a powerful threat that may

have prevented people from talking about their mental health difficulties. It is difficult to comment too much on the impact this intergenerational narrative would have had on the experiences of mental health difficulties for Jane's grandmother and Tim's mother but we do know they had to manage on their own, without the support of their families.

After talking about her uncle that has ME Jane moved on to speaking about her mother:

> Jane: My mum is, this is a difficult one isn't it. My mum...
>
> Tim: She is...
>
> Jane: I saw a psychologist once with my mum because obviously my issues that I've had and as I came out of the psychologist said to me that my mother was emotionally inept as if she had you know the lights were on but nothing was there. Since then I have actually, we had quite a good conversation with my mum didn't we, a few weeks back and before myself she lost a baby, had *spina bifida* and died when she was six months old and my mum for the first time a couple of weeks ago was talking about her reaction and since then, this is only in my opinion, she just went, shut down. […] You try and talk to her about anything regarding emotions it's, she switches doesn't she, she's like, 'ooh did you see the next door neighbour's net curtains' and yeah so there's just nothing […]

In this story Jane is suggesting that her mum has 'issues' of her own and she brings in the voice of a professional to make this judgement, maybe in the hope that it will add extra weight to her story. Jane goes on to give an account of how her mum's emotional issues have become more understandable to her since talking about them but that she continues to be emotionally unavailable. This is the first story that Jane tells and the use of a "psychologist's" voice at the beginning to comment on her mother's emotional ineptitude suggests that Jane is setting the context for her own mental health difficulties and is beginning to provide information that will aid in my understanding of her (Bamberg, 2006). Jane goes on to mention that the only other people with mental health issues are her daughter and herself. Jane makes a distinction between her daughter's mental health issues being "reactive" and her own "I'm just nuts".

What the hell is going on?

When I ask Tim "where do you think your ideas about mental health come from, why do you understand it in the way that you do" he talks directly to Jane:

> Tim: Because I've had to. You know, because understanding why you cut, ummm...
>
> Jane: Used to...

Tim: Used to, understanding why you are doing this to yourself. But I originally thought it was…or the way I took it, it was against me. It was like you're doing it to hurt me. […] I remember one time taking you to [name of hospital] and kicking you out.

Jane: Yeah I remember that.

Tim: Literally kicking you out (laughter).

Jane: Ummm yeah, I remember that.

Tim: Because I was a bit angry. Ummm...

From this extract we get a sense from Tim that he had to know why Jane was doing the things she was doing because to begin with it felt very personal against him and he would feel very angry with her for doing it. They go on to talk about some other things that were happening for Jane including attempting to hang herself, getting chased by the police and taking an overdose. Jane talks about her limited recollection of the events: "I can't remember a lot of it to be honest with you… I can remember the big overdose when I nearly died. Cause that's just one of the times that I'd ever seen you angry."

Tim talks about his initial response to these events being "shock, just what the hell is going on, you know. And it was going through my mind, I just want to walk. I'm out of here you know." And he describes the impact it had on his emotions: "Yeah when all this was happening it was, you know, I was angry all the time: Angry at the situation, angry at why it was happening, and my ability not to be able to control it". We get a picture from Tim's account of how difficult it was for him initially to have any understanding and Paul agrees with this saying "I was clueless at that point too."

Tim talks about how "health professionals, police, […] the local CMHT" all helped him by explaining what was going on and he could then explain to the children.

From this section of the interview we hear how distressing this period was for everyone and how difficult it was initially for them to make sense of what was happening. Ayres (2000) in her research into the process of meaning-making in narratives of family caregiving identifies the important role of explanations for construction of meaning. She shows how negative explanations can limit caregiving strategies (Ayres, 2000), and although her research was into physical health conditions, it seems likely that these findings can be applied to caregiver's meaning-making in mental health difficulties. For Tim we can see how in the absence of any

other information he tried to make his own sense of what was happening and interpreted Jane's behaviour as an attack on him. Tim describes how this left him feeling angry and that he found it hard to care for her, considering leaving, and on one occasion kicking her out.

Wanting more information

Tim describes how mental health "wasn't really spoken about" in his family when he was younger and how "the whole understanding, all the different ranges of mental health it was never explained to me at school or anything like that". Tim seems to be questioning whether some knowledge about mental health prior to these experiences may have made it easier and possibly less of a shock. This fits with Ayers' (2000) research which suggests that had Tim had more understanding of mental health difficulties he may have been less likely to interpret Jane's behaviour as a personal attack and may have been more able to offer care and support.

Paul describes how understanding his mum's difficulties was a process of "learning as you go" and it was not until after the first couple of admissions that he started to understand a bit more. Paul commented that it would have been helpful to have had more information earlier than this to make his experiences less worrying. Research with young people whose parents have a mental health problem has frequently shown that they want more information about this (Tunnard, 2004). Nolte (2013) identifies how important it is for children to "develop a clear understanding of their parents' difficulties" (p.42) because this has a protective function and reduces the likelihood that the child will feel responsible. Information also helps the child to make sense of the parent's behaviour and experience it as less frightening and unpredictable. This is one of the issues that programmes like the *Kidstime* project attempt to address by inviting young people to talk about mental health issues and develop an age appropriate understanding of what is happening for their parents (Cooklin, 2012).

Understanding mental health difficulties

When I ask Jane whether she has struggled "for most of your children, sort of most of your adult life" she tells the story of her own mental health difficulties:

> Jane: No, well I started off with anxiety, it's really weird because I can remember my parents split when I was ten and I can remember when I was 13/14 and my dad taking me to the doctors and then I was sent out into the waiting room and then I just remember my dad coming out and saying 'the doctor said I've got to give you lots of cuddles.' […] looking back now I used to get a lot of tummy pain so I'm thinking you know, maybe that was anxiety. Then when I was about 18/19 I started getting panic attacks, that was fine,

we could live with that and obviously we got married and we had the kids, that was fine. Then umm a few bits of OCD traits crept in, which was manageable, it was fine. I was working and living a normal thingy and then his mum passed away and it just went 'wooooooof' into a big massive, just...

Paul: Mess.

In this extract we can see how Jane begins and ends this account with two key events that she identifies as contributing to the start of her difficulties (her parents' separation) and the significant increase in intensity of them (the death of Tim's mother).

In thinking about how his family understand mental health difficulties Tim talks about how his father and brother don't really get it:

Tim: When trying to understand what's happening in the past with Jane it's, I'm trying to explain to him what's going on and he just doesn't get it.

Paul: I don't think [Tim's brother's name] would either

Jane: No [he] doesn't get it either

Tim: Yeah [he] just says oh, he hasn't said this to me he's said this to you 'you're always going to be ill, you've got this problem.'

Tim goes on to say that although his dad struggles to understand he is able to put that aside and try to offer support. Tim suggests that his father doesn't really understand the emotional impact of it all and describes his response as the "donut syndrome" because he will bring round Tesco donuts to "sugar coat" any crisis.

This conversation gives us an indication of why Tim's mother may have felt unable to talk about her distress or self-harm with her family. Tim describes how his understanding has definitely changed over time and that at one point in time he probably shared similar views to his brother. This suggests that their understanding was shaped by an intergenerational narrative but that Tim's understanding changed as a result of his experiences with Jane.

When Jane first considers whether her beliefs have changed over time she talks about how her father brought her up to be accepting of people that were unwell. However, as Jane thinks about this further she remembers that actually when she first had anxiety attacks her "worst fear in the world was being admitted to the nuthouse". Jane describes how uncomfortable it feels to look back on herself thinking like that but acknowledges that her views were informed

by her social context. Jane and Tim talked about the asylum in their local area and how people would talk about there being "nutters and crazy people" in there who would "bite your ears off". During this conversation Jane and Tim discuss how mental health would often have been associated with people that were "physically and mentally handicapped", people that today may be known as having learning disabilities. Jane and Tim discuss the negative language they would have used to describe people but this was "what was going on" for their generation when they were children. They also discuss how depression and things were not really talked about but schizophrenia was and people with schizophrenia would have been seen as "crazy, scary, nutty people".

When Jane and Tim talk about the dramatic change in their understanding from then to now they partly cite their parents as an influence but the main factor they identify is their lived experience. Kellas and Trees (2006) identify how families may change their beliefs in response to the stress and disruption caused by difficult family experiences. In Jane, Tim and Paul's accounts we hear about the intergenerational narratives that have shaped family beliefs but their willingness to participate in the research indicates that they are no longer operating according to a belief that mental health difficulties should not be talked about.

These findings have important implications for stigma because many families will never experience severe mental health difficulties and may continue to hold beliefs that have been passed down the generations of their family. Here we can see why stigma may remain relatively stable despite ongoing campaigns for change (Time to Change, 2008).

Paul's perspective on this issue is interesting because he represents a younger generation and yet still describes how it was "learning as you go" because there was never anything in school about mental health difficulties until his mum became unwell.

"Laughing, crying and talking about it"
When I ask the family what has helped them to "pull together" and be supportive Tim talks about how his view of Jane's difficulties has helped:

> I think it's just the view of you know, it's a temporary thing, it's not a permanent thing.
> So we've always thought about it, well in my view as an illness and you get through it,
> you get past it, get over it and you support Jane. You know if she'd busted a leg you know
> it's a physical thing. She's just got busted head (laughter).

By drawing on a medical conceptualisation of Jane's difficulties Tim removes any blame that could be attributed to her or the family (Dallos et al., 1997). This represents a significant shift in his understanding from when he first experienced her cutting as a deliberate act to hurt him. There is also a sense that Tim is saying you would never walk away and leave someone for a physical illness so why would it be acceptable to leave them for a mental one. This ties in with Jane's comments that people need to realise you can be "unwell in the mind" not just the body.

Jane describes how she couldn't understand at the time why he stood by her:

> You know I can remember screaming at Tim you know, 'why the hell are you with me' and him just standing there and going 'because I love you' and I'm just like 'what'. I mean now I say it and I get all choked up and I think 'ohh bless him'.

Jane goes on to describe how important her relationship with Tim has been and how it has helped her:

> Laughing, crying and talking about it, you know. I mean even now when I'm having a crappy day or crappy few days he'll just stand there and he'll say to me, give me a hug and that's it, I'll just cry. Which is something I've always had a problem with but since I've learned how to cry it's been a lot better. And ermm you're quite good at making me cry now aren't you?

In this story we hear about the strength of the relationship between Jane and Tim and how important his support has been to her in the difficult times but also now during a period which she describes as "recovery". There is a sense that Tim is able to help her to stay 'well' by helping her to regulate her emotions through crying.

Feeling and being treated like a person again

Jane talks about herself as being "well into recovery" and an important part of this being her decision to apply for nursing training. We hear about the impact this is having on her life: "I do feel worthwhile, I do feel like I'm doing something and it's like it has always been there but just never come out". She goes on to talk about the importance of feeling that she has a purpose:

> It's having a purpose. But I think to have a purpose you've got to do it for yourself. You can't expect somebody to do it for you but you need support and I think that's the important thing having support and having somebody that's sort of having the faith in you that you can do this.

In talking about "recovery" Jane is positioning herself with a social movement in which people began to challenge the mental health systems by writing about their experience of major mental illness and the negative impact of the system alongside stories of "hope, empowerment, and a journey of recovery" (Kirkpatrick, 2008, p61). The idea of recovery is associated with becoming more fully human (Deegan, as cited in Kirkpatrick, 2008) and we hear this in Jane's story of recovery "so I think that it's made me feel like a person again and not just a label", which Jane contrasts with her experience of the system as being de-humanising: "my god how can they treat people like that. We're humans you know." Jane describes how staff at the CMHT changed their attitude towards her when she started university and how horrible she finds this: "Why should somebody be treated like that, you know, it doesn't matter what you do as a profession if you're unwell you're unwell."

In their research into mental health patients' experience of being misunderstood Gaillard, Shattell and Thomas (2006) identified how people's mental illness and diagnosis became a "totalizing frame of reference" and how it overshadowed their other qualities and reduced their identity to a single aspect of their lives.

Labels matter

In the first interview Jane talks about the experience of being labelled and how she went "absolutely ape" when she was diagnosed with a 'personality disorder' and has since managed to change it with the help of a psychologist. In the second interview I return to this issue of labels and Jane describes some of the stigma she has experienced from services as a consequence of the actual diagnostic label she was given. Jane tells us how depression compared to personality disorder made a significant difference to the ways she was treated by mental health service staff:

> Interviewer: Last time […] you listed different labels that you've been kind of given but actually that's not something you wanted and that those different labels have been quite difficult at times depending on what it was.

> Jane: Yeah, because you find that a lot of mental health staff they look at the diagnosis and not the person. So, one of my diagnoses […] was depression, I had an admission and […] they couldn't do enough, they were lovely, helpful, everything. Umm the next time I was admitted my diagnosis had been changed to borderline emotional […] personality disorder and that was it, I could have just been a piece of poo on the floor. […] so that's why I don't like labels.

Tim also talked about a similar difference in attitude in Accident and Emergency when Jane was seen for pneumonia rather than an overdose.

> if she'd slashed her belly open they'd be you know stick a canula in but not really be sort of too you know, bothered about it if it hurts because 'oh this person hurts herself so it doesn't matter if I hurt her' sort of thing.

In these extracts we hear stark examples of the de-humanising treatment Jane experienced and how her diagnosis affected this. Jane talks of the stigma in other mental illnesses but feels that it is self-harm and suicide attempts that attract the most negative responses even though they are a communication of intense distress and suffering. Jane feels that lack of education has a lot to do with the stigma and that people do not seem to understand that you can be "unwell in your mind as well as your body, just because you can't see it, it doesn't mean it's not there."

It's not always easy to laugh

When we talk about how the family cope humour emerges as something which they have always had as a family but which has been an important resource for coping with difficult events. The use of humour is evident throughout the interview with this family and even when talking about quite extreme and potentially traumatic experiences they use humorous descriptions and laugh a lot:

> Tim: I remember restraining you. You were trying to hang yourself.

> Jane: That was when I fell on you (to son)

> Paul: Oh bloody hell

> Jane: I shouldn't laugh (laughter) that's when he pulled me out of the tree and I landed on him, because I was really fat then as well. […] and I squashed your legs didn't I

> Paul: You fell out and somehow I managed to drag you back in here. That's when you started running around like a dog.

> Tim: (laughter)

> Jane: (laughter) stop laughing, it's not funny. Well I know you shouldn't laugh but looking back now I just think 'oh my god' I was, the stuff I got up to

> Tim: Umm

> Jane: Getting my bum stuck in the window (laughter)

Paul: (laughter)

I get a sense that humour is quite protective against the difficult feelings that talking about these events brings up but that it also strengthens the bonds between the family members.

Both Tim and Paul talk about times when they were finding it hard to cope and experienced some emotional difficulties of their own. Tim talks about isolating himself in the house and not feeling able to even go to the shops across the road "all this was happening it was probably just stress and anxiety on my part. Ermm, I found it a little difficult to go out. So even going over the shop, I just didn't want to, you know."

He also describes times when he has "boiled over" and "destroyed something" and he tells the story of a minor event triggering his anger:

> There was a KitKat on the ceramic hob, […] my daughter had come down and she had eaten half of it and just left it there and gone out. And I had just cleaned the place and I saw that and I just went 'bing' red. I punched the KitKat and (laughter) actually I went through the ceramic hob and destroyed the, well it was just ruined, the whole thing was ruined.

Paul also describes a time when he was finding it hard to cope and attributes this to "stress from normal daily lives". Paul describes how he went "a bit mental" and "a bit depressed" because there was just too much stress with work and home life. He identifies that talking made things feel easier and gradually the stress reduced and he started to feel a lot better. Jane talked about how her "ears prick up" when either of them show any signs that they might not be coping and she describes how she is able to recognise when Paul is stressed because he goes from being very laid back and "taking the piss" to being grumpy, slamming doors and swearing or being completely quiet. Nicholson et al. (as cited in Nolte, 2013) identify that parents are typically fearful of their children developing mental health difficulties and so will "scrutinise their children for signs of mental health difficulties" (p.32). This is an important theme for Jane because there are strong social discourses about mothers with parental mental health difficulties being unable to care for their children. On two occasions during the interviews Jane and Tim make reference to Paul not having been affected by his mother's mental health: "So you're about the only sane one aren't you my dear" and "But you came out okay though didn't you".

How are families supposed to manage?

At the end of the interview I asked the family whether there was anything they wanted to add before we finished. Tim took this opportunity to comment from his perspective about what services could have done to support them. Paul talks about there being no service out there that can help family members support someone in crisis and described the dilemma of calling an ambulance or the police because it doesn't feel serious enough and yet there is no-one else available to ask for help. Paul describes the chaos of having to physically restrain Jane to prevent her from harming herself and having to ring the police or try and get her to Accident and Emergency where she would be made to sit for four hours with the "pissheads". Jane described how this would make her "feel like shit". In this final section we can hear how isolated and ill equipped Tim has felt in trying to support Jane. Many families are expected to live with and support family members 24 hours a day and they get no training.

Interviewer reflections

On completing the interviews with Jane, Tim and Paul I was left with the sense that the intensely difficult experiences they have been through have strengthened the bonds between them. In the interviews they created a family identity of being "close knit" and very supportive of one another. They described how their sense of humour has helped them to cope, as a family, and stick by each other when life got difficult. However, we also heard from Tim that it wasn't always like that, there were times when all he wanted to do was to walk away. When Tim described how you would not leave someone with a busted leg and Jane has just got "busted head" we hear social discourses about the moral obligation to care for each other in families (Breheny and Stephens, 2011) and to stand by the ones we love 'in sickness and in health'.

I also felt that in sharing with me some of the most difficult experiences they have been through the family were able to tell an even more powerful story about their ability to overcome their difficulties. I was left with an impression of 'triumph over adversity' and the beginning of a new chapter in their lives. Jane was due to qualify within two months of our interviews and Paul had announced he would be moving out of the family home.

REFLECTIONS ON THE THREE FAMILIES COMBINED

In this section I will present my analysis and discussion of the three families combined. By considering the patterns and divergences in the narratives of the three families we can gain further insight into how families narrate their experiences of mental health difficulties. It also

gives us an opportunity to look in more detail at the interactional elements of storytelling, and the processes involved in constructing identities (Bamberg, 2006).

I will begin this section by thinking about one of the intergenerational narratives that was identified in all three families "it is not okay to talk about mental health difficulties" and I will also consider how different family members' relationship with distress communicated a further dimension to this narrative "it is not okay to have mental health difficulties". This will provide an opportunity to look at how stigmatising beliefs are managed by the families and to consider the relevance of these findings for stigma in the wider social and cultural context.

Having done this I will move on to looking in more detail at what happens when families talk together about mental health difficulties. Through these interviews I have come to understand how complex this process is and how many factors need to be taken into consideration when analysing families' conversations. I have chosen to write about stigma and beliefs about mental health difficulties first because these are two important factors that influenced how the families in this research talked about their experiences.

The legacy of a label

In these interviews we can see some of the intergenerational narratives that have influenced the families' experiences of mental health difficulties. For all three families we learned that previous generations held a belief that it was not acceptable to talk about mental health issues and so family members would be isolated in dealing with their difficulties. Implicit in this message is the idea that there is something wrong or bad about having mental health difficulties and it is something that should be kept secret. This message can be related back to the history of how people with mental health difficulties have been thought about and treated in previous generations. In the interviews we see evidence from all three families that stigmatising beliefs have been passed down the generations and continue to have varying degrees of impact on their lived experience. As Jane and Tim discussed, it was in recent history that people were put in asylums and despite having a better understanding of mental health difficulties Jane still feared being put in "the nut house" when she first experienced mental health difficulties. As outlined in the *Introduction* the prevalence and detrimental impact of stigma is widely recognised (WHO, 2002) and yet efforts to change beliefs have had limited success (Time to Change, 2008).

From Jane's family and Claire and Sally we heard how their lived experience of mental health difficulties, through themselves or their family member has helped to change some of their beliefs and understanding about mental health difficulties. They attribute this to their need to understand so they could cope, but also their contact with mental health services and the information they were given by professionals. Sally and Tim both talked about how their change in understanding has helped them to move away from stigmatising beliefs and this meant they were more able to offer care and support to their relative. Sally in particular highlighted how this changed over time and how in the early days she did not know how to talk to or support Claire because she did not understand what was happening.

In contrast to Sally and Tim's experience we learned that for Leona and Mark the narrative about mental health difficulties being unacceptable and something which people should not talk about has continued to have a marked impact on their family life. Unlike Sally and Tim, Leona has never been involved with Mark's contact with mental health services and it is possible that this has made it more difficult for her to change her beliefs about mental health issues. It is also important to recognise that Leona represents a different generation in the research and was brought up at a time when the stigma associated with mental health difficulties was more prevalent and perhaps more powerful because of the fear of being locked in asylums. Sally and Tim talked about how their change in understanding enabled them to offer more care and support to Claire and Jane, perhaps Leona was unable to support Mark because this intergenerational narrative prevented her from engaging with his experience and seeking greater understanding.

Despite Sally, Tim and Paul being able to talk about how they understand mental health difficulties and how this has helped them to move away from stigmatising beliefs there is still evidence of these beliefs in their talk and interactions. They give a clear message that it is okay for 'you' to have mental health difficulties, but I do not want to be seen as having them.. Tim, Paul and Sally all talk about times when they have experienced intense levels of distress and periods of not coping but they make it clear that this is not the same as having a mental health problem.. They do this by identifying Mark, Claire and Jane's difficulties as 'different' to their own, in terms of intensity of distress or 'odd' behaviour. For all family members with the exception of Claire it seems that accepting the label of mental health difficulties was experienced as a threat to their identity and so they all used a range of discursive strategies to try and manage this. This included: contextualising their difficulties; locating their distress in the past; denying they have any mental health needs; and drawing on different explanatory

models of mental health difficulties. Even when one of the 'well' family members (Sally) has been diagnosed with a mental health problem they make it clear that this was a very temporary thing and give the message that it is not the same as their relative's difficulties.

This demonstrates to us how powerful stigma is and that even in families where their beliefs have significantly changed there is still a dominant discourse about what it means to have mental health issues. This is where it becomes important to remember that families are not operating in isolation and even if they are trying to move away from stigmatising beliefs they still live within and are affected by the beliefs and values that exist within their wider social and cultural context. To understand the impact of the wider context on people with mental health difficulties we need to look no further than the negative consequences we heard about from Jane, Claire and Mark. Some of the consequences they talked about were familiar from the literature and relate to the more broader quality of life issues: being labelled as "ill" or "mad"; social isolation; loss of employment; de-humanising treatment and breakdown of relationships. Other consequences, which this research has more clearly highlighted, are the more subtle, harder to detect and yet equally damaging relational consequences that are played out in families day to day lives: normal behaviour being pathologised; opinions being discredited and being denied a 'voice'. This helps us to understand why family members may make desperate efforts to avoid being labelled with mental health difficulties. These appear to be some of the relational mechanisms through which stigma is maintained. Family members protect themselves from the label by locating the pathology within their relative, who becomes seen as "increasingly different from the others" (Dallos et al., 1997, p.377). This gives some insight into why it may be so difficult to change stigma in the wider social context.

The other aspect of stigma which was present in the interviews and can help us understand why it is so difficult to change is the idea of 'courtesy stigma' (Goffman, 1963 as cited in Karnieli-Miller et al., 2013) or stigma by association. This is the stigma that extends to family members and as described in the *Introduction* can result in them being rejected, blamed or devalued (Karnieli-Miller et al., 2013). During the interviews it was clear that the families rarely talked with anyone outside of the family about mental health difficulties and the experiences they were going through. The literature on stigma indicates that this often happens because of courtesy stigma or stigma by association. For parents and partners there is stigma around being blamed for causing the person's difficulties or not helping them to get well/ stay well (Corrigan and Miller, 2004). For children and parents the stigma is more about

contamination and people believing if your child or parent has mental health difficulties you probably do too (Corrigan and Miller, 2004). In the interviews we could see how this stigma was affecting how the families responded to mental health difficulties. Both Sally and Leona worked hard to explain why their children had mental health difficulties in an attempt to resist the blame associated with contamination stigma.

It is unsurprising that families did not speak about their experiences with many other people given the risks associated with this. Again, we can see from this how stigmatising beliefs are maintained because the silence perpetuates the idea that mental health difficulties should not be talked about and that there is something bad and/or shameful about them. When the discourses are so powerful it can be difficult to risk talking about these issues and yet we know that people's attitudes and beliefs will not change unless these messages are directly challenged and they are given information that contradicts the stereotypes.

For Claire, Jane and Mark we can also see the effect stigmatising narratives have on their own willingness to align with a label of mental health difficulties. Jane and Claire show a willingness to accept the label but they both work hard in different ways to make sure they do this in a way that reduces the negative implications. For Jane we see her labelling herself as 'mad' back then, describing herself as "nuts" or "off [her] tree", but on the 'recovery journey' now. This is a discursive strategy which places her in a position of being able to say that was then, this is now, and in doing this she can distance herself from the stigma and negative consequences of having a mental health difficulty.

For Mark we see a different process of negotiation which may be because of his intermittent contact with services and to my knowledge has never been given a label, but is also likely to be because of the stigma within his family about mental health difficulties. He has to make a difficult choice between accepting the label and having his opinions discredited and his behaviour pathologised, or rejecting the label but not being able to get help and support. Mark's struggles with the label gives us insight into why some people may be reluctant to seek help from services.

These findings demonstrate some of the relational mechanisms which maintain stigma within families and highlights the negative impact stigma has on families' experiences of mental health difficulties. This give us some insight into the reasons why stigmatising beliefs are so difficult to change. There are significant implications of this for the assumptions we make when working with families but also for the strategies the government and other organisations

use in attempting to address stigma at a societal level, issues I will return to in the *Clinical Implications* section.

What happens when we talk

Analysing the transcripts for all three families and looking at the narratives that emerge has shown the complexities involved when families talk together about their experiences of mental health difficulties. The transcripts show that the process of narrating is not simply a recounting of past events but instead is a complex, multi-layered, fluid process which is influenced by family members' attempts to negotiate a range of factors. These include: construction of their preferred identity; their positioning by each other but also by their involvement with this research and by social and cultural discourses; issues of power[3]; the state of their family relationships; and intergenerational beliefs about mental health difficulties.

The context of the interview is important to acknowledge here because recruitment through mental health services positioned one member from each family (Mark, Claire and Jane) as people that have experienced mental health difficulties and gave the other family members the opportunity to be positioned or position themselves as 'well'. This places Mark, Claire and Jane in a difficult position because we know from the previous section that they have experienced negative consequences of being labelled with mental health difficulties including having their opinions discredited and not being able to have a voice. Each of the family members has a different strategy for navigating this issue depending on what other factors they must also address. By considering the differences between the families in dealing with these issues we can begin to see what influence different factors have, what strategies family member's use to address the issues and what impact this has on the process of narrating their experiences.

Mark begins the interviews by accepting the position he is given and then attempting to provide the context to his difficulties signalling to me that his difficulties are understandable. Had the interview been with Mark on his own it is possible that he would have been happy to position himself in this way throughout the interview as his experience with other

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[3] It is important to acknowledge that much has been written about power in different contexts and it is a very complex phenomenon which continues to be debated. For the purposes of this research I refer to relational power which family members use when they are trying to establish or protect their preferred identities.

professionals has shown him that he can have mental health difficulties and still have a voice. However, Mark is not only narrating his experiences to me; his mother is also present in the interviews and she is in a position of being able to support or dispute his account. Immediately we see Leona disputing Mark's account by suggesting Aunt Jenny is not a member of the family and in doing so she is undermining Mark's attempts to justify his mental health difficulties. Later in the interviews we learn that Leona holds the intergenerational belief that it is not okay to talk about or have mental health difficulties and it becomes likely that this is part of the reason for her denial of Aunt Jenny as a family member. This issue is further complicated by the fact that Mark and Leona both told me before the interviews that they have a difficult relationship and that Mark is an adopted child and so the issue of who is family is not straightforward.

To manage this conflict or difference of opinion they each attempt to demonstrate their own credibility and the credibility of their accounts. Mark and Leona both work hard to try and establish themselves in a position of power, which increases the likelihood that their account will be seen as credible. For example, when Leona contests Mark's inclusion of Aunt Jenny in the family he responds by telling a story in which he can position Leona as a bad mother. Here Mark would seem to be discrediting Leona so that his account is accepted. This is important to Mark because Aunt Jenny is an important part of his justification for why he has mental health difficulties. This influences how the interview unfolds because Leona is then forced to try and establish her own credibility and she does this by telling a story that disputes Mark's account and positions herself as a good mother. As the interviews progress the conflict continues between Mark and Leona and we eventually hear Leona using Mark's mental health difficulties as a reason not to believe his account. This is a contradictory position for Leona to take because prior to this she has clearly stated that no-one in her family has any mental health difficulties. Leona may have resorted to this because her identity as a mother was at risk and other attempts to establish her credibility had been unsuccessful. Leona needs to remove Mark's power if she wants to prevent him from being able to challenge her account and she does so by drawing on a label which is associated with powerlessness. Once Leona has done this Mark is forced to respond again but this time his personal credibility has been compromised and so he no longer has the power to offer a different account. Instead he must find a way to become credible again, and so here we see him stating explicitly that he does not have mental health difficulties. Mark is forced into a position of contradicting his earlier account in which he outlined the reasons why he does have mental health difficulties.

Within this example we can also see how both Mark and Leona use a strategy of drawing on broader cultural narratives about good parenting or mental health difficulties in an attempt to strengthen their own accounts. By using dominant discourses they are increasing the likelihood that their account will be seen as credible and will therefore be more easily heard and accepted. They are also using discourses which have power implications, adding weight to their attempts to demonstrate their own credibility and discredit the other.

When considering the process of Mark and Leona's storytelling we can see from their transcripts that there was very little collaboration or co-authoring of accounts. Instead there are large sections of uninterrupted speech from each of them and on rare occasions sections of conversational storytelling (Kellas and Trees, 2006) in which one would tell a story and the other would interrupt with comments. It is likely that their difficult relationship prevents them from collaborating to create shared stories and it is also possible that the intergenerational narratives in Leona's family mean she is reluctant to join in these conversations with Mark.

Jane uses a different approach to Mark to make sure her positioning by the research does not mean her opinion is discredited. By talking about being on the 'recovery journey' and reflecting on her past experiences of mental health difficulties Jane establishes herself in a powerful position. From this position Jane is able to use the recovery movement to establish her own credibility while at the same time distancing herself from any negative assumptions people may make. It may be easier for Jane to hold this position within her family because she is interviewed with her husband and son who have supported her through her difficulties. In this family we can see how relational power within the family is less contested when talking about mental health issues because they are not offering accounts which threaten each other's preferred identities.

In Jane's family we also see a different pattern to the narrating when compared with Mark and Leona. They engaged in shared joint storytelling for large sections of the interview, constructing family accounts of events and experiences together. On occasion they would change and narrate their account individually but this was typically only when telling stories of their experiences that are not shared by the others, for example, when Jane talks about her childhood. There is a sense throughout the interviews that Jane, Tim and Paul have negotiated the difficult experiences associated with Jane's mental health as a family and that sharing information and talking together have been features of this process.

For Claire and Sally we also see different issues arising and different processes of narrating their experiences. Claire makes no attempt to dispute the label of having mental health difficulties at any point during the two interviews. Instead she does a great deal of work to contest the negative associations of the label, using her stories to construct other people with mental health problems as "nice people" and "bright people". In thinking about why Claire uses a different strategy to Mark the history of her difficulties and her current circumstances seem important. Claire and Sally tell stories in which she has had mental health difficulties from the age of 6, and as the interviews progress it seems that Claire has grown up with the understanding that this is a part of her identity.

Claire and Sally's pattern of narrating was also different to the others and again perhaps reflected Claire's history of being identified as having mental health difficulties. Claire and Sally moved between 'conversational storytelling' and 'shared joint storytelling' (Kellas and Trees, 2006, pp.4-5). At times when Sally was the main narrator we would see Claire as the co-author usually offering comments and demonstrating agreement with Sally's perspective. When Claire took the lead in narrating a story, which happened less frequently, Sally would begin as a conversational partner but this would often progress into shared joint storytelling where they would construct the story together. The power dynamic is important in considering how Claire and Sally narrate their experiences. Sally is currently Claire's carer and this role is enacted within the interviews, with Sally dominating the narrating process, even when talking about events from Claire's life story (Stephens and Breheny, 2013). Sally is in a different position to Tim, Paul and Leona because she is the only family member that was not recruited through mental health services but has been previously diagnosed with mental health difficulties. Sally finds it very difficult when she finds herself talking about these things in the interview and is adamant that she is not "mad". By maintaining power in the relationship Sally can control the stories that emerge and in doing so can protect her own identity. Unfortunately the consequences of this for Claire is that the pathology continues to be located within her and Sally uses discursive strategies of minimising her own difficulties and emphasising Claire's.

We can see from this section that the process of constructing identities changes significantly when there are multiple family members present during the interviews. Bamberg (2006) talks about how people construct, contest and negotiate their identities through 'small story' everyday interactions, a process which is made more dynamic in the presence of other family members. This research demonstrates how relational power is used by the family members to

increase the credibility of their accounts when their preferred identities are under threat. For example Leona is positioned by Mark as a 'bad mother' and must then work hard to contest and negotiate this if she does not want to accept it as part of her identity within the interviews. One of her strategies for doing this is to place herself in a more powerful position than Mark. However, this is not a simple task because each time Leona contests Mark's view he offers further evidence to re-position her as a bad mother. Eventually Leona must resort to placing Mark in a powerless position and in doing so leaves him no option but to deny his mental health difficulties and risk being unable to get understanding and support.

We can also see from this analysis that the family as a whole and each member has different things at stake which affect how they talk about mental health difficulties: identity construction and reluctance to identify as mentally ill; positionings within the family (negotiation of own and others' position); attempts to meet their needs; and attempts to gain understanding and support from family, from services and from the researcher. This has significant implications for clinical work because many services operate by offering individual interventions to people. This may reinforce the pathologising of one family member and it fails to take account of their social environment and what family processes or dilemmas may be maintaining their difficulties. Dallos et al. (1997) concluded from their research that "we need to try all the harder to avoid colluding with pathologising practices" (p.396) and while there are things clinicians can do on a local level it also requires a shift in how services conceptualise mental health difficulties. I will return to this point in the *Clinical Implications* section.

Finally, I have shown in this section the complex processes involved when family members talk together about their experiences. The narratives families create during an interview are influenced by their relationship to the topic being discussed, the state of current relationships, the struggle for power and credibility, attempts to construct individual and shared identities, historical relational patterns, social and cultural discourses and intergenerational beliefs and values. There are implications of this for research, in that many aspects of a family's shared understanding will remain unavailable to the researcher when people are interviewed on their own. I feel that interviewing families together and attempting to analyse their accounts in this way has allowed me to capture a richness in the data that like Van Parys & Rober (2012) has "opened up new ways of understanding the complex, dialogical processes in families" (p.10).

CHAPTER 4: CONCLUSIONS

CONCLUSIONS

I realise as I reach the end of this project that my research idea may have been overly ambitious. I never imagined how complex a process it would be to analyse families' stories and I now understand why it has rarely been attempted and why Van Parys and Rober (2012) tried it on a very small section of transcript.

I began this project with a straightforward definition of the term 'intergenerational narratives' and clear research questions, which I expected to be able to delineate easily within the research. It was initially exciting, but very daunting, to discover that it would not be so simple. As I analysed my data I was forced to revisit my understanding of the term "intergenerational narrative". On occasion there were the stories I had come to expect about the great aunt that was mad and put in an asylum and the messages this contained about mental health difficulties being something you should get locked up for. But most of the time the intergenerational narratives took on a different form. Rather than static accounts of past events they were moments of talk and interaction between family members. The narratives were dynamic and fluid, open to challenge and negotiation and subject to change dependent on what messages were being conveyed.

In the introduction to this project I wrote about systemic theory and the idea that intergenerational beliefs influence families' experiences of mental health difficulties. I also identified that to date little has been written about how intergenerational beliefs are maintained and passed between the generations. This research demonstrates that beliefs about mental health difficulties are present in the stories families tell about previous generations but they are also communicated through small story interactions, moments of talk or moments of silence. Through a combination of silence and simple statements "no-one in my family has mental health issues" Leona communicates the intergenerational belief to Mark that it is not okay to have mental health difficulties.

I also realised that what my research was giving us most insight into was the ways in which families use social interaction to actively construct their experiences and perform their identities (Bamberg, 2006). This relates to my research question: '*How are mental health issues talked about in the family'*. My research has also shown how influential family members are in each other's performance of identity and how they draw on wider social and cultural contexts to position each other *which related to my third research question: 'What*

influence do intergenerational narratives have on family members' construction of individual and shared identities?. In this respect I have learned that to understand families' experiences and the ways in which they narrate these experiences we must recognise that it is not just the context of the interview that is inextricably bound with the social and cultural contexts (Phoenix, 2008), but it also their lives and the lives of previous generations.

This very issue meant that while my research identified some of the intergenerational narratives and times when they were more or less influential on families' beliefs and understanding about mental health, the influence of these narratives could not be separated from that of the social and cultural context.

It is important to acknowledge that the full potential of this data could not be realised within the bounds of this project, but what I have attempted to do is to take the first step towards working with the richness and complexity of the data rather than separating it out into individual strands which lose sight of the importance of social interaction and context for shaping the ways in which people narrate their lives.

CLINICAL IMPLICATIONS

There are some important implications for clinicians and services from the findings of this research:

The importance of involving families

Clinical work in mental health services often involves seeing people in a clinic or inpatient setting on an individual basis. Under these circumstances the relational and wider social and cultural contexts may be forgotten or demoted in their significance. This research has demonstrated how influential family members are in each other's identity construction and storytelling. By only working with individuals in services clinicians gain no insight into how these processes may be affecting the person's lived experience of mental health problems. The 'pathologising practices' which happened in all three families make it very difficult for people to move out of an "ill" position and should be addressed by services by working with families rather than individuals. By offering individual interventions services are reinforcing the pathologising of one family member and may be inadvertently setting people up for long-term involvement with services (Dallos et al., 1997).

Tackling stigma

Recent findings from the Time to Change campaign have shown that despite significant investment they were unable to meet the targets set for their first four years of improving public attitudes and reducing discrimination by 5%. This research has shown that even in families where they feel their understanding about mental health difficulties has changed and they have moved away from stigmatising beliefs the negative ideas and attitudes about mental health difficulties are still being maintained. These families have had first-hand experience and access to far more information than people would get through stigma campaigns and yet mental health difficulties are still experienced as an intense threat to their preferred identity and in defending against this they may inadvertently pathologise one member and/or maintain stigmatising discourses. This research has highlighted again the negative consequences of being labelled with mental health difficulties and raises the question of whether seeing a family member experience these negative consequences increases the likelihood that family members will feel threatened by the label and will inadvertently maintain the stigma through relational mechanisms.

This research indicates that for stigma to change it is not enough for people to have more information or to have contact with more people that have mental health difficulties. Further research is needed into the mechanisms that help to maintain stigma and a new approach is needed which attempts to address the negative consequences people experience when they are diagnosed with mental health difficulties.

Trying not to do more harm than good

In addition to reinforcing beliefs about 'pathology' within families there is also evidence from this research that services and professionals may share in stigmatising beliefs and that these influence their practice and in some instances mean that contact with services may do more harm than good. Jane's description of her treatment for mental health compared to physical health provided a shocking example of this and brought home how powerful and entrenched stigmatising discourses are. This research has shown how embedded stigma is within our cultural and social discourses and professionals as much as family members come to the field of mental health with pre-existing beliefs that may be very entrenched.

In this research we have seen that loving, supportive families that oppose stigma may continue to be influenced by it and are likely to be unaware of its presence and the impact it has on their family members. This may be similar for professionals and to change people need to

understand the impact of stigma on their practice and be given support to reflect on their beliefs about different diagnoses. I also believe that it is the responsibility of every clinician to challenge stigma among professionals in a thoughtful way.

METHODOLOGICAL CONSIDERATIONS

Strengths

A main strength of this research is that it uses an innovative approach to exploring families' experiences of mental health difficulties. As such it contributes to our understanding of the processes involved when families talk about, make sense of and narrate their experiences. Researcher elicited and interviewer prompted accounts have been criticised because the context does not represent how stories are told and used in people's everyday lives (Schegloff, as cited in Stokoe and Edwards, 2006). While this is a valid criticism I feel that by including multiple family members in the research this project has given us insight into the nature of family interactions and their influence on storytelling and construction of identity that is likely to be representative of these processes beyond the interview context.

Further to this, the research also set out to explore an under-researched topic: the influence of intergenerational narratives on people's lived experience of mental health problems. In doing this I was able to demonstrate how difficult it is to separate the influence of intergenerational narratives from social and cultural discourses. Although, we did gain some insight into how beliefs and understanding of mental health difficulties persist across generations and may affect people's ability to get help. It also gave us some understanding of why stigma may be so powerfully maintained in society because it is passed from one generation to the next. A process that is likely to happen when children are socialised into the world by their families (Pratt and Fiese, 2004).

Limitations

There were two key limitations to this study. Firstly, recruitment through mental health services meant that one family member was positioned as having a 'mental health difficulty' from the beginning of the interview. This seemed to influence the content of the stories because the families focused on their experiences of mental health in relation to this family member and talked less about their wider family and previous generations. To get a better understanding of the influence of intergenerational narratives it may be helpful to recruit from outside services and interview three generations of the same family, although recruitment for this would likely be very difficult.

Another limitation to the findings is that families were unlikely to participate if they find talking about their experiences threatening. The findings are likely to be biased because they are based on those families who may be more willing to talk about mental health difficulties. Although, it is worth noting that it was never the intention of this research that it should or could be generalised to other families experiencing mental health difficulties.

SUGGESTIONS FOR FURTHER RESEARCH

Given that this is one of the first attempts to use narrative analysis and discursive psychology to analyse families' jointly constructed stories about mental health difficulties there is much scope for further research into this topic.

First, as described earlier it was not possible within the limitations of this project to get the full potential from the data, but further research could be done with the same dataset. Secondly it would be interesting to look in more detail at how the families constructed a shared family identity (Gordon, 2007) and what impact this has on how they cope with mental health difficulties. Thirdly, having reflected in the analysis section on the impact of family relationships on the process of narrating and constructing identities (Trees and Kellas, 2009) it would be interesting to approach the data using a relational lens. . And finally, it would be interesting to take small sections of the data that represent different storytelling styles and look in more detail at the interactional processes to understand further how families narrate their experiences.

While this research has furthered our understanding of the processes that are part of families' everyday interactions, it is important to acknowledge that my presence in the interviews as a mental health professional changed the interactional dynamic. To reduce the influence of the researcher and gain further insight into how mental health difficulties are talked about in families more creative methods could be used. For example, family members could be given a question or set of questions to discuss without a researcher present. Also, in this research families were only interviewed together. It would be useful to do a family interview followed up by individual interviews with each family member or vice versa to gain further insight into how the interactional processes influence families narrating and may shape both the content and the processes involved in storytelling.

Another area for this research would be to interview families in CAMHS services where children are the 'identified patient'. The power dynamics and issues of blame and stigma are

likely to be different in these circumstances and could provide interesting information for the way in which child and adolescent services work with young people.

In this research video recording was used as a back-up to audio in case it was difficult to determine who was speaking. It was beyond the scope (and ethics approval) of this research to use those recordings for any other purpose but future research could use video recording to include non-verbal communication as another dimension in the analysis of family interactions (Riessman, 2002).

PERSONAL REFLECTIONS

> Stories can have a powerful effect on the listener, because accepting the invitation into the storytelling relationship can open the listener to seeing, feeling and hearing life differently. (Kirkpatrick, 2008, p63).

I have chosen to end this research in the way that it began by sharing with you some reflections on my own personal experience of being with these families and their stories. In the same way that I had never imagined how rich and complex the data would be I was also not prepared for how certain aspects of life in my own world would seem different (Frank, as cited in Kirkpatrick, 2008) on completing this research. My relationship with the 'lodger' has taken another turn and while my heart will always sink when he is in town the rucksack is no longer burdened with memories I wish to forget. I have put it in storage and replaced it with a bag of memories that I want to hold on to, that represent our families fight against these difficult circumstances, that show our love and commitment to each other and that make us laugh together.

It is not just the families, their stories and my hours spent with the transcripts that has made life in my own world seem different. It is also the wonderful conversations that I have had with my supervisor during which she has so warmly shared stories from her research and her life that have both moved me and enriched my understanding of my research and my own life.

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APPENDICES

APPENDIX A: LITERATURE SEARCH STRATEGY

1. The first stage involved a review of books in the university library and database searches using Web of Science, Google Scholar and Psych Info. The terms used in the search in various computations were:

   'mental health' OR 'mental illness'

   AND

   'illness narrative; narrative; family; intergenerational; *generational; stories; lived experience; experience

2. This initial search reviewed literature from 2000-2012.

3. The second stage involved following up on relevant references cited within any articles and books identified in stage 2.

4. Specific attention was paid to the following journals: Narrative Inquiry, Journal of Family Therapy, Family Process

5. I was also a member of a peer support group with four other trainees from my cohort that were using Narrative Analysis. A number of papers were exchanged between members.

6. I contacted Corrine Squire at the Centre for Narrative Research to identify whether she was aware of any studies using NA for whole family interviews. Corinne was unaware of any studies that are completed but did mention some that were being planned by the Thomas Coram Institute.

7. Additional searches were completed one month prior to completion of this thesis in order to gather the most up-to-date literature.

APPENDIX B: CRITERIA FOR APPRAISING QUALITATIVE RESEARCH

Specific prompts for each criteria can be found in the article by Walsh and Downe (2006, Table 4, pp.114-115).

Stage of research	Essential criteria	Criteria Met (where)?
Scope and Purpose	Clear statement of, and rationale for, research question/ aims/ purposes	**Yes** (details in *Introduction*)
	Study thoroughly contextualised by existing literature	**Yes** (details in *Literature review* section of *Introduction*)
Design	Method/design apparent and consistent with research intent	**Yes** (See *Methodology, Why Qualitative Research and Why Narrative Analysis*)
	Data collection strategy apparent and appropriate	**Yes** (See *Methodology*)
Sampling Strategy	Sample and sampling method appropriate	**Yes** (See *Methodology*)
Analysis	Analytic approach appropriate	**Yes** (See *Methodology and Findings/Discussion*)
Interpretation	Context described and taken account of in interpretations	**Yes** (See *Findings and Discussion*)
	Clear audit trail given	**Yes** (Throughout project)
	Data used to support interpretation	**Yes** (See use of verbatim quotes in *Findings/discussion*)
Reflexivity	Researcher reflexivity discussed	**Yes** (See *Findings and Discussion and Setting the Context*
Ethical dimensions	Demonstration of sensitivity to ethical concerns	**Yes** (See *Methodology*)
Relevance and transferability	Relevance and transferability evident	**Yes** *(See Findings and Discussion, Conclusions, Clinical Relevance, Methodological Considerations, Ideas for Further Research)*

APPENDIX C: PARTICIPANT INFORMATION SHEET

University of Hertfordshire
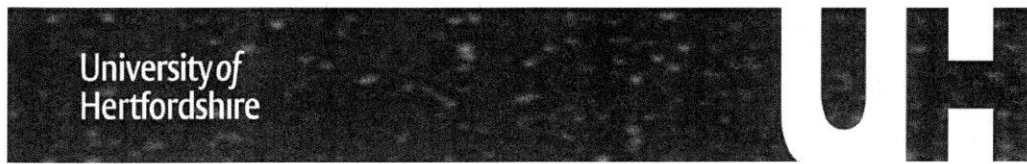
Participant Information Sheet

Family stories about mental health difficulties: An intergenerational perspective.

Why have I been given this information sheet?

You and your family are invited to take part in a piece of research being conducted by Louisa Rhodes, Trainee Clinical Psychologist.

Before you decide if you would like to take part, it is important that you understand why the research is being done and what it would involve. Please take time to read the following information carefully and feel free to talk to others about the study if you wish.

This information sheet hopes to answer any questions you might have about the research. If there is anything you are unclear about or want more information about, please feel free to contact a member of the research team on the telephone numbers below.

What is the purpose of the research?

This research hopes to gain a deeper understanding of the influence of intergenerational stories on families' experiences of mental health problems. This research is being carried out as part of a doctoral training programme in Clinical Psychology at the University of Hertfordshire.

Why have I been invited to take part in the study?

Several families where at least one member is identified as having a mental health problem have been invited to take part in this research. It is hoped that those who agree to take part will share with the researcher their family stories about mental health problems.

Do I have to take part?

It is up to you to decide. We will describe the study in this information sheet and you will have an opportunity to discuss it with the researcher. If you agree we will ask you and your family to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the care you receive in any way.

If I agreed, what would be involved?

If you agreed to take part in this research you and your family would meet with Louisa Rhodes, Trainee Clinical Psychologist. At the first meeting Louisa would talk to you about the research, to make sure you have all understood what it would involve. You would then have an opportunity to ask any questions before being asked to sign a consent form, which would show that you have agreed to take part.

If you then felt ready to continue, Louisa would interview your family as a whole about your experiences for about 60-90 minutes. Louisa will then arrange to meet with you a second time (approximately 1 week later) to continue the interview with your family. Louisa will be recording the

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interviews using audio and video recording equipment and the recordings will be destroyed as soon as transcripts of the interviews have been typed.

What kind of questions will she ask?

This research is interested in how stories within your family may influence your experience of mental health problems. Louisa will draw out a family tree with you and then ask you to talk about any family stories about mental health problems, including your thoughts and feelings about your current experiences of this. This will not be a structured interview. Louisa will ask questions that will help you to tell your family stories.

What will happen to this information?

The recording of the interviews will be typed out to help Louisa to uncover common themes that are important in understanding the influence of stories on families' experiences of mental health problems. A professional transcription service may be used; in this case, confidentiality agreements will have been signed. The typed out transcripts will be made anonymous.

Louisa will be supervised throughout this research by Lizette Nolte and Dr Pieter Nel, Clinical Psychologists at the University of Hertfordshire and Dr Lorraine Davies-Smith, Clinical Psychologist at the Complex Care Service. These supervisors will have access to anonymised versions of the information Louisa has collected and will oversee the research. This information will remain in a locked and secure place until it is destroyed.

As part of the doctoral programme, Louisa's work will be assessed and anonymised sections of the information she collects may be looked at by the examiners. Louisa will write up a report of her research and a shorter article for publication in an academic journal. Within this report she may include anonymous extracts of the interview to illustrate themes that have been discussed. These extracts will not include any information that could identify participants. Louisa will ask you if you would like to hear what she finds from her research; if you do, she will arrange this with you.

Will my taking part in this study be kept confidential?

This proposed project will interview members from three families. All family details will be anonymised for the purposes of Louisa's thesis.

All information which is collected about you during the course of the research will be kept strictly confidential. As with any health professional, there are limits to confidentiality. If during your meetings with Louisa you disclose any information which suggests that either you, or someone else, is at risk of harm Louisa will be obliged to breach confidentiality and inform a member of your care team. Louisa will do her best to discuss this with you before following such a course of action.

What are the possible disadvantages and risks of taking part?

You will be asked to discuss your family's experiences of mental health problems, which could be potentially upsetting for you. If during the interview you feel upset, you will be given the choice of not answering a question, taking a break or stopping the interview. Following the interviews, Louisa

University of Hertfordshire

will be available if you need some time to talk about any issues raised. Louisa will also be able to advise you of who you can talk to if you need further support.

What are the potential benefits of taking part?

We cannot promise the study will help you, but we hope that the information we get from this study will help improve the experiences of other families living with mental health problems.

What will happen if I don't want to carry on with the study?

If you decide you want to withdraw from the study you should let the researcher (Louisa Rhodes) know using the phone number given at the end of this information sheet. If you have completed the interview you will be asked what you would like to happen to the data. It can either be included, or destroyed. Either option is perfectly acceptable. **Your decision of whether to take part or withdraw from the study will not affect the care you receive.**

Who has reviewed this study?
This study has been approved by the Hertfordshire NHS Research Ethics Committee (Protocol Number: 12/EE/0344). It has also been approved by the Hertfordshire Partnership NHS Foundation Trust Research and Development Department.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher (Louisa Rhodes) who will do her best to answer your questions. Alternatively you could contact the research supervisor, Lizette Nolte (see contact details below). If you remain unhappy and wish to complain formally, you can contact the Patient Advice and Liaison Service (PALS) at Herfordshire Partnership Foundation Trust on 01727 804629. If you would like further independent advice you can contact the local Independent Complaints and Advocacy Service (ICAS) on 0845 456 1082.

Contact Details:

Louisa Rhodes
Trainee Clinical Psychologist
Tel: 07855 520120
Email: l.rhodes2@herts.ac.uk

Lizette Nolte
Clinical Psychologist
Academic Supervisor, University of Hertfordshire
Tel: 01707 286322

Senior Support Worker – on behalf of ▒▒▒▒▒ Local Research Collaborator

Version 2, 06/08/2012

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APPENDIX D: INTERVIEW SCHEDULE

Project Title: Family stories about mental health difficulties: An intergenerational perspective
Version 1: June 2012

Semi-structured interview schedule

The following questions will be used as a guide for the topics to be covered during the interview. Questions will only be used when necessary but where possible interviews will be allowed to flow without interruption from the researcher.

All interviews will begin with construction of a genogram and this will be used to facilitate the telling of intergenerational narratives. During the interview the following will be covered and a number of prompts are included to help the interviewer.

Theme 1: What are the intergenerational narratives that seem relevant to how the family experience mental health problems.

Who else in the family has or had similar difficulties?

Does anyone else in the family have a mental health problem or has anyone else previously had one? (they may or may not have received professional help for this)

Theme 2: What influence do intergenerational narratives have on families' beliefs and understanding of mental health problems.

What is your understanding of your own/mum's/dad's mental health problem?

Why do you think your mum/dad developed these difficulties?

Why do you think other people might develop mental health difficulties?

Theme 3: How are mental health problems talked about within the family.

When it first became apparent that you/your mum/your dad had a mental health problem were you able to talk about it as a family. Did this apply to your extended family too?

Are there people in the family that have a different understanding of mental health problems to you?

Theme 4: What are the coping styles and strategies that emerge from these narrative constructions.

What has helped you to get through the difficult times?

What have you noticed about what has helped your family through the difficult times?

APPENDIX E: ETHICS APPROVAL CONFIRMATION LETTERS

NHS
Health Research Authority
NRES Committee East of England - Hertfordshire

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Telephone: 01223 597733
Facsimile: 01223 597645

08 August 2012

Miss Louisa Rhodes
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
46 Jervis Road
Bishop's Stortford
CM23 3TT

Dear Miss Rhodes

Study title:	**Family stories about mental health difficulties: An intergenerational perspective.**
REC reference:	**12/EE/0344**

Thank you for your letter of 06 August 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of insurance or indemnity		01 August 2011
Investigator CV - Rhodes		06 July 2012
Letter from Sponsor Letter from Professor Senior		06 July 2012
Other: Supervisor CV - Nolte		02 July 2012
Other: Semi-structured interview schedule	1	28 June 2012
Other: Participant Debrief Sheet	1	28 June 2012
Other: Summary Feedback Sheet		13 March 2012
Other: Summary Feedback Sheet 2		13 March 2012
Other: Flowchart for Research	1	06 July 2012
Participant Consent Form	2	06 August 2012
Participant Information Sheet	2	06 August 2012
Protocol	2	06 July 2012
REC application IRAS A and B	101092/3407 09/1/680	11 July 2012
Response to Request for Further Information - Letter from Louisa Rhodes		06 August 2012

Statement of compliance

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

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
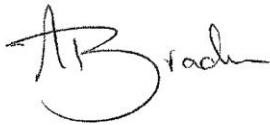
<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/EE/0344	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

PP

Dr Steve Eckersall
Chair

Email: Anna.Bradnam@eoe.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

Email to: l.rhodes2@herts.ac.uk
                         Mrs Lizette Nolte (Academic Supervisor) l.nolte@herts.ac.uk
Copy to:

                         Dr Jamil Ahmad, Barnet,
                         Enfield and Haringey Mental Health NHS Trust
                          j.ahmad@nhs.net

NHS
Health Research Authority

NRES Committee East of England - Hertfordshire

Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

Tel: 01223 597733
Fax: 01223 597645

30 October 2012

Miss Louisa Rhodes
Trainee Clinical Psychologist
Cambridgeshire and Peterborough NHS Foundation Trust
46 Jervis Road
Bishop's Stortford
CM23 3TT

Dear Miss Rhodes

Study title:	**Family stories about mental health difficulties: An intergenerational perspective.**
REC reference:	**12/EE/0344**
Amendment number:	**Amendment #1 Substantial**
Amendment date:	**12 October 2012**

The above amendment was reviewed on 31 October 2012[by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Lone Working Policy		19 September 2008
Evidence of insurance or indemnity From Gallagher Heath		06 August 2012
Notice of Substantial Amendment (non-CTIMPs)	Amendment #1 Substantial	12 October 2012
Covering Letter From Key Investigator Louisa Rhodes		11 October 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.
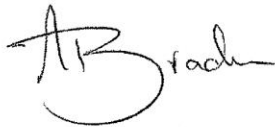
R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

12/EE/0344:	Please quote this number on all correspondence

Yours sincerely

PP

**Dr Steve Eckersall**
Chair

E-mail: Anna.Bradnam@eoe.nhs.uk

Enclosures:	List of names and professions of members who took part in the review
Email to:	l.rhodes2@herts.ac.uk
Copy to:	Mrs Lizette Nolte (Academic Supervisor) l.nolte@herts.ac.uk
	Dr Jamil Ahmad, Barnet, Enfield and Haringey Mental Health NHS Trust j.ahmad@nhs.net

APPENDIX F: CONSENT FORM

University of Hertfordshire   UH
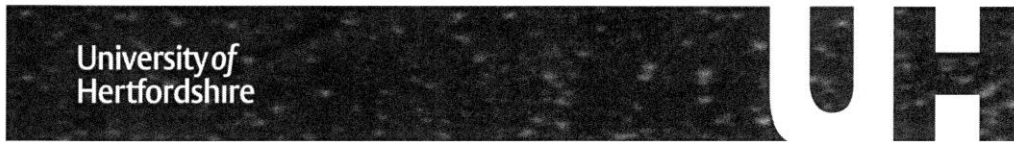
CONSENT FORM

Project Title: Family stories about mental health difficulties: An intergenerational perspective.

Statements by Participant

☐ I confirm that I have read and understand the information sheet for this study.

☐ I understand what my involvement will entail and any questions have been answered to my satisfaction.

☐ I understand that I can withdraw at any time without my care being affected in any way.

☐ I understand that I can decline to answer any questions that I am not comfortable with.

☐ I understand that my involvement in the research will have no impact on the care that I receive.

☐ I understand that all information obtained will be confidential and exceptions to this have been discussed with me.

☐ I understand that the interviews will be recorded using audio and visual recording equipment and that the recordings will be destroyed once the interviews have been typed.

☐ I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

☐ I agree that research data gathered for the study may be published and I am aware all possible precautions will be taken to protect my anonymity.

☐ Contact information has been provided should I wish to seek further information from the investigator at any time for purposes of clarification.
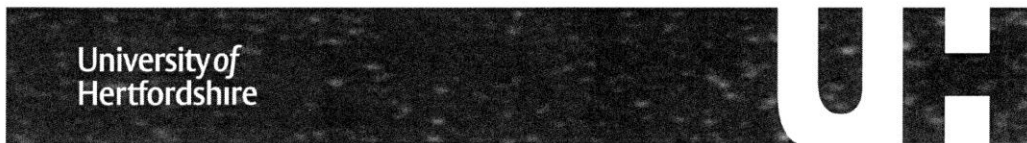
Participant's Name:

Participant's Signature

Date

Investigator's Name   Louisa Rhodes

Investigator's Signature

Date

This project has been approved by the Hertfordshire NHS Research Ethics Committee (Protocol Number: 12/EE/0344)

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APPENDIX G: DEBRIEF SHEET

University of Hertfordshire   UH

Debrief Sheet

PROJECT TITLE: Family stories about mental health difficulties: An intergenerational perspective.

Debriefing information

Thank you very much for making this study possible. By sharing your family experiences, it is hoped that this will help our understanding of how family's stories influence their experience of mental health problems and the ways they develop to cope with these difficulties.

Research findings suggest that the way families' experience and respond to mental health problems may be influenced by their family attitudes and expectations that are passed on between generations through family narratives (stories). We still have a limited understanding of the influence of these narratives, and this is what is being investigated.

The information you provided may help other families living with mental health problems.

The information you provided will be kept confidential, and after analysis the tapes will be destroyed. As a participant, you have the right to withdraw the information you have provided at any time.

If this research has caused you or your family any distress please discuss this with your care team at the Complex Care Service.

Alternatively below are some resources that you may find useful:

The Samaritans
Website: www.samaritans.org/
Tel: 08457 909090

If you have any further questions or would like to be informed as to the outcome of this study, then please contact me at the email address below.

If you have a complaint to make about your involvement in this research, please contact Lizette Nolte whose details are below.

Name of researcher: **Louisa Rhodes**; Email: l.rhodes2@herts.ac.uk
Name of supervisor: **Lizette Nolte**; Email: l.nolte@herts.ac.uk

Department of Clinical Psychology
University of Hertfordshire
College Lane Campus
Hatfield
AL10 9AB
Tel: 01707 286322

Thank you for participating in this study.

This project has been approved by the Hertfordshire NHS Research Ethics Committee (Protocol Number: 12/EE/0344)

Version 2, 06/08/2012

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