BEHIND CLOSED DOORS: A GROUNDED THEORY OF THE SOCIAL PROCESSES THAT DESCRIBE HOW PARENTS TALK TO THEIR CHILDREN ABOUT PARENTAL MENTAL HEALTH DIFFICULTIES

LIZETTE NOLTE

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Boat captain: “Do you want a chicken biscuit?

Hushpuppy: (shakes head no)

Boat captain: “They good for you. I been eating these all my life. I keep the wrappers in the boat ‘cause they remind me of who I was when I ate each one. The smell makes me feel cohesive.”

Hushpuppy: “I want to be cohesive.”

Boat captain: “I’m sure you will baby, I have no doubt in my mind.”

Beasts of the Southern Wild (2012)

ABSTRACT

Since the government commissioned the Crossing Bridges programme in 1998 (Falcov, 1998) and through legislation and a number of government policies and initiatives since, there has been emphasis on addressing the needs of families where there are parental mental health problems. Furthermore, there is a fast-growing body of research pointing to the needs of these families. However, service structures, development and provision have lagged behind. Most often parents with mental health difficulties have access to services addressing their individual mental health needs while their needs as parents and the needs of their children remain largely invisible.

One such need that has been highlighted repeatedly in the literature is the need for children to have information about and make sense of their parent's mental health difficulties. Given the lack of services to respond to this need, it is most often left to the parent to make decisions about and respond to their child's search for understanding.

This study is a qualitative study that explores parents' experiences of decision-making and responding to this need, and the social processes and dominant discourses that impact on these experiences.

Fifteen parents with mental health difficulties were interviewed, using semi-structured individual interviews, which were transcribed, and interpretive Grounded Theory was employed to analyse and interpret the data.

The grounded theory that was constructed suggest two main social processes that impact on parents' talking with their children about parental mental health issues. Firstly, within a relational context, parents were *Negotiating mutuality* between themselves and their children. Secondly, within an identity context, parents had to navigate *Holding on to self, holding on to life.* These social processes indicate that both parents' relationships with their children and also their own sense of themselves within the context of their mental distress powerfully shape telling, talking and keeping silent.

Implications of these findings both in relation to clinical interventions and future research are considered. In particular, the importance of positioning the parent as active role-player in the healing of their child, and positioning the child as active role-payer in their own meaning-making, are highlighted. Furthermore, developing 'double-stories' beyond the mental health story and beyond 'information' is emphasised and the importance of a sense of continuity of self and identity over time for parent and child is accentuated. Finally, the importance of allowing for complex and ever-evolving understandings of mental distress is indicated, and the role of both talking and remaining silent in this process is stressed.

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Dedication

For Anli and René…

1. INTRODUCTION

1.1. INTRODUCTION

This thesis presents a grounded theory of how parents with mental health difficulties experience talking to their children about parental mental distress. Social processes and discourses that impact on parents' decisions in relation to helping their children make sense of the parent's difficulties are presented.

1.2. THE CONTEXT OF PARENTAL MENTAL HEALTH

Mental distress is universal and occurs in all societies and cultures. It is present at any one time in about one in 10 people (Smith, 2004) and it is widely accepted that throughout a person's lifetime there is between a one in four and one in six chance of experiencing a period of mental distress (Goldberg & Huxley, 1992).

Many people who experience mental health difficulties are also parents (Office of Population and Censuses and Surveys, 1995). It has been suggested that between a third and half of adults known to mental health services have dependent children (Falcov, 1998; SCIE, 2008a). Despite this there is widespread denial of the sexuality and fertility of, and the importance of parenting for, people with mental health issues (Gladstone, Boydell & McKeever, 2006; Howard, 2000), and clinicians still regularly do not give priority to information regarding the parenting status of mental health service users (Ofsted & CQC, 2013). That leaves a lack of awareness within mental health services regarding the parenting experiences of adults in their care. Furthermore, children of parents with mental health difficulties continue to be largely invisible to the mental health professionals that support their parent.

Thus, an increased awareness and understanding of the needs of families where there are parental mental health concerns is needed. Families affected by parental mental distress are amongst the most vulnerable in our society – such families are more likely to experience social isolation, financial hardship, and marital discord and to be excluded from health and social care provision (SCIE, 2009a, 2009b). Their children are at increased risk genetically, psychologically, and environmentally (Beardslee, Versage and Gladstone, 1998). Current estimates suggest that amongst children whose parents are known to mental health services between one-third and two-thirds will experience difficulties themselves (Griggs, 2000; Rutter & Quinton, 1984). Many children of parents with mental health problems take on caring responsibilities in their families (Aldridge, 2006; Aldridge & Becker, 2003). The 2001 census showed that of the one hundred and seventy five thousand young carers known about in the UK almost a third cared for someone with mental health problems (Barnardo's, 2008) and it has been estimated that the number of young carers might be significantly higher (BBC, 2010).

Furthermore, parenting within the context of parental mental distress can be fragile and parents with mental health issues are at high risk of losing custody of their children (Howard, 2000; Kaplan, Kottsieper, Scott, Salzer & Solomon, 2009). Seeman (2004), drawing together findings from a number of studies, reported that more than 50% of people with a diagnosis of schizophrenia and known to services will become parents and of these only approximately half will retain some custody of their children.

The above highlights the necessity of giving the highest importance to responding to the needs of families where there are parental mental health concerns (Parker, Beresford, Clarke, Gridley, Pitman, Spiers, Light, 2008).

1.3. UK LEGAL AND POLICY FRAMEWORK

Looking at activity over a number of decades, one could indeed conclude that parental mental health and the children of parents with mental health issues have become very important to the government, National Health Service (NHS), social care services and the 3rd sector.

1.3.1. Government initiatives – legislation and policy development

Much of the current clinical and academic development in the United Kingdom in relation to parental mental health has been driven by legislation and recent government initiatives. Within England these include *The Children Act 2004* (HMGov, 2004)*, the National Service Framework* (DoH, 1999a)*, The Framework for the Assessment of Children in Need and Their Families* (DoE, 2000)*, Every Child Matters 2003* (DCSF, 2004), and *Working Together to Safeguard Children* (DoE, 2013).

These have had the aim of putting legal and policy frameworks in place that make it clear that the needs of the child are always paramount; make it clear that concern for the welfare of the child is everyone's responsibility; prioritise better working relationships, collaboration and information-sharing between services; promote a common core of training for the mental health workforce; promote a common assessment framework to ensure that the needs of all in the family are attended to during an assessment; and promote earlier intervention and prevention.

Furthermore, according to the *Mental Health Act* (DoH, 1999b) adult mental health workers are expected to take children into account when care plans are formulated and in-patient services are required to have policies on family visiting. Also, it has been national policy for some time that adult mental health services should provide a range of co-ordinated services to meet the needs of carers of people with mental health difficulties, including young carers (DoH, 2002a).

1.3.2. Crossing bridges and beyond – an explicit focus on parental mental health

As early as 1998 the Department of Health [DoH] commissioned the Crossing Bridges project (Falcov, 1998) that came up with a comprehensive review of the available research and existing services, made clear and pragmatic recommendations for service development and made available useful training tools. Since then much further guidance has been issued. Since *the Laming report* on the death of Victoria Climbié, adult mental health services have been required to know whether patients are parents and whether they are in contact with children (House of Commons Health Committee, 2003). Also, following the 2007 review of the Care Programme Approach process in England, the new guidance recommends that the needs of children of parents with mental health difficulties are included in care plans and that the needs of all family members are routinely assessed (DoH, 2008). The National Patient Safety Agency produced a *Rapid Response Report* in which it outlines what is expected from mental health services in relation to preventing harm to children whose parents have mental health difficulties (NPSA, 2009). The *Munro Review of Child Protection* (Munro, 2011), following the death of baby Peter Connelly, called for a focus on direct engagement with families and stronger partnerships between practitioners and families.

There has also been clear guidance for antenatal and postnatal care through the development of the DoH's strategy for women's mental health – *Women's Mental Health – Into the Mainstream: Strategic Development of Mental Health Care for Women* (DoH, 2002b), the National Institute for Health and Clinical Excellence's [NICE] clinical management and service guidance document for antenatal and postnatal mental health (NICE, 2007) and most recently, *The 1001 Critical Days* cross-party manifesto (Leadsom, Field, Burstow & Lucas, 2013), highlighting the importance of early intervention and prevention in the period from conception to aged two, including where parents have mental health concerns.

In 2007 the government developed its *Think family* reports to improve the lives of families at risk (Cabinet Office, 2007 & 2008). The reports pointed out the large number of vulnerable families (including families experiencing mental health issues) there are in the UK and emphasized how these difficulties were often passed from generation to generation. Most recently the government published *No Health Without Mental Health* (DoH, 2011), which promised to put psychological problems on a par with physical ones. It set out a number of objectives to improve outcomes for people with mental health problems and also to improve the mental health and wellbeing of the nation. Furthermore, this document stresses the connections between mental health, housing, employment, and crime. There really appears to be a strong indication from consecutive UK governments that they are serious about improving mental health services. Health minister Norman Lamb made the commitment of “prioritising mental health like never before” (Hitchcock, 2013, para. 1).

1.3.3. Service structures, development and provision lagging behind

However, figures show that mental health spending is in fact falling further behind physical health spending and is going down overall (Ramesh, 2012; Buchanan, 2013). Furthermore, despite all these developments and increases in awareness and understanding of the changes needed (Britten & Cardwell, 2002; Falcov, 1998; Frank, 2002; Royal College of Psychiatrists, 2002), service structures, services and clinicians have been slow to respond and obstacles have proven difficult to overcome (Leverton, 2003). Press coverage to raise awareness of mental health issues remains scant, and stigma has proven very difficult to address (Hitchcock, 2013; Time to change, 2008).

Furthermore, Ofsted & the Care Quality Commission [CQC] (2013) recently released a report, *What about the children?,* that shows that progress in addressing the complex needs of families where there are mental health problems is disappointing. It reported that mental health services still did not consistently consider the impact of the adult mental health difficulties on children. Joint working between children’s social care services and adult mental health services was described as of variable quality. It also highlighted how the fact that children are not being identified, leaves them not receiving help, and at times at risk of harm, and called on the government to make it mandatory for mental health services to collect data on children whose parents or carers have mental health difficulties.

Within mental health services a commitment to view people within the context of their lives and relationships is difficult to maintain. Many factors contribute to this and these have been well documented in the literature (Britten & Cardwell, 2002; Falcov, 1998; Hetherington, 2003; SCIE, 2003, 2009a; Smith, 2004; Tunnard 2004). They include a lack of collaborative relationships between services, lack of resources, lack of awareness amongst workers and a lack of knowledge about the effects of parental mental health issues on children, about talking to children and about positive interventions available. Furthermore, adult services are inaccessible to children and the medicalized and individualized approach that prevails within adult mental health services continually takes the focus away from the family (Göpfert & Mahoney, 2000). Within adult mental health services parenting is not generally considered a mental health issue within adult psychiatry unless there are child protection concerns (Howard, 2000). Services have also been criticised for at times assessing parenting, family life and mental health without consideration of cultures and ethnicities (Maitra, 2005; Singh & Clarke, 2006), disadvantaging families from minority backgrounds (SCIE, 2008b).

Finally, negative societal and media attitudes continue to stigmatise people with mental health problems, especially those who are parents (Falcov, 2000; Göpfert and Mahoney, 2000), and this may also affect families' experiences within services. These factors can lead to a lack of trust from parents with mental health difficulties in accessing mental health services and disclosing difficulties relating to parenting and to their children.

1.3.4. Conclusion

It is clear that we are still very far off from adequately addressing the needs of parents with mental health problems and their children and that there is an urgent need to continue to work towards a fuller understanding of the needs of these families and how best they can be met. This is the context in which the current study is situated. The study focuses on the perspective in the literature that children need information about, and need to form an understanding of, a parent's mental health difficulties. However, given the lack of awareness, understanding and provision of services for these families described here, the burden to support children in developing such understandings most often falls on parents. Thus, this study explores parents' experiences of this and the social processes impacting on their experiences.

An overview of the thesis is now provided to orientate the reader.

1.4. OVERVIEW OF THE THESIS

In this introductory chapter the mental health context within which the research is situated is set out before the literature is reviewed in Chapter 2. In this chapter the literature on impact of mental health problems in people's lives, parenting within the context of mental health problems and the effects of such mental health problems on children is considered before the research in the field of parental mental health is reviewed. The research is considered with a focus on qualitative research exploring the experiences of parents and children, and in particular the research area of information-sharing and talking about parental mental health issues. The construct of coherent narratives and how it relates to wellbeing is then reviewed, before finally the limited available research literature in relation to the focus of the study, namely children's developing understanding of their parent's mental health issues, is considered.

In Chapter 3 the research questions are presented and in Chapter 4 the research methodology is discussed. Justification for a qualitative study and in particular a Grounded Theory study is presented. Finally Grounded Theory methodology is described and critiqued.

In Chapter 5 the research design and procedures are presented and critiqued, including ethical considerations for the study, the reflexive position adopted by the researcher and service-user consultation.

Chapters 6, 7 and 8 set out the findings of the study, firstly through an introductory chapter that presents a holistic perspective of the grounded theory that has been constructed, followed by a detailed presentation of the grounded theory in the following two chapters. These are followed by a final discussion chapter, Chapter 9, setting out the clinical implications of the study and suggestions for future research. A short conclusion to the study follows in Chapter 10.

Before moving on to a review of the literature, I want to refer briefly here to reflexivity within the research process and in particular to the theoretical orientation of the research and the use of language within the socio-political context of this project.

1.5. REFLEXIVELY ENGAGING WITH THE RESEARCH PROCESS

Embarking on research in the field of parental mental health, this research study enters into a number of passionately contested and emotionally laden arenas (e.g. the nature of ‘mental illness’; the values surrounding parenting, and motherhood in particular; and understandings of what is in the best interest of children). Charmaz (2013a) states that from a social constructionist perspective, instead of aiming for ‘neutrality’ the researcher takes an explicit value stance from the beginning. The aim is thus to hold an awareness of and make transparent the researcher’s values and stance in order to allow the reader to view the findings of this study within the context of these positionings. Here I will briefly reflect on my theoretical orientation and the implications that flow from this for the study. I have chosen to use both first and third person positions here and at different times in the report to engage with the more personal aspects of the research process and to ensure that my voice, as a researcher-author, remains visible throughout the text.

1.5.1 Theoretical orientation

A systemic and narrative orientation shapes my clinical work and preferred stance. These approaches view the experiences of all in the family and social environment as important. Furthermore, these approaches take a depathologizing stance and give value to people’s own understanding of their difficulties and its possible solutions. They invite the adoption of a relational and contextualized approach to mental health and distress, a consideration of active responses to social injustices and an awareness of the importance of language and meaning, as will now be discussed.

1.5.1.1. Contextualized approaches to mental health and distress

In line with systemic and narrative practices, the impact of mental health difficulties on persons’ lives and on their families is considered within the context of these difficulties (Mason, 2004). The relevance of the wider social, economic and political context to mental health and also to parenting is well established. There are numerous correlations between socio-economic status and the quality of parenting and child development outcomes (Attenborough, Hawkins, O’Driscoll & Proctor, 2000; Göpfert, Webster & Nelki, 2004a; Davies, 2010; Singer, Tang & Berelowitz, 2000; Tunnard 2004; Williams, 2002). Furthermore, it is well documented that many of these effects of social inequality and discrimination will have a potentially profound impact on mental wellbeing (Midlands Psychology Group, 2007; Nolte, 2007; Wilkinson & Kitzinger, 1996). Those in difficult life circumstances are more likely to experience stressful life events and traumas (e.g. being victims of crime, experiencing financial crises, living in dangerous neighbourhoods, etc.). Also, physical and sexual violence and abuse, more often experienced by those who are vulnerable or marginal in society, are also known to potentially have a powerful impact on mental health and wellbeing (Attenborough, et al., 2000; Goodman, Dutton & Harris, 1995; Hall, 2004; Tew, 2002a; Williams, 2002). Finally, social inequalities and invalidation powerfully structure and are deeply imbedded in people’s personal sense of identity and this can impact on wellbeing (Williams, 2002).

Therefore, when considering the impact of parental mental health difficulties on children, it is impossible to consider these separately from the context in which they occur, the potential impact on quality of life for the family, and the direct impact any of these factors can have on the child (Attenborough, et al., 2000; Williams, 2002). Thus, a contextualized and situated approach was taken within the research.

1.5.1.2. Research as addressing social injustice

From a systemic and narrative viewpoint, conducting research is not a neutral act (Gaddis, 2004; Smith, 1999). Dulwich Centre Publications (2004, p. 35) argue "far from trying to achieve or maintain neutrality in research, it is becoming more widely accepted that all research involving marginalized communities concerns matters of justice". Research can thus be understood as a form of action (Waldegrave, Tamasese, Tuhaka & Campbell, 2003).

Starting out in this project from such a perspective, I was therefore interested in undertaking research in ways that were congruent with the values of equality and addressing marginalization that inform my clinical work and that are central to my professional and personal life (Crocket, 2004). Furthermore, I was aware that those who would participate in my research would be vulnerable to marginalization through their mental health difficulties, but also potentially through poverty, their cultural and ethnic background and migration status. I felt that this would be significant to hold in mind within the research account (Crocket, 2004; Crocket, Drewery, McKenzie, Smith & Winslade, 2004; White, 1995).

1.5.1.3. Language-use and current discourses surrounding human distress

Within a systemic and narrative perspective, language and discourse are seen as centrally important. Where moments of sadness, grief, worry, emotional pain and despair form part of human experience, in modern times such sadness, distress and human struggle have been problematised within current dominant social discourses

(Boyle, 2007, 2011; May, 2007; Newnes, 2008). Many recent government policies and initiatives (e.g. the Happiness Index (ONS, 2012); IAPT (DoH, 2012)) promise easy access to happiness and imply a moral obligation to be happy [see e.g. Midlands Psychology Group, 2007; Nel, 2009; for a more in-depth critique of these developments]. Experiencing mental health problems thus becomes a moral failure. These discourses around mental distress have significant implications for the identities, relationships and lives of those experiencing severe and enduring mental distress that needed to be attended to in this study.

Once a person experiences such difficulties they often enter psychiatric services and receive a psychiatric diagnosis. An intense debate was started by the recent publication of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition [DSM V] (APA, 2013) in professional publications and the media (e.g. Doward, 2013; PLOS Medicine Editors, 2013). Concern was expressed about the increasing medicalization of distress and behaviour in adults and children and it was argued that diagnoses use a language of disorder and deficit that can negatively impact on and shape a person’s view of life, their identity and confidence (DCP, 2013). Also, psychiatric diagnoses can be described as decontextualizing and thus obscure the links between people’s experiences, distress and behaviour and their social, cultural, familial and personal historical contexts (Nehls & Sallmann, 2005). Furthermore, such diagnoses are associated with stigmatizing social attitudes (DCP, 2013). Given the contentious nature of this area, the decision has been made throughout this document to use the terms “mental health difficulties”, “mental health problems” and “psychological/mental distress” interchangeably. The researcher has chosen not to use the term “mental illness” or any diagnostic categories.

1.5.2. Two early researcher stories

I have chosen at three different points in the thesis to include more personal ‘stories’ taken from my research diary to position myself at different stages of the research journey. The first two stories are presented here and were written before the start of the research as I was considering aspects of 'self' that would influence the project.

Extracts from research reflective diary:

The story of being a white Afrikaner

Being born a white Afrikaner in South Africa and growing up at the height of the Apartheid years has politicized me in my view of life. It has powerfully sensitised me to the grave potential implications of 'othering' on people's lives. I find myself with a wish to align myself with the marginal, the excluded, the 'Other'. However, I am also aware of my white skin, my middle class clothing, my education and professional status and how this can and will be perceived.

The story of the fierceness of motherhood

From the first moment I learned that I was pregnant, I was taken over by something so fierce, so physical, so mystical... It has profoundly shaped who I am in the world and how I live my life. Now people laugh when I talk about 'my boys' with such entitlement, embodiment. But it also comes with a perplexity about parents for whom it is not like that…

Both my political self and my personal self enter this research journey alongside my professional clinician and researcher selves. These influences will be returned to throughout the thesis in relation to each aspect of the project.

1.6. CONCLUSION

In this introductory chapter an overview of the thesis was provided and the research was situated within the field of parental mental health and the political, legal, structural and personal contexts implied in the study. In the next chapter the existing literature will be reviewed.

2. LITERATURE REVIEW

2.1. INTRODUCTION

The researcher entered the field of parental mental health research with existing knowledge of the literature [see Chapter 5 for an exploration of the meaning of this existing knowledge for the study], including a number of key references (e.g. Falcov, 1998; Göpfert, Webster & Seeman, 2004; Reder, Mc Clure & Jolley, 2000; Tunnard, 2004), and drew on this as a starting point for the literature review. A thorough literature search was then conducted, using a variety of electronic databases. Furthermore, the reference lists of all reviewed papers were searched for further relevant papers and colleagues and experts in the field were consulted about relevant references. Given the length of time that had passed by the time the final report was written, a full search of relevant data bases was repeated in the final year of the project, going back five years [for a full description of the search strategy, please see Appendix 1].

What follows is an overview of the literature relevant to the research question and a rationale for conducting the current piece of research. As indicated before, the researcher is making choices here about the language used, the emphasis placed, the conclusions drawn, informed by personal and professional experience, values, beliefs and fore-understandings (Shaw, 2010). Therefore, these provide the reader with a context on which to draw when considering the findings of the study.

2.2. OVERVIEW

As no previous studies could be found directly addressing the current research questions, it was important to review the generic parental mental health literature to explore how this theme has been indirectly explored, but also to search the literature for other areas that might relate to the current research question.

Therefore this literature review firstly briefly reflects on the experience and implications of developing mental health difficulties for a person’s life and especially where a person is a parent. Parenting, particularly within the context of mental health issues, is then discussed, followed by a consideration of the impact of parental mental health issues on children. Research within the field of parental mental health is then reviewed, with a particular focus on qualitative research focussing on children's understanding of parental mental health difficulties and communication about parental mental health issues in the family. The review goes on to consider the wider literature in terms of children's understanding of mental health difficulties, using the theoretical frame of coherent narratives. Included in this are descriptions of relevant clinical interventions. Finally, the literature is reviewed for studies relevant to children's understanding of mental health problems and communication about mental health issues in families.

2.3. THE IMPACT OF MENTAL HEALTH PROBLEMS ON PEOPLE'S LIVES

Despite many people living meaningful and fulfilling lives while experiencing mental health problems, severe mental distress is often devastating in its impact on people's lives and place in society (Cunningham, Oyebode & Vostanis, 2000; Hinden, Biebel, Nicholson & Mehnert, 2005; Johnston, Schurer & Shields, 2011; Maybery, Ling, Szakacs & Reupert, 2005; Montgomery, Mossey, Bailey & Forchuk, 2011; Mowbray, Oyserman, Bybee, MacFarlane & Rueda-Riedle, 2001; Rose, Mallinson & Walton-Moss, 2002). The user movement, Hearing Voices Network (Dillon, 2014), the Just Therapy group (Waldegrave, Tamasese, Tuhaka, & Campbell, 2003) and others (e.g. Campbell, 2007; Cowling, 2004; May, 2007) have increased our awareness of the challenging and painful experiences of those who live with psychiatric diagnoses and encounter mental health services.

First person accounts tell of the intense shock, disbelief, feeling of unreality and confusion that can accompany a diagnosis of 'mental illness' (e.g. Aiken, 2010; Stockell & O'Neill, 1999) and much has been written about the implications of such a diagnosis for people's lives (Boyle, 2007; Campbell, 2007; Johnston, 2000, 2011; Moncrieff,

2007) and identities (De Barbaro, Opoczynska, Rostworowska, Drozdzowicz & Golanski, 2008). A diagnosis can be accompanied by hospitalization on a mental health ward and this experience can represent a significant crisis (Aiken, 2010; Hawes & Cottrell, 1999; Savvidou, Bozikas, Hatzigeleki & Kararvatos, 2003; Scheyett & McCarthy's, 2006; Scott, Robinson & Day, 2007; Woods & Springham, 2011). Also, the effects of psychotropic medication (e.g. drowsiness, loss of alertness, reduced energy, feeling physically unwell, etc.) have profound impacts on people's quality of life (and potentially on their ability to parent) (Cowling, 2004; Falcov, 1998; Moncrieff, 2007) and there is often the intrusion of experts into the privacy of family life, which families can experience as highly stressful (Maitra, 2005).

Importantly, people with mental health difficulties are seen as 'other' and can often experience stigma. Despite improvements in recent times in the knowledge regarding mental health problems in the general public, this has not translated into improved attitudes towards people with such problems (Hinshaw, 2004). People with mental health difficulties might experience ostracism and discrimination in their neighbourhood or find themselves shunned by their community (Buchanan & Murray, 2012; Hinshaw, 2004, 2005; Hinshaw & Cicchetti, 2000; Kelly, 1999; NICE, 2009; Terkelson, 1987a, 1987b). Some researchers have reported that the effects of stigmatization are more debilitating and difficult to overcome than the mental health problems themselves (e.g. Hinshaw & Cicchetti, 2000; Wahl, 1999, cited in Buchanan & Murray, 2012).

2.3.1. Conclusion

Mental health difficulties can be seen as accompanied by potential losses on many levels. These could include the loss of the capacity to exercise adult responsibility, the loss of previous expectations, the loss of satisfaction from work, the loss of dignity and self confidence, the loss of the ability to relate optimally, the loss of close relationships (including a partner, family or friends; and most painfully the loss of contact with one's children), the loss of privacy, the loss of contributing to one's community and the loss for some of hope. It is clear that all these factors will have a strong potential impact beyond the lives of individuals with mental health difficulties themselves. These factors could powerfully impact on those close to the person, and in particular on the children of those who experience mental health difficulties.

A discussion of parenting and in particular parenting within the context of mental health problems now follows.

2.4. PARENTING

Parenting is one of the most highly valued social roles in society (Ackerson, 2003b; Thomas & Kalucy, 2003) and parenthood is a normative life experience for many people, one that often defines the roles and meaning of adulthood. The literature highlights how ideas about what constitute good parenting abound (Cleaver, Unell & Aldgate, 1999; Kinsman and Wildman, 2001; Göpfert, Webster & Nelki, 2004b), and strong discourses exist of what is best and 'natural' in relation to parenting (although these vary drastically over time and context [see e.g. Rothbaum, Rosen, Ujiie & Uchida, 2002; Weingarten, Surrey, Garcia Coll & Watkins, 1998 and Walters, 2011 for detailed descriptions of these]). These constructions of parenting exclude parents who love their children, but have difficulties of their own that sometimes get in the way of meeting their children's needs. These parents are often judged harshly in our society and their different experiences of being a parent may be misrepresented, diminished or dismissed (e.g. teenage mothers, lone parents, working mothers, etc.); included in this group are parents with mental health problems (Fox, 2009; Poole, 1996; Spiegelhoff & Ahia, 2011).

Motherhood in particular has strong connotations in our society (Phoenix & Woollett, 1991). The ideology of motherhood is a potent force in shaping the lives and experiences of women (May, 2008). The constructions of mothering and the ‘ideal mother’ seem on the surface to celebrate motherhood, but in reality promulgate standards of perfection that are often unreachable (Cowdery & Knudson-Martin, 2005). Furthermore, childbearing women are subject to prohibitions of their activities (Oates, 1997, 2002) and the everyday tasks of mothering are socially devalued. The tendency for society and science to attribute adverse outcomes in children to maternal fault (McNab & Kavner, 2001; Weingarten, et al., 1998) links with the pervasive practices, in particular in the mental health literature, of mother-blaming, and increases women’s tendency to blame themselves (Oates, 2002). Therefore, many mothers discover that it is extremely difficult to mother well in relation to the social norms of the ideal mother (May, 2008; Phoenix & Woollett, 1991).

2.4.1. Parenting within the context of mental health problems

Bias and stigma may have led the professional community to assume that parenting is a role that is not valued by individuals with mental health problems. However, recent qualitative studies suggest that parenting is a highly valued role for parents who have mental health difficulties (Cowling, 2004; Davies & Allen, 2007; Mowbray, Oyserman & Ross, 1995; Sands, 1995). Many parents with mental health difficulties parent well (Falcov, 1998; Fraser, James, Anderson, Lloyd & Judd, 2006). Despite this, mental health problems do pose many challenges to the parenting role (Aiken, 2010; Anonymous, 2010; Davies & Allen, 2007; Fraser, et al., 2006; Gorney, 2007; Turner, 1993; Wilson & Crowe, 2009), both due to the mental health difficulties themselves and society’s responses to people with such problems. These challenges include, amongst others, potentially impaired parenting performance (Cassell & Coleman, 1995; Cleaver, et al., 1999; Davies, 2010; Göpfert, et al., 2004a; Nicholson, et al., 1998a; Thomas & Kalucy, 2003), problematic parent-child interactions, diminished financial resources for the family, social network constriction and frequent physical separations (Göpfert, et al., 2004a; Gorney, 2007; Mowbray, et al., 1995; Rutter, 1985; Smith, 1991; Williams, 2002). Many of these factors are associated with potential risks to children or constraints to their development and wellbeing (Nicholson, Sweeney & Geller, 1998b; Tebes, Kaufman, Adnopoz & Racusin, 2001). For some who experience mental health difficulties family life and the responsibilities and challenges of parenthood can also be experienced as having a negative effect on their own wellbeing and recovery from mental health problems (Falcov, 1998; Lippett & Nolte, 2007).

The aim of child welfare policies is surveillance of parents who are deemed at risk of not being able to meet their children's needs or who pose a risk to their children, with the threat of removal of children as the ultimate sanction of the state. Inadequate parenting as a result of mental health issues is one of the most common grounds on which parental rights are terminated (Ackerson, 2003b, Fox, 2009, Kaplan, et al., 2009). Parents with mental health difficulties have a strong sense that they need to prove themselves as parents (Lee, 2005). This has the potential effect that parents become suspicious and worried about the interference or valuation by outsiders (Maitra, 2005), increasing isolation and discouraging help-seeking. This can create a context that potentially increases the vulnerability of children (Tew, 2002a).

2.4.2. Conclusion

Mental health difficulties might have profound impacts on people's ability to parent in their preferred way. Despite these serious challenges Ackerson (2003b) states that a major failing of our current approach is to either assume that a parent with mental health issues is inherently flawed and unable to parent or, alternatively, that once their situation stabilizes, that all is well. He advocates a more balanced understanding that allows for the ebbs and flows that these difficulties often bring to a person's life and parenting (see also Duncan & Reder, 2003; Göpfert, et al., 2004a). This calls for a more nuanced and sophisticated response from professionals to parents with mental health problems.

The specific impact mental health difficulties in a parent may have on the family, and in particular the children will now be more explicitly discussed.

2.5. EFFECTS OF PARENTAL MENTAL HEALTH PROBLEMS ON CHILDREN

Many have raised awareness of the impact of parental mental health issues on children (e.g. Lancaster, 1999; Landau, Harth, Othnay & Scharfhertz, 1972; Manning and Gregoire, 2006; Reupert & Maybery, 2007) and what we know about this impact has been reviewed in the literature (e.g. Cooklin, 2008; Manning & Gregoire, 2006; Nolte, 2013; Singleton, 2007; Somers, 2007; Tunnard, 2004). The mental health issues of a family member challenges the functioning of a family more than most other issues, and is often protracted or even lifelong (Boursnell, 2007; Langrock, Compas, Keller, Merchant & Copeland, 2002). Family life for a child whose parent has a mental health problem is complex and challenging (Bibou-Nikou, 2004; Mordoch & Hall, 2002) and the literature highlights children's experiences related to the lack of control, chaotic family life and community environments and possible maltreatment (Prilleltensky, Nelson & Peirson, 2001), leaving children vulnerable to experiencing difficulties, including developing mental health difficulties themselves.

However, any individual risk factor is seldom seen as causal, but rather risk factors impact through a complex interplay of dynamic, interactive processes over time (Oates, 2002). Furthermore, many factors protect children and interact with risk factors (Langrock, et al., 2002; Place, Reynolds, Cousins & O'Neill, 2002) to ameliorate the impact on children (Mordoch & Hall, 2002). Many children also talk more positively about skills they develop due to dealing with a parent's mental health problems (Bromley, Hadleigh & Roe, 2013; Dulwich Centre, 2008). Finally, research confirms the important role parents themselves and other caring adults can play in helping families remain strong and mutually supportive in times of crisis (Beardslee, Salt, Versage, Gladstone, Wright & Rothberg, 1997; Focht & Beardslee, 1996; Focht-Birkerts &

Bearslee, 2000), leading Focht-Birkerts & Beardslee (2000) to call for a redefinition of resilience to include the reparative potential of families, that is relational resilience.

2.5.1. Conclusion

It can be concluded that the simplistic view that children of parents with mental health problems can always be seen as ‘damaged’ and that those who remain well are extraordinarily resilient, should be challenged (Gladstone, et al., 2006; Oates, 2002; Place, et al., 2002; Prilleltensky, et al., 2001). This is not to diminish the substantial literature that indicates the potential devastating effects parental health issues can have on children’s lives (as discussed below). However, it does call for a view of the impact on children that allows for complexity and the acknowledgement of both risk and protective aspects, as well as the complex and dynamic interaction between these (Gladstone, et al., 2006).

The existing research within the field of parental mental health will now be reviewed.

2.6. RESEARCH IN THE FIELD OF PARENTAL MENTAL HEALTH

2.6.1. Introduction

Mental health research in general has tended to focus on the impact of mental health problems on the individual experiencing the difficulty, with little or no attention given to those around the person (Tunnard 2004). When taking family members into account, research in the field of parental mental health has traditionally focused on the relationship between parental ‘psychiatric disorder’ and poor outcomes for children (Smith, 2004), with the main aim of the research being to predict and explain relationships between parental ‘mental illness’ and ‘psychopathology’ in the child.

Much research has been carried out on specific psychiatric diagnoses to determine if and how they impact on children and what the likelihood is of the children developing similar or other mental health difficulties themselves (Bassani, Padoin, Philipp & Veldhuizen, 2009).

2.6.2. Diagnosis-focused research

This large body of research will not be reviewed here in full, for reasons of space, but some examples are given and briefly discussed:

Much attention has been focused on parental (especially maternal) depression (SCIE, 2008a). A number of authors have undertaken reviews of research studies looking at the impact of parental depression (e.g. Cox, Puckering, Pound & Mills, 1987; Cummings, Keller & Davies, 2005; Downey & Coyne, 1990) and post-natal depression (e.g. Murray, 1992) on children. Impacts on children of maternal depression have been found for children from infancy to adolescence (Smith, 2004) – these include problems with language development and intelligence, behaviour difficulties, reduced social and emotional competence, sleeping problems, physical ill health, parent-child relationship issues and attachment difficulties (see e.g. Schwartz, Dorer, Beardslee, Lavori and Keller, 1990).

Similar research has been carried out with other psychiatric diagnoses, e.g. schizophrenia (see Bosanac, Buist & Burrows, 2003 for a recent review), substance abuse or dependence, anxiety and eating disorder diagnoses, indicating increased risks to children. However, there is strong evidence that the type of parental mental health problem is not a strong predictor of the type of problems that children go on to experience (Rutter & Quinton, 1984). In response to this critique, there has in recent times been more of a focus on developing an understanding of the mechanisms by which mental health problems experienced by parents may impact on children, and thus how these increase the risk of poor outcomes for children.

2.6.3. Mechanisms of impact research

Consideration has been given to genetic factors, but also the complex interaction of genetic and environmental influences, the direct exposure to difficulties, the influences of associated factors (e.g. conflicted partner relationships or poverty) and disruptions to parenting (Smith, 2004) and parent (mostly mother)-child relational difficulties (e.g. Goodman & Brumley, 1990; Graunbaum & Gammeltoft, 1993).

Some of the theories relating to the mechanisms of impact imply direct effects of parental ‘symptoms’ on children, while others imply an effect via intermediate or mediating factors (Smith, 2004). A significant example of such research is the seminal UK-based study by Rutter and Quinton (1984). They found that about a third of children with a parent with mental health difficulties developed persistent difficulties themselves, one third showed transient problems and one third showed no disturbance at all. The effects on the child were independent of the diagnosis a parent had been given, but more determined by the social and interactional consequences of their problems. They found hostility and relational disharmony in the parents’ relationships particularly problematic.

The implication of this position is that the impact of associated actions, parenting ability, relationships or the home environment are more important in explaining impacts on children than the diagnostic label applied to the parent’s mental health problem (Smith, 2004).

2.6.4. Conclusion

There is a significant body of research evidence that shows that children can be negatively affected where a parent has mental health difficulties and are at increased risk of developing mental health difficulties themselves (e.g. Duncan & Reder, 2000; Duncan & Reder, 2003; Falcov, 1998; Focht & Beardslee, 1996; Leverton, 2003; Tunnard, 2004). However, it is now understood that it is not the nature of the diagnosis of the parent per se that impacts on children, but rather that the social and interactional aspects often associated with mental health issues pose a risk to children (Puckering, 2004). This large body of research highlights the importance of paying attention to more than the person experiencing mental health problems to also consider the context of the person, and especially the importance of including the children, if the needs of such families are to be fully addressed.

However, this research has also been criticised by a number of authors (e.g. Bassett, Lampe & Lloyd, 2001; Boursnell, 2007; Garley, Gallop, Johnston & Pipitone, 1997; Graham & King, 2005b; Meadus & Johnson, 2000; Oates, 2002; Tebes, Kaufman, Adnopoz & Racusin, 2001; Van Parys & Rober, 2012). These authors point out that the research has been overwhelmingly focused on mothers and especially the impact on attachment, contributing to the endemic mother-blaming within the mental health culture. Very little attention has traditionally been paid to fathers who experience mental health difficulties. Furthermore, in many studies the cultural background of the participants is not referred to (Leverton, 2003) and the amount of research specifically relating to parents with mental health problems from BME background is limited, with the coverage of different minority groups patchy (SCIE, 2008b).

A further critique is that most of the research is carried out through the lens of a medical model. As a result much of the information that would be valuable from a clinical perspective (i.e. social context and relationships) is not available or not provided in a format that fits with this perspective. This makes it difficult to assess the usefulness of the research and its implications for clinical practice. The research has also been criticised for being only pathology-focused in considering impacts on children, not accounting for potentially more subtle, but pervasive impacts on children's lives beyond a pathology frame, e.g. experiences of guilt, lack of confidence, etc. (Hinshaw, 2004). Furthermore, the research has often been carried out within institutional settings and few studies are done within community settings.

Finally, the children of those with mental health difficulties within this type of research are pictured as the passive receivers of adverse outcomes of their parents' difficulties. Too little focus has been placed on the potential for resilient outcomes for children, the stories of "hope and promise that can accompany even severe mental illness as it exists in families" (Hinshaw, 2004, p. 402). Furthermore, according to Van Parys & Rober (2012) the process of transmission is presented as a simple and linear one-directional and fixed process. Research has consistently shown that a significant proportion of children of parents with serious mental health issues show no discernible evidence of problem behaviours or difficulties (e.g. Rutter, 1966, cited in Tebes, et al., 2001; Rutter & Quinton, 1984).

There has traditionally been a lack of research trying to understand the experiences of parents with mental health difficulties and their children from their own perspective. In more recent times such qualitative research is becoming more available and this body of qualitative research will be discussed next.

2.6.5. Qualitative research exploring the experiences of children of parents with mental health problems

2.6.5.1. Introduction

In recent years mental health researchers and practitioners have been shifting their focus to adjust to a new awareness of the importance of the voice of the child. This shift has also impacted on research within the parental mental health field and there has been a growing number of studies addressing the young person’s perspective, exploring the lived experience of children and young people living with a parent with mental health difficulties (e.g. Aldridge 2006; Bromley, et al., 2013; Cogan, Riddell & Mayes, 2005; Farzin, 2008; Fudge & Mason, 2004; Garley, et al., 1997; Gorin, 2004; Handley, Farrell, Josephs, Hanke & Hazelton, 2001; Maybery, et al., 2005; Meadus & Johnson, 2000; Mordoch, 2010; Mordoch & Hall, 2008; Östman 2008; Riebschleger, 2004; Shah & Hutton, 1999; Singer, et al., 2000; Stallard, Norman, Huline-Dickens, Salter & Cribb, 2004; Totsuka, 2010, 2013; Van Parys & Rober, 2012).

One of the difficulties of reviewing this body of research lies in comparing such diverse studies. Included are studies undertaken in a number of different countries (including the UK, US, Canada and Australia). The studies differed in the seriousness and variation of the mental health difficulty of the parent (e.g. some studies only focused on depression, some on any mental health problems and some on severe and enduring mental health issues), the parents included (a number of studies only focused on mothers) and the analysis used (surveys, focus groups and individual interviews were used to obtain data and different methodologies e.g. Grounded Theory, IPA and Thematic Analysis were used for analysis). Some of the studies were modest in size (e.g. one including only three participants) where others involved more detailed and thorough aims. The children also varied in age, including children from as young as 5-years old, up to the age of 18. Despite these reservations it is clear that notwithstanding the diversity of the studies there are strong overlaps in terms of important themes highlighted by the children across the studies. This also remains a relatively small body of research. Therefore the case can be made for grouping these studies together.

Gladstone, Boydell, Seeman & McKeever (2011) and Tunnard (2004) have presented reviews in the literature. For the purposes of this study this research was reviewed particularly in relation to the theme of the current research question, namely the children’s experiences of understanding their parent’s mental health difficulties and their sense of receiving information. The majority of qualitative studies exploring the views and experiences of children and young people living with a parent with mental health issues inquired into their understanding of the parent’s mental health problems and their views of obtaining further information.

2.6.5.2. Children’s understanding of a parent’s mental health problems

Children had varied explanations of their parents’ mental health problems and the causes and triggers for the problems (Colmer, 2005; Garley, et al., 1997; Singer, et al., 2000) and could clearly describe their parent’s behaviour when they were unwell and how this affected them (Singer, et al., 2000). Totsuka (2010, 2013) also highlighted the lived experiences of the young people and what they witnessed in their day-to-day lives, naming this as “experiential knowledge” (2013, p. 136) and pointed out that “informational knowledge” (2013, p. 136) could either complement and validate experiential knowledge or contradict it and vice versa.

2.6.5.3. Information

A number of studies highlighted this experiential knowledge, with children describing learning through seeing and experiencing (e.g. Bromley, et al., 2013). An important example of such research is the Canadian-based Grounded Theory study by Mordoch and Hall (2008) interviewing 22 children (aged 6-16). These authors provide a very rich description of how children in their study developed an intricate understanding of the changes and challenges in a parent in relation to their mental health issues. They then described the complex strategies children and young people employed in dealing with the potentially overwhelming experiences of their lives in the context of their parent’s mental health issues. This developing of experiential knowledge is also reflected in research by e.g. Riebschleger (2004), Garley, et al. (1997) and others. It was clear from these studies that children could detect signs that their parent was becoming distressed and developed strategies to respond to these situations.

Other studies tended to place the focus on what Totsuka (2010) would describe as informational knowledge. Most studies reported that children felt that they had little information about their parents' difficulties and the help they received (e.g. Bromley, et al., 2013; Farzin, 2008; Garley, et al., 1997; Handley, et al., 2001; Meadus & Johnson, 2000; Riebschleger, 2004; Shah & Hutton, 1999; Stallard, et al., 2004, etc.). Young people reported that they struggled to understand the mental health problems, leading to fear, confusion and uncertainty (Bromley, et al., 2013; Handley, et al., 2001) and that they wanted more information (Fudge & Mason, 2004; Mordoch, 2010; Östman, 2008). In a study by Dunn (1993) children with parents with a diagnosis of a psychotic illness were interviewed in adulthood and reported being isolated from information, not being given explanations about their mother's behaviour, and that hospitalisations and treatments were not explained to them. This, in their view, contributed to the effects their parent's difficulties had on their lives.

Information required by the children and young people included knowing how their parent became unwell, likely consequences of their difficulties and the help they receive (Farzin, 2008; Garley, et al.,1997; Meadus & Johnson's, 2000; Stallard, et al., 2004). In relation to a parent's stay in hospital, children expressed a need to have some of their questions about their parents' difficulties answered, e.g. wanting to know when their parent was moving wards and when they would be likely to come home (Handley, et al., 2001; Scott, et al., 2007). Some wanted to know what would happen to their parent and themselves. Also young people wanted to know things like what's going to happen and how to handle it (Totsuka, 2010).

This summary shows that some information the young people were looking for was factual. However, some information was also to do with the process of coping with great uncertainty and unpredictability within potentially traumatic life experiences, information that cannot be directly and easily provided, but needs to be figured out over time and in relationship with the unfolding situation and those in it.

2.6.5.4. Obtaining information

Much of what children know about their parent's mental health problems was learned through observation (Bromley, et al., 2013; Mordoch, 2010, Totsuka, 2010). Other kinds of information about mental health problems were elusive (Handley, et al., 2001; Mordoch, 2010). Often they felt frustrated, fearful, lonely and helpless in their struggle to obtain information (Colmer, 2005; Garley, et al., 1997; Meadus & Johnson, 2000) and were even described as on a "quest for information" about their parent's difficulties (Garley, et al., 1997, p. 100).

It was found that many children selectively shared their experiences with trusted others, including their parents, peers, friends, and helpers (e.g. counsellors, teachers). Sharing their experiences helped them validate these experiences and decreased feelings of isolation. Children reported finding it easier to share with children undergoing similar experiences, for example other children with a family member with mental health issues (Mordoch & Hall, 2008).

Some parents explained their mental health problems and the behaviours that came with it to their children and some guided and encouraged their children to share how they were managing (Mordoch & Hall, 2008). However, parents' attempts to protect their children from harmful information, or their inability to focus on their children's needs often could create barriers to talking (Mordoch, 2010). The well parent or extended family could also interpret parental behaviour or give advice on what to do when the parent was unable to (Mordoch, 2010). However, some studies reported that children found a reluctance in those close to them to discuss their parents' difficulties (e.g. family members, teachers).

Some studies highlighted that it can be difficult for children themselves to talk both to a well and 'unwell' parent about the problems (e.g. Van Parys & Rober, 2012). Also, children in single-parent homes often monitored their parent's situation alone and struggled to make sense of what was happening (Mordoch & Hall, 2008). Children sometimes obtained information through chance, e.g. conversations inadvertently overheard (Mordoch, 2010). Children and young people also tried to find information from other sources, e.g. asking their GP, volunteering for a mental health charity. One participant in Garley, et al.'s (1997) study (pre-internet) looked up the 'disorder' in an encyclopaedia, where in more current research children indicated finding information through printed materials and via electronic media (Mordoch, 2010).

2.6.5.5. Implications of having or not having information

There is a view informed by current studies that having accurate information about mental health difficulties is protective of children. In a small study Falcov (1998) demonstrated that children who had received a good explanation of their parent's mental health problem showed fewer signs of 'disturbance' on objective measures compared to a control group who had received no explanation. Also, Perez-Gavino (2012) found that the different responses children displayed, as reported by their mothers, were likely to be underpinned by their perceptions and understanding of their mother's behaviour. Mordoch and Hall (2008) found that children's lives and their feelings about their parents were affected by, amongst a number of factors, what they understood about mental health problems. Children who were knowledgeable about mental health issues were better able to interpret their parent's behaviours. Their knowledge helped these children to experience less uncertainty about what was happening and made their painful emotions less intense. Where the children did not have the full picture of what was going on, they imagined unrealistic scenarios of, for example, their parent dying, which added to their emotional turmoil (Mordoch & Hall, 2008).

A significant study here is the work of Scherer, Melloh, Buyck, Anderson & Foster (1996). In this UK-based study of 57 children and their mothers (of whom half had severe and enduring mental health difficulties) mother-child observations were carried out alongside measurements of parenting style, parent mental health, child behaviour and child's self-perceptions in order to explore the relation between children's perceptions of maternal mental health problems and children’s psychological adjustment. The study reported that children’s perceptions of their mother’s mental health were significantly related to their psychological wellbeing and with an increase in confidence and a positive sense of self and reductions in confusion and self-blame. Scherer, et al. (1996) highlighted that the ways in which children attached meaning to experiences and how they integrated these into their sense of identity and worldview, influenced resilience. However, where mental health is concerned, Scherer, et al. (1996) found that this involves the ability to understand often ambivalent and contradictory behaviour in others. They concluded that when mothers and children disagree in their perceptions of the mother’s behaviour, children manifest more behaviour problems and less self-competence.

Interestingly these authors found that children with mentally ‘unwell’ mothers did not perceive their mothers to have more psychiatric distress than children with psychiatrically ‘well’ mothers. They therefore hypothesized that young children may be inclined to deny or minimize the presence of emotional distress in their mothers. Scherer, et al. (1996) states that children can be taught to perceive and comprehend their mother’s behaviour accurately, and mothers with mental health issues can be helped to identify and empathize with the effects of their emotional troubles on their children.

A number of studies demonstrated that children experience undue hardship when they have incomplete information about their parent’s mental health issues (e.g. Mordoch, 2010) and strongly supported interventions that teach children individually and in groups about their parent’s difficulties and treatment, as a way of helping them cope (Meadus & Johnson, 2000). Others also recommend that mental health professionals should have training to increase awareness and develop skills in addressing family issues with their clients and in communicating effectively with children and young people about their parent’s difficulties (Bromley, et al., 2013; Mordoch, 2010; Scott, et al., 2007).

2.6.5.6. Contradictory views

It is therefore clear from this body of research that emphasis is placed on the importance of giving children and young people information. However, some studies with children and young people reported mixed results about what they themselves wanted. A number of studies showed that not all children and young people necessarily wanted to know more about their parent’s mental health difficulties and that some children did not want to feel burdened by their parent’s mental health issues (e.g. Armstrong, 2002, cited in Totsuka, 2013; Bromley, et al., 2013; Colmer, 2005; Stallard, et al., 2004, Van Parys and Rober, 2012). The nature of the information and how it is communicated have also been highlighted as important – some children have requested that information be age-appropriate (Farzin, 2008) and others suggested that information should be shared in ways that were not frightening (Mordoch, 2010). Aldridge and Becker (2003) and others have also warned about information-overload and recommended that children should only receive information when they need or want it.

This indicates that there are at times uncertainties for children about talking and knowing about parental mental health issues.

2.6.5.7. Importance of context

Colmer (2005), in her UK-based IPA study including 17 interviews with members from 8 families, began to offer a way of understanding this ambivalence in relation to children having more information. She highlighted the importance of the implications of different possible explanations for children and other family members and argued that ideas about the causes of parental mental health problems were significantly influenced by the ways in which understandings of the problems relate to powerful emotional states, such as guilt, blame, fear and shame. She also noted a dissonance between the understandings that participants held about their experiences and the medical discourses (see also Maybery, et al., 2005). She warned against explanations "all (being) lumped together" (p.73).

Totsuka (2010) took these insights further. Like Colmer (2005) she found that the meanings young people attach to their parent's symptoms or behaviour might influence their need for information. She also found that the amount and accuracy of information the young people had did not always appear to relate to their sense of satisfaction with the information. This led her to conclude that understanding develops in a complex way over time in multiple layers of context. For example, young people's relationship with information could be influenced by external factors, such as their care-taking role and the availability of support. Furthermore, she speculated that parents' ambivalence about talking and children's reluctance to know could be recursive, that is it might be that the less information the parent provides, the more inhibited the young person might feel about asking, e.g. out of fear of upsetting the parent, protectiveness or loyalty. She concluded that young people are active participants in the process of developing understanding, and their own experiential knowledge has an important part in this process.

A further study that sheds light on the complexity of the issue of young people's understanding is that of Belgium researchers Van Parys and Rober (2012) who undertook a Thematic Analysis of 14 interviews with children. They found three themes that spoke to an understanding of children's experience of making sense of the parent's mental health difficulties. Firstly, they found that "overall knowing in the family was very diffuse and varied over time (children stated that they 'forgot' certain information) and what was known also differed from one family member to the other" (p. 5). Most often many questions remained for the children where they did not believe or did not understand the parent's explanations. In their attempts to find out more, children sometimes felt that they were not allowed to know or were being protected from inappropriate information. Children sometimes overheard information when adults were arguing or discussing things. Secondly, they emphasised talking in the family as difficult, with many hesitations and silences. Finally, they reflected on the relational context of talking, knowing and understanding – children in their research tended to behave in ways that made the parent feel less burdened, more comforted, etc. (non-verbally as well as verbally).

A final study (a re-analysis of the data from a previous Grounded Theory study) that can aid in understanding the complexities of obtaining information, talking and understanding for children, is the Canadian-based research by Mordoch (2010). She found that children developed a "kaleidoscope" (p. 20) perspective of their parent's mental health problems, piecing together parts of the story through what they are directly told, information they find out, what they see and information that comes to them inadvertently, with some of this falling into familiar and predictable patterns, although always with an element of unpredictability. The silences surrounding mental health problems could often lead to misinformed perceptions on the part of children and efforts to protect children or the provision of vague explanations often led to unnecessary worry and ambiguity for children. Children were also sensitive to the stigma surrounding mental health problems, and this impeded their understanding. While they did not have much information, they were still expected to manage their circumstances of living with a parent with mental health issues. Mordoch (2010) concluded that children's understanding was fragmented and constructed over time within a context of ambiguity.

2.6.5.8. Conclusion

Evidence is mixed as to children's knowledge and understanding of a parent's mental health problems. In relation to information and learning about their parent's mental health difficulties, research points to children gaining understanding in different ways over time, including, for some, conversations with a parent or other adult, for many through observation, and sometimes through other sources. There is a general view from this research that most children want more information and that having an accurate understanding of their parent's difficulties is protective. However, recent research has highlighted the complexities of relationships, meaning and context that shape knowing and gaining understanding. This shows that ambiguity and silences often surround a parent's difficulties, leading to children having partial and fragmented understanding. Mordoch (2010) concludes that research on when and what to tell children is needed to ensure that all children receive timely and developmentally appropriate and helpful information.

This review provides a window into the lives of children living with parents with mental health issues and their meaning-making in relation to their parent's difficulties. Given the critique of Gladstone, et al. (2006), Totsuka (2010) and others with regards the construction of children as passive beings or 'objects' and victims rather than as individuals that actively participate in their social lives within traditional parental mental health research, this expanding body of research shows us the rich and complex ways in which children make sense of and actively respond to their circumstances (Murdoch and Hall, 2008; Van Parys & Rober, 2012).

Research exploring the experiences of parents with mental health difficulties will now be discussed.

2.6.6. Qualitative research exploring the experiences of parents with mental health problems

2.6.6.1. Introduction

There are fewer qualitative studies looking at the experiences of what Boursnell (2007) calls the 'silent' parents with mental health difficulties in relation to their parenting and their children (Ackerson, 2003b; Bassett, Lampe & Lloyd, 1999). Most of what we have learned in the past decade about the experiences of parents with mental health problems is based on small sample research of mothers in the public sector with severe mental distress and multiple stressors such as poverty and ethnic minority status. The majority of mothers in the studies were divorced, separated or never married and most mothers fell in the unemployed or low socio-economic categories (Nicholson, Biebel, Hinden, Henry & Stier, 2001). We know little about the experiences of fathers (see LeFrançois, 2010 and Styron, Pruett, McMahon & Davidson, 2002 for recent reviews of this limited body of research).

The qualitative studies with parents with mental health issues (including Ackerson, 2003a; Bassett, et al., 1999; Blegen, Hummelvoll & Severinsson, 2012; Boursnell, 2007; Cowling, 1999; Davies & Allen, 2007; Diaz-Caneja & Johnson, 2004; Dipple, Smith, Andrews & Evans, 2002; Handley, et al., 2001; Maybery, et al., 2005; Montgomery, et al., 2011; Montgomery, Tompkins, Forchuk & French, 2006; Mowbray, et al., 1995; Nicholson, et al., 1998a & 1998b; Perez-Gavino, 2012; Sands, 1995; Stallard, et al., 2004; Stormont, Craig, Atakan, Loader & Williams, 1997; Thomas & Kalucy, 2002 & 2003; Wang & Goldschmidt, 1994; Wilson & Crowe, 2009) are once again diverse. They were carried out in different counties (including the UK, US, Australia, Canada, Norway and New Zealand), with different populations (e.g. in-patients, those who have lost custody of their children, those in very deprived circumstances, etc.; in terms of the ages of children including from under fives to late adolescence; some including only mothers), using different ways to gather data (including focus groups and individual interviews) and analyse data (e.g. Grounded Theory, IPA, Thematic Analysis and Discourse Analysis).

However, given the limited research available in this area and given the large overlap in themes identified within the different projects, it is deemed appropriate to group them together. Dolman, Jones & Howard (2013) carried out a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental health problems. Nicholson, et al. (2001) and Montgomery (2005) also conducted overviews of the literature on parents with mental health issues, as did Tunnard (2004) as part of a wider review of all parental mental health literature. For the purposes of this study, this body of research was particularly reviewed in relation to the theme of the current research, namely the parents' views of their children's understanding of their mental health difficulties and their views on providing their children with information.

Less attention is paid to this theme in research with parents than with children. Like the research with children, research into parents' views on explaining their mental health problems to their children consistently adopts a position that children need information about the parent's difficulties and should have a good understanding of their parent's mental health problems (e.g. Falcov, 1998; Tunnard, 2004). In the adult literature there is also a stronger assumption of a shared understanding of what it is that children need to understand, namely a parent's 'mental illness' diagnosis.

2.6.6.2. Contradictory views

Two main positions emerge from the literature. On the one hand researchers found that some parents were reluctant to discuss their mental health difficulties with their children (e.g. Stormont, et al., 1997). Some potential reasons for this included finding it difficult to acknowledge the impact of their mental health problems on their children and a concern about the children being removed from their care (Maybery, et al., 2005; Tunnard, 2004). Colmer's (2005) research highlighted how explaining mental health problems to children was a source of distress for parents. Some parents were aware that children were confused, but had mixed views about how helpful it was for children to know more, especially knowing about suicide. Shame and guilt also impacted on what parents could or would tell. Parents worried that talking could enhance fear. Other reasons parents gave for not wanting their children to have more information included a sense that there was nothing more to know, a sense that information would not help, or that children were too young or would not understand (Maybery, et al., 2005).

In contrast, other researchers found that parents had given thought to what their children knew about their mental health problems, for example Handley, et al. (2001); Maybery, et al. (2005) and Stallard, et al. (2004) all found that the majority of parents did not feel that their children understood their mental health problems and many reported that no one had talked to their children about their difficulties, but these parents mostly thought that it would be helpful for their children to have more information. They were keen for children to understand that their parent's mental health problem was not their fault, and to know that the parent could not help their behaviour or the treatment they received, e.g. hospitalization. In Colmer's (2005) research some parents felt that "sharing and discussing [parental mental health issues] had enhanced closeness and understanding between them" (p.107). In Singer, et al.'s (2000) study most of the mothers in the study had attempted to offer some explanation to their children regarding their problems and were clear about omitting some details, such as suicidal behaviour, that they judged would upset the children too much. Maybery, et al. (2005) and Tunnard (2004) highlighted the importance that parents gave to the age of their children and that they wanted different information to pass on to their children at different times in their lives. Nicholson, et al. (1998a) reported that many parents wanted advice about how to talk to their children about their mental health problems and treatment.

2.6.6.3. Process over time

A recent study provided a more process-orientated view on the issue. Montgomery, et al. (2006) in their Canadian-based Grounded Theory study interviewing 20 mothers, found that a core theme of 'keeping close' described mothers' efforts to have meaningful relationships with their children in the context of mental health issues and suffering. To this end, mothers chose strategies that would hide their difficulties for the sake of protecting their roles as mothers and their children. Strategies including masking the problem and censoring their speech served to imitate ideal perceptions of mothering while making the mental health problems invisible to their children. Mothering with mental health problems, however, became a vortex of contradictions, resulting in mothers realizing that this position cannot be maintained and that they could not keep close through pretending to their children that mental health problems did not exist. Mothers then sought treatment, hoping to learn how to be with their children more authentically, including finding a way to share their experiences with their children. This again points to a more developmental and relational perspective on developing understanding of parental mental health issues in families.

2.6.6.4. Importance of contextual factors

Two important contextual factors ran through all the research in relation to parents and it is necessary to consider these here:

2.6.6.4.1. Fear of custody loss

A theme that powerfully runs through all the qualitative research with parents with mental health difficulties is an intense fear of losing custody of their children. This fear permeated all that parents would say in research, affected communication with professionals, leading to people masking their symptoms, to reluctance to seek help and to reluctance to disclose difficulties in parenting (Ackerson, 2003a; Bassett, et al., 1999; Blegen, et al., 2012; Boursnell, 2007; Dipple, et al., 2002; Kundra & Alexander, 2009). This is not an unrealistic fear, as parents with mental health problems are highly vulnerable to losing custody of their children (Dipple, et al., 2002; Kaplan, et al., 2009; Kundra & Alexander, 2009).

2.6.6.4.2. Stigma

A second theme that pervades all the research with parents is the devastating impact of stigma. “The corrosive effects of stigma were cited in over three-quarters of the studies” reviewed by Dolman, et al. (2013, p. 177). One of the most worrying consequences of stigma was that it prevented parents from talking about their difficulties openly and, importantly, from seeking help (e.g. Ackerson, 2003a; Bassett, et al., 1999; Boursnell, 2007; Wilson & Crowe, 2009). Furthermore, parents were often reporting extreme concern about the impact of secondary stigma on their children

(Diaz-Caneja & Johnson, 2004; Dolman, et al, 2013). Parents also described self-stigma where they saw themselves as bad parents due to stigma being internalized. Wilson & Crowe (2009) described the high levels of strenuous self-surveillance that parents developed in response to these experiences.

Thus, "issues such as stigma and fear of custody loss mitigate against the establishment of a meaningful therapeutic relationship with health professionals" (Dolman, et al., 2013, p. 189).

2.6.6.5. Conclusion

This review provides quite a confusing, uncertain and incomplete picture of how parents feel about their children having information about their mental health problems.

In their conclusions many authors looked away from the parents to recommend ways to assist the children with learning about their parent's mental health difficulties. For example, Cowling (1999) concluded that children should be educated about their parent's mental health issues and that there should be a support person for the children to talk to as well as programs where children can gain support and understanding. Maybery, et al. (2005) also concluded that children needed to be debriefed by a mental health practitioner after a parent had a period of hospitalization, while Diaz-Caneja & Johnson (2004) recommended family meetings and "having a professional explain to children the nature and effects of their mother's illness" (p. 479). It would be interesting to understand why parents are not seen as a more significant partner in this process.

Furthermore, it is again important to pay attention to how the research constructs the parents. In contrast to the diagnosis-based research, portraying the parents as 'causing' their children's difficulties, here there is a risk of under-emphasising the complexities and challenges for parents of mental health issues, and to gloss over the potential impacts of their difficulties on their children within the context of the parents’ good intentions and vulnerability. This could potentially set up a dichotomy between the parents as perpetrators of harm or alternatively as misunderstood victims – such a split would not be helpful or productive within our understanding of the lives of these families.

2.7. CHILDREN’S UNDERSTANDING OF PARENTAL MENTAL HEALTH PROBLEMS

2.7.1. Introduction

In addition to the qualitative studies reviewed here, the wider literature was considered in relation to children’s understanding of parents’ mental health difficulties and a search was carried out for studies exploring the interaction within families about parental mental distress and providing information or explanations to children. This will now be discussed, paying particular attention to the concept of coherent narratives.

2.7.2. Coherent narratives

This section will explore the relationship between having a coherent understanding of one’s experiences and exhibiting resilience and wellbeing, as described in the literature. This will be linked to children developing an understanding of their parent’s mental health issues. Current thinking within clinical practice will also be considered.

2.7.2.1. Introduction

From a social constructionist perspective it is claimed that throughout life people consciously and unconsciously create narrative accounts to organize the chaos of existence into a coherent[1] life story (Murray, 2003). This life story defines a person's sense of self and "has been identified as one of the most productive ways of identity construction, display, and negotiation" (Tovares, 2010, p. 3).

In the literature on resilience (e.g. Byng-Hall, 1995; Rutter, 1985) it is highlighted how the ways in which people attach meaning to experiences, and how they integrate these into their sense of identity and worldview, influence resilience and wellbeing. Thus, the ability to have a coherent account of one's experiences and relationships is widely seen in the literature as a factor that can protect against the impact of negative, difficult and painful life experiences (ACT Mental Health Consumer Network & Dulwich Centre, 2003; Byng-Hall, 1995, 2002; Cooklin, 2004; Daniel & Wren, 2005; Fonagy, Steele, Steele, Higgitt & Target, 1994; Fredman & Fruggle, 2000; Rutter, 1985). Medved and Brockmeier (2008, p. 68) state that "in recent literature, there is increasing support for the suggestion that narrativizing traumatic experience of injury or disease is crucial to comprehending, and ultimately, coming to terms with trauma".

Developing coherent accounts of challenging experiences has been found to be important in a number of areas where potential disruptions are present, such as divorce and forming a reconstituted family (Daniel and Thompson, 1996 cited in Stern, et al., 1999), loss and deprivation (Bowlby, 1988 cited in Stern, et al., 1999) and sexual abuse (Bentovim and Davenport, 1992 cited in Stern, et al., 1999).

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[1] Coherence here is simply seen as an account that makes sense to you and to others, and that has continuity, that is it is able to predict the "ongoingness of things" (p.37), linking past, present and predicted future (Penn, 2001). Coherence has elsewhere been defined as "the capacity to connect events and to take various simultaneous perspectives" (Stern, et al., 1999, p. 355) and Medved & Brockmeier have stated that coherence can be based on thematic, spatial, temporal, historic, compositional (e.g. genres, narrative models or points of view) or rhetorical and stylistic (e.g. metaphors, parables, etc.) aspects.

2.7.2.2. Coherence within the context of parental mental health

Frank (2004) points out that illness or trauma introduce a new unsettling narrative into a life story, and that this has complex implications that require much emotional and relational work for the person and their loved ones over time in order to re-conceive of their lives in a way that incorporates this new development. This can be seen as also applicable to where a parent begins to experience mental health problems. It is very difficult to make sense of the often confusing, disruptive, disturbing experiences that can accompany mental health difficulties and often persons themselves and their loved ones can be left bewildered (Andrews, 2006). Trauma theory would suggest that such experiences constrain information processing and thus the development of narrative coherence (Vetere & Dallos, 2007). When trauma is experienced, often meaning-making becomes confused and stories of experiences become incoherent and fragmented (e.g. Fonagy, et al., 1994). "It is the possibility of making sense of (such) difficult life experiences and integrating positive and negative aspects that is necessary. This search for coherence seems to be part of resilience as much as other protective factors, like family cohesion, flexibility, communication, and problem-solving" (Stern, et al., 1999, p. 355).

Mental health difficulties in a parent can also expose children to many potentially traumatic, fear-inducing and confusing experiences and children can be left with no framework for interpreting their parent's extra-ordinary behaviour (Focht-Birkerts & Beardslee, 2000). These children will nonetheless work to construct some form of understanding of the changes they see in their parent (Gorin, 2004). Altscuhler and Dale (1999), Cooklin (2004; 2006), Place, et al. (2002) and others have warned that in the absence of being given information, children will continue to develop their own understandings and that these may well be more frightening or unhelpful than the reality around them. In a robust review of existing literature, Hill (2004) posited that where a child is able to integrate behaviours and experiences related to the parent's mental health difficulties into an overall secure relationship with the parent, this might be protective. Thus developing a good understanding can reduce children's fears and anxieties and help them to think clearly and trust others; furthermore it can enable them to have a greater sense of control and regulate their emotions (Walsh, Schofield, Harris, Vostanis, Oyebode & Coulthard, 2009). Tunnard (2004) concluded that communication between family members could strengthen children's ability to move on in life, without worrying unduly about the parent's problems. Therefore, it has become generally accepted as helpful and protective for children to have information about the parent's mental health difficulty.

2.7.2.3. Clinical responses to the connection between coherence and wellbeing

The importance for children to have information about their parent's mental health problems and for parents and children to talk together about mental health difficulties is now widely accepted not only by researchers, but also by clinicians – more is being written about the important role services have to play in facilitating these conversations and supporting parents in helping their children make sense of their experiences (e.g. Barnardo's, 2003; Beardslee, 2002a; Cooklin, 2004; Daniel & Wren, 2005, Focht & Beardslee, 1996; Fredman & Fruggle, 2000; Reupert & Maybery, 2007, 2009a; Royal College of Psychiatrists, 2004).

Many clinical interventions have been developed to respond to parental mental health issues in families – for recent reviews of the literature on these, see the critical review conducted by Fraser, et al. (2006); overviews by Reupert and Maybery (2007, 2009a, 2009b) and Reupert, Goodyear, Eddy, Alliston, Mason, Maybery and Fudge (2009) [Australian interventions]; reports comparing specific aspects of current interventions by Hinden, Biebel, Nicholson, Henry and Katz-Leavy (2006), Hinden, Biebel, Nicholson, Henry and Stier (2002) and Krumm, Becker and Wiegand-Grefe (2013); research into key ingredients of successful interventions by Goodyear, Cuff, Maybery and Reupert (2009a); Hinden, et al. (2005); Morson, Best, de Bondt, Jessop and Meddick (2009); and Van Doesum and Hosman (2009) and Hosman, van Doesum and Sandvoort (2009) [Dutch interventions] and reviews of barriers to developing effective interventions in the UK (Falcov, 1998), Australia (Maybery & Reupert, 2009a) and Norway (Reedtz, Lauritzen & Van Doesum, 2013).

A number of different clinical approaches have been adopted in devising interventions, the most significant of which will be discussed here, namely psycho-educational, narrative and systemic.

2.7.2.3.1. Psycho-educational approaches:

Those advocating a psycho-educational model (at times informed by cognitive or cognitive-behavioural therapy) emphasise the need for children to receive more, and also more accurate, information about their parent's 'illness', e.g. the diagnosis, symptoms and prognosis (Alakus, Conwell, Gilbert, Buist & Castle, 2007; Beardslee, 2002a; 2002b; Clarke, Hawkins, Murphy & Sheeber, 1995; Clarke, Hornbrook, Lynch, Polen, Gale, Beardslee, O'Connor & Seeley; 2001; Coldwell, Meddings & Camic, 2011; Focht & Beardslee, 1996; Grove, Reupert & Maybery, 2013; Orel, Groves & Shannon, 2003; Reupert & Maybery, 2009b; Stallard, et al., 2004). Others have also focused on family attitudes and behaviours (e.g. critical comments, emotional 'over-involvement', hostility) that influence the course of a psychiatric 'illness' (Vaughn & Leff, 1976). Falcov (1998; 2004) and Cleaver, et al. (1999), amongst others, suggest educating children about 'mental illness' and ways of coping effectively with their parent's difficulties as well as promoting open discussions about mental health problems within the family. They also believe that families need information about the services available to them, how services will communicate with one another, how to access these services and what to expect when entering them.

Many resources for children and parents (e.g. fact files, leaflets and internet resources from e.g. the websites of Bernardo's, Mind (2004), Royal College of Psychiatry (2012), Young Minds, COPMI (Australian Infant Child Adolescent and Family Mental Health Association, 2009), Survivalkid (Drost, Cuijpers & Schippers, 2010; Drost & Schippers, 2013), etc. and books (Clarke, 2006; Chovil, 2004)) are widely available. Interventions (e.g. Focht & Beardslee, 1996; Grove, et al., 2013; Riebschleger, Tableman, Rudder &

Onaga, 2009; etc.) informed by psycho-educational principles have been developed. For a review of these interventions, see Reupert & Maybery (2009a).

A particular UK-based intervention based on these principles is the Kidstime multi-family project developed by Cooklin (Cooklin, 2004, 2008, 2012; Cooklin, Balmer, Hart, Rose, York & Falcov, 2006). Kidstime brings together children and their parents and focuses explicitly on helping children and young people find an explanation of 'mental illness' acceptable to them and their parents. Naming the difficulties is seen as important because many children of a parent with mental health problems will strongly identify with that parent, might become preoccupied with details or nuances of the parent's thinking or behaviour and might come to unhelpful conclusions about what their experiences mean.

2.7.2.3.2. Narrative therapy approaches:

Drawing on a post-structural perspective narrative therapists have recently taken a strong position in relation to therapeutic work aimed at addressing trauma, including with children of parents who experience psychological distress (e.g. ACT Mental Health Consumer Network & Dulwich Centre, 2003; Denborough, 2010; Dulwich Centre; 2008; Pluznick & Kis-Sines, 2008, 2010). A narrative approach to families where a parent experiences mental health problems draws on the principles of narrative practice, including separating problems from people; collaborating; uncovering positive information about people's useful ways of viewing and dealing with difficulties; taking a political position that would validate individual experiences and provide an understanding of the powerful forces operating in people's lives; acknowledging the importance of context and connectedness; and offering the possibility of discovering directions people prefer for their lives and relationships (White, 2005, 2006, 2007; White & Epston, 1997).

This moves the debate beyond whether we should be talking to children about their experiences relating to their parent's mental health difficulty and what we should be talking about, to include a focus on the 'how' of talking and clinicians' contribution to such conversations. White (2005) emphasised the importance of talking in ways that are psychologically and emotionally safe. He held a position that many traditional therapeutic interventions can be harmful in two ways. Firstly, it could be re-traumatising. Secondly, it could contribute to reinforcement of the negative identity conclusions that people who have been traumatised often hold about themselves. He therefore emphasised the importance of context-specific and “experience-near” conversations (White, 1995, p.50). These positions are applied by narrative therapists when working with families where there are parental mental health difficulties.

2.7.2.3.3. Systemic approaches:

Drawing on a social constructionist theoretical base, and with an emphasis on meaning-systems, systemic work with families where there are parental mental health issues has been described in the literature (e.g. Asen & Fonagy, 2012; Cooklin & Gorell Barnes, 2004; Daniel & Chin, 2010; Daniel & Wren, 2005; Messant & Solarin, 2013; Place, et al., 2002).

Systemic work challenges the code of silence that often exists in families where a member has mental health problems (Place, et al., 2002). From this perspective, Daniel & Wren (2005) emphasise the importance of multi-layered conversations with significant others as well as between aspects of the self as a way coherent understandings are shaped. These authors promote the exploration of painful or troubling experiences in conversations, allowing for the mutual consideration and exploration of beliefs and emotions about these experiences, but also encourage clinicians to work towards a balance of stories by including positive or ‘normal’ stories. Importantly, a shared meaning of the ‘illness’ is sought, linking cognitive information to family members’ individual and collective experiences. By families talking together it also allows for aspects of the child’s story to be incorporated into the family understanding of what is going on. Overall, it can be said that a systemic approach allows for the exploration of the “complex, evolving and interweaving stories that family members narrate” (Daniel & Wren, 2005, p. 126).

2.7.2.3.4. Conclusion

These three approaches are informed by different epistemological positions and take different approaches to talking. However, all share a commitment to the importance of talking within families about parental mental health issues. An important factor when considering these interventions is what each assumes need to be talked about, that is, whether an assumption is made of a given conceptualization of experience, or whether family members' meaning-making is actively explored and thus understandings become open for negotiation. Furthermore, what is spoken and what remains unsaid within the different approaches is important. As Altscuhler and Dale (1999) suggest within a physical health context, it is as if there are two levels of knowledge about illness – the one relates to information about the illness while the other relates to fear and uncertainty surrounding it. More often that not, knowledge about the illness is shared more readily than knowledges relating to the uncertainty and fear or other emotional experiences. This is also relevant to talking about a parent's mental health issues. Finally, how the talking happens need to be considered, in particular how complexity is responded to.

2.7.2.4. Coherent narratives: a conclusion

There appears to be a general consensus amongst researchers, clinicians, parents and children about the need for information and the usefulness of talking together about parental mental health problems. In response to this consensus a large number of clinical interventions have been developed to facilitate children's understanding as well as talking within families.

Despite this consensus there are many constraints on these developments. These include, societal attitudes and stigma (Bibou-Nikou, 2004, Gorin, 2004; Hinshaw, 2004); professional constraints, including constraints in service structure and delivery and professional knowledge and skills base (Bibou-Nikou, 2003; Brunette & Dean, 2002; Clark & Smith, 2009; Daniel & Chin, 2010; Falcov, 1998; Ofsted & CQC, 2013; Stern, et al., 1999); parents' knowledge, ability and confidence as well as wish to protect their children and fear of losing their children (Absler, 1999; Alakus, et al., 2007; Bibou-Nikou, 2004; Cowling, 2004; Focht & Beardslee, 1996; Gorin, 2004; Lippett & Nolte, 2007; Place, et al., 2002); other family members' burden, confusion and lack of understanding and information (Stern, et al., 1999); and children's fear of upsetting their parent or worry about stigma and burden (Totsuka, 2010; Van Parys & Rober, 2012). Thus, talking about parental mental health issues, either within or outside of clinical contexts, cannot be assumed. Often mental health problems remain a "secret within the family" (Grove, et al., 2013, p. 8).

Before moving on to consider the current research project, a wider exploration of children's understanding of mental health was undertaken as it applies to the current area of interest.

2.8. PERSPECTIVES ON CHILDREN'S UNDERSTANDING OF MENTAL HEALTH

2.8.1. Studies exploring children's understanding of mental health problems

How children understand mental health issues relates to the current study and will be discussed here. Unfortunately, there is very limited research in this area (Walsh, 2009). Two significant reviews have been carried out of the literature (Walsh, 2009; Whal, 2002) and the findings of these are presented here.

2.8.1.1. Definitions of mental health and mental 'illness'

Given that the concepts of 'mental health' and 'mental illness' are such contested constructs, it is interesting that these are often presented in research as if they are clear and universally shared and understood (Walsh, 2009). In reality they are often very difficult to define and explain, not only for parents and children, but also amongst practitioners. Walsh (2009, p. 117) emphasises the importance of highlighting the "complexity and difficulty of defining mental health and ill health for children and for adults. Research in the area so far appears to make assumptions that there is an agreed definition of mental ill health and compares children's understanding to this".

2.8.1.2. Children's knowledge about mental health and mental health problems

The reviews of the existing literature concluded that, as one might expect, children's age had an important impact on what they understood of mental health and mental health problems. It was found that young children did not really have an understanding of mental health problems and might confuse mental 'illness' with physical illness or intellectual disability. As children became older, their understanding developed and older children were more likely to link mental health issues with a person's behaviour, emotions and thoughts. Older children demonstrated a sophisticated understanding of mental health problems that included both internal and external causes for the difficulties, alternatives to the medical explanation of 'illness' and an accommodation of complexity (Walsh, 2009; Whal, 2002).

Despite this sense that many children had quite a well-developed understanding of mental health issues, the reviews found that this was not the case across the board and that there were (albeit limited) research findings (e.g. including children from minority ethnic backgrounds) that did not show a familiarity with the constructs of ‘mental health’ or ‘mental illness’. Therefore, one might conclude that context is important in terms of the relationship children might have with these constructs (Walsh, 2009; Whal, 2002).

2.8.1.3. Children’s attitudes towards those with mental health problems

As is the case with adult research (Hinshaw, 2004) it was found that despite these often sophisticated understandings of mental health issues, this did not seem to have a positive impact on attitudes towards those with mental health problems. Negative attitudes toward people with mental health difficulties were found to be present with even the youngest children and this negativity was found to increase with age (Wahl, 2003). However, some research indicated that stigmatizing attitudes were mediated to some extent by accurate mental health knowledge and (satisfactory) personal experience of people with mental health issues (Walsh, 2009).

2.8.1.4. Conclusion

These reviewers concluded that, given the sophisticated understanding children had of mental health problems, children whose parent had mental health issues should be included in discussions about their parent’s difficulties and about the services available to them. The prevalence of stigma from a very early age is a disturbing finding of these reviews. The reviews also clearly indicated the need for further research.

2.8.2. Studies exploring the interactions within families around parental mental distress

2.8.2.1. Research into how families make sense of and respond to mental health difficulties of a family member over time

Much research has reported on the burden of mental health problems on relatives. However, little is known about family sense-making over time when living with a family member with mental health issues. One recent study attends to this. Rose, et al. (2002) in their Grounded Theory study (interviewing 29 participants from 17 families 3 times over a 2-year period in the US) showed that living with the uncertainty of mental health issues, the unpredictability of the person's problems and progress and fears about the future were the main concerns for family members. Families felt that they lacked clear information about their family member's difficulties. "Families had many questions and a sense of confusion" (p. 527), including questions like 'how bad is it?', 'how permanent is it?', 'what caused it?', 'how long will it last?' and 'how disruptive will it be?'. Family members often became caregivers for their family member and needed to provide on-going support and practical help while grappling with their lack of understanding. They wanted normality for their family member, but were often "consumed by questions of unpredictability" (Rose, et al., 2002, p. 525).

These researchers found that family members responded to such difficulties in a number of ways. Often they tried to see difficulties as biological illness. The uncertainty led them to work hard to figure out the subtleties of the symptoms and to worry about what these meant. Rather than drawing on abstract factual information, families tried to make sense of mental health problems as a personal experience. They described a process of meaning-making over time where they arrived at a personal position on expectations, explanations and strategies. They were challenged by the cultural climate of secrecy and stigma.

This study again paints a picture of sense-making over time, that includes information in the sense of knowledge, but also other knowledges related to developing skills in dealing with uncertainty, unpredictability and crisis, as well as stigma, and developing a personal way of relating to their family member and their circumstances over time.

2.8.2.2. Research that provides insight into the processes surrounding and shaping conversations about parental mental health difficulties in families

Very little research exists that provides an insight into how families communicate about parental mental health difficulties. The study referred to earlier by Van Parys and Rober (2012) makes a valuable contribution in this regard. Families were interviewed about children's experiences of their parents' mental health difficulties and this analysis provides a rare insight into the processes surrounding and shaping the conversations that can happen within families. These authors highlighted the many factors that impact on what is expressed and what is concealed and the moral dilemmas faced by the mothers and children in their study around this. These complex considerations happened within the context of mutual love, concern, compassion and care; of a mother wanting to be a good mother and do what is best for her children; of children wanting to protect their mother, but also wanting to have a good mother and for things to be better; and, within both sides' uncertainties about whether the mother would be able to meet these expectations, despite her best intensions and everybody's best attempts.

This research describes a subtle, complex, intricate to-ing and fro-ing in conversations over time. From the child's perspective this could lead to a sense of futility about the attempts to help the parent, but this is also mediated through the child's experience of the mutuality of closeness. This study paints a picture of an experience of multi-layered, circular understandings, fluctuating and evolving over time, with each person in the relationship shifting and responding to the other.

A further study that adds to these findings is Rhodes (2013) who interviewed families about intergenerational mental health narratives. In this Narrative Analysis she showed how meanings about mental health problems were ever shifting, evolving and changing, mediated by the multi-layered contexts of relationship networks, relational power dynamics, psychological hopes and preferred identities. This study also highlighted the powerful role of stigma within the communication about mental health issues.

These two studies strongly challenge the given nature of 'information' in most research studies and show the complexity of pinning down what it is that needs to be understood and the meanings attached to different understandings moment-to-moment within family relationships and conversations.

2.8.2.3. Research that provides insight into the effects of talking about parental mental health difficulties within families within a clinical context

One clinical intervention focuses specifically on families talking about parental mental health issues and has been systematically researched – therefore it is relevant here. It is the work and research of Beardslee and colleagues (see e.g. Beardslee, 2002a, 2002b; Beardslee, et al., 1997; Beardslee, Wright, Gladstone & Forbes, 2007; Focht and Beardslee, 1996; Focht-Birkerts & Beardslee, 2000; Riley, Valdez, Barrueco, Beardslee, Sandler & Rawal, 2008). They developed the Preventative intervention programme (PIP), later renamed as the Family Intervention (FI) for families where a parent has a mental health problem. This model of intervention has been systematically researched over time in the US and also more recently in Scandinavia (Pihkala, Sandlund & Cederström, 2011), and has been adapted for use with different cultural groups (e.g. Latino families – see D'Angelo, Llerena-Quinn, Shapiro, Colon, Rodriquez, Gallagher & Beardslee, 2009; high risk urban families – see Podorefsky, MacDonald-Dowdell & Beardslee, 2001; Finnish families – see Solantaus & Toikka, 2006; and Swedish families – see Pihkala, et al., 2011).

The aim of this programme is the prevention of mental health difficulties and the development of resilience in children of parents with mental health problems. It is a family-based programme and is preventative in that it targets children who do not show particular difficulties. The principle of the programme is that silence often surrounds parental mental health difficulties, but that talking about these problems is protective for children. This work and research show that initiating communication about the parent's mental health problem was in many ways a challenging task for parents, partly because of the feelings of guilt and shame and partly because of the difficulty of finding appropriate words and formulations to describe the difficulties to their children (Pihkala, et al., 2011). However, talking appeared to have benefits for the parent-child relationship, the child's understanding and the child's wellbeing.

Focht-Birkerts & Beardslee (2000) have written about their developing thinking over time in relation to FI. They state that originally the aim of FI was to provide the children with cognitive information at a time when they were old enough to understand and integrate such information about mental 'illness'. Over time they found that the distress the children encountered was one of the most difficult things for both parents and children to talk about, and that such distress was often vigorously denied. They observed that the pain these children felt seemed to be "bulging through the seams of the 'not-yet-said'" (p. 421). Thus, the researchers found that the children's need for integrating distressing affective experiences is both greater, and the task more difficult, than had been supposed, and requires a process beyond the provision of cognitive information. Therefore, they have concluded that the movement of experience from private to public through dialogue is one of the primary curative aspects of their intervention (FI). They speculate that the process of affect-elaboration may be an important aspect of recovery for families experiencing mental health issues. This places conversations about parental mental health problems between parents and children at the centre of improved wellbeing for all.

2.9. CONCLUSION AND JUSTIFICATION FOR THE RESEARCH

There is strong evidence collected over many decades of the potential negative impact of parental mental health difficulties on the lives of children. However, it is now generally accepted that it is not the particular mental health diagnosis of the parent per se that is damaging to children, but rather the numerous challenging impacts of mental health problems on families.

Developing a coherent understanding of their parent's difficulties is considered here as one important factor that mediates the impact of parental mental health difficulties on children. This was considered from a number of different perspectives, including research, clinical, as well as the views of parents and children themselves. There appears to be general consensus about the importance of information about parental mental health issues for children and of the value of families talking together about a parent's mental health issues. However, it is clear from this review that there are many obstacles for parents, children, practitioners and in the wider society to such open conversations.

Furthermore, this review problematizes the idea of 'information' and where for some researchers this was 'a given', namely that children need information about the diagnosis and treatment of the parent's 'mental illness', other studies challenged this assumption. Questions are raised about what is observed and experienced in addition to what is spoken in words; what is fixed and clear and what remains fluid and evolving; what is about cognitive knowledges and what about emotion expression and elaboration; and what can be explained alongside what needs to be learned. That communicating about mental health is a process over time is illustrated by a number of studies. Dominant societal discourses about mental 'illness' impacts on conversations and the devastating impact of stigma runs through many aspects of the review.

A number of innovative interventions have been developed from different theoretical perspectives to support practitioners in helping families, especially children, to develop a coherent understanding of a parent’s mental health issues. However, due to a significant number of service restrictions, these interventions are not readily available, very few family members of those who use adult mental health services in the UK will be included in the therapeutic work with the individual, and most practitioners will not feel confident in offering such help. Therefore, most parents are left to their own devices to make choices about helping their children to make sense of parental mental health issues behind their own closed doors. This leads to the current research question, namely how do parents think about and approach the process of talking to their children about their mental health difficulties.

It is hoped that this study will make a novel contribution to the existing literature on parental mental health difficulties by focusing on the choices and actions of parents in relation to enabling their children’s understanding of their mental distress, and on comprehending the processes involved in these choices and actions. It is anticipated that the outcomes of this study will contribute to a richer understanding of the experiences of this group of parents and it is hoped this will lead to raised awareness of the needs of these parents and their families and will be used to develop more effective and appropriate services. Furthermore, it is hoped that this study will contribute to the voices of these parents entering the debate about their families and the services they might benefit from.

3. RESEARCH QUESTIONS

RESEARCH QUESTIONS

The following research questions will be addressed by this study:

- How do parents account for what they tell and how they tell their children about their mental health problems?

- What social processes inform the choices parents make, their experiences of these choices and their described actions around talking to their children about their mental health difficulties?

- Are there particular social discourses within society and/or mental health services that impact on these social processes in terms of the choices, experiences and actions of parents in relation to talking?

4. RESEARCH METHODOLOGY

4.1. INTRODUCTION

Guba and Lincoln (1994) state that the question of method follows from the researcher's paradigm, that is "the basic belief system or worldview that guides the investigator" (p.195). Therefore it is important to firstly describe the paradigmatic positions adopted in this study. Following this, methodological choices and procedures will be discussed.

4.2. ONTOLOGICAL POSITION

This study is informed by the researcher's acceptance that all that is known is socially constructed and that there are always multiple and ever changeable constructions of each situation. Social constructionism holds that 'knowledge' is locally and relationally produced and is therefore always historically and contextually bound and always shifting and changing (Gergen & Gergen, 1991). Furthermore, critical theory (Charmaz, 1995) which was also drawn on, posits that these constructions crystallize into a series of structures that are taken and experienced as 'real', 'natural' and unchangeable (Guba & Lincoln, 1994). This position counters the relativism of a more 'pure' social constructionism that dominant constructions can be easily 'shaken off', challenged or exchanged for another.

4.3. EPISTEMOLOGICAL POSITION

From this social constructionist and critical theory perspective epistemology is subjectivist and transactional. The researcher and researched are seen as relationally linked and the values of the researcher are seen to inevitably influence the inquiry, mediating what can be reported (Guba and Lincoln, 1994). Therefore, instead of aiming for ‘neutrality’ the researcher “takes an explicit value stance from the beginning” (Charmaz, 2013b) and makes it transparent for the reader.

These paradigmatic choices fit with undertaking a qualitative research study.

4.4. CHOOSING TO UNDERTAKE QUALITATIVE RESEARCH

Qualitative research is concerned with the “construction and negotiation of meaning and the quality and texture of experience” (Willig, 2001; p.15), allowing for complexity, diversity, contradiction and multi-layered accounts in the data to be considered and explored (Charmaz, 2003). Within qualitative research people’s experiences of a phenomenon, the meanings attached to their experiences and the exploration of what people do in their everyday lives can be richly explored (Silverman, 2000). Qualitative methods are inductive and hypothesis-generating, allowing for new and unexpected possibilities to emerge (Willig, 2001). It foregrounds the points of view and experiences of the people studied (Elliot, Fisher and Rennie, 1999), often people whose views have traditionally been excluded (Ashworth, 2003).

4.5. CHOOSING A RESEARCH METHOD

All available qualitative research methods were considered in relation to answering the research questions. A rationale for choosing to use Grounded Theory as the method for this study is provided here.

4.6. CHOOSING GROUNDED THEORY

The term Grounded Theory is very widely used and seems to be erroneously used to describe a wide variety of approaches to qualitative research or even in some fields just as an alternative to the term qualitative research in general. Therefore, before exploring the basis for selecting Grounded Theory as an approach for this study, I will firstly give an overview of the theory, history and development of Grounded Theory.

4.6.1. Introduction

Grounded Theory has been described as a “systematic, yet flexible methodology for collecting and analysing qualitative data to construct theories that are grounded in the data themselves” (Charmaz, 2006, p. 2). Traditional research often neglects “the main work of science – thinking and discovering” (Rennie, Phillips & Quartaro, 1988, p. 139), whereas Grounded Theory provides researchers with a “heady freedom” (p. 145) to explore complex phenomena. Denzin (2007) cited in Plummer & Young (2010) identifies positivist, postpositivist, constructivist, objectivist, postmodern, situational and computer-assisted forms of Grounded Theory. This “spirit of methodological innovation keeps Grounded Theory relevant in changing times and contexts” (Plummer & Young, 2010, p. 308).

Traditionally Grounded Theory was employed where a relevant theory did not already exist or in areas where little was known (Hutchinson, Johnston & Breckon, 2012; Rose, et al., 2002). Over the years there has been an ever-expanding use of Grounded Theory in the social sciences, alongside a general rapid expansion in qualitative research methodologies (O’Connor, Netting & Thomas, 2008).

4.6.2. A history of Grounded Theory

Glaser and Strauss (1967) can be seen as two of the people who first contributed to the establishment of qualitative methods within scientific research through their development of the Grounded Theory methodology, and Grounded Theory can be seen as one of the earliest systematic forms of qualitative inquiry (O’Connor, et al., 2008). It has its roots in sociology, symbolic interactionism and pragmatist philosophy (Clarke, 2005). Grounded Theory sought to shift the sociological focus from theory verification to theory generation (Glaser & Strauss, 1967). Within the context of its development, namely the research world of the 1960s, Glaser and Strauss were initially occupied with developing a method that was systematic, attempting to address the “distorting subjectivities” of the researcher (Clarke, 2005, p.2). Thus, traditionally Grounded Theory research could be seen as aligned with positivist values (O’Connor, et al., 2008).

Soon after the publication of the seminal text ‘Discovering Grounded Theory’ (1967) Glaser and Strauss’s paths split. Strauss, teaming up with Corbin (Strauss & Corbin, 1994) moved Grounded Theory to a more post-positivist position, acknowledging that understanding is imperfect. They also moved Grounded Theory closer to interpretivism by integrating aspects of symbolic interactionism. This begins to reposition the researcher as an author who reconstructs meaning in the research process (Mills, Chapman, Bonner & Frances, 2007). However, Grounded Theory researchers were still framed as tabula rasa, going into the research arena as ‘not knowing’ (Clarke, 2005).

More recently, responding to postmodernism and adopting constructionist values, Grounded Theory has been adapted to include an interpretive and relativist (‘perspectival’) stance (O’Connor, et al., 2008) and has been re-interrogated, remodelled, updated and re-interpreted to fit with current epistemological and methodological shifts (Charmaz, 2006; Clark, 2005).

As interpretive Grounded Theory is the method used in this study it will now be discussed in detail.

4.6.3. Interpretative Grounded Theory

Kathy Charmaz (2003, 2006) and Antony Bryant (2003; Bryant & Charmas, 2007) were the first researchers to explicitly name their work as constructivist Grounded Theory, resituating the researcher in relation to participants and rethinking the role of the researcher as author. Adele Clark (2005) has taken these developments further to allow for a more full engagement with a postmodern paradigm.

Whereas in a traditional view of Grounded Theory the goal is a conceptual theory outside of time, place and people, that is ahistorical, acultural and transcendent, in interpretive Grounded Theory there is an "analytical necessity of addressing context" (Clarke, 2005, p. 18) and "knowledge and knowledge productions are (described as) situated and noninnocent" (Clarke, 2005, p. 18). "Clarke's method of situational analysis challenges us as Grounded Theorists to locate participants in their social world – a world that is full of actors other than themselves" (Mills, et al., 2007, p. 78). Grounded Theory becomes grounded in the situation, thus making the broader situation of the phenomenon under research the analytical ground (Charmaz, 2011).

This form of Grounded Theory continues to rely on accepted Grounded Theory tenets of theoretical sensitivity, theoretical sampling, constant comparative methods, coding, memoing and diagramming (Clarke, 2005), but adds to these, mainly through radically transforming systematic mapping and diagramming and a revisioning of position of the researcher and the researcher-participant relationship (Charmaz, 2011; Plummer & Young, 2010). According to Clarke (2005) situational analysis provides us with the tools to be able to "draw together studies of discourse and agency, action and structure, image, text and context, history and the present moment – to analyse complex situations of inquiry broadly conceived" (p. xxii) and to fully account for power.

4.6.4. Conclusion

Grounded Theory was therefore seen as a suitable methodology for this study for the following reasons: firstly, it is particularly suited to exploring areas where very little is known (Willig, 2001), as is the case for the current research question. Secondly, through looking at social processes Grounded Theory enables researchers to gain a better understanding of what people are doing as well as why they are doing it (Pidgeon, 1996) – therefore it would allow for both the exploration of the choices parents make in relation to talking to their children about parental mental health issues, as well as the reasons for these choices. In addition, new developments in Interpretive Grounded Theory would also enable the exploration of the different discourses within which these social processes are situated. Furthermore, as Atkinson, Coffey and Delamont (2003, cited in Clarke, 2005) state, Grounded Theory is a way of "having ideas on the basis of empirical research" (p. 150) and thus, in this relatively unexplored area, the fact that Grounded Theory allows for conceptual development and theorizing was seen as a strength of the method. Finally, in considering the complex contexts within which this research is situated (both in relation to mental health and the socio-political environment) the inductive nature of Grounded Theory, leading to an open, flexible approach (Charmaz, 2003), was a further advantage. Grounded Theory was thus selected as the most appropriate methodology for this study and the Grounded Theory method will now be discussed. For a description of the reasons why other available and potentially suitable qualitative methods were not selected, please see Appendix 2.

4.7. GROUNDED THEORY METHOD

Strauss and Corbin (1998) quoted in Khaw (2012, p. 138) noted "researchers should stay within the general guidelines [of Grounded Theory methods but]…use the procedures and techniques flexibly according to their abilities and the realities of their studies".

Grounded Theory can be identified by a number of strategies true to the method and these will now be described.

4.7.1. Concurrent sampling and analysis

Unique to Grounded Theory is that analysis start as soon as there is data. Coding begins immediately, and theorizing based on this coding does as well, however provisionally (Clarke, 2005).

4.7.2. Coding

Glaser and Strauss (1967) and Straus and Corbin (1994) describe a process where data analysis occurs at each point of the data collection, with open, axial and selective coding. Coding gives the researcher "analytical scaffolding" (Charmaz, 2005, p. 34) on which to begin to build their theory.

Coding starts with open coding: word by word, line by line, segment by segment coding is undertaken, defining for each word, line or segment what activity is occurring. The researcher works towards recognising multiple frames of reference, giving all data a fair reading, rather than just selecting what is of interest or looking for preconceived ideas or concepts (Allen, 2011). These codes largely constitute the individual, relational, and discursive elements surrounding the situation (Khaw, 2012). 'In vivo' codes are abstracted from the language of the data and used to ground the Grounded Theory analysis in the language used by participants – these in vivo codes are used to 'grab' the reader's attention and capture the essence of the category (Strauss & Corbin, 1998 cited in Plummer & Young, 2010).

Axial coding is the second level of coding. In axial coding the researcher is making connections among the initial codes to bring data back into a coherent whole. That is, the data are re-organized in new ways by making connections between the categories and constructing broader themes.

Selective coding is the process of drawing the connections made in axial coding to derive a theory about a particular phenomenon.

4.7.3. Memo writing

As the categories are being developed the researcher starts to write memos to make the properties of the category clear, specify the conditions under which the category occurs, describe its consequences and show the relationship to other categories (Charmaz, 2003). Memos might include hunches, ideas, suggestions for further sampling, explanations for categories chosen, links to literature, etc. (Pidgeon & Henwood, 1996). One of the ways memo-writing is used is in making constant comparisons (Glaser & Strauss, 1967).

4.7.4. Constant comparison

Grounded Theory emphasises the micro-analysis of data through constant comparison, that is all units of data are compared to all other units of data to raise questions and explore properties and dimensions in the data. By increasing the researcher's sensitivity to the data and their meaning, constant comparison enables rich understandings from the data. One of the paradigmatic characteristics of interpretive Grounded Theory is constant comparison for expansion and thickness, rather than precision.

4.7.5. Theoretical sampling

In Grounded Theory sampling is not driven by attempts to be ‘representative’ of some social population or its heterogeneities, but explicitly and especially by theoretical concerns that have emerged in early provisional analysis of data. Such theoretical sampling focuses on finding new data sources (persons, things or information) that can best explicitly address specific theoretically interesting facets of the emergent analysis. The goal of theoretical sampling is to sample concepts, incidents, or behaviours that are significant in light of the developing ideas and themes that can sharpen the researcher’s conceptualisation.

4.7.6. Saturation

Traditionally saturation was seen as the point where data collection can end due to the fact that no new categories are emerging. Saturation within this more interpretive approach to Grounded Theory is more open, that is, saturation occurs when no new information emerges to add to meaning (O’Connor, et al., 2008).

4.7.7. Theoretical sensitivity

Theoretical sensitivity refers to an individual’s ability to “render theoretically their discovered substantive grounded categories” (Glaser, 1978, quoted in Wuest, 2000, p. 55). So, theoretical sensitivity is what helps the researcher move beyond pure description to see theoretical possibilities in the data. Disciplinary or professional knowledge as well as both research and professional experience that the researcher brings to his or her inquiry, can be seen as enhancing theoretical sensitivity (Strauss & Corbin, 1994, cited in Wuest, 2000) as it becomes part of constant comparison.

4.7.8. Situational analysis

In addition to these processes as part of traditional Grounded Theory, Clarke (2005) has expanded the method by adding situational analysis. Situational analysis can be used from the start of a study alongside coding, but can also be used with data coded already in the traditional Grounded Theory approaches to coding.

Situational analysis can be described as a set of analytic diagramming tools that elucidates complexities in a project. It allows for the key elements and conditions that characterize the situation of concern to be considered and visually explored (Clarke, 2005). Clarke (2005) describes three types of maps that form the basis for this higher-level analysis. These are:

- Situational maps, laying out the major human, nonhuman, discursive, and other elements in the research situation of inquiry and provoking analysis of relationships among them;
- Social worlds/arenas maps, laying out the collective actors, key non-human elements, and the arena(s) of commitment and discourse within which they are engaged in on-going negotiations, enabling meso-level interpretations of the situation;
- Positional maps, laying out the major positions taken, and not taken, in the data vis-à-vis particular axes of difference, concern, controversy around issues in the situation of inquiry (Clarke, 2005).

The major use of these maps is to open up the data further and interrogate it in fresh ways, allowing the researcher to analyse more deeply, moving more and more "into and around the data" (Clarke, 2005, p. 84). These maps also assist with reflexivity within the research process, and Clarke (2005) states that part of the process of making situational maps is to allow the researcher to get to information, assumptions, perspectives etc. that one brings to the project and to include these into the maps if appropriate. Furthermore, according to Clarke (2005), as scholars and clinicians in the field of our research and with the theoretical background we bring to the study, we might suspect that certain things may be going on that have not explicitly appeared in the data – situational analysis allows us to attempt to articulate any such “sites of silence” (Clarke, 2005, p. 85) in our data. As these are less familiar aspects of Grounded Theory, a more detailed discussion of situational analysis is included in Appendix 3.

4.8. CRITIQUE OF GROUNDED THEORY

Grounded Theory has been described as more realist-based, compared to other qualitative methods, in that it assumes a reality that can be discovered (e.g. Willig, 2001), but this has convincingly been challenged by a number of authors (e.g. Charmaz, 1990 as cited in Willig, 2001; Clarke, 2005; Pidgeon, 1996) showing that Grounded Theory can be used from a social constructionist and critical theory position.

From a social constructionist perspective Grounded Theory has been criticised for the concept of ‘theory’, as this implies some truth that can be known. However, “theory (can be seen to) consists of plausible relationships produced among concepts and sets of concepts” (Strauss and Corbin (1994) as quoted in Silverman, 2000, p. 78). A theory provides a footing for considering the world, a framework for critically understanding phenomena and a basis for considering how what is known may be organised. A ‘theory’ therefore does not need to imply a final truth, but rather could provide an evolving and changing framework for an organisation of what we understand (Silverman, 2000).

Grounded Theory has also been criticized for fragmenting the data. Fragmentation of a participant’s story derives from compiling many stories and adopting pieces of them to tell an analytic story. Analytic writing, particularly Grounded Theory analysis, does fragment the data, but also contains safeguards against transposing the researcher’s agenda on to participants’ stories or merely importing juicy details from them (Charmaz, 2002; 2013a). Inductive methods move the analysis forward from the start, by beginning with the data – snippets and stories embedded in the analysis must earn their way into the narrative. Grounded Theory, through its fracturing of the data, permits multiple analyses and thus allows for the representation of differences, complexities and multiplicities (Clarke, 2005). Thus, fragmentation within Grounded Theory could be seen as a strength of the method.

Finally, Willig (2001) argues that Grounded Theory does not take into account the role and impact of the researcher upon the inductive process and as a result does not address the issue of reflexivity. However, this criticism has been robustly addressed in recent developments within interpretive Grounded Theory (Charmaz, 2006, 2013b; Clarke, 2005). Within constructivist/tionist Grounded Theory the researcher becomes a reflexive and reflective co-constructor of theory. Specific Grounded Theory strategies, including memoing and mapping, aid such reflexivity.

4.9. CONCLUSION

Where interview data is used, as is the case in this study, Grounded Theory directs the researcher to develop an explanatory framework that represents how participants understand and manage a central problem in their lives. This method will enable the answering of the current research question.

In the next chapter the research design and procedures will be discussed.

5. RESEARCH DESIGN AND PROCEDURES

5.1. INTRODUCTION

The research design and procedures, including ethical considerations and the consideration of quality issues for this study, will now be discussed. The nature of this account necessarily creates a sense of a linear temporal process. However, inevitably this was not the case in practice, and the reality of the research was that there was a constant moving between different aspects of the research, e.g. between the data and the literature. This is in keeping with the Grounded Theory method.

5.2. RESEARCH DESIGN

As this research was interested in parents' descriptions of the choices they make around talking to their children about parental mental health issues, as well as their reasons for making these choices, it was decided that in-depth interview data would be best suited to providing this information. Individual interviews were selected, as it was anticipated that parents might experience potential shame or discomfort in talking about this sensitive topic in the company of other parents and that this might inhibit the quality of the data. Finally, in line with the Grounded Theory method, a semi-structured interview was selected to allow the researcher to cover areas of exploration that were viewed as significant, while also allowing the tracking of areas of interest to the participants. It was anticipated that between 12 and 20 participants would be interviewed (depending on recruitment and saturation).

Limitations to interview data have been discussed in the literature (Charmaz, 2002; Polkinghorne, 1997, cited in Charmaz, 2002; Potter & Hepburn, 2005; Silverman, 2001). These needed to be taken into account throughout the study and the impact on the research and on answering the research question will be returned to in Chapter 9.

5.3. RESEARCHER REFLEXIVITY[2]

Research within a postmodern frame moves us into arenas where subjectivity is both assumed and appreciated, inviting an understanding of qualitative research as an interconnected and mutually influential series of dialogical processes (Russell & Kelly, 2002). There is general agreement that transparency in relation to such processes and subjectivities is central to producing a trustworthy empirical research report (Shaw, 2010, 2013) and this requires reflexivity from the researcher.

Reflexive researchers recognize that “social science research is always and importantly an *interpretative* activity” (Wren, 2004, p. 476) and that the ‘interpreters’, both ‘us’ (researchers) and ‘them’ (who and what we are ‘studying’), are embodied and situated (Clarke; 2005). The researcher therefore attends to the effects of research-participant interaction on the construction of data and to power- and trust-relationships between researchers and participants (Hall & Callery, 2001). Furthermore, the researcher accepts that their view of the world combines both insight and blindness and works to attend to this ‘blindness’ throughout (Allen, 2011).

The relationship of Grounded Theory researchers to reflexivity has evolved together with the method. More recently reflexivity (addressing the influence of investigator-participant interactions on the research process) and relationality (addressing power and trust relationships between participants and researchers) have been incorporated into interpretive Grounded Theory (Charmaz, 2006; Hall & Callery, 2001).

Employing an interpretive Grounded Theory approach, a reflexive stance was adopted at each stage of the research process. I worked to be explicit about my own stance, values and knowledges and to make transparent moments when the research changed

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[2] Russell & Bohan (1999) cited in Russell & Kelly (2002) define reflexivity as “a process of honouring oneself and others in our work through an awareness of the relational and reflective nature of the task” (p. 3/18). Rather than attempting to ‘bracket’ researcher values, knowledges and biases in order to try and prevent or limit their impacts on the findings (see e.g. Ahern, 1999), it is acknowledged and valued that the researcher influences and is influenced by the research (Willig, 2001).

direction and emphasis, when my assumptions and exploration were challenged or when other voices highlighted alternative perspectives (Shotter, 2012) – all these happened both in small and subtle ways, but also in more dramatic ways, leading to a research report significantly different from what was initially anticipated. In my experience, this was supported through the method of Grounded Theory itself (especially through the strategy of constant comparison and also through memo-writing). Furthermore, I used a reflective diary, supervision, peer support (including data analysis sessions, research presentations and formal and informal discussions with peers) and others' reviews of transcripts and analyses to enhance reflexivity. These processes all focused on ensuring that the subjectivity of the research project could be understood as a strength of the study.

From this reflexive position, I will in this section move between a third and first person account to reflect the more situated position of myself as researcher, and integrate personal and professional reflections within the account where appropriate.

5.4. EXISTING KNOWLEDGE AND GROUNDED THEORY

Over the years the relationship between the Grounded Theory researcher and existing knowledge in the field has changed. Initially there was a commitment to enter the arena of research as 'tabula rasa' (Glaser and Strauss, 1967). Wuest (2000) describes how Grounded Theory has moved away from this original relationship with existing literature (Glaser, 1978, cited in Wuest 2000) to a position where the existing literature is used as data to support the emerging theory (Charmaz, 2006, Clarke, 2005). It is now acknowledged that not only will the researcher by necessity enter the research field with existing knowledge, experiences and values, but that this can be a strength responded to with reflexivity and accounted for with transparency. Existing literature can both serve as a starting point in sensitizing the researcher to the area of inquiry, and aid in the later stages of concept development (Dilks, Tasker & Wren, 2008).

I already knew the field of parental mental health well before entering it from the position of researcher. I had been working in adult mental health NHS services for 10 years prior to taking on a role within a specialist parental mental health team. As a member of this team I offered clinical services to families where a parent experienced mental health difficulties, I consulted to adult mental health, child and adolescent mental health and social care services in relation to parental mental health issues, and regularly provided teaching and training to different professional groups in this area. Furthermore, I was also involved in different ways with previous research projects in the field. Thus, I already had clinical experience of working in the field, was familiar with much of the existing literature and had formed ideas about the relevant issues to the extent that enabled me to teach and train colleagues.

These existing knowledges have often been enabling, but at times also restricting during this project. My aim is to make both these processes visible to the reader. What I have enjoyed most about the project, is how surprising the development and outcomes of the project has been for me and how often I have been taken away from my pre-existing views.

5.5. ETHICS

The British Psychological Society (2010, p. 5) defines research ethics as “the moral principles guiding research from its inception through to completion and publication of results”.

5.5.1. Ethical approval

Ethical approval for this study was sought from and granted by Camden & Islington Community Local Research Committee as well as the local Research and Development Ethics Committee of the relevant Mental Health Trust [see Appendix 4]. Informed consent, the position of the researcher, confidentiality, right of withdrawal from the study, sensitivity during interviews and support and follow-up were specifically considered and will now be discussed.

5.5.2. Ethical considerations

This research involved a vulnerable group of people, namely persons diagnosed with severe and enduring mental health difficulties. However, this area of research is seen as making a contribution to providing more suitable care for this group and allowing their views and perspectives to enter the discussions about service development to address their needs. Therefore I believe that the research project was justified.

Nonetheless, it was essential that care was taken in how this study was carried out.

5.5.2.1. Informed consent

Participants gave informed consent. Where on-going psychological crises could interfere with the capacity to consent, potential participants were not put forward for the study. A letter explaining the study, its aims and the process of the research were given to potential participants by their care-coordinator, together with an information sheet with all the details about what the study involved [see Appendix 5 and 6]. Where English was not their first language, a translator they were familiar with translated all the information into their first language. Participants were given an opportunity to ask questions about the study and clarify any uncertainties before agreeing to take part. Any form of deception of participants was actively avoided.

5.5.2.2. The position of the researcher

The position of the researcher as employee of the Mental Health Trust, but not a staff member of the adult mental health services, was made explicit to potential participants. The researcher’s connection with adult mental health services at the time through liaison and joint working was explained.

5.5.2.3. Confidentiality

Confidentiality was protected at all times. Demographic information was stored in a locked cabinet, separately from the recordings and transcripts. Transcripts were kept on a password-protected computer and anonymized. Exceptions to confidentiality was made explicit to participants before they agreed to take part; that is, were any issues to come to light during the interviews that caused concern for their or their children’s safety the researcher would have a duty to bring this to the attention of social care services. None such issues came to the fore. All audio-recordings will be wiped, following a three-year period after completion of the study.

5.5.2.4. Withdrawal from the study

It was made clear to participants that they had the right to not answer any questions during the interview and to withdraw from the study at any time without being penalized in any way (e.g. without it affecting their care from services).

5.5.2.5. Video-recording for training purposes

Initially there was a hope that where consented to, interviews could also be video-recorded and that such recordings could be used for future training purposes. Therefore, ethical approval was sought and granted for such recordings and this was included in the consent form. However, only one person consented to this and was video-recorded. This video-recording will be wiped on completion of the study.

5.5.2.6. Sensitivity during interviews

During this study sensitive issues were discussed with the participants. Preserving the psychological wellbeing and dignity of participants at all times was the highest priority. In this regard normal clinical sensitivity was used in conducting the interviews. Where participants became distressed during the interview, they were given the option of discontinuing the interview, of taking some time out before continuing or to move away from the specific aspect being discussed. On all occasions participants expressed a wish to continue with the interview. However, as researcher, but also clinician, I used my clinical experience to respond sensitively to distress and create opportunities for processing difficult moments in the interview.

On one occasion I also let the person know at the end of the interview that I was concerned about them and agreed with them that I would contact their care-coordinator after the interview to let them know of my concern, which I did.

5.5.2.7. Support and follow-up

Participants were only included in the study with the knowledge and agreement of their care-coordinators and the consultant psychiatrist of their community mental health team. Support and follow-up was therefore available to all participants.

5.6. SERVICE-USER CONSULTATION AND INVOLVEMENT

The position was taken in this project that the involvement of those with lived experience expertise could enhance the study. Inspiration was taken from The Royal College of Psychiatry (2004) and Barnardo's (2003) as well as reports from the Social Perspectives Network (2003) and views from Narrative therapy research (e.g. Crocket, 2004; Crocket, et al., 2004; Dulwich Centre Publications, 2004), the Just Therapy group (Waldegrave, et al.,2003) and others (Teram, Schachter & Stalker, 2005) to creatively consider the relationship with those within the field of research.

5.6.1. Consultation with user research group

As a first step, on completion of my research proposal and upon gaining ethical approval for the study, I approached the User Research Group of my NHS Trust. I wanted to present the research proposal to them, discuss the information sheets and semi-structured interview schedule and gain their perspectives on the relevance of the study, the ethics of the study and any perspectives that they held due to their experiences. I was given an opportunity to present my research proposal and did so to a group of four adult mental health service-users with an interest in research, facilitated by a research manager employed by the Trust. Unfortunately this was not a positive experience and I felt that little was gained from this encounter.

The following is an extract from a memo I wrote in my reflective research diary after the meeting:

A very disappointing meeting – no actual, let alone equal, relationship was possible… the professional dominated the meeting and it felt like any true exchange of views was discouraged. It felt like it was assumed to be a tokenistic tick-box exercise on my part to say that I 'did' service-user involvement.

5.6.2. Piloting the interview

Following this meeting, I approached a local third-sector support group for users of mental health services and requested a consultation about my research. I met with a focus group made up of four members (past or present adult mental health service users who were also parents) from their group, both to 'try out' the interview schedule and to gain their views about the research.

The focus group met for about one and a half hours. After being informed about the research and the nature of their participation, participants all signed consent forms. As it was a group situation, we discussed ground rules and members were told to only share with the group what they felt comfortable with. We then engaged in a conversation based on the questions from the semi-structured interview schedule. On completion of this discussion, they were asked to reflect on the clarity and appropriateness of the information sheet and consent form, on how they experienced the interview questions, how the interview flowed, and how potential interviewees might experience taking part in the interview. They were also consulted on areas that might be of importance to them that was not covered in the interview. Participants were given a £10 voucher to thank them for their participation and help with the project.

Both the interview and discussion afterwards were recorded and thematically analyzed. Overall the feedback was that the information sheet, consent form and interview questions were understandable and accessible. Four main points emerged from this consultation that impacted on the project, namely firstly, the importance of gaining prospective participants' trust; secondly, a sense that people really valued an opportunity to talk about their children within the context of their mental health difficulties and an expressed sense that the interview could be helpful or 'therapeutic'; thirdly, a sense that parents did not always feel that they knew how their children were feeling or what they were experiencing and that they wished their children could be involved in similar research and also in interventions from services; and finally, noticing that all participants did not identify with a label of 'mental illness' [these points and their implications for the study are set out in more detail in Appendix 7].

Following this period of consultation, I embarked on recruiting participants to the study.

5.7. RECRUITMENT

5.7.1. Recruitment procedures

Care coordinators and support workers within four Community Mental Health Teams and workers within a parental mental health third sector team were informed about the study through a number of presentations at relevant team meetings where they had a chance to have any questions answered and uncertainties clarified and also through letters explaining the study and requesting their support for the research [see Appendix 8].

The profile of potential participants as given to these workers was that they would be persons presenting with severe and enduring mental health difficulties who use community mental health services. They would have been given a psychiatric diagnosis (including schizophrenia, bipolar disorder, depression with psychosis, multiple personality disorder, etc.), but without a specification about the time since diagnosis.

Participants had to be a parent, and to have at least one child between the ages of four and 18, either living with them or living away but in contact with them. The age of four was specified, as that is developmentally the age where children start to use language effectively enough to be able to make sense of experience through language and explanation (Cleaver, et al. 1999; Papalia, Olds & Feldman, 2008). The age of 18 was chosen as the upper cut-off age as this can be seen as the age after which a child can be viewed as a young adult, which is outside the focus of this study (although naturally it is accepted that parents and adult children continue to share experiences around a parent's mental health difficulties and adult children continue to need to make sense of these experiences). Persons were not to be approached by their care-coordinators if they were viewed as too vulnerable at the time.

The mental health workers were then given letters and information sheets explaining the aims and nature of the study to hand out and discuss with potential participants [See Appendix 5 & 6].

5.7.2. Recruitment difficulties

Recruitment to this study proved very difficult and despite knowing that there were many service-users who met the inclusion criteria for this study, it took more than a year to recruit the first 12 participants, despite consistent robust efforts. The possible reasons for this will now be considered.

Full data were not obtained on the numbers and characteristics of parents who met the inclusion criteria but were not approached for the study by their care-coordinators, but given the demographics of the teams, it is clear that this is a large number. It has been reported in the literature that parents might be difficult to identify due to the underestimation by adult mental health services of the importance of parenthood for users of mental health services and therefore a lack in recording information about parenting in clinical notes (Falcov, 1998). Where care-coordinators were aware that their clients were parents, one reason given for not approaching them was that care-coordinators felt that it could cause too much distress for their clients to talk about their children in the context of their mental health difficulties. This has also been reported in other studies (e.g. Diaz-Caneja & Johnson, 2004; Gorin 2004; Tunnard 2004). This hints at the attitude of adult mental health practitioners towards the topic of parenting, maybe seeing it as somehow ‘dangerous’ or particularly sensitive.

Other researchers in the field of parental mental health have also reported difficulties with recruitment (e.g. Pihkala, et al., 2011), stating that a considerable number of parents invited to take part in their study had declined. Full data were not obtained on the numbers and characteristics of parents who were approached to take part in the study, but who declined. However, I am aware of a number of people who agreed to take part, but then became too unwell before they could be approached for interview. This indicates the great uncertainty and turmoil that characterizes the lives of those who experience severe and enduring mental health difficulties and their families at times.

Furthermore, as previously discussed, this research addresses sensitive topics that could be experienced as shameful, stigmatizing or threatening to participants and only parents who were willing to discuss these issues with a stranger would have agreed to take part (Allen, 2011). Stallard, et al. (2004) reported difficulties in recruiting through adult mental health services and speculated that some reasons for this included parents’ pre-occupation with their own difficulties, lack of acknowledgement of impact on their children, a sense of shame, guilt, and blame, and protectiveness towards their children. Fears of child protection might in particular have inhibited participants. Boursnell (2007) stated that parents were reluctant to identify themselves as parents with mental health issues to researchers, often because they feared their children being removed from their care.

Most of the participants who did agree to take part in the study did so based on a close and trusting, often longstanding, relationship with their care-coordinator or support worker. Therefore, those not well engaged with mental health services, with more fragile relationships with services, with more complex needs or who were more vulnerable in terms of their mental health difficulties at the time, are likely to be under-represented in the research.

5.7.2.1. Recruiting fathers

It was particularly difficult to recruit fathers to this study. Despite all information, both verbal and written, referring to either ‘parents’ or ‘mothers and fathers’, only mothers were recruited to the study – ‘parents’ appeared to be heard or read as ‘mothers’. This has also been reported by other researchers (e.g. Dulwich Centre, 2008). When recruitment of fathers was more explicitly pursued, surprise was expressed that fathers were part of the study and care-coordinators struggled to think of men they were working with who were fathers. In the end, despite persistent attempts, only two fathers were recruited to the study.

Recent reviews highlight the lack of research on the experiences of fathers and very few studies focusing particularly on the experiences of fathers were identified within the current review of the literature (Evenson, Rhodes, Feigenbaum & Solly, 2008; Lumsden, 2011; Nicholson, Nason, Calabresi & Yando, 1999). The lack of research with men in the family has been widely written about (SCIE, 2008a, 2008b). Fathers have been very much neglected in research and service development within the field of parental mental health (Alakus, et al., 2007; Hinshaw, 2004). Many researchers who did attempt to include both fathers and mothers struggled to recruit fathers (e.g. Langrock, et al., 2002). Despite some changes in fathers’ involvement in child care, mothers are generally still considered the ‘experts’ regarding children and the work of taking care of children is still primarily done by mothers (Cowdery & Knudson-Martin, 2005). Many researchers have indicated that more research with fathers is required (e.g. Diaz-Caneja & Johnson, 2004; Drost & Schippers, 2013; Dulwich Centre, 2008; Styron, et al., 2002).

5.8. PARTICIPANTS

For this study 15 participants were recruited [see Table 1] through a purposive sampling method. Given the context of the research (multi-cultural inner-city community), participants were purposefully representative of a wide range of cultural, educational, occupational, religious and socio-economic backgrounds. Many people living in the area and using the mental health services through which I recruited are first generation migrants and many do not have English as a first language. In the parental mental health service much of our work took place through interpreters. Therefore it felt ethically necessary and right to also offer this as an option when I was recruiting, despite the additional complexities it would naturally add to the interview, transcription and analysis (see 5.8.1.).

Table 1: PARTICIPANTS

Participant ***Pseudonym**	**Age**	**Culture / Ethnicity (self-description)**	**Intimate Relationship Status** **Employment status**	**Children**	**Reason for using mental health services (self-report)**	**Duration of contact with mental health services**	**Number of times in hospital for mental health (self-report)**	**Services involved**	**Family circumstances**	**Comment**
Participant A: ***Ann*** Mother	45	White British	Divorced Living with partner On sick leave from her job within health management	<u>2 children:</u> Son: 21 (lives abroad) Daughter: 15 (lives with participant full time)	Bipolar affective disorder	21 years	3	CMHT (Consultant psychiatrist; psychologist)	Children's father involved	Recruited through clinical psychologist
Participant B: ***Beverly*** Mother	41	African Caribbean	Lone parent Unemployed (would like a part-time job)	<u>2 children:</u> Daughter: 19 Daughter: 6 (both living with participant full time)	Depression	19 years	2	CMHT (Out-patients clinic, CPN); Social Care: Children in Need (Children's social worker)	Children have different fathers; father of youngest child has contact; Troubled relationship with family – older sister, brothers; Parents and sister passed away	Recruited through CPN <u>Concerns:</u> Youngest daughter some learning difficulties

Participant C: **Carla** Mother	44	Asian	Divorced Lone parent Unemployed	3 children: Daughter: 18 (living with participant part time) Twin sons: 13 (living with participant full time)	Bipolar	7 years	2	CMHT (CPN); Young Carers; Chance UK; Home help	Children have two different fathers – daughter's father involved; Mother involved	Recruited through CPN
Participant D: **Dayo** Mother	38	Black African	Divorced (end of relationship contributed to mental health difficulties) Lone parent Unemployed (loss of job contributed to mental health difficulties)	4 children: Son (18) (no contact) Daughter (14) (irregular contact) Son (12) (regular contact) Son (5) (living with participant part time)	"Over stress"	7 years	6	CMHT (Out patients clinic; social worker); Social services (Children in need social worker); Outreach services	Many family members live in her country-of-origin; Brother and sister live nearby and are involved	Recruited through CMHT Social Worker Concerns: Youngest son has learning difficulties
Participant E: **Eileen** Mother	25	Black African	Regular but inconsistent relationship with boyfriend Lone parent	2 children: Son (5) (living abroad) Son (2) (living with participant full	Post-natal depression	8 years	2	CMHT (Out patients clinic; CPN); Social Services (Children in need social worker)	Family in country –of-origin; looking after her son – she speaks to him on the telephone and she hopes to be able to go back there	Recruited through CPN Not fluent in English, declined interpreter

			Unemployed	time) Participant pregnant					soon	Concerns Housing serious concern
Participant F: ***Faith*** Mother	30	Black African	Lone parent Unemployed	3 children: Daughter (6) Son (4) Son (3 months) (all living with participant full time)	Schizophrenia	9 years	1	CMHT (Out patients clinic; CPN); Children in need social worker	Very little family support	Recruited through CPN
Participant G: ***Gareth*** Father	50	White British	Divorced Contact with children over holidays Works irregularly within creative fields (music, acting)	2 children: Daughter (20) Son (16) (irregular contact with both)	Bipolar	11 years	3	CMHT (Out-patients clinic; Adult social worker); Service-user art group	Ex-wife involved; close family friends involved	Recruited through CMHT Social worker
Participant H: ***Hannah*** Mother	38	Black African	Married Unemployed	4 children: Daughter (8) Daughter (5) Daughter (3)	Psychotic depression	3 years	1	CMHT (Out patients clinic; CMHT social worker)	Husband involved; sister and her family involved	Recruited through CMHT Social worker Concerns: Daughter has some learning

				Son (3 months) (all live with mother and father full time)						difficulties at school
Participant I: ***Izzy*** Mother	41	Mixed race: Caribbean and White	Lone parent Unemployed	2 children: Son (22) Daughter (10) (daily contact with son who has left home, daughter lives with her full time)	Psychotic depression and anxiety disorder	1 year +	0	CMHT (Out patient clinic, CPN, Support worker)	Mother involved	Recruited through support worker Concerns: Housing of serious concern – unsuitable for herself and child
Participant J: ***Jiyan*** Mother	48	Kurdish	Married (tensions in marriage) Unemployed	1 child: Son (16) (lives with his mother and father full time)	None	Currently discharged	0	GP, CAMHS parenting group, physical health services (previously psychological therapy, counseling); Family Action	Husband involved (strained relationship); mother and extended family involved	Recruited through Family Welfare Association Building Bridges Program Interviewed using a Kurdish interpreter Concerns: Multiple physical health issues
Participant K:	44	White English	Lone parent	1 child:	Multiple personality	6 years	2	CMHT (out patient clinic,	No family involvement	Recruited through support

Karen Mother			Unemployed	Daughter (15) Son passed away, aged 6	disorder, psychosis, anorexia nervosa			support worker); specialist mental health and support services	mentioned	worker
Participant L: ***Lamine*** Father	45	Algerian	Married Unemployed (was businessman in country-of-origin)	4 children: Daughter (9) Daughter (5) Daughter (4) Son (2½) (all live with father and their mother full time)	Depression Schizophrenia	5 years (also incident in country-of-origin in 1983)	2	CMHT (Out patient clinic, CPN)	Wife involved	Recruited through CPN Not very fluent in English, but declined interpreter
Participant M: ***Mualla*** Mother	34	Turkish	Divorced (tensions in relationship) Unemployed	1 child: Daughter (13) (lives with mother full time)	Depression Panic attacks	7 years	0	CMHT (Out patient clinic); Home treatment team; Family Action; Social services children in need service; Primary care psychologist (ended)	Ex-husband involved (strained relationship); Relationship with family-of-origin has broken down	Recruited through Family Welfare Association Building Bridges Program Interviewed using a Kurdish interpreter Concerns: Multiple physical health

										issues
Participant N: Mother	34	White British	Married Unemployed (irregular work as a dancer)	1 child: Son (4) (lives with father and mother full time)	Stress	1 year	0	CMHT (mental health liaison officer), GP, PMHT	Husband involved; family-of-origin and family-in-law involved	Recruited through PMHT: NB! Recording could not be transcribed due to file being corrupted and not retrievable participant moved out of area and interview could not be repeated
Participant O: ***Omette*** Mother	26	Orthodox Jewish	Married Self-employed (Pilates teacher)	3 Children: Son (5) Son(4) Daughter (1½) (live with father and mother)	Depression	1½ years	2	CMHT (Out patient clinic; CPN)	Husband involved; extended family and community involved	Recruited through CPN

5.9. DATA COLLECTION

Once potential participants had informed their care-coordinators that they were willing to be approached about the research, their contact details were passed on to me and I telephoned them to discuss the research process and where appropriate to arrange a meeting to conduct the research interview. Most interviews were conducted at the participants' homes. My employing Trust's lone worker policy was followed. A few participants preferred to be interviewed at the CMHT base and one participant was interviewed at my team base.

At the start of each interview the information sheet was discussed again with each participant, any questions answered and the consent form [see Appendix 9] discussed and signed. Data were collected using one-off semi-structured individual interviews of about an hour-and-a-half in duration. The semi-structured interview schedule [see Appendix 10] was seen as a guide, and was adapted at points through data-collection in line with the Grounded Theory approach (Charmaz, 2006) (see 5.10.2.).

The questions for the semi-structured interview were guided by the literature within the field of parental mental health and the researcher's disciplinary experience of working with parents with mental health difficulties (Charmaz, 2003). The different themes and areas covered by the interview schedule were very carefully considered. For example, it was seen as necessary to explore how parents understood their own mental health problems as well as their views on the impact of these problems on their children, before exploring their views on helping their children understand these difficulties. It was also viewed as important to acknowledge through the questions that parents were not shaping their children's understandings in isolation, and to explore how others contributed to this process where relevant. Finally, it was anticipated that there would be mixed perspectives amongst participants about either talking or not talking about their mental health issues with their children and it was seen as important to explore these different positions with an equal curiosity. The research supervisor (who is experienced within the field of parental mental health and an experienced researcher) and a peer research group, as well as the group of service-user consultants (as discussed above), reviewed the interview schedule.

Despite this careful consideration and consultation, the impact of the questions could not always be predicted. Research participants bring their histories of previous positioning and their expectations of the interviewer and the interview to the research context. Naturally participants want to be viewed favourably (Phoenix, 2008). This research interview could be considered a context where the participant is being asked to tell of his/her experiences without knowing whether the interviewer is a sympathetic ally or potentially threatening adversary (Phoenix, 2008). For example, it was seen as important to start with questions about the participants' children before talking about mental health problems – this was to create a space to talk about the children outside of the context of the parent's mental health. However, as this was early in the interview and a relationship of trust had not been fully established, parents were often cautious and answered this question ['Tell me a bit about your children?'] with hesitation – a typical response was: *Um (3) what do you mean? In what way do you mean? (Beverly).* As researcher I therefore worked hard during interviews to make my intentions and values visible.

Many conflicting reports can be found in the literature about how willing parents with mental health problems are to talk about their parenting and their children within the context of research. Some researchers have a concern that parents are defensive when providing self-report accounts of their parenting (e.g. Graham & King, 2005a; Ramchandani & Stein, 2003; Singer, et al., 2000). Despite the sensitivity of the topic and the issues of trust highlighted in the literature and the consultation with service-users, rich and detailed information regarding the research question, including concerns about the impact of their difficulties on their children from some participants and problematic aspects of parenting, mental health problems, and talking was elicited.

I was struck by the intimacy created in many of the conversations (through the stance of the researcher, the order and focus of the questions, the wish of participants to use the opportunity to talk about their children, etc.) and felt privileged to be sharing that conversational space with them. As was the case in this research, other researchers have also reported that parents were appreciative of the opportunity to talk about their children (e.g. Wang & Goldschmidt, 1994). Despite this, it is important in the analysis to hold in mind the context of the research and to assume that the interviews were powerfully shaped by this context.

5.9.1. Interviewing through an interpreter

Most participants did not have English as a first language, but many were fluent in English. However, a number were not fluent and were offered the option of an interpreter. Three participants declined having an interpreter present, but spoke broken English and found taking part in the interview in English quite challenging. This did influence the quality of data from these interviews as at times the intention of the participant and what they were trying to express was less clear. It is difficult to know the reasons why these participants chose not to have interpreters present, but given the literature one could speculate that they might have been influenced by either the stigma attached to experiencing mental health difficulties, or alternatively by a fear of talking with others about their children.

Two participants, both Turkish-speaking, did opt to have an interpreter present. Tarozzi (2013) emphasizes that it is essential for interpreters to know the topic of the research and to have direct knowledge and experience within the field in order to avoid decontextualized translations. Therefore, two interpreters were selected who were familiar with the mental health field (both with extensive experience as interpreters in mental health contexts, while also continuing their own studies, one in becoming a CBT therapist and the other doing a masters degree in family observation) and who had worked with me on numerous occasions. It is also essential for interpreters to have cultural knowledge, as translation can be seen as intercultural mediation (Tarozzi, 2013) – if ignored it may cause misunderstandings, can become impoverished and can lose its semantic power, the “shades of meaning” (p. 4/14) that are important. Therefore the two interpreters were both familiar with the Turkish culture and the culture of the mental health services. They were familiarized with the study and materials through in-depth discussions.

The choice was made that the translation would only be ‘checked for accuracy’ informally. The interpreter for each interview listened to a part of the other interpreter’s interview (with their consent) and confirmed that it was a valid interpretation. This is based on the view that there is nothing like a perfect translation (Roth, 2013; Tarozzi, 2013) – ‘correct’ or literal translation is impossible (Eco, 2003, cited in Tarozzi, 2013). A process of understanding is implicit in every translation. From this position the interpretations were seen as a valid and ‘good enough’ version of what was intended by the interviewee. I used the reflective time before and after the interview to explore any struggles, uncertainties or difficulties the interpreter might have experienced.

5.9.2. Power in the research relationship

With regards the relationship between the researcher and participants in the current study, a number of factors related to power were taken into account. These include potential power differences related to ‘race’ and class, mental health diagnoses, the differences between service provider and service user, language differences, amongst others. In this regard I had the intention to foster a moral equality (in contrast to role inequality) where both the research participants and myself could grow, learn, and change through the research process (Russell & Kelly, 2002). It is hoped that an open and direct approach, a receptiveness and visible response to feedback, and the skills and understanding developed through the years of working within adult mental health services went some way to addressing or minimizing the impact of these differences (Allen, 2011). However, to some extent, these power imbalances did remain.

This power imbalance and how it could potentially negatively impact on the interview is reflected in a diary entry after the final interview. During the interview the participant's 1-year-old daughter was present. At one point during the interview the baby started crying and wanted to be fetched from where she was sitting. However, the participant did not move for a considerable period of time. I made the following entrance in my research diary after the interview:

The interview became difficult when the little one was crying. She left her to cry more and more insistently and I became more and more uncomfortable and distracted. I felt that I wanted to go and pick up the baby and give her a cuddle. I indicated that she was welcome to go to her baby, but she said 'no, let her cry'. As a mother and as a therapist I could feel myself judging her for this. She made light of it, saying her culture did things differently, but I had the power as professional and as researcher…

Later I wrote a short memo about this incident:

My "fore-understanding" (Shaw, 2010, p. 238) – views about parenting informed by my class, culture, family-of-origin, professional sensitizing to child protection issues, risk-averse culture – all impacted on this moment. It reflects the power of the child protection discourse promoted by government policy, NHS, Social Care, and my role as clinician that that was the first thought in my mind. It makes me aware of how hard participants are left working to present a 'good self', but is the tide against her? I need to hold the needs of the child in that situation alongside confronting the potential prejudices of my response, interrogating them, moving beyond them and subsequently incorporating them into my understanding of this research question…

5.10. TRANSCRIPTION

All interviews were audio-recorded and transcribed. Unfortunately with one interview, the audio-file became corrupted and despite extensive attempts on my part as well as expert technical support, the interview could not be retrieved. Therefore this interview could not be used for this study. This is a loss, especially as this was one of the few interviews where the participant's child was younger in age and it provided rich reflections on the choices made by the parent in this regard. A further participant chose to take part in the research, but did not consent to audio-recording of the interview. This presented a dilemma that was dealt with by taking verbatim notes, and reading them back to the participant to check that it had been recorded as she had intended. The final three interviews were transcribed by a transcription service (see Appendix 11 for confidentiality agreement].

Transcription can be seen as the start of the analysis, and Tarozzi (2013) highlights that transcribing an interview is always a translation act, stating that in Grounded Theory research "there is nothing automatic about transcription. It is the first analytical level, since it is an interpretive job that reduces complex verbal and non-verbal communication to a unique textual dimension" (p. 8/14). The transcriptions produced a vast amount of unstructured data (Pidgeon & Henwood, 1996).

5.11. EARLY DATA ANALYSIS AND THEORETICAL SAMPLING

5.11.1. Starting analysis

In line with the Grounded Theory approach data collection and data analysis happened simultaneously (Charmaz, 2003; Pidgeon & Henwood, 1996). As mentioned above, transcription can be seen as the first stage of engaging with the analysis as the researcher intimately engages with the data and in the to-ing and fro-ing of transcription, the researcher becomes very familiar with the data. Following transcription, interviews were read and some early coding was done. This early analysis was at the thematic level and served to ground the research process within the context of the inquiry (O'Connor, et al., 2008). It began the Grounded Theory process of constant comparison in that, as each new interview was undertaken and then transcribed, the hearing, reading and re-reading and initial coding of earlier interviews were available to the researcher.

5.11.2. Early shifts in perspective

This early engagement with the data led to some specific shifts in perspective and initial theoretical sampling.

From the first interview, I became aware that assumptions would have to shift and understandings expanded. This is well demonstrated by a few extracts from the research reflective diary following early interviews:

Extract from memo following interview with Ann:

That turned out very different from what I anticipated! Where does information come from? The internet!? Of course in these days it is not going to be a sealed vacuum within which chosen information can be distributed from a professional to a 'patient', from a parent to a child! Also, who is telling who?! She says her daughter tells her what happened when she was unwell.

Extract from memo following interview with Beverly:

That tender moment after the sectioning – 'are you alright? Yes, you…?' This is not about 'telling', it is the negotiation of relationships that we all have to do, the talking, touching, seeing… Everything cannot be communicated through words! Understanding develops in many different ways…

<u>*Extract from memo following interview with Carla:*</u>

How is mental health problems used to negotiate the stuff that needs to be negotiated between parents and children? More on everyday basis… Hmmm, again talking rather than telling…

5.11.3. Initial theoretical sampling

It is clear from these extracts that from the first interview and throughout the study my views, beliefs, values, perspectives and ideas about the participants and the research questions were challenged and changed. Grounded Theory holds an awareness of the heuristic value of developmental research designs and exploratory data analytical strategies (Clarke, 2005) and therefore through theoretical sampling the researcher can be responsive to changing awareness and the development of new ideas.

Theoretical sampling involves constructing tentative ideas from the data and then examining these ideas through further empirical enquiry (Charmaz, 2006). Theoretical sampling can therefore be seen where emergent themes are allowed to influence subsequent sampling and data collection (Hutchison, et al., 2012). As these initial ideas developed, further interviews continued to be open-ended, but included these emerging concepts, e.g. including more in-depth explorations of participants' own understandings of their mental health difficulties, moving beyond exploring specific 'telling' events to include more exploration of how parental mental health concerns enter everyday talk in the family, exploring in more depth the nature of the parent-child relationship, increasing awareness of silences and communication beyond words, etc. This is in line with Grounded Theory practice (e.g. Rose, et al., 2002; Mills, et al. (2007).

5.12. A RESEARCH JOURNEY TORN IN TWO

As I was considering that I might soon be approaching the end of this period of data collection (I had interviewed 12 participants) and contemplating moving on from this stage of the research process, I was diagnosed with a life-threatening illness. The research journey stopped, abruptly and completely. As I embarked on a long process of treatment, I did not think about my research; I expected never to return to it.

The following extracts from the video recording of the TED talk ‘Suddenly, my body’ (Ensler, 2011), with which I related very strongly at that time, capture something of the experiences I had then and since – the shock and intensity, as well as the re-connection with life and with vulnerability, not just my own, but everyone’s – that accompanied this experience. I moved from that academic space of being ‘all in my head’ to suddenly being ‘all in my body’ and this came with a new perspective on and openness to life:

> *“For a long time, there was me, and my body... Me was a floating head... I took more than my body had to offer...Then I got cancer -- or I found out I had cancer. It arrived like a speeding bird smashing into a windowpane. Suddenly, I had a body, a body that was pricked and poked and punctured, a body that was cut wide open, a body that had organs removed and transported and rearranged and reconstructed, a body that was scanned and had tubes shoved down it, a body that was burning from chemicals. Cancer exploded the wall of my disconnection… Before cancer, the world was something other... Now I lay down in the grass and I rub my body in it, and I love the mud on my legs and feet. Now I make a daily pilgrimage to visit a particular weeping willow by the Seine, and I hunger for the green fields in the bush outside Bukavu. And when it rains hard rain, I scream and I run in circles… It was finally being in my body. It was the sorrow that's taken so long. It was finding my place and the huge responsibility that comes with connection... It was a million prayers. It was a thousand hallelujahs and a million oms. It was a lot of anger, insane humor, a lot of attention, outrage. It was energy, love and joy. It was all these things. It was all these things. It was all these things in the water, in the world, in my body.”*

A year-and-a-half later I did slowly return to work as clinical psychologist in the Parental Mental Health Team. However, things had changed and very significant financial cuts were being made. The Parental Mental Health Team changed from being a valued specialist team, to being a luxury and add-on and finally to being cut. There followed a yearlong process of redundancy.

During this period, I did re-engage, albeit ambivalently and tentatively, with my research and conducted three final interviews. And then I left this position and embarked on a new professional path as researcher and academic.

5.13. RE-ENGAGING WITH THE RESEARCH PROCESS

This was the point where I felt more able to begin to re-engage with my research, but it required a processing of the practical implications of these disruptions and a new relationship with myself as researcher and with the research questions, methodology and process.

5.13.1. Two new researcher stories

Following the two personal stories presented in the introduction (see 1.5.2.), two further stories marking this moment in the research journey are presented here.

Extracts from research reflective diary:

The story of embodiment

I can no longer be so separate from my research – we are all parents doing the best we can with what life brings us. Who am I to say what is the best way to be – a person, a parent… I who had to look my children in the eye, knowing that what I was about to *say would hurt them, change their lives forever… I see a new physicality in what my participants told me, I too embody this research now, it is no longer a project that only involves my head… there is something new, meditative, spiritual about it… where do I go with this within the world of academia, of the Tavistock, of Grounded Theory…?*

The story of losses

As I re-engage with this research journey it is within the context of many losses – personal losses of (the illusions of) wholeness and certainty, and of a (safer) sense of separateness from the research, of self as a professional, and of a sense of robustness; but also more than that. I have lost my clinical community. With the Parental Mental Health Team having been cut, I am cut off from my work and identity within the field of Parental Mental Health, from my 'direct line' to the professionals who supported this research, and from those who participated in my research. Having been away from the doctorate course for a long time my research community have moved on too, and when I attend doctoral events there are very few faces I recognize. I miss the camaraderie and companionship. I also realize that people now think differently about me, and maybe do not necessarily see me as a 'researcher', which is good and bad…

5.13.2. Practical implications and new limitations on the study

5.13.2.1. Disrupted interviewing and the concept of saturation

Due to the unexpected and abrupt interruption of recruitment and the loss of opportunity to return for further recruitment, I realized at this point that the 15 interviews that had been completed would now be my full data set. From a Grounded Theory perspective data is gathered until a point of saturation is reached, and I had to consider whether the data that was there was 'enough'. Theoretical saturation is often a troublesome concept in the Grounded Theory literature (Allen, 2011). I struggled with it from the beginning of the study and had to consider it carefully at this point. The final conclusions I drew in relation to saturation will be discussed in the data analysis section below (see 5.14.4.).

5.13.2.2. Lost opportunities for further theoretical sampling

Not only would there be no further individual interviews, but at the proposal stage I had sought ethical approval for a more extensive study. Following the analysis of the individual interviews this analysis was going to be presented to practitioners recruited from the community mental health teams involved in the study within a focus group setting – these focus group conversations would then have been transcribed and analyzed. Following this, the original analysis and the analysis of the focus groups would then have been returned to any of the original participants who were interested and willing to continue to be involved. This would either have been in a focus group or in follow-up individual interviews (depending on the number of participants interested and their preference) and their comments and responses would then have been included in the final report.

The aim of this process would not have been the 'verification' of the 'truth' or 'accuracy' of the accounts and analysis, but rather as a further 'layer' of information, or in Grounded Theory terms theoretical sampling, to further develop the emerging theoretical constructs. This process would also have attempted some redress of the power difference between the participants in research and the audience to that research by building in a more overt reflective and 'discursive' loop. I therefore had to consider whether the study was still comprehensive enough without these further processes of data gathering and theoretical sampling, not only in academic terms in order to be presentable as a doctoral thesis, but also whether it would be too much of a sacrifice in terms of my values as a researcher and hopes for the study.

5.13.2.3. A commitment to continue

Following a number of conversations with my supervisor as well as other research colleagues, I found myself on a long haul flight with all my transcripts and was reading through them late into the night and into the early hours of the morning. I remembered each participant well, remembered the context of the interview, my experiences of it and the laughter and tears shared in the process. I was struck again by the richness, complexity and diversity in the data. I also reminded myself of the appreciation many participants expressed for having been given an opportunity to talk about their children within the context of their mental health difficulties, often for the first time, and also how important it was for some of them to make a contribution that might change things for the better for parents with mental health issues in the future. As the plane landed I committed myself to writing up the data from the individual interviews.

Much later, at a recent Qualitative Research in Psychology conference, I was re-assured and heartened by Kathy Charmaz's (2013a) response to a question from the floor. She said there is no prescription in Grounded Theory about the number of participants one should have, how much if any theoretical sampling one should do or any other prescription – rather, "do the study that it possible within the context!", she said (see also Charmaz, 2011). I guess that is what I have ended up doing.

5.14. REVISITING METHODOLOGY

In addition to the above, at this stage I also became concerned about whether Grounded Theory was still the 'correct' methodology for this study. Two particular issues concerned me, namely whether it would allow for the new sense of where my 'self' could fit into the study, and secondly whether it could accommodate a less ‘clean’ analysis and ‘expert’ final theory that I felt would be unattainable within my new relationship to the research.

Extract from reflexive diary entry:

Is Grounded Theory still right for this research? I feel so humbled. I have become ‘softer’ in my ambition for the study – not focused anymore on finding that grand theory that will ‘explain it all’ [and that maybe I thought I already knew before I started the research]… Having experienced the complexity and contradictions of illness and parenting in such a direct way I do not feel it would be reflective of what I had learned to ‘clean that up’ into a ‘nice’ abstract theory!!

5.14.1. Considering researcher voice and positionings in Grounded Theory research

A postmodern stance puts the focus on our knowledge production and challenges us to ask ourselves who is authorized to make knowledges about others, what kind of knowledges are we making and how can we justify that these are legitimate. I was increasingly aware of how multiple selves were impacting and interacting with the research participants, the data, the processes of research, towards a co-construction of the final research product. It required a method that could make this transparent.

5.14.2. Embracing a more ‘messy’ analysis

Furthermore, I had a new appreciation of the complexities, heterogeneities, contradiction and richness in people’s experiences and in the stories they tell about these experiences, also within research interviews. Furthermore, I acknowledged the partiality of any ‘theory’ or knowledges produced through research (Shotter, 2012). I committed myself to a more ‘messy’ analysis that would accommodate this awareness of complexity and partiality.

5.14.3. Considering ‘theory’ in Grounded Theory

Rather than ‘something that explains something’, Shotter (2012) described a theory as something to pay attention to and within which to notice this or that dimension; something that describes around, creates a shape from, the data. A theory can focus on the development of sensitizing concepts (as opposed to definitive concepts) that can provide, rather than prescriptions of what to see, directions along which to look (Clarke, 2005). The research can thus work towards a theory as framework or scaffold that helps to make sense of the area and process that the research question relates to (Shotter, 2012).

5.14.4. More fully embracing an interpretive Grounded Theory

At this stage I revisited the more current literature on Grounded Theory, in particular Clarke (2005), Charmaz (2006) and feminist Grounded Theorists (Allen, 2011; Wuest, 1995, 2000) and I realized anew how significantly the boundaries of Grounded Theory work have extended in recent times (O’Connor, et al., 2008). Current literature in the field confirmed that postmodernism has shifted emphasis in Grounded Theory research to positionalities, partialities and situatedness (Clarke, 2005; Allen, 2011). “The expected product is no longer a truth, but an acceptable rendering of what has been produced in the moments of the inquiry” (O’Connor, et al., 2008, p. 31), with an emphasis on plurality (Russell & Kelly, 2002).

Feminist Grounded Theorists (e.g. Allen, 2011; Plummer & Young, 2010; Scheyett & McCarthy, 2006; Wuest; 1995, 2000) have emphasized the incorporation of diversity and context in Grounded Theory studies and have developed perspectives on the importance of reflexivity by “acknowledging the contextual and relational nature of knowledge, rejecting subject-object dualisms, and valuing the relationship between the researcher and participant in the research process” (Plummer & Young, 2010, p. 306). Allen (2011) states that feminist Grounded Theory moves away from the “colonial enterprise” (Allen, 2011, p. 23) of trying to understand the ‘exotic other’ and from denying the importance of the experiential, the private, the personal, but rather focusing on these, thus “value(ing) the private and personal as worthy of study” (p. 28). Furthermore, it emphasizes that knowledge generation is a social process, paying particular attention to the ways in which structural and system factors intersected with family efforts to promote health, thus fitting with the more discursive emphasis introduced by Clarke (2005).

Inspired by the above I felt re-engaged with the Grounded Theory method and could once again identify with Willig’s (2001) sense of adventure.

5.15. DATA ANALYSIS

Due to the long break from the research, I returned to analysis by reading and re-reading all transcribed interviews. I then re-visited all early coding that had been done and also re-coded interviews.

5.15.1. Coding

Codes were inductively created directly from the data (Pidgeon & Henwood, 1996). Whilst coding, constant comparative methods (Glaser & Strauss, 1967; Strauss & Corbin, 1994; Pidgeon & Henwood, 1996) were used. Thus, an iterative process of moving backwards and forwards between coding and conceptualizing data developed (Dilks, et al., 2008).

Open and in-vivo coding, focused coding, axial coding and selective coding, followed by situational mapping techniques (Clarke, 2005) were undertaken as described in the previous chapter [see Appendix 12 for an example of a full coded interview]. In addition to the maps described by Clarke (2005), other diagramming techniques were also found to be useful in providing a visual representation of the data at different stages of the analysis [see Appendix 13 for an example of early visual maps of the data and Appendix 14 for maps generated through Situational Analysis].

Writing memos offered a creative process for describing the conceptualization of the data (Glaser & Strauss, 1967) and was the research strategy that was most valued during the current study. Observations about each interview, alongside any initial ideas about codes and connections, were recorded (Charmaz, 2006). Subsequent memos played a crucial role in refining the developing theory (Khaw, 2012). Some became part of this final report, e.g. the section below on saturation started off as an extensive memo to work out my own position on the concept, where others remained reflections on developing ideas [see below for some examples].

Engaging in reflexivity continued during analysis. One example relates to the concept of ‘coherent narratives’:

Memo following re-engagement with the literature after an ‘invited speaker’ session:

I have emphasized all along the importance of coherence. BUT! What is coherent? Might it be more about resilient rather than coherent narratives… what shapes can sense making take? Does it always make sense? What can be meant by an ‘explanation’? Maybe there are some things that cannot be understood or explained, some things that cannot be put into words? Can this be acceptable? Has the focus on coherence been mine, rather than my participants’ – can I tolerate the incoherence, uncertainty, incomprehension…? Gerrit Loots’s invited speaker session and their paper [Sermijn, Devlieger & Loots, 2008] – a researcher could one way or another forcefully create a coherent whole… The creation of “coherent” connection is not always possible. Returning to my data with this lens, I think I might have avoided the chaos and incoherence implied in some experiences described by participants…

5.15.2. Developing a Grounded Theory

Once data were assigned to categories, categories and subcategories were added or eliminated until possible relationships between the categories began to develop and greater and greater degrees of abstraction were engaged in (O'Connor, et al., 2008) [see Appendix 15 for earlier frameworks and structures used to organize categories and sub-categories].

Throughout this analytical phase I came to value what Glaser (2002, p. 5/14) calls "the carefulness of the Grounded Theory method". Through all the "tedium of constant comparison" (Glaser, 2002, p. 10/14) one does develop such an intimate relationship with one's data and is constantly invited back into grounding any ideas in the data.

5.15.3 Later shifts in perspective

This intimate engagement with the data brings the researcher to turning points, new developments, reconsiderations and re-conceptualizations throughout the research process (Charmaz, 2006). In these final stages of the research, through this intimate staying with the research data, certain aspects became more fore-grounded, while other perspectives shifted and new meanings emerged. These perspectives are presented in the chapters that follow, but a couple of examples to illustrate such shifts are presented below:

Moving away from an either or position:

Mutuality… both-and… seem more important – parents are not either good parents or bad parents, not either protecting their children or expecting them to protect them… For these parents these things exist alongside one another.

Increasing awareness of the importance of identity:

These parents feel so bad about themselves as parents at times… more than that – even dangerous. If one experiences oneself as 'toxic' to one's children, one would move away from them at difficult times rather than move towards them. This is 'doing what is best' from that perspective. Therefore, is identity – one's sense of self – central to what is possible in terms of talking and remaining silent?

As each of these shifts in perspective and understandings occurred, there was a return to the data to revisit it with the particular lens in mind.

The final conceptualizations of these shifts, reconsiderations and re-conceptualizations are presented in the results chapters.

5.15.4. Triangulation

Most coded transcripts were read by and discussed with the primary supervisor. Furthermore, the researcher attended data analysis sessions where sections of data and analysis were discussed with peer researchers. These conversations were not used as member checks to confirm the analysis that had been arrived at (Smith, 2012), but rather as critical theoretical sounding boards to encourage reflection upon and exploration of alternative interpretations and perspectives in relation to the data (Guba & Lincoln, 1994).

An example relates to a session where I presented data relating to the talk between parents and children. The comments I wrote following this session was as follows:

Memo following peer supervision (data analysis sessions):

I took extracts of the parents' reported talk between them and their children – as my colleagues read this, one person reported feeling very angry. As a child of a parent with mental illness who was a young carer, (s)he feels that the parent in the transcript is not acknowledging the loss of their child's childhood. I feel protective of my participants, but again and again through this research I am forced to consider the children of these parents and hear my research and the sense I am making of the data through their ears. At the end of the conversation, another colleague summarized the contradictions, complexities and struggle captured by it, saying 'it's bloody hard' – that sums up well what I feel! Everyone is struggling here – can I 'externalize' the mental health difficulties and place the parents and children 'on the same side', rather than against one another?

5.15.5. Saturation

Saturation within an interpretive approach to Grounded Theory is more open, that is saturation occurs when no new information emerges to add to meaning (O'Connor, et al., 2008). As mentioned before, I found saturation a complex concept. I saw saturation as problematic within a postmodern paradigm from which one assumes that there are always new, multiple alternative constructions of the data available.

For the purposes of this study I began to think of saturation as a point where the structure that evolves for the analysis (the themes and sub-themes) reaches a point of coherence and of being able to account for all or most of the data. Therefore it acknowledges the fact that other co-constructions could have been made, e.g. with another researcher looking at the data, or this researcher using different theoretical or clinical lenses to analyse the data. However, with this researcher using particular theoretical and clinical lenses and being familiar with the ‘feel’, the structure and performances of the different interviews and what was co-constructed as salient in those intimate research moments, a point can be reached where the structure that is co-constructed to account for the data reaches a point where it can account for all the data without the researcher having to add categories, themes or sub-themes.

As the analysis unfolded a structure within which to report the data started to develop. However, in early interviews I had to constantly return to the structure, to add, remove, integrate, re-name or expand on the categories developed. To assist with this, a category named “Other” [named such to account for anything that did not fit at that stage of the analysis] was added to the end of the structure. Within the analysis of each interview anything that could not be accounted for by the current structure was added into that category. At the completion of the analysis of that interview, I then looked at those aspects, and considered where they could fit within the structure. New categories were then added, and/or existing categories expanded, changed or adjusted to account for the new information. Past interviews were then returned to and re-read through the lens of the new additions to see how the data would fit with these new data – this can be seen as the “wallowing in the data” described by Clarke (2005, p. 84). One example of something that was placed in the “Other” category during a later interview, and then through re-analysis of earlier interviews became central to the analysis, was issues of identity, initially coded as ‘sense of self’, ‘sense of self as parent’, ‘sense of self as person with mental health difficulties’. For the purposes of this study it could be said that ‘saturation’ was achieved when at the end of the analysis of each interview nothing had been placed in the “Other” category, that is, all data in the interviews could be accounted for within the structure that had been achieved at that point. For this project, that point was arrived at by interview 9.

5.15.6. Theoretical sensitivity and re-contextualizing

Theoretical sensitivity refers to a researcher's ability to "render theoretically their … substantive grounded categories" (Glaser, 1978, quoted in Wuest, 2000, p. 55). Therefore, theoretical sensitivity is what helps the researcher move beyond pure description to see theoretical possibilities in the data. Wuest (2000, p. 55) states that "the investigator's knowledge of relevant literature and theoretical schemes comes into play" at this stage of the analysis. Disciplinary or professional knowledge as well as both research and professional experience that the researcher brings to her inquiry enhance theoretical sensitivity (Strauss & Corbin, 1994). The emerging theory is merged with and recontextualized by previous established theory, which provides the mechanism to demonstrate the usefulness of the emerging theory. The term 'sensitizing concepts' has been utilized within Grounded Theory to define these 'starting points' of knowledges of existing theory and also own professional experience (Glaser, 1978 cited in Allen, 2011), suggesting directions along which to look. Therefore, there was a constant moving between analysis and theory during this stage of the process. Finally, this process allows the researcher to write up their Grounded Theory report.

5.16. QUALITY IN QUALITATIVE RESEARCH

The notion of quality within qualitative research is a complex and multi-faceted topic that has been widely written about (e.g. Angen, 2000; Parker, 2004; Spencer & Ritchie, 2012; Tracy, 2010). In line with a social constructionist paradigm, I have chosen not to draw from quality criteria that emphasize the 'true' nature of knowledge as revealed in qualities such as accuracy, validity and reliability. Rather, specific criteria, suitable to qualitative research, developed to consider quality in Grounded Theory studies, and interpretive Grounded Theory studies in particular were employed.

5.16.1. Quality issues in interpretive Grounded Theory research

In conjunction with the growth of qualitative research, there has been a call for the development of agreed assessment criteria to help discern quality in qualitative research. Some have suggested that more specific criteria need to be developed in order to account for the diverse range of methodological approaches and modes of data collection and analyses adopted (e.g. Hutchinson, et al., 2012). Therefore, specific criteria for assessing the quality of Grounded Theory research were considered. Hutchinson, et al. (2012) have argued that many studies demonstrate a poor understanding of the Grounded Theory methodology or fail to present an adequate account of the research process. They conclude that in order to further legitimize Grounded Theory and to encourage greater research rigour, researchers need to fully engage with the method. To this end they have developed a set of criteria for judging the quality of a Grounded Theory study and these were used in relation to the current study. Furthermore, Charmaz (2006) have also developed criteria to assess the quality of interpretive Grounded Theory research and these were also used. These and how they were considered within this study is presented in Table 2.

Table 2: QUALITY CRITERIA USED FOR THIS STUDY

Criteria	Description	Application to this study
Grounded Theory appropriate method for this study = justification of the methodological choice (Hutchinson, et al., 2012)	Was justification presented for adopting a Grounded Theory approach?	Clarification that a social constructionist/ interpretive mode of Grounded Theory was adopted and why provided.
Sampling aimed at facilitating theory generation (Hutchinson, et al., 2012)	What evidence is there to suggest that sampling was conducted to facilitate theory generation? How and on what grounds were the initial sample selected? Did theoretical formulation guide some of the data collection? How? Did theoretical sampling occur?	Data gathering decisions were openly presented; Purposive sampling strategy described; Appropriate sample for study recruited; Justification for sample provided and limitations discussed; Evidence of initial theoretical sampling and explanation for limitations discussed; Sampling processes determined by the research question
Concurrent involvement in data collection and analysis phases of the research (iterative process) (Hutchinson, et al., 2012)	Is there evidence of concurrent involvement in data collection and analysis?	Evidence of concurrent involvement in data collection and analysis presented, e.g. emergent themes influenced data collection; examples of iterative process provided (see 5.10.2. & 5.14.3).
Development of initial concepts and categories from the data itself (Hutchinson, et al., 2012)	Covers a wide range of empirical observations – What techniques were used to construct or develop these categories (e.g. codes, memo writing, comparisons, questioning, use of attributes, etc.)? What evidence is there to suggest that these concepts and categories	Coded transcript and analytic structures as well as maps and diagrams presented as appendices (see Appendices 12, 13, 14); Examples of memos provided (see 5.5.1., 5.8.2., 5.10.2., 5.12.1., 5.13., 5.14.1., 5.14.3., 5.14.4.).

	were generated from the data itself? Do the initial categories cover a wide range of empirical observations; was the initial focus broad?	
Advancement of theoretical development during each step of data collection and analysis (Hutchinson, et al., 2012)	How did theory development advance through each step of data collection and analysis? What major categories were presented? What techniques were used to construct and develop these categories (e.g. axial coding, focused coding, systematic comparison, questioning, memo writing)?	Number of major categories presented (see appendices 13, 14, 15); Maps and diagrams presented (see appendices 13, 14, 15); Analysis as nonlinear process – use of open and more advanced coding and analytical techniques shown through presented transcript, analytical framework, memos, maps and diagrams (see Appendices 12, 13, 14, 15, Sections 5.5.1., 5.8.2., 5.10.2., 5.12.1., 5.13., 5.14.1., 5.14.3., 5.14.4.).
Always remaining open to new possibilities emerging from the data (Hutchinson, et al., 2012)	How is open to new possibilities in emerging theory demonstrated?	Examples of turning points, new developments, re-considerations or re-conceptualizations presented throughout (see e.g. 5.10.2. & 5.14.3; also 5.11. & 5.12.).
Making systematic comparisons (Hutchinson, et al., 2012)	How is it demonstrated that constant comparison was used? Are the categories theoretically dense?	Evidence presented that constant comparison and memo writing was used (see 5.14.5.; also 5.5.1., 5.8.2., 5.10.2., 5.12.1., 5.13., 5.14.1., 5.14.3., 5.14.4.).
Evidence of theoretical density, resulting in the presentation of a theory from which hypotheses can be generated (Hutchinson, et al., 2012)	Clear links between individual categories and subcategories/ dimensions and the larger core category; Clear links between individual categories and subcategories as	To allow the reader to make judgements of this, an example of a coded transcript and the developed analytic structures as well as maps and diagrams presented as appendices (see Appendices 12, 13,

	well as between individual categories and the larger core category? Have the dimensions of categories and subcategories been explored? How were the core categories selected and on what grounds were the final analytical decisions made? What evidence is there to suggest that the results offer new insights?	14, 15); Examples of memos provided throughout (see 5.5.1., 5.8.2., 5.10.2., 5.12.1., 5.13., 5.14.1., 5.14.3., 5.14.4.); Results and discussion presented together to make clear where links to previous theory could be made and where new or alternative perspectives were presented.
Evidence of theoretical saturation (Hutchinson, et al., 2012)	What evidence of saturation is presented?	Saturation and how it was conceptualized within this study considered in detail (see 5.14.5.).
Rich descriptions of the entire research process, including justification for all the decisions made = transparency (Hutchinson, et al., 2012)	Was a transparent account of the entire research process captured?	A detailed transparent account of all the procedures and decisions that took place provided (see Chapter 5).
Credibility (Charmaz, 2006)	Intimate familiarity with topic; data sufficient to merit claims; systematic comparison; categories cover wide range of empirical observation; strong logical links between data and argument; enough evidence for claims so that reader can come to independent assessment (Charmaz, 2006).	Intimate familiarity with topic through research, literature, experience; Intimate familiarity with data demonstrated; Transparency, e.g. examples of points of turning and re-consideration; Strong reflexivity throughout; Many quotes from participants used throughout.
Originality (Charmaz, 2006)	New and fresh insights offered; analysis provides new conceptual rendering of data; significance of work; findings challenge, extend or refine current ideas, concepts and	Results and discussion presented together and linked to existing theory to indicate where new or alternative perspectives were introduced (see Chapters 6, 7, 8 &

	practice (Charmaz, 2006).	9).
Resonance (Charmaz, 2006)	Categories portray fullness of studied experience; revealed both liminal and unstable taken-for-granted meanings; drawn links between larger collectivities/ institutions and individual lives; findings make sense to participants or those who share their experiences, offering them deeper understandings about their lives and worlds (Charmaz, 2006).	Intimate familiarity with topic through research, literature, experience; Richness and complexity in data presented in final results and discussion.
Usefulness (Charmaz, 2006)	Interpretations that can be used in everyday world is offered; generic processes suggested and examined for tacit implications; further research is sparked; Contributes to knowledge; contributes to making a better world (Charmaz, 2006).	Specific recommendations made for clinical practice and service development; Specific recommendations made for further research.

5.17. CONCLUSION

In this chapter I attempted to present a transparent account of the research journey and process of this study. In keeping with social constructionism, the results of this study will now be presented as my interpretation of the data. The reader is invited to consider these results through the lens of the context that has now been described.

6. DATA ANALYSIS AND DISCUSSION: INTRODUCTION

6.1. INTRODUCTION

In this chapter an overview of the grounded theory of parents talking with their children about their mental health difficulties is presented – an outline of the findings are provided and visually represented [Diagram 1] before the different categories are discussed in detail in the next two chapters. In line with the epistemological and theoretical framework of this study, this theory is not presented as a final truth, but rather as a co-construction between the researcher, participants and the reader, within a particular context and at this specific point in time.

6.2. OVERVIEW OF THE GROUNDED THEORY FRAMEWORK

The grounded theory is presented within two main categories, namely *relational* and *identity* contexts for telling, talking and keeping silent. Within these two categories, two social processes were identified, namely within the relational context, *Negotiating mutuality,* and within the identity context, *Holding on to self, holding on to life.* These two aspects can be described as 'meta-processes' that organize the more complex and detailed processes relating to telling, talking and keeping silent within families.

6.2.1. Relational contexts for telling, talking and keeping silent

Relational contexts for telling, talking and keeping silent refer to the ways in which relationships, primarily between parent and child, but also between the parent-child dyad and others (including professionals, family members and society), impact on the experiences and choices of parents in relation to talking to their children about their mental health difficulties. Within this category the meta-process identified is *NEGOTIATING MUTUALITY.* This refers to the many different ways parents are challenged to balance the needs of their children with their own needs and also balance their preferred ways of parenting and relating to their child with the realities of their lives created within the context of their mental health struggles.

As part of the social process of *Negotiating mutuality*, it was found that parents started off with younger children *Judging readiness,* that is, working to determine whether their children were ready and able to cope with information and talk about the parent's mental health difficulties. Under *Judging readiness* there was an initial social process with younger children of *Protecting innocence,* where parents worked to protect their children from knowledge or awareness of their mental health difficulties. However, as children grew up, parents realized that their children were aware of their difficulties and being affected by these difficulties and they had to *Acknowledge awareness.* This was a painful process for parents, and they coped with it through three processes: firstly by *Remembering family stories of mental distress*, that is drawing on their own experiences of not being given information about mental health issues in their families; secondly by *Casting children as knowing and knowledgeable,* that is by taking a position that their children already knew much and understood their mental health difficulties; and finally, *Relying on maturity,* where children were cast as particularly mature and therefore able to deal with their knowledge of their parent's difficulties.

Once parents had to *Acknowledge awareness,* a further and on-going process of *Navigating reciprocity* came into play. This involved the constantly shifting balances between parenting and living their lives on the one hand and managing the potentially devastating impact of their mental health issues on the other. Two social processes were constructed in relation to this: firstly, parents worked at *Maintaining their lives together,* that is *Wishing to stay close and connected* and *Striving for normalcy and valuing the everyday;* and secondly, parents moved between *Protecting and being protected* in the relationship with their child, which involved trying to *protect* their child, but also *being protected* by their child and at times *requiring the protection* of their child.

6.2.2. Identity contexts for telling, talking and keeping silent

Identity contexts for telling, talking and keeping silent refer to the identity implications of mental health difficulties and societal responses to these difficulties, and the impact of these identity implications on the experiences and choices of parents in relation to talking to their children about their mental health difficulties. Within this category the meta-process identified is *HOLDING ON TO SELF, HOLDING ON TO LIFE.* This refers to the intense struggles for parents to hold on to an acceptable sense of self and an experience of their lives with their children within the challenging context of their mental health problems and social understandings of and responses to these problems.

Within *Holding on to self, holding on to life* two social processes were identified, the first of which was *Living a compromised life.* This refers to the struggle people experienced of living with mental health problems and included: *Living in a nightmare,* referring to the impact of experiencing periods of intense psychological distress; *Living with a wounded future,* referring to *Living with losses* on many levels relating to self and life as it was before mental health problems, and *Living with uncertainty;* and *Living a difficult life,* referring to many other challenges apart from mental health challenges in people's lives. Secondly, the social process of *Struggling to preserve a self, preserve a life* was constructed, referring to the challenges people faced in trying to make sense of mental health issues. Within *Struggling to preserve a self, preserve a life* three social processes were identified: parents had to attempt to *Find a framework* for understanding their mental health problems; they had to *Make sense of self as illness, illness as self;* and finally parents had to work at *Tentatively constructing a new (well/unwell) self.*

This grounded theory is set out visually in Diagram 1 below.

Diagram 1: TELLING, TALKING AND KEEPING SILENT

RELATIONAL CONTEXTS FOR TELLING, TALKING AND KEEPING SILENT

Negotiating mutuality

- **Judging readiness**

  - Protecting innocence
  - Acknowledging awareness
    - * *Recalling family stories of mental distress*
    - * *Casting children as knowing and knowledgeable*
    - * *Relying on maturity.*

- **Navigating reciprocity**

  - Maintaining their lives together
    - * Wishing to stay close and connected
    - * Striving for normalcy and valuing the everyday
  - Protecting and being protected
    - * *Protecting*
    - * *Being protected*
    - * *Requiring protection*

IDENTITY CONTEXTS FOR TELLING, TALKING AND KEEPING SILENT

Holding on to self, holding on to life

- **Living a compromised life**

  - Living in a nightmare
  - Living with a ‘wounded future’ (Penn, 2001)
    - * Living with losses
    - * Living with uncertainty
  - Living a difficult life

- **Struggling to preserve a self, preserve a life**

  - Finding a framework
  - Making sense of self as illness, illness as self
  - Tentatively reconstructing a new (well/unwell) self

6.2.3. Conclusion

In this chapter an overview of the grounded theory that has been constructed was presented and the main social processes within the theory described.

What follows in Chapter 7 and 8 is a detailed exploration of these different processes. These will also include links back to the literature. A discussion chapter that draws out the connections between the processes presented in the results chapters and discusses the clinical implications follow these chapters.

7. DATA ANALYSIS AND DISCUSSION: 1

RELATIONAL CONTEXTS FOR TELLING, TALKING AND KEEPING SILENT

7.1. INTRODUCTION

In this chapter the data in relation to the first analytic category – the relational contexts for telling, talking and keeping silent – is discussed. The main social process identified in relation to these relational contexts was *NEGOTIATING MUTUALITY.* In *Negotiating mutuality*, the intense struggle for parents to balance on the one hand, their wish to protect their children and shield them from the impact of their difficulties and for normality in their life together, and on the other hand, their acknowledgment of their children's awareness of their difficulties and their own need for understanding and support in managing their mental health problems, is made visible. This struggle for balance leads to a constantly shifting relationship with telling, talking and keeping silent. Within *Negotiating mutuality* a number of social processes impacted on parents' efforts to negotiate a workable and satisfactory mutuality, both with their children and other significant people in their lives, and from that mutuality to make choices in relation to talking about their difficulties. These were:

NEGOTIATING MUTUALITY

- **Judging readiness**
  - Protecting innocence
  - Acknowledging awareness
    - * *Recalling family stories of mental distress*
    - * *Casting children as knowing and knowledgeable*
    - * *Relying on maturity*

- **Navigating reciprocity**
  - Maintaining their lives together
    - * *Wishing to stay close and connected*
    - * *Striving for normalcy and valuing the everyday*
  - Protecting and being protected
    - * *Protecting*
    - * *Being protected*
    - * *Requiring protection*

7.2. NEGOTIATING MUTUALITY

The literature often implies the importance of a ‘telling occasion’; that is, a moment in time when the parent or a professional explains the parent’s mental health difficulties to the children (e.g. Cooklin, 2004, Tunnard, 2004). The participants in this study described almost no such ‘telling occasions’ where parents initiated conversations with their children in order to explain their mental health problems to them.

Rather, complex relational social processes impacted on parents at different times, informing their decisions about talking to their children about their mental health issues. The main social process identified as shaping how talking played out between parents and their children, namely *Negotiating mutuality,* shows the many subtle and fluid factors involved. These will now be discussed in relation to firstly, *Judging readiness* and secondly, *Navigating reciprocity*.

7.2.1. Judging readiness

Age was a central factor for parents in relation to what children should and could know about parental mental health problems. However, this did not so much refer to biological age, but rather a parental judgement of psychological maturity and ‘readiness’.

Parents of young children wished for their children to have a ‘normal’ childhood and to not be aware of or affected by their mental health issues. Thus, through not talking about their mental health difficulties and through trying to hide the signs of their difficulties from them, they were hoping to protect the innocence of their children.

7.2.1.1. Protecting innocence

"Angels" (Lamine[3])

Young children were seen as innocent, unaware and unable to understand a parent's mental health issues. Parents believed that children should have a normal childhood.

> *R: What do they know about your treatment or the time you were in hospital?*
>
> *Faith: They have no idea. They are very young. They don't understand it, they don't know. They are still very young – they won't understand anything like that. When they are big, I'll explain everything to them. (…)*
>
> *R: How would you know when they are old enough, when they are ready to be told?*
> *Faith: When they are 15 – then they can understand it better. (p. 3, l. 92)*

Parents assumed that their young children did not notice any aspects related to their mental health issues. When parents considered that they might have noticed, there was a sense that younger children would 'forget'.

> *Omette: "Um … it was quite a long, a long time, um …… that they were, they were out of the house, um … could have been even something like … like, two and a half months (…) that they were out … um, so I don't know if we can say children forget what their parents are like but, you know, it was … the same mother, I looked exactly the same so … um … while, while they were out of the house I was sleeping all the time but they didn't know that, so …… when they*

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[3] All names are pseudonyms in order to protect the anonymity of the participants.

> *came home I was with them and, you know, there was no, there was nothing different so …" (p. 6, l. 179)*

At times the parents of younger children worked hard to prevent the children noticing their behaviour.

> *Omette: "… but mentally I was okay so there was no need to explain funny behaviours, it's not as if I was doing funny things so the children need to know that mummy's not well, so, um, and there was, um, you know, I was able to … to sort of smile at them when they came in and … so it wasn't like I was sitting there, you know, with a glum face all the time and, you know, my husband having to say 'mummy's depressed so she can't smile', you know, I was able to … to put on a bit of a show in front of them … so …" (p. 9, l. 291)*

It was important for the parents to see their children as enjoying themselves, 'being children', having a 'normal childhood'.

> *Lamine: "They, they don't live with me in my room, they are always part of the time, they are with the mum, you know what I mean. [R: Mm, yeah, yeah.] They are downstairs, living room, they are watching the TV, they are in the kitchen, they are having food, they are enjoying themself, they laugh, they… play around, they, they play and most of the time the mother she take them to the playground and that and that and that…" (p. 9, l. 234)*

Therefore, parents hoped to shield their young children from their mental health difficulties. This fits with other literature highlighting parents' choices not to talk to their young children about parental mental health issues and to hide difficulties from them in order to protect them (e.g. Absler, 1999; Focht & Beardslee, 1996).

7.2.1.2. Acknowledging awareness

However, as children became older, and due to the nature of mental health issues, there came a time when this position became impossible to maintain. Children were witnessing difficult and at times very disturbing situations and were proactive in trying to make sense of these experiences. Whereas the parents' wish to protect their children would deter them from initiating conversations about mental health issues with their children, the children were often seen as proactive in searching out information. Thus, parents had to acknowledge their children's awareness of their mental health problems and that they could not hide these from them anymore.

> *Gareth: "…and also they have had to be around a lot of it…" (p. 19, l. 832)*

Sometimes this involved the parents acknowledging that their children had witnessed and experienced bizarre and frightening behaviour.

> *R: When you made a suicide attempt and you went into hospital, um, did she know what had happened and where you were?*
>
> *Mualla: Once she was at school so she wasn't there…Once I was going to jump from the balcony she held my legs … … she shouted 'mum!'.*
>
> *R: So she stopped you?*
>
> *Mualla: Yes. (p. 14, l. 432)*

> *R: So if I asked her what sort of experiences you've had, would she know anything about hearing voices?*
>
> *Izzy: She (1) she um yeah, she would probably [quietly] know… because sometimes I swear back, you know what I mean [laughs], sometimes I get annoyed.*
>
> *R: When they are talking to you, you may answer them back?*
>
> *Izzy: Yeah [laughs]*
>
> *R: Would she ask you about that – who you're talking to?*
>
> *Izzy: Yeah. I say just stupid people talking in me head. (p. 16, l. 711)*

It therefore became clear to parents that their children were aware of their mental health issues. Parents described their children asking questions, trying to understand what was happening and what would happen next. For a while parents might try to explain away what their children were noticing.

> *Hannah: "I was just telling her 'I am just a bit tired, because I have just come out of hospital so I am just a bit tired' (…) Yes, it was very hard for me to deal with, because I was thinking 'I'm just lying to my own kid', but at the same time I just I just wanted her to get on with her school work instead of thinking about me too much." (p. 13, l. 584)*

However, the parents found that the children would not always be satisfied with such answers to their questions, and would keep probing, using their observations to judge their parent's explanations, looking to make sense of what was going on.

> *Hannah: The older one was always asking about what was happening – the older one was asking me a lot (…)*
>
> *R: What sort of things did she ask you?*
>
> *Hannah: 'If you are ill, well what's the problem?' (…)*
>
> *R: So she wanted to know what was wrong?*
>
> *Hannah: Yeah. I was just telling her I had a headache.*
>
> *R: Um. A headache?*
>
> *Hannah: Yeah. I just said headache.*
>
> *R: Yeah? (…) Um. Yeah, so she kept asking questions?*
>
> *Hannah: Yeah, she kept asking questions. (…) Yeah. No, she wasn't sure, but when she saw me drinking medicine, she would ask 'why are you drinking your medicine?'.*
>
> *R: Yeah. Yeah. Yeah. Tricky questions for you?*
>
> *Hannah: Yeah.*
>
> *R: What would you say?*
>
> *Hannah: I say 'it's the medicine I came with from the hospital – I have to finish it' (…)*
>
> *R: Yeah, you have to think on your feet really.*
>
> *Hannah: Yeah. Huh! Think of a quick answer! [Laughs] (p. 23, l. 1048)*

Therefore parents had to acknowledge their children's awareness of their mental health problems and had to find ways to respond to their children's active attempts to make sense of what was happening.

> *Lamine: Yeah, my old daughter, she knows what, how happen, she knows what happened… … My old daughter, she quite, she's started to understand… (R: Yeah) Because she's quite, not, not a child, she's nine, she's getting nine old, you know what I mean… (p. 10, l. 253)*

Here it is clear that the parents experienced the children as actively seeking to understand what is happening with their parent and to make meaning of their observations and experiences and this is in line with previous research (e.g. Mordoch and Hall, 2008; Riebschleger, 2004). Even though we see children here as active agents in their attempts to make sense of their experiences, research involving children themselves needs to be held in mind here. Researchers such as Totsuka (2013) and Van Parys and Rober (2012) have emphasised the recursive process between parents and children. Thus, just as parents are influenced here to open up conversations by their children's questions, these authors have speculated that parents' ambivalence about talking could inhibit the child from asking and talking. This is therefore not a one-directional process and one could assume that despite these parents' experience of the insistence of their children on information, there might have been many questions the children felt unable to ask or observations and experiences they felt unable to comment on or explore with the parent.

For the parents the intense struggle to manage their wish to not upset their children and have their innocence spoiled became severely challenged over time. Thus, within the context of a growing acknowledgement in parents of their children's awareness of their mental health issues and their children's probing questions, parents started to consider whether and how to talk to their children about their mental health problems. Gradually many parents described how their responses came to include 'illness' and finally 'mental illness' or 'mental health problems', but with a sense that this was used quite broadly.

Often this decision to share some information appeared to be in-the-moment choices, based on the particular circumstances, often responding to their children, as opposed to a pre-considered and thought-through process with a clear intention on behalf of the parent. Instead of ‘information’ about diagnosis being given to children, decisions about talking and talking itself appeared to happen on a more immediate and informal basis, interwoven with the everyday lives and relationships of all in the family.

> *Ann: “…so we’ve sort of talked about like what’s, what happened and what like I felt and what happened to me rather than me like explain…” (p. 17, l. 774)*

> *Karen: “It probably happened because there was a difficult moment or she said ‘but I have told you this’ or there would be times when she would be like ‘Mum! Mum’ like she would say it’s like you are completely not here... [R: Okay.] ...and I think I told her then and said well actually it is because the other person [one of her multiple personalities] is dominant...” (p. 22, l. 972)*

There was also a sense that the ‘naming’ of a mental health issue at times stopped rather than encouraged further talking – the information about a mental health experience in the parent appeared to lead to the focus shifting to the parent and what they might need in the situation and away from the child’s need to understand or to be re-assured.

> *Izzy: “I don’t explain nothing to my son really, I just tell him ‘I’m depressed’. He’ll say ‘what’s the matter’ and I’ll say ‘I’m depressed’ and he’ll go ‘Oh, muuummm…’ (p. 18, l. 782)*

With the increasing awareness that their children were noticing came the need for parents to also more specifically consider the impact of their mental health difficulties on their children. In considering this, a few moments occurred where a parent claimed that there was no impact on their child(ren).

> *Faith: No, it has not changed anything. There are no impact, no effects.*
>
> *R: No good or bad impact?*
>
> *Faith: No.*
>
> *R: It sounds like it is important to you that there is no impact?*
>
> *Faith: Yes, because they need me.*
>
> *R: Yes.*
>
> *Faith: The mother takes care of the children, no one else will take care of them. (p. 3, l. 110)*

However, this position was seldom maintained. Mostly, there was acknowledgement of the possible impact of the parent's mental health difficulties, for example due to witnessing strange behaviour or visiting a psychiatric ward in a hospital. Parents worried about this impact. They appeared to be watchful, trying to 'read the signs' in their children, interpreting their actions and determining from that how their children were coping with impacts of their mental health struggles. Parents were often well aware of the potential impact of their mental health difficulties and expressed genuine concern for their children.

> *Karen: "I think it has made her more anxious about (4) me staying well … … [R: Yeah, and what does she do with that anxiety?] Nothing, that's the problem... Well, she was um I think she was about 7 when she collapsed in the street with chest pain and I had to call an amb…, well, some people in the street said 'you have to call an ambulance' and we had to go to hospital and even the medic in the ambulance said 'I have never seen a child that young with chest pain that bad' and it turned out it was anxiety and she then went to a place in C_____ (area) um (…) To the [Child and Family Consultation Service]. The woman that*

> *she saw was great and she said to Louisa [daughter] 'imagine in your chest there is a box and you have put so many worries in the box and now the box has become so full and that when you first had it open that it caused the chest pain…" (p. 24, l. 1063)*

In particular, parents were concerned about the children developing mental health difficulties themselves.

> *Carla: "A worry is um I hope it is not hereditary, you know, um, because I wouldn't want to see none of my children go through what I've been through, you know, so I just say to them keep yourself well – if you have problems, come and discuss them with me, or my mum or somebody, you know, who you're close to and you know talk about things. My daughter I say, just you know, keep on a level, don't get yourself involved with boys now. Um, you know, get a job, have a career, live your life and then, you know, you can do all that when you get a bit older, you know." (p. 2, l. 57)*

It is important to point out though that not all the parents shared this concern of children developing mental health issues themselves. For example, Gareth stated that he had no concern that his children would develop similar difficulties to him. It is interesting to note that in the study by Jeffery, Clement, Corker, Howard, Murray & Thornicroft (2013) fathers with mental health problems differed from mothers in only one aspect of the study, namely whether they felt that their children were affected by their mental health difficulties. However, due to the low number of men in this study, it is not possible to make any gender distinctions here. Furthermore, Graham did feel that his children had been emotionally affected by his mental health problems.

Overall, this study, in line with much existing research (including Ackerson, 2003a; Colmer, 2005; Diaz-Caneja & Johnson, 2004; Göpfert, et al., 2000; Handley, et al., 2001; Maybery, et al., 2005; Stallard, et al., 2004; Wang & Goldsmidt, 1994), found an intense concern and sadness in parents when considering the impact of their mental health difficulties on their children. This is in contrast to other research (e.g. Boursnell, 2007; Sands, 1995; Singer, et al., 2000; Stormont, et al., 1997; Thomas & Kalucy, 2002) where parents were found not to identify themselves as someone with mental health problems, did not identify their difficulties as an issue for their children or found it generally difficult to acknowledge the impact of their problems on their children.

The current research contributes to our understanding of these contradictions found in the literature by highlighting how acknowledgement of impact was not held as a fixed position by parents, but that parents could move between acknowledgement and no acknowledgement, influenced in the moment by the specific context, the relationship, their own needs, and their judgement of what was required in the situation (e.g. *Faith* above describes no impact on her children within the context of her awareness of her responsibility for them and the fact that there is no one else to take care of them). The context of the research interview can be seen as part of this.

It has been shown thus far that parents often arrived at a position of *Acknowledging awareness* of their mental health difficulties in their children. The transition from seeing the children as innocent and unaware to acknowledging their awareness as well as the potential impact of the parental mental health problems on them could be very difficult and challenging for parents and could involved ambivalence, sadness, guilt and self-blame. Three processes enabled parents to deal with their children's awareness, namely *Recalling family stories of mental distress; Casting children as knowing and knowledgeable* and *Relying on maturity*.

7.2.1.2.1. Recalling family stories of mental distress

In aid of struggling to accept that their children were aware of their mental health problems, many participants recalled trans-generational stories of mental health problems, often vague, confusing and at times disturbing, and often remaining unspoken and incomprehensible. There were formless memories of a family member being hospitalized, families talking together in whispers behind closed doors about particular family members or visits to hospital wards. Most often participants described as children being excluded from conversations about a family member's mental health issues.

> *Carla: "They talked about it. They knew what was going on. You know, as we was little they did not like us to know." (p. 8, l. 351)*

Even though for some, parental mental health issues had torn through their childhoods and profoundly shaped their life paths, information was not forthcoming and understanding was lacking.

> *Ann: "No, I discovered it much later. I think I was 4 when I was put into care – I was fostered when I was 4 and I then got into a children's home from 6-10 and I used to visit her in the hospital and she would come and visit me once a year, like yearly visits and I had I had no idea – I just knew that she wasn't well, I didn't know what it was…" (p. 27, l. 1220)*

Not being given information or explanations about mental health issues in childhood often shaped an intention towards greater openness with their own children about mental health problems.

> *Karen: "…because sometimes parents think you shouldn't tell children, you shouldn't, you know you should keep them, they should not know about these things and they say things and you don't know what they are talking about because you don't know half the conversation and it's like you don't, oh no,*

> *that's an adult thing and you spent your whole life going round and not understanding why things are difficult and you know. And I think things were difficult for my mum but she never said 'this is what's difficult' – maybe I could have helped. But you're just running round in circles, not knowing." (p. 29, l. 1313)*

Thus, many participants were encouraged by their own experiences of not being given information about a family member's mental health issues to have a more open relationship with their own children.

7.2.1.2.2. Casting children as knowing and knowledgeable

Over time many parents came to view their children as knowledgeable and well informed with regard to their mental health problems. Many assumptions were made about what the children understood, based on what they had witnessed and experienced and how they acted, as opposed to what was explored with them in actual conversations.

> *Carla: "Um (1) I've don't really talk about my illness you know, with the boys, but I think as they have seen me and observed me being well and unwell, they've just you know, know, they know. They've just picked it up, you know." (p. 13, l. 556)*

> *Gareth: "It wasn't, it wasn't nice, but they seem to have, they seem to have been robust – they talked about… well, we didn't talk about it, but they have been very supportive recently about other things… (trails off)" (p. 14, l. 615)*

Here it can be seen how parents would refer to what they observed in their children and how they interpreted their behaviour – a look, a gesture, a reaction – as evidence of the children's understanding of their difficulties. However, it was not clear what the children's understanding actually was and whether the children would agree with the parent's view about what was communicated, namely a sound understanding of what was going on and an awareness of what the parent might be experiencing. It appears that the child was left to gradually piece together snippets of information and observation into an understanding – the parent assumed this to be a full understanding, but this was not checked out with the child, and the emotional responses of the child was not discussed.

Thus it can be seen that these assumptions were powerful ways to deter from more direct and detailed conversations about the parent's mental health difficulties and could potentially leave the child with confusion and misunderstanding. Many parents of older children described a wish to have an open relationship with their children and to talk to them about everything related to mental health issues. However, the openness was found to be more relational – feeling comfortable and at ease with one another, being kind, caring, supportive and accepting and talking about everyday concerns. Talking directly about mental health concerns was described much less often and instead communication relied on non-verbal cues, hints, little bits of information and a general connecting around difficult moments. This links to other research findings that children learned about their parent's difficulties mainly through observing and experiencing (e.g. Bromley, et al., 2013; Garley, et al., 1997; Mordoch and Hall, 2008; Riebschleger, 2004; Totsuka, 2010).

As reported in the literature review though, most studies reported that children felt that they had little information about their parent's difficulties and the help they received, struggled to understand the parent's problems and wanted more information (e.g. Bromley, et al., 2013; Farzin, 2008; Fudge & Mason, 2004; Garley, et al., 1997; Handley, et al., 2001; Meadus & Johnson, 2000; Mordock, 2010; Östman, 2008; Riebschleger, 2004; Shah & Hatton, 1999; Stallard, et al., 2004, etc.). Thus, witnessing and experiencing is likely *not* to equal understanding or coping in the way that the parents appeared to assume or hope for in this study, and it seems clear that this assumption that the children knew and understood could actually hinder the development of such understanding.

7.2.1.2.3. Relying on maturity

Within the context of acknowledging their children's awareness of their mental health difficulties, children were also often described as particularly 'mature'. Seeing the children as mature allowed the parents to feel more comfortable with their awareness that their children knew about their mental health problems and with sharing information about their mental health issues with their children.

> *Carla: "They um have a lot of understanding. They're very mature for their age* [13] *as well, I feel, you know, because the other day they were saying to me 'mum, we're going to get a job soon, a part time job, Saturdays and Sundays.' So I said 'that's good', you know." (p. 1, l. 37)*

> *Ann: "…we were talking yesterday actually about how um one of her friends said that she actually looked up to her, like as a role model, like because she's so um mature in some ways. Like even though she has a lot of fun, enjoys herself she still um got lots of maturity about her about the way she thinks about other people, cares about other people…" (p. 1, l. 30)*

Here we see that with the growing awareness that their children noticed and were affected by their mental health issues, parents moved from casting their children as innocent to casting them as mature, and that this shift was independent of the age of the child. This appears important in relation to seeing their children as able to deal with the complex knowledges related to the parent's mental health issues.

Thus *Recalling family stories of mental distress, Casting children as knowing and knowledgeable* and *Relying on maturity* enabled parents to deal with the awareness that their children knew about and were affected by their mental health issues.

7.2.1.3. Judging readiness: a summary

It has been shown here that parents wish to protect their children by hiding their mental health problems from them. However, as the children grew older and they began to ask questions, parents could not avoid acknowledging that they were aware of the parent's difficulties and that they witnessed actions related to mental health issues. Parents then had to develop ways to talk about their mental health struggles, but continued to have ambivalence about this. They continued to try to protect their children and felt concern and sadness about the impact of their mental health difficulties on their children. Therefore, the parents described the children more often initiating the conversations about parental mental health problems through their questions and actions. It was very rare for parents to describe 'telling events', where they specifically explained, for example, a mental health diagnosis to their children in any detail, although there were a few such examples. More often a general and vague 'naming' of the difficulties as 'mental health problems' occurred. Parents dealt with their acknowledgement of their children's awareness of their mental health issues through recalling their own need as a child for more information about mental health problems in the family, casting their children as knowing and knowledgeable and through viewing their children as particularly mature.

The findings up to now, to some extent, mirror the findings of Montgomery, et al. (2006) as described in the literature review. These authors also described a process whereby the mothers in their study wished to protect their children from their mental health difficulties and protect their relationship with their children by hiding their difficulties from them. Their study also captured the struggles and contradictions that came with trying to maintain this position, leading to a realization that it could not be maintained. Mothers in that study then sought treatment, hoping to learn how to be with their children more authentically, including finding a way to share their experiences with their children. However, in the current study it was found that even though most parents arrived at a similar position, this proved not to be an endpoint or resolution of the dilemmas of talking. Rather, a number of challenges continued for the parents, often pulling them in different and contradictory directions in relation to talking to their children about parental mental health issues. This will be further developed in the next social process, namely *Navigating reciprocity*.

7.2.2. Navigating reciprocity

With acknowledgement of awareness there was a relational shift towards reciprocity. Where as with younger children parents were attempting to hide, protect and maintain innocence, there was now a shift to cast the children as more active agents in shaping the shared understanding of the parent's mental health issues and managing it in their lives. However, despite this shift, parents' accounts in relation to their children's knowing remained filled with contradiction and ambivalence and parents took up different positions at different times.

The different positions Carla takes at different points during the research interview is here used as one illustration of how positions shifted and changed.

> *Carla: "I have never hid nothing from them. They've been there throughout, you know, they've seen you know all of it and heard about all of it, you know." (p. 17, l. 737)*

And,

> *Carla: "Well, (1) I don't hide nothing from them, from my children. 'Cause I'm very open with them and they're open with me as well, you know. You know, well I hope they are. And we do talk a lot, we have a good communication, you*

> *know. And um, if they have any questions, they would ask me, you know." (p. 16, l. 703)*

And,

> *R: Do you think there might be questions that they have?*
>
> *Carla: If they have, they haven't asked. And I always say to them feel free to tell me anything, you know.*
>
> *R: So you really encourage them to… (talks over)*
>
> *Carla: Yes, to talk to me and I say if you can't talk to me then talk to my mum, or talk to somebody, you know, they've got cousins, they've got aunties, they've got others. You know, we're a close-knit family. So they can go to somebody and say whatever's bothering (them), you know. (p. 13, p. 507)*

But elsewhere in the interview,

> *R: Has there been times when there have been specific things that you have wanted to tell them … or given them more information about?*
>
> *Carla: Hmm, sometimes. But I don't wanna unload my problems onto them, you know, 'cause I just want them to grow up as normal as they can, you know. I don't want my illness to affect them in any way. Or for them to be afraid of it or of getting it or you know whatever, you know… (p. 13, l. 587)*

And,

> *Carla: "I do encourage them to take their education and um, go to university when they leave school and get a good job you know. And just be somebody, you know. And not really let my illness affect them as young men growing up." (p. 2, l. 45)*

Thus, it is argued that a number of social processes interact in a complex way to continuously invite parents into different, often contradictory positions in relation to talking about mental health problems. The social processes constructed as shaping this ambivalence and contradiction for parents were *Maintaining their lives together* and *Protecting and being protected*.

7.2.2.1. Maintaining their lives together

In the parents' view, both parents and children worked hard to maintain their lives together. Parents deeply valued their relationships with their children and often it provided them with hope and happiness within challenging times. Two social processes were important in *Maintaining their lives together,* namely *Wishing to stay close and connected* and *Striving for normalcy and maintaining the everyday.*

7.2.2.1.1. Wishing to stay close and connected

Almost all parents reported that it was extremely important to them and in their view to their children to maintain a close bond and remain connected. Parents deeply valued their relationship with their children and often, within the context of their challenging lives, their children were what gave meaning to their lives and made it worth carrying on. At times their children were all they were living for, and many felt that having the children kept them well. They were also intensely aware of the responsibility they had for their children and wanted to stay well to look after them.

> *Izzy: "She cheers me up. She's the light of my life, you know, she's like the light – if she wasn't here, like I said, I would kill myself because I just don't see the*

> *point of what's going on. I can't live like this every day in day out, day in day out, just getting more intro… in my own head." (p. 17, l. 771)*

However, mental health issues could at times interfere with their connection with their children.

> *Karen: "I think it's much better than it was. To be honest, I wasn't that connected to Louisa [daughter], although I would not say that in front of Louisa, but in the beginning I found it very difficult. But since I've had the therapy it's made a big difference to me. It has been really worth it, it's made a big difference. And the medication, it keeps me calmer and N______ [other personality] is not such a problem. I don't get that completely overriding unable-to-cope-with anxiety, …it's better, which means I can stay calm, which means I can enjoy things Louisa is doing." (p. 29, l. 1296)*

Parents felt at times that their mental health issues threatened their relationship with their children, that they could lose this connection, for example due to what the children would witness when they were experiencing intense distress. Therefore, this closeness needed to be robust and endure through difficult times related to the parent's mental health issues and other life stresses. Underlying all considerations for many parents was the fear of losing their children or losing their relationships with them. This was at times within the context of child protection concerns, but often also where parents were concerned about the choices the children were making that might involve moving away from them (either moving away emotionally by not communicating, or physically, e.g. by going to live with the other parent).

> *Ann: "(2) um (2) well it's just when you are actually ill, like obviously when you are psychotic, then it's impossible to be a mother… you are just … and I think*

> *um (1) that was something that upset her as well. I know that she, there was one point when I wanted her to come home – she was actually with her with um her dad's partner and I want… living at their house and I wanted her to come home, I was a lot better and she felt that I wasn't and that I was that I would get angry um and I wasn't the mum that she knew, that I was an angry mum and I I felt sometimes that she that she was manipulating the situation and that I was, I felt that I was well, so it was difficult." (p. 11, l. 484)*

Parents were very grateful and relieved that their relationship with their children could withstand their mental health issues.

> *Gareth: Um I think that was (3) a major thing [becomes upset and is close to tears] sorry. (11) I think there's more to it for them, because it was pretty horrible last time, so, for both of them, but they don't stop loving you when the problems come. (p. 16, l. 729)*

At times the parents experienced that the mental health difficulties had brought them closer to their children and had strengthened the relationship.

> *Omette: "… and also when you go through something difficult and you have only your little, you know, only your little baby with you then you two become very, you know, very close, it's the only thing you have really …" (p. 5, l. 143)*

At times talking could enhance this closeness. Parents became more comfortable with their children's need for understanding, redefining it as a way to maintain the relationship, protect their child and keep close. For some parents being open about their mental health difficulties was seen as a virtue, a sign that they were good and caring parents, not hiding things from their children and not misleading them.

> *Izzy: "It's made us closer – real close – very plain speaking and open to each other..." (p. 14, l. 613)*

When closeness and staying connected were threatened by periods of acute mental distress and hospitalization, tentative talking could enable reconnecting after these difficult times.

> *R: Do they ask you about what happened or comment on what happened?*
>
> *Beverly: They just ask me if I'm alright, 'are you okay, mummy', and I go 'Yeah, I'm fine, I'm alright' (spoken quietly, tenderly).*
>
> *R: So there's just a bit of them making sure you're okay afterwards? That's the way you sort of… 'cause it's moving on from that sort of big conflict, emotional bit, ambulance, police, everyone, sort of situation and then having to, to reconnect again with each other…*
>
> *Beverly: Yeah. (p. 16, l. 700)*

Where talking enhanced closeness and connection, humour often played an important part. Very difficult things could be talked about in a funny and playful manner and this enhanced intimacy. This way of talking also appeared to be helping parents and children make sense of their challenging experiences, enabling them to have a more shared and coherent understanding.

> *Ann: "… but Sarah [daughter] used to say sometimes that you couldn't tell the patients from the staff (laughs) which I don't know that that's a bad thing (laughs heartily)" (p. 23, l. 1042)*

> *Dayo: "Yeah, we're sitting here (in living room in her flat) then I was telling them that and we were like joking (both laugh). Sometimes when I was ill for the third time, I was dancing, I was dancing, then they they were seeing me dancing then when I get well they remember me 'mum, you know what what you was doing? You were dancing'. You know the song [both laugh] and they started dancing the way I was dancing! And then I was laughing. [R: Everybody laughed?] Everyone laughing." (p. 15, l. 655)*

Closeness did not always need words to be communicated though.

> *Izzy: "She's my star. She's my little star. She copes with… like sometimes I wake up and she says 'do you want…', 'come on mum, wake up – bacon and egg' (Laughs) [R: Laughs] Make me breakfast – made a load of mess, but made breakfast. Yeah." (p. 6, l. 270)*

Furthermore, talking was not always the way parents thought closeness could be maintained – at other times not talking was a way to remain close and connected to their children.

> *Mualla: I tried to make her forget about this.*
>
> *R: How do you do that?*
>
> *Mualla: By hugging. (p. 15, l. 458)*

Thus, parents highly valued their parenting role and wished to stay close and connected with their children and this fits with the wider literature on parents with mental health issues and also with the literature on children of parents with mental health difficulties who frequently describe a wish for and the presence of close meaningful relationships between parents and children (Bromley, et al., 2013; Gorin, 2004; Mordoch and Hall, 2008; Östman, 2008; Van Parys & Rober, 2012).

However, in the current study parents described diverse views on how to maintain this closeness with their children. Parents described how they and their children at times tried to maintain the connection through talking (e.g. through openness about their difficulties, or through using humour to process traumatic or painful experiences and work towards shared and more manageable memories), while at other times parents and children hoped to maintain the connection through not talking, or expressing closeness in non-verbal ways (e.g. hugging and acts of kindness) rather than in words. Where talk was used to maintain closeness, talking most often did not happen in 'grand narratives' of explaining, but rather in the 'small stories'[4] of the everyday and the ordinary (Tovares, 2010). These small pieces of talk about the parent's difficulties, woven into on-going family conversations, maintained intimacy and were threaded together towards constructing a more coherent family understanding of parental mental health difficulties (although they could contain many gaps and contradictions).

The closeness described here between parents with mental health difficulties and their children is significant as it has been found that the ability of family members to forge satisfying relationships within the context of mental health issues greatly affects the degree of burden and stress, and that strong family bonds and familial commitment

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[4] 'Small stories' is a concept borrowed here from Narrative Analysis (Georgakopoulou, 2006,2007; Phoenix, 2008; Tovares, 2010). Families use small stories that are embedded in everyday naturally occurring interactions as one means of contributing to the construction of a shared family identity, a seeming "patchwork of small stories" (p. 3). Small stories focus on the stories we tell in passing, in our everyday encounters with one another – focusing on small stories allows attention to be paid to under-represented narrative activities, such as tellings of ongoing events, deferrals of tellings, and refusals to tell. Also, it accounts for materials that are not neatly storied into a beginning, middle and end or that appear incoherent (Phoenix, 2008). Within Narrative analysis "small stores are viewed as important sites for identity work" (Tovaris, 2010, p. 2).

may moderate burdens associated with care giving (Rose, et al., 2002). However, the meaning and implications of this closeness is important to consider. Concern has been expressed about some contexts for this closeness, pointing to lax or permissive approaches to discipline as well as a caring burden for the children that at times accompanied this special sense of closeness (Ackerson, 2003b). Ackerson (2003b) also expressed concern that the parents' view of their relationships could at times appear excessively idyllic, thus maybe not fully acknowledging the impact of their mental health issues and the potential lack of appropriate boundaries between parent and child.

In the current study, it was clear that the parent was not able to maintain an idyllic conceptualization of the parent-child relationship over time, but had to acknowledge the impact of their mental health issues on their children and on the relationship. Closeness and connection needed to withstand the onslaught of the impact of severe and enduring mental health difficulties again and again. It was therefore based on mutuality in difficult times, rather than a one-directional caring relationship.

> *R: …and still prioritise their needs and what she needs from you and looking after her – how do you do that?*
>
> *Izzy: Well sometimes I don't think I always prioritise her – sometimes she just needs to go beside, walk beside me, because I can't… sometimes that's what she has to do, but most of the time I try to meet her needs. (p. 26, l. 1183)*

Children were seen to help carry the burden, make do, share the responsibility, get on with it and offer companionship for their parent alongside the parent's love, nurturing and care.

7.2.2.1.2. Striving for normalcy and valuing the everyday

A second social process that enabled *Maintaining their lives together,* was *Striving for normalcy and valuing the everyday* which was an important part of the relational social processes that impacted powerfully on talking and keeping silent in the family. Parents felt that they and their children appreciated sharing everyday tasks related to parenting and family life, free from having to consider the mental health issues. Being able to focus on school related events, future plans, exams, boyfriends and the 'normal' activities of meals, getting ready for the day, etc. became valued and significant. One powerful way parents and children achieved this, according to the parents, was to frame good periods as having come through the difficult times and having now left these behind them. This was often the case despite the parent regularly experiencing a return of psychological distress and where there were cyclical patterns of mental health problems.

> *Carla: "I think what they appreciate with me is that I can still look after them, you know. I can still get out of my bed every day and make, see they're at school and on time with their coming (home) there's a meal on the table in front of them and um I still maintain all, I do all that. You know." (p. 11, l. 465)*

When mental health issues challenged this normalcy and the joys of the everyday were threatened, parents worked hard to try and hold on.

> *Izzy: They can still lean on me – I'm not all the time um (1) indisposed. Just sometimes. And summer's coming, so it should be better. It's brighter outside.*
>
> *R: So your mood cheers up a bit when it's summery (talks over)*

> *Izzy: Yeah, when it's summery. I can take Cassie [daughter] to the park and that then. But then it's just me and her, but I'll take some cousins, some little cousins – she needs someone to play with. (p. 21, l. 925)*

When the normalcy was temporarily lost through mental health difficulties, both parents and, according to the parents, also their children, worked hard to regain it and valued when they could experience it again. Often, after difficult times, parents (and children too, from the accounts of the parents) appeared relieved and grateful for the normality of everyday routines, for the opportunity of talking about the mundane tasks and aspects of everyday life.

> *Dayo: "…when I am getting better, like now getting better, they are happy now, happy (inaudible) They go to school, they come back home, 'mum, what are you doing? What are you doing during the day? What did you do? What is it for eating?' such things, yeah. I can make food for them, yeah yeah." (p. 16, l. 688)*

There were times when normalcy and the everyday remained unavailable for extended periods of time, or in specific areas of life never became available, due the specific nature of the parent's mental health issues. Under these circumstances parents experienced that both they and their children missed it and longed for it.

> *Karen: "I think it would have been nice to do some things with Louisa [daughter], like maybe sit in a coffee shop with a coffee, 'cause I don't drink any hot drinks, I did not eat any hot food for five and a half years so yeah, maybe sitting in a restaurant with her, or buying something with her of um… (1) like having what's that make-up thing called, like having a facial done." (p. 28, l. 1253)*

Talking and keeping silent both could become part of how normalcy and the everyday was achieved, on the one hand the children inviting the parent into normality, on the other the parent suggesting normalcy to the children.

> *R: Would the children say now still that they think that their mummy is a bit quiet? Or tired?*
>
> *Hannah: Um (1) yes, sometimes they ask me 'mummy why are you sad?' (becomes tearful).*
>
> *R: Um. Um.*
>
> *Hannah: Now the second one can also ask now 'oh, mummy, you look sad'.*
>
> *R: Um-hum. What do you say?*
>
> *Hannah: (1) I just say 'no. I'm not sad'. She'll she'll bring some schoolwork and she'll say 'okay, then help me with this' (…) Yeah (smiles) yeah, then I start doing her homework. (p. 19, l. 841)*

Wishing to regain normalcy and return to the everyday after times of crisis could be a strong deterrent against talking about mental health problems.

> *R: So when when the children saw that you were not here and then they came to visit you in hospital, how did they understand what was going on?*
>
> *Hannah: They didn't want… I didn't want them to (1) um, I didn't want them to think too much about me. I just wanted them to concentrate in their schoolwork. (p. 10, l. 421)*

Thus, parents felt that they and children both worked hard to maintain or regain the normal and everyday or what Shotter (2008) calls the “amazingness of the ordinary” and this could often strongly discourage talking about the parent’s mental health problems.

However, mental health difficulties often threatened living a normal and predictable life, and the ordinary and taken-for-granted flow of life could easily be lost. Some participants described that, despite their hopes and best intentions and their children’s persistent efforts, they were unable to find or hold on to normality or the everyday in some areas or periods of their lives with their children. This could lead to the mental health issues remaining a focus of family life and could lead to confusion or distress for the children. Families therefore had to learn to live a life and develop notions of ‘normality’ that accounted for the mental health issues. This is in line with earlier research (e.g. Fjone, Ytterhus & Almvik, 2009; Rose, et al.; 2002; Scheyett & McCarthy, 2006 and in particular Knafl & Gilliss’s (2002) synthesis of research into families living with chronic illness).

7.2.2.2. Protecting and being protected

In addition to *Maintaining their lives together,* a further social process impacting on *Navigating reciprocity* was *Protecting and being protected.* Parents described a mutual vigilance for them and for their children, constantly monitoring one another and working to mediate the impact of the mental health difficulties on one another and on themselves. At times this involved the parents *protecting* their child. However, at other times it was about the parent *being protected* by the child and even *requiring protection* from their child due to the nature of their mental health problems.

7.2.2.2.1. Protecting

A first social process within the context of *Protecting and being protected* was parents *Protecting* their children. Parents often expressed a strong wish to protect their children and moderate the impact of their mental health difficulties on them. At times this might be more an intention, wish, or preferred position, but might not always materialize. Alternatively, there were at times a move between a position of protecting their children and not being able to protect them, as influenced by the context.

> *Karen: "But I hope that things can be a bit different, like I am trying to change things so that she does not get over-anxious about things I would have gotten over-anxious about as a child, like going to a movie or buying herself something. (R: Is she anxious about doing things like that?) She used to be… she's getting better, but she used to be terrible and I try to say 'yeah, you buy that, yeah, go go go for it'. (R: Okay) So she does get very anxious, but I think it's just before I used the medication I used to be like 'do you really need it?', you know, all those sorts of things, so I think there is still a little bit of that in her of 'do I really need it?'…" (p. 26, l. 1174)*

At times parents used talking to try and determine what children made of their experiences, how they had been affected or to reassure themselves about their children being well and not hurt or 'damaged' by their problems. Parents also used talking as one way to mediate the impact of their mental health difficulties on their children and protect them where possible. This could take the shape of parents reassuring their children, providing them with information or providing them with space to talk about their experience of the parent's difficulties and the impact on their lives. Other times it involved providing advice on staying emotionally and psychologically well. When children were reluctant to talk to the parent, parents were worried about what they were hiding, about how they were doing and about them 'bottling things up inside them', which they thought could potentially lead to mental health problems.

> *Izzy: "I think Billy [son] was more affected. [R: Yeah?] Yeah. But he don't talk, he's introvert, he won't want to talk to no one. That's why I now at an earlier stage asked for someone for Cassie [daughter] to talk to. Because my son experienced me going through an addiction. [R: Okay.] You know what I mean? Um, so (1) he's probably got a lot of resentments, angry, you know what I mean? [R: Um.] And not able to express it. I want him to, I want him to be able to, what I want Cassie to do is to have someone to talk to, for her to express any frustrations or anger, if she's angry with me and she won't show it to me. You know what I, she's not showing it, 'cause she does not want to upset me, but I want her to be able to get it off her chest, you know." (p. 3, l 121)*

At other times not talking was seen as the way to protect children, to not let the parent's mental health issue become the focus of their lives.

> *Gareth: "…and with the children I left it for a while and I wasn't going to, I didn't want to say (2) … … No I don't want to remind them." (p. 21, l. 929)*

In addition to parents wishing to protect children from the impacts of their mental health issues, at times parents also had a sense that they themselves could have a negative impact on their children.

> *R: If I was to ask you about … these … these times when… when you have sort of reached the end of your tether and when people have been interfering and*

> *major things have happened, and then other people come in and say 'she's ill' umm – what do you think your children have made of those times? Beverly: (1) um, a bit upset.*
>
> *R: They get a bit upset?*
>
> *Beverly: Yes. Scared.*
>
> *R: Yes? What might scare them?*
>
> *Beverly: Afraid, they get afraid of me… [appears close to tears] (p. 9, l. 368)*

Therefore, parents felt at times that their children needed protection from them, rather than the mental health problem. There was a sense that, as 'the problem', as 'the cause' of the child's difficulties, they were in some way harmful or even 'toxic' to the child, in some way 'contaminated' as a parent, and therefore could somehow 'contaminate' or damage their child, thus needing to protect the child from themselves.

> *Karen: "I worry that I am a bad influence on her, (1) that I will be detrimental to her long term. [R: Um.] Health, happiness, mental state (sad little laugh) [R: Um.] And that she um yeah that it's not good for her around me." (p. 4, l. 159)*

This sense of potentially being a danger to their child and their child needing protection from them could potentially lead to the parent distancing themselves from the child and could greatly inhibit the parent experiencing themselves as someone who could or even should assist their children in their meaning-making, thus powerfully inhibiting talking.

Therefore, parents worked hard to protect their children, but were aware that at times they were unable to do this and even experienced themselves at times as what the child needed to be protected from. Where both talking and not talking were at different times seen as ways to protect, protection from oneself however could be distancing and silencing.

Finally, under *Protecting* there were times when the children appeared to be protecting themselves by not talking to the parent about parental mental health issues. Parents found that difficult and it made them concerned about their children's wellbeing.

> *Beverly: "I try to, but it's like she don't want to hear it. I've tried many a times, many occasions, I would go in her room and I sit on her bed and I want to like like the way how my sister died, she was 34 when she died, you know, and every time I bring it up, bring it up – it's like she don't want to hear it, she don't want to know. So I just, I just leave it, there's no point, you know." (p. 13, l. 567)*

Thus, according to the parents children appeared at times to use distancing as a coping strategy. This stands in contrast to the process described above of wishing to stay close and connected and suggests that at times children had to make a very hard choice between wanting to stay close and connected on the one hand and protecting themselves on the other. Thus, distancing could be a coping strategy for children in difficult times. This fits with other research (e.g. Badger, 1996 cited in Rose, et al., 2002; Jeffery, et al., 2013; Riebschleger, 2004).

7.2.2.2.2. Being protected

A second social process within the context of *Protecting and being protected* was *Being protected.* Due to the nature of the mental health issues parents at other times hoped for or required the help and protection of their children. Also, it appears that children's love for their parents, their worry about the situation and their wish to be helpful led to them at times working hard to check up on the parent and mediate the impact of their mental health difficulties on their parent and on the life of the family.

Children were experienced as observant about their parent. They were watchful and vigilant, noticing when the parent was struggling, making attempts to help and support, putting their own needs in the moment aside. The parents were aware that the children were taking on this responsibility, but mostly found it helpful. At times they felt guilty or sad about their children finding themselves in this position.

> *Mualla: "She doesn't seem like, I mean … If there's sad music, a kind of song, when I was crying she just stopped the music … … She doesn't want to see me like that, crying and sad." (p. 13, l. 416)*

> *Carla: "Well, we just get on, you know, we get on with it now. But um what they do when I am feeling a bit tired or whatever they say 'mum go and have a lie down' and they'll just be downstairs watching telly or on the computer or whatever – they don't make no noise, they just let me rest because they know I come back down and then I do what I have to do you know and even if the dinner is cooked, they will serve their dinner and eat. You know." (p. 12, l. 517)*

Parents noticed children asking many questions about the parent's mental health and how they were doing as a way to check on the parent. Often, they would then try to reassure or help the parent.

> *Izzy: It is something that I've had to explain to her 'cause there has been times when I've not been able to go out and that, so I've had to say 'Cassie [daughter], I don't feel well. I'm depressed' and when I'm depressed I cry all the time. So (1) it's obvious I'm depressed. She sees me cry and say 'Oh, mum, don't cry…'*

> *R: If she has seen you cry she would have worked it out, not wanting to go out and that sort of thing?*
>
> *Izzy: Yeah. Yeah. She comes and cuddles me up, yeah, she comes and comforts me. (p. 17, l. 734)*

This included where the children were noticing and checking whether the parent had taken their medication.

> *Dayo: "You know I say 'I'm not feeling well, when David [youngest son] he comes sometimes and he say 'mum'. 'Cause when I'm a little bit upset, yeah, I'll be crying and she come 'mum, don't cry – you want to take your medication?'. He's only five…" (p. 12, l. 512)*

At times the talking was about the child helping the parent make sense of their mental health difficulties, rather than the other way around. The parent might be confused or unable to remember what happened during a period of mental distress, and the children, having been witnesses to what happened, may be the holders of these memories and may help the parent fill in the gaps – this could be seen as a process of mutual sense-making and processing of traumatic or difficult experiences.

> *Ann: "I mean some things are very clear in my mind like I can remember that I can remember dreams that I had while I was in the hospital, but other things are not clear like* Leon *[partner] and Sarah [daughter] would tell me that they would take, that I went down to M___ Street with them and I would rush up to people and say oh, where did you buy that jumper or where did you buy that coat and so being very over-friendly and talking to like say an old an old man was sitting on a bench I would be chatting away to the old man on the bench and being very talkative…" (p. 6, l. 265)*

Some parents also described how silence on the part of the child could be attempts at protecting the parent.

> *Carla: It's upsetting, because I was putting my children at risk as well as myself you know [upset].*
>
> *R: Do you think the children remember that as well?*
>
> *Carla: I've never asked them and they don't discuss it with me. No. I do – actually, it isn't, I do…I say to them 'do you remember when I did this or that' and they say 'no' – because they were about 6 years old at the time, you know, if they remember, probably they do not want to upset me.*
>
> *R: What might they be worried about?*
>
> *Carla: Maybe that it might upset me again, and um I might get ill. (p. 10, l. 442)*

Thus, here we have descriptions of the constant vigilance of the children and the hard 'emotional work'[5] they were doing to protect the parent from the potential negative effects of the parent's mental health issues. Again, there was not a fixed position on talking and not talking within the context of *being protected,* but rather parents and children would, depending on the context, their resources at the time and their interpretation of all the factors involved, at times prefer or opt for talking while at other times for keeping silent as a way for the parent to be protected.

Sometimes the initiating action was the child asking a question, maybe seeking understanding, maybe needing comfort or reassurance or requiring action on the part of the parent (e.g. wanting to understand crying, needing help with homework).

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[5] Emotion work is a term first used by Hochschild (1979) to describe unpaid emotional work that a person undertakes in their relationships with family and loved ones. Hochschild (1990) distinguished between two types of emotion work, namely evocation and suppression of emotion, and this could be done through cognitive, bodily and expressive techniques.

However, upon receiving a response, seeking stopped and communication became about the child reassuring and supporting the parent. No further questions were asked and the child did not appear to express a need for comfort or care in the face of at times frightening information, or anger or frustration at not being able to have their needs met. Children appeared to become focused on trying to protect the parent.

Parents in this study seemed to value this care and support received from their children, and did not frame it as a problem. However, at times they expressed a sense of guilt, shame or sadness. This finding of protection and care by children of parents with mental health difficulties is in line with most previous research (e.g. Aldridge, 2006; Bromley, et al., 2013; Handley, et al., 2001; Maybery, et al., 2005; SCIE, 2008b; Tunnard 2004; Van Parys & Rober, 2012).

Children who provide care and nurturing to their parent are often described in the literature as 'young carers' (Aldridge, 2006; Aldridge & Becker, 2003). Aldridge & Becker (2003) note that the literature on young carers has recently started focusing more on the less tangible aspects of caring – the 'being with' rather than the 'doing for' someone. This seems significant in the context of the current findings. In the literature such care-giving has been considered both a source of risk as well as a protective factor that provides children with a constructive family role during times of stress (Gladstone, et al., 2006).

This care-giving role taken by young carers is often debated in the literature. Within systemic literature this role for children could be described as 'parentification', but it could also be framed as reciprocity when considered within the wider findings of the current study and employing a narrative frame. It has been argued that 'parentification' of children should not be considered an inherently problematic dynamic (Byng-Hall, 2002, 2007; Van Parys & Rober, 2012). Rose & Cohen (2010) in a meta-synthesis of findings of qualitative research into experiences of young carers reported on the importance of whether caring is integrated into the emerging identity of the caring young person; and Jurkovic (1997) cited in Rose & Cohen (2010), described adaptive care-giving as relying on recognition of the child's contribution and the extent and duration of the care-giving underpinned by notions of reciprocity and balance of care in the relationship.

7.2.2.2.3. Requiring protection

A final social process in relation to *Protecting and being protected* was *Requiring protection.* Due to the parent's mental health difficulties, there were times when the parent needed the children to notice, understand and respond caringly to their mental health needs. At these times the parent hoped for and required the child's support.

> *Mualla: "You can't hide from the child … … It's better if the child accepts you as you. Maybe then she doesn't make her mother angry … I want her to be understanding … … I want her to understand my pain but of course I can't …expect that she can understand all the pain that I feel." (p. 16, l. 498)*

When the child noticed and responded in a supportive way to the parent's need for care, parents framed this as the child being 'good'. Children were framed as helpful when they noticed and responded to the parent's mental health difficulties by not being troublesome.

> *Carla: "They're thirteen now, so they're much older - they've come through all the other you know, the other stages, you know, so now, I think they know. They don't try and um pressurize me." (p. 12, l. 540)*

Parents found it challenging when the children did not respond as they needed them to. Mental health difficulties became the context within which this was negotiated.

> *Jiyan: "I try to tell him that he knows as well that I have a sleep difficulty – I keep walking around the house instead of being in sleep, being in bed and also I am in pain um... As a respond I get, as a respond he tells me I am psychologically ill and I need to be at (the psychiatric) hospital." (p. 8, l. 320)*

Talking about the parent's mental health difficulties thus here had the function of regulating the child's behaviour.

> *Beverly: "Yeah, umm, 'cause when I did umm, did umm get upset, you know my daughter she like (1), it's like even her, even she was, the way she was acting, was getting on top of me as well, 'cause she wasn't, she didn't wanna hear what I had to say, 'cause it was my life, it's me. She's here because of me, not because of anybody else – I'm her mother so she should listen to what I have to say and not take other people's advice about my life, 'cause they don't know. It's <u>me</u>, it's my life, <u>I'm here, ain't I</u>! So she's got to listen to me, and she don't want to listen to me [very animated, getting upset]." (p. 14, l. 604)*

Where the parent felt that the child was not understanding, more severe explanations and actions could follow to ensure a full appreciation of the mental health difficulties and the relational implications or demands that follow from this for the child. At times this could take a worrying and disturbing turn.

> *Jiyan: "Once I said I would go up to upper floors to jump off – the husband and the son stayed up all night and watched me." (p. 8, l. 341)*

This could leave the child overwhelmed and isolated. Sometimes, even though they required and relied on their child’s support and understanding, parents felt guilty.

> *Izzy: I wish I could see Lydia [support worker] more often.*
>
> *R: Is it? Yeah?*
>
> *Izzy: ‘Cause sometimes I want to talk about… I want to talk and there’s no one to talk… I can’t talk to Cassie [daughter]…*
>
> *R: Um.*
>
> *Izzy: … ‘cause that’s the problem – I‘m an adult and she’s a child and she’s only keeping adult company. So when I talk to her I need to constantly remind myself that she’s a child.*
>
> *R: Um. So there are things that you want to talk about that you feel you can’t talk to her about?*
>
> *Izzy: Yeah. Yeah. And sometimes things I do talk to her about I think I shouldn’t have talked to her about. (p. 22, l. 972)*

Here it appears that the mental health problem is presented as a relational negotiation where the parent wants to be clear about why they are unable to do certain things or need the child’s care and understanding, or for the child to relinquish expectations. The mental health issue is presented as a context for how the relationship can work. It is a powerful strategy as it is presented as non-negotiable and the stakes can be very high, e.g. the threat of return of the ‘illness’ or of suicide. Charmaz (2002) has stated that an aggressive ‘sad tale’ can be used strategically to evoke sympathy, guilt, and help within relationships. However, this strategy risks driving people away, particularly when anger and resentment form the tone of the story (see e.g. Beverly or Jiyan above).

Following such periods, it could be difficult for the parents to re-establish themselves in the parental role and to regain closeness and connection. Discipline could also be more difficult.

> *Jiyan: "He appears to be um persistent and [translator checks word in Turkish with participant] stubborn. You know, there are some children, other children who are mild and approachable, which my son is opposite. If we say something he tends to do otherwise or something different." (p. 3, l. 98)*

Thus, at times talking could be about the parent *Requiring protection* from their child. Parents could negotiate aspects of the parent-child relationship through reminding the child of their mental health issues or inviting support or care from their child or by warning of dire potential consequences. At times the stakes in these conversations could be very high. Also, closeness and connection could be compromised and the parental role undermined. Therefore, despite the parents being aware that they *required protection* at times, they were also conscious of the potential relational implications of this.

7.2.2.3. Navigating reciprocity: a summary

> *"First she makes me angry then she makes me camomile tea." (Mualla)*

Parents described here how they and their children worked at *Maintaining their lives together* through *Wishing to remain close and connected* and *Striving for normalcy and valuing the everyday*. However, these parents and children also worked at *Protecting and being protected,* with parents working hard at *Protecting* their children (and children occasionally at protecting themselves), while also being aware that they were at times *Being protected* by their children and acknowledging that sometimes they were *Requiring protection* when they were overcome by the intensity of their mental distress or the requirements of parenting. Thus, relationships could move between closeness and intimacy built on warmth and loving connection and an intense vigilance and closeness forged by the mutual need to protect. Importantly there were times when the parent experienced themselves as ‘toxic’ or detrimental to their children and therefore this could be silencing or distancing. Similarly, there were also times when the children felt overwhelmed by the parents’ difficulties and therefore distanced themselves from the parents in order to protect themselves.

Thus, closeness and protection are constantly changing and being re-negotiated. It is clear that at times these goals could be in conflict with one another and both parents and children would have to make choices in the moment between being close and protection. The interaction between these two processes of *Maintaining their lives together* and *Protecting and being protected* could therefore lead to ambivalence and challenges in the relationship and contradictory positions in relation to talking and staying silent for both parents and children.

Some specific relational implications were described. At times the wish for normalcy and closeness took parents and children away from more open conversation and undermined the development of understanding. For some, when the parent had lost the ability for a period of time to parent due to mental distress, it was difficult to return to the parent-child relationship for all involved. Furthermore, even though disruption of closeness and connection could often be repaired following a period of crisis, painful memories of frightening and disturbing experiences could continue to haunt the relationship. The parents found it particularly difficult when they sensed that their children needed protection from them or when their children felt the need to make distance as a way of coping with challenging times.

These findings highlight the interwoven links between positive and negative times in relationships where parents experience mental health difficulties, as has also been shown elsewhere in the literature (Breheny & Stephens, 2011; Coldwell, et al., 2011;

Dulwich Centre, 2008; Pluznick & Kis-Sines, 2008). These twists and turns, ebbs and flows are constantly playing out through telling, talking or keeping silent.

The findings have been related to the wider discussion in the literature on young carers. This study invites a consideration of 'young caring' and 'parentification' literature within the context of the other social processes described under *Negotiating mutuality* – this has highlighted relational complexity and the challenges and contradictions children might experience in this regard. The clinical implications of this will be returned to in Chapter 9.

7.3 RELATIONSHIPS BETWEEN THE PARENT-CHILD DYAD AND OTHERS: IMPACT ON NEGOTIATING MUTUALITY

For the social process of *Negotiating mutuality* relationships other than the parent-child relationship impacted on talking and keeping silent and was part of *Judging readiness and Navigating reciprocity*. Again, complex factors interacted and at times could lead to confusion, contradiction and ambivalence. The impact of these other relationships on the social process of *Negotiating mutuality* will now be discussed. This includes others making decisions about readiness and protection and the influence of trust in others on negotiating mutuality.

7.3.1. The impact of others and other sources of information on judging readiness

Parents and children did not deal with the impact of the parental mental health issues in isolation. In times of intense difficulties, due to the nature of mental distress, parents found themselves at the mercy of the help and kindness of others.

> *Carla: "She [neighbour] brought me back in the house, she closed the front door then she must have got a number, my phone number, my mum's phone number, phoned my mum and told my mum to come down straight away. So two neighbours – the neighbour over the road came as well and um they were um they um, they (were) talking to me and saying to me it's alright, you know..." (p. 9, l. 393)*

This was not always a choice, but could be forced upon the parent by the nature of the mental health issues, and particularly hospitalization. This makes hospitalization a particularly vulnerable period for parent and child, separating them and challenging their aims of *Wishing to stay close and connected* and *Striving for normalcy and maintaining the everyday* as well as *Protecting and being protected*. Others gained influence over the parent-child relationship in these times.

> *Ann: "I think um when I was in the hospital I know um when I was in the [state hospital] that one of the nurses was actually very supportive 'cause Sarah [daughter] used to come and see me from school, like straight from school, she'd come and visit me on the ward and they could see as well you know that she was a very mature girl um when I was actually I was ready to be discharged and I wanted Sarah to come home to me and her dad had rung up the hospital to see how I was and um I remember the doctor, I said to the doctor could Sarah, 'cause Sarah wanted to come back to me then and I remember um I said to the doctor she is very mature, you know she'll be fine back with me you know bla-bla-bla and the nurse actually said you know backed me up and said yes she is…" (p. 15, l. 681)*

Others were at times responsible for the care of their child. Therefore, at such times the responsibility for *Judging readiness* and explaining a parent's mental health problems to a child fell on others' shoulders. This could be a mental health practitioner, the other parent, a family member, a family friend or neighbour or even another sibling.

> *Dayo: "But when it come to the second time, Eric [eldest son], he understood a little bit, because he was a little bit grown up,... (…) at home he says he was telling Brian and Phyllis [younger siblings] 'mum's not well, she's sick – we have to work' and he was doing home …homework, yeah – housework, he was helping me for the housework when it [mental health issues] come for the second time. (p. 7, l. 311)*

However, parents often did not see it as a problem that others were talking to their children about parental mental health issues. There was often a lack of curiosity about these conversations others were having with their children. Sometimes they preferred and valued others taking the role of speaking to their children – there was a sense that others could get to the truth of what their children were experiencing and this could be reassuring for parents.

> *Mualla: "I want to know more about what she wants. She talks about it but still … she might still keep something to herself and … They can get more from conversation with my daughter for instance … They can deal with this information more appropriately." (p. 24, l. 770)*

At times parents also felt that the children preferred to talk to people in the family other than themselves about the mental health issues. Often the parent found this reassuring.

> *“R: When you imagine that conversation between the two of them [daughter and ex-husband’s partner], do you feel comfortable with how that might have gone or what she might have said or does that make you…*
>
> *Ann: Yeah, it’s quite sort of – she would have been sensible um and uh she’s been sort of supportive about my illness so I think that would have gone quite well yeah” (p. 18, l. 808)*

Some children learned about their parent’s mental health problem from mental health practitioners. Once again the parents did not have a curiosity about or clear knowledge of who had spoken to their children, what had been said or how the child had responded to these conversations. They were appreciative of others taking on this role and seemed to trust the practitioners implicitly.

> *Beverly: (2) Well, she knows about it, she knows about it, ‘cause she’s always talking to the people (1) that help me – they always talk to her, ask her how she’s doing…*
>
> *R: That will be the people from here [Community Mental Health Team]?*
>
> *Beverly: Yeah, they ask her how she feels, they are always involved with her as well. They speak to her all the time. She knows – it’s not like she doesn’t know, or listening to other people – she’s listening to the people who are helping me, that’s who she’s listening to. So she know. (p. 12, l. 542)*

Finally, some children’s information about diagnoses was not obtained from the parent or others, but rather from other sources, e.g. the Internet. It appeared that children at times would take initiative in searching for information and would use the readily available information on the Internet.

> *Ann: "…she did her own research anyway and got on the computer and found out and her friend went on the computer for her and was looking up this and looking up that so I think to be honest she knows more about it than I do (laughs)" (p. 14, l. 615)*

Thus, alongside parents own *Judging readiness* and their wishes for what their children should know, a number of other conversations were potentially taking place and other sources of information was available that children could explore on their own.

7.3.2. The impact of trust in others on negotiating mutuality

Whether there was trust or mistrust within relationships with others impacted on *Negotiating mutuality* and on the parent-child relationship. Where trust was present, parents' conclusions on *Judging readiness* were valued and respected and parents and family members or professionals involved in their lives were able to agree on whether and/or how to talk to children about the parent's mental health issues.

> *R: So when the social worker spoke to the children, were you worried that they might say something that… (talks over)*
>
> *Hannah: Yeah, I was very worried as well – I was around all the time when they were talking to them, I was sitting there as well. I would not leave them alone, because I would have told them 'you are going too far now'.*
>
> *R: Did you ever feel that they did go too far or said something that you thought the children should not be talking about?*
>
> *Hannah: No, no, because the one I had she was really really good. She was <u>very</u> good, yeah. She understood, yeah, that I do not want the children to know exactly what I am suffering from. (p. 15, l. 646)*

Where trust was absent though, there was a more complicated or negative view of the talking that would happen elsewhere or the impact that family members or professionals could have on the relationship between parents and their children.

> *Karen: "Yeah, I do. I think 'what are they saying? What are they saying?' and like is she gonna hate me, is she gonna, are they gonna, is she gonna come back with an image that I'm a crap mother and that I've really not done a good job of bringing her up, so I'm anxious about that." (p. 33, l. 1484)*

In these conversations there was again a lot that was unclear. Parents did not have and did not seem to have tried to obtain detailed knowledge or insights into what conversations were happening between their children and others in relation to their mental health difficulties. This might be because the lack of trust did not allow for such open conversations or due to power differences, e.g. between practitioners and service-users.

7.3.3. Relationships between the parent-child dyad and others – impact on negotiating mutuality: a summary

Due to the nature of mental health difficulties parents in this study were hospitalized and heavily medicated for periods of time following a mental health crisis or sharing responsibilities of parenting with others when unable to meet these themselves. Therefore they were at these times reliant on others to take care of their children. As part of this caretaking others at times talked to children about their parent's difficulties. Thus, the opportunity for parents to make decisions about what, when and how to talk to children about parental mental health issues, was often lost. Therefore, in this study talking had at times been superseded by circumstances. This fits with the existing literature – for example, Diaz-Caneja & Johnson (2004) reported that, given the nature of mental health difficulties, it was often at times when information was most needed or wanted that others would be talking to children rather than the parent.

Some of the parents also expressed a wish for their children to have someone outside the family to talk to. An assumption was made that the child was negatively affected by the parent’s mental health issues, but unable to express this and a value was also expressed that it would be good for the children to have someone to talk to. Here the parents could be protecting themselves from a fuller knowledge of what the child was experiencing, as it might be considered that it could be too devastating, too overwhelming to hear what they were ‘really’ thinking and feeling about their parent and their difficulties.

Also, given parents’ awareness of their children’s wish to protect them, they had a sense that their children might be able to open up to others more and that this could be protective. Finally, given that at times parents felt that their children needed protection from them and that they could have a detrimental impact on their children, it could be at times that they felt it would be more helpful and protective for their children to talk to another. Thus, there was a view that children should be able to express their thoughts and feelings, but that it could be helpful if someone else was available to fulfil this role.

It was striking how often parents were unaware of whether others in their children’s lives were talking to them about their mental health problems or whether the children were seeking information in other ways and if so, what the nature of the information was. Despite the children often spending time with other parents, family members or friends, and irrespective of whether these relationships were trusting relationships or not, there was mostly silence about what they were saying to the children when the children were with them, often during or following periods of crisis. Often services involved with the children were seen as delivering a practical service and parents seem to have spent little time considering the conversations the children and practitioners might be having together about the parent’s situation.

It was interesting to observe that this lack of knowing and active seeking of understanding, as well as the lack of a critical or questioning perspectives on the care received, was situated within the context of the absences of more political voices (e.g. as are represented by those campaigning against medical diagnoses or for better mental health services and care during hospitalization). This point will be returned to in the final discussion.

7.4. CONCLUSION

In this chapter the challenges to parents of *Negotiating mutuality* have been discussed. Firstly, it was shown how parents worked at *Judging readiness* of their children to receive parental mental health related information, initially *Protecting innocence* of younger children, but gradually having to *Acknowledge awareness* and accept that their children noticed and were affected by their mental health issues. *Recalling family stories of mental distress*, *Casting children as knowing and knowledgeable* and *Relying on maturity* helped parents tolerate this awareness.

Once parents *Acknowledged awareness,* they had to *Negotiate reciprocity.* Parents worked to *Maintain their lives together* – they valued their parenting role and *Wished to stay close and connected* with their children and they *Strove for normalcy and valued the everyday*. However, mental health difficulties and periods of crisis challenged these goals and created a need for *Protecting and being protected* to mediate the impact of mental health problems on them and their children, at times *Protecting,* at times *Being protected* and at times *Requiring protection* from their children.

Both talking and keeping silent were used by parents and children at different times to attain these goals, but occasionally these created ambivalence and contradictions for parents and children and it was described how the goals of *Maintaining their lives together* and goals of *Protecting and being protected* could be in conflict with one another. Thus, decisions about talking and staying silent remained fluid, being constantly negotiated within the context of the specific circumstances and judgements about the implications of speaking or not speaking. Relationships with others around the parent and child, including family members and mental health practitioners, impacted on the talking that happened between parents and children.

Aspects that interact with these relational processes are the identity implications of mental distress, that is, given and received images of self that might emerge within the telling and talking about mental health problems. The words and actions of loved ones and others influence an evolving sense of self within the context of suffering and loss that accompany enduring mental health issues (Charmaz, 2011) and impact on roles and positions in the family (Coldwell, et al., 2011).

These identity contexts for telling, talking and keeping silent will be discussed in the next chapter.

8. DATA ANALYSIS AND DISCUSSION: 2

IDENTITY CONTEXTS FOR TELLING, TALKING AND KEEPING SILENT

8.1. INTRODUCTION

In this chapter the data in relation to the second analytic category – the identity contexts for telling, talking and keeping silent – are discussed. The main social process identified in relation to these identity contexts was *HOLDING ON TO SELF, HOLDING ON TO LIFE.* In *Holding on to self, holding on to life* parents' struggle to maintain a sense of themselves and of their lives despite the devastating impact of severe and enduring mental health concerns is discussed. The constant effort required from the parents to negotiate a workable and satisfactory sense of self and of their lives impacted on telling, talking and keeping silent in their relationships with their children. A number of social processes formed part of this.

These were:

HOLDING ON TO SELF, HOLDING ON TO LIFE

- **Living a compromised life**
    - Living in a nightmare
    - Living with a wounded future
        - * Living with losses
        - * Living with uncertainty
    - Living a difficult life

- **Struggling to preserve a self, preserve a life**
    - Finding a framework
    - Making sense of self as illness, illness as self
    - Tentatively reconstructing a new (well/unwell) self

8.2 HOLDING ON TO SELF, HOLDING ON TO LIFE

The literature often implies that, within the context of what to tell children, the concepts of 'mental health' and 'mental illness' are clear and universally shared and understood. This implies a clarity of what can or even should be communicated to children within the context of parental mental health concerns (Walsh, 2009). However, mental health and 'illness' are multifaceted and often contested constructs.

In this study it was found that making sense of mental distress, and of oneself and one's life within the context of mental health concerns, was often complex, confusing and contentious for parents. Parents in this study reached no clear or final understanding, but rather meaning-making shifted and changed over time, shaped by many contextual factors. The main social process identified as shaping how this unfolded was *Holding on to self, holding on to life.* Within *Holding on to self, holding on to life,* two social processes were constructed in relation to parents' experiences of mental distress and their attempts to make sense of their difficulties and of themselves and their lives. These processes are: *Living a compromised life* and *Struggling to preserve a self, preserve a life.* These will now be discussed.

8.2.1. Living a compromised life

Within *Holding on to self, holding on to life* the first social process constructed was *Living a compromised life. Living a compromised life* refers firstly to the embodied experiences of living with severe and enduring mental health issues – this includes both the immediate powerful impact of periods of intense mental crises, *Living in a nightmare,* as well as the ongoing nature of struggle that accompanies living with mental health problems, *Living with a wounded future.* Furthermore, participants described *Living a difficult life,* referring to many challenges of day-to-day life that went beyond the experiences of mental distress. These factors have important implications for making sense of mental health concerns and therefore for telling, talking and keeping silent due to the challenges posed to identity and coherence.

8.2.1.1. Living in a nightmare

When intense and severe experiences of mental distress entered participants' lives, it was often extraordinary and bizarre and could feel indescribable. Such experiences could be terrifying, confusing, overwhelming and disorientating. The world became an unsafe place and relationships threatening. There was often an overwhelming sense of fear and fragility in the face of such unknown and unpredictable experiences.

> *Ann: "I had more of a frightening experience… I had terrible nightmares and I thought horrible things like I thought that Ian Brady was something to do with my father and that maybe I was a victim of Ian Brady and Myra Hindley and had managed to escape and so it was all very… [R: Yes scary…] Yes scary and quite negative apart from in the very early well one day I remember before I went into hospital I actually ran up the street in my night clothes and I was shouting to people 'why won't you help me' 'why won't you help me' and people were trying like I remember a woman on a bike and she was actually kicking out at me and saying 'get away from me' and then my neighbour, fortunately my neighbour went past on his motorbike and he and he stopped for me and he was like 'Ann, are you okay?' like and I hugged him and he hugged me and then he called for… he called his mum and they took me in…" (p. 4, l. 178)*

Participants struggled to fully articulate the force of these experiences and drew on powerful metaphors to try and communicate what they felt.

> *Gareth: "It's (1) everything feels (1) magnified, and clear, there is absolutely no (1) I think the problem is, especially for other people, it is just so clear… [R: Yeah.] You don't know why you're bothering (laughs) so it does, it's, but it's also tremendously physical, it's like a (1) um (6) it's not a tirade, it's beyond a tirade, it's a typhoon… … it's a, it's, yes, it's a violent storm and anybody who is around that is sure to be a bit startled…" (p. 15, l. 663)*

People's minds could be confused, leaving memories of events fragmented, elusive to recall and 'forgotten', or events could be recalled in particularly vivid embodied detail, both of which could be intensely disturbing.

> *R: What was it like when you came and then these problems started?*
>
> *Faith: A nightmare.*
>
> *R: Some people tell me that they can remember everything about what happened when they were a patient in hospital, others say that they have big gaps where they do not remember everything – what is it like for you?*
>
> *Faith: The memories are all there – you can still remember it but you do not want to talk about it. I remember <u>everything</u> (upset, tearful).*
>
> *R: It sound like it is very hard to think about.*
>
> *Faith: Yes. I am not comfortable talking about it. (p. 2, p. 58)*

At times within the context of such trauma the story lost coherence, splintered and broke.

> *Gareth: "I also think (1) some of the complications I never really understood it all whether, I never understood particularly the full account of her, of how I'm, but I never (inaudible-upset)… Um-hum. Yeah yeah. I just felt the most outrageous indignation, because they… and it's partly that they're just not fast enough on their feet, which I (inaudible) or (1) if I ask a question, wait for the answer. I'm not saying I'm… but in that state it was like being tortured …" (p. 14, l. 627)*

Thus, here we see participants describing extreme, confusing, disorientating and overwhelming experiences related to periods of psychological crisis and for many the memories of these experiences were very painful. These experiences often left participants feeling fragile and frightened. Participants struggled to find words to capture these memories and making meaning of such experiences could therefore become extremely difficult. Experiences of extreme psychological distress have been described in the literature as lying on the fringes of symbolization where words fail (Brockmeier, 2008; Frank, 1995; Freeman, 2008; Frosh, 1997; Woods & Springham, 2011) – "a land that remains desperately nameless, frightening and fragmentary" (Stern, et al., 1999, p. 354), and this fits with the findings in the current study.

The nature and sheer force of these experiences undermined narrative coherence, and Frank (1995, 2004) has described attempts at meaning-making of such experiences as chaos narratives. Often people learn to censor these narratives and thus can remain silent or feel silenced about such experiences. This has clear implications for parents' own ability to make sense of their mental health difficulties and therefore for helping their children make sense of their mental distress.

8.2.1.2. Living with a ‘wounded future’ (Penn, 2001)

Beyond these experiences of intense distress participants found that once a period of mental distress had been experienced, their sense of self and their lives were altered irrevocably and they found themselves *Living with a wounded future*. Two social processes were part of this, namely *Living with losses and Living with uncertainty.*

8.2.1.2.1. Living with losses

Participants described *Living with losses* in many areas of their lives directly related to their mental health issues. Most participants described the challenges that accompanied being hospitalized. Many experienced radical changes in other areas of their lives directly as a consequence of having mental health difficulties. Often, and most painfully, there was a sense of losing their identity and the person they were before they experienced mental health difficulties.

Sectioning under the Mental Health Act and hospitalization was a particularly prevalent context for loss and separation. These experiences were often traumatic, at times shaming and led to being away from loved ones.

> *Hannah: Yeah, it was very upsetting.*
>
> *R: Was it more to do with what you were experiencing yourself or was it more about the circumstances you were in or what did you find most difficult about that time?*
>
> *Hannah: It was both – it was what I was experiencing and then the hospital so it was the um (1) my third one was a baby and they promised me that we were going to be with her, but it did not happen…*

> *R: It did not happen?*
>
> *Hannah: No. My baby was removed to my brother-in-law's house and my sister-in-law was looking after him… … it was really very difficult. (p. 6, l. 248)*

In addition to these experiences of hospitalization participants described losses in many areas of their lives that they related directly to the mental health difficulties, e.g. losses of relationships, loss of the ability to work, loss of consistent contact with children, loss of confidence that they would be able to do the things they were able to do before, etc.

> *Gareth: "And I am no longer with their mum and fairly recently I separated from my wife whom I met after leaving that um (that relationship) and um and I think the main the main impact on our relationship was that the manic episode I had when she was around…" (p. 1, l. 23)*

Many taken-for-granted parts of self were lost or became unavailable to them.

> *Mualla: "I used to enjoy cooking, cleaning …It took one hour to make all the house clean and tidy … I used to cook lots of different meals but now even cooking one meal is a kind of ..." (p. 8, l. 254)*

Most powerfully, many participants experienced being treated differently because of their mental health problems. People acted in ways that could be experienced as bizarre, strange or frightening by others. Thus, at the time when they were experiencing extreme vulnerability and might be most frightened themselves, others might respond to them as dangerous and frightening, moving away (at times literally running away) and leaving them alone. In particular, they could be perceived as frightening or dangerous to others.

> *Omette: “I had a one-to-one because I once thought that somebody was outside that had come to rescue me, had come to get me from hospital and I was trying to get out and so they thought I was, I was dangerous …so they put on the one-to-one, it was a very awful experience. ” (p. 2, l. 41)*

Not being responded to in a humane manner, not being treated with dignity, not being acknowledged and respected and not being cared for and nurtured at these particularly vulnerable times, could lead to intense human suffering. Often it was difficult for people to hold on to a sense of self that was acceptable to them.

> *Ann: “I suppose that it’s very frightening being ill, very frightening indeed, and that they [staff on mental health ward] should remember that you are going through maybe like the most awful experience that you could ever (starts crying) go through really… (crying) it’s like being in a nightmare. And I think they should remember that you are not a child (almost angry). Sometimes you get treated like <u>a child</u> (angry emphasis) (5)…” (p. 25, l. 1111)*

The self that was known before was lost and what was left could not be grasped.

> *Lamine: “I don’t know, I do not hear, that is I don’t know, I don’t know, I don’t know what happened to me, I don’t know... [R: Yeah] I used to be good, I used to be alright, I used to be happy man, I used to be successful and happy. Yes, normal, normal.” (p. 6, l. 152)*

Therefore, beyond the immediacy of the intense experiences of mental crises, people also experienced losses on many levels related to selfhood and to life as they knew it. This was often experienced as intensely disorientating, confusing and frustrating.

8.2.1.2.2. Living with uncertainty

A second social process constructed in relation to *Living with a wounded future,* is *Living with uncertainty. Living with uncertainty* refers to the great uncertainty that often accompanied the cyclical patterns of participants' mental distress. Once there had been a first experience of severe mental distress, these parents faced uncertain futures in relation to themselves and their health, their circumstances, as well as their children's future and wellbeing. At times uncertainty hovered in the background, while they were getting on with their lives, but at other times circumstances could bring it right to the foreground where it would preoccupy them and colour everything they did. This undermined a clear sense of self and of life.

In relation to their own mental health, there was a sense amongst these parents that they could 'become unwell' at any time. They described monitoring themselves for any signs associated with periods of mental distress, feeling uncertain about what was 'normal' and what a sign of something sinister. They worried that, should they become intensely distressed again, it might happen at a time when their children needed them (e.g. for school related events, in challenging times, etc.) and that they would be unable to be there for them. Support systems were fragile and they worried about who would care for them and their children, should they be unable to do so themselves.

> *Ann: "Yeah that's all I can do and I can't I can't live in fear um but then there is that fear and it I think that's probably what annoys me most of all – why should I have to live with this worry and sometimes when I can't sleep, that's one of*

> *the signs of me becoming ill so when I can't go to sleep you might think 'oh my God, I'm gonna become ill' or if I sometime feel a little bit odd I, you know, I get some warning signs, like things seem a bit sinister or a bit ugly and if things seem just a little bit like that I might think 'oh, am I becoming ill' and hopefully I'm not and I haven't been, but I think that's the thing …" (p. 21, l. 938)*

There was a powerful sense of the unpredictability of mental health issues; that things might appear fine, but that mental health concerns (either theirs or their children's) might catch them unawares and overcome them or those they cared about at any moment.

> *Izzy: "I don't know, I'm on an edge, yeah – I don't know what's over the other side of the edge, and I'm on this edge but trying to balance, right, my life, my family and me are here [indicates a line in the air], but there's something dark over there [points] and I don't know what is over there and it frightens me, I don't know what… what will happen over there, do you know what I mean. So I try to stay along on the line." (p. 10, l. 421)*

For these parents life felt perpetually uncertain and the nature of their difficulties made it impossible to predict the future, meaning that their story remained fragmented and incomplete. Uncertainty had implications for telling, talking and keeping silent as it made it difficult to know what story to tell. No reassurances could be given; no promises of a better future could be relied upon. No one knew what would happen next. Uncertainty also created fears and concerns that could be difficult to tolerate, leading to attempts 'not to think about it', which discouraged reflection and conversation.

Thus, parents described life being irrevocably changed since developing mental health problems. The familiar was lost and a new sense of self and life had to be found.

However, many factors challenged this search for understanding. The situation appeared to be constantly shifting and changing in relation to their mental wellbeing and therefore they lived with great uncertainty. Furthermore, often others' perceptions of them were changed by the mental health problems and were in conflict with their own experiences of self, forcefully challenging their sense of identity and coherence. This is described in the literature by Stern, et al. (1999) as "ontological insecurity" (p. 357), where even the most fundamental components of the self and the world can seem uncertain and unreliable. Charmaz (2011) states that continued uncertainty is the reality of many people with chronic health conditions and this was also the case for mental health concerns for the parents in this study. Once again, this has clear implications for parents' ability to help their children make sense of their mental health issues.

8.2.1.3. Living a difficult life

A final process constructed under *Living a compromised life* was *Living a difficult life.* This refers to the fact that people described living difficult lives far beyond living with a mental health problem. People described difficult childhood experiences, struggles with poverty, migration, social marginalization, lack of suitable living conditions, relationship breakdown, loss and bereavement, physical health issues, etcetera.

> *Izzy: "…look where we're living, in front of a skip, big rats run across out there, you know what I mean?... … I see no way out, these places they're putting me to live in, this this is not helping me. And I'm a recovering addict, you know what I mean, this is not, this is not, it's not, it's probably strength of character, a decision I made that I have stopped when I was in prison, that I'm not using, but this could send anybody to use, these places where they put people, you know, I'm vulnerable, and they're not, they're not taking it into account. So I don't know." (p. 4, l. 141)*

Parents often made no distinction between talking about mental health concerns and these other life concerns, grouping together the things they themselves and their children were worried about. Parents' lives were not organized around their mental health difficulties alone, or necessarily defined by their mental health diagnosis – their lives were about living in their circumstances, surviving and finding a way to be in the world alongside those circumstances. Parents also described their children not distinguishing between mental health problems and other problems.

> *R: And would she be more thinking, if she was to look for a reason why, say why you were not buying new clothes, would she be first likely to think oh it's because we don't have any money or would her first thoughts be oh mummy's not well.*
>
> *Izzy: Umm (3) 'she's got no money' (p. 17, l. 759)*

Thus, parents expressed concerns about many different aspects of their lives and not just their mental health difficulties. They did not make a distinction between their mental health concerns and other concerns impacting on their lives, including poverty, migration, housing issues, physical health concerns, etcetera. Parents in other studies have expressed similar concerns with regards the impact of other factors in their lives related to their mental health issues, and have emphasised the impact on their lives and their parenting (Ackerson, 2003b; Bassett, et al., 1999; Dipple, et al., 2002; Nicholson, et al., 1998a & 1998b). Often parents did not describe their lives as defined by their mental health problems and thus, this diffused what children could be told or needed to understand of the challenges facing their family.

8.2.1.4. Living a compromised life: a summary

In *Living a compromised life* it has been shown that the parents in this study described mental health related experiences that powerfully disrupted and challenged their sense of self and of their lives. In *Living in a nightmare* the intense, disorientating and destabilizing embodied experiences that often accompanied a mental health crisis was described. These experiences were often difficult to capture and express in language. Without the language for one's experiences, such experiences dissolves and cannot be shared (Weingarten, 2001). Thus, experiences can remain unstoried and unprocessed and this could have significant implications for parents' ability to develop a coherent and congruent account of their difficulties and judge from that what an age- and context-appropriate account would be to share with their children.

Furthermore, one needs to consider that for many their children witnessed, and were included within, the above events and the silence surrounding these aspects of their parent's difficulties might leave these traumatic events unprocessed, unaccounted for and unacknowledged for the children too. This might thus have an impact on their meaning-making. Moreover, the implications for the child of the message that these events are somehow unspeakable should be considered in relation to their relationship with their parent and their own sense of their place in the world.

Following this, *Living with a wounded future* highlighted the many ways participants were *Living with losses* related to their mental health difficulties – this pointed towards the ways in which people's lives were changed and the suffering they endured due to their experiences related to mental health concerns, potentially leading to a loss of a clear sense of self and of a familiar life. Furthermore, experiences of mental health concerns also involved *Living with uncertainty,* where the constant uncertainty that accompanied mental health problems compromised people's sense of a reliable future and a predictable sense of self and life. Frank (1995, 2004) states that the experience of continued uncertainty can separate people from ordinary reality and can create a barrier between them and their loved ones, and can also undermine coherence.

Finally, participants experienced *Living a difficult life* and no distinction was made between talking about mental health concerns and talking about other life concerns, including the challenges of poverty, unsuitable housing, migration, etcetera, grouping together the things that challenged their, and their children's, day-to-day lives. Neither parents nor their children appeared to consider the mental health problems as something separate from the other difficult experiences in their lives. This is in contrast to mental health practitioners who might see a person's mental health issues as distinct and as the focus of how we view people's lives.

Together these processes undermined a clear or final understanding of mental health issues and a coherent story of self and life, thus potentially powerfully impacting on telling, talking and keeping silent.

Once they had experienced a period of mental health difficulties, accompanied by all the challenges as described under *Living a compromised life*, parents in this study had to make sense of these difficulties and of their selves and lives in the context of their mental health problems. They thus engaged in a process of meaning-making where they worked towards finding an explanation or understanding that accounted for their experiences. However, this was not a straightforward process and they often found themselves standing on shifting ground. This will now be discussed under the social process *Struggling to preserve a self, preserve a life.*

8.2.2. Struggling to preserve a self, preserve a life

The above process, *Living a compromised life*, led to people drawing conclusions about themselves and their lives, albeit fluid, incomplete and momentary and they found themselves *Struggling to preserve a self, preserve a life*. The identity conclusions people draw in relation to their mental distress have implications for their sense of themselves and their lives, and will inform their choices and actions, including whether, when, how and about what to talk to their children within the context of parental mental health issues. Therefore, the data will now be considered in relation to these conclusions. The social processes that will be discussed include the processes of *Finding a framework, Making sense of self as 'illness', 'illness' as self* and *Tentatively constructing a new (well/unwell) self.*

8.2.2.1. Finding a framework

Under *Struggling to preserve a self, preserve a life* the first social process was constructed as *Finding a framework.* In *Finding a framework* parents needed to decide which framework best helped them make sense of the struggles they had in their lives, e.g. a mental illness framework, a psychological distress framework or a life circumstances or stress framework. This most often was within the context of entering the world of psychiatric care where they had been given a psychiatric diagnosis as an explanation for their psychological distress. They needed to consider their own personal understanding of what they experienced in relation to this diagnosis. They then had to put their experiences alongside this information and consider whether the information accounted for the experiences they had had. Some took a more active role within this process, others a more passive role.

Working to find an understanding often involved drawing on existing knowledges of mental health and 'illness' and processing their own experiences, alongside a consideration of whether to seek out information, considering information received, both in formal mental health contexts and through informal ways, e.g. the internet, and positioning themselves in relation to this information. This often led to conflicting, incomplete or confusing understandings.

Some parents accepted the diagnostic label and saw it as a valuable way to conceptualize their difficulties.

> *Omette: "… perhaps it took them a while to realise what the matter was with me, I don't know, but they didn't tell me for a long time until one day I asked*

> *them 'what's the matter with me?' and she said 'puerperal psychosis' and I said 'does that mean a nervous breakdown?' and the simple language was 'yes', um, but perhaps it would be nice if they could tell me that earlier so that I could know, because I was in such a state that I couldn't even talk …" (p. 11, l. 344)*

Accepting that one is 'mentally ill' could be a difficult process. It did not always provide solutions and came with significant implications for life.

Alternatively, some parents rejected the 'mental illness' label given to them by mental health services. In the context of rejecting a mental illness framework, alternative frameworks needed to be adopted or developed to make sense of psychological distress.

> *R: I wondered whether you have always thought that these times, that that means you are sick, or, or how did you come to think of it as an illness?*
>
> *Beverly: …(2) It's not me – it's what the doctors say.*
>
> *R: The doctors say…?*
>
> *Beverly: Yeah, it's what the doctors say.*
>
> *R: Do you have sort of a different idea about what is going on for you?*
>
> *Beverly: I just thought it was interference, people, people interfering in my life, not letting me get on with what I want to do. (p. 7, l. 274)*

> *Lamine: "You know how they says these bad things happens to you because, because God hates me, that's why. My God hates me…" (p. 6, l. 147)*

Parents tended not to construct a single, final, complete and coherent explanation of either mental illness or another framework. Rather, often many different aspects informed their overall explanation, drawing on a number of frameworks, including at times genetics, chemical imbalances, stress, childhood trauma, life circumstances, relationship difficulties, etc. – these could at times appear contradictory, but participants moved fluidly between these different positions, depending on the context and the implications of the explanations. Understanding developed as a process over time. Often an understanding was reached, only to be contradicted by further developments in their mental wellbeing, requiring a revision of understanding.

> *Ann: "I was quite shocked because (1) as I said, well I think I was shocked to become ill because I always thought it was post- (partum) psychosis and I'd only become ill again if I had another child so in 2004 that was a big shock um … … … um and (1) as I said they described it as Affective Disorder when I was ill in 2004 so I didn't know that I had Bipolar um and then I was told that hopefully I wouldn't become ill again or if I ever did it would be when I was sixty or so so… I wasn't expecting necessarily to have another episode or to have it so soon and also I had been told that I could stop my medication so I wasn't on medication for a prolonged period of time um but I don't know I mean I've just recently I've looked on the internet about the um the descriptions of bipolar and some things fit and some things don't…" (p. 24, l. 1075)*

Understanding remained incomplete, fluid and changing. People's explanations contained many gaps, uncertainties and contradictions. Much confusion remained.

> *Lamine: "I'm not a doctor, you know what I mean… [R: Mm] I been, I've seen, I've seen millions of doctors, you know what I mean, all day ask question, question, question, nothing happen, you know what I mean. How they … they change all my medication, you know what I mean. [R: Mm, mm] So no-one's*

> *sure, no-one’s sure, you know what I mean, and eh, I, I, I,… [R: Mm, mm] You know what I mean, I haven’t got much choice anymore, ...” (p. 18, l. 495)*

Thus, finding a coherent framework for understanding of mental health difficulties was a challenge for these parents. The story that there was to tell was often not clear and unfolded chaotically. Furthermore, the parents’ frameworks were continuously being re-negotiated, depending on changing perspectives and other changes in the development of their mental health problems.

For some a dissonance was noted between the meanings they held about their experiences and the ‘purely’ medical discourses of explanations. These participants did not always relate to or accept the mental health diagnosis or treatment as carried out by mental health practitioners. Even where such diagnostic frames did help participants in making sense of their experiences, many contradictions and uncertainties remained, and explanations appeared to remain fluid and ever evolving. This fluidity in explanations would naturally have a strong effect on what parents could explain to their children. Thus, the suggestion in some of the literature that there is a clear, medically informed explanation that parents can be given by practitioners and then can pass on to their children (e.g. Cooklin, 2004, 2006, 2012; Focht &Beardslee, 2005) is problematized by this study.

It is interesting to note that despite these disagreements around meanings and at times the rejection of psychiatric diagnoses, participants did not challenge mental health practitioners, and continued to visit services, as this was at times their only access to help and support. The combination of participants not fully accepting a diagnosis or the fact that the medication was having any beneficial effect, while continuing to use mental health services and not challenging practitioners or sharing their alternative views with them (possibly due to a fear of losing access to practical help and someone who supports them, or alternatively of sanctions like hospitalization or an increase in medication), might create a misconception in mental health practitioners of ‘insight’, that is that the participants agreed with the diagnosis and understood what they were being treated for.

Furthermore, this could also hide a divide between what mental health practitioners were considering children should understand about the parents' difficulties and what the parents considered important for them to know. It might also mean that, when practitioners did speak to their clients' children, they were having very different conversations with them from the conversations the parents were imagining or hoping for.

8.2.2.2. Making sense of self as 'illness', 'illness' as self

The second social process related to *Struggling to preserve a self/preserve a life* was *Making sense of self as 'illness', 'illness' as self.* This study has shown that when people developed psychological difficulties, their sense of self was severely challenged. Therefore, participants struggled to reconstruct a clear sense of self within the context of their evolving mental health problems.

For many participants it was difficult to incorporate the mental health issues into their sense of self, but also equally difficult to preserve a recognizable sense of self, separate from the mental health problems.

> *Omette: "… um, I realised that I, that I was behaving odd but I didn't, I didn't associate it with mental health … um, you know, mental was a term that didn't, didn't suit me, like, and um, I never thought it would happen to me, although I was under a lot of stress when it happened and it was bound to happen, um, I still didn't think it would happen to me… … Especially if you've not thought of yourself as somebody with those sorts of difficulties, it's a shock, it's very dramatic, it's disturbing because it's so unusual." (p. 4, l. 102)*

Within this context, it was important to them to hold on to familiar, pre-existing aspects of self and this included seeing themselves as separate from their mental health issues.

> *Ann: "I looked on this American website and there was a, it was a quite interesting for the advice on various topics, but they had like chat-rooms and I just found it very, not so much negative, but I found that everybody identified themselves as these people with bipolar, whereas I don't identify myself as a person with bipolar – although I have bipolar I feel that isn't me…" (p. 26, l. 1169)*

However, often people were confronted both by their own sense of self and others' perceptions of them, seeing them as one with their difficulties.

> *Gareth: Um I think my relationship with it is I suppose I just feel whatever me is and whatever it is, we are inseparable so there seem…*
>
> *R: It is a part of (you)?*
>
> *Gareth: Yeah. [interruption] Yes. And I'm part of it, I don't see it as particularly separable, but the… I suppose just the um I think one of the problems is how that that that – I keep saying it – the bubble effect… …but the bubble effect is to leave you visible so that when you're not in the state, whatever the state, or even in, within the care of the services, whatever, you are still yourself but this bubble appears between you and your nearest and dearest.*
>
> *R: Alright.*
>
> *Gareth: …because you are also this thing … (p. 10, l. 448)*

Parents also experienced that when they were standing in a 'mentally ill person' identity, it impacted dramatically on their lives. Where they experienced great divides between how they perceived themselves and how others perceived them, this challenged their sense of self as well as their relationships.

> *Beverly: "'Cause they say I'm sick. It's always the 'oh, you're sick, you're gonna end up in hospital'. The story of my life." (p. 15, l. 664)*

Furthermore, they experienced great divides between their perceptions of themselves and their preferred selves or how they wanted to be in the world, for example experiencing themselves as hurting those they love.

> *Lamine: "You know what I mean, she's [wife] suffering about me, she's, she's my care… [R: Mm] she's my care and I feel sometimes sorry for her, you know [R: Mm] what I mean, because she deserve a better, better person, not, not like what, how I am." (p. 8, l. 195)*

These experiences could lead to drawing negative identity conclusions.

> *Gareth: "…the whole <u>thing</u> becomes a (5) a what's it, a <u>demon</u>…" (p. 11, l. 484)*

> *Karen: "…'cause I worry about being a parasite…" (p. 19, l. 871)*

Thus, participants struggled with finding a way to incorporate the difficulties into their sense of self and to hold on to a recognizable and acceptable self alongside the mental health problems. It could be difficult to find the boundaries between self and psychological issues – it could become unclear whether the old and taken-for-granted self from before the ‘illness’ was still there, who the new self with the ‘illness’ was, whether there was a self left that was not the ‘illness’, where the ‘illness’ stopped and the self began. Thus, a sense of self was often lost in the chaos and unpredictability that the mental health issues brought. It required of the participants to learn the politics of being an individual with mental health issues in a world where this is associated with danger, violence, ineffectiveness, dependence and other negative and constraining characteristics. This could potentially lead participants to draw negative conclusions about self.

In addition to the clear implication of the challenge within *Making sense of self as illness, illness as self* for finding a coherent and congruent version of the self to present in conversation, there are other implications for talking. The person will be challenged to make choices in relation to how prominent their mental health issues will be in the person they wish to present to others, including to their children. Furthermore, where there are discrepancies between what the person wishes to present of themselves and what others validate, this could cause tension, conflict and disruption in these relationships.

8.2.2.3. Tentatively reconstructing a new (well/unwell) self

Finally, within *Struggling to preserve a self, preserve a life* the social process of *Tentatively reconstructing a new (well/unwell) self* was considered. It has been shown above that the familiar and taken-for-granted self is often lost within the context of developing mental health problems. The literature on chronic illness points towards a reconstructing of the self, following this loss of self when illness enters one’s life. This could involve regaining a valued self, finding a story of hope, courage and self-growth to tell about the illness (Charmaz, 2011) and/or gradually trying on a coherent illness narrative (Weingarten, 2001).

However, these stories were under-emphasised within the current data. The tentative and temporary, underdeveloped stories of reconstructing self are presented here before reflecting on why these perspectives are not more strongly and readily available or better developed.

Small stories of hope:

One response for some participants was holding on to hope for periods between times of psychological distress or after longer periods of stability, but this was a fragile kind of hope. Hope was found in different places - some parents drew on historical knowledges of people who had recovered from mental health problems; others remembered their personal characteristics and the fact that they had been able to endure much in their lives up to this point; some relied on sheer willpower, willing themselves to be well and stay well; others trusted the medication they were taking to keep them well and believed in the knowledge and skill of the mental health practitioners involved with their care; and finally, a few drew on religious beliefs to sustain hope within the context of constant uncertainty.

> *Eileen: "I realised it and I just want to pray I thank God that He can help me to stop everything and continue to drink my medication, because I know that medication, God will help me but medication will also be good." (p. 5, l. 200)*

Thus, many participants managed to construct a hope that enabled them to live their lives within the context of uncertainty and change. Often this was a hope that they had left the mental health difficulties behind. The hope that periods of distress would not return again could powerfully discourage talking. It was framed as 'hopefully' behind them, meaning that no further talking was necessary. Not remembering or thinking about it sometimes also was seen as a way to maintain stability and therefore hold on to hope, thus again discouraging talk. However, the hope was fragile and tentative and could easily be lost. This has also been described elsewhere in the literature (e.g. Mattingly, 2008; Rose, et al., 2002).

A few specific small stories of reconstructing selves:

For Carla a new self was about maintaining a stable state, staying on an even keel – the 'illness' is still there, but can now be managed by staying calm, taking medication, keeping things level.

> *Carla: "It is, and that is over the years, because I've had it for 6, 7 years now you know and I can see the difference. You know there was a time when I first had it I was just sleeping and eating and I was well out of it – I couldn't hold a conversation or nothing. I couldn't even be bothered with the children or nothing, you know. My mum had to come in again and look after them. You know, feed me as well, you know and now I'm at a point where I don't feel that I've got any kind of problem, you know, I'm not pressurised, I'm not financially in difficulty, nothing, you know. A normal person." (p. 21, l. 937)*

For Ann the restoration came through strong and enduring family relationships – through adopting a normalizing, irreverent and playful approach, mental 'illness' could be managed. Strong relationships were experienced as supportive and nurturing, repairing of hurt and pain and sustaining in the difficult times. Love could conquer all.

> *Ann: "I suppose it does make you strong as a family, 'cause you've been through such a lot (tearful) and you do love each other and it's funny as well and life's a funny thing (blows nose) and I think we know that, like in our heart, like that's one thing that in our family life's mad (laughs), because uh, things are strange and that we can laugh and we can joke about it and uh yeah, you just get strong as a family or it can do um (4) and you can get through the other side of it – I think that's the main thing…" (p. 26, p. 1157)*

Ann also kept the hope alive for reclaiming parts of her identity, her strength, herself as a working person, and she worked towards that with the support of loving relationships.

> *Ann: "I just think I'm a very strong person – I've always felt that I'm a very strong person and I feel like in my life like my mother had bipolar so I wasn't brought up with my mother and um and I left home, well my foster parents, and I sort of had to look after myself basically and I just do feel that I am very strong. I feel that the bipolar, I don't feel as strong as I have been, but hopefully I think I will be strong again." (p. 27, 1206)*

For Faith, there was just a sheer determination to 'move on', to reclaim her life, to parent her children and get on with things. She was not going to let mental health problems determine her or her children's destiny.

> *Faith: "You move on with your life – you do not let it hold you back. It is not the end of the world." (p. 5, l. 217)*

Finally, for Gareth, there was an acknowledgement that his mental health problems had not only restricted his life, but in other ways had also enhanced his life. He talked about deep and meaningful friendships that had developed and been strengthened through experiences connected to his mental distress. In particular he valued the strong relationships with his children, the openness that had developed between them and the confirmation of their love for him and his for them.

> *Gareth: "…the curious thing I'm not particularly one for the glass as half full thing, but there has been bonuses to this as well, that is something that can sometimes be forgotten or neglected." (p. 2, l. 935)*

For these participants trying to regain a valued self remained a fragile position though, with the constantly present threat of 'relapse'.

> *Carla: "If I'm left alone I might just relapse. [R: But on a day-to-day basis at the moment it's not (talks over)] No, my mind's still occupied you know, I've got such a busy life. I'm so occupied I don't really think about my illness. You know, some days I feel that I haven't even got an illness - I just take my medication, that's it, you know." (p. 21, l. 928)*

These stories are often under-developed, and fragile within the context of ongoing difficulties. Many factors contribute to this, including the fluctuating nature of mental distress for many people and the difficulty of finding an 'even keel', the wider struggles with housing, poverty and social isolation, and finally the stigma of mental 'illness' that undermines, and does not sanction, these more positive responses to one's difficulties.

8.2.2.4. Struggling to preserve a self, preserve a life: a summary

Within this section the social process of *Struggling to preserve a self, preserve a life* was discussed. Three processes were constructed, namely *Finding a framework, Making sense of self as 'illness', 'illness' as self* and *Tentatively constructing a new (well/unwell) self* to describe the meaning-making processes people engaged in following the development of mental health problems. The disruption and destruction caused by mental health struggles powerfully challenged people's sense of self and their lives and participants had to find a way of understanding their mental health problems. Furthermore, they had to reconstruct a sense of self and their lives that was acceptable to them and accounted for their experiences, following the sense that the self was lost once mental health difficulties emerged. This struggle to hold on to a sense of self and a sense of one's life within the context of mental distress appeared to be a never-ending process and had significant implications for parents' identity construction and their sense of their lives and for their understanding of their distress. A few participants managed to tentatively construct a new self, but this was often fragile and easily lost. Furthermore, it became unclear at times who loved ones, mental health practitioners and society were seeing and responding to when relating to the person – uncertainty about the gap between one's own self perception and the perceptions of others could thus infiltrate relationships.

In the wider literature it has been reported how long-term illness makes multiple and repeated assaults on persons' sense of self, and maybe never more so than when it is a mental 'illness'. With mental 'illness', more so than in physical illness, there is often no clear distinction made between the individual and the 'illness'. The person often takes on or is assigned a diagnostic label as a part of his or her self-identity (Adame & Hornstein, 2006), meaning stories of 'illness' become stories of self. It has been reported that this loss of personal identity when people are labelled as 'mentally ill' is one of the most painful aspects (Scheyett & McCarthy, 2006) and the problem of how not to lose oneself and one's identity in the process of becoming a 'psychiatric patient' has been described as an on-going challenge (De Barbaro, et al., 2008).

Following trauma one both grows forward into a new person, but also backwards reviewing the past as the person you are becoming, thus integrating life experiences into a coherent and meaningful whole, albeit including the trauma (Kling, 2012). This process involves both storying one's self and one's experiences and a process of 'calibration' in response to living with the new self and others' reactions to self. However, the current research points to the multiple challenges the particular nature of mental health difficulties pose to this process of reconstructing a coherent sense of self and a continuous sense of one's life. Therefore, it was clear that this on-going process powerfully impacted, both through identity and relational factors, on telling, talking and keeping silent. In particular it problematized the taken-for-granted nature of what can be told within the context of parents helping their children understand parental mental health problems.

8.3. STIGMA

One specific context for the process of *Holding on to self, holding on to life* is the social stigma attached to mental health issues. Stigma powerfully impacted on all the social processes related to *Living a compromised life* and *Struggling to preserve a self, preserve a life.* Therefore it is important here to present the data in relation to stigma and consider its impact on identity contexts for telling, talking and keeping silent.

Stigma was a powerful thread that ran through all of the data and most participants described impacts of stigma on their lives. In addition to examples already presented, a few further examples are presented here.

> *Lamine: "Some people when I, when I was living in W_____ City, They say that, neighbour they are calling me 'mad man'." (p. 17, l. 462)*

> *Gareth: "And so the label helps even then and in fact (2), that's what I do – I tend to meet new people, they then tend to start to become friends but I always tell at that stage, 'cause if anything is going to happen it's best if they know – I've lost a few friends, quite a few actually." (p. 8, l. 322)*

Stigma could at times be a powerful barrier to talking, not just between parent and child, but also in talking outside the family on a number of levels. The parents did not want conversation with outsiders about the parent's mental health issues, both to protect themselves as persons and as members of their community, and furthermore, to protect their children from potential stigmatizing responses, e.g. bullying or teasing and finally, to protect the parent-child relationship by not letting societal views of ‘mental illness’ influence their child against them.

> *Omette: “Um … no. I would have preferred that they, that they say I was on holiday rather than go to school and say ‘my mother’s not well, she’s in hospital’ you know, it wasn’t something that within our community you want everybody to know about so …“ (p. 10, l. 302)*

> *Dayo: “Sometimes they don’t talk to people. They just keep it for themselves at home. They don’t want people to know their mum, she’s sick*.” (p. 11, l. 489)

Stigma impacts on identity aspects of this study, as stigma could contribute to the negative self-perceptions people arrived at. Furthermore, participants found it particularly difficult when their own understanding of their difficulties or themselves clashed with or were contradicted by the understandings of those around them, and stigma could significantly contribute to this gap. This fits with the significant wider literature on stigma – for example, Coldwell, et al. (2011) found that the understanding someone has of a person’s mental health difficulty powerfully shapes the interactions with the person who has the diagnosis. Thus, stigma can significantly shape telling, talking and keeping silent and needs to be constantly considered when working to understand talk within families where there is a parent with mental health problems.

This will be further explored in the next chapter.

8.4. CONCLUSION

The onset of severe mental distress requires the narrative enterprise of (re)-constructing one's self and one's life in meaningful and coherent ways within the context of the mental health issues (Baldwin, 2005). However, in this chapter it has been shown how the extreme embodied experiences of mental distress, the losses of self and the life that was known that was endured, the uncertainty that had to be managed and the many other challenges life brought alongside the mental health concerns made it difficult to hold on to an acceptable and coherent sense of self and one's life. In the literature the way people describe themselves and their lives within the context of severe and enduring mental health issues has been described as "impoverished narratives" (Lysaker, Wickett, Campbell & Buck, 2003, p. 538). Suffering can lie beyond words and the 'unspeakable' remains so, as it cannot be tolerated (Daniel & Wren, 2005). Often people are rendered silent by such experiences (Charmaz, 2002, 2013).

Thus, meaning-making proved difficult as the nature of the mental health issues were ever shifting and changing. Participants did not describe reaching a full, final, complete or coherent understanding of their mental health problems and there were limited signs that people were able to reconstruct a new well/unwell self. Rather, participants in this study described a conceptualization of their difficulties that was multiple, ever-changing, relational and contextual. Therefore, the view that there was a clear and final understanding that could be communicated to children was challenged. Talking was therefore conceptualized as a moment-to-moment negotiation of the understanding of mental health struggles and of identity and this fits with other recent research (Rhodes, 2013). Stigma contributed to both the sense of a 'contaminated' or broken self for those with mental health problems and to rendering participants silent (Baldwin, 2005). There is also an implication that for some the wish to preserve a parent-self and personhood that was acceptable could be in conflict with providing a clear, but compromising explanation of difficulties (e.g. of 'mental illness').

In the next chapter the relationships between the social processes presented in the results chapters will be discussed in order to consider the clinical implications and implications for future research of the study.

9. FINAL DISCUSSION

9.1. INTRODUCTION

In this chapter a summary of the main findings is presented, with connections between the relevant social processes highlighted. This is followed by a discussion of the theoretical, clinical and contextual issues raised by the study and a consideration of guidelines for clinical practice. Methodological factors are considered and suggestions for further research are made. Finally there is a closing self-reflection.

9.2 SUMMARY OF THE STUDY'S FINDINGS: TELLING, TALKING AND KEEPING SILENT

9.2.1. "A violent storm" (Gareth)

For many participants in this study severe and enduring mental distress is like a violent storm sweeping into their families' lives, often without warning. It relentlessly takes hold of a person's life and removes reason, choice, stability and predictability. It corrupts the mind, changing perception and giving rise to confusion, while creating a turmoil of fierce and overwhelming emotion. It not only takes over the person, but sweeps along [6]everyone in close proximity. It disrupts relationships and creates division and separation. Those close by might often be left confused, hurt, betrayed and disturbed by what is witnessed and experienced. For children, innocence can be lost and nurturing and protection can become unattainable. The unpredictability of where and when these storms will erupt makes life perpetually uncertain. Dreams for the future are lost as plans repeatedly come to nothing. The rhythm of life is continually interrupted.

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[6] It is important throughout the discussion of the findings and their implications to hold in mind that this is based on the perceptions and understandings of the parents and that naturally, were the children to be interviewed, their views might have either agreed with or contradicted those of their parents.

Through the presence of such severe mental distress the person and their family become ‘other’ in their community and in society. The person is cast as strange, incapable, frightening or even dangerous. They make others uncomfortable and are often avoided. Stigma sticks to them and those close to them like their shadows. There is intense suffering.

9.2.2. The ordinary and the everyday

However, in between, around, alongside and despite these experiences, life goes on. The ordinary and the everyday survive. People get up, cook meals, go shopping. Children go to school, do homework and play. Families watch television, laugh together, discuss their days. Cups of tea are made, hugs are given. There is hardship – often money is in short supply and inadequate housing challenges the ability to create a home. Family may be far away or no longer there. But hardship is shared, compromises are accepted, sacrifices are made, kindness and tenderness repair. Love survives. A fragile hope prevails that this time it will be different.

9.2.3. Talking and being silent within the ebbs and flows of mental distress

Within these ebbs and flows of mental distress, families had to make sense of their experiences. Both talking and keeping silent were shown to be part of this process. It was shown how parents were anxious to keep their mental health difficulties from their young children in order to protect them and maintain their innocence. However, this position was not sustainable. Children’s questions and comments confronted parents with the children’s awareness of their mental health difficulties.

From this point onwards parents had to negotiate mutuality while also maintaining their sense of self and their lives together and, towards these aims had to consider whether and how to talk to their children about their mental health problems. The decisions around this appeared to be made in the moment, depending on the context and the function talking or keeping silent could serve. Talk, when it happened, was often informal, interwoven with everyday conversations and often general and partial. At times referring to the mental health difficulties of the parent halted conversation.

9.2.3.1. Talking

Talking often helped parents to experience themselves as a 'good parent', not misleading their children, and to experience their relationship with their children as more authentic. Talking could enhance closeness in the parent-child relationship. In particular, following a mental health crisis, tentative talking could help to re-connect and heal a ruptured relationship. Talking in these contexts was at times humorous, thereby expelling the lingering ghosts of the periods of crisis.

Parents reported that talking about mental distress could at times help their child make sense of their experiences of the parent's difficulties. It could also from time to time help the parent 'fill in the blanks' about times of distress and thereby support their own sense-making process. According to the parents, talking was regularly a way for children to check up on their parent, and at times for the parent to check up on their child in terms of one another's mental wellbeing. Parents also reported that talking was often used by children to reassure and encourage the parent and at times by the parent to advise and guide the child in order to keep them well – thus, there were attempts through talking at mutual understanding, meaning-making, monitoring and protection.

Talking was also employed at times to maintain the ordinary and the everyday, on the one hand 'normalizing' mental health issues as part of people's lives and on the other, where children would invite parents away from the mental health problems into the ordinary. Where the parent did not feel up to meeting the needs of their child, had to defend their actions, or needed the child's help, support or understanding or where the parent wanted to reduce the child's demands on them, talking about the parent's mental health problems could be employed as a device to achieve these aims.

9.2.3.2. Keeping silent

The chaotic, confusing and fracturing experience of mental distress could powerfully silence parents, as it could at times be impossible to find a coherent account for telling. The incompleteness of understanding also undermined talking. Furthermore, the uncertainty that accompanies mental health issues as well as the hope that prevails that things will be different could both strongly discourage talking at times. Stigma, the sense of shame that accompanies the experience of stigma and the fear of the implications of talking within the context of stigma, was a further strong discouragement from talking. Internalized stigma, that is parents' sense of themselves as 'mentally ill' and thus 'contaminated' or potentially 'toxic' for their children, could be a strong deterrent from talking and could lead a parent to distance themselves from their child.

However, at other times keeping silent was an active choice. Like talking, keeping silent could be a way of being close and connected. According to the parents, keeping silent was at times a way the child tried to protect the parent and often a way the parent attempted to protect the child from the impact of the mental health issues, trying not to burden them with their mental distress. Also, like talking, keeping silent could be a way to maintain the ordinary and the everyday, here not allowing the mental health problem to become the focus of their lives, but rather focusing on 'normal' things. In particular, following a mental health crisis, a wish to return to the ordinary could strongly discourage talk of the mental health problems and the impact on the family. Finally, despite this being very painful for the parent, at times not talking appeared to be the child's way to create some distance from the parent in order to protect themselves from the impact of their parent's mental health problems.

9.2.4. Conclusion

Both talking and keeping silent served different functions at different times in the parent-child relationship. It is clear that both talking and keeping silent could at times help with meaning-making, strengthen the relationship and aid living life in preferred ways, while at other times leaving experiences un-storied and creating confusion, worry and distance between parent and child. Thus a complex picture emerged.

These findings will now be considered within the context of the existing literature before the clinical implications are discussed.

9.3. THEORETICAL CONSIDERATIONS AND LINKS TO EXISTING LITERATURE

The findings of this study have been linked with existing research throughout Chapters 7 and 8. However, before turning to specific clinical implications of the current findings, it is also important to consider in a broader sense the implications of these findings for the field of parental mental health as a whole. In this section the findings of the study will therefore be linked back to a number of implicit theoretical stances that, it is argued, are found within the literature and these will be reconsidered in light of these findings.

These are in relation to:

- The impact of stigma
- The suffering of children
- The marginalization of the parent
- Expectation of a good, coherent and complete ‘illness’ story
- Privileging talk

9.3.1. The impact of stigma[7]

The social practices of pathologising lives are "one of the great marginalisations of contemporary culture" (Michael White, 1995, p. 113).

The impact of stigma for those with mental health difficulties and for their loved ones has been consistently highlighted in the literature (e.g. Buchanan & Murray, 2012; Hinshaw, 2004, 2005; Hinshaw & Cicchetti, 2000; Kelly, 1999; NICE, 2009; Terkelson, 1987a, 1987b). Furthermore, both parents (Dolman, et al., 2013) and children (Totsuka, 2010; Van Parys & Rober, 2012) have emphasised the significant impact of stigma on their lives within the qualitative research in the field of parental mental health, as reviewed in Chapter 2.

However, despite this, the literature on interventions for providing children with information about parental mental health problems or for improving communication around parental mental health issues in families, mention stigma far less often and recommended interventions tend not to suggest actively considering stigma. The current study points towards a reconsideration of this tendency.

The findings of this study have highlighted the significant identity implications mental health issues can have for parents and the powerful impact that this can have on talking about the mental health concerns with their children. These identity implications are powerfully shaped by stigma. This links with other studies that also emphasise the prevailing impact stigma can have on communication about mental health issues within the family and between the family and the outside world (Rhodes, 2013; Stern, et al., 1999; Van Parys & Rober, 2012). Stigma will therefore be considered here more fully and the implications for intervention explored.

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[7] Stigma has been conceptualized as comprising ignorance (lack of knowledge), prejudice (negative attitudes), and discrimination (negative behaviour) (Jeffery, Clement, Corker, Howard, Murray & Thornicroft, 2013). People experience discrimination when they perceive that they have been treated unfairly, due to a particular attribute, in this case having mental health problems.

9.3.1.1. The ‘normalizing gaze[8]’

‘Normal’ has been applied to humans since the 19th century and has become taken for granted within Western culture; that is, as if it exists outside or separate of its historical and cultural origins (White, 2004). The psychiatrically ‘ill’ are still often construed as incompetent, irresponsible, unpredictable, dangerous and in need of social control. Even in situations of apparent integration, people persist in using subtle but powerful ways of excluding the mentally ‘ill’ (Jodelet, 1991, cited in Morant, 1995; Rhodes, 2013). It has been shown in this study and has also been widely reported in the literature (Aldridge & Stevenson, 2001; Buchanan & Murray, 2012; Dallos & Hamilton-Brown, 1997; Madigan, 1999; Morant, 1995; Ord & R, 2013; Rhodes, 2013; White, 1989, 2004; etc.) that these stigmatizing perspectives have significant implications for people’s sense of self.

Unfortunately, participants reported experiencing stigma and discrimination not only in the personal spheres of their lives, but also from the mental health practitioners from whom they receive care. This has also been reported elsewhere in the literature (e.g. Adame & Hornstein, 2006; Aiken 2010; Gaillard, Shattell & Thomas, 2009; Madigan, 1999; Morant, 1995). In mental health settings the mental ‘illness’ can become a totalizing frame of reference and, as participants described in this study, this can negatively shape experiences such as periods of hospitalization and hinder trust within relationships with practitioners.

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[8] The effects of this ‘normalizing gaze’ directly relates to ideas of power (Foucault, 1964/2006; White, 2004). Modern power is constricting because its operations and effects become invisible, or its effects are attributed to the person experiencing those effects, rather than to the dominant socially constructed discourses (Hutton, 2008; White, 2004, 2007). See these references for a fuller discussion of modern power.

9.3.1.2. Implications of stigma for parenting and family communication

Within the context of parenting as persons with mental health problems, the pervasive fear of losing custody of or contact with children due to these mental health concerns has been highlighted, and even though in the current study all parents were actively caring for their children, the fear of losing their children or the relationship with their children was ever present. These concerns reflect to some extent the real problems this group of parents experience in parenting, but seems to go beyond this in that the valued role of parent and the stigmatized role of 'mentally ill' person appears to be viewed as incompatible (Diaz-Caneja & Johnson, 2004) and parents appeared to struggle to maintain a sense of a moral or 'good' self (May, 2008).

In relation to parenting, a study by Jeffery, et al. (2013) reported that a significant proportion of mental health service users experienced discrimination in relation to parenthood. These authors identified that people with mental health issues experienced being seen as unfit parents, incapable and inadequate in a parental role. Parents felt judged as parents and perceived services as overprotective of their children and overzealous in any interventions to protect the children. Other authors have also commented on this assumption that parents with mental health issues would have a detrimental effect on children in their care (Turner, 1993). Parental mental health problems might quickly be used to explain any difficulties their child experienced (Nicholson, et al., 1998a & 1998b).

Importantly, the current study has highlighted how these societal stigmatizing views could be internalized, leading parents to see themselves as detrimental to their children's wellbeing. This can have significant implications for parental identity, the parent-child relationship and the sense parents have of their ability to mediate the impact of their mental health issues on their children, thus impacting on talking and keeping silent in the family.

Stigma also has a powerful influence on the wider family. A number of parents in the current study showed concern about the social implications of stigma for their children and this at times restrained them from open communication about mental health issues (see also Jeffery, et al., 2013). Family members are also influenced by social and psychiatric discourses of ‘mental illness’ and therefore there is the potential of stigmatization in the family itself as a couple of the participants in this study described, leading to parents potentially losing the respect of their children and authority within the family, undermining the ability to parent (see also De Barbaro, et al., 2008; Rosenfarb, Miklowitz, Goldstein, Harmon, Nuechterlein & Rea, 2001).

9.3.1.3. Conclusion

It is clear that stigma can have a powerful impact on talking and keeping silent within the family. To be more fully responsive to families where there are parental mental health problems, practitioners should directly address the impact of stigma on the lives of all in the family within their interventions. This should include exploration of internalized self-stigma in parents, stigmatizing views within the family, as well as fears related to stigma that could inhibit open communication within the family and with those outside the family. The identity implications that accompany mental health issues for parents should also be addressed as part of family work. Furthermore, practitioners should reflectively examine their own stigmatizing beliefs and practices. Finally, practitioners are encouraged to move beyond the therapy room and join parents and campaigners in robustly battling stigma in society (Gee, Khalaf & McGarty, 2007; Stormont, et al., 1997; Thomas & Kalucy, 2002 & 2003).

9.3.2. The suffering of children

“Childhood is increasingly being constructed as a precious realm under siege from those who would rob children of their childhoods” (Jackson & Scott, 1999, p. 87).

The parental mental health literature has over many decades increased our awareness of the potentially grave implications of parental mental health problems for children. This literature, alongside the findings of the current study, highlights the necessity of considering and responding to the suffering of these children. However, it is argued here that there is a polarization between the suffering of the child and the hardship endured by parents with mental health problems implicit in the literature. The socio-political factors resulting in this split have been explored elsewhere, resulting in a difficulty in looking at families holistically (Featherstone, Broadhurst & Holt, 2012). Throughout this research project it was challenging to make visible the struggles faced by parents with mental health problems, without this implicitly diminishing the potential suffering endured by children. It is argued here that this polarization within the field between the needs of the parent and the needs of the child undermines strong therapeutic engagement and effective therapeutic work with families where there are parental mental health concerns. Through richly exploring the experiences of parents in this study, an argument has been made that a simplistic consideration of the 'best interest of the child' is insufficient. Therefore, the complexity of this concept will be more fully explored here.

9.3.2.1. Constructions of childhood

In our society children are valued as precious. Childhood is often associated with dependence, vulnerability and innocence (Jackson & Scott, 1999). Great concern is expressed when children have to grow up too quickly and not experience childhood to the full. Thus, "constant vigilance is required in order to protect, preserve and manage childhood" (Jackson & Scott, 1999, p. 97). The child is often portrayed as passive and at the mercy of external stimuli (Prout & James, 2005). It has been argued that such constructions of children as passive beings in relation to the impact of their parent's difficulties on them are also present in much of the parental mental health literature, as opposed to seeing children as individuals that actively participate in their social lives (Gladstone, et al., 2006; Totsuka, 2010, 2013).

However, it has been shown in this study (based on the parents' perspectives) and elsewhere (Mordoch & Hall, 2008; Prout & James, 2005; Riebschleger, 2004; Totsuka, 2010; Van Parys and Rober, 2012; Walsh, 2009) that children very actively and consciously participate and help shape their lives and the lives of those around them. This is not in any way to discount the real dangers and challenges facing children and the potential devastating impact of parental mental health difficulties on their lives, or to misrepresent the complexity of the situation and importance of context, but it does re-position children within our awareness and thus opens up new possibilities for clinical intervention.

9.3.2.2. Being confronted with suffering

This study, and the parental mental health literature in general, compellingly confronts us with suffering, including the suffering of children. It is clear from the current study, and also consistently reflected in the literature, that children potentially endure suffering – developmentally, emotionally, relationally and socially – due to their parents' mental health difficulties. Such suffering can be enduring and unrelenting. It forces us to consider the meaning of suffering within the context of a parent's mental health problems.

However, in this study and elsewhere (Dulwich Centre, 2008) it is also clear that for these participants this suffering most often occurred within the context of what parents experienced as mutual love between parent and child, mutual concern about the impact of the mental health issues and a mutual wish to protect. We know of course that, despite this context of love as described by the parents, parents are not always able to act from this love – the nature of their mental health difficulties, the impact of their own experiences of childhood and of being parented, as well as life circumstances and relationships that often accompany the presence of mental health problems, can lead to parents at times neglecting, hurting, not protecting or acting with hostility towards their children (as has been shown in this study, as well as elsewhere [see e.g. Memarnia, 2014]). We know from earlier research that these can be some of the most damaging experiences for children (see e.g. Rutter & Quinton, 1984). It is thus essential that the suffering of children is comprehensively considered and rigorously responded to.

Unfortunately though, within this consideration of the suffering of the child, the parent is potentially blamed and judged for the suffering. Featherstone, et al. (2012) have highlighted how parents are increasingly seen “simply as conduits for ensuring the welfare of their children through the taking of parental responsibility” (p. 622). Where there are parental mental health concerns, the societal view that parents should always be able to put their children’s needs first and should protect children from any hurt or damage caused to them (May, 2008), is therefore challenged. Thus, within a child-centred consideration of the suffering of the child, great constraints are placed on the potential for acknowledging, validating and addressing the needs of the parents. It discourages a full appreciation of the suffering experienced by the parent, can obscure the positive aspects of the parent-child relationship and can disqualify the parent as an active agent in responding to the suffering of the child. Thus, this has significant implications for intervention.

9.3.2.3. Conclusion

It is argued here that the current western constructions of childhood and parenthood, alongside the meanings attached to mental ‘illness’, strongly impact on how suffering is understood where there is parental mental health problems. It invites us to pitch the suffering of the child against, rather than alongside, the suffering of the parent. This, it is argued, is a powerful constraint in responding to the needs of all in the family and in utilizing the potential active contributions of both children themselves and their parents in responding to suffering related to the parent’s mental health problems. It is acknowledged that this is a very complex issue. However, as Van Parys and Rober (2012) argue, a ‘both-and’ position, that is, allowing for the contradictory, the complementary and the reciprocal, should be considered. This needs to include a full consideration of the suffering of all in the family. That could be a suitable response to the complexity that has been shown in this study.

9.3.3. The marginalization of the parent

"We fully agree that disorganized environments where children are neglected and parents are affected by alcohol or drug abuse [or other mental health problems] are predictive of serious problems…but we wish to resist the psycho-centric proclivity to locate the source of the child's problems in the parent's psyche." (Prilleltensky, Nelson & Peirson (2001) p.152).

Within the parental mental health literature involving children, parents are most often cast as 'objects' that need to be understood, 'managed' and 'survived' by the children, but rarely as active agents in mediating the impact of their difficulties on their children (Smith, 2004). In the literature on interventions to facilitate understanding and meaning-making in children of parents with mental health problems, parents are often notably absent (with perhaps the exception being Beardslee and colleagues' Family Intervention Programme [see Beardslee, et al., 1997; Beardslee, Swatling, Hoke, Rothberg, Van de Velde, Focht & Podorefsky, 1998]). Thus, there is a sense that parents are not seen as willing or able to contribute to the healing of their children. Furthermore, the current study showed how participants' identity, and in particular their parenting identity, was powerfully challenged when they experienced mental health problems and how this had significant implications for their own sense of being able to contribute to the healing of their child. Thus, this perception of parents has significant implications for talking and keeping silent in the family and will be explored in more depth here.

9.3.3.1. Identity implications of ‘mental illness’ labels for parents

In the current study it was shown that parents often did not experience themselves as best placed to respond to their children’s reactions to their mental health problems and at times even viewed themselves as ‘toxic’ to their children. The implications of acting from such a ‘spoiled’ (Bülow, 2008; Goffman, 1963) – defected, damaged, deranged or dangerous – identity were highly significant for these parents’ lives. It could take parents away from their hopes and dreams for themselves as parents and for their children (White, 2005). Parents at times created distance from their children in an attempt to protect their children from themselves (see also Beardslee, et al., 1998), thereby silencing potential conversations between them and their children about the impact of their mental health problems. Furthermore, these totalizing negative identity conclusions obscured the many positive experiences parents described between themselves and their children, and the many aspects of parenting parents continued to feel able to fulfil.

9.3.3.2. The relational context of trauma and the nature of resilience

In contrast to these perspectives, it is argued here that this study points to the relational context of trauma and suffering and by implication the relational pathways to resilience. Experiencing pain in life is not ‘pathological’. Rather, as Focht-Birkerts and Beardslee (2000) argue, it is the lack of adequate emotional attunement and responsiveness to painful emotional experiences that renders them unendurable and thus a source of trauma and damaging distress. Furthermore, pathways to resilience occur not where all conditions leading to wellness are favourable, but rather where some compensate for others (Prilleltensky, et al., 2001). Thus, where a parent fails their child, the parent could have an opportunity to rectify this failure by providing understanding, recognition and comfort for the child’s distress; that is, the parent could respond to the child’s need for a trusting reconnection (Focht-Birkerts &

Beardslee, 2000). Parents can greatly benefit from the rediscovery and reconstruction of an enduring sense of self, and in particular a parent-self (Davidson & Strauss, 1992, cited in Barker; Lavender & Morant, 2001), regaining a sense of self-determination and the opportunity for participation as well as the experience of competence and self-efficacy in order to move towards wellness (Prilleltensky, et al., 2001). This can also significantly benefit their children (Focht-Birkerts & Beardslee, 2000).

9.3.3.3. Conclusion

It is argued that, whenever possible, parents should be seen as key persons in responding to and mediating the impact of their mental health issues on their children (Beardslee, et al., 1997; Focht & Beardslee, 1996; Focht-Birkerts & Beardslee, 2000). This is not to remove responsibility from parents, but to extend their responsibility to include contributions to healing. Research confirms the important role parents can play in helping their family remain strong and mutually supportive in times of crisis (Tunnard, 2004). This is more likely where parents are willing and able to encourage their children to talk about their experiences and then respond to their child's pain in an accepting way, even if their mental health problems and accompanying behaviour has caused the pain. This requires parents experiencing themselves as active agents in mediating the impact of their mental health difficulties on their children and will often require practical support and on-going help from mental health practitioners. This should be considered when planning interventions.

9.3.4. Expectation of a good, coherent and complete 'illness' story

"You can't make schizophrenia nice… Just as sufferers of physical illness are often expected to make up for their 'flawed' status by being brave little Pollyannas, mentally ill people need to exhibit compensatory features in order to earn the right not to be

> *discriminated against… … All people who are mentally ill deserve human contact and support, not just the 'good' ones" (Glosswitch, 2013, para. 6).*

As has been discussed, when a person develops mental health problems they need to make sense of their experiences in order to tell a coherent story about their difficulties (Stern, et al., 1999). In the parental mental health literature people are often constructed as logical, rational beings who simply need to be given the correct information in order to tell such rational 'illness' stories (Whittaker, 2009), for example to their children. Furthermore, it has been highlighted in the literature that there is an assumption within parental mental health research of an agreed definition of 'mental ill health' (Morant, 1995; Walsh, 2009). However, it has been shown in this study that this meaning-making is all but an easy, clear or ever-completed process. This has significant implications for talking about parental mental health issues and will thus be discussed here.

9.3.4.1. Professional conceptualizations of mental distress

Much has been written about the 'official' knowledge production regarding 'mental illness' (Clark & Mishler, 1992; Clarke, 2005). The meaning and implications of psychiatric diagnoses has been repeatedly highlighted in the literature (see e.g. Boyle, 2007; 2011; Division of Clinical Psychology, 2013; Johnstone, 2000, 2011a, 2011b, Rapley, Moncrieff & Dillon, 2011; etc.) and it is beyond the scope of this thesis to review this extensive body of literature.

However, it is important to point to the politics of 'illness' narratives. Diagnoses do not only convey information about bodies or minds – they have real effects for the storyteller and the people who listen to the story and thus they alter lives (Clark & Mishler, 1992; Frank, 2004; Hydén, 2008; Reed, 2012; Weingarten, 1999). This can certainly be argued about psychiatric diagnoses which function to determine criteria of normalcy; objectify, infantilize and pathologize the person; narrow the repertoire of available narratives; and create an asymmetrical and intimacy-eroding relationship between the giver and receiver of the diagnosis within the clinical encounter (Avdi, 2005; Dallos & Hamilton-Brown, 1997). This relates to the clear identity implications of having such a diagnosis shown in this study.

Furthermore, much of contemporary psychiatry has been criticised for attempting to reduce the experiences of distress to biological events that are removed from people’s lived experience. Despite great advances in neuropsychiatry, “the present-day medical discourse of chemical imbalance and faulty neurotransmitters fails to capture the complexities of many people’s subjective experience of distress and coping” (Adame & Hornstein, 2006, p. 137) as it does not take full account of psychological suffering or individual differences and the individual meanings for particular persons (Hydén & Brockmeier, 2008; Mishler, 1984), as described by participants in the current study.

9.3.4.2. Personal stories of mental distress

In contrast to these ‘official’ knowledges, there are the “untamed stories” (Sermijn, et al., 2008, p. 3) people themselves tell about their difficulties. People in this study had developed their own, often partial and contradictory, understandings and views about their mental health issues. Stories about long-term mental health difficulties were made difficult by the fact that people were still in the middle of them (Bülow, 2008). It was shown that stories built bit by bit on unstated mundane actions and silent realizations, alongside drama and dialogue.

With new information and experiences came re-negotiations of meaning and relationships, and also new questions (Coldwell, et al., 2011; Dulwich Centre, 2008; Pluznick & Kis-Sines, 2008; Whittaker, 2009). People’s narratives about their difficulties were determined by factors in their situation, operating in the moment in which they were evoked. People made sense of mental health problems as a personal experience

(Rose, et al., 2002) and often alongside and inseparable from many other challenges in their lives.

For some people diagnoses formed part of their understanding of their mental distress and helped them make sense out of chaos and could reduce blame and guilt (Colmer, 2005). For others it did not form part of their understanding. Often people's descriptions of their mental health difficulties were not coherent and well-ordered (Brockmeier, 2008) or 'nice', and included what Glosswitch (2013, para. 4) describes as "the instability and ugliness of some types of mental illness…". Also, as Stern, et al. (1999) have argued, different understandings were useful at different points in time. Often, people found a story to tell that allowed them to carry on with their lives – as Prager (2013) states, "no matter how stark the reality …human being(s) fit it into a narrative that is palatable…". However, at other times hope was lost and there wasn't any best story to tell (Frank, 2008).

Therefore, it is argued that people experiencing mental health difficulties, as well as those close to them, develop understandings over time that are contextualized and personally meaningful and that include the intense struggle that can accompany mental distress. This 'developmental' and contextual nature of a family's relationship with a mental health problem has also been acknowledged elsewhere in the literature (e.g. Drost & Schippers, 2013; Terkelsen, 1987a, 1987b).

Furthermore, people's understandings were about more than 'information' and making sense of experience. Understanding needed to include the life lessons learned over time within the context of struggle and adversity, lessons about how to deal with uncertainty, how to respond to crises, how to sustain hope, how to re-connect after relational rupture, what to expect and when to let go; that is, developing resilience in the face of living a compromised life.

9.3.4.3. Implications of contrast between professional and personal understandings

Studies have revealed how an asymmetry often arises in conversations between 'patients' and doctors, as a result of which the patient's knowledges and interpretations are not given sufficient scope in clinical encounters. The practitioner organizes and sums up the service-user's narratives into a medical narration that then becomes the basis for the continued clinical intervention (Mishler, 1984) and thus disrupts the person's own meaningful account (Ingrassia, 2013). In this system lay knowledges held by those experiencing the difficulties are rarely recognised by practitioners and, even when recognised, are usually marginalized, when put alongside professional knowledge regarding the health issue. 'Ill' persons are characteristically deemed to have unspecialized knowledge of their own bodies and minds (Madigan, 1999) and are rarely given active voice and participation in the production of authoritative knowledge on their difficulties (Barker, et al., 2001; Clarke, 2005). Therefore, in this context reaching an understanding can be seen "as a fragile act, (that) can easily be abandoned or undermined in the course of clinical care" (Mattingly, 2008, p. 74). People are limited in the extent to which they can be understood in terms of their own understandings of their difficulties and are invited into a more passive relationship to these difficulties.

Furthermore, this privileging of a medical understanding can contribute to the perception of a clear explanation of mental distress that is shared by all. This can create a sense that children need only to be provided with information during a 'telling event'. However, despite such psycho-educational occasions clearly being potentially valuable to children, given the developmental and contextual nature of meaning-making as shown in this study, addressing the issue of providing children with an understanding of a parent's mental health problems once is not enough (Reed, 2012). This perception potentially obscures the constantly evolving process of meaning-making, co-constructed in conversations over time. Focht-Birkerts & Beardslee (2000) describe how in their work with families understanding slowly evolved as the child matured, the parent experienced crises and recovered stability and the child was repeatedly given permission to speak and their responses welcomed. They concluded “it is a long-term process that changes slowly over years and is accompanied by a great deal of ambivalence and fear” (p. 433).

Furthermore, in line with the findings of this study, these authors (Focht-Birkerts & Beardslee, 2000) have highlighted the need to go beyond ‘information’ to include sharing of emotional responses and development of life skills and knowledges over time in response to the unfolding difficulties. These are knowledges that cannot be explained, but need to be experientially learned. However, a therapeutic context can provide a valuable safe and containing environment within which to conceptualize, clarify and validate these developing knowledges.

9.3.4.4. The absence of critical voices

In exploring pre-existing understandings of mental health issues, one could have expected that people in this study might comment on media depictions of mental ‘illness’ or societal views of the mentally ‘ill’. However, these perceptions did not come up in the interviews. Overall there was an absence of reflections on wider issues related to mental ‘illness’ and society. Also, there was very little questioning of the discourses within the psychiatric world and no mention at all of a more political perspective or any alternative social connections (e.g. with survivor-groups, support groups, recovery-orientated approaches, service-users networks, etc.).

Rather, people’s concerns remained close to home, local and specific to their lives. There was a strong sense of looking inward and also of the parents feeling observed, judged, scrutinized and monitored (e.g. by mental health practitioners, social care workers and wider society). The situational and social worlds/arenas analyses (Clarke, 2005) [see Appendix 14] showed this dilemma for these families. Where home life is usually a private arena, the one space where people are left to their own devices and from which people have a choice of what to make public, this was less the case for these parents. However, this was hardly challenged. Parents appeared to a large extent passive within these relationships with others, maybe due to internalized stigma, maybe due to power differences and a sense of dependence, maybe due to the manifestations of their difficulties and a lack of energy and focus to engage with the issues actively.

Furthermore, this scrutinizing and judging gaze was not returned. The concern of parents was with the very local, the personal, e.g. how to negotiate with services to meet individual needs, hoping for some action that would improve their own individual day-to-day circumstances, rather than on critically considering their care within mental health services or the wider world of mental 'illness'.

One consideration in this regard is that parents with mental health difficulties are not collective actors; that is, there is the absence of a collective identity and commitment to act together (Clarke, 2005). This powerfully impacts on how they are situated (Mishler, 2005, cited in Hydén & Brockmeier, 2008), that is as individualized, isolated, lone voices (Clarke, 2005), in their relationship with the organized mental health system. This can potentially significantly shape the relationships they can have with services and how they position themselves in relation to dominant mental health discourses.

9.3.4.5. Conclusion

It has been shown in this study that people struggled to make sense of their mental distress and that gaining understanding was a contextual and developmental process. Furthermore, it has been reflected on here that there often was a dissonance between professional and lay conceptualizations of mental distress, and an absence in the research interviews of more critical and collective voices in relation to dominant mental health discourses.

Thus, it is argued that more space should be opened up within the clinical encounter between service-users and mental health practitioners for exploration of different understandings and joint meaning-making (Charon, 2005, 2007). Frank (2004, p. 158) encourages jointly "(finding) the fitting story(/ies)" and situating these within the context of people's lives (Candib, 2004). This study also points to a need for this joint meaning-making to include a greater interest in people's own narratives, or "untamed stories" (Sermijn, et al., 2008, p. 3), and to go beyond information to include the development of life skills and knowledges of dealing with adversity over time. Furthermore, it seems important to see meaning-making as continually part of on-going therapeutic conversations, rather than something that can be viewed as 'completed', both for parents and for their children. Finally, it requires giving up the fantasy of fixing through attempting to narrate a whole, unbroken story of what is broken (Frank, 2004), and requires us as practitioners to tolerate the ebbs and flows of people's experiences.

9.3.5. Privileging talk

"In the face of profound disruption, containing stories of what is happening may emerge, or there may actually be a 'narrative wreckage'" (Stern, et al., 1999, p. 376).

In the existing literature and within the helping professions talk is privileged as a way to explain, make sense, process, release and relieve. The absence of talk is often viewed as dysfunctional or weak (Reed, 2012), leading to isolation, things being 'bottled' up and ultimately to pathology. Furthermore, the privileging of talk can at times imply that talking and developing an understanding – for example by children about their parent's mental health difficulties – is equivalent to them not being upset or affected by it (Aiken, 2010) or to coping well. However, it has been highlighted in this study that silences and fragmented thoughts mark experiences alongside talk and stories. Silences may at times be imposed and at times be a conscious choice, and may arise from people's awareness of, and actions towards, their situations. Thus, the implications of and alternatives to privileging talk will be explored here.

9.3.5.1. Silence as a rational and meaningful response

This study has highlighted the intense struggle that can accompany mental health crises as well as everyday life lived within the context of mental health problems. Making meaning of such experiences is thus a constant challenge. One possible response to such events is silence, abandoning the search for words for what lies on the edge of awareness and comprehension and can never be fully captured in language (Charmaz, 2002).

Choosing on the other hand to express these raw emotions, to respond to perceptions of injustices and to speak about suffering is a more risky affair, especially where others have the ability to choose and make decisions about one's life. People may withdraw in horror, withhold their support or care, act to increase control or sanction persons in other ways (Charmaz, 2002, 2011). Therefore, talking about such experiences requires a careful choice, based on a judgement of others' potential responses and the implications for oneself and one's life and relationships. Sometimes the risk might seem too large, and silence prevails.

Moving away from a fixed assumption that talk is good, Reed (2012) encourages a more nuanced understanding of the decision-making involved in talking and choosing to stay silent. From the data in the current study it is apparent that parents experienced both themselves and their children as having compelling reasons both for talking and for keeping quiet. It is therefore important to gain an understanding of the reasons families may have for the decisions they make in this regard, rather than framing the absence of talking as 'dysfunctional', 'weak' or a form of 'denial' (Reed, 2012).

Furthermore, it is clear from the data that addressing the conflict experienced between a wish to talk openly and a fear of the implications of talking openly for both parents and children, will not be addressed once only, but will have to be revisited and re-negotiated within the day-to-day life of the family (Scheyett & McCarthy, 2006).

9.3.5.2. Telling broken stories

Should there be a wish to talk about such events, the potential challenges to coherence were clear in this study. Stories might not be well developed – “they are undecided, fragmented, broken, narrated by voices struggling to find words towards meaning and communication” (Hydén & Brockmeier, 2008, p. 2). One could argue that language, and in particular medical mental health language, may not provide a way for satisfactory meaning-making of such experiences.

It leaves the question of where such experiences fit and how to make sense of them; furthermore, whether talk would require the capacity to acknowledge and include the traumatic, the shameful and the outrageous, leaving nothing out of a human life, or whether parts of the experience of psychological distress should remain unspoken. It can be argued that the implications for persons experiencing such extreme psychological distress when these experiences remain excluded, untold, unexplored and unacknowledged, may be grave. Rather, “storytelling that seems to be incoherent, or broken, may show something important about the experience of illness and even about the medical encounter” (Bülow, 2008, p. 149).

9.3.5.3. Conclusion

People’s silences as much as their talk are powerfully shaped by the nature of their experiences and the perceived implications for themselves and others that might emerge within the considered talk. This persistent conflict between the wish and the struggle and fear of talking openly within families about mental health concerns needs to be accounted for (Reed, 2012), and the meaning of silences should be explored rather than assumed. Furthermore, practitioners should make it their business to encourage people to tell their stories, even if these are quiet and broken, or communication is not through language (Hydén & Brockmeier, 2008).

9.3.6. Theoretical considerations and links to existing literature: conclusion

In this section a number of theoretical reconsiderations of stances in the parental mental health literature, following from the current study, have been explored – these were in relation to the impact of stigma, the suffering of children, the marginalization of the parent, expectation of a good, coherent and complete ‘illness’ story and the privileging of talk. These aim to provide a theoretical and conceptual stance or orientation that can inform clinical practice and point to some specific practical guidelines for service development and clinical practice that will now be discussed.

9.4. GUIDELINES FOR SERVICE DEVELOPMENT AND CLINICAL PRACTICE

As clinicians we are challenged to respond meaningfully to the complexity that parents described in this study. It is argued here that a number of factors potentially impact on the possibility of an imaginative and constructive response by clinicians to the impact of severe mental distress for families, as well as to these clinicians’ attempts to respond to these challenges through talking and keeping silent. A number of practical guidelines that flow from the findings of the study and the implications as discussed above, will now be presented. Guidelines will be discussed at a service level and therapeutic level.

9.4.1. Guidelines at service level

There are some clear guidelines for service structures that flow from this study. This is firstly in a general sense for all generic services that will come into contact with families where there are parental mental health concerns. Furthermore, there are also guidelines for services specifically aimed at addressing parental mental health issues in families.

9.4.1.1. A need for responsive, comprehensive and integrated generic services

The multiple needs over time of all in the family where there are parental mental health concerns have been highlighted by this study. In the UK clinicians in generic NHS and Local Authority services, e.g. community adult mental health services, child and adolescent mental health services and social care services, are most often the services to have contact with these families. Recommendations in relation to these services and their responses to families where there are parental mental health concerns are regularly and consistently made in the literature (e.g. Falcov, 1998; Tunnard, 2004). In particular, early intervention and taking a proactive preventative approach has been the focus of government initiatives and investment in recent times (Featherstone, et al., 2012). Furthermore, closer links between adult and child mental health services and social care services (as well as with the police, schools and the third sector) and services that are more sensitive and responsive to the needs of service-users as parents have been highlighted (Ackerson, 2003a; Stormont, et al., 1997; Thomas & Kalucy, 2002 & 2003; Tunnard, 2004) and are relevant here.

However, current service structures work against such developments, due to the different cultures in services, the specific and narrow focus of each service, the high thresholds for accessing services and the lack of interaction and overlap. Furthermore, the current trend is towards primarily short-term, focused and standardised de-individualized interventions (see Featherstone, et al., 2012 for a fuller exploration of the histories and implications of these factors). Thus, within the current system, practitioners are repeatedly confronted with the discrepancy between the complexities of difficulties and challenges they encounter when meeting with families and the requirement to provide time-limited, standardised packages of care, often focused on only one part of the family and one aspect of their situation. It is argued here that these current service structures and trends limit the effectiveness with which the complex needs of families struggling with parental mental health concerns can be responded to. The implications of short-termism, de-individualisation, fragmentation and target-driven approaches on quality of care, service-user satisfaction and staff morale is already beginning to be highlighted in the literature (e.g. Broadhurst, Wastell, White, Hall, Peckover, Thompson, Pithouse & Davey, 2010; Featherstone, et al., 2012; Hall, Parton, Peckover & White, 2010), but will only become fully apparent over time.

In contrast, the findings of this study point towards more long-term, comprehensive and intensive individualized and integrated models of intervention that promote strong sustained relationships with families over time within a non-judgemental and flexible framework (Totsuka, Muir, Metzer & Obi, 2014).

9.4.1.2. Drawing on models of long-term intensive intervention for specialist services

Alongside these generic services, specialist parental mental health services providing interventions for families with parental mental health concerns over time would be best placed to respond to the complex needs of families where there are parental mental health problems (Bailey, 2010; Britten & Cardwell, 2002; Central and North London Mental Health NHS Trust & NSPCC, 2006; Daniel, 2010; Loshak, 2012). However, unfortunately these services are seldom available within the NHS in the UK and in the current climate of austerity more are disappearing.

Despite these current structures and trends, promising approaches have been developed within the parental mental health field (e.g. Hinden, et al., 2005) and elsewhere [see e.g. multi-family therapy (Asen & Scholz, 2009); multi-systemic therapy (Curtis, Ronan & Borduin, 2004); the Hope for Children and Families modules (Bentovim, 2014); the work of The Troubled Families Unit (Aitkenhead, 2013; Casey, 2012; Totsuka, et al., 2014); the work of Kids Company [although primarily focused on the young person] (Batmanghelidjh, 2006; Batmanghelidjh & Kids Company, 2013); the Kids Time projects (Cooklin, 2004, 2008, 2012; Cooklin, et al.), etc.] that can be drawn upon to guide effective service development for parents with mental health difficulties and their children, should the political climate and service structures in the UK allow for such developments.

These interventions and approaches share three key elements that it is argued here are highly important in meeting the needs of families where there are parental mental health issues, based on the findings of the current study. These are, firstly, a focus on all in the family within the same service; secondly, offering longer term intensive interventions and fluid entry into and exit from the service, accompanying families over time and being responsive to their needs (e.g. offering out-of-hours services, offering consistency in workers and offering fluid re-entry into services when needed); and finally, offering a comprehensive service, thus being able to respond to a wide range of difficulties in the family (including needs beyond the mental health difficulties, e.g. housing needs, benefits issues, school- and education-related needs, immigration concerns, etc.).

Finally, these services are well placed to support the commitment of recent governments to early intervention (Allen, 2011). As the current study has shown, difficulties can develop for families at different times in their evolving relationship with the parent's mental health issues, and building strong sustained relationships with families and being responsive to this unfolding relationship can potentially prevent more severe or prolonged problems from arising. Most importantly, fully supporting parents in helping their children manage the impact of parental mental health difficulties in their lives has the potential to break the cycle that often exists across generations of mental health problems and impact on children.

9.4.1.3. Conclusion

An argument has been made here for longer term, individualized, flexible, responsive and comprehensive services with an emphasis on sustained therapeutic relationships and early intervention to meet the complex needs of families where there are parental mental health concerns over time.

Next, guidelines for therapeutic work will be discussed.

9.4.2. Guidelines for therapeutic work

In addition to these guidelines for service structure, guidelines for therapeutic work are also suggested by this study. Suggestions will be made here for specific interventions clinicians working with families where there are parental mental health concerns can employ to address the needs of these families in relation to talking and making sense of parental mental health concerns.

9.4.2.1. Creating spaces for talking together and talking individually over time

The findings of this study have challenged the assumption of ‘telling occasions’ between parents and children. Rather, it has been found that parents and children interweave talk about parental mental health difficulties into everyday conversations. It has also been shown that talk does not only happen once, but rather that there is an ongoing need for conversation around the evolving family circumstances and unfolding events and that understanding develops slowly over time. Both parents and children have been described by the parents as actively striving for and working towards meaning-making around parental mental health concerns.

Within this context, the main approach offered in the literature of providing children with psycho-education about their parent’s mental health problems, can be seen as only one intervention into understandings that began to form long before the intervention and will continue to form after the intervention. Thus, such psycho-educational interventions would be enhanced by opening up spaces for the existing understandings and meaning-making of both parents and children, thus striving to bridge the gap between professional and personal understandings and working towards shared meaning-making, rather than presenting a fixed explanation to children. Furthermore, rather than seeing these interventions as completing the task of explanation to children, following these interventions parents and children would benefit from continued accompaniment in developing their evolving understandings of mental distress (Barker, et al., 2001).

A number of specific interventions, suggested by the current findings, in relation to talking together and talking individually will now be discussed:

9.4.2.1.1. <u>Talking together</u>

<u>Intervention – Resisting invitations into silence:</u> This study has shown that at times following psychological crises, parents and children can conspire against talking, taking a position that all is well and that the problems have been left behind. It is important that the therapist acknowledges and celebrates opportunities for normalcy and the everyday, but also works to actively use these times to address what occurred and to learn from a crisis to help mediate the impact of future crises.

Here it might be particularly important to find ways to talk about what was witnessed by children in times of parental mental crises, carefully moving away from a position that these aspects should not be discussed. In this study families have shown how contexts of tenderness, togetherness and even humour could hold and facilitate these potentially painful conversations. Giving and sharing information in safe, non-overwhelming and age-appropriate ways and in a containing, conversational style can further help parents and children during these conversations.

<u>Intervention – Alignment with the parent</u>: It has been highlighted how difficult such family conversations, exploring the parent's mental health problems and its impact on

the children, can potentially be for parents, and therefore carefully facilitating these conversations, while actively supporting the parent and managing the intensity of the conversations (Pihkala, et al., 2011) is important. Here the role of the therapist can be conceptualized as, where possible, strongly aligning with the parent in mediating the impact of the parental mental health difficulties on the child.

Intervention – Externalizing: The position from where the family have these conversations is important. Families could be provided with the opportunity to view negative aspects of the parent's mental health problem as something 'outside' or 'apart' from the representations of the parent and from the hopes and dreams the parent might have for their life and for their child, through externalizing practices (White, 2005; White & Epston, 1990). By externalizing the parent's mental health difficulties, the family members are able to see the parent as separate from the problem, thus allowing parents and children to unite in exploring together their hopes for family life. This allows for a move away from a polarized view of the needs of parents and children.

From this externalized position it can be valuable to facilitate decision-making about families' preferred relationship with their difficulties while acknowledging that at times the difficulties may take over (Mason, 2004). There should be allowance for the mental health issues not to dominate life where possible – that is, the parent and their children could have a "secondary relationship" (Mason, 2004, p. 18) with the difficulties, allowing for their relationships with one another to remain central and making space for the ordinary and everyday.

Intervention – Telling 'double-stories', acknowledging the positive alongside the negative: In addition to externalization, therapeutic work needs to respond to the constant interaction between the positive and the negative within their lives and their relationships, as described by the parents in this study. Telling 'double-stories' (White, 2006) is particularly useful in responding to this complexity. It is important to fully hear, acknowledge and validate the difficulties faced, but also to fully hear, acknowledge and validate the skills and knowledges developed by living through the difficulties and the responses and resistances to the difficulties (Denborough, 2010; Pluznick & Kis-Sines, 2010; White, 2006).

This could include finding the relational places the mental distress could not touch. This can be achieved by searching for stories of care, love, and personal agency alongside stories of suffering, failure in love or care and lack of influence or control. Furthermore, what a parent is able to do for their children, despite the challenges (Pluznick & Kis-Sines, 2010; Walsh, 2009; White, 2005) could be made visible and given significances and the ways parents continue to love and cherish their children could be included and valued. The challenge is to not silence the difficult times, but also not neglect the unique and positive aspects, thus honouring complexity and multiple storylines in relationships between parents and children.

The aim of these therapeutic interventions is thus not to justify the parent's actions of hurt, abuse or neglect or to dislodge or replace memories of hardship (Denborough, 2010). However, it seeks to accompany these recollections with memories of responses, skills, values and specific knowledges. This frees the child from having to disregard their feelings of love, care and compassion. Furthermore, it frees the parent to take an active position in the healing of their child, and enables the therapist to actively invite the parent into this position.

Intervention – situating the parent as active agent in the protection and healing of the child: It has been highlighted in this study that it could be highly valuable to provide the parent whose child has been affected by their mental health problems with an opportunity to recognise and understand the child's distress and provide comfort to their child. This could enable parents to empathise with their child's experiences, without that negatively impacting on their sense of self or their parenting identity. Focht-Birkerts & Beardslee (2000, p. 420) state “the risk to children can be diminished if the context within which the emotional pain is experienced is changed”, that is, if parents are willing to respond in an accepting and validating way to their children's reactions of pain, even if they themselves have caused the pain.

Intervention – deconstructing stigma: As has been shown in the previous section, it is important for interventions to directly address the impact of stigma. Thus, narrative approaches can enable the deconstruction of stigma within the lives of the family (Freedman & Combs, 2002; White, 1989, 1995). Family members can be helped to consider internalized stigmatizing views of self, potential stigmatizing views of the parent with the mental health issue and fears about being stigmatized by those outside the family. This will allow a consideration of the impact of stigma on talking within the family and the development of skills in managing the impact of stigma on the lives of all in the family.

Thus, in summary, families can gradually over time develop a language for discussing the parental mental health issues and its impact on family members and can develop skills for responding to challenging periods or times of crisis. Furthermore, families can reflect on and review their unfolding relationship with the parent's mental health problems and value their own and one another's positive responses to the difficulties.

In addition to these shared spaces for talk, the findings also point to the potential importance of providing individual spaces for both parents and children to talk about their experiences.

9.4.2.1.2. Talking individually: Parents

Parents' experiences were shown to include suicidal thoughts or actions, bizarre, frightening and confusing mental experiences and traumatic events, for example in relation to hospitalization or periods of crisis. Modelling clear boundaries about what to share with children, while also allowing parents opportunities to process such experiences, seem important.

Also, it has been discussed how difficult parents found it to regain a coherent and acceptable sense of self within the context of their mental health problems, and such identity work might best happen away from the children where the parent feels able to engage with the complexities and contradictions involved:

Intervention - Providing respectful witnessing for suffering: It has been shown in this study how the most troubling and disturbing aspects of mental distress can often remain outside of conversation. Providing a context for the telling and receiving of frightening, disturbing and overwhelming stories, however terrifying, incoherent or painful (Gaillard, et al.'s, 2009; Whittaker, 2009) and placing nothing outside the scope of respectful attention in conversations with parents is significant (Charon, 2005, 2007; Weingarten, 2004; Whittaker, 2009).

Intervention – Co-constructing a workable identity: In addition to bearing witness, supporting parents in making sense of their mental health difficulties and of themselves within the context of these difficulties, is important (Baldwin, 2005; Charon, 2005; Wellard, 1998). Given the identity implications of mental health difficulties shown in this study and elsewhere (Barker, et al., 2001; Davies & Allen, 2007), introducing interventions specifically aimed at strengthening identity can be very powerful. For example, Denborough (2010) uses the idea of “memory traces” (Rassool, 2007, quoted in Denborough, 2010, p.65) to illuminate personal values in life that remain and thus develop a sense of a historical continuity of self, despite and around the difficulties (Chandler & Lalonde, 1998 cited in Denborough, 2010). Furthermore, as Davies & Allen (2007) have emphasised, integrating the sense of self as someone with mental health issues and the sense of self as a parent, is necessary. Supporting people in their meaning-making in this way may begin to give some shape to the reality of their at times overwhelming experiences (Brockmeier, 2008).

Intervention – Addressing power in relational negotiations: Finally, in this research parents described on occasion needing or wishing for the care and protection of their children. At times it was clear how the mental health problems became a powerfully non-negotiable tool in the parent's attempts to have these needs met. Furthermore, to help them cope with acknowledging their children's awareness of their mental health problems, parents often cast their children as particularly mature and as knowing and knowledgeable about their difficulties, increasing what they felt could be expected of their children. These perceptions and interactions potentially posed challenges to the parent-child relationship and to the wellbeing of the child, and could restrain the child's own meaning-making. The struggles or vulnerability the parent themselves may be experiencing at these times, could obscure these impacts on their children. Thus, it is important to create a safe space for parents to develop an awareness of such perceptions and relational patterns, consider their needs at these times and develop strategies to respond in ways that may be less detrimental to the child. The findings of this study, as well as the family therapy literature, points towards the importance of the therapeutic consideration of the parent’s own history and transgenerational patterns in this regard (Andolfi, Angelo & de Nichilo, 1989).

9.4.2.1.3. Talking individually: Children

In addition to the potential value of talking to parents on their own, parents consistently indicated that they wanted their children to have a space to talk about their experiences free from a need to protect the parent, and therefore opportunities for children to have such conversations could be important. Providing them with a context for understanding the parent’s difficulties allows them to separate what happens from their own identities, to, as Michael White used to call it, “come to reasonable terms with” (Denborough, 2010, p. 63) their lives and histories.

Intervention – Exploring subtle but pervasive impacts on children: In these conversations with children it is particularly important to explore not only the risk factors, but to pay close attention to the more subtle, pervasive impacts of the parent’s difficulties. Here, paying attention to emotions (e.g. guilt, lack of confidence, uncertainty, worry, anger or fear) might be particularly significant (Focht-Birkerts & Beardslee, 2000). There is a need for these potentially disturbing affective experiences to be acknowledged and integrated into the lives of the young person without judgement or sanction.

Intervention – Acknowledging children’s responses to the challenges posed by their parent’s mental health problems: In addition to this acknowledgment of hardship experienced by children on many levels, from the parents’ accounts and the wider literature it is apparent that much of the ‘information’ children wished for in relation to understanding their parents’ difficulties spoke to the challenges of living with uncertainty and hardship. Helping children develop the skills of living in difficult circumstances could go a long way to helping them experience their situation as more manageable and strengthening their resilience (e.g. how to respond to uncertainty, how to reconnect with a parent after a crisis, how to find activities and relationships outside of home life to sustain them in difficult times, etc.). This should include naming, acknowledging, validating and strengthening children's own positive responses to hardship and supporting them in making changes and developing new skills where they are struggling (White, 2006).

9.4.2.1.4. Conclusion

It is suggested here that both family talk and individual conversations with parents and children could be therapeutically important. When talking individually with parents and children there will need to be an on-going consideration of how individual conversations could feed back into family conversations so as to allow developments in these conversations to benefit the on-going family discussions. Thus, therapy can provide an opportunity to "reinvigorate the conversations" silenced by the mental health problems (Penn, 2001, p. 33), to regain a conversation in which conversational intimacy and clarity can be discovered in relation to the painful and previously 'unspeakable' experiences the family have shared. Families can be helped to remain strong in times of crisis by building relational resilience through these shared conversations over time.

9.4.2.2. Creating spaces for complex understandings of mental distress

In addition to the above, it is further necessary to consider therapeutic responses to the complexity in understanding of mental distress that was described by parents in this study. The findings of this study have challenged the assumption of a clear, medically informed explanation of parental mental health problems. Furthermore, being provided with such information did not equal understanding for participants. Therefore, within the therapeutic encounter ever-changing contexts need to be attended to, mutability needs to be acknowledged and constant re-evaluation of meanings needs to be facilitated.

Again, a number of specific interventions, suggested by the current findings, in relation to creating spaces for complex understandings of mental distress are now discussed:

<u>Intervention: Creating spaces for the negotiation of meaning:</u> This study highlights the multifaceted nature of people's understanding of their distress and the divide that there often was between professional and personal understandings. Opportunities for dialogue between professional and lay understandings (Barker, et al., 2001; Combs & Freedman, 1999; Cronen & Lang, 1994) could therefore facilitate joint meaning-making, thus "allowing for a wider range of less problematic narratives and subject positions to emerge" (Avdi, 2005, p. 493). Here a stance of openness, curiosity, 'not-knowing' and collaboration as developed within postmodern family therapy approaches (Anderson, 1997; Anderson & Goolishian, 1988, 1992; Hoffman, 1993) and focussing on "language system(s) and linguistic event(s)" (Anderson, 1997, p.2) are particularly valuable. Furthermore, Mishler and colleagues' (1989, cited in Ingrassia, 2013) suggestion of the attentive interview, "characterized by attentive questioning and listening" rather than interrupting and asserting authority through presentation of an alternative professional explanation to the personal explanation held by the person (Ingrassi, p. 147), is useful.

This could include exploring the complex stories people tell of their experiences (Mattingly, 2008), thus creating a context where these multiple stories about parental mental distress can co-exist (Altscuhler & Dale, 1999) and evolve over time. In particular, changing meanings and understandings should be tracked over time with the family (e.g. following periods of crisis, when new information has been received, when children move into different developmental stages and their needs change, etc.) within the context of their evolving relationships. The ways in which other significant figures in children's lives play important roles could also be acknowledged and explored as part of these conversations. This study has shown how unfamiliar parents were with the discussions about their mental health issues that were taking place between their children and others in their lives. Adding understandings that are forming within these relationships (e.g. with the other parent, another family member, the parent's mental health worker, etc.) to the conversations between parents and children could allow for greater openness and coherence.

Intervention – remaining curious about parents' positions and choices: Once a parent's own meaning-making becomes viewed as meaningful and useful, it allows for a different engagement with the positions the parent takes in relation to talking to their children about their difficulties (Reed, 2012). This study has clearly shown the complex, nuanced and intricate processes informing parents' choices and actions in relation to talking and remaining silent. Thus, there can be a move away from a construction of parents as for example 'in denial' or 'lacking insight' towards an active exploration of the perspectives, understandings and needs informing parents' choices about what, when and how to tell their children about parental mental health concerns. Adopting a gentle and curious form of enquiry around talking and silences allows for richer understandings to develop.

From this open and curious exploration, parents might acknowledge struggles in different areas relating to talking with their children about parental mental health issues. For example, parents might appreciate help in their transition to acknowledging awareness or where they experience a conflict between for example a need for closeness and connection and a need to protect. At other times, they might have valid and useful reasons for keeping silent around certain areas or issues, and the clinician could work to understand these better. In these ways families can be accompanied in their moving between talking and silences over time.

Thus, through therapeutic conversations that allow for complex understandings and storylines in relation to parental mental health issues to co-exist, all experiences and perspectives can be included and contradictions can be accommodated and explored. Furthermore, the therapist can accompany the family through the different choices they make in relation to talking and remaining silent over time, working to understand rather than judge such choices. This could facilitate understanding and coherence as the stories around the parent’s mental health concerns continue to evolve over time, and through this resilience could be enhanced (Byng-Hall, 1995; Medved & Brockmeier, 2008; Rutter, 1985).

9.4.3. Conclusion

This section has presented a number of guidelines for service development and clinical practice that flowed from the findings of the study and the theoretical considerations as discussed earlier. The importance of family-orientated, accessible, responsive and comprehensive services for families where there are parental mental health issues was emphasised. Furthermore, creating spaces for talking together and talking individually (for both parents and children) over time and creating spaces for complex understandings of mental distress to be shared were discussed. Within this the significance of casting both parents and children as active meaning-makers and creating contexts for telling ‘double-stories’ where positive aspects of the relationships could be acknowledged alongside suffering and challenges, were stressed. Also, the importance of considering identity implications of mental health problems (especially within the context of stigma) within therapeutic work was highlighted. Through these processes both talking and keeping silent can be understood and valued.

This concludes the reflections on implications for clinical practice. I will now return to some final methodological considerations before considering future research.

9.5. METHODOLOGICAL CONSIDERATIONS

Methodological strengths and limitations were comprehensively considered in Chapter 5 in relation to: method, recruitment, participants, interviewing and finally the disruption of the research process and the implications for the scope of the study and theoretical sampling. Here some final considerations are presented as the end of the study approaches.

9.5.1. Limitations of interview data

The limitations of interview data was acknowledged in Chapter 5 and will here be considered in more detail. Charmaz (2002) highlights the importance of being aware of disparities between lived experiences and accounts of it – stories do not encompass all experiences – researchers select events to tell the story, but bringing events together imposes a higher order on them than actually occurred (Polkinghorne, 1997, cited in Charmaz, 2002). As we strive for coherence, “interviews… elicit rational accounts that explain events and justify actions” (Charmaz, 2002, p. 304). Furthermore, the researcher actively contributes to the constructions of meaning within the interviews (Potter & Hepburn, 2005). Given these criticisms of interview data, the researcher aimed to make the research process visible, and to show moments of incoherence or broken and contradictory narratives as well as times when the researcher as interviewer was striving for coherence or meaning, thus shaping the stories told.

Furthermore, based on what is known about parents with mental health problems and their fears about losing custody of their children, it can be assumed that this would have influenced participants’ choices of what to tell and wishes to be perceived positively. The way the researcher was part of the local services and the implicit power imbalances would also have impacted on how participants chose to talk (Lumsden, 2013). These factors need to be held in mind when considering the findings of this study. However, it was interesting to note that parents mostly welcomed the opportunity to talk about their experiences and their children and indicated that they had not had the opportunity before to talk about these things.

Finally, one of the criticisms of interviews is that they only provide a certain unique account of the experiences of research participants at a specific time within a specific context (the research interview) (Potter & Hepburn, 2005). From a social constructionist perspective this limitation of the interview format needs to be acknowledged, and interview responses treated as actively constructed narratives between the participant and researcher and this needs to be taken into account when interpreting the research.

9.5.2. Limitations in absence of observation of talk

Some questions in relation to talking and being silent within the family were not answered by this study. As we do not have access to the actual conversations between parents and children, it does not tell us about the talk that naturally occurs between parents and their children about parental mental health difficulties. Importantly, it also does not tell us about the children's experience of the telling or absence of telling and about how that changes outcomes for children. This point will be returned to when considering directions for future research.

9.5.3. Transferability

The grounded theory presented here is situated within the specific context of the current study and therefore claims are not made about transferability. Nevertheless, it is hoped that it provides clear directions along which to look (Clarke, 2005) when considering talking and keeping silent within the context of parental mental health problems. The findings point to service development considerations, positions for therapists, and guidelines in relation to content and process of therapy, that it is hoped will provide helpful guidelines for practitioners to consider when working with families where there are parental mental health concerns. Attempts have been made throughout to robustly link this research to existing literature in order to increase transferability. Furthermore, as Wuest (2000) states, the strength of Grounded Theory as a method of theory development is that it is modifiable with new data. Therefore, through the continued use of emergent fit the theory can be expanded, revised, and adjusted to maintain its usefulness in explaining how parents and children talk together about a parent’s mental health difficulties (Wuest, 2000). This will be considered further under future research.

9.5.4. Conclusion

This section, together with earlier reflections in Chapter 5, presented a number of methodological considerations that need to be held in mind when considering the findings of this study and future research.

9.6. FUTURE RESEARCH

Further research that might build on the current study will now be discussed.

9.6.1. Expanding on the current study

Theory generation in Grounded Theory is an “ever modifying process” (Glaser, 1978, quoted in Wuest, 2000, p. 51). Wuest (2000) warns against the “generation of isolated theories” (Wuest, 2000, p. 51) and suggests the continued evolution of a Grounded Theory through emergent fit. That is also the hope for this study.

Triangulating the findings from this study with the perspectives of firstly, the children themselves and also of those surrounding the parent and child (in particular the other parent, grandparent, or other close family members) on talking and being silent, would greatly enrich the current study. From this research it is clear that the conversations between the child and others about the parent’s mental health difficulties are not only obscured from researchers and clinicians, but also from the parents. This speaks directly to the current research question and thus should be a priority for further research.

Furthermore, within the context of this study the taken-for-granted position in the literature that ‘children want more information’ appears simplistic. A study building on other researchers’ work which positions children as active agents in the construction of their lives and relationships (Mordock & Hall, 2008; Riebschleger, 2004; Van Parys and Rober, 2012), but that focuses specifically on children’s relationship with talking and being silent inside and outside of their families, and that allows for the complexities around children’s choices that the current study hints at, is indicated.

Also, the current research moves the debate away from ‘information’, and highlights the importance of a wider understanding of human responses to trauma, change and uncertainty within the context of mental distress and the meaning-making processes around these. Thus, emotional attunement and responsiveness, attention to what lies outside language and the way talk is relationally constructed become worthy foci for further research.

Moreover, this project has shown how difficult it is to come to an understanding of the meaning-making processes within families around parental mental health problems. Even if we were to be able to go ‘behind the closed doors’ of families living with parental mental health problems and observe their ‘every-day’ conversations, capturing the unique and individual subtleties, nuances, contradictions and complexities of how understandings are formed and “diffuse” (Van Parys & Rober, 2012, p.1), how understandings shift and change, become clear, but then disappear over time, would be a challenge to fully and richly represent through research. Gladstone, et al. (2006) highlight that to date research fails to recognise that experiences of ‘mental illness’ may have a unique meaning for each member in a family. The lack of knowledge of individual perspectives and responses underestimates the complex tasks families face in making sense of mental distress.

However, as this study begins to show, our understanding can be greatly enhanced by opening up conversations that allow for such subtleties, nuance, contradictions and complexities to emerge, either as here, within individual conversations, or as Van Parys and Rober (2012) and other researchers are beginning to show (e.g. Rhodes, 2013), with research with families talking together. Therefore, qualitative analysis of whole-family conversations allowing for the study of interactional data would be highly valuable. In particular, the current study points towards the importance of accessing small stories (Tovares, 2010) in research into how parents and their children together come to make meaning in relation to parental mental health problems; that is “the exploration of narratives as embedded in daily, often mundane, activities and situations” (Tovares, 2010, p. 3-4).

Finally, looking back on this study, it is clear that there are a group of more vulnerable, marginalized and socially excluded parents, those who are not well engaged with services, those who fall outside the benefit, educational and health systems (e.g. those who have entered the country illegally) and those who have lost custody of their children, whose views are not represented in this research. It has been highlighted how difficult it is for researchers to identify and gain access to these parents (Aldridge, 2013) and recommendations have been made to recruit through peer identification, word-of-mouth and snowballing strategies and to collaborate actively with these parents in order to represent their views in the research literature (Aldridge, 2013, 2014). This should be a high priority within the parental mental health field, as these “multiply vulnerable” parents (Aldridge, 2013, p. 4) and their families are more at risk due to histories of multiple trauma and their isolation and marginalization.

9.6.2. Gendered perspectives within parental mental health research

9.6.2.1. Research with fathers

The absence of fathers in research has already been highlighted and it has been shown how difficult it was to recruit fathers to the current study. The fact that ‘parents’ were heard as ‘mothers’ within this study indicates that research specifically focused on fathers might be more useful. It is clear from the limited literature and data in this study that fatherhood is a potentially highly significant role for men with mental distress and it is essential that research begins to highlight this.

The current study highlights that fathers’ mental health problems, like mothers’, might significantly impact on relational and identity contexts and this needs to be further explored. Thus, the meaning and experience of fatherhood and the interrelationship between fatherhood and mental distress needs to be a priority within parental mental health research.

9.6.2.2. Research with mothers

Despite motherhood dominating the parental mental health literature, the current research highlights gaps in our understanding of the meaning of motherhood for women with mental health difficulties and their experiences of their identity as mothers within the context of their mental health issues, their experiences of parenting and the choices they make in relation to the parent-child relationship. Thus, further research that specifically explores these identity-sites for women with mental health difficulties who are parents is indicated.

9.6.3. Meaning-making around mental distress

A key aspect that is highlighted by the current study within the context of parents talking to their children about parental mental health problems was the parents’ own meaning-making around their mental distress. This is an under-researched area that requires further attention.

The following areas are relevant:

9.6.3.1. Talking within psychiatric contexts

This study showed a dissonance between how mental health practitioners explain mental distress to service-users and the meanings people hold themselves around their difficulties. This becomes even more complex when account is taken of other aspects like poverty and migration, given the findings in this study that parents did not discriminate between mental health issues and other difficulties. Therefore, talk between clinicians and users of mental health services deserves further attention. Process research of therapy sessions where clinicians are working with families where there are parental mental health problems would allow for the analysis of such talk.

Furthermore, discourse analyses investigating the ways pathological identities are constructed, maintained or dissolved in talk within psychiatric contexts, specifically with regards to psychiatric diagnosis, are scarce and highlighted as significant within the current study.

9.6.3.2. Subjective experiences of psychological distress

Adame & Hornstein (2006) claim there is a paucity of research on narratives of emotional distress. The current study powerfully highlights people’s struggle to make meaning and come “to reasonable terms” (Denborough, 2010, p. 65) with their mental health issues. Further research to understand this struggle and explore what facilitates movement towards a personal sense of coherence would help guide clinicians working with the clients where there are parental mental health issues (see as example, Lysaker, et al., 2003).

9.6.4. Identity implications of mental distress

This study has shown that mental distress has significant identity implications for people, and maybe in particular for parents. There is a wide body of research within health psychology focusing on the identity implications of living with chronic illness. Applying this research within a mental health context is relevant here. How people make sense of who they are once they are living with mental health difficulties; how they story who they were before and who they become; how they experience where the ‘illness’ ends and they begin – all these are valid foci for further research. In relation to identity, the current research has evoked a particular interest in positions people take up within the context of integration vs. externalization of ‘mental illness’. Furthermore, the mechanisms of how children separate and integrate the person of their parent and the mental health issues (Walsh, 2009) are worthy of exploration.

Finally, the current study provides guidelines for clinical practice particularly relating to families talking together about parental mental distress. Thus, how to facilitate this process within a therapeutic context requires further investigation. In particular, there is scope to further develop and evaluate systemic, narrative and other therapeutic interventions that focus on these guidelines.

9.6.5. Contextualization of mental distress

This research has once again shown that on-going research into the impact of and ways to combat the presence and effects of stigma around mental health issues in society is essential.

Thus, there are a number of fruitful avenues that have been highlighted here that might be taken up to build on the current research.

9.7. FINAL SELF-REFLECTIONS

As I approach the end of this project, I have Harding's (1991, cited by Charmaz, 2002, p. 321) concept of "strong reflexivity" in mind, where the invitation is to envision our research participants gazing back at us and the research process from their standpoints, and to then also stand behind them and look at social and cultural specificity of our project and its location with other projects, while we look forward to shaping the next step in the process.

As I reflect on the above, I notice much that I had in common with my participants - experiencing the ups and downs, the achievements and challenges, the joys and sorrows of life and of parenting. I also noticed differences. These mostly related to levels of marginalization related to racial and cultural minority status, experiences of poverty and daily financial concerns, and experiences of trauma and abuse. In particular, I became aware of a view of concerns around health or wellbeing coming into one's life as a discreet (yes, often traumatic) event within a life that might otherwise be progressing relatively smoothly. Coming to terms with such life-changing events within the context of many other daily stresses and challenges requires something quite different. I therefore hope that I have done enough to fully situate my research within the context of the complex challenges of people's lives.

9.7.1. Impact of own illness experience

Having experienced illness myself while undertaking this research, and having been confronted personally with "the precarious nature of what upholds and grounds our loves" (Hydén & Brockmeier, 2008, p. 2), I found myself less fixed on the 'ifs' and 'hows' and 'whens' of talking about illness. I found myself instead becoming more interested in the experiences behind the choices – does one's own confusion and uncertainty make it difficult to know how to help others understand what is going on;

is there worry that the balances in relationships will shift too much (e.g. in giving and receiving care); that ‘normality’ will be lost and life will become defined by only this one thing; is there protection and if so, by whom and from what (Reed, 2012)? These questions informed by my personal experience, have impacted on the direction of the research and allowed for a more open curiosity about the experiences surrounding choices around talking.

Furthermore, as researcher I noticed myself being drawn throughout this process to choose between the viewpoint of the parent and the viewpoint of the child, and found myself empathising with one position now, with the other position the next moment, especially in the context of crisis, or severe difficulties in the parent that clearly powerfully impacts on the child. I was constantly challenged with representing the pain, anguish and struggle of the parent, while not in the process minimising or denying the suffering caused to children; with working to represent the impact on children of their parent’s mental health difficulties, while not ascribing blame or judgment on parents.

I have come to view this dilemma of dualism as powerfully situated within stigma. When I experienced my own illness while undertaking this research, conversations about the fact that my children will be powerfully impacted by me as their mother being ill was initiated by both myself and more significantly by those responsible for my care. However, despite these being extremely painful conversations, practitioners went out of their way to help me not relate this to blame or shame. Rather, I was invited as the expert on myself, my children and my family, to give direction to how best to mediate the potential impact on my children, while being provided with containing and essential support in how to implement such strategies to protect my children and my own parenting identity. None of us came through this process unscathed, but through the help I received, and most importantly and significantly, through the stance of non-blame from practitioners, the relational intimacy was maintained, or where lost regained, and my identity as a parent protected. I believe that one of the main factors that get in the way of a similar approach to the impact of a parent’s mental health problems on their children is stigma.

9.7.2 Conclusion

Like many researchers I have been significantly shaped and changed by undertaking this research, personally, professionally and academically – I am very grateful to have had this opportunity.

A final researcher story:

Extract from research reflective diary:

A last story from behind my own closed door…

As I re-engaged with this research project I was confronted with the need to find a way to manage my own hopes and expectations for the future with my own newly acquired illness-identity. This involved much ambivalence on my part and the part of those close to me about whether I can and should still engage with such strenuous and challenging activities as doctoral research and what my life goals should be, what my life energy should be put into. My and others' hopes for me and expectations of me had shrunk to fit in the constraints of the illness description… like my participants I had, slowly over time, to negotiate who I was, wanted to be and could still be, within and alongside this new dominating organizing context of my self. It has been highly personally meaningful for me to reclaim some aspects of my professional self, albeit in a new way. I am left with a strong hope that such reclaimings of preferred identities will also be possible for those who participated in my research.

10. CONCLUSION

10.1. CONCLUSION

Life is 10 000 joys, and 10 000 sorrows – Buddhist saying

This study contributes to the existing literature on parental mental distress by presenting how a group of parents considered talking and being silent about their mental health issues with their children. It offers a rich exploration of the complex and evolving ways talking and being silent played out in relationships between parents and their children. Within the context of a significant focus throughout the parental mental health literature on the importance of information and developing understanding, I argue that this makes a novel and valuable contribution to the field.

At the end of this study I reflect on whether we as professionals imagine people who consult us who experience psychological distress and who are given labels of 'mental illness' as living within the boundaries of these 'illnesses'. What I have found rather, with those who participated in my study, was that their distress lived within the boundaries of their lives, alongside many other aspects of their lives. There were indeed times when their distress and its manifestations in their lives were centre stage, but there were also many other times when what was most visible was the ordinariness of everyday life, love, laughter, worries about money and children's education, tears, irritations, and silence, doing the washing up, cooking a meal, doing the housework. Within this reminders or questions might appear relating to mental health struggles, a television program, a song that played a lot when someone was last on an inpatient unit, a talk at school, something a friend said… at these times, small stories would be told, each a little piece of a puzzle that adds to a family and individual understanding of the why's and how's of the difficulties, and informs the choices of how to live with the struggles, challenges, uncertainties and contradictions that come with these difficulties.

As a clinician I argue that we are invited by the findings of this study to re-orientate ourselves to this perspective. The grounded theory co-constructed in this study requires us to move away from sterile, information-based, one-off and simplistic 'explanations' of parental mental health problems 'to' children. Rather it requires us to conceptualize talking in families about parental mental health problems within a framework that addresses the complexity described by the participants – one that allows for subtlety and nuance, for ambivalence and contradiction, and for development over time at a pace that fits with the family. Such a framework also challenges us to (re-)conceptualize relationships between parents and children where there are parental mental health issues as interdependent and reciprocal. Furthermore, it invites us to reposition the parent as central to the endeavour of protecting children and the children as active participants in this process.

This poses a challenge for services and practitioners on many levels. On a service-development level this conceptualization moves away from recent developments shaped by the cuts imposed on the National Health Service, with many specialist services (like the parental mental health team of which I was part) being cut. This not only loses the expertise and opportunity of specialist interventions, and the flexibility that allows for involvement with families over time, but also leaves the responsibility with generic services who are already overwhelmed by work loads. On a service-level, interventions that allow for complexity and ambiguity, and that require slow evolution of meaning-making over time, flies in the face of the trend towards short-term, one-size-fits-all interventions. In many ways this grounded theory highlights the many levels on which we are failing these families where there are parental mental health struggles.

10.2. Finally

The process of writing is "an interpretive, personal and political act" (Denzin & Lincoln, 1994, quoted in Russell & Kelly, 2002, p. 12/18). We often speak from a very privileged position and it is important that we spend our privilege well. As this research goes out into the world, I will have to judge whether I have done this. "Research represents a series of extended conversations” (Russell & Kelly, 2002, p.11/18). As I conclude this text, the conversation is extended. You as reader begin to actively engage with and interpret my construction of my participants’ telling. I look forward to hearing your responses, interpretations and reciprocal stories.

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12. APPENDICES

Appendix 1

LITERATURE SEARCH STRATEGY

LITERATURE SEARCH STRATEGY

A number of stages were followed in reviewing the existing literature in relation to the research question. These are set out below:

1. **Review of familiar literature:**

   Due to my clinical role within a Parental mental health team and involvement in previous research, I was already familiar with a number of key books and papers – this made a useful starting point for the literature review. It was important to revisit these with the particular research question in mind. These also provided in their own reference lists helpful pointers towards other key references, which were then followed up.

2. **Initial exploratory electronic search**

   Next an exploratory search was undertaken (initially with no time restrictions) using Google Scholar and the most significant social sciences and psychology databases, including PsychINFO, Web or Science, Medline, Pubmed

   Search terms included in different combinations:

   - parenting, mothering, motherhood, fatherhood, mothers, fathers, parents, parental, family, family life AND/OR mental illness, mental health issues, mental health problems, mental health difficulties AND/OR impact, coping, effects AND/OR talking, meaning-making, understanding, information.

   The references found through this search were followed up where appropriate. Searches for particular authors were then carried out, based on these references and any relevant articles cited within the reviewed papers were also followed up, repeating this process for each new reference.

3. **Internet search for key documents**

   The internet was searched for documents and resources relating to the area of parental mental health and to the research question, including a search for relevant DoH policies; website offering support and information to parents and/or children; NICE guidelines, Child protection policies, etc.

4. **Consulting experts**

   Colleagues with expertise in the field were also consulted about relevant papers and these were followed up as above.

5. **Final electronic search**

   Due to the length of time since the first search, a final search, repeating the process in stage 2 and 3 above, was carried out towards the end of the study, looking back over a 5-year period.

Appendix 2

CONSIDERING OTHER QUALITATIVE METHODS

CONSIDERING OTHER QUALITATIVE METHODS

Other qualitative methods were also considered before Grounded Theory was decided on. An account will now be give for why other qualitative methods were not selected for this study.

Grounded Theory and Interpretative Phenomenological Analysis (IPA):

These two methodologies have much in common. Both offer a somewhat more subjectivist focus on participants' experience, looking at phenomena from the perspective of those experiencing them and both focus on meaning. They can potentially also use very similar methods for data gathering and analysis, although IPA tends to almost exclusively rely on interview data, where Grounded Theory often use other data sources, e.g. texts or documents, media (e.g. newspaper data), etcetera.

However, IPA (Smith & Osborn, 2003) focuses powerfully on individual 'voice' and its representation – this makes it a more individual centred method, with less focus on the social and situational which is emphasised in Grounded Theory. Grounded Theory offers the possibility to go beyond 'the knowing subject' to also address and analyze salient discourses within the situation of inquiry. IPA aims to enter the lived experiences of the participants in the research, whereas Grounded Theory is interested in social processes. IPA can be viewed as more concerned with 'underlying cognitions', beliefs and attitudes (Willig, 2001) and therefore implies that these are there to be 'discovered', situating itself within a realist paradigm. Grounded Theory concerns itself with analysis rather than '(re)representation' (Clarke, 2005, p.8) by fracturing and pulling apart stories. Furthermore, IPA accounts less for the influence of the researcher on the research, whereas in Interpretive Grounded Theory all reports are seen as deeply mediated by the researcher (Clarke, 2005).

Grounded Theory and Narrative Analysis (NA)

NA aims to reveal the underlying structure of our narrative accounts that shape not only the way we account for our actions and those of others but also our very identity. NA researchers look at narrative structure to see how the texts were accomplished and organised, treating respondents' accounts as carefully constructed stories (Murray, 2003). Narrative analysis aims to explore and illuminate individual stories but does not aim to explore shared stories across the data or theorize around these stories. Grounded Theory has been criticized for fracturing or pulling apart stories, (e.g. violating the integrity of participants' narratives (Riessman, 1993)), but Clarke (2005) sees this as a strength of Grounded Theory, allowing for an analytical rather than (re)representational approach.

NA also has a temporal frame, tracking participants' stories over time and maintaining the temporal integrity of participant accounts. This approach is not a fit with the current research question.

Grounded Theory and Discourse Analysis (DA):

This study is concerned with social discourses and the impacts thereof on the participants and their experiences and actions, and therefore it was important to consider DA as methodology for this study. DA (Gee, 2005) sees language as a social performance and as productive. It explores how people use discursive resources in order to achieve interpersonal objectives in social interactions. Willig (2003) states that DA should ideally be used to analyse naturally occurring text and talk – therefore DA would have been a valuable methodology for analysing the actual conversations between parents and children about a parent's mental health difficulties should one have been able to gain access to such conversations. However, if used in the current study it would place the focus on the conversation between the participant and the researcher, which would provide very different data that would not answer the current research question looking at the processes related to the experience and actions of participants. As a matter of fact, DA questions the value of the category ‘experience’ itself and conceptualises it as a discursive move (Willig, 2003). This would take the focus away from allowing the experiences and views of the research participants to be centred. One could argue that Grounded Theory draws more on a hermeneutic of empathy and DA more on a hermeneutic of suspicion (Willig, 2013), the former being more in line with the current research question. Furthermore, although DA researchers agree that discursive constructions have ‘real’ effects in people’s lives, viewing talk only as ‘performance’ takes the focus away from these in a way that does not fit with the ethos of this study.

However, as this study evolved, discourse became more important, and therefore a situated Interpretive Grounded Theory approach as developed by Clarke (2005) was adopted that allowed for the inclusion of discourse within the analysis (see 4.6.3. in Chapter 4 and 5.13 in Chapter 5).

Appendix 3

SITUATIONAL ANALYSIS

SITUATIONAL ANALYSIS

Clarke (2005) describes drawing on four theoretical roots as she takes Grounded Theory methodology around the postmodern turn. These are, traditionally, symbolic interactionism, and for the further development of Grounded Theory, the work of Michel Foucault, taking the non-human explicitly into account and finally situational analysis through mapping.

Three types of maps are described:

Situational maps

Situational mapping supplements axial and selective coding. Clarke (2005) suggests firstly developing a messy map and then from that an ordered/working version. Once developed, these maps can be used with freedom and creativity by the researcher. For example, Khaw (2012) and colleagues adapted their messy map to focus in on just one particular phenomenon within the larger situation that they then developed in an ordered map and which became central to their analysis. Clarke (2005) also describes how elements in her own work were at times categorized under multiple headings as their salience can be quite differently inflected in this way and all sites of their appearance deserve consideration. Importantly, these maps also allow inclusion of ‘sites of silence’, that is the capturing of initial ideas or processes that are not explicit from the collected data, allowing for the consideration of these within the analysis. As is illuminated through the consideration of the theoretical roots underlying this form of analysis, it is important here to highlight the significance of this type of analysis even in a situation where the researcher is deeply focusing on small-scale intimate human interactions, as is the case in this study. From a social constructionist perspective all the human interaction in the situation is constituted in and through the properties and conditions of the broader situation. Therefore these elements need to be specified and the density and significance of structural and material conditions need to be fully explored and accounted for in the analysis. Once the maps are drawn they are used to do relational analysis, taking each element in turn and considering its relationship to every other element, and specifying the nature of that relationship. Messy and ordered maps and relational analysis should always be accompanied by memo writing (Clarke, 2005). Memo writing allows for noting new insights, signalling shifts of emphasis or direction, detailing further directions, etc.

Social worlds/arenas maps

"The tremendous strength of grounded theorizing after the postmodern turn lies in its meso-level analytic frameworks of which social world/arenas maps are key"

(Clarke, 2005, p. 110)

Social world and arenas mapping adopts a more macro-level approach within the analysis, exploring key collective actors and social worlds that operate in the situation of concern. Arenas can be seen as discursive sites – all actors in these sites have their own perspectives and commitments vis-à-vis the situation/arena and these are articulated through discourse, often in complex ways. Social worlds can be defined as "universes of discourse" (Mead, 1938/1972 and Strauss, 1978, quoted in Clarke, 2005) through which people organize social life. Each social world has its own primary activity. Social worlds/arenas are where individuals become social beings again and again through their actions of commitment to social worlds and their participation in those worlds' activities, simultaneously creating and being constituted through discourses. Commitments can be understood as both part of identity construction and as predisposition to act. People typically participate in a number of social worlds simultaneously and such participation usually remains highly fluid. Individual and collective identities are constituted through commitments to and participation in social worlds and arenas. Simultaneously, individuals compose social worlds. In wider arenas people commonly act as representatives of their social worlds, performing their collective identities. To make a social world/arenas map, one enters into the situation of interest and tries to make collective sense out of it. Specifying the key social worlds and arenas relevant to the situation under investigation and visually representing these social worlds and arenas is the major analytical task for this map. There might also be what is described in Clarke (2005, p. 112) as "segments of social worlds" – such segments can be social or reform movements within a particular world, or parts of worlds deeply committed to different facets of the world’s work. Any such segments need to be represented on the map as well. Discourses per se are not explicitly represented on social worlds/arenas maps - instead, the focus of these maps is on collective social action. Once the social worlds/arenas have been identified, the relative size, power and placement on the map can be considered. The next task is once again memoing about the maps. Once the basic social worlds/arenas map is done for the situation of inquiry, it becomes the basis for other forms of entering and interrogating the data. The analysis of social worlds/arenas is deeply rooted in symbolic interactionism and focuses on “meaning making social groups” (Clarke, 2005, p. 109) and collective action.

Questions of power enter the analysis here and lead to questions about how people organise themselves in the face of others trying to organise them differently, and how they organise themselves in relation to the broader structural situations they find themselves in and with which they have to come to terms. These maps also allow for the analysis of reluctant participation in social worlds. Some actants are implicated in situations, rather than being part of the communication. They can either be physically and/or discursively present in the social world/arena. The concept of implicated actants can be particularly useful in the explicit analysis of power in social worlds and arenas.

Once again, it is important to note here that even where one’s research project is using in-depth interviews focused on individuals’ lived experiences of something as with the current study, the phenomenon of interest will be imbedded in social worlds and arenas – scenes and sites of collective action. These social structural elements deserve articulation in project narratives, as they are fully present and quite consequential in the situation that the individuals are describing and in which their specific (inter)actions that are the focus of the research take place. So one’s research could be a study only from the perspective of one segment of a social world in the arena (in the current case, parents with mental health difficulties), but the presence of all the other worlds are pervasively experienced and consequential for the participants. Moreover, the views from that one world often are far from singular. Where one’s research represents the views of people who are not collectively organised or in communication with one another (again, as in this study), these people will themselves be varyingly aware of and involved with the social worlds and arenas in which their difficulties are studied, but those worlds are largely consequential for them. They are implicated actors in those worlds.

Positional maps

The goal of positional mapping is to represent the positions articulated “on their own terms” (Clarke, 2005, p. 126), not the terms of the researcher, but rather the researcher’s best efforts to grasp and represent the positions taken in the discourse. This further contributes to the democratic theory of representation mentioned above.

“Perhaps the most important and radical aspect of positional maps after the postmodern turn is that positions are not correlated/associated with persons, groups or institutions, but rather the aim is to move “beyond the knowing subject” (Foucault, 1973, quoted in Clarke, 2005, p. 126) and therefore not “represent” individuals or groups. Positions in positional maps are positions in discourses. Individuals and groups of all sorts may and commonly do hold multiple and contradictory positions on the same issue. Positional maps represent the heterogeneity of positions.

To do positional maps one first seek to elucidate from the data what the basic (often but not always contested) issues are in the situation of inquiry about which there are different positions, and array these dimensionally in some way. Analytic fracturing – basic Grounded Theory coding and situational and social worlds/arenas mapping – opens up the data for positional analysis. Thus, coding allows the researcher to see and ultimately carefully name the different positions held down in the data. A number of positional maps are likely to be produced for a project, and as always with Grounded Theory there is then the need to memo about these maps.

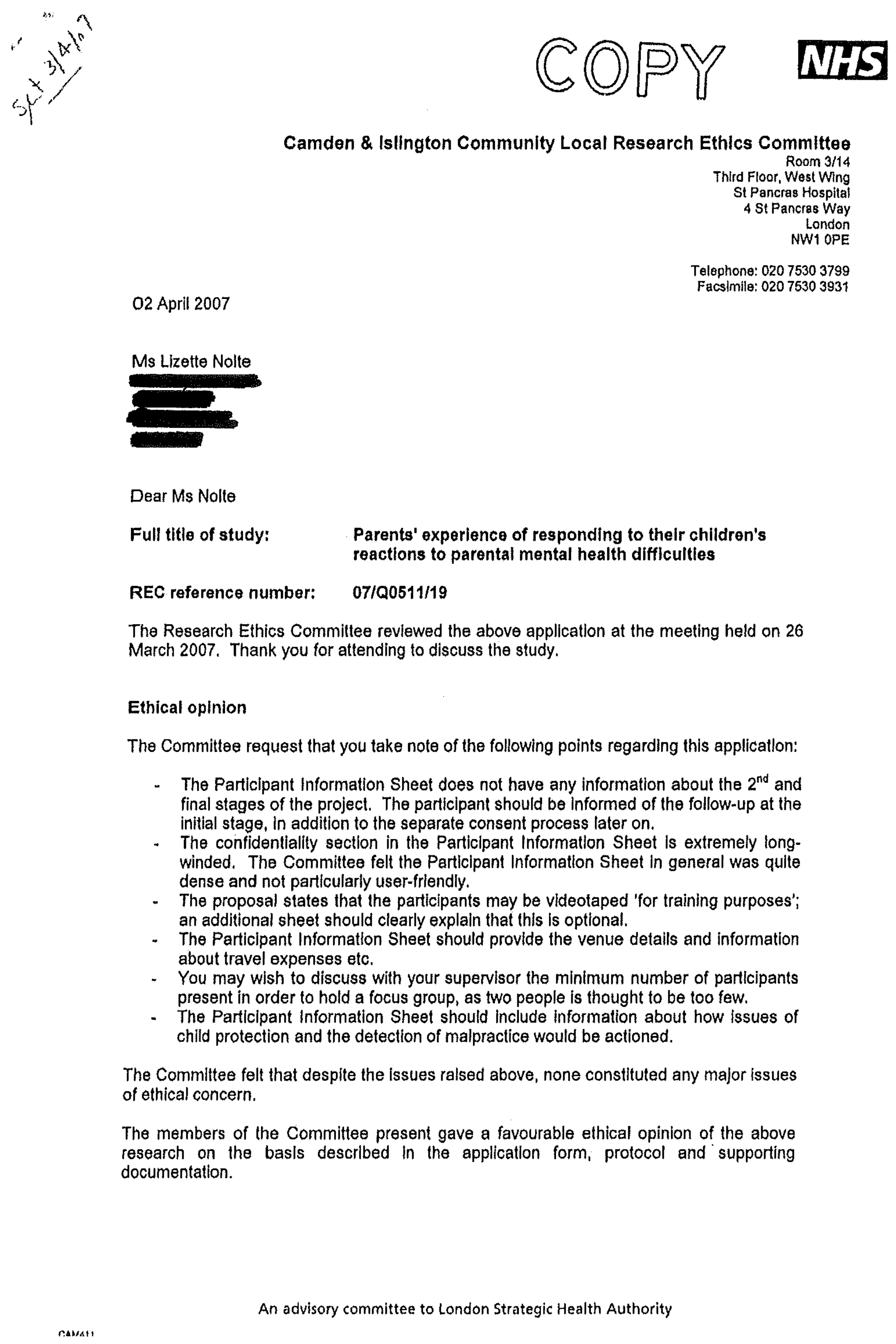
In Clarke’s (2005) opinion positional maps help us with a few particular difficulties we have as researchers – firstly, she states that we are constantly blinded by binaries and find it difficult to move beyond them at the cost of heterogeneities; secondly, it is difficult for us to see that which we do not expect; also, it is difficult to see that which we do not grasp or understand; and finally, it is difficult for us to hear silences. Also, in her view positional maps allow us to “attempt to step outside the politics of representation that tend to routinely and at times tediously imbricate us in various politics of identity” (p. 127). Positional maps allow us to articulate these doubts and complexities.

Clarke (2005) encourages researchers to look at these three types of maps as “analytic tools to be used on their own or with discourse data and/or along with and complementing other theoretic and analytic approaches” (p. 146).

Appendix 4

LETTERS OF ETHICAL APPROVAL

LETTERS OF ETHICAL APPROVAL



Snt 3/4/07

COPY **NHS**

Camden & Islington Community Local Research Ethics Committee
Room 3/14
Third Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

Telephone: 020 7530 3799
Facsimile: 020 7530 3931

02 April 2007

Ms Lizette Nolte
[redacted]

Dear Ms Nolte

Full title of study: **Parents' experience of responding to their children's reactions to parental mental health difficulties**

REC reference number: **07/Q0511/19**

The Research Ethics Committee reviewed the above application at the meeting held on 26 March 2007. Thank you for attending to discuss the study.

Ethical opinion

The Committee request that you take note of the following points regarding this application:

- The Participant Information Sheet does not have any information about the 2nd and final stages of the project. The participant should be informed of the follow-up at the initial stage, in addition to the separate consent process later on.
- The confidentiality section in the Participant Information Sheet is extremely long-winded. The Committee felt the Participant Information Sheet in general was quite dense and not particularly user-friendly.
- The proposal states that the participants may be videotaped 'for training purposes'; an additional sheet should clearly explain that this is optional.
- The Participant Information Sheet should provide the venue details and information about travel expenses etc.
- You may wish to discuss with your supervisor the minimum number of participants present in order to hold a focus group, as two people is thought to be too few.
- The Participant Information Sheet should include information about how issues of child protection and the detection of malpractice would be actioned.

The Committee felt that despite the issues raised above, none constituted any major issues of ethical concern.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

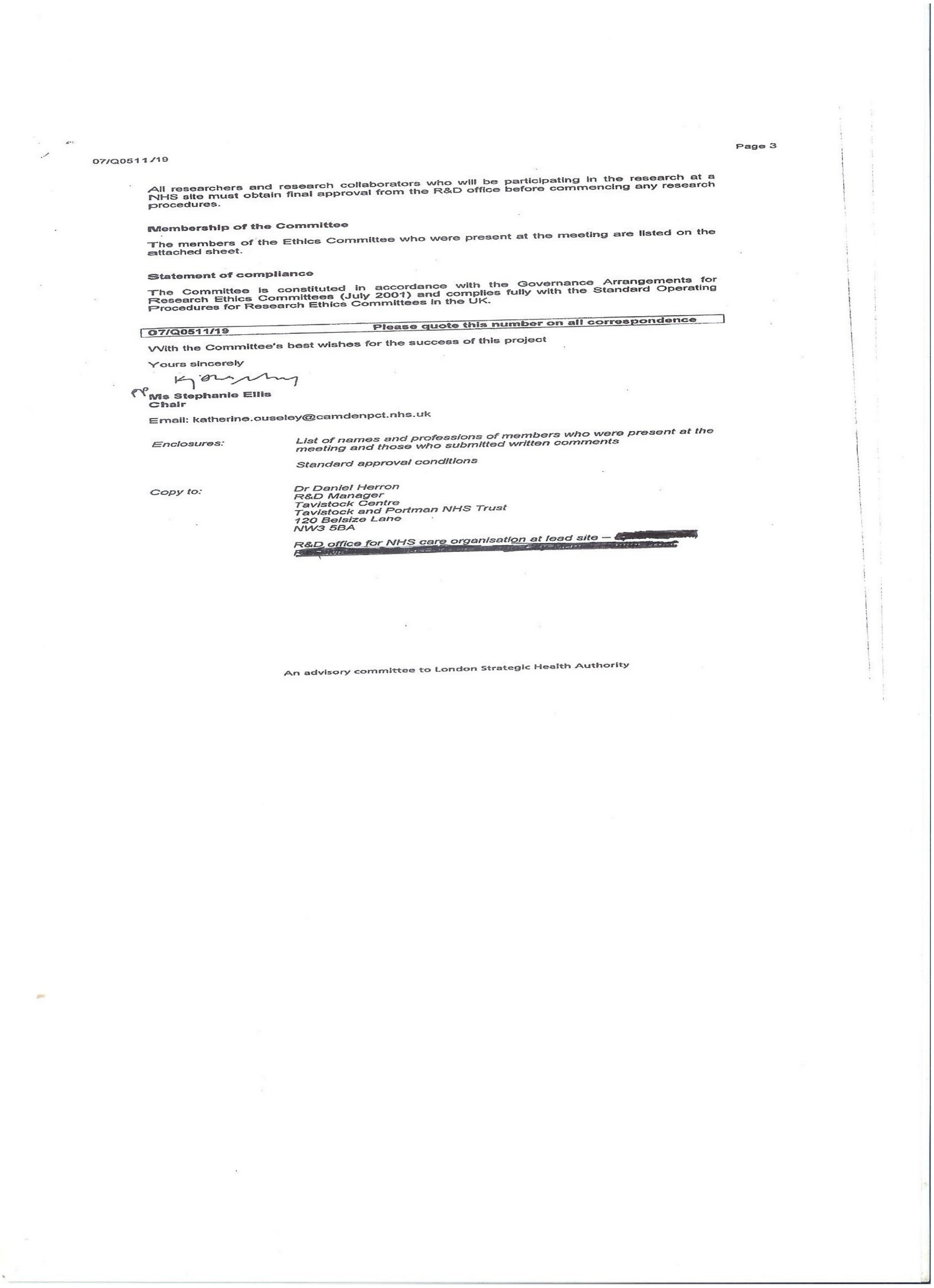
Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application		01 February 2007
Investigator CV	Supervisor's CV - Bernadette Wren	
Investigator CV	C.I. - Lizette Nolte	29 January 2007
Protocol	Version 1	29 January 2007
Covering Letter		24 February 2007
Summary/Synopsis	Version 1	29 January 2007
Letter from Sponsor	Dr Daniel Herron, R&D Manager, Tavistock & Portman	23 January 2007
Peer Review	Reviewer Dr Bernadette Wren	02 February 2007
Peer Review	Charlotte Burck, Tavistock Registration Board	20 November 2006
Interview Schedules/Topic Guides	Focus group for mental health workers; Version 1	29 January 2007
Interview Schedules/Topic Guides	For individual interviews; Version 1	29 January 2007
Interview Schedules/Topic Guides	Focus group for service users; Version 1	29 January 2007
GP/Consultant Information Sheets	Letter to Team Leaders; Version 1	29 January 2007
GP/Consultant Information Sheets	Letter to Consultant Psychiatrists; Version 1	29 January 2007
Participant Information Sheet: For mental health workers	Version 1	29 January 2007
Participant Information Sheet: For service users	Version 1	29 January 2007
Participant Consent Form: For mental health workers	Version 1	29 January 2007
Participant Consent Form: For service users	Version 1	29 January 2007
Confidentiality Agreement for transcribers/interpreters	Version 1	29 January 2007

R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.



All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q0511/19	**Please quote this number on all correspondence**

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

Yours sincerely

pp **Ms Stephanie Ellis**
Chair

Email: katherine.ouseley@camdenpct.nhs.uk

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* *Standard approval conditions*
Copy to:	*Dr Daniel Herron* *R&D Manager* *Tavistock Centre* *Tavistock and Portman NHS Trust* *120 Belsize Lane* *NW3 5BA* *R&D office for NHS care organisation at lead site –* [redacted]

An advisory committee to London Strategic Health Authority

Camden & Islington Community Local Research Ethics Committee

Attendance at Committee meeting on 26 March 2007

Committee Members:

Name	*Profession*	*Present?*	*Notes*
Dr Simon Adelman	MRC Research Training Fellow	Yes	
Professor Chris Brewin	Professor of Clinical Psychology	Yes	
Professor David Caplin	Senior Research Investigator, Professor of Physics	Yes	
Ms Saffron Clackson	Policy Analyst	Yes	
Dr Vari Drennan	Senior Lecturer	Yes	
Ms Stephanie Ellis (CHAIR)	Former Civil Servant	Yes	
Dr Angela Hassiotis	Senior Lecturer in Learning Disability Psychiatry	Yes	
Mr Matthew Lewin	Journalist and Author	No	
Ms Irenie Morley	Assistant Registrar	Yes	
Dr Roshan McClenahan	Speech & Language Therapist	No	
Professor Judith Stephenson	Professor of Sexual & Reproductive Health	Yes	
Ms Eleni Yerolaki	Specialist Counsellor	No	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Katherine Ouseley	Committee Coordinator – Minutes

An advisory committee to London Strategic Health Authority

Camden & Islington Community Local Research Ethics Committee
Room 3/14
Third Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

Tel: 020 7530 3799
Fax: 020 7530 3931

26 July 2007

Ms Lizette Nolte
[redacted]

Dear Ms Nolte

Study title: **Parents' experience of responding to their children's reactions to parental mental health difficulties**
REC reference: **07/Q0511/19**
Amendment number: **1**
Amendment date: **20 July 2007**

The above amendment was reviewed at the meeting of the Sub-Committee of the REC held on 26 July 2007.

Ethical opinion

The members of the Committee present 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
Participant Information Sheet	Version 2	20 July 2007
Notice of Substantial Amendment (non-CTIMPs)	1	20 July 2007
Letter of invitation to participant	Version 2	20 July 2007
Covering Letter		20 July 2007

Membership of the Committee

The members of the Committee who were present at the meeting 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 (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/Q0511/19:	**Please quote this number on all correspondence**

Yours sincerely

Katherine Ouseley
Committee Co-ordinator

E-mail: katherine.ouseley@camdenpct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

Copy to:

Dr Daniel Herron
R&D Manager
Tavistock Centre
Tavistock and Portman NHS Trust
120 Belsize Lane
NW3 5BA

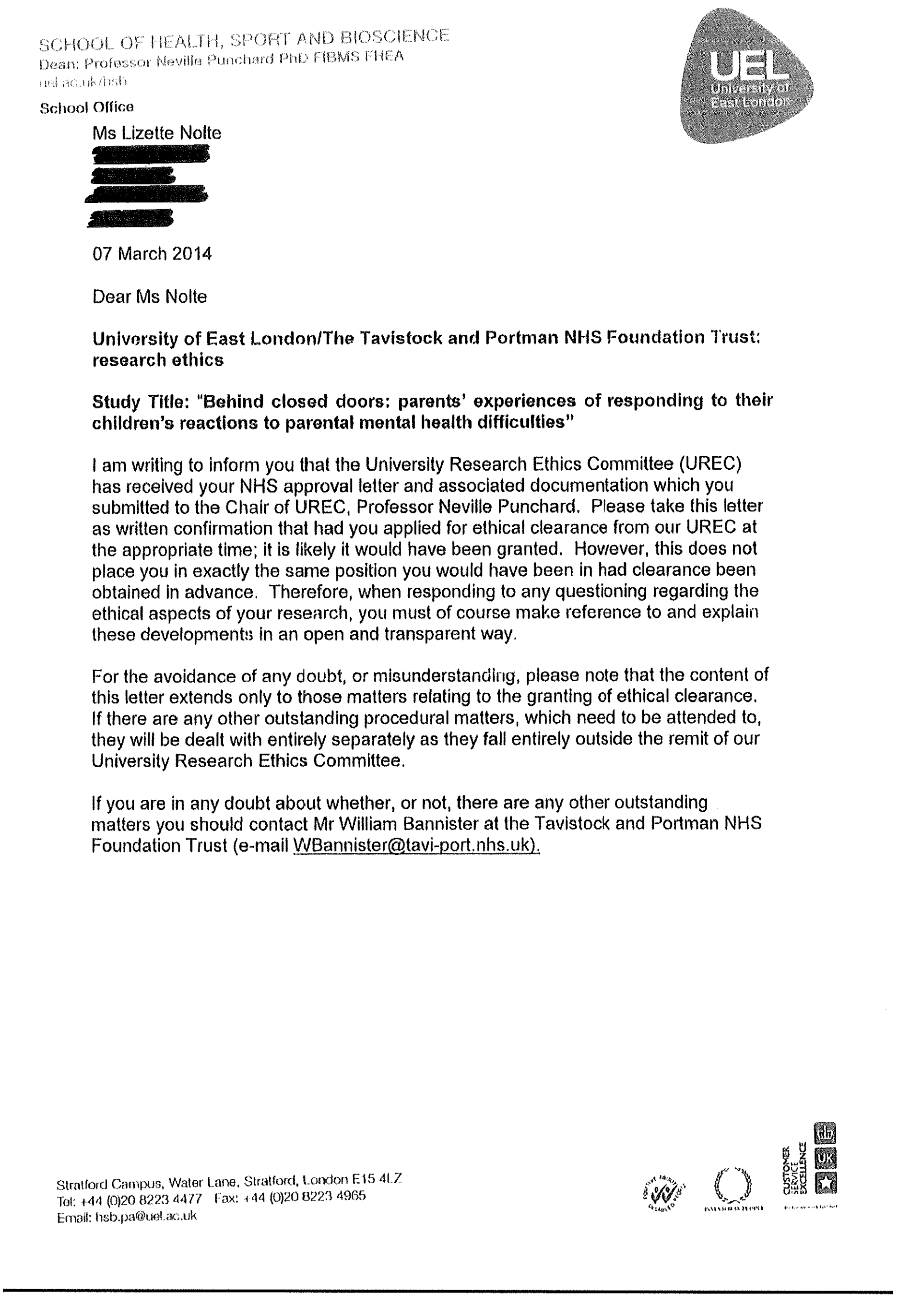
R&D office for NHS care organisation at lead site – [redacted]

Camden & Islington Community Local Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 26 July 2007

Committee Members:

Name	*Profession*
Ms Stephanie Ellis (CHAIR)	Former Civil Servant
Dr Angela Hassiotis	Senior Lecturer in Learning Disability Psychiatry
Dr Simon Adelman	MRC Research Training Fellow



SCHOOL OF HEALTH, SPORT AND BIOSCIENCE
Dean: Professor Neville Punchard PhD FIBMS FHEA
uel.ac.uk/hsb

School Office

Ms Lizette Nolte
[redacted]

07 March 2014

Dear Ms Nolte

University of East London/The Tavistock and Portman NHS Foundation Trust: research ethics

Study Title: "Behind closed doors: parents' experiences of responding to their children's reactions to parental mental health difficulties"

I am writing to inform you that the University Research Ethics Committee (UREC) has received your NHS approval letter and associated documentation which you submitted to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that had you applied for ethical clearance from our UREC at the appropriate time; it is likely it would have been granted. However, this does not place you in exactly the same position you would have been in had clearance been obtained in advance. Therefore, when responding to any questioning regarding the ethical aspects of your research, you must of course make reference to and explain these developments in an open and transparent way.

For the avoidance of any doubt, or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance. If there are any other outstanding procedural matters, which need to be attended to, they will be dealt with entirely separately as they fall entirely outside the remit of our University Research Ethics Committee.

If you are in any doubt about whether, or not, there are any other outstanding matters you should contact Mr William Bannister at the Tavistock and Portman NHS Foundation Trust (e-mail WBannister@tavi-port.nhs.uk).

Stratford Campus, Water Lane, Stratford, London E15 4LZ
Tel: +44 (0)20 8223 4477 Fax: +44 (0)20 8223 4965
Email: hsb.pa@uel.ac.uk

PP Yours sincerely

pp: Catherine Fieulleteau
Ethics Integrity Manager
For and on behalf of
Professor Neville Punchard
Chair of the University Research Ethics Committee (UREC)

Tel.: 020 8223 6683 (direct line)
E-mail: c.fieulleteau@uel.ac.uk

c.c. Mr Malcolm Allen, Dean of Postgraduate Studies, Tavistock and Portman NHS Foundation Trust
Mr Will Bannister, Associate Director, Education and Training, Tavistock and Portman NHS Foundation Trust
Professor John J Joughin, Vice-Chancellor, University of East London
Professor Neville Punchard, Chair of the University of East London Research Ethics Committee
Dr Alan White, Director of the Graduate School, University of East London
Mr David G Woodhouse, Associate Head of Governance and Legal Services

Appendix 5

LETTER TO POTENTIAL PARTICIPANTS

LETTER TO POTENTIAL PARTICIPANTS

Dear ____________________________,

I am a Clinical Psychologist employed by [redacted] and I am currently undertaking a Doctorate degree in Systemic Psychotherapy at the Tavistock Clinic in London. As part of this course I am carrying out a piece of research with the title: *Behind closed doors: exploring parents' experience of responding to their children's reactions to parental mental health difficulties.*

For this study I wish to interview service users of mental health services who are also parents about their experiences of any reactions their children might have had to their difficulties and how they have responded to these. I hope to learn from parents about their concerns, fears and hopes for their children, about problems they have encountered and solutions they have tried and about what they think services could do to support them or their children better. The aim of this study is to gain a better understanding of what it is like for parents who use mental health services and to use this understanding to influence future development of services.

For anyone interested in taking part in this research, it would involve a single interview with myself of about 1½ hours. The interviews are confidential. (However, should it transpire from the interview that someone or their children are at risk, I have a duty to contact Social Services.) The interview would be recorded to allow me to transcribe it, but all tapes will be wiped on completion of the study and participants will not be identified by name in the transcripts or any other records of the study – this is to protect confidentiality. Also, participants can refuse to answer any questions during the interview and can withdraw from the study at any time.

Your decision to take part/not in this study, or any aspect of your participation will not influence the care you receive from mental health services in any negative way.

Thank you for your time,

Lizette Nolte

(tear off here)

I, ____________________________ (name) am interested to be interviewed by Lizette Nolte for the research project "*Behind closed doors: exploring parents' experience of responding to their children's reactions to parental mental health difficulties".*

I am/have been a user of mental health services. I am a parent of the following child(ren) between the ages of 4 and 18:

____

____

____

I agree to be contacted by Lizette Nolte through my care-coordinator to arrange an interview.

Signed: ______________________________ Date: ____________________

Appendix 6

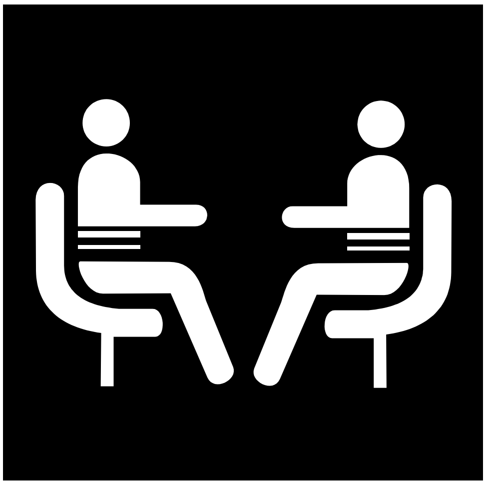
INFORMATION SHEET

INFORMATIONS SHEET (presented to participants in the form of a leaflet)

BEHIND CLOSED DOORS:

Parents' experience of responding to their children's reactions to parental mental health difficulties

DO YOU HAVE SOMETHING TO CONTRIBUTE FROM YOUR OWN EXPERIENCES?



SOME INFORMATION ABOUT THIS STUDY

You are being invited to take part in this research study. Should you decide to take part in the study, I will meet with you for an interview. This interview will last about 1 ½ hours. This will take place either at your home or in a room where we will have the necessary privacy to have an uninterrupted conversation. This could conclude your participation, but you will also be given the opportunity to join a group of participants who will discuss the findings of the study.

You do not have to take part in the study. It is entirely voluntary and it is up to you to decide whether or not to take part. If you do take part, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision not to take part or to withdraw will not affect the care you receive within mental health services in any way now or in the future.

I cannot guarantee the study will be of benefit to you personally, but the findings from the study could help improve the services for users of mental health services who are parents.

Here are some questions you might have about taking part in this study:

How confidential will the interview be?

Recording of the interviews –

The interview will be audio-recorded and transcribed – the audio-tapes and the transcripts will be stored securely and only I will have access to them (sometimes transcribers are used to help transcribe some tapes, but no personal information is ever made available to them and they have to sign a confidentiality agreement). No information that can identify you, like your name, address, etc., will be included in the transcripts; rather, codes will be used for identification. The anonymous transcripts will be viewed by others, including research supervisors and peer researchers, but they will not be able to identify you from these as all identifying information would have been removed. On completion of the study the audio-tapes will be wiped. It is anticipated that the study will be completed within two years.

Video-recordings –

You will be given the opportunity for a video-recording to be made of the interview. This will be for the purpose of training of staff members of the Trust after the study is completed. The training will have the aim of informing staff members of the findings of the study and the video-recordings will make the findings more 'alive' for the staff, strengthening the impact of the learning and allowing staff to hear 'first hand' what participants had to say. Your name or other identifying details will not be included on the video, but your face or voice might be recognized. Consent for this part of the study is dealt with separately from the rest of the study and deciding not to have a video-recording made will not affect your participation in the study in any way. If you agree to a video-recording you can change your mind at any time, even after the interview has been recorded. Should this occur the video-recording of the interview will be destroyed.

Who will have access to the recordings, transcripts or findings?

Excerpts from all the transcripts (it is anticipated that between twelve and sixteen people will be interviewed) will be presented to a group of practitioners from Community Mental Health Teams, but again all identifiable information will be removed before hand. A summary of the reactions and comments of the group of mental health workers will be shared with you. You will be invited to join a focus group made up of all the participants in the research to discuss all the findings of this project. Again, participation in this group is completely voluntary and choosing not to join the group will not effect your participation in the rest of the study in any way. Should you choose not to take part in the focus group, you will still be able to share your ideas with me should you wish to do so.

Any exceptions –

I shall work hard to keep all information that could identify you completely confidential. The only exception to this will be if there was a risk of harm to yourself or others – I am bound by the normal duty of care to bring any such concerns under the attention of the appropriate authorities so as to access the necessary support.

What do I do if I wish to make a complaint?

If you have a concern about any aspect of this study, you should ask to speak with myself as researcher and I will do my best to answer your questions or address your concerns. My contact details are on the back page of this leaflet. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure of the Trust. Details can be obtained from your care coordinator, the Trust website or any other Trust site, or contact Tel: [redacted].

What will be done with the findings?

You will receive a summary of the final results of the study and will have an opportunity to comment on these findings.

The results of the study will also be presented throughout the Trust, through different presentations and training events. No identifying information about you will be included in any report, presentation or training material, unless you have agreed to a video recording being made.

It is hoped that the results will be published in a professional journal in order to share the information with other practitioners. Again, such an article will contain no identifying information.

How is the study funded and will I receive payment for taking part?

I am funding the project myself, with some contribution from the Trust. There is no payment involved for myself as the researcher, for mental health workers involved, or for people taking part in the research. However, as a thank you for taking part in the study and to compensate for any expenses incurred due to your participation, you will receive a £10 shopping voucher from Marks and Spencer's.

Has this project received ethical approval?

This study was given ethical approval by the [redacted] Research Ethics Committee.

Thank you very much for taking the time to read through this information and considering taking part in this research.

Should you now wish to participate in this project, please let your care-coordinator or doctor know as soon as possible. Once I hear from them, I shall contact you to arrange a time for the interview.

Please contact me with any questions or comments:

Lizette Nolte

[redacted]

Tel. [redacted]

Email: [redacted]

Appendix 7

IMPACT OF SERVICE USER INVOLVEMENT ON THE STUDY

IMPACT OF SERVICE USER INVOLVEMENT ON THE STUDY

Four main points emerged from the focus group consultation with service-users that impacted on the project:

1. Lack of trust of professionals

One participant in the focus group in particular emphasized the mistrust people are likely to feel towards me as a mental health practitioner, especially one interested in their children. As a mother who had had contact over a long time with mental health and social services, she spoke about a deep mistrust of professionals' motives when they discuss her children, given a number of very painful experiences over the years. She advised that I would have to think carefully how to gain the trust of participants.

This impacted on my approach in interviews with my participants in a number of ways, some of which were intentional and some I was less aware of, but noticed as I was transcribing and analysing the interviews. At the time I made the following decisions in relation to my stance as interviewer: I explicitly distanced myself from practitioner language ('jargon'), habits and approaches. Rather, I tried to connect on a human and personal level, to get to know the person as much as possible on their own terms, what Shotter (1998) refers to as a dialogical relational stance in which 'ordinary' forms of expression are included. Where possible, I avoided professional settings, and most participants were interviewed in their homes. I also opted for self-disclosure where appropriate and for example talked about my own children when asked or my disagreement with some mental health practices (e.g. separating child and adult services) where it felt appropriate. Furthermore, I tried to have a balanced approach and talked about what was positive about their children and their experiences of parenting alongside any difficulties they were describing.

On reflection, as I was analysing the interviews, I noticed that my concern about gaining the trust of my participants might at times also have been a limitation. At times I might have been overly affirming and at other moments I might have been discouraged from exploring some potentially difficult areas. Furthermore, based on the powerful response from this person, as well as the overwhelming presence of this concern in the literature as discussed in chapter 2, one should assume that, despite my sense of a warm connection with many participants, there would still have been some silences with regards their children during the interviews. Overall though, I value having received this direct advice before embarking on my interviews, as it led me to work hard for establishing close, trusting relationships with the participants and this in my view enhanced the study.

2. Sense that the interview could be helpful or 'therapeutic'

A further point that emerged from the focus group came up at the end of the group, when a participant talked about how important it felt that someone wanted to ask about her children and that it was meaningful for her to talk as a parent. Therefore, although it was always made clear to participants that the interviews were for research purposes, I held in mind that there might have been few previous opportunities for participants to talk about their children. This gave me confidence to embark on these conversations with participants and confirmed to me the importance of research in this area.

The contradiction in the two statements above was also noticed, where on the one hand there is always suspicion when professionals ask about children within the context of mental health, but on the other there is a longing to talk as a parent about one's fears and concerns, as well as the joy found in parenting and in one's children. It saddened me that this person felt she had not had many opportunities to talk in this way and made me more committed to the project and to sharing the findings with colleagues. It also pointed towards clinical implications of the research as is discussed in the discussion section of the thesis.

3. Involving children in similar research

The participants in the focus group pointed out that they would want their children to have an opportunity to take part in such research at some point as well. They expressed an interest in what their children would say and thought that their views were important and should be considered by professionals. This points both to the case made by parents that the views of their children mattered, but also shows a wish within the parents to know what their children 'really thought' about them as parents and about the impact their mental health difficulties has had on their lives. They did not appear confident that they would be able to anticipate what their children would say if asked these questions. This point is discussed in the results and discussion sections.

4. Identification with label of 'mental illness'

It was also interesting at this point to note that one person in the focus group, even though attending a support group for people with mental health difficulties, did not relate to the label of someone with a mental health problem. This theme would become more important as the research unfolded and is considered in detail within the results and discussion sections.

Appendix 8

LETTERS TO PSYCHIATRISTS, CARE COORDINATORS AND VOLUNTARY SECTOR WORKERS

LETTERS TO PSYCHIATRISTS, CARE COORDINATORS AND VOLUNTARY SECTOR WORKERS

Parental Mental Health Team
[redacted]

To Consultant Psychiatrists
Adult Mental Health Teams

28 September 2007

Dear Dr ________________ ,

Re: Planned research project involving your patients

I am a Consultant Clinical Psychologist in the Parental Mental Health Team who has a remit to work closely with Community Mental Health Teams to support children and their parents where parents have mental health difficulties.

As part of my role in this team, I am planning to undertake a research project with the title:

Behind closed doors: Parents' experience of responding to their children's reactions to parental mental health difficulties

This will be a qualitative Grounded Theory study, using individual semi-structured interviews and focus groups to gather data. Through this study I aim to research the experiences of parents with mental health difficulties of the effects of their difficulties on their children and how they have chosen to respond to these. In particular, the research will look at parents' experiences of telling/talking about or not telling/talking about their mental health difficulties with their children, the dilemmas they have faced around these issues and the factors that have informed their choices in this regard. The study is informed by the research on coherent narratives, indicating that having a coherent understanding of traumatic experiences can enhance the ability to process these experiences and increase resilience. The hope is that this will inform service development for these parents and their families, enabling the development of preventative interventions for children being affected by parental mental health problems.

In practice what this study will involve is that around 12 current users of services of the four Community Mental Health Teams in [redacted] will be recruited to be interviewed for the study. They will be parents of children between the ages of 4 and 18. The analyses of these interviews will be presented to a focus group of practitioners from the CMHTs and the analyses of both processes will also be presented to the original service users interviewed.

I hope that you will support this project.

In particular your support will be appreciated in the following matters:

- As this study relies on potential participants being identified by care-co-ordinators, your support of the care-co-ordinators in identifying potential participants will be highly valued.
- I will be informing you of all names of service users who give consent to be interviewed – I shall appreciate your feedback regarding any participants who you consider too vulnerable to participate
- The findings of the study will be disseminated to the teams on completion of the study – any comments or feedback will be much appreciated.

I shall keep you informed as the study progresses. Please contact me should you have any questions, concerns or suggestions.

I can be reached on:

Tel [redacted]
Email [redacted]
Address: [redacted]

Kind regards.

Yours sincerely,

Lizette Nolte
Consultant Clinical Psychologist

Parental Mental Health Team
[redacted]

To Team Leaders
Adult Mental Health Teams

26 September 2007

Dear _________________,

Re: Planned research project involving service users from your teams

As a member of the Parental Mental Health Team who has been working closely with all the Community Mental Health Teams to support children and their parents where parents have mental health difficulties, I am planning a research project with the title:

Behind closed doors: Parents' experience of responding to their children's reactions to parental mental health difficulties

This will be a qualitative Grounded Theory study, using individual semi-structured interviews and focus groups to gather data. Through this study I aim to research the experiences of parents with mental health difficulties of the effects of their difficulties on their children and how they have chosen to respond to these. In particular, the research will look at parents' experiences of telling/talking about or not telling/talking about their mental health difficulties with their children, the dilemmas they have faced around these issues and the factors that have informed their choices in this regard. The study is informed by the research on coherent narratives, indicating that having a coherent understanding of traumatic experiences can enhance the ability to process these experiences and increase resilience. The hope is that the findings will inform service development for these parents and their families, enabling the development of preventative interventions for children being affected by parental mental health problems.

In practice what this study will involve is that around 12 current service users of the four Community Mental Health Teams in [redacted] will be recruited to be interviewed for the study. They will be parents of children between the ages of 4 and 18. The analyses of these interviews will be presented to a focus group made up of about 3-5 staff members from the four CMHTs and the analyses of both processes will also be presented to the original participants. I am aiming to start recruitment early in 2007.

I hope that you will support this project.

In particular your support will be appreciated in the following matters:

- This study relies on Care Co-ordinators to recruit potential participants to the study. This should not require much additional work for Care co-ordinators, but they will have to go through their case loads and identify potential participants (for those who completed our original questionnaires, they will already be aware of whom to consider). They will then also have to discuss the study with those they identify as potential participants (hopefully as part of their normal visits). They will be given all the appropriate information to give to their clients.
- Once enough participants have been interviewed, I will invite members from the team to take part in a one-off focus group interview to discuss the findings. The group interview will last for about 2 hours. Your support for one or two members of your team to take part in this discussion will be appreciated.
- The finding of the study will be disseminated to the teams on completion of the study – any comments or feedback will be much appreciated.

I shall keep you informed as the study progresses. Please contact me should you have any questions, concerns or suggestions.

Yours sincerely,

Lizette Nolte
Consultant Clinical Psychologist

Parental Mental Health Team
[redacted]

To all Care Co-ordinators
Adult Mental Health Teams

28 September 2007

Dear Care Co-ordinator,

Re: Planned research project involving service users from your teams

As a member of the Parental Mental Health Team who has been working closely with all the Community Mental Health Teams to support children and their parents where parents have mental health difficulties, I am planning a research project within the field of Parental Mental Illness with the title:

Behind closed doors: Parents' experience of responding to their children's reactions to parental mental health difficulties

This will be a qualitative Grounded Theory study, using individual semi-structured interviews and focus groups to gather data. Through this study I aim to research the experiences of parents with mental health difficulties of the effects of their difficulties on their children and how they have chosen to respond to these. In particular, the research will look at parents' experiences of telling/talking about or not telling/talking about their mental health difficulties with their children, the dilemmas they have faced around these issues and the factors that have informed their choices in this regard. The study is informed by the research on coherent narratives, indicating that having a coherent understanding of traumatic experiences can enhance the ability to process these experiences and increase resilience. The hope is that the findings will inform service development for these parents and their families, enabling the development of preventative interventions for children being affected by parental mental illness.

In practice what this study will involve is that around 12 current patients of the four Community Mental Health Teams in [redacted] will be recruited to be interviewed for the study. They will have to meet the following criteria:

- Be currents users of Adult Mental Health Services
- Be parents of at least one child between the ages of 4 and 18.

They do not have to:

- Live with their children
- Be using mental health services for any specific length of time

Analyses of these interviews will be presented to a focus group made up of about 3-5 staff members from the four CMHTs and I hope that you will consider taking part in this. It will involve a one-off interview of the group lasting about 2 hours. The analyses of both processes will also be presented to the original participants. I am aiming to start recruitment in January 2007.

I hope that you will support this project.

In particular your support will be appreciated in the following matters:

- This study relies on you as Care Co-ordinators to recruit potential participants to the study. This should not require much additional work, but you will have to go through your case loads and identify potential participants (for those who completed our original questionnaires or who have consulted our team, you might already be aware of whom to consider). You will then also have to discuss the study with those you identify as potential participants (hopefully as part of your normal visits). You will be given all the appropriate information to give to your clients.
- The finding of the study will be disseminated to the teams on completion of the study – any comments or feedback will be much appreciated.

Without your help this study cannot take please – I hope that you will see this as a worthwhile project and contribute to recruitment of enough participants to make it work.

I shall keep you informed as the study progresses. Please contact me should you have any questions, concerns or suggestions.

Yours sincerely,

Lizette Nolte
Consultant Clinical Psychologist

Appendix 9

CONSENT FORM

CONSENT FORM

Title of project: *Behind closed doors: parents' experience of responding to their children's reactions to parental mental health difficulties*

Researcher: *Lizette Nolte*

I hereby agree to be interviewed as part of the above mentioned research project. I confirm that I have read and understand the information leaflet for the above study. All my questions regarding the nature, aims and procedures of this study have been answered to my satisfaction. I am aware that the interview will be recorded.

The following has been explained to me:

- I am free to refuse answering any questions during the interview or to stop the interview at any stage.
- I am free to withdraw from the research at any time.
- My decision to take part or not take part in this research; withdraw from the study or not answer any questions or any other part of my participation in this project will not negatively affect the care I receive from mental health services now or in the future.
- I will not be identified at any stage of this research, including in the transcript of the interview, in any report for the Trust or any training materials and if this research is written up for publication.
- The researcher has the normal duty of care to bring any risk to myself or others under the attention of the appropriate authorities.
- If I have any issues I wish to raise about how this research was carried out, I can complain to the Trust and the relevant information in this regard has been passed on to me.
- I have been assured that on completion of the study all audio-tapes will be wiped.

Name of Participant: ___________________ Date: ________ Signed: ___________

Video-recording for training purposes:

I **AGREE / DO NOT AGREE** (cross out as appropriate) that this interview can be video-recorded for the purposes of use in training events for mental health workers within [redacted].

The following has been explained to me in this regard:

- The purpose of the training is to improve mental health workers' awareness of the needs of service users in their role as parents and of the needs of their children with the hope of improving services.
- The video-recordings will only be used within [redacted] Trust.
- Those involved in my care within mental health services may view the video.
- I can withdraw consent for the use of the video-recording at any time.

Name of Participant: _______________Date: __________ Signed: ____________

Participation in focus group discussion:

I **WISH TO PARTICIPANTE / DO NOT WISH TO PARTICIPATE** (cross out as appropriate) in a focus group discussion of the findings of this study (the analyses of the individual interviews and of the responses from mental health workers).

The following has been explained to me in this regard:

- The purpose of the focus group is to give the participants in the research an opportunity to reflect on the findings of the study and express any comments, concerns or disagreements and to reflect on the experience of taking part in this study.
- The discussion will be audio-recorded/video-recorded and transcribed.
- No identifiable information on any member of the focus group will be included in the transcript or any other document describing this study. On completion of the study the tapes will be wiped.

Name of Participant: ______________Date: __________ Signed: ____________

Appendix 10

INTERVIEW SCHEDULE

SEMI-STRUCTURED INTERVIEW - INTERVIEW SCHEDULE

Can you tell me what made you interested in taking part in this study?

Can you tell me about your children – who are they; how are they growing up; what are you proud of about them; what worried about?

Can you tell me about your understanding of the reasons for your use of mental health services? How long have you experienced *(their own description of their difficulties)* and how does it manifest itself/affect your life?

Is this the same or different from how your care-coordinator/psychiatrist or someone in your family would describe the reasons?

What are your views of the terms "mental illness"/ "mental health problems/difficulties"?

How have you come to know this problem/difficulty/illness? – What have you learned/come to know about it? How have you come to know this? Does it feel like you know it well, or is it still unfamiliar or confusing? How is this knowing the same or different from the mental health professionals' knowing?

I would now like to give you some space to talk about your children in the context of these difficulties we have been talking about.

What do you think has been the effects of these difficulties on your children? What reactions have you noticed in them – emotionally, behaviour, school, friends? Has anyone else commented on any changes in them? What positives have come to your children from this? (3) What worrying effects have there been for them? (3)

How has it been for you responding to/managing these effects (if they thought there were any) on your children? What have you tried? What has worked well? What did you feel has not worked as well? Where did the idea to do (*their own description of what they have tried)* come from? If you were talking to another parent starting out on this journey, what advice would you give them?

How do you think your children have come to know about this problem/difficulty/illness? – What have they learned/come to know about it? How have they come to know this? How is their knowing different to yours or is it the same?

Do you think children need to understand *(their own description of their difficulties)* in their parent? Or do you think it is better for them not to know too much?

[*If they believe children should have an understanding]* How did you come to this view? What information have you used to make this decision? And anything else? Has this always been your position or has it changed over time? Is there anything that would change your view about this? Who do you think is best placed to help them get this understanding?

Or

[If they do not believe children should have an understanding] How did you come to this view? What information have you used to make this decision? And anything else? Has this always been your position or has it changed over time? Is there anything that would change your view about this? Has anyone tried to explain things to your children without your consent/agreement?

Who else is involved with your children (in taking care of them when you are having a difficult time/in their day-to-day care/at times when you are in hospital/someone from the mental health services/someone at their school/anyone else)

Do they also make decisions about what the children should/should not know/be told? Do you and (*who they named)* have similar/different views on this? (How do you know this? How much is this discussed?) What effects have you noticed in your children of your decision about talking/not talking to them? Have you noticed any changes in this over time?

How do you hope mental health workers will respond to your comments? What are your expectations in this regard? Is there anything you think mental health services can do that you or your children would find helpful regarding the things we have been talking about?

How did you experience the interview? Any advice? What advice would you give to another parent in your position?

Appendix 11

CONFIDENTIALITY AGREEMENT WITH TRANSCRIPTION SERVICE

CONFIDENTIALITY AGREEMENT WITH TRANSCRIPTION SERVICE

Confidentiality

Title of the research project: *Behind closed doors: parents' experience of responding to their children's reactions to parental mental health difficulties*

Researcher: *Lizette Nolte*

I, Margaret Clow, on behalf of Executive

Typing, undertake to treat all information related to this study as strictly confidential.

I will:

- not disclose any information to which I have access during my work on this study
- store all information in a safe and secure way while I have it in my possession
- return all information and material related to this study to the researcher on completion of my task and destroy/ delete all versions of recordings or transcriptions related to this study from my computer on completion of the task.

Signed: Margaret Clow

Print name: Margaret Clow

Date: 30.08.12

Appendix 12

TRANSCRIPT OF INTERVIEW WITH ‘ANN’

TRANSCRIPT OF INTERVIEW 1

PARTICIPANT A
INTERVIEWED: 17 October 2007

1	I am aware that this is being recorded.		
2	Thank you very much.		
3	I wonder whether you can start just by telling		
4	me a bit about your children?		
5	Uhmm, I've got 2 children – I've got a son	2 Children:	
6	who's 21, and he's living in America now,	Son 21 - US	Demographics
7	he's working there and I've got a daughter	Daughter 15	
8	who's just turned 15.		
9	Okay. Can you say a bit about how you think	("Proud" introduced	
10	they're doing, how they're growing up, what	by researcher)	
11	you feel proud of about them…		
12	Uhmm, well, my son, I'm very proud of him,		
13	because he's done very well in his career. He		
14	didn't do very well in school, uhmm he	Transient problems	"minimising"
15	actually didn't get any GCSE's and he was	Tells lightly re	difficulties?
16	often in trouble as well (laughter), but he was	trouble	Bad then -
17	actually, in adulthood he's actually done		good now
18	really well. He worked for Gordon Ramsey at		
19	the [redacted] and uhmm he's now gone to		
20	work in Miami as a chef out there and uhmm		
21	he's got a very nice partner and he's living a	Speaks re pride in son on initiative	
22	really good life. He's enjoying himself	of researcher	
23	immensely so I feel really proud of him and	Proud of enjoying	Witnessing
24	my daughter uhmm, she's had quite a difficult	Daughter difficult time	Enjoying himself: normality happy
25	time uhmm. He was, my son wasn't here this	↓	
26	time that I was ill, uhmm and my daughter	She has seen me	Impact of
27	was and she saw me have several relapses,	be unwell - she	seeing her
28	uhmm but she's managed to do very well at	was there ↓	unwell vs
29	school, she's uhmm top of the class in all her	Still did well at school	not seeing
30	subjects and uhmm we were talking yesterday	Talking together -	⇅ ?
31	actually about how uhmm one of her friends	warmth in telling	maturity
32	said that she actually looked up to her, like as	Friends notice her	noticed by
33	a role model, like because she's so uhmm	maturity ⇒	others
34	mature in some ways. Like even though she	She is mature	+ caring
35	has a lot of fun, enjoys herself she still uhmm	Thinks about other	
36	got lots of maturity about her about the way	people	
37	she thinks about other people, cares about	Care about others	
38	other people, uhmm, but I just feel very proud		
39	of both of them		
40	Yeh, so it's it's also not just you as a mother		
41	thinking that, but actually other people		
42	noticing …		
43	Other people noticing yes		

44	Other people, like her friend saying it about		
45	them, so it's really something about them that		
46	is noticeable by other people		
47	Yes, definitely, like her learning mentor –	Support at school due to PMI	Support: School
48	because I was ill she had a learning mentor at		
49	school and uhmm in the card that she wrote		
50	she wrote very similar things, that, you know,		
51	that [redacted] was uhmm cares for other	caring	
52	people and is very mature and has done very	maturity	
53	well and the teachers say that even though	doing well despite hard time – resillience	Doing well "despite" PMI
54	she's had a hard time she has managed to		
55	really do do very well and to get on and	doing academically well	
56	academically she is doing very well but also		
57	she gets on with all her friends. She's just had	socially well	
58	her 15th birthday and we had 17 people	importance of having friends	Support: Friends
59	sleeping over		
60	(Loud laughter) Oh!! That's brave of you!		
61	Exactly, yes it was, but she has she has fun		
62	So she has good friends and she got a strong	good friends strong network	
63	network around her…		
64	Yeh, Definitely definitely. So… I just I do		
65	feel very proud of both of them. Uhmm but		Talking; Talking in context of support for parent?
66	my daughter I feel like I can talk to her as	"I can talk to her"	
67	well. Like we spend quite a lot of time talking		
68	and when she gets home from school we		
69	spent a lot of time talking about things and		Talking as indication of closeness
70	we are very close, so I'm very pleased about	very close	
71	that as well.		
72	It is a very special relationship for you		
73	Yeh, yeh, I think so		
74	What about things you worry about. Well you		
75	must have been a little worried about your		
76	son when was he getting you know at school		
77	and was getting into trouble, but he's come		
78	through that , but are there any current		
79	worries you have about them, or things you		
80	sort of hope will turn out alright?		Fear of child developing MI
81	Well, my daughter yesterday we were talking		
82	and we were talking about uhmm bipolar and	Worried re bipolar	
83	she was saying that she's done a lot of		
84	reading about it and uhmm (1) one thing that	reading re bipolar	Information: Independent reading
85	she learned was that bipolar tends to start	worried re approaching common time of 1st episode	
86	when people are in their late teens		
87	Okay		
88	And so she was saying oh mum, what would		Talking together re fears of MI
89	what would happen if I got it uhmm (1) and	What if I got it	

esearcher:
ealising as mother
o mother

esearcher's frame

90	so uhmm so we were talking about that and	Talking about daughters fears struggling for answer	Daughter initiating conversation	
91	so I just feel although there is a genetic uhmm			
92	component I feel my son is now 21 and he's			
93	doing fine and my daughter for some	uncertainty	↓ → fears	
94	although you can't, you just don't know	"you just don't know"	mother responding	
95	what's gonna happen uhmm, I thought just			
96	feel, well hopefully she won't have it. But I	hoping she won't become ill		
97	didn't become ill until I had my children, so		Responding in context of uncertainty	
98	you know it's a bit scary I'll just have to wait	uncertain unpredictable scary → fear		
99	I probably have to wait until they (I?) have			NO certaint
100	children and see if anything happens to me	wait and see		
101	but uhmm but I'm saying the chances are that	finding way to respond	medical	
102	you won't get it		developmental	No control
103	Uhm	"Illness" – medical explanation	"get it" → sense of influence/control	
104	Uhmm, but it's I think it's the first time that			
105	she's actually really thought about it. She			
106	hasn't really thought about it in terms of in	New developmental stage – illness in relation to self		
107	relation to her before. She's just felt that			
108	she'll be okay, that she wouldn't become ill,		uncertainty	
109	but you just don't know, so I suppose because	You just don't know		
110	my mother and my brother also uhmm has			
111	bipolar, there is that worry that it could uhmm	genetic	〃	
112	happen to my children	could happen to children		
113	I would like to ask you about that a little bit		Transgenerational stories of MI	
114	more if that's okay, but maybe first uhmm if	worry		
115	you can say just a little bit about yourself you			
116	have been saying about bipolar and maybe if			
117	you can just explain the reasons why you			
118	have been using mental health services?			
119	Uhmm well I had post-(partum?) psychosis	Medical	Ill at birth of both children	
120	after each of my children were born uhmm	Changing dx over time connected to birth of children		
121	and I was ill for I was ill for a year and a half		?meaning ?relationship	
122	after my son was born and I was ill, I would			
123	say for a year after my daughter was born and			
124	then I was well for 12 years and then in 2004			
125	I became ill again and it was described as			
126	Affective Disorder - I wasn't given the label	"given the label"	given the label	
127	Bipolar Disorder uhmm and then (1) last			
128	November, so that's in 2006, I had an episode			
129	again and this time I was given the label	given the label		
130	Bipolar Affective Disorder and I had uhmm		disruption over time	
131	about I think 3 relapses in that period so I	3 relapses quite well		
132	became quite well and was discharged from		long periods of changing health unsettledness	
133	hospital and then I became ill again on	became ill again		
134	several occasions and had to go back into	back into hospital		
135	hospital			

136	Hmm, so so the the uhmm name of Bipolar			
137	was something that the doctors gave to you?			
138	Yeh			
139	And did that fit for you, did you think yes			
140	that's what it is, or did you have some other			
141	idea about what might be going on?			
142	I I was quite shocked because (1) as I said,	Shock	shock	Re-evaluation -
143	well I think I was shocked to become ill	"shocked to become ill"		sense of self in
144	because I always thought it was post-			relation to
145	(partum?) psychosis and I'd only become ill	explanation relating to childbirth	given 'wrong'	MHP
146	again if I had another child so in 2004 that	& no longer true	explanations	
147	was a big shock uhmm but I was only ill I	big shock		
148	went to the [redacted] (hospital) that time and I was actually	unexpected	unexpected	continually
149	in the [redacted] (hospital) for three months and when I			having to
150	came out I actually felt well uhmm. The only	felt well		adjust own
151	thing I had was like chronic fatigue – I was			understanding
152	diagnosed with either chronic fatigue or			in context
153	fibroid (myalga?) uhmm so I had difficulties			of
154	with that but in my mental health I actually	mental health okay	up & down	experiences
155	felt okay where as this time 'round it's been			info from mx
156	very long and drawn out uhmm and (1) as I	long, drawn out		info from internet
157	said they described it as Affective Disorder	worse		
158	when I was ill in 2004 so I didn't know that I			
159	had Bipolar uhmm and then I was told that	I was told	given 'wrong'	
160	hopefully I wouldn't become ill again or if I	won't be ill again	info	
161	ever did it would be when I was sixty or so so			||
162	I wasn't expecting necessarily to have another	wasn't expecting	hope - dashed	
163	episode or to have it so soon and also I had		unexpected	
164	been told that I could stop my medication so I	told could stop mx	wrong info	
165	wasn't on medication for a prolonged period			
166	of time uhmm but I don't know I mean I've			
167	just recently I've looked on the internet about	Info from internet	info from	
168	the uhmm the descriptions of bipolar and	some things fit +	internet	
169	some things fit and some things don't	some not.		
170	Oh right yeh			
171	Uhmm But then some things that don't fit at	don't fit at all	doubting label?,	
172	all and like the experience I went through			
173	when I was becoming ill like I know that a lot		label	
174	of people have this euphoric time when they		↕ & not perfect fit	
175	have like mad spending sprees and they feel		experience	
176	very creative and it's all wonderful and they			
177	enjoy themselves even though it is quite			
178	damaging where as I didn't have that at all – I	did not happen	comparing own	
179	had more of a frightening experience, I would	like for some	info the	
180	have, I had terrible nightmares and I thought	others	internet info	
181	horrible things like I thought that Ian Brady	Negative experience		

182	was something to do with my father and that		
183	maybe I was a victim of Ian Brady and Mara	scary experiences in context of illness	
184	Hindly and had managed to escape and so it		
185	was all very		
186	Yes scary		
187	Yes scary and quite negative apart from in the	scary negative	Very personal, very distressing, very disturbing experiences
188	very early well one day I remember before I		
189	went into hospital I actually ran up the street		
190	in my night cloths and I was shouting to	Why won't you help	
191	people why won't you help me why won't	public experience of distress	↕
192	you help me and people were trying like I	fear?	meanings?
193	remember a woman on a bike and she was	humiliation / shame?	
194	actually kicking out at me and saying get	embarrassment?	messages from
195	away from me and then my neighbour,	stigma?	others re MI
196	fortunately my neighbour went past on his	Neighbour helped	- stigma
197	motorbike and he and he stopped for me and		- rejection
198	he was like [redacted] (self) are you okay like and I		- invited into shame
199	hugged him and he hugged me and then he	helped	
200	called for he called his mum and they took		
201	me in 'cause [redacted] (partner) had just I think I had		
202	already been to the hospital on the Friday and	crisis	
203	then they've given me tablets to take at home	hospital	
204	and then this was and so I had been at home	mx	
205	and so he had left me just to go and get some	alone for short	
206	keys to do for work or just to give some keys,	time	
207	he has a twin brother, he had to get some keys	?cannot be left	loss of adult
208	to him for work and then just in that very	? childlike	freedom
209	short period that he was gone that's when I	responsibility of partner?	control
210	ran up the road, but I remember before that	(- no blame)	
211	though I saw the most amazing colours like		
212	behind my eyes like really beautiful colours		
213	and patterns uhmm and then I ran up the road		
214	and nobody was helping me and I just felt I	nobody was helping	
215	would and I was saying I would help you and		
216	I remember feeling that really upset that	upset; let down	messages from
217	'cause I felt if anyone was in difficulty that I	own values	others re MI
218	would help them but nobody was prepared to	nobody was prepared to help	- no help
219	help me they were all apart from my	alone/isolated	- isolating
220	neighbour		- rejection
221	That must have been such a frightening		‖
222	experience to be to feel so out of control and		Stigma
223	Yeh		
224	Nobody coming to your		
225	Yeh		
226	Aid really		
227	Yeh, yeh apart from him and it was just lucky		

feeling extremely vulnerable (little girl?) – frightened – in need of help, begging – feels in danger
↓
responded to as dangerous (wild animal?) – frightening – to be run from (get away from – seen as causing danger

shock! Wanting to distance self from such views, align with participant also identity: see her as "intelligent woman"?

228	that he was going past on his bike 'cause I	vulnerable	traumatic memory
229	could have been under a bus (laughs) – it was	makes light	
230	on [redacted] Road and it is very busy	concerns as for child	↓
231	Oh yes very busy	in danger	extreme psychological distress
232	Yeh, where the traffic lights are		
233	Oh Yes		
234	And someone has actually a little girl was	concerns as for child	
235	knocked down and killed on that corner and I	identify with "little girl"	
236	was just I ran across the road and then I was	vulnerable	dangerous ?
237	saying I was on my knees and I was saying	vulnerable - exposed	⇕
238	help me help me why won't you help me and	begging for help	vulnerable
239	this woman was sort of kicking out at me,	rejection stigma	
240	shouting at me and I just I really and I felt... ?	seen as ?dangerous	
241	and then Could have picked up	? "mad" ???	
242	Quite shocking	← Researcher response ——	→ my shock: communicated..
243	Yeh, it is and then I remember [redacted] (partner) had		
244	locked me in and I managed to escape out	locked in?	dangerous
245	into the street in the night and I was shouting	escaped night time	⇕ vulnerable ?
246	help me help me at the top of my voice and	shouting begging for help	
247	then eventually someone did call the police	police	"
248	and he called the ambulance and the police	ambulance	
249	arrived but they had to uhmm he had		
250	managed to take me back in and then locked	locked in again ?	
251	the door again and then they had to break the		"
252	door down because we I had been kicking at	kicking	
253	it, I was so frightened I'd been kicking at the	"I was so frightened	"
254	door trying to get out of the house and	feels in danger)	
255	thinking about all this business about Ian	(seen as dangerous	
256	Brady and what have you – it's very	very frightening	
257	frightening		
258	Yes, absolutely		
259	So…		
260	When you think back to that period now what		
261	is that like for you? ✓		
262	(2) It's … I think it's quite it feels quite		self as strange
263	strange that you could have those thoughts	strange I had those thoughts	distance — looking at self,
264	uhmm and also things aren't very clear and	things aren't clear	not familiar
265	get muddled like uhmm my recollection I	muddled	
266	mean some things are very clear in my mind	some things very clear	confusion
267	like I can remember that I can remember	clear dreams in	no memory
268	dreams that I had while I was in the hospital,	hospital	
269	but other things are not clear like [redacted] (partner)	other things not clear	"strange behaviour"
270	and [redacted] (daughter) would tell me that they would	daughter as holder of memories	Talking:
271	take, that I went down to [redacted] Street with	telling her	partner & daughter
272	them and I would rush up to people and say	strange behaviour	filling in memory
273	oh, where did you buy that jumper or where	filling gaps	gaps

shock at response of public
↓
"I am not like that"
?

Fear → Disgust → Confusion →

researcher:
Bringing ill and
well identities
together?

274	did you buy that coat and so being very over	over friendly	
275	friendly and talking to like say an old an old	others' descriptions	
276	man was sitting on a bench I would be	talking re self	
277	chatting away to the old man on the bench	as other	
278	and being very talkative but I mean	talkative	Talking:
279	Would you say that that was out of character		
280	for you?	→ you ↔ stranger	Not 'knowing'
281	I do tend to talk to people (laughing)	?	the 'ill' self
282	Do you? (laughing)	link ill person to self	Not remembering
283	Like if I am at a bus stop or something like		-impact on
284	that people would often talk to me and you	Identity	meaning
285	know I would talk to them uhmm, but for …		making
286	lots of things I can't remember and then other	can't remember	
287	things I can remember very very clearly	remember very	
288	Okay yeh	very clearly	
289	Yeh	traumatic memories	
290	Can I ask you uhmm just to talk a little about		
291	your children in the context of all you have		
292	just said about sort of the history of the times		
293	you have been unwell?	Doubt re my	
294	In what respect?	→ intentions?	
295	Like I was wondering whether you think it	Difficult area to	
296	has had an effect on them? Whether any good	explore ?	
297	has come out of it? Or whether any difficult ✓		
298	things have come out of it for them? Sort of		
299	anything you've noticed.	tentative	
300	Uhmm (1) I think mainly I would talk about	reflective?	
301	my daughter because it's easier because with	impact on	
302	my son, my son was uhmm (2) very, he was 6	daughter	
303	when I had [redacted] (daughter) uhmm and was ill then. I	age - development	
304	think well actually no, I can talk about him	no, also on son	Child
305	because it had a negative effect on him…	negative	Received
306	he… I think it affected him at school uhmm	affected at school	support
307	he had some difficulties and he had he saw a	difficulties	→ What did ψ say?
308	child psychologist uhmm for a while uhmm	saw ψ when	Child —
309	after [redacted] (daughter) was born so that did have an	mother unwell	Impact:
310	impact on him	(aged 6)	• witnessing frightening
311	So you would make a link between the		behaviour
312	difficulties he was having and you being		• separation
313	unwell?		• frightening
314	Yes, I would say definitely because it because		environment
315	it was very my I think my behaviour uhmm	behaviour	of hospital
316	could be quite frightening uhmm and I was in	frightening	↕
317	hospital I was in [redacted] (hospital) which wasn't a	in hospital	age of child
318	very pleasant environment and uhmm he	unpleasant environment	
319	would come and visit me in [redacted] uhmm	(son visited there	

Researcher: Related experience "over reaction of school"	320	so I think definitely it did impact on him	?	
	321	uhmm		
	322	What sort of difficulties did he have?	Difficulties with Behaviour in school	
	323	Just in terms of his behaviour at school		
	324	wasn't, you know his behaviour at school was		
	325	quite bad at school uhmm but then sometimes		Children's well-being & behaviour interpreted in context of parent's MI
	326	it was things that were just silly like I	Everyday behaviour interpreted within context of illness	
	327	remember, I know he flushed someone's		
	328	jumper down the toilet and then but then		
	329	uhmm when he was a bit older he wrote some	normalizing	
	330	he wrote stories which they were concerned	Wrote dark stories School concerned – 'on the radar' – interpreted in context of illness	
	331	about at school but I felt to be honest they		
	332	were just his imagination but wrote some		
	333	really scary like horror stories but he'd been		Need to minimize perceived impact on children.
	334	watching X-Files and things like that and he		
	335	was very interested in the X-Files and I just	normalizing	
	336	felt that it was more him than anything else	just his nature	
	337	but they were they were quite concerned	they were concerned	
	338	about it and uhmm he was diagnosed with	dx with dyslexia added complexion	
	339	dyslexia as well so that sort of added to that		Stigma?/ Perceived as stigma?
	340	uhmm and then when I was ill in 2004 I think	older when ill again	
	341	he was a lot older well he was a lot older and		
	342	he was he'd been at college and he'd gone to	college	
	343	his catering college there and then he was on	more independent?	
	344	holiday uhmm and uhmm 'cause I went to the	less directly involved ↓	
	345	[redacted] (hospital) he would come and visit me in the		
	346	[redacted] (hospital) but I was I was away I wasn't really	?	
	347	around so much and my daughter while I was	visited in hospital better hospital	
	348	in the [redacted] (hospital) went to live with her - she's got	daughter went to live with half-brother (not father)	
	349	a younger half brother and she actually went		
	350	to live with them and so she was away from	she was away from me (∴ no impact ?	
	351	me uhmm so the only time it had an impact		Impact: being with parents (parent dangerous to child)
	352	on her was when she came to visit me in the		
	353	[redacted] (hospital) uhmm she felt that things were very	only impact when with parent?	
	354	nice and uh you know it was very calm uhmm		
	355	and I didn't seem so bad and we were talking	nice hospital environment – calm, I did not seem so bad	↓ no contact = no impact
	356	again talking about this last night and she was		
	357	saying how uhmm it was much you know	talking last night	Talking re hospital / – impact of good/bad care
due to interview coming up?	358	very different. And it was a question of I went	went in and came out better	
	359	in there and I seem to come out and I was		? United around criticism of hospital
	360	better where as uhmm being in the [redacted] (bad hospital)	anger re negative hospital environment	
	361	she was saying that she actually felt very		Talking ; ? Role reversal – concern of child for parent
	362	angry uhmm she felt angry about me being		
	363	there. She felt that I shouldn't have been there	not good care	
	364	and she felt that the care that I received		– opinions re care
	365	uhmm because I kept relapsing she felt that it		

wasn't the right care uhmm and she just felt that it was a really horrible environment and she just she was very angry about it and that's what we were talking about last night her main feeling was one of anger. Also she had to uhmm then live with my, her dad's partner and that was a new partner uhmm so she had a big upheaval in her life – she went to live with somebody new, had to, they lived in [redacted] (place) - so she had to commute to school, like you know get up very early every morning and she uhmm had a lot of time off feeling tired and stressed and uhmm but what she did say was that her main feeling was one of anger.	daughter did not approve of environment in hospital very angry main feeling anger had to live with father's new partner big upheaval disruption to school commute get up early lot of time off tired and stressed main feeling anger	Role reversal? daughter angry re services for parent. Impact on child: disruption upheaval tiredness stress missing school angry for mother
Yeh		
She just felt sort of <u>very very angry</u>…	++ angry	protective of mother
About the sort of care that you were receiving…?		
Yeh		
And thinking that they weren't doing the right thing to help you ?		anger
Yeh and then angry that angry that she had to move uhmm angry that I came out of hospital and everything seemed fine, she came back to live with me, and then I would have a relapse and she would have to go back to her dad's partner, so I think because things weren't straight forward <u>like it had been before</u> when it was a lot more straight forward whereas this time it was very up and down uhmm that's what she said that she <u>just felt angry about everything</u>. She actually said that she was in the house uhmm one day and that she threw a glass across the (room/kitchen) and smashed it against the wall – she was just telling me yesterday what she'd, I don't know why I didn't hear about it, but she was just telling me yesterday what had happened you know that she just did feel so furious about everything uhmm but in some ways now I feel well as I said we have always been very close uhmm and we've always talked a lot, but I think we do <u>probably talk even more</u>.	++ angry angry re relapses disruption upheaval hopes dashed not straight forward more complicated up and down unpredictable ++ angry expression of anger I did not know furious about everything very close always talked a lot talk even more	changing manifestation of illness anger having to adjust understanding of problem blames hospital? anger extended upheaval Talking: child telling of an distress anger protect mother anger Talking within context of relationship
? → Really?		
Yeh, we just talk about things all the time, I	We just talk all the time	Illness brought closer and made them talk more

closeness in relationship
↓
increased intimacy

Vulnerable time for child :

Having to negotiate changes in understanding
↓
not with help of parent as parent unwell

becomes unwell – goes into hospital – comes out well
↓
becomes unwell – goes into hospital – comes out and appears well – relapse – back into hospital

412	don't know why we ended up talking about		
413	this yesterday, uhmm (1) but we have a lot of	We have a lot	
414	fun as well you know not just all talking	of fun as well	Having fun
415	seriously about things – we just tend to be	not just serious talk	together
416	very close in that way and make time for each	very close	
417	other uhmm…	time for each other	Closeness
418	Do you think that you being unwell has had		
419	an impact on your relationship with each		
420	other?		
421	(4) Uhmm (5) well it must have done but I	Unsure re impact	
422	don't know don't know how	on relationship	
423	I was wondering because you were saying		
424	how close you are I was wondering whether		
425	you think that would have been exactly how it	Closeness	closeness
426	is now if you had not been unwell or in a	despite	despite
427	way…	(rather than	rather than
428	I think we might have been just as close	because of)	because of
429	anyway because we always have been	illness	illness
430	Yeh		
431	But I think maybe this you know the fact that		
432	she's mature like a lot of teenagers don't want	maturity	
433	to speak to their parents and you know I	norm: teenagers don't talk to	
434	suppose the fact you know she's had to grow	parents	Maturity –
435	up so that's probably impacted on it uhmm	she's had to grow up	need to grow
436	that she has had to uhmm grow up in some	had to grow up	up
437	ways but as I said again even though she's		
438	had to grow up and she's been mature she's	mature	
439	still silly at times and she has her fun with her	able to be silly	Important that
440	friends and she goes out	has fun friends	she is not
441	She's being a teenager	goes out	serious all the
442	Yeh, she is still doing teenager things	"still" – illness	time ↓
443	Yeh	did not take this	can act like
444	Yeh exactly uhmm but uh (1) I don't I don't	away.	
445	know I think uhmm (3) I think it's probably		"normal
446	made her she can be quite bossy in some	bossy	teenager"
447	ways, because she's had me, well she's had		
448	me sort of not being a mum to her uhmm and	she's had me not being a mum	had me not being
449	maybe needing a 'cause when I become ill I		a mum
450	become like a baby as well. That's actually	when ill becomes like a baby	↑
451	one of the signs of me becoming ill I'll		
452	actually start talking like a baby and become	talking like a baby	"more bossy"
453	and like turn into a foetal position and uhmm	foetal position	(authority?)
454	you can't when you're ill you can't be a real	cannot be a real mother	↓
455	mother so I think maybe sometimes like she		
456	can be like she's the mum rather than me	she's the mum	Role reversal
457	Hmm		Identity: 'Real mother' but for illness times

Yeh, how do you deal with that, how do you			
respond to that?			
I think it depends what what it is – uhmm (3)			
yeh it just depends what she's what she's		responsibility/ care giving	
telling me uhmm sometimes she gets on my	gets on my nerves	⇕	?responsibility of child
nerves like she 'cause I put on a lot of weight			
after I became ill and then she'll be telling me	daughter advises mother / ?discipline	control/ influence	
oh you shoudn't be eating this and you			
shouldn't be eating that like when she goes on	worries of child for mother? –	Taking on	
like she's now on a healthy eating 'cause	eat healthy?	child telling parent what to do	
she's been getting ill, she's been run down	been run down		
and uhmm so then it's like you sort of feel			
like you can't do anything yourself – you	you feel like you can't do anything yourself	← sounds like statement of	
have to do what she's doing (laughter)		a teenager	
She's in charge		↓	
She's in charge!(laughter) (Researcher's frame)		role reversal	
Yeh, in that way sometimes, like [redacted] my			
partner we laugh sometimes like she is like			
very very bossy all the time	very very bossy		
Yeh			
Yeh (laughs)			
Would you … it was a hard thing you were			
talking about when you were talking about			
not being able to be the mother you want to			
be uhmm and I was wondering whether you			
could say a bit more about that			
(2) uhmm (2) well it's just when you are		Talk in context	
actually ill, like obviously when you are	when you are	of different	
psychotic, then it's impossible to be a	psychotic impossible	understandings	
mother… you are just … and I think uhmm	to be mother	of situation	
(1) that was something that upset her as well.	upset daughter	↓	
I know that she, there was one point when I			
wanted her to come home – she was actually	I wanted her to	conflict	
with her with uhmm her dad's partner and I	come home		
want.. living at their house and I wanted her		↓	
to come home, I was a lot better and she felt	I was a lot better	painful as	
that I wasn't and that I was that I would get	but she felt I wasn't	cannot ?control	
angry uhmm and I wasn't the mum that she	I wasn't the mum	perceptions…	
knew, that I was an angry mum and I I felt	she knew	sense of self	
sometimes that she that she was manipulating	anger unfamiliar	in conflict	
the situation and that I was, I felt that I was	manipulating I felt I was well	with perceptions of others	
well, so it was difficult. And also this year	difficult		
she actually started at a new school uhmm	she decided	independence	
rather than go to the school here, she decided	live away from mother	make own decisions	
that she was going to live with them because		decision in	
she was worried that I might become ill when	worried she will become ill	context of unpredictability of illness	

504	she was doing her GCSE's so she decided in	Worried re disruption	
505	the summer and I was very angry and upset	during GCSE's	
506	about that and I felt that I was well but then in	angry	Negotiating
507	the end I decided okay, if that is what she	upset I felt that I was	choices in context of
508	really feels then let her do what she wants to	well	MH difficulties
509	do uhmm but I had a feeling that the		
510	relationship between her father and partner	other disruptions	
511	would break down which it did and then (1)		
512	she didn't feel happy in the new school and	adjustments	
513	she wanted to come home so that's what	she wanted to	
514	happened – she ended up coming home. So I	come home	
515	felt in a way that I had allowed her to do what		
516	she wanted to do uhmm and it ended up being		
517	the best thing that I could do		
518	So she discovered for herself		
519	She discovered for herself but I felt in some	I was well	ongoing
520	ways like she was being maybe herself a little		uncertainty
521	bit manipulating of the situation because as I	manipulating of	
522	said, I did feel that I was well at this time and	the situation	
523	she felt, then I don't it's difficult to know	used illness in normal adolescent	using illness
524	how genuinely someone's worries are – she	conflicts	in
525	had the right to be worried that I could	she had the right to	
526	become, because I could become ill again at	be worried.	communication/
527	any time and that is still the same situation	I could become ill	conflict
528	now – I could become ill again – yet she's	again at any time	in negotiating
529	decided to come home and be with me. But I		relationships
530	felt as well that her father and his partner		
531	uhmm manipulated her too they're very in		
532	their household uhmm like things are more		Finances
533	comfortable like financially because he		
534	doesn't provide me with much support uhmm		Hope for
535	and I haven't been working for the past year		returning to
536	now – I should be going back to work soon –		normality
537	but uhmm I think you know there was that	using illness in	
538	kind of uhmm manipulation on their part that	negotiation of	
539	they were sort of	contact following	what are others
540	Influencing her…	divorce	telling daughter?
541	Influencing her yeh in that way uhmm but		Unpredictable:
542	then there was the genuine concern that	concern re	
543	uhmm yes I could become ill and she had a	ongoing	ongoing
544	right to be concerned about that.	uncertainty	uncertainty
545	So is it difficult to have the normal sort of		- even when well
546	parent child relationship – so that sometimes		concerns re could
547	it's almost as if it turns around or she is in a		change any
548	position where she has to make decisions that		moment
549	someone else at that age wouldn't make and		

550	then it needs to move back again to	conflict re where daughter should stay.	
551	Yeh, that's exactly, because I remember when		
552	I came here actually we had a meeting here		
553	and it was between her father and uhmm the		
554	partner, well actually he, her father and	meaning of her wanting to live away for A?	
555	partner [redacted], had actually split up uhmm at		
556	Christmas because apparently he'd had an		
557	affair and uhmm [redacted] (daughter) had decided that	feeling...? rejected angry betrayed powerless...?	
558	she wanted to go and live with [redacted] (father's ex-partner) and I		
559	remember the social worker was saying well		
560	she's – she was only 14 then – and the social		
561	worker actually said well if you went … she's	not receiving support from services	
562	old enough to make her own decisions and if		
563	you… by the time you took it to court she		
564	would be 15 and then you wouldn't be able to		Negotiating difficult decisions within context of MHD + involvement of services
565	say one way or the other, but then I felt I had		
566	the uhmm residence order and I said you		
567	know at the end of the day [redacted] (ex-husband's ex-partner) has got		
568	nothing to do with [redacted] (daughter) so she not going		
569	to go and live with her – I don't care what	angry fighting for daughter 'I'm her mother'	
570	you're saying, I'm her mother and she's not		
571	going to be making this decision to go and		
572	live with somebody else and then, so then at a		
573	later stage when in the summer things had		
574	changed and in the summer when [redacted] (daughter) –		unable to influence how she wants
575	her father had agreed, I didn't agree to her		
576	going to stay with them and I rang social		
577	service and they said the social worker was	conflicting advice	
578	then saying oh, no she can't make that		
579	decision – you've got the residence order, it's		
580	up to you. So one thing was said at one time,		
581	then another thing was said at another time	daughter given a lot of authority	Confusion for daughter
582	and I felt, no she's not old enough to be		
583	making these decisions anyway, but she had	many others with say that has more influence	
584	been given a lot of uhmm authority because		
585	people were saying, her dad was saying, the		
586	partner was saying, social services were		
587	saying and then retracting what they had said		
588	and changing it, so I think that was, that was		
589	quite difficult but	Difficult	
590	That puts you in a very difficult position of		
591	still trying to be a parent to her		
592	Yeh yeh, I think that was quite difficult that	too much freedom	too much freedom
593	she did have too much uhmm freedom in		
594	some ways you know to be making these		
595	important decisions		

596	You talk a lot about your closeness with each			
597	other and how actually able you are to talk			
598	about things. What uhmm are your own views			
599	about whether children should know about	Researcher		
600	say in your case bipolar uhmm illness uhmm	using her words		
601	or whether it's best for them not to know too			
602	much – what is your…			
603	Well, I think they should know	I think they should know (ie MD)	Strong belief children should know	
604	They should know?			
605	Yeh, definitely.	Definitely		
606	Have you always thought that or is it			
607	something that you			
608	I've always thought that – I've always			
609	thought that about everything really to be	General value	All areas of life	
610	honest. I don't believe in secrecy in families I	Don't believe in secrecy in families		
611	think if there is anything that is like important		No secrecy re important things	
612	or major impact you need to be honest about			
613	it so something like that you need you know	You need to be honest		
614	you need to be open and honest about it and		Values honesty	
615	also she did her own research anyway and got	Daughter found out for herself anyway - own 'research'		
616	on the computer and found out and her friend		Daughter learning about it independently with friend	
617	went on the computer for her and was looking			
618	up this and looking up that so I think to be	Internet		
619	honest she knows more about it than I do (laughs)	friend found information for her		
620	So she went and explored for herself			Daughter more keen for information than mother.
621	Yeh	She knows more than me	"Knows more than me"	
622	Did she tell you she was planning to do that?			
623	She told me that she had done when she had	Told mother after		
624	already done it.			
625	And your sort of feeling about that when she			
626	told you?			
627	No absolutely fine – as I said I think she	Mother did not mind		
628	probably does know more than I do because I			Child telling mother
629	remember I have sort of read things when	Try to find out when ill - cannot remember	Cannot remember	
630	I've been ill which then I can't remember			
631	Yeh			
632	Then just very recently I went on a …well in			
633	fact it was last weekend I went on an			
634	American website and was sort of looking at	Went on website recently to look for information		
635	that, but uhmm I uhmm, but I find it hard to		Cannot retain	
636	retain the information anyway and then I was	hard to retain		
637	sort of looking at Bipolar 1, and Bipolar 2 and	- mx ? - illness? - difficult emotionally ?		
638	I was thinking well I'm sure Dr [redacted]			
639	said that I was Bipolar 1, but actually I felt			
640	more like Bipolar 2, so what is the difference.	confusion disagreement?	Confusion	
641	There does not seem to be much difference		Struggling to make sense	

642	between them anyway uhmm (1) but I do I do		
643	feel that it's uhh it's you know, you have	Can happen	
644	something that is going to impact on family	again	
645	life or that might happen again, I think people	Family knowing	
646	need to be prepared and uhh and if you, if a	so they can be	
647	parent is ill in hospital the children need to	prepared	
648	know why they're in hospital uhmm I think it	Children need to	
649	needs to be age related obviously – you know	know reasons	
650	people shouldn't be burdened with or children	for hospital	Q:
651	shouldn't be burdened with information that	Age related	Intellectual
652	they can't understand but my daughter you	Not burdened	understanding
653	know she is very bright and uhmm she is	with information	↕
654	going to understand whatever there is	which cannot	Emotional
655	Yeh	understand	coping
656	To understand.	Daughter is very	+ capacity
657	The belief that things in the family that	bright	to hear
658	impacts on everyone need to be open and		
659	talked about – where do you think that idea		Understand
660	comes from? Is it from your family,		⇅ ?
661	I don't know		Cope
662	or just yourself, your own values…?		
663	I did not have a proper family upbringing		
664	myself 'cause I was actually brought up in	Brought up in	
665	care and then well then I was fostered	care	Q:
666	actually at the age of 10 and I left my foster	Foster care	Nature of
667	parents when I was 17 and I don't see them so		'informational'
668	I don't know – it's just something that I've	Don't identify	factual?
669	had myself.	role model/	
670	You've always been	someone who	
671	Yeh yeh	shares value	
672	Is there someone from the other people		
673	around you – either your family or you were		
674	saying about your ex-partner or your current		
675	partner or the medical staff that you've been		
676	involved with – has there been any views that		
677	was sort of different from you – people		
678	saying you should be telling her more or you		
679	should be telling her less or she shouldn't		
680	know?		
681	I think uhmm when I was in the hospital I		
682	know uhmm when I was in the [redacted] (hospital) that	Support from	
683	one of the nurses was actually very	nurse	
684	supportive 'cause [redacted] (daughter) used to come and	daughter visited	
685	see me from school, like straight from school,	in hospital	
686	she'd come and visit me on the ward and they		
687	could see as well you know that she was a		

688	very mature girl uhmm when I was actually I	Information –	
689	was ready to be discharged and I wanted	sharing based	
690	[redacted] (daughter) to come home to me and her dad had	on intelligence	
691	rung up the hospital to see how I was and	& maturity	
692	uhmm I remember the doctor, I said to the		
693	docor could [redacted] (daughter) 'cause [redacted] (daughter) wanted		
694	to come back to me then and I remember		maturity
695	uhmm I said to the doctor she is very mature,	Very mature	emphasised
696	you know she'll be fine back with me you	↓	↓
697	know bla-bla-bla and the nurse actually said	∴ she'll be fine	to support
698	you know backed me up and said yes she is	mx involved in	openness
699	Really	decisions re	and
700	Yeh, so I think uhmm I would say that no one	daughter	ability to
701	specifically said say this or say that but I		cope
702	think you know they were aware that [redacted] (daughter)		
703	was quite a you know grown up girl uhmm	grown-up	
704	one of the nurses – her children went to the		
705	same school uhmm		
706	So you felt they supported your decisions	support from	
707	Yeh, yeh I do	staff re openness	
708	And was there any times when you felt that		
709	someone sort of did not agree with you?		
710	When you were saying that your, you're		
711	you're your ex- uhmm [redacted] (daughter)'s father, your		
712	ex-partner and his new partner, that they were		
713	influencing her against you – do you think it		
714	was to do with how they were talking about		
715	what was going on with you or was it to do		
716	with other things?		
717	I think mainly other things uhmm (1) and		
718	also, well, and also the illness – they would	Would use	
719	use the illness against me, but then… 'cause	illness against	used illness
720	there were times when I was well and you	me	against her
721	know [redacted] (daughter) could've, well [redacted] (daughter) did		
722	come back to me when I was well and then		
723	she went away again, but I feel uhmm, they		
724	would use the illness against me like it's	use illness against	
725	almost like in the summer when she decided	me	
726	that she wasn't going to come home uhmm I		
727	think definitely that would have mainly came		
728	from her, but I think it would have come from		used
729	them as well saying you know that I could	they said I may	uncertainty
730	become ill at any time and this that and the	become ill again	
731	other so I think uhmm they would have a		
732	negative a negative view	Negative view	
733	Can you remember the first time you had to		

explain something about this to her or to give her any information? Can you think when that might have been?		
(5) uhmm (2) no, because (2) in 2004 she she was actually with like me when I became ill – like it happened very suddenly	she was with me when I became ill – very sudden	Learn about illness by "being there" = witnessing
Okay		
And we were walking across the common and I actually for some reason thought that everyone was from East Enders – there were people around so I was saying 'oh, they're from East Enders'. I was taking her to stay with her friend, uhmm, well actually it was for the day and so I was walking home and so she must have been well she had just finished junior school and (1) then (1) I brought her back home… Oh no, well it actually started actually I went to somebody's house and felt quite strange, for Sunday dinner, and then her cousin had cut her foot and I thought it was a trick – I thought they were, she'd cut it really badly and I thought later on I thought this was a test – it wasn't real. And then my friend phoned me and there was actually something wrong with the BT line and so the phone kept going , ringing and I couldn't hear anything, so I was oh they're testing me. But that was what I felt, that I was being tested. So she actually was aware of what I was, not of what was happening, but what I was doing…	daughter witnessing frightening behaviour? confusing behaviour? she was aware of what I was doing = psychotic behaviour	Witnessing frightening behaviour
Yeh, yeh…		
When I first became ill and then she witnessed me actually becoming like a baby and also I would speak French when I become ill for some reason and I start writing in French, so I'm writing all this mad stuff and then apparently she always says to me she can never forget me saying in a very quiet voice 'the horses are whispering in the garden' and she that made her feel a bit, she was a bit scared then uhmm so we've sort of talked about like what's what happened and what like I felt and what happened to me rather than me like explain and then then I sort of ended up in the [redacted] (hospital) and then being transferred to the [redacted] (other hospital) because I am a	she witnessed me daughter witness to "mad stuff" can never forget frightening behaviour Not explain, rather talk re what was seen	Talking as making sense of frightening experience Not explain rather, talk re what was seen

Mental Health Act Manager so that's why I had to go to the [redacted] (the hospital) uhmm so I've never sort of had to and also I think her younger brother's mum she – it's all… I've got a very complicated life (laughs briefly), but she used to be, she used to be my old school friend and she ended up going off with [redacted] (daughter)'s dad when I was yeh, when I was ill with [redacted] (daughter) and uhmm anyway we ended up eventually patching things up for the sake of the [redacted] (daughter) and her half brother because her dad and her split up and I won't go into all that but uhmm so for the sake of the children we did sort of make a sort of reasonable, well we only speak on the phone really and arrange for [redacted] (daughter) to go and stay with her, but that is who she stayed with when I was uhmm when I was ill in the [redacted] (hospital) and so [redacted] (ex-husband's ex-partner) probably told, well she did actually tell her quite a bit because [redacted] (she) had been around – she had come to help when I was ill with [redacted] (daughter) and uhmm she had also seen me when I was ill after [redacted] (son) as well so she did uhmm she did have information	(Knowledge re mental ill health) Never had to explain – was in hospital Person she stayed with during illness probably told no actually told quite a bit Knows her and has seen her unwell – pass on info	Parent away ↓ Others explained
When you imagine that conversation between the two of them do you feel comfortable with how that might have gone or what she might have said or does that make you…		↓
Yeh, it's quite sort of – she would have been sensible uhmm and uh she's been sort of supportive about my illness so I think that would have gone quite well yeh	sensible info supportive trust that would have gone well	Trust this
That's reassuring in a way for you…?		
Yeh		
That there was someone you could count and and who did have the information.		
Yeh		
Do you think uhmm – you were saying about [redacted] (daughter) going on the internet and so on, going on her own sort of mission to understand it and to really get information, to make sense of it. Do you think she and [redacted] (son) have been quite similar in their reactions in their wish to understand?		
No, I think [redacted] (son)'s been, [redacted] (son) when I became ill in 2004, I know uhmm I spoke to his dad		

Asking about: "Information about "illness"
Facts ... (vs... ? experiences...)
→ What is useful?
→ to know for whom?
→ Is it about "knowing"?

and and his dad said like, 'cause he was actually spending a lot of money, like he was buying a lot of gadgets and stuff like that and he said to his dad that's his, he felt quite a bit afraid and uhmm maybe a bit afraid for himself and by buying things it was his way of sort of blocking out the negative thoughts uhmm (2) now I've forgotten what I was	son coped by spending money he was afraid afraid for himself blocking his ⊖ thoughts (by buying things)	Coping by moving away from feeling experiences
About whether they deal with it differently.		
Yeh and I think this time around uhumm he probably hasn't done anything, like you know he went he went to [redacted] (country abroad), I became ill the end of October, he went to [redacted] (country abroad) on December the 9th and uhmm I really don't feel you know he's he gets in touch with me by email and ringing me but I feel he's just getting on with his life. I don't think he's been really bothered about it all. He's been bothered about me and upset for me but not uhmm he wouldn't be looking up and also then he didn't look up on the internet or he just wouldn't be like immerse himself in any sort of information.	lives abroad Getting on with his life Bothered about me Upset for me would not Immerse himself in info	vs Coping by moving forward - wanting to know more + understand
If I asked him why you had to go into hospital what do you think he would say?		
Oh, he would know why I had to go into hospital		
So he would say you had bipolar?		
Yeh.		
So he knows and he thinks about it as well. And does he, would he talk in more detail than that or would he just say she's got bipolar illness.		
Yeh, I don't know if he would know anymore detail to be honest.	Son would not know detail	
But [redacted] (daughter) would know ?		
Yeh, as I say [redacted] (daughter) would know more than me (laughs)		
She would know why it happened, what the symptoms are…?		
Yeh	Daughter knows details	
What the treatment is?		
Yeh.		
She would know all those sort of things?		
Uhugh		
Yeh		

And does she ask you lots of questions about it?		Not often in conversations
No we don't normally talk about it really. I mean as I say last… yesterday for some reason we were talking about it and then occasionally uhmm we might talk about what happened and uhmm or even with [redacted] (sister) sometimes or we might make jokes about it uhm.	Don't talk about it day-to-day occasionally talk re what happened sometimes joke about it.	Not always serious conversations: sometimes "laugh + joke"
So you can sort of laugh about it		
Yes we can laugh and joke about it sometimes and you know just occasionally we might talk, 'cause as well it is coming up on the 31st will be the date that I became ill on the 30th actually of October so I'm coming up to that time and so we talk about 'oh I can't believe that it's nearly a year' and then we might get into a conversation about what I did uhmm and uh (1) I remember coming home from work, I'd had a meeting at work which had been very stressful and I had text somebody that I had had the meeting with I wanted to, I couldn't spell the work 'professional' and [redacted] (daughter) said that she remember me getting sort of quite upset that I couldn't spell 'professional' uhmm and uh so yeh we do we we talk about it.	laugh and joke anniversary of illness conversation re what I did talk re the minute detail "do you remember when"	memorable times, eg anniversary conversations re behaviour daughter telling mother
How those conversations work, and you tell and sometimes make a joke and you talk about specific things like oh you couldn't spell professional and then you became upset – do you think there's a purpose to those conversations? Do you think it's a way of processing it or making sense of it or do you think it's just memories and ..		
I think it's just memories, really to be honest uhmm (1) and then sometimes I mean I mean for me I think like because I don't remember a lot of it, it's quite interesting you know, and you know we can all be a bit obsessed with ourselves sometimes so it's interesting like to know what I did, and	"quite interesting" filling in information know what I did	developing a more coherent understanding?
Not in an upsetting way? Or…		
No, I don't find it upsetting really I just – the way I feel about it, I think some things are upsetting like the horrible nightmares and		

researcher's frame, but do give either/or & not a fit

Q. meaning for her daughter's experience of these conversations?

918	things like that and things that I thought		
919	things about my father – whom I haven't	some things	Relationship
920	seen, well his dead now, but I haven't seen	upsetting eg	with difficulties:
921	since I was thee and uhmm… but most of the	talking of father	
922	time I don't feel, well, I don't feel upset about		• just something
223	it – I feel that it's something that happened to	something	that happened
924	me. And I feel, I suppose I might feel a bit	that happened	• angry
925	angry as well in some ways 'cause I feel not	angry	• why me?
926	like oh, it's not fair or why me, but a little bit	not fair	• not fair
927	it's not fair, why me, you know. I think,	why me	• annoyed
928	especially 'cause I went through it with my		• uncertain-
929	children and that's all I expected to happen to	that's all I	• hopeful
930	me and if I had another child, fair enough, but	expected to	
931	I didn't expect to become ill otherwise and	happen (then	
932	(1) so I do feel, I just feel annoyed, it's like	more!)	Evolving
933	it's annoying uhmm and I I feel uhmm (6)	"bargaining"?	understanding
934	yeh, I just feel it's something that happened	annoyed	of difficulties
935	to me, it could happen again, but hopefully it	uncertainty	
936	won't uhmm	hope	
937	But that's all		
938	Yeh that's all I can do and I can't I can't live	can't live in fear	
939	in fear uhmm but then there is that fear and it	But fear!	
940	I think that's probably what annoys me most	↓	Relationship
941	of all – why should I have to live with this	Annoyed Why?!	with uncertainty:
942	worry and sometimes when I can't sleep,		
943	that's one of the signs of me becoming ill so	looking for	• fear
944	when I can't go to sleep you might think 'oh	little signs –	• vigilant for
945	my God, I'm gonna become ill' or if I	interpret as	signs
946	sometime feel a little bit odd I, you know, I	illness	• worry
947	get some warning signs, like things seem a bit		• angry – want
948	sinister or a bit ugly and if things seem just a		to live free
949	little bit like that I might think ' oh, am I		from this way
950	becoming ill' and hopefully I'm not and I		
951	haven't been, but I think that's the thing	Hope +	sort of on
952	You're sort of on the lookout…	uncertainty	the lookout
953	You're on the lookout		
954	Do you think [redacted] (daughter)'s on the lookout – do		Hope in context
955	you think she has, like you have certain		of uncertainty
956	indicators, do you think she thinks oh she's		
957	like that, or she's talking like that?		Talking:
958	I think she would be on the look out uhmm		Explain
959	you know if I was behaving strangely or said	daughter might	relaps signs
960	anything strange or definitely she she'll be	be on the	
961	aware uhmm and we went through the signs,	lookout	
962	the primordule signs	we went through	
963	Oh did you?	the signs	

I went through them with [redacted] (partner) and her uhmm so I think, I think most of the time she feels that I'm well now. I feel, I mean, that's another thing that we do we do talk about, because I don't, I feel (1) well, but I feel, I suppose mentally I do feel well, but I I feel very very tired all the time so in myself I am not a 100% uhmm. I get up very late and I find it hard to get going, I find I uhmm I don't have any energy really. Like yesterday I got up very late, I went to the gym and then I had to go and have a lie down after I've been to the gym uhmm (2) – I don't know why I'm saying what I'm saying ↑became distracted → current worry?	Talked partner and daughter through relapse signs Uncertainty re how well she is doing	Talking: Sharing info/ facts
Talk about the signs		
Yeh, so I do sometimes say, like I would say to her I have actually asked her like how do you think I am, do you think I'm well and I'd say to [redacted] (partner) as well 'cause I've had a back to work meeting and I've got to go to another one and we talk about whether I should go back to work or not and uhmm so (1) we can have those sorts of conversations about about how	Asking daughter re how she is doing; also partner Talked re should I go back to work?	Talking: Part seeking re-assurance Talking: Decisions in context of illness
Do you talk about what would happen if you were ill again?		
Yeh, we've talked about that and what she said is that she wants to do is stay at home and, with [redacted] (partner) – she's not going to go to anywhere else so	She will not leave again	Talking: Reassurance Fear of losing child again.
So that is a conversation that you could have together as well?		
Yeh, yeh we had it and that's what she you know – she wants to stay where she is and uhmm and she said that she definitely definitely does not want me to go to the [redacted] (bad hospital)	〃 quality of hospital/care	Talk Reassurance Decisions in context of illness
She does not believe that they were looking after you in the best…?		
No no she just feels it was awful and uhmm I don't know 'cause I feel in some ways uhmm I could have gone to the [redacted] or (good hospital) somewhere, because I was a Mental Health Act Manager, but I decided that I wanted to stay in the [redacted] (bad / local hospital) because it was close for her and [redacted] (partner) to come and visit me uhmm	Close to allow visits	Hospital: Importance of visiting

Her rights – wanting her to have access to good services ?

researcher taking a position

Retracting Back into researcher mode

and now that I've done that I think if I became ill again it would then be hard for me to go elsewhere … I don't know		
No, I don't think so, I think it would be still your choice		
Uhmm, but		
I guess that does make me think about how you feel in general that uhmm that services have been treating you, how they've responded to what you needed, maybe particularly what you needed as a family? Or as well, what you think [redacted] (daughter) and [redacted] (son) needed all throughout if you think about what's been available or what you would have wanted differently?		
(2) I think, I don't think it was too bad in the [redacted] (hospital), I think, well I don't, in some ways it was, because it was very, I was on [redacted] Ward and it was very chaotic a lot of the time – I mean there was some nurses that were excellent nurses there, really really good, and there were other nurses you just felt didn't care less. There were some nurses that you just felt had really had enough uhmm (2) and then there was others who you just felt were really a bit – not bullying (1) but like there was one nurse in particular who who used to drive me around the bend but she was good in the sense that she would actually make you get up and make you get dressed rather than lying in bed all day which was actually good for you although you know it seemed horrible, but [redacted] (daughter) used to say sometimes that you couldn't tell the patients from the staff (laughs) which I don't know that that's a bad thing (laughs heartily)	ward chaotic a lot of the time Some good care some not Couldn't tell the pts from the staff	Quality of care: Unsupportive environment for families? Inconsistency in care Irreverence? Reclaiming some power? Making it lighter?
Do you think, because you were mentioning the one nurse who was sort got to know [redacted] (daughter) a little bit as well and could think about your relationship with each other and that was something that was really useful to you wasn't it?	One nurse got to know daughter & thought re relationship	Luck? Personality of nurse / values of nurse?
Yeh		
Was that an experience that you had often – that someone would make the effort of knowing her as well or or …		Rather than imbedded approach / policy of ward, hospital.

Yeh, there was a few nurses who defiantly did – I'd say definitely, yeh – I'd say uhmm there was probably four nurses who who did that	Nurses who thought re family & her daughter.	Holding children in mind over time.
Did that make a difference to you?		
Yeh definitely and I think they were very good and I do go back there – I take magazines there sometimes and they're always like very pleased to see me and uhmm ask how I'm getting one, ask how [redacted] (daughter) is, ask how [redacted] (son) is, even the domestic workers as me like how [redacted] (son) and [redacted] (daughter) are. Yeh, so, that's quite nice uhmm	Ongoing relationship Ask after daughter	
Would you actually say that that made a difference to you… 'cause I guess from some people you would have had that experience and from other people not – do you think it's something that should be encouraged or …		
Yeh, I think so – like seeing you as a whole person and I uhmm but I think I was, I was quite shocked when I was there as well 'cause there was some very negative things I saw. I think that's the trouble uhmm like I remember I mean there was some very bad language was used uhmm and I swear myself but I don't expect it in a professional capacity like someone saying oh, like even as a joke 'oh you fucking idiot' or you know, and I think and I was really shocked and then someone talking about uhmm the patients as if they were actually in charge of the ward – somebody who wasn't in charge of the ward would actually talk like they were in charge of everybody and I found that quite odd and uhmm but and uhmm some things I found – there was behaviour I found very unprofessional.	seeing you as a whole person shocked by some experiences unprofessional	Whole person: See different aspects to me than my illness Shocked by hospital environment
If you could make a sort of a list of three things that you think that uhmm staff should always remember, that you think makes a difference to your care, what would you say?		
I think uhmm the main thing, well I think for myself just that I'm an intelligent woman and probably most of the other people there are – not always, I think there's big differences as well, between people on wards – and there	Remember I am an intelligent woman	Whole person

Leading question! ←

Did not ask: Did children ever witness these?

Predicted talk: What researcher wanted her to say / to know?

are some people like when I went onto [redacted] Wards, the mixed wards, there was people who obviously had difficulties, I was very unhappy being placed on a mixed ward – uhmm but I think that… That your intelligence doesn't go away because…		
Yeh exactly uhmm so I think that's the most important thing uhmm (5) I try to think of other things uhmm (9) – I suppose that it's very frightening being ill, very frightening indeed, and that they should remember that you are going through maybe like the most awful experience that you could ever (starts crying) go through really Yeh	upset – very very frightening worst experience ever	It is very very frightening to experience MHD'
(Crying) it's like being in a nightmare, And I think they should remember that you are not a child (almost angry). Sometimes you get treated like a child (angry emphasis) (5) Um So in some way you are still an intelligent adult person going through something really horrific and that that should be respected and acknowledged Yeh You were thinking about how that was really hard Yeh (3)	Like being in a nightmare Not a child! Treated like a child	Infantalized Whole person – adult – more than difficulties ↓ In absence of this – impact on role as parent? authority?
We are sort of coming to the end of our conversation (laughs a little) And I was wondering if if I was a mother who had just become ill for the first time and I was sort of scared about my children and what was gonna happen and I came to you for advice what what do you think you would tell me? What advice would you give me?		
It will get better (very softly) It will get better?	It will get better	Hope?
You'll get through it. And that your children will love you (tearful) (2) I guess I would need to hear that – have you needed to hear that in the beginning: that the illness won't stop your love for each other… Yeh yeh	You will get through it. Your children will still love you	Fear re losing children losing relationship

Between you and your children…		Still love laughter closeness fun
Yeh		
Yeh		
Is there anything in the context of your bipolar illness and of the impact on family life and on your children and of how you as a family have come through this, that that you think is really important and that I didn't ask you about and you want to to tell me about?		
(2) Uhmm (1) I suppose it does make you, strong as a family, 'cause you've been through such a lot (tearful) and you do love each other and it's funny as well and life's a, funny thing (blows nose) and I think we know that, like in our hart, like that's one thing that in our family life's mad (laughs), because uh, things are strange and that we can laugh and we can joke about it and uh yeh, you just get strong as a family or it can do uhmm (4) and you can get through the other side of it – I think that's the main thing – I think that's one thing that I said I looked on this American website and there was a, it was a quite interesting for the advice on various topics, but they had like chatrooms and I just found it very, not so much negative, but I found that everybody identified themselves as these people with bipolar, whereas I don't identify myself as a person with bipolar – although I have bipolar I feel that isn't me	Make you stronger as a family life's funny family identity playful joking stronger get through Rejects idea of illness as identity Not who I am	Strength and resillience as a family Also laughs & have fun (Playful identity "my family is mad" Self ≠ illness "
That's not who you are…		
No, definitely not. It is just something that has happened to me and it may happen again uhmm and although you obviously it is something that you are living with, but I just, I don't feel it that way, that you are living with it all the time – I think it will be something that either happens or it doesn't happen, and has happened, hopefully it won't happen again.	Something that has happened to me, separate from me something you live with Happens Hope	" Illness as clearly separate from self Hope + uncertainty
It's interesting that because in a way the things that you say uh sort of speak to the same thing – about still being the person you are and of this being an illness that comes into your life and you have to deal with it at times, but then it goes away again		

Relationship of this position to talking in family?

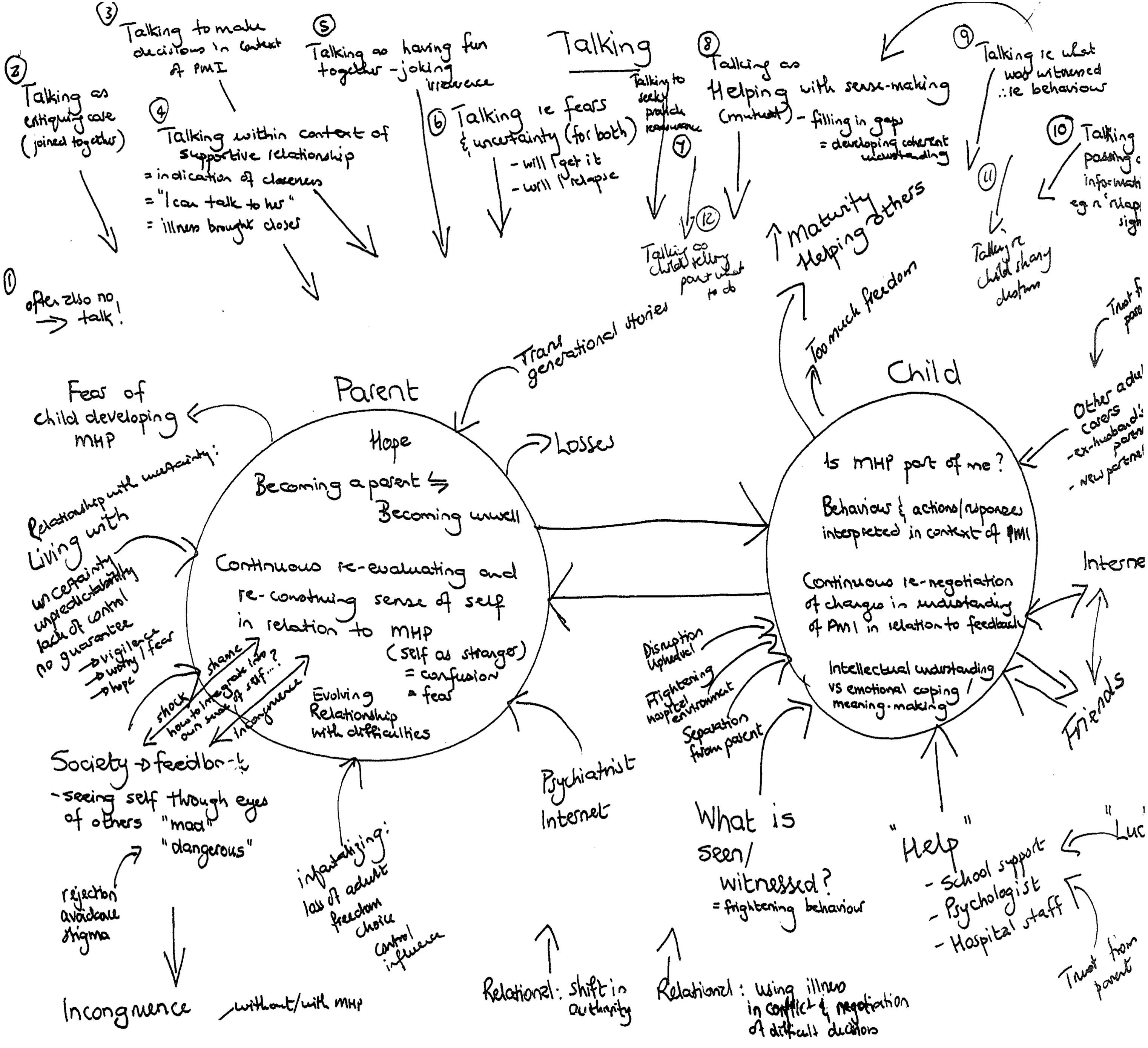
Yeh		
And that it's it's not become your identity		
Uhmm		
And I guess I am interested in how you have managed to hold onto that, because there is a lot of pressure almost you know of being defined in a certain way, so when you come into mental health services, that can be all that someone is interested in, but that you have managed to sort of hold on to something else about yourself that is beyond just bipolar, and I wonder how you've done that?		
I just think I'm a very strong person – I've always felt that I'm a very strong person and I feel like in my life like my mother had bipolar so I wasn't brought up with my mother and uhmm and I left home, well my foster parents, and I sort of had to look after myself basically and I just do feel that I am very strong. I feel that the bipolar, I don't feel as strong as I have been, but hopefully I think I will be strong again.	Very strong person mother bipolar had to look after myself Illness has taken away some strength, but hope to regain.	(+) Sense of self Was a child of parent with bipolar herself Less strong Hope re future
The when when you were taken away from your mother's care because she was unwell – did did you know why that, why that was at the time, or did you discover that …		
No, I discovered it much later. I think I was 4 when I was put into care – I was fostered when I was 4 and I then got into a children's home from 6-10 and I used to visit her in the hospital and she would come and vist me once a year, like yearly visits and I had I had no idea – I just knew that she wasn't well, I didn't know what it was.	Did not know re mother's bipolar Visited mother in hospital Yearly visits I did not know what it was	Was not given explanation re mother's illness Hospital visits Did not understand
Did you make a distinction between a physical not well and a mental not well?		
(2) I don't know – I had no idea to be honest		Lost relationship with own mother due to bipolar — meaning for her re maintaining relationships?
You don't sort of remember thinking about it?		
I don't remember, yeh		
Yeh		
I think I've asked all the things I wanted to ask and uhmm I just wanted to say thank you very much for taking the time to come. I will turn this off now and then I could…………		

Lost opportunity in interview?
Could have explored more.

Appendix 13

INITIAL VISUAL MAPS OF DATA

INITIAL VISUAL MAPS OF DATA



Appendix 14

MAPS GENRATED THROUGH SITUATIONAL ANALYSIS

MESSY SITUATIONAL MAP

Trans-generational mental health narratives

Hope for the future

Strangers

Physical health
problems

Other family members

Community

Family friends

Anti-benefits discourses /
“scrounger” discourses

Uncertainty re the future

Bad housing

Parents/grandparents

Neighbours

Poverty

(Ex)/Partner/Other parent

The Everyday / ordinary

Teachers

Housing and
Benefit system

Migration

HOPE

LOVE

SCHOOL

PARENTS WITH
MENTAL HEALTH
DIFFICULTIIES

CHILDREN OF PARENTS
WITH MENTAL HEALTH
DIFFICULTIES

Losses / trauma

Siblings

Development of
children

DoH

WORRY and
UNCERTAINTY

Bizarre experiences

FEAR

Developmental, behavioural or
health concerns re children

CPN/ Adult social
worker/ support worker

NHS MENTAL
HEALTH SERVICES:
CMHTs

Discourses re
social services:
taking children
away

INTERNET / MEDIA

CHILDREN’S
SOCIAL CARE

Psychotropic medication

Psychiatrist

Leaflets / booklets

Discourses re mental health
practitioners being very busy /
overworked vs kind and helpful

STIGMA

Discourses re childhood

PSYCHIATRIC
HOSPITAL

Protection of children

Big Pharma

Cultural care giving practices

Discourses re
mental illness

NHS Cuts and
reorganization

Discourses re parenting

Contested nature of psychological distress
- Medicalizing of psychological distress /
pro- and anti- diagnosis debate

Psychologists /
counsellors / therapists

Gendered discourses re mothering and fathering

ORDERED SITUATIONAL MAP

Individual human elements /actors
Parents with mental health issues
Children
CPNs, social workers, support workers
Psychiatrists
Children's social workers
Psychologists/counselors/ therapists
(Ex)/partners / parents
Own parents / grandparents
Siblings
Other family
Family friends
Neighbours
Community
Teachers
Strangers

Collective human elements / actors
UK NHS Mental health services
Psychiatric hospitals
UK Social care services
Housing and benefits organizations
School
[Immigration services]

Discursive constructions of individual and/or collective human actors
Discourses re mental illness
Discourses re social services: taking children away
Discourses re mental health services being under threat / being cut
Discourses re mental health practitioners being very busy / overworked vs kind and helpful
Discourses re parenting
Gendered discourses re mothering and fathering
Discourses re childhood
Discourses re benefits / "scrounger" discourses

Political / economic elements
NHS cuts and reorganization
Poverty
DoH
Big Pharma

Temporal elements
Transgenerational mental health narratives
Development of children over time
Uncertainty re the future
Hope for the future

Major debates / debates (usually contested)
Contested nature of psychological distress - Medicalizing of psychological distress / pro- and anti- diagnosis debate
Stigma (Stigmatizing of psychological distress)
Protection of children

Non-human elements / actants
Diagnosis
Psychotropic medication
Internet and media
Leaflets / booklets
Bad housing
Physical health problems
Loss / trauma
Developmental / behavioural / health problems of children
Bizarre experiences
The everyday / ordinary
Love
Fear
Worry and uncertainty
Hope

Implicated / silent actors / actants
DoH
Big Pharma

Discursive constructions of non-human actants
Stigma
Contested nature of psychological distress - Medicalizing of psychological distress / pro- and anti- diagnosis debate

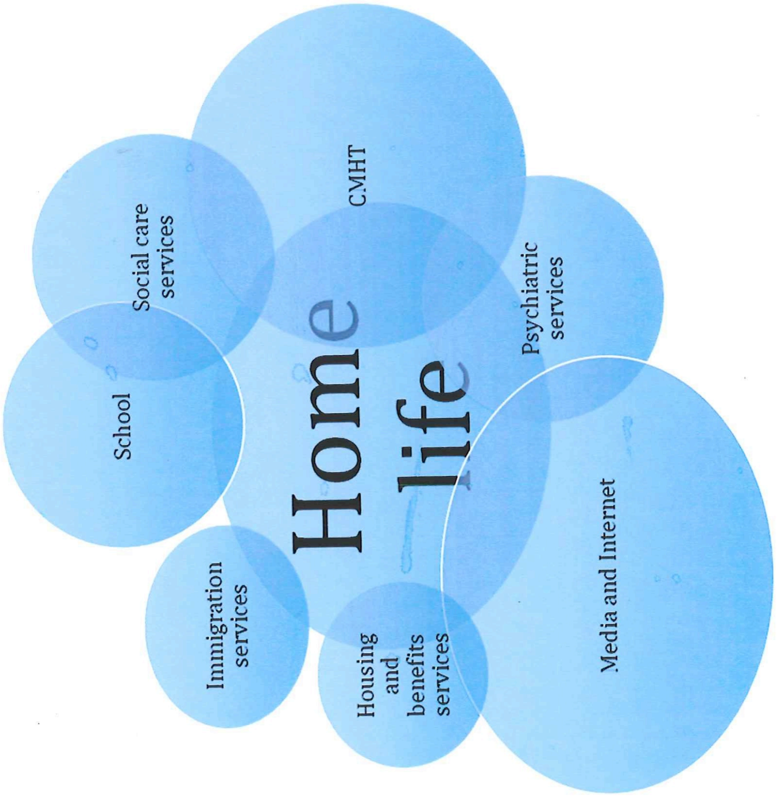
Socio-cultural / symbolic elements
Migration

Spacial elements
Bad housing

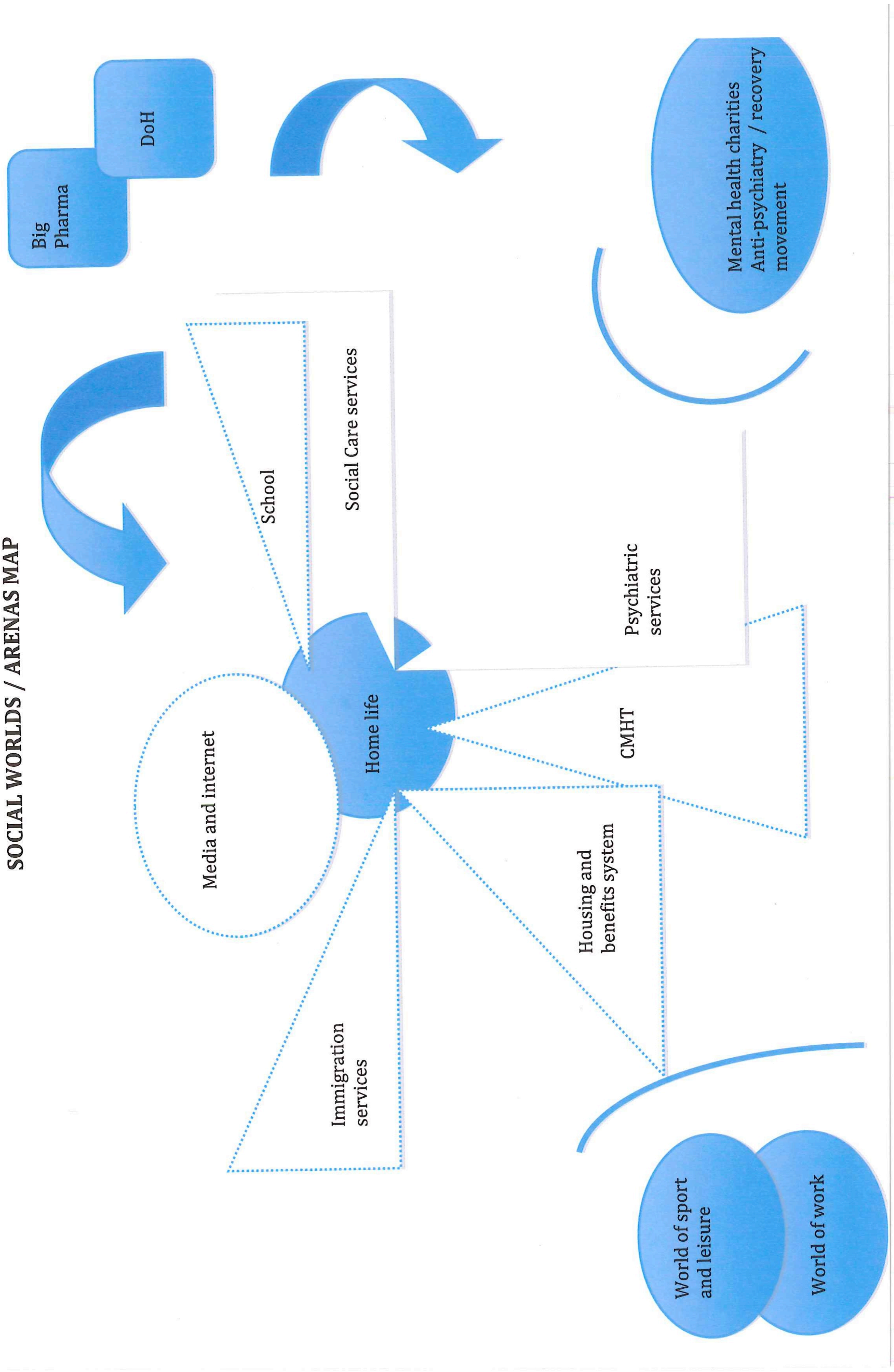
Related discourses (historical, narrative and/or visual
Media (coverage of mental health)

Other key elements
Love
Fear
Worry and uncertainty
Hope

Social worlds/Arenas map 1

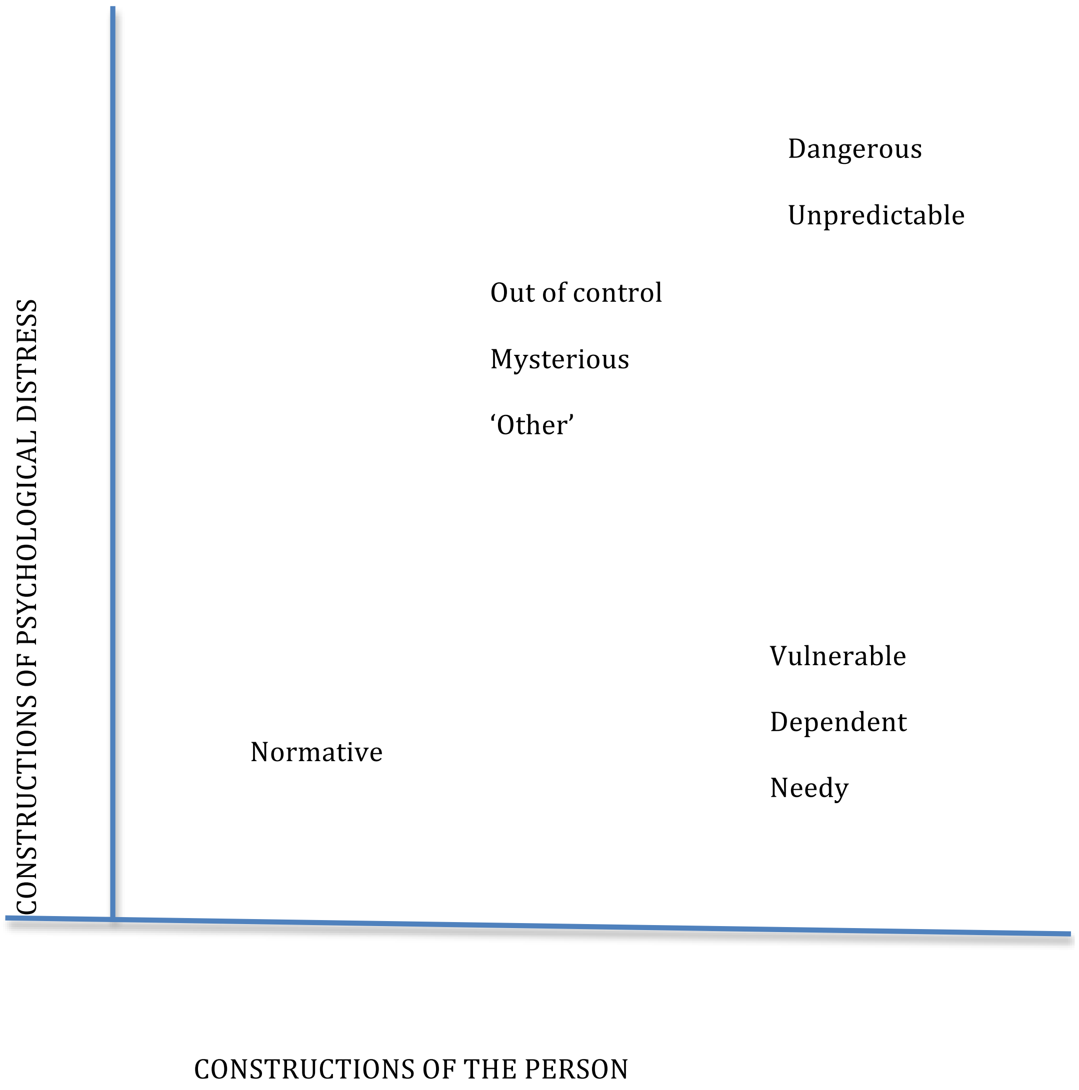


Social world/arenas map 2



POSITIONAL MAP

“MAD, BAD or SAD”



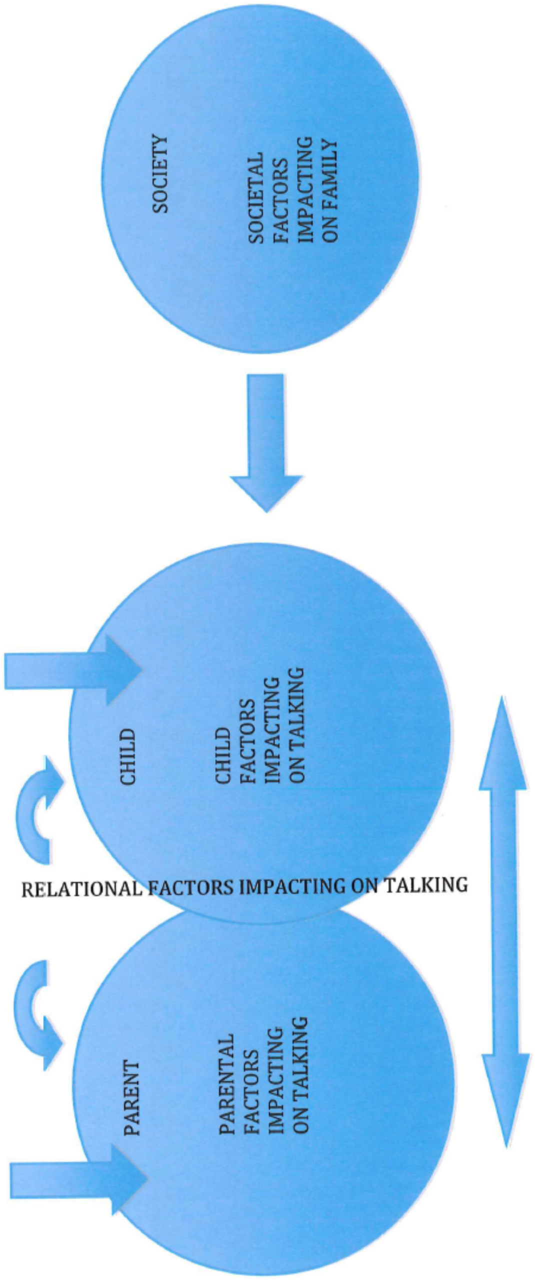
Appendix 15

EXAMPLES OF EARLIER FRAMEWORKS AND STRUCTURES USED TO ORGANISE DATA

EXAMPLES OF EARLIER FRAMEWORKS AND STRUCTURES USED TO ORGANISE DATA

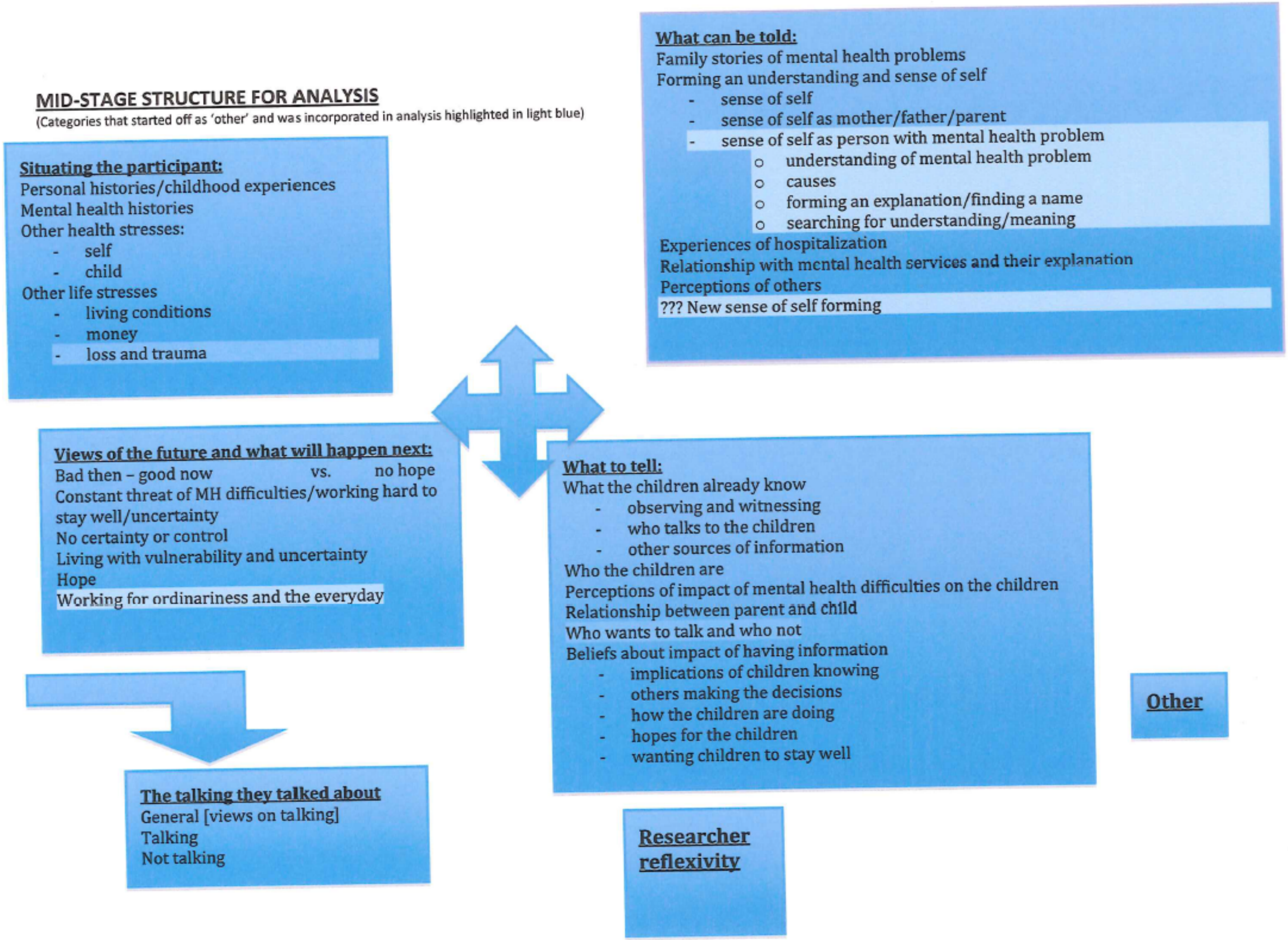
EARLY STRUCTURE FOR ANALYSIS

TALKING FAMILIES DID TOGETHER RE PARENTAL MENTAL HEALTH ISSUES



MID-STAGE STRUCTURE FOR ANALYSIS

(Categories that started off as 'other' and was incorporated in analysis highlighted in light blue)



Situating the participant:
Personal histories/childhood experiences
Mental health histories
Other health stresses:
- self
- child

Other life stresses
- living conditions
- money
- loss and trauma

What can be told:
Family stories of mental health problems
Forming an understanding and sense of self
- sense of self
- sense of self as mother/father/parent
- sense of self as person with mental health problem
    - understanding of mental health problem
    - causes
    - forming an explanation/finding a name
    - searching for understanding/meaning

Experiences of hospitalization
Relationship with mental health services and their explanation
Perceptions of others
??? New sense of self forming

Views of the future and what will happen next:
Bad then – good now vs. no hope
Constant threat of MH difficulties/working hard to stay well/uncertainty
No certainty or control
Living with vulnerability and uncertainty
Hope
Working for ordinariness and the everyday

What to tell:
What the children already know
- observing and witnessing
- who talks to the children
- other sources of information

Who the children are
Perceptions of impact of mental health difficulties on the children
Relationship between parent and child
Who wants to talk and who not
Beliefs about impact of having information
- implications of children knowing
- others making the decisions
- how the children are doing
- hopes for the children
- wanting children to stay well

The talking they talked about
General [views on talking]
Talking
Not talking

Researcher reflexivity

Other