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Children of parents with mental illness: Parental disclosure,
children's illness beliefs and the development of a shared
understanding of mental illness in the family.

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Declaration

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Abstract

There is widespread agreement that children should be educated about a parent's mental illness. For this to occur there are a number of areas which require further research. To date, little is known about what parents themselves think about the disclosure of mental illness to their children. It is also unclear how the process of disclosure occurs in families with mental illness. Children's own knowledge of parental mental illness has not been systematically explored and it is not known what children know about aspects of their parent's illness. This thesis explored how families, where a parent has mental illness, discuss or do not discuss a parent's mental illness. This was explored from the perspective of different family members, including children whose parent has mental illness, the parent with mental illness, the partner of a parent with mental illness, ex-partners of parents with mental illness and step parents of children who have a parent with mental illness.

Study One was an explorative qualitative study which aimed to examine parental beliefs about the disclosure of mental illness. Semi-structured, face to face interviews were conducted with parents (n= 26) regarding their thoughts about disclosure to their children about the mental illness of a parent. Participants included parents with mental illness, partners of parents with mental illness, ex-partners of parents with mental illness and step parents of children whose parent has mental illness. Participants ranged in age from 27 to 50 years old (mean age of 39 years). Interviews were audio taped and interview data was analysed using thematic analysis. Analysis suggested that disclosure about mental illness is a difficult process and rarely are parents able or willing to provide their children with information about all aspects of their illness.

Study two was an explorative study, utilising the Leventhal (1980) framework of illness understanding, which aimed to examine children's knowledge of their parent's illness. Children's ideas about the disclosure process were also examined. Semi-structured, face to face interviews

were conducted with 40 children who had at least one parent with mental illness. Participants ranged in age from 7 to 17 years old (mean age of 11.9 years). Interviews were audio taped and subsequently analysed. Thematic analysis of the data suggested that children had varying degrees of understanding about their parent's mental illness and that this was not often associated with the age of the child. The data within the second study also highlighted that there are a number of children who would prefer not to know about their parent's illness.

In order to provide a comprehensive view of the disclosure of mental illness within a family context, this thesis briefly examined the family view of disclosure as well as familial beliefs about mental illness. Study three was a secondary analysis of selected findings from both studies one and two which aimed to compare three families' views about familial communication regarding mental illness. Individual family member's accounts of their beliefs about aspects of mental illness were examined and compared with other family members' beliefs. The congruence and incongruence of family accounts was highlighted.

This exploratory thesis provides a much needed insight into the experience of disclosure from both a parent and child perspective. It is also the first study to provide a structured examination of children's beliefs about parental mental illness. There are a number of key clinical implications which are informed by the findings of this thesis. The assumptions which underpin the claim that all children should be educated about a parent's mental illness need to be carefully considered. Parents have difficulty explaining aspects of mental illness to children and, importantly, some parents actively choose not to explain specific elements of mental illness to their children. Some children do want more information about their parent's mental illness, however others actively avoid talking about the illness or avoid seeking out further information. From a clinical perspective, people working with parents with mental illness or their children need to be mindful of the difficulties for both parents and children around the disclosure of mental illness to children.

Chapter One: Broad literature review and location of the present thesis

This chapter examines the broad literature around parents with mental illness and their children and locates the current thesis amongst the previous literature. This chapter firstly defines the key terms and ideas frequently used within this thesis. A background to the existence of children of parents with mental illness is provided; the prevalence of children of parents with mental illness within Australia is examined and the literature regarding the effects of mental illness on parenting is explored. The detrimental effects of being the child of a parent with mental illness are highlighted alongside recognised potential for resilience among these children. This review then examines the literature which explores the experience of children of parents with mental illness and highlights the concept of educating children about parental mental illness. Significant gaps within the current literature are highlighted, the research questions are presented and the chapter concludes with an overview of the present thesis.

1.1 Clarification of terms which are used frequently within this thesis

The focus of this thesis is on children of parents with mental illness and their parents. The recent increase in acknowledgement of children of parents with mental illness has also brought new terminology for this population of children. Within the research arena, children of parents with mental illness are commonly referred to as COPMI. For the majority of this thesis the acronym COPMI will be used. In addition when referring to children who have parents who do not have mental illness, the acronym non-COPMI will be used where appropriate.

The term mental illness is used throughout this thesis. The terms mental illness and mental disorder are often used interchangeably within the literature. The World Health Organisation defines mental illness as “generally characterised by some combination of abnormal thoughts, emotions, behaviour and relationships with others” (World Health Organisation, 2011).

Within this thesis the general term ‘mental illness’ is most often used, rather than specific diagnoses. Specific mental illnesses are referred to within later chapters. These include Schizophrenia, Bipolar Disorder, Depression, Borderline Personality Disorder and Obsessive Compulsive Disorder, to name a few. A full description of each of the illnesses mentioned by participants within this study is provided within Chapter Two: Methodology.

1.2 The existence of COPMI

The latter half of last century brought a massive change in the treatment of people with mental illness. The long-term routine institutionalisation of people with mental illness ceased and a new model of deinstitutionalisation was introduced. Deinstitutionalisation removed people from institutions and placed them within communities. Living within communities afforded people with mental illness greater freedoms, including an increased ability to have children. Accordingly, people with a mental illness are now more likely to have and raise children compared to previous years (Devlin & O'Brien, 1999).

Only recently has it been recognised that those with mental illness do indeed have children. There has been widespread denial of sexual activity among the mentally ill (Senn & Carey, 2008). Early research examining the provision of care to people with mental illness has been bound by a belief that people with mental illness rarely get married (Greenberg, Kim & Greenley, 1997; Horwitz, 1993); researching with an assumption that marriage is a necessary condition for having children. Indeed, some previous research has denied the presence of COPMI (for example see Horwitz, 1993; Horwitz, Tessler, Fisher & Gamache, 1992) and

even relatively recent research has ignored the existence of COPMI (Hatfield & Lefley, 2005).

There is also denial and a lack of recognition within psychiatric rehabilitation services that people with mental illness may also identify as parents. One indication of this is hospital intake forms where, in Australia, it is still not compulsory to ask the admitted patient about whether they have any dependants (Australian Infant, Child, Adolescent and Family Mental Health Association [AICAFMHA], 2001; Luntz, 1995). This has also been found in countries such as the United States where the patient or client's family role or responsibilities are not addressed by providers and there is no standardised data collection on parenting status (Nicholson, Biebel, Hinden, Henry & Stier, 2001; Nicholson, Geller & Fisher, 1996)

People with mental illness can and do have children. Research has indicated that, contrary to the idea that people with mental illness have diminished fertility, this population in fact has children at the same rate (if not higher) than people without mental illness (Lane et al., 1992; McLellan & Ganguli, 1999; Nicholson, Biebel, Katz-Leavy & Williams, 2002). Göpfert, Webster and Seeman (1996) suggest that as many as 50% of people with a mental illness are parents, while Nicholson and colleagues (2002) suggest that the majority of American adults with mental illness are parents.

1.3 Prevalence estimates of parents with mental illness and their children

It is difficult to gain an accurate estimation of the exact number of parents with mental illness and their children. This is due to a lack of a systematic collection of data about people who have mental illness who are also parents (Cowling, 1999; Cowling, Luk, Mileskin & Birleson, 2004; Luntz, 1995; Nicholson et al., 2001). Data is not systematically collected about the parenting status of people with mental illness for a number of reasons. Firstly, it has been suggested that there are a large number of parents with mental illness within the community

who do not seek treatment (Cohler, Stott, & Musick, 1996). Secondly, if parents do seek treatment they may not indicate that they have children. Parents may fear losing their children to Child Protection Services as a result of their illness and, as such, may not claim to be parents when seeking psychiatric help (Garvin, McAllister, & Phillip, 2002). The fear parents have about losing custody of their child is a realistic fear given that there are a disproportionate number of COPMI in out of home care (Cowling, 1996; Handley, Farrell, Josephs, Hanke & Hazelton, 2001; Joseph, Joshi, Lewin & Abrams, 1999; Leschied, Chiodo, Whitehead & Hurley, 2005; Mowbray, Oyserman, Zemencuk & Ross, 1995b; Nicholson et al., 2001). Thirdly, the denial of the presence of children of parents with mental illness, in addition to the denial of parenting status of parents with mental illness, by both researchers and service providers alike, also contributes to the difficult task of estimating the prevalence of families where a parent has mental illness (Nicholson et al., 2001).

There is, therefore, a distinct lack of COPMI prevalence data available. Although an exact figure is unknown, the number of COPMI within the United States is said to be “millions” (Nicholson et al., 2002, p.129) and although estimates of COPMI within most European countries is lacking, one study suggested that there were as many as 1.6 million COPMI in the Netherlands (Boel, van der Zanden & Smit, 2007).

Recently the difficult task of attempting to estimate the number of children within Australia who have a parent with mental illness was undertaken. Early estimates suggested that there were over 27,000 children in Australia living with a parent with Schizophrenia, Depression or Bipolar Disorder (Cowling, 1999). A more recent study examining prevalence suggested that the number of COPMI within Australia is actually much higher than first thought (Maybery, Reupert, Patrick, Goodyear & Crase, 2009). In an innovative study, Maybery and colleagues (2009) triangulated data from three sources in an attempt to provide the most accurate estimate. Their results suggest that there may be (with estimates varying depending on illness

severity) as many as 23% of children within Australia (between 60,000 and approximately one million) who are in families where a parent has mental illness (Maybery et al., 2009). These estimates, even when using the conservative figure of 60,000 children, indicate the significance of the population of children and families with mental illness.

1.4 Effect of mental illness on parenting

Although the parenting status of people with mental illness continues to be denied by some mental health service providers as well as many researchers (Mowbray & Oyserman, 2003; Nicholson et al, 2001; Nicholson & Deveney, 2009), others do acknowledge the parenting status of people with mental illness and have researched the area. Research highlighting the parenting role is scarce but important. Falkov and Cowling (2009) state that talking with parents about their parenting role is as important as talking to them about the symptoms of their illness.

1.4.1 What the research says about parenting with mental illness

The term ‘parent’ in research of this nature most often refers to a mother with mental illness. Fathers with mental illness are neglected within this area of research, although there are a handful of studies which do include fathers (Downey & Coyne, 1990; Nicholson, Nason, Calabresi & Yando, 1999; Reupert & Maybery, 2009b; Styron, Pruett, McMahon & Davidson, 2002). This inequality within research has led to claims that paternal mental health does not impact on the child (Smith, 2004) although it seems likely, given what is demonstrated in the following section, that paternal mental health does impact on children. The unique experience of the father and the effect that mental illness has on his parenting is largely absent from the studies included in this section.

Research has shown that a number of areas of parenting are affected by mental illness. At the severe end, parental mental illness has been linked with child abuse and neglect (Falkov,

1997; Jacobsen & Miller, 1998). Parents with mental illness have also been found to use physical punishment with their children more often than do parents without mental illness (Nobes & Smith, 1997). Adult mental health workers have highlighted that parents can have diminished insight into their own mental illness, as well as a lack of insight into the possible effects of their illness on their children (Maybery & Reupert, 2006). In their comprehensive review of research examining parenting and mental illness, Oyserman, Mowbray, Meares and Ferminger (2000) found that, in comparison to parents without a diagnosis of mental illness, parents with mental illness were less responsive to their infants, less emotionally available and less involved with their pre-schoolers, and less encouraging with their school aged children. In addition parents with mental illness, in comparison to parents without a diagnosis of mental illness, were found to be inconsistent, less happy, less talkative with their children, more critical with their children and found to have an inability to sustain social interaction (Oyserman et al., 2000).

It is worth noting that often in research, assumptions are made that negative parenting outcomes are a direct result of mental illness, rather than as a result of the cascade of negative circumstances which can often surround parents with mental illness. Negative circumstances can include single parenting, divorce or marital discord, having lower socioeconomic status and being socially isolated (Smith, 2004). There are clearly negative outcomes associated with being the child of a parent with mental illness, as will be shown later in this chapter, however it is vital that these are interpreted carefully and the cause attributed correctly.

There is growing agreement that it is not usually the mental illness itself that affects children, rather it is the behaviours associated with symptoms which are most important. As Duncan and Reder (2003) state, there are a number of behaviours which are common across mental illness diagnoses and it is these which are most important when talking about parenting and mental illness. These authors summarised the main behavioural manifestations of symptoms

which are common across most types of mental illness, and outlined the possible effect of the behaviours on COPMI. Their table summarising these points has been reproduced below (Table 1).

Table 1

Common Behavioural Manifestations of Symptoms and their Impact on COPMI (Adapted from the table by Duncan and Reder; 2003, p.199)

Parental behaviour	Potential impact on child (in addition to attachment problems)
Self-preoccupation	Neglected
Emotional unavailability	Depressed, anxious, neglected
Practical unavailability	Out of control, self reliant, neglected, exposed to danger
Frequent separations	Anxious, perplexed, angry, neglected
Threats of abandonment	Anxious, inhibited, self blame
Unpredictable/chaotic planning	Anxious, inhibited, neglected
Irritability/over-reactions	Inhibited, physically abused
Distorted expectations of reality	Anxious, confused
Strange behaviour/beliefs	Embroided in behaviour, shame, perplexed, physically abused
Dependency	Caretaker role
Pessimism/blames self	Caretaker role, depressed, low self esteem
Blames child	Emotionally abused, physically abused, guilt
Unsuccessful limit-setting	Behaviour problem
Marital discord and hostility	Behaviour problems, anxiety, self-blame
Social deterioration	Neglect, shame

1.4.2 What parents say about parenting with mental illness

More recently the experience of parenting with mental illness has been explored. For many parents with mental illness, the role of parenthood is highly valued (Falkov & Cowling, 2009; Kelly, 1999; Nicholson, Sweeney & Geller, 1998; Savvidou, Bozikas, Hatzigeleki, Karavatos, 2003; Thomas & Kalucy, 2002) even though some parents feel that they are seen by mental health professionals as patients first and parents second (Handley et al., 2001). Research suggests that generally parents with mental illness face a number of parenting issues which are common to all parents, such as the stress of day-to-day parenting (Kelly, 1999; Nicholson et al., 1998).

The experiences which are unique to parents with mental illness include experiencing stigma, sacrificing their own mental health in order to be present for their children (such as in the case of not taking certain medications in order to avoid lethargy or unclear thinking) and fearing the loss of custody of their children as a result of their diagnosis or illness-related behaviour (Nicholson et al., 1998; Savvidou et al., 2003). Parents with mental illness may also fear the loss of custody which may occur if they are not adherent to treatment (Busch & Redlich, 2007). Some parents have reported experiencing difficulty with housework, being constantly tired and having a lack of motivation to do things with their children (Thomas & Kalucy, 2002, 2003). Others have spoken about worrying about the impact of their illness on their children (Falkov & Cowling, 2009; Handley et al., 2001; Kelly, 1999; Savvidou et al., 2003), having feelings such as isolation and shame and missing their children whilst in hospital (Falkov & Cowling, 2009; Savvidou et al., 2003).

1.5 Effect of parental mental illness on children

There is a substantial body of research which has examined the effect of parental mental illness on children. The research on COPMI has generally examined one of three areas:

detrimental effects of having a parent with mental illness, resilience of COPMI and the experience of being a child with a parent with mental illness.

1.5.1 Detrimental effects

As Foster, O'Brien and McAllister (2004) demonstrate cogently in their review of risk and protective factors of COPMI, detriment to children has long been the dominant paradigm through which COPMI have been studied. The detrimental effects of living with a parent with a mental illness have been widely documented.

The majority of research focusing on COPMI examines the high incidence of mental illness in these children. Children of parents with a mental illness have a greater chance than non-COPMI of developing a mental illness themselves (Beardslee et al., 1996; Goodman & Gotlib, 1999; Hay, Pawlby, Angold, Harold, & Sharp, 2003; Halligan, Murray, Martins & Cooper, 2007; Pawlby, Sharp, Hay and Keane, 2008) and, as such, are more likely to utilise mental health services in their own adulthood. Of all COPMI, between 25-50% will experience mental illness themselves as compared to 10-20% of the general population (AICAFMHA, 2001; Beardslee, Keller & Lavori, 1993; Beardslee, Versage & Gladstone, 1998; Goodman, Adamson, Riniti & Cole, 1994; Green, 1994). These figures suggest that COPMI develop mental illness at higher rates than the general population however they also highlight that not all COPMI will develop mental illness in their lifetime.

Implicit within the research examining mental illness in COPMI is the question of transmission. The exact mechanism for transmission remains unclear, although given that not all COPMI develop mental illness themselves it has been assumed that transmission is via a number of factors and genetic transmission is not absolute (Devlin & O'Brien, 1999; Goodman & Gotlib, 1999; Pound, 1996; Rutter, 2004). As mentioned, there are a number of negative circumstances, which are not directly related to mental illness, which can often

surround families with mental illness. Environmental factors, such as living in a stressful situation, low socioeconomic status, domestic violence, divorce and social isolation are often found to be associated with mental illness in parents (Goodman & Gotlib, 1999; Smith, 2004). Other possible non-genetic contributors to the increased mental illness found in COPMI include exposure to symptoms of mental illness and possible disruptions to parenting.

Parenting can be disrupted by a number of circumstances. These commonly include the parent being hospitalised, the child being removed from the parent's care, or the parent being physically with the child but not able to be emotionally present due to the effects of medication or certain symptoms. Each of these circumstances can affect the attachment between a parent and a child. The attachment between a child and a key caring figure (most often a parent) has been found to affect the development of a child's sense of self (Bowlby, 1969). This in turn affects the way in which a child relates to other people and affects their view of the world (Bowlby, 1969). In order for a child to develop a positive sense of self, the child requires a relationship with their caregiver characterised by consistency, responsiveness and availability, both physically and emotionally. Many of the behavioural manifestations of symptoms (listed within the previous section) have the potential to render the parent inconsistent, unresponsive and unavailable (Beatson & Taryan, 2003; Cicchetti, Rogosch & Toth, 1998; Herring & Kaslow, 2002, among others). The attachment relationship which can develop in the midst of these behaviours can lead to the child developing a poor sense of self, expectations that relationships with other people may not be positive, and a negative view of the world. Each of these outcomes, in turn, can be a risk factor for mental illness in later life (Berry, Barrowclough & Wearden, 2007).

In addition to increased mental illness rates, there are numerous other possible detrimental effects for COPMI. Research suggests that COPMI rely heavily on emotion focussed coping strategies such as withdrawing and distancing themselves from parents and others (Maybery,

Ling, Szakacs & Reupert, 2005). These coping strategies have been found to endure through to adulthood (Kinsella & Anderson, 1996). Reinforcement of such coping strategies can occur when children are exposed to parents with maladaptive coping strategies, such as suicide attempts (Lancaster, 1999). The coping literature suggests that long term reliance on emotion focussed coping strategies can be detrimental (Folkman & Lazarus, 1988) and can contribute to the development of mental illness (Taylor & Stanton, 2007).

Cogan, Ridell and Mayes (2005a) examined the coping styles used by COPMI and compared them to the coping styles of non-COPMI. Their findings indicated that COPMI were less able to cope effectively than their non-COPMI peers. Cogan and colleagues found that COPMI often blamed themselves for their parent's illness, a finding which they believe emphasises the importance of providing COPMI with information about their parent's mental illness. Education about parental mental health is thought to be a major contributor to effective coping in COPMI (Cogan et al., 2005a).

Feelings of guilt and lowered self esteem (Lancaster, 1999; Taylor & Ingram, 1999) have also been demonstrated in COPMI. Similar to maladaptive coping strategies, feelings of guilt and lowered self esteem could possibly continue into adulthood (Kinsella & Anderson, 1996). Guilt feelings are thought to develop due to the child feeling embarrassed about their parent's behaviour, and/or a lack of knowledge and understanding about the illness. This typically occurs when a child starts school and is able to compare their parent to other children's parents (Lancaster, 1999). Misunderstanding of a parent's symptoms can often occur, for example children can attribute parental mental illness symptoms such as low mood (in the case of Depression and Bipolar Disorder) to something they have done wrong themselves, and this may be one mechanism by which guilt is triggered. Carrying a sense of responsibility for a parent's symptoms may impact on a healthy view of self (Lancaster, 1999).

1.5.2 Detrimental effects for adult children of parents with mental illness

Historically, adult children of parents with mental illness (ACOPMI as they are often termed in the literature) have been an under-researched group (Murphy, Peters, Jackson & Wilkes, 2011b). As stated previously, COPMI are a group who are often overlooked, ACOPMI even more so. The research which has been conducted with this group indicates that the detrimental effects of growing up with a parent with mental illness are not ameliorated by age. For instance, research has found that ACOPMI have higher incarceration rates and higher mental health service usage compared to adults who did not grow up in a family with mental illness (Mowbray & Mowbray, 2006).

In her insightful study examining the experiences of being an ACOPMI, Foster (2010) found that the participants commonly reported experiencing mental health problems themselves. In addition, participants within Foster's study cited long term difficulty with both the development and maintenance of relationships. Adult children of parents with mental illness also cited ongoing caretaking responsibilities for the parent with mental illness and experienced a reluctance to ask for, or receive, help (Foster, 2010).

A meta-analytic study of the major themes within the research examining ACOPMI experiences found that ACOPMI had difficulty with family relationships and external relationships, experienced grief and sadness in relation to the perceived loss of their parent, had difficulty with their identity, and had a fear of passing mental illness to their own children (Murphy et al., 2011b). The analysis also found that ACOPMI experienced stigma and found their parent's illness difficult to understand (Murphy et al., 2011b).

It is clear from both the data available on the significant numbers of COPMI, and the research on the potential detrimental effect of living with a parent with mental illness, as well as the

actual detrimental affects experienced by ACOPMI, that the issues faced by COPMI constitute a significant public health issue.

1.6 Resilience in children of parents with mental illness

Whilst examining the negative effects of parental mental illness on children, researchers developed an increasing realisation that although there were children who experienced detrimental effects as a result of having a parent with a mental illness, there were also children who did not experience such effects. These were children for whom parental mental illness did not cause quantifiable issues (Kauffman, Grunebaum, Cohler, & Gamer, 1979; Grunebaum & Cohler, 1983). Some COPMI complete their schooling, lead mentally healthy lives and have appropriate levels of self esteem. In fact, some children were viewed as more successful than their non-COPMI peers (Grunebaum & Cohler, 1983). Initially termed ‘superkids’ (Kauffman et al., 1979), these children have since been labelled as ‘resilient’ and studied in order to ascertain what resources or characteristics these children have that other children, in similar situations, may not. If COPMI are not absolutely genetically predetermined to develop mental illness themselves then the factors which can protect them are worthy of consideration.

Rutter (2006) explains that “resilience is an interactive concept that is concerned with the combination of serious risk experiences and a relatively positive psychological outcome despite those experiences” (Rutter, 2006, p. 2). Whilst never explicitly stated, within the COPMI literature it is widely accepted that the term resilience refers to experiencing a range of negative effects as a result of parental mental illness and emerging from the experience psychologically healthy.

Research suggests that resilient COPMI have a number of protective factors which help them to maintain resilience. These factors can be grouped according to those which are fixed and

unable to be changed and those which are amenable to intervention. Fixed protective factors include such things as gender, IQ and age at parental illness onset. Factors which are amenable to intervention include such things as access to an adult without mental illness who can be a role model to the child, parental mental illness which is addressed and treated quickly, the use of problem-focused coping strategies and education about a parent's mental illness.

1.6.1 Fixed protective factors

The gender of a child has often been cited as a potential protective factor; however the research is unclear as to which gender is better protected. Some studies have found that if a child is male, he has a greater risk of having an adverse reaction to his parent's illness than does a female (Rutter, 1987; Sharp et al, 1995). Other studies have found that females are affected more by a parent's mental illness than are boys (Davies & Windle, 1997; Hops, 1995). Although the findings are inconsistent, there appear to be differences in the ways in which the two sexes generally demonstrate their reaction to their parent's illness. For example, males are more likely to react with disruptive behaviour and girls with emotional distress (Rutter, 1987; Cummings & Davies, 1994). Rutter (1987) suggests that disruptive behaviour is more likely to be punished than emotional distress and therefore could lead to problems in later life. A child's gender is not amenable to intervention, however there are possibilities for intervention to address challenging behaviour and emotional distress which in turn could reduce the risk inherent with being a COPMI for either sex.

Intellectual ability, as measured by IQ, is often cited as a protective factor for children raised in high risk settings and is often listed as a protective factor for COPMI. In their review of research examining resilience in children, Luthar and Ziegler (1991) state that in many cases intelligence has been found to enhance resilience in children. However there are also studies which have failed to find evidence for the protective nature of intelligence and other studies

which have found intelligence to be a risk factor rather than a protective factor when children experience high levels of stress (Luthar & Ziegler, 1991). Even though the protective nature of intelligence is often cited as a source of resilience for COPMI, it still remains unclear how this mechanism works and whether it is a source of resilience for all COPMI.

Children who are older at first onset of their parent's mental illness also appear to be more resilient than those who experience their parent's illness from a younger age (Rutter, 1985). This could be due to a number of reasons. One of the most accepted reasons is related to attachment. Children who are older at age of onset have a longer period of time in which to form a secure attachment with their parent. As previously discussed, there is an increasing amount of research addressing the attachment of children to parents with mental illness (Chicchetti et al., 1998; Walsh et al., 2009). Findings indicate that mental illness can affect attachment at these early stages of development (Lancaster, 1999; Walsh et al., 2009). Research suggests that education about mental illness can help with a child developing a secure attachment with their parent with mental illness (Walsh et al., 2009).

Children who are older at onset of parental mental illness are thought to attribute different meaning to illness, which is another reason age is thought to be a protective factor (Rutter, 1985). Consequences of illness, such as hospitalisation of a parent, can have different meaning for young children compared to older children. Rutter (1985) states that the experience of hospitalisation of a parent is more stressful for younger children than it is for older children. There is very little research which examines the ways in which COPMI perceive their parent's illness or the meanings they attribute to aspects of their parent's illness. The meaning that children attach to parental mental illness and symptoms is likely to be amenable to intervention.

A further reason why child's age at the onset of their parent's mental illness could be related to resilience may be due to the links outside the family that the child is able to form. A younger child is largely reliant on their parent for socialization outside the home. An older child may form relationships with other adults outside the home, largely independent of their parent. Relationships outside of the home can provide a child with a non-mentally ill role model which may, upon onset of parental illness, enhance resilience in the child. This is also viewed as a factor which is amenable to intervention and is discussed in the following section.

1.6.2 Protective factors amenable to intervention

A cohesive family is one protective factor which has been highlighted by the literature. Carbonell and colleagues (2002) conducted a study examining resilience in adolescents who were at risk for developing depression in later life. Parental depression was seen as one of the significant risk factors for these participants. Carbonell and colleagues (2002) found that resilient adolescents spent more time with their families than did their non-resilient counterparts and viewed their families as being close. One protective factor for COPMI which could therefore be amenable to intervention is the relationship between the parent with mental illness and their child.

Relationships with adults other than the parent with mental illness may also be protective. Access to an adult without mental illness who can play a mentoring role in the child's life is another external protective factor for COPMI (Fudge & Mason, 2004; Kauffman et al., 1979; Reupert & Maybery, 2007a). As Reupert and Maybery (2007a) state, this concept is closely related to the ideas around attachment and COPMI. If COPMI are unable to form a secure attachment with their parent, relationships with people outside of the home can provide the child with positive social and emotional connections necessary for resilience.

In an early study, Shachnow (1987) interviewed parents with mental illness, their partners and their children for a pilot study to determine need for preventative intervention with children who have a parent with mental illness who is in hospital. The pilot study found that those children who coped best with their parent's hospitalisation had an empathic adult, the parent without mental illness or another close adult, with whom they were able to discuss the parent's illness. These children had discussed their perception of their parent's illness with the other adult and this was deemed to be the crucial factor in their ability to cope with the illness.

An important factor that is believed to enhance resilience in children is the use of effective coping strategies. As Holahan, Moos and Schaefer (1996) state, "resilience develops from confronting stressful experiences and coping with them effectively" (Holahan et al., 1996, p. 33). Coping has been highlighted as the "crucial variable between risk and outcome" (Shachnow, 1987, p. 67). In terms of resiliency, coping strategies could be viewed as the "crucial variable" which mediates the risk of having a parent with mental illness and the outcome of either having psychological problems or being resilient. Research examining the coping strategies of the family members of people with mental illness (such as the spouses, parents and siblings of people with mental illness) found that relatives who utilize problem solving coping strategies reported lower burden over time (Magliano, Fiorillo, De Rosa & Maj, 2006).

A recent model, developed by Hosman, van Doesum and van Santvoort (2009) cogently outlines the numerous interactional factors which influence risk and resilience outcomes for COPMI. Hosman et al (2009) examine, from a developmental perspective, the pathways of transmission of psychopathology across generations. The model shows how multiple systems (such as the family, the parent and the social network) influence COPMI and, importantly, highlights how this occurs across the lifespan, beginning in utero. Although it is beyond the scope of this thesis to examine all risk and resilience factors for COPMI, it is clear, from both

the literature presented here and the model put forward by Hosman et al (2009), that not all COPMI will develop mental illness themselves and there are many opportunities across the lifespan to enhance resilient outcomes.

1.7 The experience of being the child of a parent with mental illness

As demonstrated, there is a considerable body of research highlighting the risks inherent with being a child of a parent with mental illness. There is also a growing body of research examining the factors which may protect COPMI from developing mental illness and experiencing other detrimental effects. In comparison, the examination of the child's experience of parental mental illness and their views about aspects of their parent's illness is a recent phenomenon.

The research examining the child's experience is largely qualitative in nature, the child's view of their experience is often sourced through individual interviews or focus groups (for example Garley, Gallop, Johnston & Pipitone, 1997; Handley et al., 2001; Meadus & Johnson, 2000; Riebschleger, 2004) . There are clear similarities of findings among the research which has examined children's experience. Increased responsibility was cited by many children. Children spoke about responsibilities within the home (for example cooking meals, paying bills) and responsibility for looking after the parent with mental illness (Garley et al., 1997 Handley et al, 2001; Meadus & Johnson, 2000).

Some children talked about feelings of loss related to their parent's illness (Meadus & Johnson, 2000; Riebschleger, 2004) and others talked about the difficulty emotionally and practically when a parent goes into hospital (Maybery et al, 2005). In one study children saw other difficulties in life, such as poverty and divorce, as more stressful than parental mental illness (Riebschleger, 2004).

1.8 Children's lack of understanding of mental illness

Common across the literature regarding the experiences and views of COPMI is the theme of struggling to understand mental illness. COPMI also state that they lack information about mental illness and actively seek information about mental illness (Garley et al., 1997; Handley et al., 2001; Meadus & Johnson, 2000; Pölkki, Ervast & Huupponen, 2005; Stallard, Norman, Huline-Dickens, Salter & Cribb, 2004). It is noteworthy that all available research in this area reports on very small sample sizes of COPMI, with sample sizes ranging from 3 to 26 individuals. All of the research uses qualitative methodologies.

Garley and colleagues (1997) conducted a focus group with six COPMI ranging in age from 11 to 15 years old. The study was exploratory in nature, given the paucity of research available at the time which gave insight into COPMI experiences. Garley and colleagues state that children within their study ‘_hunger for information about their parent’s illness’ (p. 100). Children within this study spoke about the frustration of trying to get answers from people regarding their questions about mental illness.

A small scale study was also conducted by Meadus and Johnson (2000) in an effort to examine the experiences of COPMI living with a parent with mental illness. In this study three 17 year old female COPMI were interviewed and findings suggested that these participants perceived themselves as lacking knowledge of mental illness. Meadus and Johnson state that the lack of knowledge led to participants feeling frustrated. Participants within this study also feared getting the illness themselves and feared their parent not getting better. All three children actively sought information about their parent’s illness as they were not provided with this information from their parents.

Handley and colleagues (2001) interviewed four COPMI, between the ages of 11 and 15 years old, and found that the children had a strong desire for information about their parent's illness. The children within this study felt that significant others were reluctant to talk about mental illness with them. Handley and colleagues state that the participants' struggle to understand mental illness led to participants experiencing fear and confusion, feeling they were to blame for their parent's illness, feelings of embarrassment and being fearful that they may get the illness themselves.

In a larger scale study, Stallard and colleagues (2004) conducted interviews with 26 COPMI, ranging in age between 6 and 17 years old. They stated that the majority of the COPMI within the study wanted to know about their parent's mental illness, although they were careful to point out that not all children wanted more information. Stallard and colleagues also stated that no child within the study mentioned being fearful of getting mental illness themselves.

Mordoch and Hall (2008) interviewed 22 COPMI aged between 6 and 16 years of age. They found that COPMI who had good knowledge of their parent's illness were able to view their parent's mental illness related behaviour as related to their illness. The authors state that this understanding of parental illness contributed to the participants being more certain about what was happening in their lives. It also contributed to participants having less intense painful emotions. Children who were less knowledgeable about their parent's illness and symptoms had higher levels of distress as they formulated other possible scenarios to explain their parent's symptoms and behaviours (such as the parent dying). Mordoch and Hall (2008) found that, of the participants in their study, those who lived in a family where a non-mentally ill parent was also present were better able to interpret their parent's symptoms and behaviours. This was attributed to the parent without mental illness being able to monitor changes in the behaviour of the parent with mental illness and subsequently discuss these changes with the child.

Retrospective research examining ACOPMI experience of their parent's mental illness also cites lack of information as an issue for ACOPMI. Although there are few studies which have examined ACOPMI experience, those that have all state that lack of information about parental mental illness was a problem for ACOPMI. The studies state that the majority of ACOPMI wanted information about parental illness but never received it (Dunn, 1993; Knutsson-Medin, Edlund & Ramklint, 2007; Pölkki et al., 2005). In one study, a lack of information about parental mental illness was linked to ACOPMI finding their parent's behaviour confusing and frightening (Dunn, 1993).

Foster's (2010) comprehensive study into ACOPMI experiences of parental mental illness indicated that participants were not necessarily aware that their parent had mental illness, but were aware that something was wrong. Foster found that most participants within her study were not informed about their parent's illness. Participants were only able to find out information about mental illness after actively searching for it, either by speaking to their non-ill parent or a health professional.

1.9 The importance of educating children about their parent's mental illness

The literature examining both COPMI and ACOPMI experiences cites a distinct lack of discussion with COPMI about their parent's mental illness. Absler (1999) states that one of the main reasons why COPMI are not informed about mental illness is that there is a common belief that talking to COPMI about mental illness will be harmful to them. There is also a belief that COPMI generally do not understand mental illness so there is little reason to talk to them about it (Absler, 1999). The predominantly qualitative research has found that when education of COPMI about parental mental illness does occur it is linked with positive outcomes for COPMI. These outcomes include resilience and effective coping, as discussed below.

In one of the first studies to do so, Beardslee and Podorefsky (1988) examined resilient COPMI perceptions of what contributed to their resilience. In the words of Beardslee and Podorefsky, the resilient COPMI within their study were “deeply aware of their parent’s illness” (1988, p. 66). The understanding of parental mental illness was seen as fundamental to the development and maintenance of resilience. COPMI within this study were able to differentiate between themselves and their parent’s illness. Among other things, this meant that the resilient COPMI did not believe that they were the cause of their parent’s illness. COPMI themselves stated that knowing that they did not cause their parent’s illness was “crucial to understanding what was happening and to their capacity to deal with the experience of having a sick parent” (1988, p.66).

Beardslee and Podorefsky state that common features of resilient COPMI include, among other things, the ability to adequately cognitively appraise a situation, to understand the limits of their ability to help the ill parent, and to have a good understanding of self which is not changed by negative life events. Beardslee and colleagues (1992) used these findings to develop and administer an educational intervention for COPMI and their parents. The findings of the study suggested that the intervention, which focussed on open communication about mental illness within the family, was useful for initiating and establishing ongoing discussion within the family about mental illness.

The link between education about parental mental illness and resilience has been shown in other studies. Garley and colleagues (1997) suggest that the extent of the effect of a parent’s mental illness on a child depends on how well the child understands the mental illness; if a child has a good understanding of their parent’s mental illness then the negative effect on the child is reduced. Similarly Secunda (1997) states that resilience in COPMI is in part to do with how they conceptualise their parent’s illness. Other researchers have also found support

for the idea that the way that COPMI perceive mental illness may increase their risk for development of mental illness in the future (Garber & Martin, 2002; Goodman, Tully, Connell, Hartman, Huh, 2011). Scherer, Melloh, Buyuck, Anderson and Foster (1996) found that when perceptions of a mother's behaviour differs between children and the mother, children have more behavioural problems (as rated by the parent) and less self-competence (as rated by the child). Interestingly, Scherer and colleagues state that it is likely that COPMI have a "limited ability to perceive or comprehend symptoms of their mothers' mental illness" (1996, p. 168).

Similarly, a lack of education about parental mental illness has been linked to negative outcomes in COPMI. Lack of information about parental mental illness has been linked to COPMI blaming themselves for their parent's illness (Cooklin, 2006) and confusion and fear about the illness (Valiakalayil, Paulson & Tibbo, 2004).

Education about mental illness has also been suggested as important for its role in promoting effective coping by COPMI. The findings of the study of Cogan and colleagues (2005a) suggest that COPMI cope more effectively if they understand their parent's mental illness. Similarly, in their interview study of facilitators of COPMI-focussed intervention programs, Reupert and Maybery (2010b) found that facilitators believed that educating a child about a parent's mental illness contributes to positive coping.

Adult children of parents with mental illness also cited that education about parental mental illness is linked to coping. Kinsella and Anderson (1996) specifically examined coping in ACOPMI (as well as siblings of people with mental illness) in their interview study. Those participants who were told about mental illness in the family stated that information about the illness was "critical to effective childhood coping" (p.30). Participants who had not been told

about mental illness when they were growing up stated that information about parental illness should be provided to COPMI.

Studies examining COPMI and ACOPMI experiences of living with a parent with mental illness suggest that COPMI are rarely told about the mental illness of a parent. As the research has shown, educating COPMI about parental mental illness is linked to resilience, whereas a lack of education has been linked to detrimental effects on COPMI. Not surprisingly, given the findings of these studies, recently there have been strong recommendations by researchers to educate children about parental mental illness (AICAFMHA, 2001; Owen, 2008).

Educating children about their parent's mental illness should involve improving children's understanding of their parent's illness (Garley et al., 1997), providing age-appropriate information about parental illness (Falkov, 2004; Reupert & Maybery, 2007a) and providing older children with information about inheritability (Hay, 2004).

1.10 Educating children about parental mental illness; what do parents think?

Recent research has examined the reasons why children are not routinely informed about parental mental illness. Parents with mental illness have highlighted that they would like their child to be better informed about their illness (Maybery et al., 2005; Stallard et al., 2004).

Parents can be unsure about how to speak to their child at a developmentally appropriate level and can be confused about who should provide mental illness education to their children (Maybery et al., 2005). Parents themselves can struggle to understand their own mental illness (Handley et al., 2001).

Parental difficulty with explaining their mental illness to their children has also been found in other research (Falkov & Cowling, 2009; Nicholson et al., 1998; Thomas & Kalucy, 2002; Wang & Goldschmidt, 1996). In each of the studies regarding parental views of educating children about mental illness, parent views of explaining mental illness to their children have

not been examined in their own right. Instead, their views on this topic have been gleaned from comments they have made within studies examining other topics.

Mental health workers have been thought to be well placed to educate children about parental mental illness, although it is acknowledged that they do not often fulfil this role (Fudge, Falkov, Kowalenko & Robinson, 2004; Maybery et al., 2005; Maybery & Reupert, 2006). A recent Australian study sought to identify the barriers that exist for adult mental health services in working with clients in their parenting role and working with their children. One of the major barriers identified was a perceived lack of knowledge regarding talking with children. The study suggested that although adult mental health workers identified that they could be a source of information for children, they were often unsure about child development and how to talk appropriately to children (Maybery & Reupert, 2006).

Falkov (2004) suggests that in order for parents and mental health workers to feel comfortable about explaining and discussing mental illness with children it is important to have an understanding of age appropriate explanations. Although clearly needed, there is very little research examining the ways in which children of varying ages understand and account for mental illness.

1.11 Gaps in the literature

There are two overarching gaps in the literature which have been highlighted within this literature review. Firstly, it has been established that very little is known about a parent's own views of talking to their children about mental illness in the family. Although research suggests that many parents do want their children educated about mental illness (Maybery et al., 2005; Stallard et al., 2004), a number of aspects still need clarification. Parental beliefs about who should educate their children about mental illness are unclear; should the parent themselves explain, or their General Practitioner, their Psychiatrist or someone else?

Clarification is also needed about what the parent would like the child to be told about mental illness and whether parents encounter difficulties when talking to their child about mental illness.

Secondly, it has been established that COPMI are not often provided with information about mental illness even though education is linked to positive outcomes such as increased resilience. Importantly, research suggests that COPMI are not provided with information because the people best placed to talk to them about mental illness, such as parents or mental health workers, are unsure of what COPMI know about mental illness and are unsure about what is age appropriate for them. The literature highlighting what COPMI understand about specific aspects of mental illness is sorely lacking.

1.12 Research questions

The present thesis aims to address the gaps outlined above. Specifically, the research questions this thesis aims to answer are:

1. What is the parental view of disclosure of mental illness to their child?
2. What do COPMI know about parental mental illness and how do they find out about it?
3. What is the familial view of disclosure of mental illness and do members of the same family hold similar illness beliefs?

1.13 Overview of thesis

The literature review has highlighted the substantial lack of research into family communication and knowledge about parental mental illness. This thesis will attempt to address this significant gap throughout the chapters described below;

The methodology for the thesis is provided in the following chapter, Chapter Two: Methodology. Detailed information regarding both the parent and child participants is provided, along with information regarding the recruitment procedure, rationale for the interview questions and the process of the interviews.

Chapter Three, Study one: Parents' ideas about disclosing mental illness to their children, focuses on parents' views of talking to their children about mental illness. The chapter begins by examining the scant literature pertaining to parents' ideas about explaining mental illness to their children. Literature examining parents' views of explaining other sensitive topics to children is also highlighted. The study proper analyses and presents parental views of a number of aspects of disclosure; who explained the illness, how it was explained, the reasons why parents don't talk to children about mental illness and resources available to help with disclosure.

Following the third chapter, Chapter Four: Review: Children's understanding of mental illness reviews the research pertaining to children's knowledge of mental illness. The review uses a Leventhal (1980) framework to highlight what is known about children's knowledge of pertinent aspects of mental illness. Importantly, the review highlights what is known so far about COPMI understanding of parental mental illness and indicates the areas of COPMI understanding which are still largely unexplored.

Chapter Five, Study Two, Part I: Children's ideas about their parent's illness; symptoms, cause, treatment, timeline and consequences for the family, examines COPMI ideas about parental mental illness. Specifically, COPMI ideas about pertinent aspects of parental illness (such as symptoms and cause) are examined. This study addresses the gap in research as highlighted within Chapter Four.

Chapter Six, Study Two, Part II: Do children think they have enough information and how is information transmitted? is an extension of Chapter Five. COPMI ideas about whether they have sufficient information about their parent's illness are examined. In addition COPMI views about how they found out about their parent's illness, whether they would like more information and where they would seek further information are all explored.

Building on both Study one and Study two is Chapter Seven, Family communication and understanding of mental illness. Chapter Seven begins by examining the literature regarding family communication around other sensitive topics. This chapter then explores the experience of talking about mental illness within the family. Chapter seven also explores family beliefs about aspects of mental illness and examines whether ideas about mental illness are common among family members or whether their views on pertinent aspects differ.

The concluding chapter draws together the main findings of the thesis and discusses the clinical implications of the findings. The limitations of the thesis are addressed and the possibilities for further research are discussed

Chapter Two: Methodology

The following chapter outlines the methodology employed for the three main studies within this thesis: the parent-focussed disclosure study, the child-focussed study examining child beliefs regarding mental illness and views about gaining information to do with mental illness, and the family communication study.

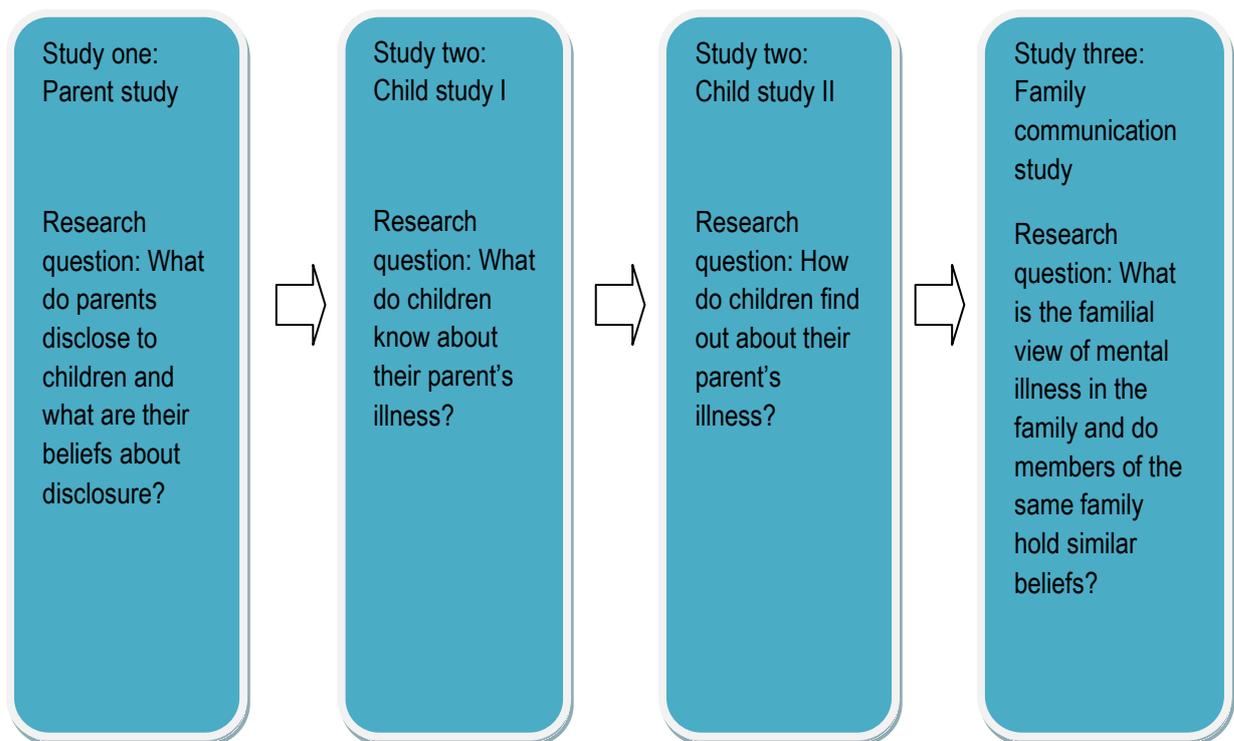


Figure 1. Diagram of the studies included within this thesis

This thesis is informed by a qualitative research paradigm. Each stage of this thesis was planned and conducted from a qualitative perspective: the development of each study, the choice of the method of data collection and the choice of analytic technique. Data collection methods and the choice of analysis will be discussed later in this chapter, however a few of the pertinent assumptions underpinning the initial development of the studies are outlined forthwith.

Firstly, there is an assumption regarding the role of a hypothesis. Qualitative research, unlike most quantitative research, is inductive. That is, prior ideas and hypotheses are not imposed on the research and a hypothesis is not necessary to commence research.

Secondly, there is an assumption regarding the type of data that is sought. The qualitative approach utilised within this thesis is concerned with exploring the meaning of phenomena, rather than proving or disproving a pre-defined theory with numbers and statistical significance. Specifically, this thesis uses participants' voices to describe their experience, rather than using participant responses on questionnaires with pre-determined response choices. Given the richness of the data sought, a smaller sample size is appropriate and sampling can be purposive rather than randomised.

Finally, there is an assumption within qualitative research regarding the role of the researcher. As opposed to quantitative research, within qualitative research the researcher often becomes immersed in the research situation. The researcher seeks to explore the meaning of the data collected and this often means that time is spent with participants, becoming familiar with them and their accounts. Other assumptions are discussed within the relevant sections of this chapter.

Recruitment of participants and the procedure was similar for all three studies. Any differences are discussed below.

2.1 Ethics approval

The University of Adelaide Human Research Ethics Committee approved the recruitment procedure and interview schedule for this study.

2.2 Participants

The focus of this thesis was not specifically about parents with a mental illness, rather it was about how families living with mental illness discuss these illnesses within the family.

Participants included parents who had mental illness, partners of people with mental illness, former partners of people who had mental illness, step-parents where the child has a parent with mental illness and children of parents with mental illness.

2.3 Recruitment

Due to the lack of funding available for travel, it was preferable for all participants to be located within South Australia, the home state of the researcher. First efforts at recruitment involved advertisements being placed in the Mental Health Resource Centre, in areas that held support group meetings for people with mental illness and/or their families. The Mental Health Resource Centre is located in Adelaide, South Australia and encompasses the Mental Illness Fellowship of South Australia (MIFSA) and the Association of Relatives and Friends of those with a Mental Illness (ARAFMI). Both MIFSA and ARAFMI run support groups for people with mental illness and their carers. Advertisements were also placed in the monthly newsletters of both MIFSA and ARAFMI for a number of months (See Appendix A for advertisement wording).

The advertisements through the Mental Health Resource Centre resulted in only three participants. Initial recruitment strategies needed to be revised in an attempt to source a greater number of participants. Accordingly, ethical approval for amendments to the recruitment strategy was sought and subsequently approved. A press release was conducted through the University of Adelaide's media unit. This resulted in radio interviews with a number of local radio stations and newspaper articles in three local publications.

It was decided at this stage to expand the study to include participants from all areas of Australia in an effort to recruit an adequate number of participants. In addition to contacting the media, support organisations from around Australia were contacted to ask if any of their members may be interested in taking part. A number of people who work in the field also sent emails to their colleagues asking them to forward the information to anyone who they thought may be interested. Emailing support organisations and emailing people who work in the field were the most fruitful methods of recruiting participants.

A surprising number of participants were obtained through word of mouth and ‘the snowball effect’. After conducting interviews with some families, they then asked if their friends could also participate. In some areas (such as rural South Australia and areas of Western Australia) participants themselves organised a number of different families to be interviewed. In all cases the recruitment procedure was the same and all ethics procedures were adhered to. The recruitment procedure is outlined below. Ultimately, participants were sourced from a number of areas in Australia; Adelaide and rural South Australia (n=12 parents, n= 20 children), New South Wales (n=7 parents, n= 9 children) and Western Australia (n=7 parents, n= 11 children).

Overall the recruitment of participants took a lot longer than anticipated. Approximately one year was devoted to recruitment and interviewing participants. This is not unusual in this area of research (for example see Cogan et al., 2005a; Foster, 2006; Handley et al., 2005; Meadus & Johnson, 2000; Wang & Goldschmidt, 1994).

2.4 Procedure

2.4.1 Recruitment procedure

Potential participants (parent participants) who learned of the study through advertisements or word of mouth contacted the author by telephone to indicate their initial interest in taking part

in the project. At this stage the project was explained briefly and the participant was given the chance to ask any initial questions. After being given a brief explanation of the project the potential participant was then asked if they were still interested in participating in the project. All participants stated that they were still interested. Participants were then asked for their address and posted an information sheet for themselves (see appendix B), an information sheet for the parent about the child's participation (see Appendix C), an information sheet for their child (see appendix D) and an independent complaints procedure form. Participants were advised to read the information sheet and, if they were still interested in participating, to call and set an interview time with the researcher. All participants telephoned to make an interview time. Asking for the participants to contact the researcher at each point of the procedure was time consuming but it ensured that the participant was willing to take part in the study. Informed consent and transparency were of paramount importance in this study. In addition, to ensure that participants were able to provide informed consent, participants must not have been hospitalised at the time of the interview.

It is worth noting here that the recruitment procedure and the traits of the participants who agreed to take part are a possible limitation of the study. Firstly, advertisements for the study highlighted that the study was examining parents' and children's *discussion* of mental illness. The advertisement also called for parents *and/or* their children to be included in the study. Each of these aspects may have contributed to appealing to a certain group of parents of children with mental illness in the family. Parents who have actively chosen not to disclose to their children about mental illness in the family may have avoided participation in this study because they did not want their children to take part. Indeed, there was only one parent within the current study who had not disclosed her illness to her children at all. Parents who choose not to disclose to their child about any aspect of mental illness may have qualitatively different responses to the questions asked within this study.

2.4.2 Interview location

All interviews were conducted by the author. Interviews were conducted in a number of locations and all interviews were face-to-face. Parents and children were interviewed separately and therefore, part of the time, children were required to be in a different room from their parents. Because of this it was not always practical to conduct interviews in University offices. Participants were given a range of interview location options (such as an office at the University, a local library or park, or their own home) and asked where they would like to be interviewed. The majority of participants asked to be interviewed within their own home. This meant that the participant was not unduly inconvenienced by having to organise travel arrangements and visit an unfamiliar location. Interviewing within the home also worked well as it meant that the participant's children could be in a familiar place and play in another room while the parent was being interviewed.

2.4.3 Engagement

A significant amount of time prior to the actual interview was spent meeting the family and building rapport. This often took up to an hour prior to the interview. The information sheet was discussed at this point and the parents were given an opportunity to ask any questions they may have or voice any concerns. The participant was then asked to read and sign the consent form (see Appendix E). For all parent participants who had agreed for their children to take part, the parent interview was conducted first. There were two reasons for this. Firstly, this gave the parent a chance to get to know the author and the interview content and style before agreeing to their child participating. Secondly, information was gathered in the parent interview that was subsequently used in the child interview. For example, parents were asked whether their children knew about their illness and what their illness was called at home. This information was then used when interviewing children to build rapport and to guide the level of questions that the children were asked. The parent's own words for describing and labelling their illness were used when speaking to their children. Words such as mental

illness', 'depression', 'bipolar disorder', 'schizophrenia' for example were only used if the parent had indicated that the child knew these terms or if the child themselves used them.

At the end of the parent interview the parents were given the list of children's questions and asked if there were any questions they would prefer the author not to ask or any they thought would be problematic for the children. No participants indicated that any of the children's questions would be problematic. Parents were then asked to sign a consent form for their child (see Appendix F). Parent consent, although necessary, was not sufficient on its own for the interview to be conducted with the child. Child consent for the interview to be conducted was also required and is addressed below.

Although it would have been optimal to interview both a child and a parent from each family that participated, this did not always occur. Some families gave consent for the parent to be interviewed but not a child and vice versa. In cases where the parents did not want to be interviewed but consented for their children to be interviewed, the parent's diagnosis was established and the parent was briefed on the child's interview schedule. Parents were then asked if there were interview questions that they would prefer not to be addressed with their child.

There was no limit placed, by the researcher, on the number of children or parents interviewed from each family. Where interviews have been conducted with only one child from a family with multiple children, this was at the discretion of the parent. The limitations of the parent choosing only one child to be interviewed will be discussed later in this thesis.

It would be useful, for the reader, to have a table provided which highlights data such as the number of parents and children in each participating family. This would allow for a better sense of the overall data set. It is a conscious decision not to include such specific data here.

There is a small community of parents with mental illness and professionals and researchers in this field who are known to each other. Some parents with mental illness are active advocates who spend time at conferences and other events working with researchers and professionals with the common goal of improving recognition for families with mental illness. Providing information about the family context could lead to the identification of specific families within this thesis and, as such, it is not included here.

2.4.4 Interviews with children

In accordance with previous work conducted both within this field and with other sensitive topics, the age range for potential child participants was from seven years old to 18 years old (Finney & Falkov, 2009; Forrest, Plumb, Ziebland & Stein., 2006).

The guidelines provided by the NSW Commission for Children and Young People (2005) for conducting research with children were followed for both the consent procedure and interview process with the children in this study. Considerable time was spent talking to each child before the interview took place. During this time general topics were discussed (such as their favourite thing about school, the child's pets and siblings) to build rapport. Once rapport was established, the interview and what it entailed was discussed. At this point, the child was told about the reason for the study, the types of questions that would be asked, and the digital recorder that would be used to record the interview was introduced. It was explained that the author had just spoken to their parent about certain topics that would now be discussed with them. The child was then asked whether they would like to participate and were assured that they were free to choose not to participate.

All children stated that they would like to participate and, at this point, the consent form was presented and each point was explained. Given the wide range of ages of child participants there were two versions of the child consent form. One was targeted to younger children

under the age of 13 (see Appendix G) and the other was targeted to children over 13 (see Appendix H). Children's understanding of the consent form was ensured and each child was asked to sign their name. All participants were assured that they did not have to answer any questions they did not want to answer and that they could stop the interview at any point. Child participants were assured that if they stopped the interview, this would not upset the researcher or their parent.

2.4.5 Length of interviews

The interviews with parents varied in length. The longest parent interview lasted for 90 minutes and the shortest went for 20 minutes. On average the parent interviews lasted 46 minutes each. The length of interviews with children also varied. The longest child interview lasted for 80 minutes and the shortest interview lasted 18 minutes. On average the child interviews lasted 27 minutes.

Participants were asked for their permission to record their interview on a digital voice recorder. All participants agreed to being recorded and signed a consent form stating this. At the end of the interview each participant was paid \$20 for their time and to compensate for any inconvenience caused.

2.5 Sample characteristics

This section will outline the demographic information, firstly for the parent participants and followed by the child participants.

2.5.1 Parent demographic details.

Female participants were significantly overrepresented (n= 23) with only 12 % of the sample being male (n= 3). Parent participants ranged in age from 27 to 50 years old, with a mean age of 39 years. As stated at the start of this chapter, parent participants included parents with

mental illness (n= 17) and parents without mental illness (n= 9), the criteria for inclusion in the study was that they had a child who had a parent with mental illness. The nine parents without mental illness comprised of parents without mental illness who resided in the home with the parent who had mental illness (n= 4), ex-partners of a person with mental illness (n= 4) and a step mother of a child whose mother has mental illness (n=1).

2.5.1.1 Types of mental illness

The parent participants who identified as having mental illness were asked about the specific diagnosis of mental illness that they had received. The parent participants who identified as not having mental illness were asked about the mental illness of their child's other parent.

There were a range of mental illnesses identified, as seen below in Table 2.

Table 2

Range of Mental Illnesses Identified By Parent Participants (note, some participants endorsed more than one mental illness and this is reflected in the figures here).

Participant endorsed metal illnesses
Schizophrenia (n= 8)
Depression (n= 7)
Borderline personality disorder (n = 6)
Anxiety (n= 4)
Bipolar disorder (n= 4)
Schizoaffective disorder (n= 3)
Post traumatic stress disorder (n= 3)
Obsessive compulsive disorder (n= 2)
Post natal depression (n= 1)
Antisocial personality disorder (n= 1)
Dysthymia (n =1)

The sample size is not sufficient in this study to analyse any differences or similarities between types of mental illnesses. Instead all mental illnesses are grouped together for analysis and generally referred to under the broad term “mental illness”. Although the analysis treats all mental illnesses as a homogenous group, it is worth briefly outlining the common symptoms associated with each of the illnesses cited by participants. There are occasions in participant accounts where they talk about specific mental illnesses and specific symptoms. A cursory overview of these illnesses will allow a greater understanding of the findings of some of the analyses.

The Diagnostic and Statistical Manual of Mental Disorders is a widely used tool, both within Australia and overseas, to diagnose specific types of mental illness. The following descriptions of the mental illnesses, cited by participants within the studies in this thesis, are adapted from the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV: American Psychiatric Association, 1994). Each mental illness has an extensive list of criteria which must be met in order to obtain a diagnosis. The complete list of criteria for each illness will not be displayed here, rather a condensed version with key criteria are presented. The following are taken from the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994).

Schizophrenia: Characterised by disorganised thinking, disorganised speech, social withdrawal, delusions, hallucinations. The symptoms need to be present for at least 1 month and the diagnosis is given when the symptoms are present, intermittently, for at least 6 months.

Schizoaffective disorder: Similar to the symptoms for schizophrenia however the symptoms for a mood disorder (for example bipolar disorder or depression, as displayed below) need

also be present. Symptoms of schizophrenia occur with symptoms of a mood disorder and are preceded or are followed by at least 2 weeks of delusions or hallucinations without prominent mood symptoms.

Depression: Characterised by depressed mood, loss of interest or pleasure, weight gain or weight loss, sleep issues, suicidal thoughts, indecisiveness, fatigue, feelings of worthlessness or excessive guilt.

Dysthymia: The symptoms are largely similar to depression however the symptoms are milder and are present over a long period of time (a minimum of two years). Symptoms include depressed mood along with feelings of hopelessness, impairment in cognitive function, appetite issues, low energy, sleep disturbance.

Post natal depression: It is not recognised as a separate diagnosis within the DSM-IV. Instead it is viewed as depression with post partum onset. Commonly the symptoms of post natal depression can be thought of as the same as for depression however they occur after, and in response to, the birth of a child.

Bipolar disorder: Is characterised by manic or hypomanic episodes and can include episodes with depressive symptoms. Manic symptoms can include increased self-esteem, reduction in the need for sleep, flight of ideas, increase in risky behaviours, grandiosity. Hypomania includes the same symptoms but generally impacts less on functioning than mania.

Borderline personality disorder: Characterised by long term instability in self image and interpersonal relationships, impulsivity (for example substance abuse or reckless driving), self harming or suicidal behaviour, feeling of emptiness, mood instability.

Antisocial personality disorder: Symptoms include deceitfulness, impulsivity, failure to conform to social norms, consistent irresponsibility, lack of remorse. Characterised by a pattern of disregard for, and violation of, the rights of others.

Anxiety: There are a number of anxiety disorders. Generally, anxiety symptoms include persistent fear and worry, difficulty making decisions, difficulty concentrating. People with anxiety can experience attacks of intense terror and apprehension, shaking, dizziness, nausea and have trouble breathing.

Post traumatic stress disorder: This is a form of anxiety which occurs after a traumatic experience. Symptoms can include those for anxiety but can also include hypervigilance, flashbacks and avoidance of reminders of the traumatic event.

Obsessive compulsive disorder: This is another form of anxiety and shares some symptoms. It is characterized by obsessions which are persistent distressing thoughts and images (such as the thought of harming someone close to you) which cause marked anxiety or distress. In addition (or instead of) a person can experience compulsions which refer to the urge to perform acts or rituals (such as counting or checking) which serve to neutralize anxiety.

Eight participants either identified as having more than one mental illness themselves or identified their child's other parent as having more than one illness. This was expected given the high rate of co morbidity within the general psychiatric population (Clark, Watson and Reynolds, 1995).

The literature available on stigma and self-stigma of people and parents with mental illness (Hinshaw, 2005) indicates that mental illness is not a condition most people would falsely claim to have. Given the unlikelihood of participants claiming to have a mental illness when

they do not, self reported diagnosis was considered sufficient for this study. That is, participants themselves reported the diagnosis and this was not verified with their GP, Psychiatrist or other health provider. It was beyond the scope of this thesis to confirm participant diagnoses with their mental health provider.

Similarly, there was little to be gained, and therefore was considered unlikely that participants would falsely report that their partner or previous partner had mental illness. In addition, the author is completing a Masters (Clinical) in Psychology whilst completing this thesis and, in her clinical opinion, the symptoms acknowledged by the parents and children within this study appeared highly consistent with the mental illness they claimed to have.

Participants were not specifically asked about alcohol and drug use as a part of this study as it was not the focus of the research. Three participants spontaneously discussed their own or their partner's drug and/or alcohol use within the interview. Given that the co-occurrence of mental illness and substance use is viewed as the norm rather than the exception (Hall, Lynskey, Teesson, 2001), it could be hypothesised that there would be a number of other participants within this sample who may have a dual diagnosis.

Within the interview, three participants stated that they were of Aboriginal or Torres Strait Islander (ATSI) descent. Given that questions about cultural background were not asked as a part of the interview, no further information can be given about the cultural background of the participants.

The table overleaf outlines the pertinent demographic details for each of the parents' included within this study. Table 3 outlines parent participants' age, the number of children they have, the length of time the person has had the illness (either themselves or the child's other parent) and whether or not their children live with them. The table also states whether the parent

participant does or does not have mental illness. As stated, the parents who did not have mental illness included the partners of the parents with mental illness, ex-partners and step parents of children who had parents with mental illness. The criteria for inclusion in the study was that each parent participant needed to have at least one child (for whom they were partially or wholly responsible for) in their family who had a parent with mental illness. Extract ID is also included on the table. The Extract ID is used throughout Chapter Three when an extract from that person's interview is used to highlight a theme. The Extract ID follows a set format of: relationship to the child; number of children; illness of the parent. For example, the Extract ID for a father, who has one child and who has schizophrenia would be: ~~Father of one, with schizophrenia~~". Another example, for a mother who has two children but whose ex-partner has mental illness would be: ~~Mother of two, ex-partner has antisocial personality disorder~~".

For all analyses in Chapter Three, the data from parents with mental illness and parents without mental illness is combined and treated as one data set rather than two. The perspectives of the parent with mental illness, the partner of the parent with mental illness, the ex-partner of the parent with mental illness and the step parent of a child whose parent has mental illness are considered together. As stated previously, the study within Chapter Three is concerned with how parents talk to children about mental illness when the child is in a family where a parent has mental illness. Parents in this context include any parent within that child's life; those who identify as having mental illness and those who do not.

Table 3
Demographic Details and Extract ID for Parent Participants

ID for extracts	Participant has mental illness	Age	No. of children	Length of illness	Parent lives with child
Mother of three, with social anxiety, borderline personality disorder and dysthymia.	Y	44	3	28 yrs	Y
Father of one, with schizophrenia	Y	34	1	17 yrs	Y
Mother of two, with schizoaffective disorder	Y	44	2	16 yrs	N
Mother of three, with borderline personality disorder and schizoaffective disorder	Y	37	3	19 yrs	Y
Mother of three, with bipolar disorder and post natal depression	Y	35	3	13 yrs	Y
Mother of two, with depression and post traumatic stress disorder	Y	33	2	10 yrs	Y
Mother of three, with obsessive compulsive disorder and depression	Y	49	3	25 yrs	Y
Mother of five, with post traumatic stress disorder, depression, borderline personality disorder and anxiety	Y	41	5	7 yrs	Y
Mother of three, with schizophrenia	Y	36	3	18 yrs	Y
Mother of two, with schizophrenia	Y	44	2	25 yrs	Y
Mother of one, with schizophrenia	Y	43	1	24 yrs	Y
Mother of two, with schizophrenia	Y	42	2	7 yrs	Y
Mother of one, with bipolar disorder	Y	38	1	8 yrs	Y
Mother of four, with depression	Y	41	4	10 yrs	Y
Mother of three, with depression	Y	43	3	18 yrs	Y
Mother of one, with bipolar disorder	Y	35	1	20 yrs	Y
Mother of one, with depression and borderline personality disorder	Y	31	1	15 yrs	Y
Mother of two, partner has depression	N	42	2	10 yrs	Y
Mother of five, husband has depression, anxiety obsessive compulsive disorder and borderline personality disorder	N	45	5	1 yr	Y
Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder	N	40	3	20 yrs	Y
Mother of one, partner has schizophrenia	N	35	1	14 yrs	Y
Mother of two, ex-partner has antisocial personality disorder	N	44	2	19 yrs	Y
Mother of one, ex-partner has schizophrenia	N	27	1	9 yrs	Y
Mother of two, husband has bipolar disorder	N	50	2	10 yrs	Y
Father of one, ex-partner has schizoaffective disorder	N	40	1	18 yrs	Y
Step-mother of one, mother of child has schizophrenia and anxiety	N	40	3	6 yrs	Y

2.5.2 Child demographic details

Whilst interviewing one child, it appeared that the child had no knowledge of the mental illness that her mother had. When this became apparent the interview was discreetly concluded and no further questions about mental illness were asked of the child in order to avoid causing any potential distress. The child received payment for the interview and her parent was advised that it may have been uncomfortable to continue the interview with the child. The child's interview responses have been omitted from the analysis. The child's demographic details have been included on the demographic table (included below) with a note stating that she was not included for analysis purposes.

Of the children who participated in the study in Chapters Five and Six, the majority were male (n= 22) and 45% (n= 18) were female. Participants ranged in age from 7 to 17 years old with a mean age of 11.9 years. Of the 40 participants interviewed, only 10 participants did not live with the parent with mental illness full time. Instead, these children visited their parent with visits occurring at weekly to monthly intervals. All participants had lived with their parent who has mental illness at a recent time.

The table overleaf outlines the pertinent demographic details for each of the children included within this study. Table 4 outlines the age, sex, illness the child's parent has, the number of siblings the child has and whether or not the child currently lives with the parent with mental illness. As with the demographic tables for the parent participants, Extract ID is included. Extract ID is used throughout Chapters Five and Six to identify which participant's extract has been used to highlight a theme. Each Extract ID follows a similar set format to the Extract ID which is used for parent participants, that is: relationship to the parent; illness of the parent; and age of the child participant. For example, the Extract ID for a daughter, whose

mother has schizophrenia and who is 13 years old would be: “Daughter of mother with schizophrenia, 13yo”.

Table 4
Demographic Details and Extract ID for Child Participants (continued overleaf)

ID for extracts	Number of siblings	Child lives with parent with a mental illness
Daughter of mother with depression and post traumatic stress disorder, 7yo	1	Y
Son of mother with borderline personality disorder and schizoaffective disorder, 7yo	2	Y
Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 8yo	4	Y
Daughter of mother with bipolar disorder, 8 yo	0	Y
Son of mother with post traumatic stress disorder and borderline personality disorder, 9yo	2	N
Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo	2	Y
Son of mother with obsessive compulsive disorder and depression, 9 yo	2	Y
Son of mother with schizophrenia, 9yo	0	Y
Daughter of mother with schizoaffective disorder, 9 yo	0	N
Son of mother with bipolar disorder, 9yo	2	Y
Son of mother with depression and post traumatic stress disorder, 10 yo	1	Y
Daughter of mother with social anxiety, borderline personality disorder and dysthymia. Participant removed from analysis.	2	Y
Daughter of mother with obsessive compulsive disorder and depression, 10 yo	1	Y
Daughter of mother with depression, 10 yo	3	Y
Son of mother with bipolar disorder, 10 yo	0	Y
Daughter of father with depression, 10yo,	1	Y
Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 11 yo	4	Y
Daughter of father with schizophrenia, 11 yo	0	N
Son of mother with schizophrenia, 11yo	1	N
Son of mother with schizophrenia, 11 yo	2	Y
Daughter of mother with bipolar disorder and post natal depression, 12 yo	2	Y
Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo	2	N

ID for extracts	Number of siblings	Child lives with parent with a mental illness
Son of mother with bipolar disorder, 12 yo,	2	Y
Son of mother with borderline personality disorder and schizoaffective disorder, 12 yo	2	Y
Daughter of mother with schizophrenia and anxiety, 13 yo	1	N
Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo	2	N
Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 13 yo	4	Y
Daughter of mother with schizophrenia, 13yo	1	Y
Daughter of father with depression, 14 yo	1	Y
Son of father with schizophrenia, 14 yo	0	Y
Son of mother with depression, 14 yo	2	Y
Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo	4	Y
Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 15 yo	4	Y
Son of mother with bipolar disorder, 15yo	2	Y
Son of mother with schizoaffective disorder, 15 yo	1	N
Son of father with antisocial personality disorder, 16 yo	1	N
Daughter of father with bipolar disorder, 16 yo	1	Y
Daughter of mother with bipolar disorder, 16 yo	2	Y
Daughter of mother with schizophrenia, 17yo	1	Y
Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 17yo	4	Y
Daughter of mother with schizoaffective disorder, 17yo	1	N

2.6 Interview schedule

2.6.1 The use of semi-structured interviews

The data gathered for this study was solely derived from qualitative methods, namely semi-structured interviews. There were a number of reasons for choosing semi-structured interviews as the method of data collection. Specifically this method allowed for a wide range of responses. Semi-structured interviews also allow for in-depth exploration of participant responses.

Due to the scant research currently available regarding parent beliefs about disclosure of mental illness and child beliefs about mental illness, this thesis was largely exploratory in nature. The present research was concerned with the range of responses participants may provide. Quantitative methods (such as questionnaires) allow a participant to choose a response which has been predetermined by the researcher. These are useful when the phenomena of interest have previously been explored. Quantitative methods do not allow a participant to provide a novel response; they assume that participants have had a similar experience of a particular phenomenon. In order to gain a full appreciation of the range of responses participants may have about disclosure and their beliefs about mental illness, it was vital that the method used in the present study allowed for a wide variation in response. Qualitative methods allow for a participant to talk about their beliefs and experiences freely without having to conform to a predetermined set of responses. This allows participants unrestricted response possibilities which can help to elicit richer and more varied responses.

In addition to allowing a participant to respond freely and not be confined by a set of possible responses, semi-structured interviews allow for in-depth discussion about topics of interest. Semi-structured interviews provide space for thorough exploration of topics by the researcher and allow for elaboration by the participant if desired (Britten, 1995). Semi-structured interviews provide a conversation-like atmosphere where topics of interest can be followed up by the researcher. For example, in the current study, one area of interest was the parent experience of disclosure. Semi-structured interviews allowed the topic to be fully explored by both the researcher and participant. Exploration of this topic resulted in a much deeper understanding of the tension between wanting to disclose to children but not actively disclosing, an aspect of the data which would be difficult to convey through quantitative measures.

2.6.2 The theoretical framework guiding the interview questions and analysis

The questions for this study were developed following a review of the literature pertaining to beliefs about physical and mental illness. An approach to examining people's understanding of illness is the model put forward by Leventhal and colleagues (Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984; Leventhal et al., 1997). This is the one which was deemed to be most appropriate for the current study given its applicability to a range of illnesses and populations. These will be discussed briefly below.

The basic premise of Leventhal's model is that an individual with illness develops a model of illness which helps them to make sense of what they are experiencing. This model is informed by internal factors, such as the person's own psychological traits and symptoms of the illness, as well as external factors, such as the information a person receives about their illness and other social influences (Barrowclough, Lobban, Hatton & Quinn, 2001).

Originally developed for use with populations experiencing physical illness, Leventhal's model posits that perception of illness can be divided into five specific domains. These are identity, cause, timeline, consequence and control. Identity refers to what the illness is called and what the symptoms are. Cause refers to what the person perceives caused the illness initially (for example chemicals in the brain, stress) and what triggers the onset of illness episodes. The timeline component examines perceptions about how long the illness will last, whether it is permanent and whether symptoms are cyclical. Consequence refers to perceived positive and negative changes within the person or the family as a result of the illness. The control component refers to the beliefs held about how controllable the illness is, who controls it (for example the doctor, the person with the illness) and how it is controlled.

Leventhal's model has been developed as a quantitative questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996) and used reliably with various adult populations experiencing

physical illness such as myocardial infarction (Petrie, Weinman, Sharpe & Buckley 1996), asthma (Horne and Weinman, 2002) and back pain (Foster et al, 2008) among others. The model has also been used as the basis for qualitative studies examining the beliefs people hold about their own illness (Lobban, Barrowclough & Jones, 2005) and the understanding people have about the illnesses other people have (Lobban & Barrowclough, 2005).

More recently, Leventhal's model has been applied to adult beliefs about mental illness. The model has reliably examined people's beliefs about their own mental illness and has been applied to the illnesses of schizophrenia (Lobban & Barrowclough, 2005), depression (Karasz, 2005) and anorexia (Holliday, Wall, Treasure & Weinman, 2005) among other illnesses. The model has also examined the beliefs that carers and relatives hold about a person's mental illness. In a study utilising a quantitative measure of illness perception Barrowclough and colleagues (2001) examined the models of illness relatives held about their family member's schizophrenia and suggested that Leventhal's model is a useful tool for the assessment of relatives' beliefs. Kuipers and colleagues (2007) examined carer illness representations and found that illness perception was linked to low self-esteem and distress in carers. Kuipers and colleagues suggested that discrepancy between carer and patient illness perceptions can impact on both parties.

In contrast to research examining adults illness perceptions, research utilising the Leventhal model with child populations is in its infancy. The model has been used to assess children's understanding of the common cold (Goldman, Whitney-Saltiel & Rodin, 1991), heart disease (Veldtman et al, 2000), diabetes (Olsen, Berg & Wiebe, 2008) and more recently obesity (Babooram, Mullen & Sharpe, 2011). Very few studies exist which examine children's understanding of mental illness using a Leventhal framework. These will be discussed in detail later in the thesis.

Both the premise behind Leventhal's model and the specific domains of the model were important in the development of this thesis. The premise behind Leventhal's model is that people try to make sense of their illness or the illness of people close to them. People actively use their current knowledge about illness and are active in processing the information provided to them in order to develop a model of illness that makes sense to them (Leventhal et al, 1984). The theory of Leventhal's model fits well with the premise of this thesis: that children try to make sense of their parent's illness using both the knowledge they already have as well as information which they accrue over time from other sources.

In addition, the specific domains which constitute the model are used to inform and structure a number of sections of this thesis. Firstly, the review of literature pertaining to children's understanding of mental illness (Chapter Four) is structured according to the five domains and all literature for Chapter Four is examined with Leventhal's model in mind. Secondly, the questions within the child study (Chapter Five) are based on the five illness domains. Thirdly, the chapter examining family beliefs (Chapter Seven) about mental illness is structured in line with Leventhal's domains.

By providing a theory of illness understanding as well as a framework for examining illness beliefs, the Leventhal model allows a systematic approach to the investigation of COPMI understanding of parental mental illness and family understanding of mental illness, something which has been largely absent within the literature examining COPMI understanding of mental illness to date.

Leventhal's model has been briefly described here to provide background information about the structure of the present thesis and the basis for the questions asked within the interviews for this thesis. Aspects of the model will be described in more depth as they relate to different sections of the thesis.

2.6.3 The specific questions asked within the present study

The interview questions were guided by Leventhal's five components of illness; 'Symptoms of illness', 'Cause of illness', 'Treatment of illness', 'Timeline of illness', 'Consequences of illness', and used some of the questions from The Illness Perception Questionnaire (IPQ) (Weinman et al., 1996) as prompt questions. The interview questions are included in the Appendix (see Appendix I).

Parents were asked additional demographic questions such as their age, how many children they have and whether their children live with them (either full time or part time). The interview schedule for parent participants also included questions about their views of their children's understanding of mental illness. These questions were specifically designed for this study.

Many of the parents who participated in this study had more than one child. In such cases parents were asked questions about the disclosure of mental illness to each child and about each child's understanding of mental illness.

The wording of the interview questions was changed in certain interview situations. The parent participants in this study included those who have mental illness and those without. Therefore parents identifying as having mental illness answered all questions relating to their own illness. Parents who identified as not having mental illness answered the questions as they related to their understanding and explanation of the child's other parent's illness.

It is important to note that when parents talked about disclosure of mental illness to their children, they were not talking about the disclosure of one discrete fact. Mental illness has many facets, such as the name of the illness, symptoms, treatment and hospitalisation.

Disclosure of one aspect (such as the name of the illness, for example ‘depression’) does not automatically lead to disclosure of other aspects of the illness (such as symptoms, for example ‘suicide attempt’). In addition, some parents had told some of their children but not others about aspects of mental illness. There can be differences in disclosure within each participant’s account, depending on what aspect of mental illness they are disclosing and who they are disclosing to (for example their youngest child or their eldest child). This is important to keep in mind as within the analysis there may be quotes from the same participant which are seemingly contradictory.

Children’s interview questions were a modified version of the questions asked of their parents. They were modified only to the extent that children (as with parents who did not have mental illness) were asked to answer questions about another person’s illness rather than their own. Demographic questions were also asked of children, such as their age and number of siblings (see Appendix I for the broad list of parent and child interview questions).

In accordance with the principles of semi-structured interviews, the interview schedule was used as a guide only (DiCicco-Bloom & Crabtree, 2006). Questions were elaborated on if they were not properly understood, or omitted if they had already been answered previously. Points of interest were explored in more depth. Often the domains of interest were discussed within the course of conversation and specific questions were not needed.

2.7 Data analysis

All 66 interviews with parents and children were transcribed verbatim by the author. Transcription was a lengthy process, taking approximately six months full time to complete. The decision was made not to use a professional transcription service due to the sensitive nature of the data and also due to the assurances of confidentiality made to the participants at the time of the interviews. The process of transcription, coding and analysis of the data (as

described below) were all conducted manually by the author rather than utilising computer-based transcription and coding programs. Manual transcription, analysis and coding enabled the author to become intimately acquainted with the data and this, in turn, enhanced the process of analysis which is described in more detail below.

In accordance with the use of qualitative data collection methods, qualitative data analysis techniques were utilised for this study. Qualitative analysis is useful for interview data as it enables the researcher to examine similarities and differences across and within participant's accounts. Qualitative analysis also retains and draws upon the rich detail in responses collected through qualitative techniques.

As with all forms of qualitative enquiry it is important to state and explain the epistemological underpinnings of the methodology used. In the present study the collection of data and subsequent analysis is located within a contextualist method; that is, between the opposites of essentialist method and constructionist method (Braun & Clarke, 2006). Essentialist methods report on the reality as stated or presented by participants, constructionist methods highlight the role of the construction of discourses pertaining to reality. An epistemology that sits somewhere between these two is most appropriate for the current study; it acknowledges the ways in which participants make meaning of mental illness and it acknowledges the social context in which meaning is made, whilst focussing on the 'plain language' meaning of the data at hand (Braun & Clarke, 2006).

Thematic analysis is one technique used for analysing qualitative data. It is an ideal technique for the data collected for this study as it is "a method for identifying, analysing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). There are a number of ways to conduct thematic analysis. Braun and Clarke (2006) have recently published guidelines on conducting methodologically sound thematic analysis. The analysis of the data within this

thesis follows these guidelines. Braun and Clarke's guidelines for the process of thematic analysis (familiarisation with the data, generating initial codes, searching for themes, reviewing, defining and naming themes) are summarised, and details of the application of the analysis to the current study is provided below.

1. Familiarising yourself with the data

Audio tapes of the interviews were transcribed by the author and yielded over 500 typed pages of text. Transcription of the interviews was time consuming and involved reviewing the recordings numerous times to make sure the transcriptions were accurate. The process of conducting the interviews, transcribing the interviews and then reviewing to make sure the transcripts were correct, all assisted in familiarising the author with the data. At this stage the transcripts were read and re-read a number of times and initial ideas were noted.

It is worth noting a few of the transcription conventions used for the interview data within this thesis. These are present within the extracts used to highlight themes. Extracts are used within the analysis of both the parent and the child interview data. Although the written word generally adheres to conventions (such as capital letters at the start of sentences, commas for pauses and a full stop at the end of a sentence) the spoken word, when written verbatim, generally does not. Accordingly the extracts were edited to assist with their clarity. Capital letters, commas and full stops were added and words or sentences with unrelated detail have been removed. Unrelated detail refers to details within the interviews which have been deemed, by the author, to be 'unrelated' to the core purpose of the interviews, which is the examination of beliefs about mental illness. Where unrelated detail has been removed, this is marked by ellipses and double brackets. Ellipses are also used to indicate pauses in conversation. In addition, when the extract is part of a larger piece of text, ellipses are used to indicate that there were words before the extract (which are not relevant to the current extract), words after the extract, or both.

For example:

...you know when you start taking the right medications instead of the wrong medications and things like that. You do start to feel this, I don't know, sense of calm that you haven't had before. And it's actually quite strange...((...))...I remember the first thing I took

The extract above was taken from a larger piece of interview text, this can be seen by the ellipsis at the beginning of the extract. In the last line of the extract some unrelated detail has been removed and marked by ellipses and double brackets. Finally, the flow of speech from this participant does not end at the word “took” and this is again marked by an ellipsis.

In some extracts it is necessary to provide interview data from both the interviewer and the participant. In cases where this occurs each speaker is identified for clarity. The researcher as interviewer is denoted by *I*: . The participant's speech is denoted by *P*: (in the parent interviews) and *C*: (in the child interviews). An example from a child interview is provided below.

C: usually he's like really happy and funny and if I say "I love you" he'll say it in a weird way back to me ...it's funny

I: And if he's sick he won't do that?

C: No

(Daughter of father with schizophrenia, 11 yo)

In addition, all identifying information within the recordings of the interviews has been removed within the transcripts. Identifying information included family member's names, friends' names, the names of hospitals, doctors and clinics and the names of schools and suburbs. All editing has been completed with the utmost care so as not to change what appears to be the participant's intended meaning.

2. *Generating initial codes*

Transcripts were read and initial codes were developed. Braun and Clarke (2006) describe codes as small, discrete segments of data which are of interest to the researcher. Transcripts were searched manually and all possible codes identified and highlighted. It is important to note that sections of transcripts can be coded a number of times for as many different possible themes as are relevant (Braun and Clarke, 2006). The process of coding also works to highlight similarities and differences within the data.

An example of coding for this thesis can be seen below:

.....I've never really specifically sat them down and told themBut like during play or um....playing a board game or something I said "you know when mum used to cry and do this and do that?" I said "you know I've been in hospital and that before? I used to say that it was from my headaches and from being sad but it's nothing to do with them" and then um recently in the last year I've just said "oh it's from depression, something called depression..."

(Mother of two, with depression and post traumatic stress disorder)

This extract was coded for *–Felling child whilst doing something else*”, *–Crying as a symptom*” and *–Depression*”. Note also the Extract ID (previously explained) which is positioned below the quote. Each extract within this thesis has an Extract ID positioned below it.

3. *Searching for themes*

Once coding was complete, all codes were placed into groups with similar codes. This was the start of the development of themes. As Braun and Clarke (2006) state, a theme *–captures something important about the data in relation to the research question*” (p.82). Braun and Clarke (2006) also state that a theme is an identifiable pattern of response within the data collected. Toward the end of the stage of coding there were a number of overarching themes

and various levels of sub-themes. Overarching themes in this case refer to the main themes identified. Sub-themes refer to smaller themes within the overarching themes.

It is important to note that although the themes were developed from analysis of the data, the themes did not *'emerge'* from the data. The themes did not passively appear to the researcher, instead, as with all research utilising thematic analysis, the author was active in noting potential themes and searching for themes.

4. Reviewing, defining and naming themes

This stage involved critically examining the possible themes to determine whether they accurately captured the data. As Braun and Clarke (2006) state, themes need to be checked to make sure that they are supported by adequate data. Decisions also need to be made about whether some themes can be grouped together to make one theme or, if other themes need to be split from one larger theme into numerous themes, to accurately convey the meaning of the theme.

At this stage a proportion of the themes (approximately 10%) were cross-checked by a colleague, with experience in thematic analysis, to ensure that the data supported the themes. Any disagreements regarding the data and themes were discussed and appropriate themes were agreed upon. Although the concept of inter-rater reliability is contested within qualitative research (Armstrong, Gosling, Weinman & Marteau., 1997; Pope, Ziebland & Mays, 2000), it was conducted within the current study in the interest of transparency.

Once themes are checked, they are then placed into a *'thematic map'* (Braun & Clarke, 2006, p. 91). The thematic map works as a visual picture of the data. All of the transcripts were re read with the thematic map in mind to determine whether the map accurately captured the

data. Some themes were adjusted accordingly after re-visiting the transcripts. At this point themes were named according to what part of the data they encapsulated.

The thematic map, encapsulating the themes from both the parent and child interviews, is too large to display here. Thematic maps are positioned throughout the analysis sections of this thesis. This will enable the reader to view a snapshot of the main themes and sub-themes identified and subsequently analysed within the analysis section.

The notion of counting instances of themes is one which is still highly debated (Braun & Clarke, 2006). Braun and Clarke (2006) themselves suggest that counting the number of times an individual theme occurs across a data set runs counter to purist thematic analysis. Other researchers in the field suggest that it is one way to present pertinent themes that is transparent and understandable to the reader (Boyatzis, 1998; Pope et al., 2000). Within this thesis, instances of the majority of themes have been counted. Themes are presented in order of most to least frequently endorsed.

Research utilising thematic analysis often cites only the most frequently endorsed themes or the themes which capture the most important aspects of the data (Braun & Clarke, 2006). The studies within this thesis were exploratory in nature; this phenomena has not been examined with this population before. The responses from all participants, regardless of how many times each theme was cited, were important to capture. Due to this, all themes and sub-themes developed from the data were included within the analysis.

2.7.1 Data collected for this thesis which is not included

Initially the plan for this thesis included an exploration of parent's own beliefs about their mental illness and ACOPMI beliefs about their parent's mental illness. The data for both the parent's beliefs about their own illness and ACOPMI retrospective beliefs about their parent's

illness were collected. Lengthy recruitment and transcription time, in addition to a reduction in thesis scope (due to a change in the University rules), meant that the views of ACOPMI and parents could not be included within this thesis. It is hoped that these will be published at a later date.

2.8 Ethical considerations

Although the majority of the potential ethical issues relevant to the participants within the current thesis have been highlighted throughout this chapter, it is worth detailing them here. Due to the nature of this research, in particular the participation of both people with mental illness and children, it was vital to remain aware of the potential ethical issues at all stages of the research. The National Health and Medical Research Council (NHMRC) guidelines (2007) were consulted and adhered to as they were relevant to the studies within this thesis, specifically the NHMRC principles of integrity, respect, beneficence and justice informed the design and conduct of the research within this thesis.

People with mental illness, along with children, are viewed by the NHMRC as a vulnerable group. The very nature of this research required their participation, the views of less-vulnerable people who had not had experience with mental illness would not have provided the information necessary to answer the research questions. In addition, excluding people based on mental illness would have meant that they would not be able to give their opinion on something which was directly relevant to them, should they want to.

The possible vulnerability of both the adult and child participants was taken onto account at all stages of the research process. Firstly participants were required to contact the researcher to indicate their willingness to take part. This, in conjunction with also being required to call the researcher a second time (after reading the consent form) ensured that participation was voluntary and there was very little possibility of participants feeling coerced or pressured to participate. Information about the study was provided and it was discussed at a few points

within the research process. Prior to interviewing each participant, the researcher was satisfied that each participant was informed about the project and the process and was able to provide informed consent.

Children are a particularly vulnerable group and care was taken to inform them fully about the research and to gain informed consent from them. There are inherent issues around power when researching with children, adults are historically in positions of power over children, and this was considered when conducting the research. Children were ensured that they could refuse participation in the research or could refuse to continue to participate once they had consented. All children consented to participate and it could be speculated that children felt unable to refuse regardless of the researchers intentions. Alternatively it could be speculated that all of the children willingly consented to participate. Indeed, many of the child participants mentioned that they had enjoyed the interview and a number of the younger participants asked if they could do it again.

The research was designed to minimise any potential participant discomfort. The interview questions were relatively innocuous, and although counselling details were to be provided should a participant require them, the process appeared to provide minimal distress to the participant. To reduce discomfort, interviews were conducted at a time and a place which most suited participants. In addition, interviews were semi structured, which allowed the participant to provide as much or as little information as they wanted. Semi structured interviews also allowed for participants to provide any additional information which they thought was important.

Finally, as mentioned, respect for participants was also upheld by reducing the possibility that their interview responses or demographic details would be recognised as belonging to them.

The nature of the interviews and the participant group meant that participants could have been

easily recognisable by peers or professionals. The researcher has attempted, at all stages of the research process, to ensure participant confidentiality. The transcripts of the interviews were de identified and potential identifying demographic information has been altered.

2.9 Motivation behind the current research

Since starting this thesis, I have had many people (personally, professionally and academically) ask for my motivation behind choosing the topic of COPMI and parents for my research. I too am intrigued by other people's motivation to research in this area. Research focussed on COPMI and parents has been described as "A really important issue but very messy" (Hay, 2009, p.4). The 'messiness', extreme difficulty in accessing participants and lack of funding for research in this area has ensured that research on COPMI and parents is generally conducted by people who are passionate about this field.

To answer any possible questions about the motivation behind the current thesis I will briefly state my motivations here. Although I have approached this thesis from an objective standpoint, it is important to understand that my background in this area may have led to subtle biases or expectations about this field, which may have influenced the design of the studies within this thesis as well as the analysis.

I have had an interest in this field for a number of years. I was raised, in part, by a single mother with mental illness. I was very fortunate to have extended family who took me in permanently when I was unable to live at home. My extended family were always open about my mother's illness and actively encouraged discussion about the illness and symptoms.

For a number of years I was involved in mentoring and facilitating recreational camps for COPMI. What struck me most, in my interactions with the COPMI I mentored and those who came on camps, was that the vast majority were unaware of the reason for their involvement

in the service. Many of the children accessing the COPMI camps had never spoken to anyone about their parent's illness and were therefore unaware that their parent's illness was a commonality between them and the other children on the camp. I wondered at this stage about the level of detail they knew about their parent's illness and wondered too about the reasons behind not being told explicitly about their parent's illness.

After conducting a preliminary review of literature I became aware of the research which stated that COPMI in general wanted or needed more information about their parent's illness. At this stage it dawned on me that the parent voice was largely absent on this topic. It was then that I became interested in the parent view of the disclosure and subsequent discussion of mental illness. The resulting thesis was guided by the desire to explore what children know about the many aspects of parental mental illness whilst simultaneously exploring the parental view.

Within qualitative approaches, reflexivity is an important part of the research process. Reflexivity within research refers to the bias a researcher may bring to the research process and, subsequently, the bias and validity of the results of the research. Research is often inherently biased. The values a researcher holds can be reflected in the choice they make between a quantitative and qualitative approach to research. Values can also be reflected in the choice of participants, the choice of data collection methods and the choice of analytic techniques.

In terms of my own bias, I was aware of my 'insider status' throughout the research process. I had been a COPMI when I was younger and was now classified as an Adult Child of a Parent with Mental illness. However, there were vast differences between myself and the majority of the participants within this thesis. I was 20 years older than many of the child participants and they had experience with support programs and systems which were quite different to those I

was exposed to as a child. In addition, I approached the topic as a novel subject. I had limited experience with the topic, aside from my observations of other COPMI kids within the COPMI camps. Whilst reading the broad literature relating to COPMI, it was clear that the question of illness beliefs and disclosure of illness was a fundamental question which had not yet been answered.

I entered the research process with little personal bias, instead being biased by my Masters training in psychology. I initially assumed, given the developmental literature, that there would be a clear age-related delineation of what COPMI knew about parental mental illness. I had assumed that the findings of my research could be usefully applied to a publication about age-appropriate ways to explain mental illness to COPMI. Those expectations were not met.

In summary, in terms of reflexivity and in an effort to provide transparency, I was aware throughout the research process of my ‘insider status’ as a former COPMI, although my experience as a COPMI was not aligned with current COPMI experience. My academic bias became apparent when the results of the research were different to my developmentally-based assumptions. The knowledge of my own bias assisted in critiquing the findings of the study and reminded me to remain mindful about other possible biases which may have been present.

The next chapter of this thesis, and the first study within this thesis, examines the parent view of disclosure of mental illness to their children. How do parents disclose to children? Who is responsible for disclosing to children? Is it difficult to disclose to children? Each of these questions will be explored within the next chapter, Chapter Three.

Chapter Three: Study one – Parents’ ideas about disclosing mental illness to their children

As highlighted in the literature review in Chapter One, research thus far has indicated that educating children about a parent’s mental illness may enhance coping capacity and foster resilience within children. The literature review also highlighted that children generally receive little or no information about their parent’s illness from their parent or from mental health workers (Focht-Birkerts & Beardslee, 2000; Kinsella & Anderson, 1996; Meadus & Johnson, 2000; Stallard et al., 2004).

3.1 Parental view of educating children about mental illness, what is known so far

In order to better understand why children are not receiving information about their parent’s mental illness, the parent view of discussing mental illness with their children must be understood. Very little research has examined parent views on discussing mental illness with children. What is known about the parental view of explaining mental illness is examined below. In all cases the parent’s view of the disclosure of mental illness has been explored as a small part of a larger study, they were not explicitly asked within the studies about their experiences of disclosure. As such, parents’ ideas about explaining mental illness to their children are not explored in depth in any of the studies.

In their study examining parent’s experiences of professional intervention with their children, Wang and Goldschmidt (1996) interviewed 50 parents with mental illness. Of the parents interviewed, “very few” (p.60) had provided their children with information about their mental illness. In addition, “many” (p.60) would have liked assistance in talking to their children. The reasons for not providing their children with information were not provided within the study.

Handley and colleagues (2001) interviewed eight parents and four children as part of a larger study examining the needs of children who have a parent with mental illness. The interviews suggested that parents felt that they lacked understanding about their own illness. The study did not examine whether parents lack of understanding impacted their abilities to discuss mental illness with their children. A major finding of the study was that children had great difficulty understanding their parent's illness, an issue compounded by other people in their life being reluctant to talk about it. It is unclear whether parents had told their children about their illness. Parental lack of understanding of their own illness, coupled with children's difficulty understanding their parent's illness suggests that, for this sample, parents had not discussed mental illness with their children.

In a unique study, Thomas and Kalucy (2002) examined the views that people with mental illness have about the effect of mental illness on their family. The study was unique in that the research was originally suggested by a group of people with mental illness and they were actively involved in the development of the study. The study suggests that, for this group of 35 participants at least, over 50% reported very little interaction with their children overall and over 48% stated that their mental illness was not often discussed with their children. Given that this was a study examining participant views on a broad topic, the reasons for the lack of interaction and the lack of discussion with children about mental illness were not explored in depth.

Stallard and colleagues (2004) interviewed 24 parents with mental illness as part of a study to examine parent's views about the effect of mental illness on their children. The study found that two-thirds of the parents they interviewed would like their child to be better informed

about their mental illness. Parents ideas about who should tell their child and how they should be told were not explored.

A focus group study, involving 12 parents, conducted by Maybery and colleagues (2005) found that parents believed their children needed more education about their illness. The participants agreed that what children should be told about mental illness depended on how old the children were. As the parental focus group study was a part of a much broader study, also involving clinicians and children, the exploration of parents' views about explaining mental illness to children was limited. The study did not explore parents' views on who should educate their children; the parent themselves, their General Practitioner, their Psychiatrist or someone else. Nor did it explore what the parent would like the child to be told and what the parent themselves understands about mental illness.

The scant literature addressing parents' views about talking to children about mental illness highlights a number of issues. Parents have difficulty understanding their illness; they feel that their children need more information about mental illness but are unsure about who should provide their children with such information. Parents also have queries about how the child should be told about mental illness; what should be said and who should tell them. The findings also suggest that children struggle to understand their parent's illness. These studies did not examine whether parents had actually told their children about their illness. Nor did they comprehensively examine parents' views on what they think about talking to their children.

3.2 What we know about parental views on explaining other sensitive topics

Parental difficulty with communicating about illness is not restricted to mental illness. Parents have reported difficulty with communicating with their children their diagnoses of cancer

(Barnes et al., 2000; Kroll, Barnes, Jones & Stein, 1998) and HIV (for example Armistead, Tannenbaum, Forehand, Morse & Morse, 2001; Lee & Rotheram-Borus, 2002; Pilowsky, Wissow & Hutton, 2000). Parents have also reported difficulty discussing other sensitive topics with their children such as donor conception (Hunter, Salter-Ling & Glover, 2000; Lycett, Daniels, Curson & Golombok, 2004; Nachtigall, Becker, Quigora & Tschann, 1998) and the possible presence of hereditary conditions (Malpas, 2006) among others.

Barnes and colleagues (2000) interviewed mothers with breast cancer and found that generally children were not told about their mother's cancer at the time of diagnosis. When children were eventually told about their parent's illness, only a few children were told about the diagnosis of cancer, all other children were told their mother was ill. Mothers avoided communicating to their children about cancer. Mothers were concerned about having to answer children's questions about the illness or death and also wanted to protect their children from distress or anxiety arising from finding out about the diagnosis. Parents also stated that their children were not old enough to understand the illness. Parents who had told their children did so stating that 'children had a right to know' and also stated that they had a desire to maintain the trust of their children. Few mothers in the study had been offered help with discussing their illness with their children. Many of the mothers thought communication with their children could be helped by meeting as a family with a health professional in their own home and getting advice on how to talk to children in an age appropriate way.

Research examining parental disclosure of HIV offers some useful insights into the difficulties parents can face when deciding how to disclose to children about a parent's HIV status and may be particularly pertinent to the context of mental illness due to the similarity in social stigma often associated with the illness. Parents worry about the effect of disclosure of HIV on their children (Kennedy et al., 2010; Murphy, 2008; Rwemisisi, Wolff, Coutinho,

Grosskurth & Whitworth , 2008). Disclosure of HIV can have negative effects on children, especially if the disclosure is unplanned (Kennedy et al., 2010). Parents also worry about whether the child is too young to deal with the knowledge or whether children will be able to refrain from telling others about the illness (Murphy, 2008).

Although not an illness, donor conception is another sensitive topic which requires a parental decision about disclosure to children. Lycett and colleagues (2005) interviewed parents who had used donor insemination (DI) to conceive their children. They examined the reasons for disclosure or non disclosure to children regarding donor insemination. Approximately two-thirds of parents who were interviewed had not discussed DI with their children. These parents stated that ~~“there was no reason to tell”~~ (p.814) and also discussed a desire to protect the child from stigma and to protect the father-child relationship. Those who did disclose, or who intended to disclose, did so to avoid ~~“accidental discovery”~~ (p.814) and out of a ~~“desire for openness”~~ (p.814) with their children.

Interestingly, only a small number of parents had actually disclosed. A number of parents intended to tell their children in the future and discussed being unsure about when to disclose. The majority stated that they were planning on disclosing when their children were between the ages of 7 and 11. The remainder of parents stated that they would tell their children when they were 18 years old or when he or she asked about their conception. Of the parents who had already told their children, all children were told before the age of 5. Interestingly a previous DI study found that one third of parents who stated that they intended to disclose DI status to children still had not done so by the time the child was an adolescent (Golombok, MacCallum, Goodman & Rutter, 2002).

3.3 The need for research into parental view of explaining mental illness

Although the research examining how parents discuss sensitive topics with children is slowly gaining momentum, the research examining the discussion of mental illness with children is still sorely lacking. Research regarding discussion of topics such as parental cancer, HIV or DI is useful for providing a general understanding of how parents talk about sensitive topics with children, however it does not address how parents talk with children specifically about mental illness. The discussion of mental illness has unique challenges. The diagnosis, symptoms and timeframe of the illness can be nebulous and can change over time. Mental illness is a more stigmatised illness than many physical illnesses and this could impact the way the illness is discussed with children.

As the literature suggests, there are numerous reasons why children should be educated about parental mental illness, however it is unclear what parents themselves think about this. No research to date has examined the reasons why parents do or do not talk to their children about their illness, nor has research examined how parents manage the discussion of such a unique topic with their children. Further research is needed into what parents with mental illness think about their child being informed about their illness. The potential barriers between parents wanting their child to be informed and the child actually being informed also need to be explored.

The current study explores parental views on communicating with children about mental illness. It will be the first study to comprehensively examine parents' views about telling children about mental illness. This study will examine parents' views in detail, not as an adjunct to a larger study. This study will give a much needed insight into difficulties and barriers parents may have explaining the sensitive topic of mental illness. It will also

contribute to what is already known in the wider field about parental views about discussing sensitive topics with children.

3.4 Aim

Broadly, to examine parents views about the disclosure of parental mental illness to their children. Specifically this study aims to explore parents' ideas about what age their child was told about mental illness, who told them and the way their child was told. This study will also examine parents' views about why it may be difficult for parents to disclose mental illness to their child and what resources were useful, or may have been useful, to help with discussing mental illness with their child.

3.5 Method

The methodology utilised for the entire thesis is documented within Chapter Two: Methodology. Although it is documented elsewhere, it is worth briefly revisiting some of the pertinent information here to reorient the reader and assist in understanding the current chapter.

Twenty-six parents were interviewed for the current study. The term 'parents' in this case includes both parents with mental illness (n= 17) and parents without (n= 9). The parents without the mental illness included the other parent who lived within the household with the parent with mental illness (n=4), the ex-partner of a parent who has mental illness (n= 4) and the step mother of a child whose mother had mental illness (n=1). The study was concerned with examining how parents (parents with mental illness, the parent without the mental illness, the ex-partner of a parent with mental illness and a step parent of a child with a parent with mental illness) explain mental illness to children in situations where the child has a

parent with mental illness. For this reason the interview data from parents with mental illness and from parents without mental illness have been analysed and reported as one data set.

Within the interview parents were also asked questions regarding their thoughts about difficulties other parents may have with disclosure of mental illness. The answers to these questions have been included in the analysis. Data and extracts in which participants are talking about possible issues other parents might have are referred to within the analysis as other parents.

As discussed in the methodology chapter, the parental interview responses have been analysed using thematic analysis. Interview responses have been broadly categorised into two main groups: disclosure of mental illness and non disclosure of mental illness. Interview responses which pertain to discussing aspects of mental illness with children have been collated and analysed as a group under the broad term of disclosure. Interview responses which discuss difficulty with talking to children or reasons for not talking to children have been collated and analysed under the broad heading of non-disclosure. The remainder of this chapter has been structured accordingly. Parental ideas relating to disclosure will be explored in the first part of this chapter. The second part of this chapter will explore parental ideas concerning non-disclosure.

To improve clarity and to flow, and minimise repetition of ideas, data analysis and discussion are reported together rather than in separate results and discussion sections. In addition, the clinical implications of the results are discussed alongside the presentation of the data.

3.6 Analysis and Discussion Part I: The process of disclosure from the parent perspective

3.6.1 At what age should illness be explained?

All parents were asked their view on how old a child should be before mental illness is discussed. *Figure 2* shows the responses provided for this question.

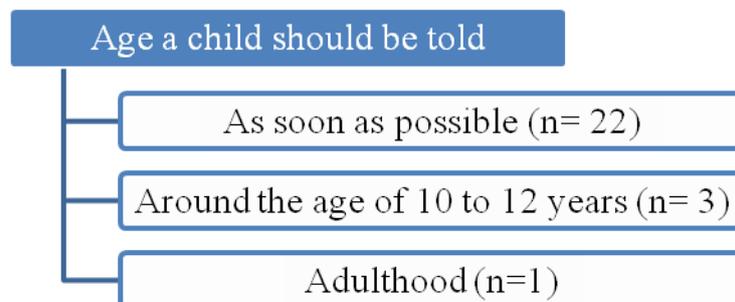


Figure 2. The age at which parents believed a child should be told about mental illness

Almost all parents stated that the child should be told as soon as possible. The following two extracts provide an example of the different ways in which parents both state and justify their reasons why children should be told. Parents were not specifically asked to justify their reasons but parents would often provide a justification.

Extract 1

...I actually think as early as possible...you know if mum's being hospitalised then it has to be explained otherwise you know.... Kids are just going to get so scared and they're gonna dread....you know....I've known kids who have hated mum for being sick..... and it's not been explained "well mum's not leaving you because she doesn't like you...she's going to hospital because she's sick"....And you know it was funny somebody I was talking to recently you know they said "it was only...you know....once they'd actually read things like the mental health act...actually mum was being taken away from us"....

(Mother of one, with depression and borderline personality disorder)

Extract 2

Um....it should be done as soon as the mental illness takes place...um.....Just you just need to be very honest with your children....um....yeah....as soon as it starts to happen...as soon as they start to recognise that there's a difference

(Mother of two, husband has depression)

Extract 3

.....you can start explaining at any age...what you need to do though is use and choose appropriate terminology....

(Mother of one, with bipolar disorder)

Interestingly, a number of parents who stated that children should be told as soon as possible had not actually told their children as soon as the illness had developed. There appeared to be a disparity between what parents believed was best for children and when they actually told their children. It could be hypothesised that this disparity could be due to parents having difficulty explaining illness to their children or not being well enough to tell their children, both of which are explored further in the next section.

There were four exceptions to the belief that children should be told as soon as possible.

Three parents believed that children should be told about mental illness at around the age of 10 to 12 years old.

Extract 4

...probably about 10..... or 12 maybe...

(Mother of one, with bipolar disorder)

One father believed his older two children (aged 13 and 12) were old enough to be told about their mother's illness but his younger son, or any child under 12, was not. He stated that a younger child may "*turn it round to suit them*" if told about the illness. This concept is

further discussed in the next section. In this instance, even though the father stated that his older children were at an age where they could understand, he had not explained fully about mental illness.

Extract 5

(Eldest child's name) now at 13...um I definitely think he'd be old enough to understand...yep definitely...(middle child's name) at 12 because he's so close with his older brother I'd say yes but 11, 10 nup...nup....nup.....I reckon they'd turn it round to suit them very much so

(Father of three, ex-partner has posttraumatic stress disorder and borderline personality disorder)

Very few parents believed that children shouldn't be told until they had reached adulthood.

One mother believed that she would tell her three children about her illness "when they'd left home" although she was ambivalent about this decision.

Extract 6

I guess I always thought when they'd left home and they were in a relationship of their own.....I struggle with do they need to know...you know there are some things...that I don't think they need to know, but then I think am I sheltering them...

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

The analysis of this question highlighted that although many parents ascribed to the view that children should be told as soon as possible, the majority of these parents had not acted on that belief. That is, parents believed that their children should be told as soon as possible, but their own children had been told at a later point. This finding came to light only after analysis had begun and all interviews had been completed. Because of this, the author was not able to access a direct explanation from parents about the discrepancy.

There are a number of factors which could contribute to such a discrepancy between beliefs about the age at which a child should be told and the age at which a child is actually told about a parent's mental illness. It could be the case that parents felt that answering the question in this way was the expected way to answer. Many of the parents were aware that their children should know about mental illness and perhaps felt that the answer of "as soon as possible" was a socially acceptable answer. Despite their belief that children should be told as soon as possible, parents could face difficulties telling children. The reasons given about why parents have difficulty disclosing to children (Part Two of the analysis) give a good insight into the reasons why there is a discrepancy between what parents believe should happen and what they actually do. These difficulties are discussed later in this section.

3.6.2 Beliefs about whether children know about their parent's illness

The first question relating to parents' views of their children's understanding of mental illness was "Do your children know about your illness?" A substantial majority of respondents stated that their children did know about the parent's illness. Only one parent stated that they had not yet told their children about the illness and didn't think that their children knew about the illness. All other parents stated that they thought their child did know about the illness to varying degrees. The first question was not designed to elicit discussion, rather it was asked so the researcher could determine which further questions to ask. All participants were later asked about reasons why people may be reluctant to discuss mental illness with children. This is discussed in the next section of this chapter; Analysis and Discussion Part II: Parent perspectives on non-disclosure.

3.6.3 Beliefs about who told children about their parent's illness

All parents who stated that their children did know about their parent's illness were then asked the question "Who told your children about your illness?" From the outset of analysis it

became obvious that there were quite distinct ways that mental illness was broached with children. Each of these formed a theme. The six themes are presented in the figure below, *Figure 3*.

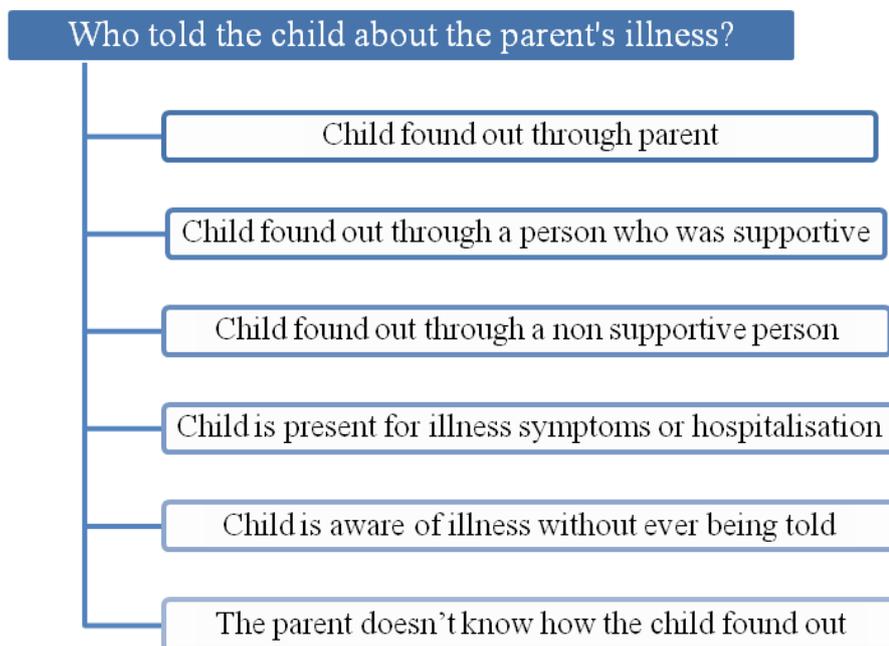


Figure 3. The range of responses parents gave for the question regarding who told their child about their parent's mental illness

When discussing mental illness disclosure with parents it became clear that the process of disclosure of mental illness is quite complex. This section addressed both the initial disclosure of mental illness as well as further explanations of mental illness. Accordingly, some parents provided responses for more than one theme within this section. This generally occurred when one person explained the illness to a child initially and then further information was provided at a later date by another person. An example of this would be when a parent was hospitalised and their child was present for the hospitalisation (coded for "the child is present for symptoms or hospitalisation") and then is told more information by their parent once they are able to do so (coded for "child found out through parent"). Each of the themes are presented below.

3.6.3.1 Child found out about mental illness through the parent.

The majority of parents had, at some stage, talked to their child about their own illness, or the illness of the other parent as relevant to their context. Only four participants stated that they had been almost exclusively responsible for disclosure and explanation of mental illness. The following are examples of responses in which the parent was responsible for explaining the illness to the child:

Extract 7

Me...yeah....well it's my sickness..

(Mother of one, with bipolar disorder)

Extract 8

..... I think I'm probably the best person (to explain the illness) but I think I've got probably more of an empathy than a lot of people might ...

(Mother of one, ex-partner has schizophrenia)

3.6.3.2 Child found out about mental illness through a supportive person (not their parent).

Six parents stated that other people had told their child about mental illness. Many parents described this as being a positive thing as the person who explained the illness was supportive of the parent, knowledgeable about the illness and often had the parent's permission to talk to the child. The supportive people who talked to the children about their parent's illness were most often from mental health services or support groups. Child-focussed mental health services and non-clinical support groups were often viewed as good resources to use to broach the topic of mental illness with children.

Extract 9

P: (describing a Child and Adolescent Mental Health worker talking to her eldest son about her quite significant and visible self harm)...it was first explained to (eldest child's name) I think by the CAMHS worker. And if I remember rightly she said that she'd told

him that it's the way that I've coped over the years.((..))...I do remember her...um...emphasising to him that it was no way related to anything to do with him so I felt comforted about that...um. Because I can tell him but he might not....I remember feeling comforted that somebody from the outside had said that to him

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Within Australia there are support groups dedicated to children who have a parent with mental illness. These are particularly prolific in the Eastern states (such as New South Wales) and in Western Australia. Most of the support groups mentioned within the interviews are affiliated with the Association of Relatives and Friends of the Mentally Ill (ARAFMI). Many ARAFMI centres have support groups for children as well as one-on-one counselling. ARAFMI was often viewed as a resource which was better equipped than parents to discuss mental illness with children.

Extract 10

I reckon ARAFMI is helping them in ways that I can't uh... which is a group where if he's going to ask those questions he'll probably ask um (support worker's name) more than what he'll ask me about it ...and from what (support worker's name) has said he's spoken to her a little bit ...so...which is good...

(Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder)

Extract 11

..... I thought getting into ARAFMI if she had questions then she could ask and they're the best ones to answer it

(Mother of two, husband has depression)

Extract 12

I: How did you first explain that it was bipolar?

P: I didn't explain it to them I let ARAFMI

I: Did you feel more comfortable with letting ARAFMI do it?

P: Yeah. I didn't have the skills.

(Mother of three, with schizophrenia)

The notion of parents not having “the skills” to discuss mental illness with children is further discussed in the next section.

ARAFMI was also seen as an ‘unbiased’ support for children:

Extract 13

...according to ARAFMI she's dealing really well with it and she's got her head together and she's....fine so as I said she probably doesn't need to go as often as she does but I just want thatthird party unbiased venting to happen....

(Step mother of one, mother of child has schizophrenia and anxiety)

3.6.3.3 Child found out about mental illness through an unsupportive person

Six parents stated that their children had been told about their illness by an unsupportive person. The unsupportive person was, in many cases, the estranged partner of the parent with mental illness. In these cases the child was told about the illness in a manner which the parent deemed to be unsupportive. This included giving the child wrong information, not enough information or, in the rare case, too much information. A child finding out about mental illness in this way was seen as a negative experience by the parents interviewed.

Extract 14

Um.....well I think the kids getting older especially (eldest) and....Like he knows that I have been in hospital a few times and because his dad was saying I was insane and all that I wanted to clarify to him that I'm not insane (laughs)

(Mother of two, with depression and post traumatic stress disorder)

Extract 15

I think at times he's (child's father) expressed his frustration to them (the three children) about my inability to cope...um I'm not sure if there's been much supportive education there

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Extract 16

I: How did you explain it to the kids?

P: Oh they weren't living with me....(ex-husband's name) explained that

I: Have you ever spoken to (ex-husband's name) about what he has said?

P: No

I: Do you trust what he's saying to them?

P: Oh....sort of....but then again some things I know would be wrong because layman's attitude is wrong

(Mother of two, with schizophrenia)

A number of parents were concerned about the information the parent with mental illness was providing the child:

Extract 17

I think that (child's mother's name) over time has done a lot of damage with the sort of things that she has been telling (child's name) and (child's name) has grown up very quickly because of it I think. And felt a lot of responsibility for looking after her mum because of it and a lot of fear for her. Like there must have been a lot of fear about what the hell's happening to mum

(Step-mother of one, mother of child has schizophrenia and anxiety)

One parent made the interesting point about children receiving unsupportive information from sources outside the home.

Extract 18

I think that's what you're got to be wary of too with these children ...how much their parents told them, how much their grandparents may have told them...may have said

something, you know what I mean. You can control their situation here (at home) but you can't control what's going on (outside of the home).....

(Mother of one, husband has schizophrenia)

3.6.3.4 Child found out by being present for illness symptoms or hospitalisation

There were a number of children who first found out about their parent's illness by being present for their parent's mental illness symptoms. Six parents talked about their children being present when the parent was experiencing symptoms of Bipolar Disorder, Obsessive Compulsive Disorder, Borderline Personality Disorder or Schizophrenia. Symptoms included compulsions, delusions, low mood, not being emotionally present and telling children about an immediate plan to commit suicide. In the extract overleaf the parent describes being hospitalised and being aggressive towards her 12 year old daughter.

Extract 19

I: And who told her, how did she find out?

P: I think it's more what she's seen..... than what she's been told...I think she's seen the brunt of it um....you know if it wasn't for (husband's name) taking care of her I don't know what would have happened.....because I couldn't be bothered

I: So what sort of stuff do you think she has seen?

P: Um...well mummy going to hospital..and being away for days on end and you know um.....Then mummy coming home then mummy gone again. And mummy always sort of yelling and screaming and smacking me.... because I'm naughty... not that she was but um....you know so...

(Mother of three, with bipolar disorder and post natal depression)

A parent who was quite symptomatic with Obsessive Compulsive Disorder described how the symptoms of her illness became a natural thing. The participant's compulsions involved the

whole family including her 10 year old daughter. Rather than discussing it, the child learnt about the illness by becoming complicit in the compulsions of washing everything and every person as they entered the house.

Extract 20

I: Did you explain to her at times when you were washing her books why you were doing it?

P: ...I think it just became a natural thing that everything got washed...You disinfected your feet before you walked on the floor and then the floor got washed and shopping got washed....It was absolutely everything....

(Mother of three, with obsessive compulsive disorder and depression)

Another parent explained how her illness was ‘obvious’ to her child:

Extract 21

P:.....it was obvious to him...((..))..like....My last suicide attempt I actually... I put them to bed and told them that I wasn't waking up in the morning andSaid goodbye to them and wrote them suicide letters andThey got quite traumatised over that

(Mother of three, with schizophrenia)

One of the participants discussed her 6 year old daughter finding out about her father's illness by becoming involved in one of his delusions. The mother discussed the incident where the father became violent while thinking he was being spied on.

Extract 22

....she thankfully had enough wits to just say "dad I'll help you find it" and so she sort of went into his delusion which was the best thing she could've done um. And eventually ... he kept hunting he tore his room to shreds um... I think he even broke his computer looking for bugs and cameras and things and then he dropped her off at the door he basically ... She ...jumped out the car and he sped off and I heard the wheels of the car

and I thought "what's that" and I come out and there's this little girl on the pavement crying

(Mother of one, ex-partner has schizophrenia)

Previous research has suggested that children would prefer to find out about their parent's mental illness from their parent, either the one with mental illness or the other parent (Fudge & Mason, 2004). Although this was true for some of the children in the present study, according to parents, the majority of children found out through avenues other than their parents. The analysis highlighted that, aside from the child finding out through the parent who participated in the study or through a supportive person, generally the child found out in a way that was unintended by the parent. Finding out through an unsupportive person, through the parent's hospitalisation or not knowing how a child found out, all occurred without the parent's planning or consent. The lack of input from the parent in each of these situations meant that generally the information children gained about their parent's illness (or aspects of their parent's illness) was inconsistent with what the parent would have liked for them to be told. As elaborated below, this experience appears to be unique to disclosure about mental illness.

Research examining disclosure of other sensitive topics to children (such as parental cancer, donor insemination and parental HIV) cites parents as the primary sources of information for children (Barnes et al., 2000; Mac Dougall et al., 2007; Murphy, 2008). There are a number of reasons why it could be the case that parents in the current study are unable to explain mental illness to their children on their terms whereas parents with cancer (for example) were able to explain their illness themselves. It could be surmised that, for the parents in the current study who identified as having mental illness, the episodic nature of mental illness means that while parents are well, they don't feel the need for their children to know about their illness, however when hospitalisation occurs, there is then a need for their child to have an

explanation. When parents are hospitalised or symptomatic they may find it harder to explain their illness to their children. For example, they may be medicated and they may be physically dislocated from their children.

Given the high rate of marital conflict and divorce in people with mental illness (Downey & Coyne, 1990; Miller & Finnerty, 1996; Mowbray, Oyserman & Ross, 1995a) it could be assumed that a number of parents with mental illness are in single parent families.

Interestingly, within the current sample, just under half of the families were two parent families. For the remaining families, headed by single parents (either with or without mental illness), there may not be another parent within the home at the time parents are hospitalised or are acutely symptomatic. This could lead to the child being told about the illness by someone outside of the family, by an estranged parent or not being told anything at all.

From the perspective of the parent without mental illness, these parents may not have custody of their children at the time of diagnosis or at the time when there are prominent symptoms or hospitalisation. This could lead to the child being told by someone outside of the family, told by the parent with mental illness themselves or not being told anything at all at the time.

Children finding out about a parent's mental illness through avenues other than their parent has clinical implications. It is important that others know what information the parents would like provided to children. If parents are well enough at onset of illness then this may be a good time to discuss the provision of information to children. If they are unwilling or unable to provide information to their children at this time then an appropriate avenue may be the establishment of a care plan. Care plans are discussed later in this section.

3.6.3.5 Child is aware of illness without ever being told

Four parents talked about their children having an ‘awareness’ of the mental illness, where the parent is not entirely certain of the extent of the child’s knowledge. This awareness appeared to develop over time often after being present for symptoms of the parent’s illness or present for doctor appointments or hospitalisation. A child’s awareness of illness was not discussed with the child, rather the parents generally assumed the child was aware. Many parents appeared to view awareness as sufficient knowledge of the illness, not seeing the need for any further information to be provided to the child. The extracts below highlight a few of the ways in which awareness was talked about within the interviews.

One parent whose partner had Post Traumatic stress disorder, borderline personality disorder and alcoholism discussed how he thought that his children only knew about their mother’s alcoholism and not the other illnesses. He states that his children have ‘seen’ their mother get drunk and that’s how they know about it. Further into the discussion however, the participant talks about his eldest child seeing his mother’s scars and therefore knowing that she cuts herself. The father stated that he had not spoken to his children about their mother self harming, instead his eldest son is ‘just aware of it’. The father’s reference to ‘nemos’ (sic) refers to the popular teenage sub-culture of ‘Emos’. A person who is ‘Emo’ is stereotyped as being, among other things, highly emotional, sensitive and prone to self harm.

Extract 23

..... the only thing they understand and that they’ve seen would be that she’d get drunk um and.....do silly things...that’s as far as my understanding of theirunderstanding of it...Why does she do it.....they don’t completely...I don’t think they’re really old enough to understand....Although the boys are talking about um....what is it...’nemos’ and um.....so they’ve come in...and (eldest child’s name) said the other day...um...to her (children’s mother)...that you’re um...What are the...one’s nemo and one’s.....(eldest child’s name) will tell you all about it he’s right up on that and he said to her that she was uh basically...self harming and (children’s mother said) “oh I don’t do that anymore”

and she got really upset at him because like he knows of people that do that....Um simply cause they do that not because they're intoxicated or anything like that....The amount of scars and trips to the hospital that she's had ...its sort of...you can't hide...that to that point. So he knows that she self harms...not that I think he accepts it but he's just aware of it... ..

(Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder)

One mother discussed the 'awareness' her younger two children have developed about her illness over the last few years. Her eldest child had received information about her illness but due to the timing of her illness onset, the younger two children were deemed too young to be told about the illness. Instead of being explicitly told about their mother's illness the two younger children were thought to have gradually developed an awareness of the illness as they have grown older. This was a common theme among the families with more than one child and will be described in more detail further on in this thesis.

Extract 24

I: Do you remember when you told the younger two?

P: Um.....I can't remember a time...no....um.....I think it's probably been an awareness they've had because that first time (youngest child's name) was one and (middle child's name) was 3 so that's...It's just been something they've grown up with....an awareness that their mum has a conditionyeah....

(Mother of three, with borderline personality disorder and schizoaffective disorder)

The following extract highlights how awareness can develop by children being present for psychiatrist appointments. In this case it appears as though the parent realises within the interview that her child may have been able to gain an awareness of her illness, something she had perhaps not thought of previously.

Extract 25

I: Do you explain going to see your psychiatrist at all?

P: Uh.....no I don't cause she's at school.....Oh actually ((sounds surprised)) she comes to the doctors with me. 'Cause a couple of times she's been sick and she's had to come along. And "where you going mum", "to the doctors", "oh ok" and Doctor (doctor's name) says "oh here's some colouring in pencils...do you want a lolly....do you want a biscuit" he makes it fun for her..(laughs)....she knows she gets a lolly or a biscuit see

I: Does she come into the room when you see him?

P: Yeah....yeah.....so

I: Do you talk about symptoms and stuff?

P: Yeah...

I: Is she just off doing her colouring?

P: Yeah.....so really she's sort of.....she's sort of aware what's going on.....we don't hide it completely from her....

I: So she's probably picked up little bits and pieces?

P: Yeah

I: Does she ever ask questions?

P: No she never asks questions...she is a curious little thing but she never really asks any questions

(Mother of two, with schizophrenia)

Later in the same interview the mother states how her daughter would have picked up on her illness by knowing that her mother was being admitted to hospital a number of times.

Extract 26

....I 'spose she would have picked up on it anyway with me going into (hospital) and all that.....

(Mother of two, with schizophrenia)

Parents within the current study often viewed awareness as sufficient knowledge; they did not see the need for further discussion or explanation of the illness to the child. Clearly a child's level of awareness of their parent's illness could depend on the age of the child and the aspects of the illness that they saw or heard about. Learning about a parent's illness in this way leaves the illness open to interpretation by children. When parents do not provide children with an explanation, children make sense of the situation by constructing their own theory which can be quite different to the reality (Absler, 1999; Rushforth, 1999).

This phenomenon is not unique to mental illness. Much of the early literature (generally pre 1990) regarding children's understanding of illness suggested that children of certain ages are unable to understand all concepts of illness and thus should not be told about illness (Rushforth, 1999). Critics of this approach suggest that regardless of whether children are given minimal information, or no information at all, a child will still attempt to make sense of what is occurring around them (Rushforth, 1999). Allowing a child to make sense of mental illness through awareness without parental input could lead to confusion. Confusion is often reported by children of parents with mental illness who also report that no one spoke to them about their parent's illness (Cooklin, 2006, Devlin & O'Brien, 1999, Stallard et al 2004).

3.6.3.6 The parent doesn't know how the child found out

There were four participants who stated that they didn't know how their children initially found out about their illness. In all cases this was due to the parent being too symptomatic

initially to talk to their children about what was happening. Each parent was hospitalised and their children were cared for by the other non-ill parent, grandparents or placed in State care. These parents assumed that the illness was explained to the children by the person caring for the children at the time however this was never verified by the parent or carer. In each case the parent was unsure of who explained it and also what was said.

Extract 27

I'm not too sure what grandparents told them...um.....what their father's told them.....

(Mother of two, with schizoaffective disorder)

Extract 28

P:that would have been the first time that they had an experience of me being in hospital...and so....That time it would've...I was extremely unwell and spent some...um.....I'm not sure who would've brought it to their attention then but I ended up being um.....They ended up being with FAYS (Family and Youth Services)So that would have been how they found out

I: So you were in hospital and they were in foster care?

P: They were in foster care

I: So at that stage someone would have told them that you were in hospital but you're not sure who?

P: Yes....I'm not sure how it happened....it was very, very traumatic for them

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Extract 29

I: Do you remember how you going into hospital was explained to her at the time?

P:yeah.....um.....I don't know...I can't remember...I can't remember a lot with her.....

I: Did someone else tell her?

P: Yeah I think so...I think so.....cause I can't.....When she was little I've got not a lot of things I can remember and I can remember more with these two (indicating the two younger children) than I can with her...So I just yeah....I would assume that you know (husband's name) or mum or dad sort of said "oh you know mum went to hospital"...
(Mother of three, with bipolar disorder and post natal depression)

3.6.4 How parents talked to children about parental mental illness

After discussing who had told their child about the illness, participants were asked about what was said to the child. Often initial discussions about the illness had occurred with children a number of years previously. Understandably not all parents could remember the exact words they had used to explain their illness to their children and parents instead described the approach they had used to explaining the illness. Parents also explained what they thought they may have said. There were three main approaches parents used to explain illness. These were *–being honest*”, using the *–mental illness is like physical illness analogy*” and *–putting a positive spin on the illness*”. Additionally, some parents explained the physical setting in which they discussed mental illness with their children. The concept of *–sitting children down*” was often contrasted with the concept of *–telling children while doing something else*”. Descriptions of what parents may have said, approaches they used and how parents physically discussed mental illness are all outlined below.

3.6.4.1 Extracts detailing the words parents used to tell their children

Below are a number of extracts in which parents discussed what they actually told their children about mental illness. The majority of parents talked about mental illness in terms of ambiguous words such as *–tired*” and *–sick*”. These extracts are presented below.

Extract 30

“sometimes mummy gets very cross, sometimes mummy gets very tired” that kind of thing...((...))...Not in terms of “mummy wanted to kill herself” no....no...it was “I got sick...medication sick”

(Mother of one, with bipolar disorder)

Extract 31

.....um I'd most probably started to talk to them about it now in the sense when you know "daddy naughty" you know when he yells or something..... ((...))... You know I've said "daddy's not well, daddy's a bit sick" you know um.... You know I try and say things like that, that "daddy is sick" and make them aware of it like that so that they don't feel that it's their fault, that they've done something wrong, that he's not talking to them
(Mother of five, husband has depression, anxiety, obsessive compulsive disorder and borderline personality disorder)

Extract 32

P: No I just said that "(husband's name) was sick"...and they were very good and they worked out (husband's name) was sick...so....
I: And did you go into further detail about his illness as they got older?
P: Nup... "(husband's name) is sick" that's it (laughs).....
(Mother of two, husband has bipolar disorder)

Some parents added further detail and stated that the parent was ~~–sad~~".

Extract 33

Um.....it was only probably about a year or two ago and he sort of said "mum why do you sleep so much" and I said "well mummy gets really sad.....you know mummy gets really tired and its all I can do is to sleep...you know". And sort of having to explain to him that you know "doctors put mummy on medicine that also made her sleepy"
(Mother of one, with depression and borderline personality disorder)

Mental illness specific words were less frequently used. These included words such as ~~–mental illness~~" or actually labelling the illness, using terms such as ~~–depression~~". Often these were used along with non specific descriptors such as ~~–tired~~" and ~~–sick~~".

Extract 34

We say that her mum's sick, that she's not very well and that she doesn't mean what she says, because it's a mental thing. It's a situation where she's mentally ill, she's not well, that's all we say, she's sick

(Step mother of one, mother of child has schizophrenia and anxiety)

Extract 35

.....well to start off with we used to just call it depression, that "Dad... was depressed" um.... 'cause he had numerous hospitalisations.....And with his ADHD as well, we called that attention deficit disorder and um... explained that "this behaviour is because of this". So that the boys actually had a very good understanding of, for their age of mental health problems and what it relates to and how it affected his behaviour towards other people and towards them um...yeah

(Mother of two, ex-partner has antisocial personality disorder)

Extract 36

I used to say that it was from my headaches and from being sad but it's nothing to do with them. And then um recently in the last year I've just said "oh it's from depression, something called depression.. and that's when um.... People....people feel sad". And they know I have gone to the doctors at (clinic name) and I just said they're the um....um...mental health doctors or depression doctors.

(Mother of two, with depression and post traumatic stress disorder)

Parents very rarely explained self harm or suicidal behaviour with children. Exceptions to this can be seen in the extracts below. This concept will be further discussed in the non-disclosure section.

Extract 37

I: And how did you explain it to her?

P:at first ...it was "mummy's in hospital and she's sick"

I: How old was she at this time?

P: Um...9...yeah..."mummy's sick and she's in hospital" ...but throughout the time I've explained to her more, so "you know how mummy was sick and in hospital?" "yeah" "well it was because mummy's way of thinking..... 'cause mummy was so sad inside and she didn't want to live any more..."

(Mother of three, with depression)

Extract 38

..... when he actually took his first overdose..... I said to them "dad's in hospital because he took too many of his tablets but he's gonna be fine blah blah blah"They actually both, at separate times during that same day. came up and asked me if he took them on purpose and I said "yes he did"

(Mother of two, ex-partner has antisocial personality disorder)

Those parents who did disclose provided an interesting insight into the ways in which the telling of mental illness is done. Frequently parents used non-specific words to describe their illness, such as *'sick'* and *'ill'*. Rarely was the diagnosis itself ever mentioned to children, with approximately 15% of participants talking about specific diagnoses with their children. This finding was consistent with the research Barnes and colleagues (2000) conducted into parental disclosure of cancer. Their study found that when parents talked to their children about the parent's illness they did not necessarily say the word *'cancer'*. Barnes and colleagues (2000) found that one of the most common reasons parents withheld the diagnosis from their children was due to a fear of the child asking questions about death. Parents within this study were not asked about why they didn't use mental illness specific words or mention the diagnosis, nor did they provide this information. It could be hypothesised that the difficulties parents cited when asked about difficulties disclosing mental illness in general could also account for difficulties with using mental illness specific terms with children. These difficulties are discussed later in this chapter.

Parents in the current study stated that the process of explaining mental illness depended on the illness in question. Some of the parents identified as having more than one mental illness. For example, all those parents who identified as having Borderline Personality Disorder also had other mental illnesses such as depression. Parents indicated that discussion with children about depression was easier than explaining a personality disorder such as borderline personality disorder. Borderline personality disorder was the most common personality disorder within the current sample, experienced by five of the participants. Borderline personality disorder is characterised by difficulty with interpersonal relationships, suicidal or self harm behaviour and an unstable sense of self, among other things (American Psychiatric Association, 1994). The stigma associated with Borderline Personality Disorder in particular has been widely documented; clinicians themselves have been found to hold negative views about people with Borderline Personality Disorder, more so than any other mental illness (Aviram, Brodsky & Stanley, 2006). Parents with personality disorders are likely to be aware of this stigma and could perhaps also hold self-stigma, an internalisation of public stigma which can result in diminished self-esteem (Corrigan & Watson, 2002; Savvidou et al, 2003).

Suicidal behaviour and/or self harm is a common symptom of Borderline Personality disorder (American Psychiatric Association, 1994). The majority of parents with Borderline Personality Disorder in the current study (as well as over half of the participants in the whole sample) had either self harmed or had attempted suicide at some stage, however only two parents had discussed this with their children. The scant research that exists on talking to children about parental suicide suggests that often children are not told about the suicide, even if they have witnessed the suicide themselves (Cain, 2002). Parental death by suicide has been linked to a range of negative outcomes for children and adolescents such as drug use, suicidal behaviour and poor family relationships (Cerel & Roberts, 2005). Interestingly Cerel and Roberts (2005) found that negative outcomes were experienced by children and adolescents of

parents who had attempted suicide as well as those whose parents had died as a result of suicide. Limited or non-existent communication with children about parental suicide behaviour is common and has been highlighted as a contributing factor to negative outcomes in children (Hung & Rabin, 2009).

There are a number of reasons provided within other research about why children were not told about parental suicide; parents were dealing with their own emotions, children were resistant to hearing about it or the child was too young at the time (Cain, 2002). There can also be fear of children viewing suicide as a way to solve their own problems (Hung & Rabin, 2009). A small number of parents within the current study stated that they feared their children learning how to self harm and that this was the reason they withheld information about self harming. The heightened stigma around personality disorders, in addition to the fact that self harm can be a main symptom in borderline personality disorder, understandably make this topic especially difficult to broach with children.

From a clinical perspective, parents may need illness-specific help with explaining their illness to their children. Clinicians need to understand that parents may hold self stigma which could add another layer of difficulty to explaining their illness. Although the one example given about a mental health worker advising against disclosing could be an isolated occurrence, clinician's do need to remain mindful about the stigma they may hold against a client and the implications this could have for helping a client explain their illness to their children.

3.6.4.2 Approaches to explaining mental illness

Of the parents who described how they explained mental illness to their children, each of them endorsed one of three main approaches as shown in *Figure 4*.

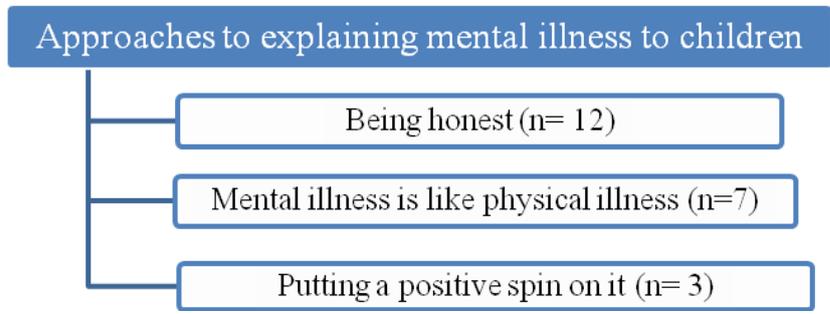


Figure 4. The three main approaches to explaining mental illness to children.

3.6.4.2.1 ‘Being honest’

One of the most common approaches parents had for explaining mental illness was ~~being~~ “being honest”. Twelve parents stated that they had been ~~open~~”, ~~honest~~”, ~~frank~~” or had a desire to ~~normalise~~” mental illness. There were a number of reasons as to why they were honest with their children. These were provided spontaneously by parents.

Parents stated that they had not wanted to ~~hide~~” aspects of their life or keep things a ~~secret~~” from their children.

Extract 39
..... I just didn’t want to leave that part of my life...um... a secret to them. And when they grow up and look back and think “oh yeah mum you used to always go to that place (mental health clinic)...what happened then?... (laughs)
 (Mother of two, with depression and post traumatic stress disorder)

A few parents stated that they were open with their children about other aspects of life, such as sex, and that openly discussing mental illness was no different. These parents talked about being open’ and honest’ as being an integral part of them.

Extract 40

... I've always beenyou discuss what's going on when it's happening even with sexual awareness you know. I've always been very open about it to the point where its.....Maybe a lot of people think that's not the right way to handle things like with (youngest son, 3) I'll say it's your penis you know um....And like growing up like with (oldest son) he's now 20 but when he was 5 or 6 he came in and said "what's a condom?" And my ex husband had actually had one given to him as a joke for a 30th birthday present, so I went and got it and I said "this is what it is", and showed them and let them feel it, and said "this is what you do with it". You know just as a fun...not as a fun thing but just to say you know "that's what it is" you know. And they just went "oh ok mum" and walked out so I've never been....And you know I know people who would cringe at that and go "oh my God how could you do that?" but I never made a big thing of it...((...))...I know another family the husband is a manic depressant and bipolar and stuff and I don't think their children know and they're the same age as (daughter) so... But I think anything that affects people in the family should be told about it you know...

(Mother of five, husband has depression, anxiety, obsessive compulsive disorder and borderline personality disorder)

Extract 41

Very matter of fact and we're very open....uh....I think with many aspects in our life...They had family education at school in year 3 (Sex education) and anything to do with health um.....awareness of your own self...has been a very normal...No fuss..just to normalise everything

(Mother of one, with bipolar disorder)

Extract 42

I felt they needed to know about it right from the start...I don't see how you can hide something like that.....Because (ex-partner's name) behaviour was so volatile and so...bizarre... I mean there was no way I could hide it from them. They were living it ...

(Mother of two, ex-partner has antisocial personality disorder)

A couple of parents discussed the importance of being honest with children so that they understood and recognised the ‘warning signs’ both in their parents and possibly within themselves.

Extract 43

...and I think children if they have a better understanding of it...they know the warning signs, they know what their parents went through, and then they have that choice to stop going down that track ...((...))...

(Mother of four, with depression)

Extract 44

... I think children definitely need to know. And children are very smart they've got um...a little safety switch in them that tells 'em something's not right here. And for them to know who to call or what to do..... is important especially if they're living with that parent. Because it can be frightening and intimidating for a child to have their superior 'cause that's what a parent is.... And... if they turn scary on them what do you do? I mean I don't even... wouldn't even know what to do if someone that was in charge of me.... suddenly went scary around me. It's a frightening thing and they almost need an action plan and really to be spelt out and practised and for them to have some sort of safe place and know what's going to happen

(Mother of one, ex-partner has schizophrenia)

A number of parents stated that they were honest with their children as they didn't want children wondering about what was wrong with the parent.

Extract 45

....you don't sort of sit there and let kids wonder. Otherwise....yeah they sort of tend to feel guilty...

(Mother of one, with depression and borderline personality disorder)

Extract 46

.....I think it is important to speak about it.....um.....((...))... I'd hate to think that maybe he was going to bed at night thinking "what's happened with mum?"...or "why did she go to that hospital?". And wondering..... ((...))...It would be dreadful to lie in bed at night just thinking snippets of something you've heard. And that's probably my greatest concern in my family situation...I'd just like there to be an understanding of "ok this is where we're at and this is what we're going to do"...

(Mother of one, with bipolar disorder)

Of those participants who stated that *'being honest'* was their approach to talking to children about mental illness, the majority had withheld information from their children about some aspect of mental illness. Although there were a number of parents who had not told their children about their illness or aspects of the illness only one parent stated explicitly that it was acceptable for a child not to ever know about a parent's mental illness.

Extract 47

...No...I think it's up to the parent...um.....I think that you know if you don't want to talk about it then that's fine you know

(Mother of three, with bipolar disorder and post natal depression)

'Being honest' was used interchangeably by parents as both an approach to explaining mental illness and as a reason why illness should be explained. Parents did not provide much detail about how *'being honest'* works as an approach. It could be assumed that *'being honest'* involves openly discussing the illness among the family, discussing all facets of the illness. Although almost a third of parents ascribed to this approach to explaining mental illness there were only two parents within the current study who did openly discuss all facets of mental illness with the whole family.

3.6.4.2.2 Mental illness is like physical illness analogy

Seven parents described likening mental illness to physical illness when explaining it to their children. Parents likened mental illness to a cold, to other physical ailments they had and to a “germ”.

One mother used her child’s knowledge of her physical ailments as a way to explain mental illness.

Extract 48

P: Well she knows ...I mean because I’ve had quite a few medical issues, (child’s name) has seen a lot of sickness, and you know, I’ve got the tummy doctor, I’ve got the throat doctor, and I’ve got...well she coined the phrase... “the head doctor”which is great (laughs)

I: And how did you explain the head doctor to (child’s name)?

P: Yeah, that he helps me keep You know....my head working properly (Mother of one, with bipolar disorder)

Similarly, one mother explained her husband’s mental illness as being like her own recent experience of cancer. The mother had a brain tumour removed around the time when her husband was diagnosed with schizophrenia.

Extract 49

...I just sort of said to her “Daddy’s..... got what’s called mental illness” and I said “ that means that part of him is sick, part of him doesn’t work properly. And you know how parts of mummy doesn’t work properly and she gets headaches, part of daddy doesn’t work”. And um she said “what part of daddy doesn’t work?” ... ((..)).....and I said to her “you know how when someone looks at you for too long and you think ‘oh that persons looking at me funny, I wonder if they don’t like me, I wonder if they’ve heard something about me’. Normal people just think ‘Oh no I haven’t done anything’ and they just forget

about it. Dad doesn't know how to do that, the button in his head that tells him to stop thinking bad thoughts is broken so he keeps thinking the bad things"

(Mother of one, ex-partner with schizophrenia)

A number of parents likened the mental illness to a cold, broken bone or some other common general illness.

Extract 50

....I've always spoken to her about ...when she was little it was like a broken arm or a cold...um and drawn the analogy...

(Father of one, ex-partner has schizoaffective disorder)

Extract 51

....it's not different to having a cold really

(Mother of three, with obsessive compulsive disorder and depression)

One parent discussed how she explained that taking medication for a mental illness was the same as taking medication for common illnesses.

Extract 52

Um...I explain it as um...you know the usual terms in that if somebody has a health condition and medication can help them to lead a better life then that's.....so they know that I take it so that I can function as optimally...

(Mother of three, with borderline personality disorder and schizoaffective disorder)

One parent described mental illness as a germ likening it to another germ, cancer.

Extract 53

..... I discussed there beinga germ which (child's name) knows that a germ is in my head...And we thought first the germ was called depression and we now know the germ is...He knows the name bipolar or manic depression and....(()) ...um...But he knows there

is a germ and he knows (friend's name) had a germ called cancer...so.....So we know about the germ...that I had a germ in my head.....I still do but its under control
(Mother of one, with bipolar disorder)

One parent stated that, for her, the mental illness is like physical illness analogy⁶ was not a helpful way of explaining her husband's mental illness. She stated that she thought she would have trouble explaining the illness to her young children in the future and commented,

Extract 54

... you know it's not something you can see like a broken leg or something

(Mother of five, husband has depression, anxiety, obsessive compulsive disorder and borderline personality disorder)

For the majority of parents who used this approach, physical illness appeared to work as a useful entry point into discussion about mental illness. It is worth noting however that there are distinct differences between mental illness and physical illness. Mental illness is nebulous, often stigmatised and is frequently surrounded by secrecy. As the participant cited in the extract overleaf stated, mental illness is not *"like a broken leg"*. Although a child's knowledge of physical illness is a good starting point for discussion about mental illness, it would be worth remembering the points of difference when explaining mental illness.

3.6.4.2.3 Putting a positive spin on it

Another, less common, approach to explaining mental illness to children was to put a positive spin⁶ on the illness. The belief that living with mental illness could be a positive thing for children was raised by three parents. In the following extract a mother describes how she talks to her children about an acute crisis intervention service coming to her house and how this is couched as a positive thing⁶.

Extract 55

Um....I just say I'm not coping and I need support and so just try to put it in a positive light in that they don't feel that they're in any way responsible for my well being, there's people there to do that um.....(..).....You know it's not a negative thing it's a positive thing...

(Mother of three, with borderline personality disorder and schizoaffective disorder)

One parent described how the experience of mental illness has made their lives ~~“better”~~.

Extract 56

Um.....I've talked to them in the context that it's really important to talk about your feelings and um...not to let things get on top of you....there's nothing that's too hard that you can't talk about it and I will understand and we'll work a way around whatever issue it is ...(..).....we've put it in a different language but I think I've used the experience to better their lives now...I think they're far more well equipped than (eldest child's name) ever was

(Mother of three, with obsessive compulsive disorder and depression)

One parent described how although she didn't believe it herself, she was positive about the illness for her child's sake:

Extract 57

.....because I'm very conscious of not saying anything negative about her mother and very conscious about saying that it is an illness and mum's sick and she will get better one day. Because I like to think that myself I really do ..I doubt it but I like to think that myself and maybe I'm saying the wrong thing to her I don't know

(Step mother of one, mother of child has schizophrenia and anxiety)

3.6.4.2.4 Physical setting for discussing mental illness with children

Although they weren't asked specifically where and how the conversation with their children took place, seven parents described how they physically explained mental illness. Very few parents stated that they sat their child down and specifically told them about the illness. Parents described telling their child while doing something else, such as playing a board game. Parents also described talking to their children frequently when the opportunity arose rather than discussing it once as a planned event.

Extract 58

..... I've never really specifically sat them down and told thembut like during play or um....playing a board game or something I said "you know when mum used to cry and do this and do that"

(Mother of two, with depression and post traumatic stress disorder)

Extract 59

Um....I've explained little bits um....you know....sort of things come up. Like he came home from school and they had, you know, pay a dollar to um...dress crazy day.....And I sort of sat down and I said you know "that's sometimes not a very nice word" sort of explained why.....(..).... (talking about child seeing other patients in a psychiatric hospital)....You know he'll see patients acting in strange ways....you know.....and I'll use that as a sort of a means to explain to him as well....um..

(Mother of one, with depression and borderline personality disorder)

Extract 60

It doesn't have to be holding hands at the dinner table and a Kleenex tissue box...it can just be quite...you know in the car driving to the supermarket... "I'm having a bit of a bad time.."...you know ...

(Mother of one, with bipolar disorder)

Extract 61

....and I suppose with mental illness you don't want to make a big thing of it as in like "oh we've got to go and sit down and discuss this"....it should just be something casual... that you discuss..

(Mother of five, husband has depression, anxiety, obsessive compulsive disorder and borderline personality disorder)

A number of parents described how talking to their children about mental illness has been a continuous conversation.

Extract 62

I really just talked to them about it.. it was always just part of our life...

(Mother of two, ex-partner has antisocial personality disorder)

Extract 63

Yeah... we often talk about it ...((...))....She'll tell me when she's got a question and she's very good...you'll work that out in a second... And she's very good at um...articulating herself and saying "what happens when this happens"...or um....wanting me to take that next step with her...And if I don't know the answers we'll go and search the net or find a book or something to find the answers and...give her some sort of satisfaction orempowerment by knowing

(Mother of one, ex-partner has schizophrenia)

Participants often contrasted this ongoing and incidental approach to talking to children about mental illness with the idea of sitting children down formally to tell them. This finding gives a rare insight into how the physical process of explaining mental illness is done in some families. No previous research, to the authors knowledge, has examined the practical detail of explaining mental illness.

In clinical terms, this finding could be useful for parents who struggle with initiating a conversation with their children about mental illness. Sitting a child down and telling them about mental illness could be seen as daunting by some parents. A more casual approach, such as discussing mental illness while playing a game or talking with the child in the car, could make instigating a discussion with children less overwhelming. Surprisingly, there is little research which examines how the telling of sensitive topics to children occurs. In one of

the few studies to do so, Lycett and colleagues (2005) found merit for a casual approach to disclosing sensitive topics to children. In the study conducted by Lycett and colleagues (2005) examining the disclosure of donor insemination to children, a third of the participants who disclosed did so as a “spontaneous conversation” (p.816) and parents found this to be a positive experience. Only five accounts of the method of disclosure were sought within the study of donor insemination disclosure. Other participants within the Lycett and colleagues study disclosed as a planned event, helped by the use of literary aids.

While parents may find it easier to disclose mental illness to their children in a casual way, whilst doing something else, there are risks inherent in this strategy which should be taken into consideration. For example, a child may not be paying attention to what is said and instead be focussed on the task at hand. They may miss important details about the illness and the ramifications of the illness. Viewing disclosure as a process could ameliorate some of the risks associated with a once-off casual disclosure.

Parents within the current study discussed the need for a continuous conversation about mental illness, rather than it being a one-off event. This finding supports previous research which has suggested that children’s age should be taken into account when explaining mental illness (Falkov, 2004; Maybery et al, 2005; Reupert & Maybery, 2007a). Although the need for a continuous conversation was only raised by a few participants, it is an important point. There are three main reasons why the idea of disclosure being a continuous process is worth supporting. Firstly, children may initially be told about mental illness when they are quite young. At this stage, their age may be taken into consideration and an age appropriate explanation given. Simple words may be used and the symptoms and ramifications may not be fully described. The concept of age-appropriate information certainly is not limited to disclosure of mental illness. The importance of age when providing information to children

has been cited by studies examining children's understanding of their own cancer (Chesler, Paris & Barbarin, 1986), parental HIV (Murphy, 2008) and children's understanding of parental cancer (Thastum, Johansen, Gubba, Olesen & Romer, 2008), to name just a few.

Research suggests that younger children do not understand the concept of heritability (Solomon, Johnson, Zaitchik & Carey, 1996). An understanding of heritability develops as children get older, thus information pertaining to the heritability of mental illness would be most useful if it was increased over time. Hay (2004) asserts that older COPMI require information about heritability. A continuous conversation about parental mental illness would allow for the inclusion of information about heritability as a child gets older.

A second reason why the continuous provision of information about mental illness may be most useful for COPMI is due to the possible initial reactions experienced when first told about parental mental illness. When children are told about parental diagnoses of other illnesses, such as cancer, they can have initial reactions of shock and disbelief (Forrest et al., 2006). Although little research has been conducted on children's reactions to illness diagnosis, the literature examining parent reactions to both their own and their children's diagnosis suggests that initial shock leads to an inability to understand what is told to them by doctors and an inability to retain the information they do understand (Kodish et al., 2004; Mack & Grier, 2004). Research examining children's reactions to parental HIV suggests that many children did not experience shock from their parent's disclosure of HIV, instead they already had guessed that their parent was sick (Murphy, 2008). It could be surmised that although some COPMI may already know something about their parent's illness, other COPMI may experience shock in relation to an initial disclosure about a parent's illness and that this shock may limit the amount of information they are able to understand and retain. A continuous conversation would ensure that COPMI are provided with further information, or

presented again with the same information at a later point when they may be better able to assimilate the information.

Similarly, being presented with information again at a later point may also provide COPMI with space in which to think about what they have learned and formulate possible questions about the illness and the ramifications of the illness. Children have been found to feel pressure from parents to ask their parents questions about HIV following disclosure (DeMatteo et al., 2002). Children of parents with HIV reported not wanting to ask questions immediately, instead they wanted to think and reflect on what had been disclosed to them (DeMatteo et al., 2002, p. 350).

A concept developed within the donor insemination literature, which is worth considering here, is that of seed planting (Mac Dougall, Becker, Scheib & Nachtigall, 2007). In a unique study Mac Dougall and colleagues examined the strategies used by parents to disclose the use of donors in their conception. One key strategy used by parents within this study was that of talking to children on an ad hoc basis in the course of daily life (Mac Dougall et al., 2007, p. 4). The authors termed this seed planting (p.4). The belief held by parents was that their children would have always known (p. 4) about their conception background and that this would ameliorate any need to have a sit down (p. 4) discussion.

A third reason why a continuous conversation about mental illness is useful is that it also ensures that all children within the same family are similarly informed about a parent's illness. A few parents within the current study made the point that when there is more than one child in the family some children may miss out on being told about the illness. If the disclosure of mental illness is a one off event at least one child within a sibling group may be too young to understand the full extent of what is being discussed. One parent within the

current study explained how explanation of hospitalisation at the time of the first hospitalisation was not sufficient for subsequent hospitalisations. In this particular case, the parent thought that she had explained her hospitalisation to all her children. She had explained the first hospitalisation and had not explained hospitalisation after that point, believing that all her children knew. What one child may understand at the first hospitalisation may be quite different to what they are capable of understanding in a few years time. Each of these factors once again supports previous research which recommended that disclosure should be seen as a process, a continuous and frequent conversation, rather than a one off event (Cain, 2002).

In summary, there is support for the idea that the disclosure of mental illness to children could best be achieved through a continuous conversation about mental illness. The majority of parents within this current study did not use this method as a way to disclose, instead disclosing as a one-off event. Parents may need information about the benefits about talking with their children in this way and may need help from health professionals with establishing and maintaining a continuous conversation with their children.

3.7 Analysis and Discussion Part II: Parent perspectives on non-disclosure

Although only one parent stated that they had not told their children about mental illness in the family, the majority of parents had withheld information about significant aspects of the illness. Parents were asked whether they had difficulty telling their own children and if they could think of reasons as to why other parents may not tell their children. There were a range of reasons given for not telling children about mental illness or about aspects of the illness (such as certain symptoms, hospitalisation or other treatment).

As the figure overleaf (*Figure 5*) shows, reasons for not disclosing fitted into one of two broad categories; reluctance to tell due to child and reluctance to tell due to parent. Within

each of these categories were a number of themes. Each of these will be discussed within the remainder of this chapter. Resources that parents believe were useful, or would be useful to help with disclosure are also discussed.

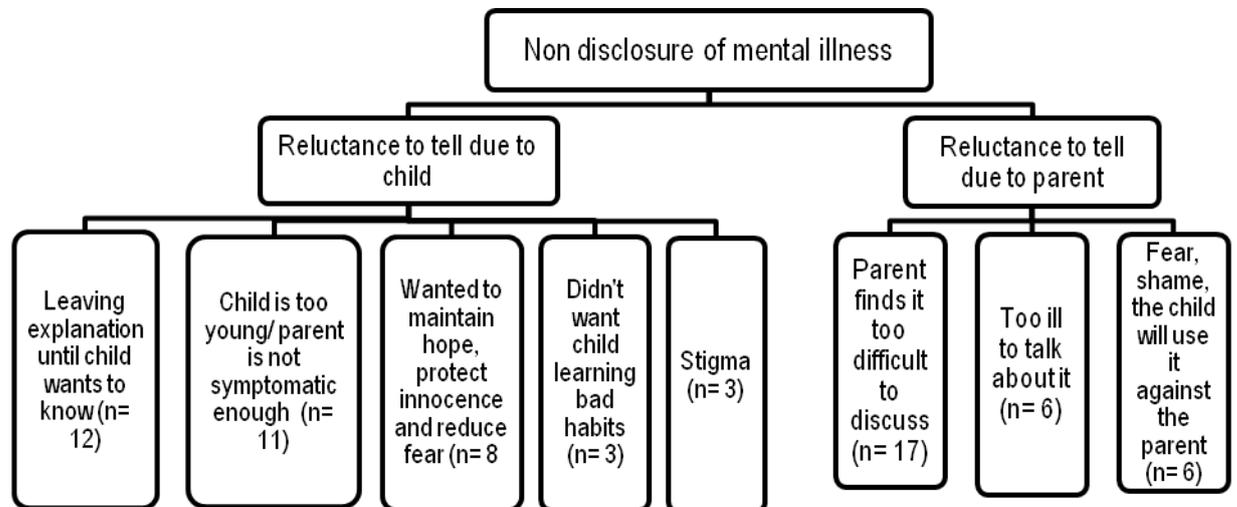


Figure 5. The themes developed from parents' responses when discussing the difficulty with disclosing mental illness

3.7.1 Reluctance to tell due to child

Parents who had not told their children about their illness or aspects of their illness most commonly cited factors to do with their children as reasons why they had not disclosed. There were a number of child-focussed factors endorsed by parents and these are discussed below.

3.7.1.1 Child doesn't want to know, or leaving explanation until the child wants to know

The most common reason parents cited for not disclosing their illness, or aspects of their illness, to their children was that they were waiting until the child wanted to know. Twelve parents stated that their children didn't want to know about their illness and that they were waiting until they thought their children wanted to learn about it.

Parents stated that they had tried to talk to their children about their illness but that their children had openly shied away from talking about it. One parent stated that she had tried to speak to her daughter about her illness but that her daughter did not seem willing to discuss the topic. Interestingly, the parent concedes that her daughter may be wary of discussing mental illness in case the discussion ~~“hurt”~~ her mother or makes her ~~“sick again”~~. Despite the parent’s acknowledgement of the child’s fear of making her mother ~~“sick again”~~ the parent still stated she would wait for the child to approach her before discussing the illness in detail.

Extract 64

Um.....I try to.....but I don't think she wants to hear it though.... She's a little moody girl, "in and out of hospital...big deal" she goes (laughs). But I think she knows.....she remembers more than she's letting on...I think she doesn't want to hurt me when talking about it...Does that make sense? She doesn't want to ...sort of say you know "I hate you" or you know um...Just in case she hurts my feelings and just in case I get sick againSO....

(Mother of three, with bipolar disorder and post natal depression)

One parent stated that the discussion about her mental illness won't be led by her, rather it will be a discussion that the daughter will probably instigate.

Extract 65

....She knows what she wants to know and what she doesn't...and um....I don't think it will be a matter of me saying "now (child's name) I'd like to talk to you about something" I think she'll probably approach ... You know when she wants to find out something she'll approach us

(Mother of one, with bipolar disorder)

The theme of waiting for children to approach parents to discuss mental illness was common across the interviews. Parents stated that they would discuss aspects of their illness with their children however they were waiting for their children to approach them with questions first.

Extract 66

If they came and asked me.... I would tell them...enough...and I don't think they want to know so I don't want to force it on them

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

Extract 67

...they haven't asked questions about it so therefore I don't see the point of bringing it up..

(Mother of three, with bipolar disorder and post natal depression)

Extract 68

I don't want to cramp their style you know...I think um.....Well if they've got questions they'll ask me and I wouldn't stop that...I'd invite that but at the same time....I don't know the time we've got together is really precious and I don't tend to talk about myself in that time..... ((...))...I'm not too sure that they're even that interested...They might be but at the same time I figure if they want to talk about it then they will ...

(Mother of two, with schizoaffective disorder)

Extract 69

...you know I'm open but at the same time she hasn't approached me...I haven't approached her to sit her down....

(Mother of two, with schizophrenia)

Parents stated that children shied away from discussion about mental illness and that they would wait until their child approached them to discuss it. Children have also been found to avoid conversation about suicide, despite parents' best efforts at explaining it (Cain, 2002). Waiting for a child to approach a parent with questions about the illness holds a few key assumptions. Firstly it assumes that the child understands that they are allowed to ask questions. It also assumes that children are comfortable asking questions. Further, it requires children to ask questions about a topic which is not openly discussed. A lack of discussion within the family about mental illness could be viewed as a reluctance to talk about the issue as was found in the study conducted by Handley and colleagues (2001). This is not a

longitudinal study so it is unknown whether, over time, the children within this study did approach their parents and receive information about their parent's illness.

A clinical implication of this choice to wait for the child to open the topic is that children may not receive any information about their parent's illness. If parents would prefer to wait for a child to approach them then it is necessary for them to make this expectation explicit to their children. In order for children to gain information about their parent's mental illness they should be assured that asking questions within the family is encouraged and expected.

3.7.1.2 Child is too young and the parent does not think symptoms are visible

The second most common reason, cited by eleven parents, for not fully disclosing aspects of their illness was that the child was too young or that the parent had not yet been symptomatic enough to warrant an explanation. Often these two reasons were used at the same time. For example parents thought that the child was too young to know about aspects of the illness and the illness was currently being well managed or 'hidden' so there was no reason to tell the child at this time.

Parent beliefs about their child or children being too young to know about aspects of the illness are shown in the extracts below. Aspects of mental illness were seen as being an inappropriate topic to discuss with a child. It was also seen as a 'complicated' concept for younger children.

Extract 70

...I do have parts that I haven't told them because I don't think they need to know just yet.....

(Mother of three, with bipolar disorder and post natal depression)

Extract 71

'Cause it's pretty complicated for her
(Mother of one, with bipolar disorder)

Extract 72

...I think that....(youngest child's name) is definitely nowhere near old enough...um...
(Father of three, ex-partner has posttraumatic stress disorder and borderline personality disorder)

Extract 73

I: Do you have any idea when you'll tell (youngest child's name)?

P: I'll probably explain it to her.....well she's gonna be 8 this year so.....I'll try and leave it til she's 10.....I think...yeah....

I: Is that because of (eldest child's name) age when you told her?

P: Yeah....yeah she took it on board...she'd understand it and that...yeah
(Mother of two, with schizophrenia)

One parent didn't believe any of her three children needed to know about her illness at the present time. The participant went against her general practitioner's advice that she should tell her children about the illness.

Extract 74

I just don't think they need to know yet
(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

One parent stated that her children's ages were the reason why she had recently disclosed her illness to them. Their age was a reason why she had not told them previously.

Extract 75

.....Um....because the children are getting older....uh....I really wanted them to know...that I have had depression and it doesn't mean I'll have it all the time.

(Mother of two, with depression and post traumatic stress disorder)

Often a parent's illness and prominent symptoms are being well managed or 'hidden' from children. This was commonly seen as a reason why explanation wasn't needed for children at the current time.

Extract 76

Yeah that [waiting until he is an adult] would be better I reckon.....Because you see I'm staying so well at the moment...so....I don't think I could really get sick....

(Mother of one, with schizophrenia)

Extract 77

I: Have you ever explained it to him (youngest child)?

P: Not reallybecause he was so young before when I was so unstable(()).....but now that he's older I've been mentally stable so I haven't really told him.

(Mother of three, with schizophrenia)

One parent made the point that her illness may be managed well enough so that her daughter never has to find out about it.

Extract 78

Yeah... and of course ...because it's an illness that.... can be quite nicely controlled with medication... You know there's also the chance that once we've got everything under control there won't be any issues with itAnd she might not even know.... at all...

(Mother of one, with bipolar disorder)

One parent discussed not needing to tell his children about their mother self harming. He stated previously in his interview that he found it a particularly difficult topic to broach with his children. The mother's self harming appears to be hidden from the children and this is a reason why the father has not yet felt the need to explain it to the children.

Extract 79

...most of the time she does it when they were asleep and they're all pretty good sleepers...uh fortunately ...(())...um.....Yeah basically....And if she's going to self harm herself, cut herself then she'd go and hide in the bathroom or hide somewhere

(Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder)

As shown in the analysis, the topic of mental illness was seen as not appropriate or too complicated for children to understand. Often symptoms were well managed and able to be hidden from younger children. When parents were well, or could easily feign wellness, they preferred to keep their children unaware of the illness until children were older. Research has shown that intent to disclose in the future is not necessarily sufficient for disclosure to take place (Golombok et al., 2002). A follow up study of parents who had used donor insemination found that a third of parents who intended to disclose to their children had not done so by adolescence (Golombok et al., 2002).

The concept of symptoms being well managed enough not to disclose to children is worthy of further consideration. A large number of parents within the present study stated that their children found out about their illness through unsupportive people, often when a parent was hospitalised or deemed too symptomatic to talk to their children themselves. There is a tension, it seems, between being well enough, and therefore assuming there is no reason to tell children about mental illness, and being too symptomatic to be able to discuss it with children.

If a parent wishes for the child to remain unaware whilst they are well, then there is an opportunity to develop a plan, made whilst the parent is well, outlining what the parent would like to be said, who should say it and when it should be said. There are a number of templates and guides on how best to establish ‘care plans’ with parents. One example is the ‘Care Plan’ (Mason and Goad, 2000) in Australia which is available to download from the internet, available for free and is accessible worldwide. Care plans traditionally focus on aspects of care such as practical help with children, for example stating who will pick up children from school if a parent is in hospital. There is scope to develop a specific care plan to outline exactly what should be said to a child about their parent’s illness whilst their parent is in hospital.

3.7.1.3 Did not want to scare the child or reduce hope, wanted to protect innocence

Eight parents had not discussed aspects of the mental illness with their children in an effort to protect children from fear, loss of hope and loss of innocence.

One mother talked about her youngest daughter asking why she had cuts on her arms (from self harming). The mother stated that she hedges and doesn’t answer her questions in an effort to protect her daughter’s ‘childhood’.

Extract 80

Yeah hedge..(laughs)....and go “ummmmmmmmmmmmmmmmm” and try and change the subject...((...))She’s so innocent and so naive as far as things like that go. There is a part of me that wants to keep her like that because I think you are so lucky that you are going to have your childhood because I didn’t.....um and I want her to have that

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

Extract 81

I: Have you ever spoken to (child's name) about your illness?

P: Not really 'cause I don't think it...I don't think I should at the moment...because he's been through hell and back with me you know...so....

(Mother of one, with schizophrenia)

Extract 82

...well with my symptoms I hear like the voice of the devil and people telling me I'm going to burn in hell.....not nice to tell a child. So it would be....from my way of thinking protecting the child from harm or unnecessary fear

(Mother of two, with schizoaffective disorder)

Protecting children was also commonly cited by parents as a possible reason why other parents may not tell their children.

Extract 83

.....that they think that it would upset their kids more knowing than not knowing that would be the main one or that it would scare them um....cause them anxiety...

(Mother of two, ex-partner has antisocial personality disorder)

Extract 84

....just to keep everything as normal as they can for their child I s'pose...

(Mother of one, ex-partner has schizophrenia)

3.7.1.4 Did not want child picking up bad habits

Three of the parents interviewed discussed how they had not fully disclosed about mental illness to their children out of fear of their children learning maladaptive habits. Instead these parents chose to only partially disclose, leaving out certain details about the illness and symptoms. Two of the parents stated that they did not want their children learning about parental self harm and suicidal behaviour.

A parent who had noticeable scars on her arms, which her children had commented on, stated that she had found it too difficult to tell her children about the origins of the scars. She was worried that her children may not respect themselves if they were to learn of their mother's self harm.

Extract 85

....because yeahas a parent I s'pose one of my biggest wishes is that they respect themselves and self harming's the total antithesis so...

(Mother of three, with borderline personality disorder and schizoaffective disorder)

One father discussed his fear of his children mimicking their mother's suicidal behaviour.

Extract 86

I: Did the kids know about it (mother's frequent suicide attempts)?

P: No....no

I: Why haven't you told them?

P:told them about her suicide attempts?

I: Yeah

P: It sort of scares me a bit...I have to say...you don't want them to try stepping out in front of a car.....yeah

(Father of three, ex-partner has post traumatic personality disorder and borderline personality disorder)

3.7.1.5 Stigma

Stigma was mentioned by three parents who were explaining why mental illness isn't fully disclosed to children.

Extract 87

....(youngest child's name) doesn't know..... because as I said I'm a bit frightened she'll say something at school or to a motherAnd then if she goes around there and

plays....There's a bit of a stigma....People are getting better about mental health but they're still very ignorant....

(Mother of two, with schizophrenia)

Extract 88

so the child doesn't look at their parent differently or they don't um...they don't put the stigma in, so they don't.... think of their family as being different from any other families...

(Mother of one, ex-partner has schizophrenia)

Extract 89

I s'pose they're fearful of inflicting the stigma on them...they don't want their kids to feel different...

(Mother of three, with borderline personality disorder and schizoaffective disorder)

3.7.2 Reluctance to tell due to parent

The alternate reasons parents provided for not telling their children about their illness or aspects of their illness were parent-focussed reasons. In contrast to the previous section, reluctance to tell due to child, the next section discusses the three main parent-focussed reasons parents were reluctant, or unable, to tell their child about their illness.

3.7.2.1 Parent finds it too difficult

The most common parent-focussed explanation as to why parents had not fully disclosed mental illness to their children was that they found it too difficult. This was cited by 17 participants. Parents commonly stated that they didn't know how to explain mental illness to their children, it was *'too hard'* and that they needed help in doing so.

Extract 90

I: Did you ever explain it to your kids?

P: No....we're working on that because my therapist he said "(parent's name) you have to tell them. You have to tell them the things that have happened to you to make you

why you are the way you are”, I can’t do it(()).....I did eventually tell my husband...and it’s really hard....

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

One mother talked about being able to discuss certain aspects of her illness with her children but finding it too difficult to explain self harm and her personality disorder. She acknowledged that she was not opposed to her children knowing about this aspect of her illness, rather she struggled with having to explain it to them herself.

Extract 91

I: Would you rather it wasn’t spoken about?

P: Um.....I think it’s really unhelpful to keep it as....like a taboo sort of subject...um...It’s not something that I feel comfortable, would feel as comfortable sitting down and saying “look when Ibecome overwhelmed I burn my arms”. I can’t bring myself to do that.....

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Difficulty explaining a personality disorder, as opposed to illnesses such as depression, was common across the participants who had personality disorders. Interestingly in this next extract the participant had asked for guidance from her service provider in how to talk to her child about her Borderline Personality Disorder and was dissuaded from talking about it.

Extract 92

.....Because you sort of then look at personality traits and it’s just so different..... to depression. And I think because....depression’s one of the things that’s so commonly discussed now I mean we were driving past the freeway the other day and there was this big banner for Beyond Blue and it’s like “woah” you know. Everyone fucking knows about depression now because Geoff Gallop had it um...((...)). I mean I’ve never ever really seen in the media,.....you see schizophrenia... you see bipolar.....depression, but I’ve never actually seen a personality disorder depicted.....((...)) I think it’s more sort of not

knowing how to explain to him.....And you sort of say to a service provider “well how do I say....?” “oh well it’s not appropriate to discuss it”....

(Mother of one, with depression and borderline personality disorder)

One mother stated that she understood why other parents found it hard to disclose to their children their less ‘socially accepted’ illnesses.

Extract 93

*...especially illnesses that aren’t socially accepted as um...being within the range that society thinks is ok...Like depression is kind of a mild mental illness but the most...the more severe ones can leave you with quite a bad name or tag or whatever.....((.....))
....Uh if I had a more severe mental illness I’m not too sure if I would (explain it to her children)....um...or if I’d just um...let the children know in bits and pieces what it was without actually naming it ...probably....*

(Mother of two, with depression and post traumatic stress disorder)

One father had not discussed his ex-partner’s suicidal behaviour with his children. He commented that he can’t understand it himself so cannot explain it to his children.

Extract 94

.....I don’t know anyone who can really understand. I know some people who have been through the same sorts of things and didn’t go that way...So the reason why she went that way I can’t explain it.....I don’t know how to explain it...I know this is what happened and I know this is how she dealt with itit’s like why...I can’t tell you why this person didn’t do it and this one has, I can’t tell you.....So how can I explain it to them....like...yeah.....

(Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder)

A number of parents stated that discussing their illness with their child was difficult and that they had received help or needed help with discussing aspects of the illness. Resources to help with disclosure are discussed in further detail later in this chapter.

Extract 95

P: I didn't explain it to them I let ARAFMI (Association of Relatives and Friends of the Mentally Ill)

I: Did you feel more comfortable with letting ARAFMI do it?

P: Yeah. I didn't have the skills.

I: And do you have any idea when you will talk to the younger one?

P: Um....Well I'm hoping....he's next on the list for the next ARAFMI group therapy learning session. So he will go to it so he will learn.

I: Do you still find it a lot easier for someone else to do it?

P: Yeah 'cause I don't know what to say

(Mother of three, with schizophrenia)

Extract 96

Um....I definitely need help to talk to them ...it's really....it would be hard to explain it

(Father of three, ex-partner has post traumatic stress disorder and borderline personality disorder)

Some parents who had already explained aspects of mental illness to their children acknowledged that they would have preferred to have had help explaining it.

Extract 97

I: Has anyone ever helped you explain your illness?

P: No..

I: Has anyone ever offered?

P: Nope...not at all....

I: Would you have liked help?

P: Yeah I would of [sic]....

(Mother of one, with depression and borderline personality disorder)

Extract 98

P: Um I would've preferred help with it (explaining her illness) I would've preferred to know how to do it properly...yeah

(Mother of five, with post traumatic stress disorder, depression, borderline personality disorder and anxiety)

Parents also stated that they were not ready to explain it.

Extract 99

I: How long has your GP wanted you to speak to the kids?

P: A couple of years

I: And what's your answer to him?

P: I'm not ready, I'm not ready...I don't know if they're ready to hear itThat's a separate thing...but I'm not ready to tell them... ..

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

One parent also stated that telling her children may hamper her recovery.

Extract 100

P: I just think that.....um.....if I would be in the same position now and be ill and all of that I wouldn't want to bring it up because why would I want to make it harder for me..... Because if they start asking questions then you have to recount all the problems or the things that have been happening.....So you know I just....yeah.....((.....))...because if I bring it up they might start to understand that it might put me back a step so....Unless they come to me and say "what did happen" then I will have to sit down and explain it to them

(Mother of three, with bipolar disorder and post natal depression)

When talking about the difficulties that other parents may encounter when explaining mental illness to their children, parents cited lack of understanding as one reason why parents may not disclose. Parents also stated that mental illness could be an uncomfortable topic to discuss and that this may prevent other parents from disclosing. Being unsure of how to answer children's questions was another reason given by parents about why other parents may find it too difficult to disclose.

Extract 101

.....lack of knowledge themselves and lack of understanding ..of not knowing how to explain it. And not even having a good idea themselves what's going on so therefore they can't give that to their kids..

(Mother of two, ex-partner has antisocial personality disorder)

Extract 102

...Sometimes it's not they don't think the child isn't ready to hear thatthey're not comfortable with how to discuss it. And I think ultimately the other thing is maybe they don't know..... what they're dealing with themselves..... And coming to grips with that and struggling with that, I think that some people are just so overwhelmed by everything, they just don't know where to start, or what to say or make it worse.....People are afraid they're going to make things worse if they talk about it ...

(Mother of one, with bipolar)

Extract 103

They may not have a comprehension of it or they may not have a support mechanism in placewhereif the kids have got questions that probably answering in depth....

(Mother of one, husband has schizophrenia)

Extract 104

..... people just aren't comfortable within themselves talking about it. They're not comfortable about it themselves...I think you've got to be..comfortable with it yourself to be able to talk about it openly....And maybe.... they choose not to because they don't really know how to as well might be another reason.....

(Mother of five, with post traumatic stress disorder, depression, borderline personality disorder and anxiety)

Almost every parent within the current study stated that it was difficult to discuss mental illness with their child. Some parents overcame this difficulty and told their children about the illness and symptoms. For other parents the difficulty of telling their children was too great and they had not yet told their children about the illness or aspects of the illness.

Parents who found it too difficult to discuss illness with their children said that it was difficult because of a number of reasons; parents didn't understand the illness themselves, they needed help explaining it and didn't know where to find help, or parents were not yet ready to explain the illness. These difficulties have been found in much of the literature examining parenting and mental illness (for example, Handley et al., 2001; Stallard et al., 2004), the literature examining parenting and cancer (Barnes et al, 2000; Kroll et al, 1998) and the literature examining parenting and HIV (Armistead et al, 2001; Lee & Rotheram-Borus, 2002; Pilowsky et al, 2000). Many parents in the current study stated that they did want to tell their children but that they could not overcome the difficulties and that telling their children was 'too hard'. The difficulty with finding help to explain the illness was common across many participants and is further discussed later in this chapter.

In thinking about service delivery, adult mental health workers are ideally placed to help parents understand their own illness or the other parent's illness. They may also be ideally placed to help parents construct and convey age-appropriate explanations to their children, however there are issues with this, as highlighted later in this section.

3.7.2.2 Too ill to talk about it

Six parents stated that they had been too ill or too symptomatic to discuss their illness with their children. Many had explained the illness after they had been discharged from hospital or after the symptoms had reduced. Parents stated that they would have appreciated hospital staff discussing the illness with their children, however it would need to be done in an age appropriate way.

Extract 105

..... I felt really disappointed about that, that somebody (nursing staff) didn't say "hey (child's name) ...mums pretty tired....she's had a big sleep...a big flight (laughs) she's a bit muddled....and she's gonna be fine". To come down to a 10 year olds level

(Mother of one, with bipolar disorder)

A number of parents stated that being too ill could be a common reason why other people did not explain mental illness to their children.

Extract 106

...a lot of people aren't at that point yet...They're not ready to explain...If you'd asked me this two years ago...I don't know what I would've saidI probably would have broke down in tears myself

(Mother of one, with bipolar disorder)

The finding that parents were too ill to talk about it obviously only applies to the parents within the study who identified as having mental illness. This concept has been discussed already within this chapter. A parent being too ill often resulted in the child finding out about the illness in a negative way, for example through an unsupportive person. In some cases where the parent was too ill to discuss it the child was not told about the illness by someone else. In these cases parents stated that they had been too ill to tell their children initially and

that they would have appreciated someone else, such as hospital staff, talking to their children about it.

3.7.2.3 Parental fear, shame and children using illness against the parent

Six parents stated that children may not be told about their parent's illness due to the parent feeling shame or wanting to maintain a sense of normality for the child. In the following three extracts this was a hypothesised reaction.

Extract 107

...yeah I can understand it...Yeah because you know there's things that you're not proud of...everyone's got them and you don't want your kids to know ...

(Father of one, ex-partner has schizoaffective disorder)

Extract 108

.... so the child doesn't look at their parent differently...

(Mother of one, ex-partner has schizophrenia)

Extract 109

I can understand why...because they want....them to think that the parent that is ill is normal

(Father of one, with schizophrenia)

One parent, although she had discussed her illness with her child, discussed being humiliated by her son discussing her illness with others.

Extract 110

P: 'Cause he did the course with them (ARAFMI) he took his course book to school and told it for news. And told everyone all about his mother's mental illness.

I: And how did that go down?

P: Well the teacher was very interested and the kids asked lots of questions and...

I: How did you feel about it?

P: I was totally humiliated.

(Mother of three, with schizophrenia)

One parent mentioned that fear of other people finding out could be a reason for other parents not discussing mental illness with their children.

Extract 111

...um maybe the fear...and especially around...I nearly lost custody of (eldest child's name)...um and I think yeah fear of other people knowing and having a diagnosis and having a mental illness and then losing your capacity...I have great fears of the legal system.....((...))... I have no faith in the legal system and I think that would be a barrier for a lot of people in explaining what was wrong with them and a fear...

(Mother of three, with obsessive compulsive disorder and depression)

Only a few parents mentioned that children might use the illness against a parent and that would be reason not to discuss mental illness.

Extract 112

.....I think like teenagers can be pretty harsh and like use it against you like if you're in an argument or something like that like, oh you know. And sometimes that does happen, oh you know, "you...you...I did give it to you I did give you that note... you must have been mentally unwell" sort of thing you know...Use it like that...So I can see perhaps why they might not want to do that...

(Mother of five, with post traumatic stress disorder, depression, borderline personality disorder and anxiety)

3.7.3 Resources to help disclose

All parents were asked whether they had used any resources to help them disclose to their children or, alternatively, if there were any resources they thought might be useful in helping their discussion with their children. The seven themes which developed from this question are shown in *Figure 6* and are outlined below.

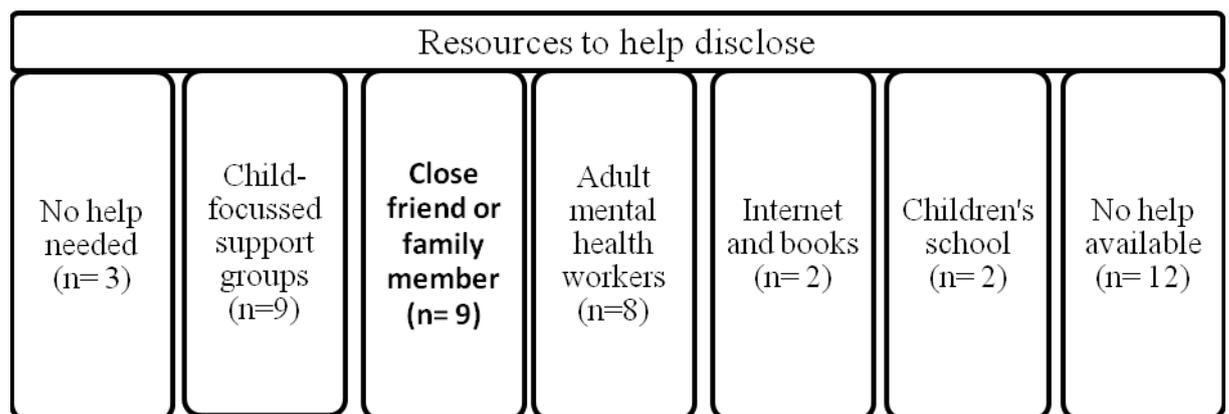


Figure 6. Resources to help with parental disclosure of mental illness.

3.7.3.1 No help needed: parents have a close relationship and are not afraid to talk to children about anything

Very few parents stated that they had either not needed any help to talk to their children or couldn't see a need for help in the future. Only three parents stated that they were happy discussing mental illness without outside help.

Extract 113

I: Would you have liked help with talking to your kids about your illness?

P: Um.....oh not really because I have quite a close relationship with my kids and.....I'm not....like afraid to talk to them about anything I think.....it took me uh.....oh probably 6 years to come to terms with having a mental illness myself so once I

came to terms with it I was ok to talk to them about it....I think it's just....coming to terms with it yourself and then letting them know....

(Mother of two, with depression and post traumatic stress disorder)

3.7.3.2 Child-focussed support groups

Nine participants cited child-focussed support (such as groups or individual therapy) as being a good possible support for their children. A number of parents whose children had already been involved in child-focussed support groups cited these groups as being a good resource which has helped their children understand their illness

Extract 114

I think groups like ARAFMI should (explain mental illness), who have got the training and who can answer the...Like my husband wouldn't have been able to answer the questions that (eldest child's name) and (middle child's name) had. He couldn't have answered them so they would've been confused...

(Mother of three, with schizophrenia)

Extract 115

CAMHS did provide...not...it was never sort of um...a really structured um easily understood kids educational thing but there was verbal I suppose support

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Extract 116

.... with the boys, for a couple of years prior to that they actually had ...a therapist who would come to our house but she would, instead of sitting down talking, she took them off to kick footies and play games. She took them paint balling, and did all of that and that was great...And they knew they always had her...(eldest child's name) didn't use her as much as (youngest child's name)....

(Mother of two, ex-partner has antisocial personality disorder)

One parent talked about how they believed that child-focussed support groups could be helpful but that their child didn't meet criteria for inclusion in the group.

Extract 117

Oh I guess...(name of child support group) at one stage.....My key worker I think initiated somebody from them to come visit and (eldest child's name) eligibility was assessed and I just got a letter back saying they didn't think he was eligible....I think mainly because when they came to interview him he was extremely....in denial and angry and.....um.....wasn't at all open to it...

(Mother of three, with borderline personality disorder and schizoaffective disorder)

A number of parents talked about child-focussed support and how they thought it could be beneficial to their child. Although each of the parents saw the benefits of child-focussed support they had not sought it out for their child at the time of the interview.

Extract 118

.....yeah like you know I'd probably ask someone like a child psychiatrist or someone like that I've just got so little trust in adult psychiatry (laughs)...((...))...

I: Have you ever thought about support groups for your son?

P:yeah.....I have actually

I: What has put you off?

P:um.....I think sort of not being able to find out enough information about 'em.....

(Mother of one, with depression and borderline personality disorder)

All parents whose children had received such support stated that child focussed groups and services were a positive experience which had been instrumental in helping their child to understand mental illness. Often such support services were able to explain aspects of mental illness that parents had difficulty explaining.

Child focussed support groups and services can be difficult to access within Australia. There is a lack of services in general for COPMI and their parents (Foster et al, 2004). Support groups and services for COPMI in Australia are frequently run by non-government organisations and often established with limited and non-recurring funding (Owen, 2008). Some parents within the current study had difficulty finding information about support groups and some were not even aware such groups existed. Within the current study, some parents also stated that their children did not meet criteria for inclusion into such groups, for example one child was not symptomatic enough to be included in a COPMI group (in this case a group for COPMI who were exhibiting behavioural problems) another displayed behavioural problems and thus was not eligible for the COPMI group in his area. Exclusion from groups on the same grounds has been found in research examining the groups available for COPMI in Australia (Reupert & Maybery, 2009a).

Child focussed services can also be difficult to access. Frequently they are provided as an intervention rather than a preventative measure (Mordoch & Hall, 2002; Nicholson, 2001). Accordingly, often a child needs to be displaying symptoms of psychopathology or behavioural difficulties in order to access government funded services. This may mean that children cannot access such services to help with understanding their parent's illness unless they have psychological difficulties. For example the current criteria for a child to access a psychologist at a reduced rate within Australia (under what is termed a 'Mental Health Plan') requires the child to have a clinical condition as diagnosed by the DSM-IV (or the ICD-10 which is another tool for classification of mental illness) (Outridge, 2009). This makes accessing a psychologist for a child (for help with understanding their parent's illness) who is not displaying signs of psychological problems prohibitively expensive for many families (Outridge, 2009). It appeared that the majority of children, approximately 90%, within the

current study, were not experiencing symptoms of psychopathology or behavioural difficulties at a level which enabled them to access child focussed services.

3.7.3.3 Close friend or family member

Nine parent participants mentioned close friends or family members when talking about disclosing mental illness to children. All but one parent spoke about friends and family member's input in a positive way.

Two parents spoke about the help they had received from friends which had helped their child's understanding of the illness. One parent cited a friend who was also an adult mental health worker who had spoken to her children. This quote was also included in the previous adult mental health worker section.

Extract 119

....Yeah I think (friend's name, an adult mental health worker) did actually do that (talk to her children about mental illness)...yeah and I think....I think she was really cautious too ...She wanted them to learn that people can actually go to hospital for other illnesses too and come home and it didn't mean that every time I went to hospital I was going to end up in (psychiatric hospital name). She was pretty good around that....

(Mother of three, with obsessive compulsive disorder and depression)

The same parent also stated that apart from herself and her friend, there wasn't anyone else who could explain it to her children.

Extract 120

Oh no.....I want it explained by someone I trusted

(Mother of three, with obsessive compulsive disorder and depression)

One parent stated that the only help they had received from adult mental health services in relation to talking to their child about illness was through a nurse who was also a family friend. In this family the parent with the mental illness was the non-custodial parent and the parent interviewed for the current study was the child's step-mother. The step-mother highlighted the difficulties the family had experienced in acquiring information about the mental illness. In this case, although she stated that the nurse had helped with the disclosure of mental illness to her step-daughter, it is clear from the extract below that very little mental illness specific information was provided by the nurse.

Extract 121

He (nurse, family friend) was very close to the family.... Had known (husband's name) and (child's mother's name) since their early 20's. Actually treated the mother and knows the sister who is also showing signs ofcraziness...strange behaviour. Very strange family.... But he's very tactful, not the sort of person to say something unless he needed And he told us a couple of years ago that we should keep an eye on things..... He didn't say "(child's mother's name) is sick blah blah blah" he just said "you need to be more..in communication with them (the mother and child, the child was at that stage living with her mother)"

(Step-mother of one, mother of child has schizophrenia and anxiety)

Other parents stated that although they had not yet received help from a friend or family member, they would be open to receiving help from them in the future or would have appreciated help with disclosing in the past. Three parents named specific friends that they thought could have been or could be helpful.

Extract 122

Um....my girlfriend because she's got a way with these two kidsBecause she's got a very close bond with my children..((...))...and I've seen her explain things that I'm thinking....

(Mother of three, with bipolar disorder and post natal depression)

Extract 123

I would have liked somebody.... when I was asleepI'd like you know maybe somebody like (friend's name), a good friend, to say "hey (child's name)".. ((..))....I'd love for there to have been aBit of an understanding because you don't know sometimes what little people see...you know...

(Mother of one, with bipolar disorder)

Extract 124

I: If you needed help telling her where would you get the help from?

P: I think I'd go to (friend's name)....

(Mother of two, with schizophrenia)

One parent discussed asking other consumers for their advice. This parent was active in a number of consumer groups and knew a number of other parents who had mental illness.

Extract 125

...I'd probably also ask other consumers on how they've done it with their kids...

(Mother of one, with depression and borderline personality disorder)

One parent stated that her own family were not a resource she could have used when discussing mental illness with her children.

Extract 126

No.....no I wouldn't know where they'd go honestly because.....no.....My family were...apart from (husband's name) were useless when I had schizophrenia...((..))...A lot of people said just pull yourself together...

(Mother of two, with schizophrenia)

3.7.3.4 Adult mental health workers

Adult mental health workers were highlighted by eight parents as a possible resource to help parents talk about mental illness with their children. Adult mental health workers included General Practitioners, Psychiatrists, Key workers and Case workers. Key workers and Case workers in these cases refer to the person who is often the main point of contact within a mental health agency for the parent with mental illness. Key workers and Case workers generally have regular contact with the parent and are responsible for liaising with other services that the parent may need.

Interestingly, although a number of parents cited adult mental health as a possible useful resource for disclosing, only one participant had actually received practical help with discussing mental illness from this source. The mental health worker in this instance was also a close friend of the parent.

Extract 127

...Yeah I think (friend's name, an adult mental health worker) did actually do that (talk to her children about mental illness)... (Mother of three, with obsessive compulsive disorder and depression)

One mother stated that she knew that her doctors were available to her should she need help with disclosing her illness to her children. This participant had not yet told her children about her illness.

Extract 128

...I have a really good support network of doctors ...Because I have them I know that they can help me and I have actually learned how to ask for help and therefore if I needed to I could with them...

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

Another mother described how her psychiatrist wanted to help her explain her illness to her children however the children were already part of a child-focussed support group.

Extract 129

P: ...well when I started with my new psychiatrist my kids were already in with ARAFMI so that was all taken care of.....umm...If they hadn't been in with ARAFMI she would've done it. She would've seen them herself and would've explained it.

(Mother of three, with schizophrenia)

Six parents stated that adult mental health workers could have been helpful when they were discussing mental illness with their children.

Extract 130

.....case workers because they're in touch with the family

(Mother of one, ex-partner has schizophrenia)

Extract 131

.....well to explain the illness...uh.....I'm thinking community nurse type person somebody who actually knew something about the illness and the effects on the family

(Mother of two, husband has bipolar disorder)

Extract 132

.....some sort of a key worker possibly that person is a good person to do it with the kids and with the parent.....

(Mother of three, with borderline personality disorder and schizoaffective disorder)

One parent discussed a negative experience she had with her Psychiatrist explaining her obsessive cleaning behaviour to her young daughter.

Extract 133

.....(eldest child's name) was in the room and the psychiatrist was saying "well you just have to elect not to do what your mother tells youIf you want to ride a bike you go out there and you do it....Don't listen to her". And I just....And then he turned around and said to me "well its probably good that you lost this baby anyway because like you wouldn't want to be bringing up the baby in this condition" and I just left the room (the participant had miscarried the day prior to the appointment)

(Mother of three, with obsessive compulsive disorder and depression)

Importantly in the context of limited access and scope of direct services for COPMI, parents also cited adult mental health services as a possible useful disclosure resource. Parents suggested that adult mental health workers could help to explain the illness, could provide information to the parent to help explain the illness or, in one case, explain the illness to the child whilst the parent is incapacitated. Only one participant had utilised such services to help explain her illness to her children. Generally, parents had already discussed their illness to some degree with their child on their own but stated that adult mental health services could have been helpful. It could be assumed therefore if adult mental health services were to offer help with explaining mental illness to children this offer would be accepted by parents.

This finding of a lack of support from services in caring for children is not unusual. Parents often do not receive help with parenting from adult mental health workers (Maybery & Reupert, 2006; Nicholson, 2001; Wang & Goldschmidt, 1996). There are a number of reasons why parents in the current study may not have received help from adult mental health services even though they appeared open to it in principle. Firstly, parents may not openly identify as parents to their mental health worker out of fear of losing custody of their children (Mowbray et al, 2000; Nicholson et al., 1998; Savvidou et al, 2003).

Secondly, if clients do identify as parents, adult mental health workers themselves may have reservations about helping to explain mental illness to children. Maybery and Reupert (2006) provide a cogent account of the issues that adult mental health workers may face when asked to attend to their client's children's needs as well as their client's needs. Adult mental health workers are often time limited and lack resources to deal with children. In addition, adult mental health workers, by virtue of their profession, can lack the skills and knowledge needed for working with children (Maybery & Reupert, 2006; Stallard et al, 2004). Research has found that services are generally targeted to the individual and have difficulty in focussing on the individual's broader circumstances. For example, Nicholson, Geller, Fisher and Dion (1993) made the point that where parents with mental illness are concerned, the most prominent concern from hospital staff is who will look after the parent, not whether the parent has children to care for. Although Nicholson and colleagues made that point almost 20 years ago, it appears this is still the case today (Maybery & Reupert, 2006; Outridge, 2009).

More recently there has been a shift from the focus of parents with mental illness to a focus on families and parents with mental illness, in an attempt to ensure the needs of all family members are met (Department of Health, 2007). This shift to a 'family focus' aims to increase mental health services recognition of parenting status, needs of parents and the needs of COPMI (Department of Health, 2007). At present it appears as though, for this sample at least, there remains a lack of acknowledgement within adult mental health services of their status as parents.

3.7.3.5 Internet and books

Very few parents cited the internet or books as sources that either had helped or could help them explain mental illness to their children. Only two people stated that they had used either of these sources to actually explain mental illness to their children. Four parents stated that

they could possibly use the internet or books in the future to explain mental illness, or aspects of their mental illness to their children.

Extract 134

.....I think.....and I know there's a website out there... "Headspace".....I'd probably start with something like that...um.....yeah and probably the COPMI websites and that....

(Headspace is an Australian website concerned with youth mental health)

(Mother of one, with depression and borderline personality disorder)

One parent stated that although she didn't think there was a book on the subject of schizophrenia, such a book would be a useful tool to help explain her illness to her daughter.

Extract 135

They used to have this book when I used to go and see Doctor (Doctor's name)about epilepsy and it was a lovely little coloured feature book about how this mum went to kindy and she has a fit and how the little girl said "don't call an ambulance that's normal for mum"...I wish they had one like that on schizophrenia((...))....I could explain it to her better I suppose

(Mother of two, with schizophrenia)

3.7.3.6 Children's school

School was mentioned by five people in relation to help with explaining mental illness. Only two people discussed school in a positive way.

One parent stated that things that the children had learned at school, in relation to mental illness, had been a useful starting point for discussions at home. This parent had not yet disclosed her mental illness to her children so perhaps the discussion was related to mental illness in general as opposed to the illness the parent had.

Extract 136

P: I think what they get at school is quite good, I know it's quite general, but it plants a seed and hey its more than I ever got...and I think that's good. ...((..))...

I: Do you think that school is covering it quite well?

P: I think they're starting to...from what my kids bring home...topics brought up around the dinner table...You know just from there I think what they're starting to do is good...

(Mother of three, with social anxiety, borderline personality disorder and dysthymia)

One parent stated that school, in particular a school teacher, could be useful in helping explaining a parent's illness to a child.

Extract 137

...someone they trust, a school teacher..um yeah...that would be good...

(Father of one, ex-partner has schizoaffective disorder)

Three parents spoke disparagingly about schools as a resource to help explain mental illness.

Extract 138

....and they're meant to be doing education in schools with kids and they're not...They're doing more on drug educations and these drugs are causing mental illness...helloooo....you know...

(Mother of one, with depression and borderline personality disorder)

One parent stated that they asked a mental illness support group to speak at their child's school to help both teachers and other students understand about mental illness. This was instigated after a number of issues had arisen at the school regarding the parent's behaviour.

In this instance the parents, and child, were required to help the school and students understand about mental illness rather than the school being a resource to help the child.

Extract 139

...I got someone from ARAFMI to come out to the school and did a whole PD (Personal Development) day on mental illness and its effects on children. And that came about more as a reaction that had happened because of the situation..... and I think it was just yeah not necessarily arrogance...just lack of understanding I s'pose ...

(Mother of one, husband has schizophrenia)

School was seen as a 'useless' resource by one parent who described a number of issues their family have had trying to receive support from the school.

Extract 140

... they're all useless...I even find um...Even with the education department that going up to (youngest child's) school because she's little...((...))...the kids really...she's got um...an anxiety disorder due to the situation with (husband's name) ok..um...And the school uses that against her so when she's bullied um.....(())..... When I went up to the school...um...they said to me "well are you sure everything's alright at home?" and I ended up taking (husband's name) for this interview and everything up at the school and I said "right here's my husband...sorry (husband's name) but as you know the school does always try to turn it round and make out well we've got mental illness in our family, that there must be problems at home...here you are everybody". Have people from the education department, principal, goodness knows what and I said "if you saw my husband in the street you'd know no different but because we've been honest with you and you've got it on paper....that there's some mental illness...". She's been bullied the poor kid's been bullied

I: So you wouldn't trust the school to educate them about it?

P: No I probably wish that I had never said anything because they're starting to turn it on us and everything.....(())..... ..Yeah I have an issue because no one seems to understand no one doesn't want to understand ...its more or less saying "oh well she's

probably a little too sensitive". And then also what they're doing they're blaming it on her disorder too..."oh well she has got anxiety..." and I said 'that's got nothing to do with it...it doesn't run in the family"...

(Mother of two, husband has depression)

3.7.3.7 No help available

Twelve parents stated throughout the interview that they either do not know how to find resources or that there are no resources available to help explain mental illness to children. This was true both historically and for parents presently trying to find help with explaining the illness.

Extract 141

...it's just..... learning about what facilities are available and then being prepared to use them that's the hard part

(Mother of two, ex-partner has antisocial personality disorder)

Extract 142

I: If you needed help answering their questions where would you go?

P: No.....there is nowhere...there is nowhere to go

(Mother of two, with schizophrenia)

A number of parents discussed how they would have accepted help had it been offered.

Extract 143

P: Yeah....um.....well I cannot remember any structured help

I: If someone had offered you help would you have taken it?

P: Oh absolutely

(Mother of three, with borderline personality disorder and schizoaffective disorder)

Extract 144

Yes to actually speak on this specific topic one-to-one with the children, I can't imagine anyone who would do such a thing but it would be a fabulous thing, a fabulous thing I believe....

(Mother of two, husband has bipolar disorder)

Two parents discussed the difficulty they had accessing information or support due to custodial issues with their child. In both cases the children had been removed from the care of their mothers and placed with their fathers due to the mother's mental illness worsening. The parents interviewed were the father of one child and the step mother of another. Both parents stated that it was difficult to access information about the other parent's illness due to privacy laws. Both parents also discussed the difficulties with talking to a child about mental illness when the other parent is reluctant about the child being told. It appears that in both cases the parents' doctors and service providers are reluctant or unable to provide information to other members of the family. This concept is further discussed in Chapter Seven.

The participant quoted in the following extract also discussed not knowing what illness her step daughter's mother has and the efforts they took to find out.

Extract 145

....because we don't know what we're dealing with...And we subpoenaed the hospitals and everything with the court documents but we never got to view them because (child's mother's name) never attended court she flatly refused...(....)..We never got to know what actual condition she has.....which is a problem....((....))Well we tried to approach the counsellor from the hospital she was in but she wouldn't deal with us because we were the other family and not their patient.....((....))....Everyone was protecting her ...((....))..I just couldn't believe that the system was against us....

(Step-mother of one, mother of child has schizophrenia and anxiety)

Strikingly, approximately 20 parents had not had any help with disclosing to their children, although most stated that they would have appreciated help had it been available. Much of the support mentioned within this section was possible support, or support parents would have found helpful, rather than the support that was actually provided.

Parents within this study stated that they would have been willing to receive support with talking to their children but that they were unsure where to find it and whether support even existed. This finding is in keeping with parental cancer research which found that parents were rarely provided with support when explaining their illness (Barnes et al, 2000). Parents within the study conducted by in Barnes and colleagues (2000) also stated that they would have appreciated help had it been offered.

There are clinical ramifications of these findings. Almost all parents within this study were receiving mental health services from an adult mental health worker such as a GP, Key worker, Psychiatrist or Psychologist. Adult mental health workers appear to be in a unique situation; they are a support that the majority of parents with mental illness access. Given that they are often the sole source of support, they are ideally placed to recognise their client's parent status and to provide help with disclosing parental mental illness. However adult mental health workers may need training from a child specialist or to be involved in collaboration with child specialists in order to do this. If unable to provide direct support with disclosure, adult mental health workers could be instrumental in providing links to other services which may assist with the task of disclosing parental mental illness to children.

3.8 Summary

The current study explored the process of disclosure of mental illness between parents and their children from the perspective of the parent. This is the first known investigation into parents' views of explaining mental illness to their children and, as such, the findings give a valuable insight into the parents' view of disclosure. Parents provided information about how they made their children aware of mental illness; who told the children, what they were told and how they were told. Although all but one parent had told their children about mental illness to some extent, most had resisted disclosing some aspects of mental illness. All

participants provided insight into the difficulties parents can have disclosing and the reasons why some parents are opposed to disclosure.

It appears there are many similarities between the experiences parents have disclosing mental illness and other sensitive topics such as parental cancer, parental HIV and donor insemination. These similarities include a difficulty with disclosure, dealing with children's feelings regarding disclosure and a difficulty with using illness-specific terminology, among others (Armistead, et al., 2001; Barnes et al., 2000; Kroll et al., 1998; Lee & Rotheram-Borus, 2002; Lycett et al., 2005; Nachtigall et al., 1998; Pilowsky et al., 2000). However the disclosure of mental illness also contains a number of unique challenges such as difficulties with explaining self harm and suicidal behaviour, periods of time when the parent appears well (and there is no perceived need to explain mental illness) and periods when a parent is incapacitated and unable to speak to children.

The current study supported, and expanded on, the previous limited research into parents' views of explaining mental illness to their children. Almost all parents (24 of 26) stated that they wanted their children to be informed about mental illness. This study highlighted that there is a clear struggle with the disclosure of certain aspects of mental illness, in particular self harm and suicidal behaviour. Almost all parents stated that they would have accepted help with explaining their illness but that they were unsure where to access such help. In many cases children were first told about mental illness by a third party, often seen as a negative event by parents. The study has highlighted that care plans may be relevant as well as adult mental health workers helping parents find suitable support services.

As shown by the current study, the process of disclosing and explaining mental illness to children involves considerable investment from parents. So far, children's ideas about the

process of disclosure and explanation of mental illness are unknown. Do children experience the disclosure process similarly to their parent? What do they know about their parent's illness? Do they want more information about their parent's illness or is the drive for disclosure based on misguided ideals rather than children's actual desire for knowledge? The following chapters examine the child's view of disclosure.

Chapter Four: Review – Children’s understanding of mental illness

4.1 Children’s understanding of physical illness

The last thirty years has seen an increase in research examining children’s understanding of biology and illness (Siegal & Peterson, 1999). Children’s views on physical illness such as stomach ache (Perrin & Gerrity, 1981), cancer (Forrest et al., 2006), HIV (Kennedy et al., 2010) and heart disease (Veldtman et al., 2000) have been examined along with children’s understanding of genetic illness and heritability of genetic conditions (Metcalf, Coad, Plumridge, Gill & Farndon, 2008). Each of these studies has provided much needed information about how children think about and talk about physical illness.

The literature pertaining to children’s understanding of physical illness is a useful resource for providing a basic insight into what children may understand about mental illness. Much of the current research into children’s ideas about physical illness is based on the early ideas of Piaget (Eiser & Kopel, 1998). As Eiser and Kopel (1998) state in their review of children’s perceptions of health and illness, current ideas about children’s understanding of physical illness posit that young children provide less complex accounts of illness, they are confused about cause and effect and are unable to differentiate between different illnesses. As children get older their awareness of contagion and germs develops and they are more able to provide a cogent explanation of the cause and process of illness (Eiser & Kopel, 1998). Research utilising Piaget’s theory has found that only older children (aged 11 years and older) are able to conceptualise that a person’s health can be impacted by their thoughts and feelings (Bibace & Walsh, 1980). One main criticism of the applications of Piaget’s model of children’s

perception of illness is that often children's perception of cause only is examined (Eiser, 1989).

A second child development theorist provides a different lens through which to view children's understanding of illness. Vygotsky built on Piaget's work by emphasising the role of social interactions in the cognitive development of children (Borzekowski, 2009). The two prominent ideas based on Vygotsky's work were that a child has a "zone of proximal development" and that this zone could be "scaffolded" by someone within the child's sphere (Borzekowski, 2009; Rushforth, 1999). The "zone of proximal development" refers to the difference between what a child is able to understand on their own (without the help of parents, peers or teachers) and the limit of what a child is able to understand with help. "Scaffolding" refers to the help provided by a parent, peer or other teacher to help with understanding.

Although there are cognitive limits on what children may be able to understand about illness, as suggested by Piaget, there is potential to develop children's understanding by identifying a child's current understanding and then providing further help from people within the child's sphere (Rushforth, 1999). Further detail regarding Piaget and Vygotsky's theories is provided in Appendix J.

4.2 Differences between mental and physical illness

Insights into children's ideas about physical illness are useful for helping to understand children's beliefs about mental illness, however mental illness differs to physical illness in a number of ways. For example, where physical illness is most often viewed as arising from a physical cause, the cause of mental illness is frequently debated, some believing that it is genetic, others believing it is a result of circumstance (Spitzer & First, 2005). Mental illness is

more often associated with stigma than physical illness (an exception to this perhaps may be physical illnesses such as HIV; Murphy, 2008). Stigma (as displayed by other people or media) could shape the way children understand and think about mental illness. Stigma toward mental illness can also lead to people being less willing to talk about it (Corrigan & Miller, 2004; Hinshaw, 2005) which in turn could lead to children unable to have their questions answered or perhaps sensing that questions shouldn't be asked. Mental illness shares some common ground with physical illness however there are clearly important differences between the two.

In contrast to the expanding literature on children's understanding of physical illness, research regarding children's understanding of mental illness is sparse (Hennessy, Swords & Heary, 2007). The research examining children's understanding of their own parent's mental illness is even more so.

4.3 The need for synthesis

The majority of studies relating to children's understanding of mental illness have examined discrete aspects of mental illness. Children are rarely asked about their understanding of all facets of mental illness. For example some studies examine what children believe causes mental illness but do not also examine children's beliefs about treatment of the illness. In addition, the research methods used within these studies are often disparate: each study using different measures, and different terminology, to examine children's understanding of mental illness.

There is a lack of synthesis of the findings of studies regarding children's ideas about mental illness. Disparate research methods has made synthesis difficult thus far (Wahl, 2002). Synthesis of the findings of studies would allow for a clearer picture of what children know

about all facets of mental illness. The chapter following this, Chapter Five: Study Two, Part 1: Children’s ideas about their parent’s illness; symptoms, cause, treatment, timeline and consequences for the family” examines children’s understanding of parental mental illness using a relatively large sample size. Before presenting the next chapter it is important to have an appreciation of the research already available which examines both COPMI and non-COPMI understanding of mental illness.

4.4 Aim

The current chapter will examine the available research regarding children’s understanding of mental illness. In an effort to synthesise the research so far, the literature will be examined and results categorized under the four commonly recognised areas of illness understanding (Leventhal, 1980; as discussed in Chapter Two). Due to the limitations of space placed on this thesis this review will be a descriptive synthesis rather than a critical review. There is certainly scope for a deeper critical reading of the research in this area, however the purpose of this review is to provide a comprehensive overview of what is known about children’s understanding of mental illness to date, which in turn will provide a background for the study which follows in Chapter Five.

4.5 Parameters of the literature included

The electronic data bases Psychinfo and Pubmed were investigated for papers which have examined children’s understanding of mental illness. In addition to the electronic research data bases, searches were also conducted on websites such as Google and Google Scholar. Articles sourced through data bases and websites were also further hand searched in order to find any studies which may have been missed by the aforementioned searches.

No lower limits were placed on the year of publication, but as the search was conducted within 2010, the upper limit for year is 2010. Modified searches were conducted in 2011 and no further studies were found. Only studies written in English (or with included English translation) were included.

A combination of the following key words were used as search terms in order to source relevant studies; ~~v~~iew", ~~a~~ttitude", ~~p~~erception", ~~k~~nowledge", ~~c~~omprehension", ~~b~~elief", ~~i~~dea", ~~c~~oncept", ~~m~~ental illness", ~~d~~epression", ~~s~~chizophrenia", ~~b~~ipolar disorder" and ~~a~~nxiety". In addition the trunk of all words was used in order to capture all possible variations of the term. For example the search term ~~b~~elie*" was used in order to capture studies with key words such as ~~b~~elief", ~~b~~eliefs" and ~~b~~elieve".

Given the paucity of research in this area, it was decided that unpublished articles and theses would be included if relevant and if able to be sourced. Relevant theses were found through data bases and relevant websites and these were ordered from interstate and overseas universities. Where possible, published journal articles were included rather than unpublished theses, if the author had published their research. Where no research has been published within a journal, data sourced from the thesis itself has been used within the current review.

4.5.1 Inclusion criteria

Within most review studies, only articles that conform to certain criteria are included, for example only those articles which have been peer reviewed. Due to the little research which has been conducted in this area, all articles which examined the criteria of interest were included. Studies which utilised either qualitative or quantitative methodology were included.

4.5.2 Exclusion criteria

For this review, papers which examine children's views of peers with mental illness are excluded, as are papers which do not specify the age of the hypothesised person with mental illness. This is largely because the review has been conducted to inform the current thesis which examines children's views of their parent's illness, not mental illness of peers. It has been suggested that children may view peers with a mental illness differently to the way they view adults with a mental illness (Wahl, 2002). In addition to this, a comprehensive review of children's views of peers with mental illness has been conducted recently (Hennessy et al., 2007).

4.6 Review structure

As stated within the aim of this study, all literature for this review has been grouped under five of Leventhal's illness domains; identity, cause, treatment, consequences and timeline. Leventhal's illness domains have been used within numerous studies examining adults' understanding of physical illness and also with children's understanding of physical illness. This framework was used to examine children's understanding of mental illness by Fox, Buchanan-Barrow and Barrett (2007), which was the first study to do so, and findings provided support for the use of the Leventhal framework in the examination of children's understanding of mental illness.

In addition to using the Leventhal illness framework, relevant literature is presented under the heading 'where do children get their information from'. In all sections, the data from studies examining non-COPMI ideas about mental illness are presented first followed by data from studies with COPMI as participants.

A table outlining each of the studies included within the review can be found within the appendices (see Appendix K and Appendix L). A table is also included within each section of the review. The tables included throughout the text contain details of each study which are included within that specific section of the review. Details such as the sample size included in each study and the age of participants are included within the tables to help provide context for the reader.

4.7 Review

The first section within this review examines research which has looked at children's understanding of the identity of mental illness, that is, understanding of the words used when talking about mental illness and understanding of the symptoms of mental illness. Almost all research examining children's ideas about mental illness has struggled with the same issue, that is, what words or terms to use when attempting to elicit information from non-COPMI children about mental illness.

Terminology for mental illness has provided researchers with a challenge since research into this topic was initiated in the 1960's (Wahl, 2002). The terms "mental health problem", "mental illness", "crazy" and specific mental illness labels such as "schizophrenia" or "bipolar disorder" have often caused confusion in children and have made it difficult to accurately access children's knowledge on the topic (Fox et al., 2007). Researchers have been required to use novel strategies to gauge children's knowledge. Much of the research within this review is conducted using vignettes.

4.7.1 Identity of mental illness

The illness component ‘identity’ refers to words used to describe mental illness as well as the symptoms of mental illness. The table below (Table 5) shows the studies which examine children’s understanding of the identity of mental illness.

Author (year)	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Country	Disorder
Non-COPMI studies						
Callan, Wilks & Forsyth (1983)	Both	Not stated	16-17	277	PNG & Australia	Mental illness
Poster, Betz, McKenna & Mossar (1986)	Both	Content analysis	8-11	168	USA	Mental illness
Poster (1992)	Qualitative	Content analysis	8-11	168	USA	Depression, Anxiety, Schizophrenia
Secker, Armstrong & Hill (1999)	Qualitative	Thematic analysis	12-14	120	Scotland	Mental illness
Bailey (1999)	Both	Not stated	11-17	106	UK	Mental illness
Sedley (2002)	Qualitative	Thematic analysis	6-18	99	New Zealand	Mental illness
Schulze & Angermeyer (2005)	Both	Not stated	16	293	Germany	Schizophrenia
COPMI studies						
Garley, Gallop, Johnston & Piptone (1997)	Qualitative	Not stated	11-15	6	USA	Mood Disorder
Bourke (1998)	Both	Not stated	Retrospective	30	USA	Range of mental illnesses
Meadus & Johnson (2000)	Qualitative	Giorgi method	17	3	Canada	Mood Disorder
Riebschleger (2004)	Qualitative	Thematic Analysis	5-17	22	USA	Mood Disorders, Schizophrenia, PTSD
Valiakalayil, Paulson & Tibbo (2004)	Both	Not stated	13-18	13	USA	Schizophrenia
Cogan, Riddell & Mayes (2005b)	Qualitative	Thematic analysis	12-17	40	UK	Affective illness
Finney & Falkov (2009)	Qualitative	Not stated	8-12	Not stated	Australia	Range of mental illnesses

Table 5
Studies Examining the Identity of Mental Illness.

4.7.1.1 Non-COPMI understanding of identity.

In one of the first studies to do so, Callan and colleagues (1983) examined the beliefs adolescents held about people with mental illness. This study was unique in that it compared the beliefs of Australian and Papua New Guinean adolescents aged between 16 and 17 years. Participants in this study completed both a Likert-style questionnaire and open ended questions. Callan and colleagues (1983) found that both groups of adolescents stated that people with mental illness would be irrational and unpredictable. Although Papua New Guinean adolescents were more likely to, both groups also stated that people with a mental illness could try to hurt themselves, kill people, chase people, talk too much, talk without thinking and roam around. Only Papua New Guinean adolescents suggested that people with a mental illness would swear, collect food scraps, walk around naked and sing. Only Australian adolescents stated that people with mental illness are similar to those without mental illness. Papua New Guinean adolescents were also more likely than Australian adolescents to state that people with mental illness are “dressed untidily, look different, laugh more and are dangerous” (1983, p.282).

Poster (1986, 1992) has conducted two studies examining aspects of children’s understanding of mental illness. The first study, conducted by Poster, Betz, McKenna and Mossar (1986), examined children’s drawings of people with mental illness and people without. Children in this study were more likely to draw people without mental illness in scenes of work and play. People with mental illness were drawn in scenes depicting suicide, aggression and inappropriate behaviour.

The second study conducted by Poster (1992), used vignettes to assess children’s concepts of mental illness. The children within this study were eight to 11 years old. Children used a number of words to describe the behaviour of people with mental illness (depression, anxiety

and schizophrenia), as portrayed within the vignettes. These words were then categorised into two groups; ~~mental~~ "illness" and ~~non-mental~~ "illness" depending on the connotation of the word (p.31). Words such as ~~e~~razy", ~~p~~hobia" and ~~d~~epressed" were categorised into a mental-illness specific category (p.31). Words such as ~~m~~ean", ~~l~~azy", ~~s~~cared", ~~d~~umb" and ~~s~~illy" formed the ~~non-mental~~ "illness" category (p.31). Seventy-three percent of participants used non-mental illness terms to describe the behaviour of people within the vignettes. Poster states that older children were more likely to use mental-illness specific words than were younger children.

In her study of 11-17 year old children, Bailey (1999) asked the open ended question ~~W~~hat happens to people with mental illness?". Responses to this question were varied however a number of children provided responses which can be categorised as symptoms of mental illness. The most common symptoms to be cited were ~~l~~ose control", ~~c~~onfused" and ~~w~~ithdrawn".

Secker and colleagues (1999) used vignettes to examine 12 to 14 year olds ideas about mental illness. Participants within this study accurately named the mental illness depicted in one of the vignettes as depression although, interestingly, they did not classify depression as a mental illness. The authors state that, after further exploration, it became clear that many of the participants had encountered people with depression. Depression was therefore viewed by participants as something within the bounds of normality and therefore not as mental illness. Participants were also asked to talk about their views of another vignette character who had symptoms of schizophrenia. All participants labelled this character as having mental illness. Terms such as ~~s~~chizo", ~~s~~chizophrenic" and ~~p~~aranoid" were used in relation to this character (p.735). Only the behaviours within the vignettes which were removed from

children's own experience, and which they had difficulty identifying with, were labelled as mental illness by the participants.

In his comprehensive study examining children's concepts of mental illness, Sedley (2002) conducted focus groups with children ranging in age from 6 to 18 years old. Participants in this study were presented with vignettes which depicted characters with anxiety, depression and schizophrenia. Sedley asked participants what the term "mental illness" means.

Participant responses were varied and included the labels "depression" (p.45), "claustrophobia" (p. 45), "paranoid" (p.45), "not normal" (p.54), "crazy" (p. 54), "weird" (p.54), "nuts" (p. 54) and "schizophrenia" (p.46). The term "schizophrenia" was used by only one participant who had a family member with that particular mental illness.

Adolescents' understanding of a specific illness, schizophrenia, was explored by Schulze and Angermeyer (2005). German students, aged between 14 and 17 years old, completed a survey regarding a number of aspects of schizophrenia. A fifth of the students did not know what schizophrenia was. The remaining students stated that schizophrenia involved split personalities, delusions, mental retardation, aggression and confusion, among other characteristics or behaviours.

4.7.1.2 COPMI understanding of identity

The study conducted by Cogan and colleagues (2005 b) was unique in that it compared the understanding of mental illness of children of parents with mental illness with children of parents without mental illness. Cogan states that both groups of children struggled to define the term "mental health problem". As expected, there were differences in the way both groups of children talked about mental illness. Children of parents with mental illness used words such as "problems", "bad days" and "depressed" to identify their parent's illness

(p.53). Children of parents without mental illness more commonly used words such as “not right”, “crazy” and “mental” (p.53).

Garley and colleagues (1997) conducted an interview study with 6 children who had a parent with an affective illness. The children within the study talked about how they knew their parent was becoming ill. Behaviours included a parent giving away money, yelling or being unable to move.

In a unique retrospective study Bourke (1998) examined ACOPMI retrospective accounts of their parent’s mental illness. The participants in this study were adults however they were asked to remember the beliefs about their parent’s illness that they held when they were children. For this reason this study is included here. When asked about symptoms that their parents had, participants endorsed 30 different symptoms. The most commonly cited were “peculiar behaviour”, “withdrawal from social activity”, “odd beliefs” and “excessively talkative” (p.93).

Although not specifically examining adolescents’ views about aspects of their parent’s mental illness, Meadus and Johnson’s (2000) study highlights two symptoms observed by participants. Meadus and Johnson (2000) interviewed three female adolescent COPMI and asked them about their experience of growing up with a parent with mental illness. The symptoms highlighted by the three participants were “confusing behaviour”, the “unavailability” of parents and an inability of parents to look after younger siblings (p.386). One participant also mentioned the symptom of self harm.

Children, aged five to 17, who had a parent with mental illness were also the focus in Riebschleger’s (2004) interview study. Although Riebschleger did not specifically ask

children questions around identity of mental illness, the children did provide an insight into how they viewed their parent's illness. Riebschleger states that the participants did not talk about symptoms such as withdrawn behaviour or irritability, instead children talked about reduced parental attention and parents being "grumpy" and "yelling" (p.27). As Riebschleger states, "only a few of the children offered a diagnostic label", these being "depression" and "manic depression" (p.28).

Adolescent views of having a parent with schizophrenia were examined by Valiakalayil, Paulson and Tibbo (2004). Thirteen adolescents (between 14 and 17 years old) described a number of symptoms their parents had. These included "auditory hallucinations, paranoia, public outbursts, sudden mood changes, anger, depression, fatigue, cognitive problems (memory, concentration), and poor communication" (p.531). Participants also mentioned their parents sleeping excessively and having a decrease in activity.

Finney and Falkov (2009) conducted a pilot study examining children's understanding of their parent's mental illness. The results of the study were presented within an article which presented the clinical implications of talking with children. As such the details of the study and findings are vague. They are included here because of the relevancy of the findings and due to the paucity of research in this area. Finney and Falkov stated that in their sample of eight to 11 year children the main response given, when talking about symptoms, is that their parent is angry or sad. Children also stated that their parent shouts and cries. Children also talked about their parent doing other things more often than usual. These included sleeping more and parents losing their temper more often. Finney and Falkov state that as children get older they notice a reduction in certain behaviour, such as a parent sleeping less or eating less.

4.7.2 Cause of mental illness

The illness component ‘cause’ refers to beliefs people hold about the cause of mental illness.

The table below (Table 6) shows the studies which examine children’s understanding of the cause of mental illness.

The findings across studies examining children’s beliefs about cause of mental illness were largely consistent. There appeared to be a limited number of causes of mental illness, although in some circumstances this was due to a children being provided with forced choice response options. Most commonly children cited “stress” or “being born that way”.

Table 6
Studies Exploring the Cause of Mental Illness

Author (year)	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Country	Disorder
Non-COPMI studies						
Maas, Maracek & Travers (1978)	Both	Not stated	7-11	60	USA	Mental illness
Callan, Wilks & Forsyth (1983)	Both	Not stated	16-17	277	PNG & Australia	Mental illness
Poster (1992)	Qualitative	Content analysis	8-11	168	USA	Depression, Anxiety, Schizophrenia
Bailey (1999)	Both	Not stated	11-17	106	UK	Mental illness
Sedley (2002)	Qualitative	Thematic analysis	6-18	99	New Zealand	Mental illness
Watson et al (2004)	Quantitative	Frequencies, means and t-tests	6,7,8th grade	1566	USA	Depression, mental illness
Fox, Buchanan-Barrow, Barrett (2007)	Quantitative	Hi-log linear analysis	5-11	89	UK	Depression, Schizophrenia, Anorexia
Fox, Buchanan-Barrow, Barrett (2010)	Quantitative	Hi-log linear analysis	6-11	240	UK	Depression & anorexia
COPMI studies						
Garley, Gallop, Johnston & Pipitone (1997)	Qualitative	Not stated	11-15	6	USA	Mood disorder
Riebschleger (2004)	Qualitative	Thematic Analysis	5-17	22	USA	Mood Disorders, Schizophrenia & PTSD
Valiakalayil, Paulson & Tibbo (2004)	Both	Not stated	13-18	13	USA	Schizophrenia
Cogan, Riddell & Mayes (2005b)	Qualitative	Thematic analysis	12-17	40	UK	Affective illness
Finney & Falkov (2009)	Qualitative	Not stated	8-12	Not stated	Australia	Range of mental illnesses

4.7.2.1 Non-COPMI understanding of cause of mental illness

In their interview study of seven to 11 year olds, Mass and colleagues (1978) found that younger children were more likely to attribute mental illness to internal factors such as “being born that way” (p.149) or being caused by a physical injury. As children got older they were more likely to attribute mental illness to external factors such as “social/environmental factors” and “wanting to act this way” (p.149). Mass and colleagues (1978) also stated that high proportion of all the children they interviewed (regardless of age) suggested that people with mental illness could change their behaviour.

The study conducted by Callan and colleagues (1983) examined both Australian and Papua New Guinean adolescents' views of the causes of mental illness. Australian adolescents cited “genetic causes”, “stress or worry”, being overworked, an accident, and childhood environment as possible causes for mental illness (p.283). The most commonly cited were “genetic causes” or “stress and worry”. Papua New Guinean adolescents also cited “genetic causes” and “stress or worry” (p.283). Papua New Guinean adolescents, unlike Australian adolescents, also cited “sorcery, magic or witchcraft”, “thinking too much about things” (such as sex) and “bad food, betel nut or alcohol” as possible causes of mental illness (p.283).

Poster (1992) asked children how they thought that a person within a vignette (depicted as having depression, anxiety or schizophrenia) “got to be the way she/he is?” (p.31). The responses were coded into internal or external causes. Internal causes included genetic factors, personality characteristics or biochemical factors. Poster found that 5th and 6th grade students were more likely to attribute mental illness to internal factors than 3rd and 4th grade students. External causes included environmental and social causes. It is unclear from the paper how many children endorsed each category of cause. The paper does state that children more often

attributed external causes to the character within the vignette depicting someone with schizophrenia, than to the character depicted as having anxiety or depression.

In Bailey's (1999) study, children were specifically asked about the causes of mental illness. There were a number of responses, two of the most cited were "stress" and "bad childhood" (p.108). Over a quarter of participants stated that the cause of mental illness was genetic. Children also commented that people could be born with mental illness.

Sedley (2002) conducted two studies within his thesis which examined, among other things, children's beliefs about the cause of mental illness. Children were given vignettes to read and then asked to discuss them within focus groups. The vignettes were provided without stating that the character had mental illness and children were asked what happened prior to the scene within the vignette and what happened after. Children therefore provided varied responses. For example some children were aware that the behaviours displayed by the characters were symptoms of mental illness and therefore provided responses about the cause of mental illness. Other children thought that a vignette character's hallucinations were due to a problem with their ear and therefore did not provide responses about their ideas around the cause of mental illness. All responses were combined for analysis and it is not possible to filter out only the responses relating to mental illness for inclusion here. Children provided responses which fitted seven main explanatory categories. Quantitative data, regarding how many children endorsed each category, is not provided within the thesis. Explanatory categories included traumatic events, doing something harmful to someone else, being possessed, using drugs, health problems, head injury and thinking problems.

Sedley's study is innovative in that it examines children's explanations of mental illness symptoms in conjunction with children's ideas about "resolutions" for mental illness

symptoms. Each of the explanations presented above have a corresponding resolution. These resolutions, or possible treatment for symptoms, will be examined in the following section; Treatment.

Although Watson and colleagues (2004) did not specifically examine children's ideas about cause, their results indicate that the majority of the children within their survey study thought that mental illness was a "problem in the brain" although there were still a number of students who endorsed the "not sure" response (p.567). A third of the participants agreed with the statement, "Individuals who have a family member with a mental illness are more likely to have a mental illness themselves" (p.567).

Fox and colleagues (2007) conducted a comprehensive study into children's understanding of mental illness using a Levanthalian framework. The study examined children's ideas about the cause of schizophrenia, anorexia and depression. It is difficult to determine what the children endorsed as the cause of schizophrenia and depression as only statistically significant findings are included in the article. They do state that the vast majority of children (81 of 89 children), interviewed by Fox and colleagues, chose responses which could be classified as external cause responses. These included responses such as anorexia was caused by "something that happened in the past" and that the person "took drugs" (p.13). Eight children cited internal causes such as the person with mental illness was "born like it" and "someone in the family had it" (p.13).

Fox and colleagues (2010) conducted a second study examining children's ideas about the cause of mental illness (among other aspects of mental illness). Children most commonly cited that it was the way the character "thinks and feels" that caused depression and anorexia. Other commonly cited causes were that they "caught it" (depression), they were "nasty to a

friend” (depression), they ~~ate~~ something bad” (anorexia) and there is ~~something~~ wrong with the brain” (anorexia) (p.612).

4.7.2.2 COPMI understanding of the cause of mental illness

Within Cogan’s (2005 b) study, COPMI cited a number of causes of mental illness. These included ~~abuse~~”, ~~where you live~~” and ~~stress~~” as well as being due to a ~~painful~~ or traumatic life event” (p.56). The same children also referred to ~~multiple stressors~~” causing mental illness (p.56). A quarter of the COPMI interviewed suggested internal causes such as the brain and heredity. Interestingly seven of the 20 children of a parent with mental illness blamed themselves for their parent’s illness. Non-COPMI also endorsed external causes, however the type of external cause was different and included homelessness, not having any friends, taking drugs and ~~living~~ in a poor area that’s full of junkies” (p.56).

Garley and colleagues (1997) asked six adolescents about their views about the causality of their parent’s mental illness. Participant responses were ~~varied~~” (p.100) but included views about a parent being born with mental illness. Other children within the study stated that mental illness was caused by childhood factors such as sexual abuse.

In his retrospective study, Bourke (1998) examined the causal attributions made by adult children for their parent’s symptomatic behaviours. Participants were asked to recall their attributions for their parent’s illness from the time they first found out about the illness to the current point in time. The most common initial attribution was ~~self blame~~” (p.75), characterised by the child blaming themselves for their parent’s illness or specific symptoms. As participants got older they no longer attributed blame to themselves. Participants at this stage stated that the cause of their parent’s symptomatic behaviours was the illness itself, citing ~~mental illness~~” and their parent being ~~sick~~” (p.76). This study differed to other research in

this area in that participant responses of cause were not further explored. Participants cited “~~m~~ental illness” as a cause of their parent’s symptoms but the cause of the “~~m~~ental illness” was not further investigated.

Valiakalayil and colleagues (2004) interviewed children of parents with schizophrenia and asked them about the causes of their parent’s illness. Past behaviour was cited as a main cause. This included drug abuse, alcohol abuse, stress, psychological problem and head injury. Participants largely viewed their parent’s behaviour as something which the parent could control. Interestingly, there was little emphasis on heritability of mental illness and the authors stated that these children believed they were “~~i~~mmune to developing schizophrenia” (p.531).

Although not specifically asked about it, some of the children within Riebschleger’s (2004) study mentioned possible causes of their parent’s illness. Some children blamed themselves and some stated that worry caused it. Others talked about the heritability of mental illness.

Finney and Falkov (2009) found that younger children thought that possible causes of their parent’s illness could be excessive behaviours, for example excessive smoking or arguing. Some children blamed themselves for their parent’s illness. With increasing age children also identified psychosocial causes such as arguments among family and financial worries. As children get older, awareness of biology and genetics and their role in mental illness increases. They state that although they are unaware of the exact mechanism of inheritance of mental illness, children are still worried about developing mental illness themselves.

4.7.3 Treatment and consequence of mental illness.

The illness components ‘treatment’ and ‘consequence’ are grouped together within this review. They are viewed as two separate illness components by Leventhal (1980). Treatment refers to the ideas people hold about what can be done to help someone with mental illness. Consequence refers to what happens to someone as a result of mental illness. They are grouped here as some studies within this section asked children questions along the lines of –‘what happens to a person with mental illness?’. This question was ambiguous and often prompted responses which would fit into both the treatment and consequence category. For example some children stated that mental illness makes the person –‘silly’ (consequence) and that they should go to –‘a mental hospital’ (treatment). The table below (Table 7) shows the studies which examine children’s understanding of the treatment and consequence of mental illness.

Table 7
Studies Examining Treatments for Mental Illness.

Author (year)	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Country	Disorder
Non-COPMI studies						
Callan, Wilks & Forsyth (1983)	Both	Not stated	16-17	277	PNG & Australia	Mental illness
Poster (1992)	Qualitative	Content analysis	8-11	168	USA	Depression, Anxiety, Schizophrenia
Bailey (1999)	Both	Not stated	11-17	106	UK	Mental illness
Sedley (2002)	Qualitative	Thematic analysis	6-18	99	New Zealand	Mental illness
Fox, Buchanan-Barrow, Barrett (2007)	Quantitative	Hi-log linear analysis	5-11	89	UK	Depression, Schizophrenia, Anorexia
Fox, Buchanan-Barrow, Barrett (2010)	Quantitative	Hi-log linear analysis	6-11	240	UK	Depression & anorexia
COPMI studies						
Garley, Gallop, Johnston, & Pipitone (1997)	Qualitative	Not stated	11-15	6	USA	Mood disorder
Finney & Falkov (2009)	Qualitative	Not stated	8-12	Not stated	Australia	Range of mental illnesses

4.7.3.1 Non-COPMI understanding of treatment and consequences of mental illness

In their study, Callan and colleagues (1983) asked adolescent participants for their ideas about “ways to cure” mental illness. Papua New Guinean adolescents most frequently stated that sending the person with mental illness to a “modern hospital” (p.284) was the way to cure them. This was followed by using “traditional medicine or magic” and “rest, peace, quiet” (p.284). Australian adolescents most frequently stated “understanding and support” (p.284) as a way to cure mental illness. This was followed by sending the person with mental illness to a “modern hospital” and then followed by “counselling or therapy” (p.284).

Poster (1992) asked children what should be done about characters with mental illnesses depicted in vignettes. The characters had schizophrenia, anxiety or depression. Responses were grouped into one of three categories; psychiatric interventions, adult non-psychiatric interventions and child-initiated interventions. Psychiatric interventions included “take to a psychiatrist” and “take to a head doctor” (p.32). Adult non-psychiatric responses included help from doctors and bosses. Child-initiated interventions involved the child helping the person with a mental illness, for example, helping them get a job, talking to them, and telling them to be calm.

Although Bailey’s (1999) question to children within her study is slightly ambiguous, the participant responses yield some data which is worth including here. Bailey asks her participants “what happens to people with mental illness?” which receives a range of responses which are categorised under “behaviour of the individual”, “responses of members of the public” and “interventions” (p.108). The most cited interventions within this study are “mental hospital” and “nursing/special homes”. Bailey then asks participants where people with mental illness should be treated. The three most cited responses were “hospital”, “at

home” and in “special homes” (p.108). Participants cited “doctor”, “psychiatrist” and “specially trained person” as the people most suited to treating people with mental illness (p.108).

Within his thesis, Sedley (2002) asked children to read vignettes, depicting characters with schizophrenia, anxiety and depression, and provide both an explanation for the characters’ behaviour and possible resolutions for the behaviour. Children were asked what could happen next to the character within the vignette. Although the children were not specifically asked about the treatment or consequences of mental illness, their responses provide information which fits within this section. As previously stated (within the ‘cause’ section of this chapter) children provided seven types of explanations for the cause of the characters behaviour. In line with this, the children then provided resolutions which corresponded with the explanations they had provided. For example if children stated that they thought the character’s behaviour was due to losing their job, they then provided a corresponding resolution such as being given their job back. Resolutions included the person with mental illness changing their thinking, fixing things that they had done wrong in life, praying, giving up drinking alcohol or doing drugs, seeing a doctor, being hospitalised or acting differently.

Fox and colleagues (2007) asked children questions about the consequences of having schizophrenia, anorexia or depression. Only significant findings are reported and as such children’s conceptions of the consequences of depression are not reported. For anorexia, older children were more likely to choose the response “see a doctor” and younger children were more likely to choose “have an operation” (p.13). In terms of schizophrenia, the most common consequence cited was that the character would need “help and support” followed closely by “do silly things” (p.13). Two other popular responses were “go to a mental hospital” and “see a psychiatrist” (p.13).

Within their study, Fox and colleagues (2010) asked children what would happen to vignette characters that had depression or anorexia. The most cited consequence for depression was that the person in the vignette would need help and support from relatives. This was followed by seeing a doctor and having therapy. The most cited consequence for the vignette character with anorexia was that they would need to see a doctor. This was closely followed by needing to have an operation. Other common responses included having therapy and seeing a doctor. Fox and colleagues (2010) asked a second group of children similar questions as a part of a second study. In this group they found that children most often recommended the vignette character with depression “have therapy” and the character with anorexia “see a doctor” (p.615).

4.7.3.2 COPMI understanding of treatment and consequence of mental illness

Garley and colleagues (1997) briefly address treatment within their study examining COPMI views of mental illness. Children of parents with mental illness within this study discussed mental illness as “something that could be controlled rather than cured” (p.101). Medication, hospitalisation and treatment from a psychiatrist or counsellor were all seen as ways to help control the illness.

Finney and Falkov (2009) state that the way children describe their parent’s treatments for mental illness become increasingly elaborate with age. Tablets and medication were the only treatments cited in Finney and Falkov’s paper. Younger children may believe that tablets can cure their parent’s illness whereas older children understand that symptoms may be controlled but the mental illness will not be cured.

4.7.4 Timeline of mental illness

The illness component ‘*timeline*’ refers to ideas people hold about what happens to people with mental illness over time. It includes ideas about whether mental illness may be cured.

The table below (Table 8) shows the studies which examine children’s understanding of the timeline of mental illness.

Table 8
Studies Examining the Length of Mental Illness

Author (year)	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Country	Disorder
Non-COPMI studies						
Fox, Buchanan-Barrow, Barrett (2007)	Quantitative	Hi-log linear analysis	5-11	89	UK	Depression, Schizophrenia, Anorexia
Fox, Buchanan-Barrow, Barrett (2010)	Quantitative	Hi-log linear analysis	6-11	240	UK	Depression & anorexia
COPMI studies						
Garley, Gallop, Johnston & Pipitone (1997)	Qualitative	Not stated	11-15	6	USA	Mood disorder
Cogan, Riddell & Mayes (2005b)	Qualitative	Thematic analysis	12-17	40	UK	Affective illness
Finney & Falkov (2009)	Qualitative	Not stated	8-12	Not stated	Australia	Range of mental illnesses

4.7.4.1 Non-COPMI understanding of the curability or timeline of mental illness

Children within the study conducted by Fox and colleagues (2007) were asked about the curability or timeline of mental illness. Only significant effects were reported. When talking about depression, seven to nine year old children were more likely than 10 to 11 year olds to state that the illness would last “less than one month” (p.13). The 10 to 11 year old children were more likely than five to seven year olds to state that the illness would last “one year” (p.13). When talking about schizophrenia, seven to nine year olds were more likely than 10 to 11 year olds, to state that the illness would last “less than one month” (p.13). The participants aged 10 to 11 years old were more likely than the five to nine year olds to state

that the illness would ~~never~~ go away (p.13). No findings were reported for the participant's views on the timeline of anorexia.

The more recent paper by Fox and colleagues (2010) examined children's perception of both curability and timeline of mental illness (among other illnesses). Children in this study were aged six to 11 years old. Overall children endorsed the ~~less than one month~~ response regarding the curability/timeline of depression and ~~six months to one year~~ for the curability/timeline of anorexia (p.616). Analysis of responses by age group provides further detail about children's ideas about curability/ timeline. When discussing depression, children aged six to seven years of age were more likely to endorse ~~less than one month~~, children aged eight to 11 years of age were more likely to choose ~~one to six months~~ (p.616). When discussing anorexia, children aged six to seven years of age, as well as those aged 10 to 11 years of age, were more likely to choose ~~one to six months~~ whereas children aged eight to nine years of age were more likely to choose ~~six months to a year~~ (p. 616).

4.7.4.2 COPMI understanding of curability or timeline of mental illness

Although not specifically asked about how long they thought their parents would have mental illness, some of the children within the study conducted by Cogan and colleagues (2005b) provided information about this within their interviews. Some of the children within the study stated that they believed their parent would have mental illness forever. There were also children within the study who described wanting their parent to ~~get better~~ or ~~get cured~~ (p.57).

As stated in the previous section, the COPMI within the study by Garley and colleagues (1997) discussed mental illness as ~~something that could be controlled rather than cured~~, suggesting that their parent would have mental illness for life.

Finney and Falkov (2009) discuss children’s ideas about prognosis of their parent’s illness. They state that younger children may see mental illness as having a prognosis similar to a cold or other common childhood illness, that is brief and with an end point. As children get older they might come to understand that their parents may have periods when their symptoms are reduced and other periods when their symptoms increase. Older children may develop an understanding that their parent will have mental illness for life.

4.7.5 How do children acquire their information?

Although it is not one of Leventhal’s illness components, in line with the overarching theme of this thesis, the question of the source of children’s information about mental illness is included here. The table below (Table 9) shows the studies that included information about how their participants found out about mental illness.

Table 9
Studies Examining Sources of Information

Author (year)	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Country	Disorder
Non-COPMI studies						
Secker, Armstrong & Hill (1999)	Qualitative	Thematic analysis	12-14	120	Scotland	Mental illness
Schulze & Angermeyer (2005)	Both	Not stated	16	293	Germany	Schizophrenia
COPMI studies						
Garley, Gallop, Johnston & Pipitone (1997)	Qualitative	Not stated	11-15	6	USA	Mood disorder
Handley, Farrell, Josephs, Hanke & Hazelton (2001)	Qualitative	Thematic analysis	11-15	4	Australia	Major affective disorder
Riebschleger (2004)	Qualitative	Thematic Analysis	5-17	22	USA	Mood disorders, Schizophrenia, PTSD
Cogan, Riddell & Mayes (2005b)	Qualitative	Thematic analysis	12-17	40	UK	Affective illness

4.7.5.1 Non-COPMI sources of information

There are few studies which have examined where children's information about mental illness comes from. The studies which focussed on non-COPMI all stated that these children most often received information about mental illness from the media, most commonly television. Schulze and Angermeyer (2005) found that two thirds of their participants (secondary school students from Germany) obtained information about mental illness from the media. The remaining participants received information from friends and family, school and books. Cogan and colleagues (2005b) results were similar in that of the children within her study who did not have a parent with a mental illness, the majority cited media as their main source of information.

Although not specifically asked about the source of their understanding of mental illness, some children within the study by Secker and colleagues (1999) did talk about where some of their information came from. Participants within the study gained information from media sources such as popular television programs.

4.7.5.2 Sources of information for COPMI

There are few studies examining the source of information about mental illness for children of parents with mental illness. Interestingly, the findings of each of the studies are quite similar. Generally children cited their own experience (for example, experiencing a parent's change in mood or behaviour) as the main source of information. Of interest are the reports within these studies of children not receiving any information. Handley and colleagues (2001) found that the children within their study "experienced a reluctance on the part of significant others, including teachers, to talk about mental health issues" (p.225). Additionally some children within the study were told nothing about parent's illness and some were given conflicting information from different family members.

Similarly most of the children within Riebschleger's (2004) study, who were also children of a parent with mental illness, stated that they had not been told about their parent's mental illness until they had attended a preventative program. Participants within the study conducted by Garley and colleagues (1997) spoke about knowing that their parents had certain symptoms but not being able to find out any information about it. In one case a child spoke about actively researching her father's illness in the library at school.

The children of parents with mental illness within the study by Cogan and colleagues (2005b) cited their own experience, their parent telling them, their own research or information from older siblings as being the source of their understanding of their parent's illness. The children within this study also spoke about their parents trying to conceal their illness from their children. Only three of the 20 children of parents with mental illness in this study had spoken to a mental health worker regarding their parent's illness.

4.8 Discussion

This review was conducted in order to examine the extent of research into children's understanding of mental illness. The review was structured according to five of Leventhal's illness domains and one additional domain. This allowed a diverse and disparate body of research to be collated and presented in a meaningful way. This section will briefly examine the key findings from each section of the review.

The research around children's ideas about identity (signs and symptoms of mental illness and the labels used) indicates that non-COPMI generally associate mental illness with negative labels and symptoms. Non-COPMI participants were more likely than COPMI participants to use words or terms which implied that people with mental illness were dangerous and

unpredictable. Derogatory words such as crazy, nuts, dumb and weird were also common among non-COPMI participants.

Not surprisingly, COPMI participants did not view their parent's illness in the same way as non-COPMI participants perceived other adults with mental illness. COPMI children talked about their parent being grumpy, yelling, being angry and sleeping more, among other things. COPMI children didn't use words such as crazy and nuts to describe their parent's illness, nor did they portray mental illness as dangerous. Given that the age groups of the children within some of the studies were similar, it appears that Piaget's ideas about children of certain ages only possessing limited knowledge about illness may not fit with the current findings. The ideas of Vygotsky, that children can be helped to learn more through the input of others, may be a better theory through which to view the current findings: that COPMI had more sophisticated knowledge about mental illness than non-COPMI.

Although there were a number of causes of mental illness cited within each study, the majority of participants within each study cited similar causes. Causes cited included stress, traumatic events (in childhood or currently) and genetics. Unlike non-COPMI participants, some COPMI cited themselves as the cause of their parent's mental illness.

When asked about treatment of mental illness children's responses were varied, however there were a number of similar responses given. For non-COPMI these included suggestions that the person with mental illness be hospitalised or that they should see a doctor. Help from relatives and friends was also cited. For COPMI participants, generally medication and hospital was seen as a possible treatment for their parent's illness.

Few studies examined the timeline of mental illness. Those that did generally found that younger children believed that people with mental illness could get “better” over time. Older children were more likely than younger children to state that people with mental illness would have the illness for life. The findings appeared to be similar for both COPMI and non-COPMI.

In terms of the source of information about mental illness, non-COPMI were more likely than COPMI to state that they had learnt about mental illness from the media. Some COPMI also cited the media as the source of their information; however they also cited their own parents and their own research, among other sources. Children of parents with mental illness commonly experienced difficulty attempting to find out information about their parent’s illness.

Within this review, each of the studies examining COPMI understanding of mental illness had a relatively small sample size in comparison to non-COPMI studies. Sample sizes ranged from four to 22 COPMI within a study. The small sample sizes, coupled with only a small number of studies which provide information about COPMI understanding of mental illness make it hard to develop a clear picture about COPMI comprehension of mental illness across all domains.

The Leventhal framework has been widely utilised within research examining adult and children’s conceptualisation of physical illness (Petrie & Weinman, 1997; Horne and Weinman, 2002). The research within the physical illness domain indicates that this framework is a useful tool to elicit both adult and child understanding of illness.

The majority of studies included here examined one or two aspects of Leventhal's illness perception model. Very few studies examined the understanding of identity, cause, treatment, and timeline within the same study, using the same group of participants. Within the current review, Fox and colleagues' two studies (2007, 2010) of non-COPMI utilised the Leventhal framework (examining all domains except for identity) and provided the most comprehensive information of all studies about children's conceptualisation of mental illness. To date, the domains within the Leventhal illness perception model have not been used to examine COPMI understanding of their parent's illness.

It is likely that the examination of beliefs about all aspects of mental illness will provide a more comprehensive, and more accurate, picture of what is known about mental illness. As Leventhal and Cameron state; ~~the~~ examination of isolated variables may prove valuable in particular situations, but will do little to advance understanding or aid in the development of a communicable body of knowledge" (Leventhal & Cameron, 1987, p. 134).

The findings of this review indicate that in comparison to what is known about children's ideas about physical illness, few studies have examined children's understanding of mental illness. Of those that have, the majority have examined non-COPMI understanding of mental illness. In almost all domains of illness understanding there were key differences between non-COPMI and COPMI understanding of mental illness. It is not appropriate to use what we know about non-COPMI understanding as the basis for what COPMI understand about parental mental illness. Research examining COPMI understanding is still in infancy and is limited by small sample sizes and a lack of dedicated research into COPMI understanding alone.

It is clear from this review that the scant research into COPMI understanding of parental mental illness could be significantly enhanced by researching all domains of illness through the use of a Leventhal framework. Ideally a larger number of participants would be recruited as well as participants in a wider range of ages, to give a clearer picture of COPMI understanding of mental illness at different ages. With each of these factors in mind, the second study, Study two: Children's ideas about their parent's illness; symptoms, cause, treatment, timeline and consequences for the family was developed.

Chapter Five: Study Two, Part I – Children’s ideas about their parent’s illness, symptoms, cause, treatment, timeline and consequences for the family

As shown in the literature review in Chapter One, there has been a strong call for children to be educated about a parent’s mental illness (AICAFMHA, 2001; Owen, 2008). COPMI themselves have requested more information about parental mental illness (Cogan et al., 2005a; Fudge & Mason, 2004; Garley et al., 1997; Handley et al., 2001; Meadus & Johnson, 2000; Pölkki et al., 2004; Riebschleger, 2004). Educating a child about a parent’s mental illness has been suggested to increase resilience in COPMI and ameliorate some of the detrimental effects of being a child of a parent with mental illness (Beardslee & Podorefsky, 1988; Garley et al., 1997; Goodman et al., 2011). Within the scarce research examining ACOPMI experience, ACOPMI have stated that they did not receive information about their parent’s illness and that this would have been helpful (Dunn, 1993; Foster, 2010; Kinsella & Anderson, 1996; Knutsson et al, 2007; Pölkki et al, 2005).

In order to provide COPMI with useful age-appropriate information, it is important to first examine what COPMI understand about parental mental illness at various ages (Stallard et al., 2004). As Finney and Falkov (2009) state, intervention is more effective when COPMI feelings and beliefs about their parent’s illness are known.

Chapter Four, ‘Review- Children’s understanding of mental illness’, highlighted that although there is a growing body of literature about non-COPMI understanding of mental illness, very little is known about what children know about their own parent’s illness. In addition,

although the studies utilising the Leventhal domains to assess non-COPMI understanding of mental illness (Fox et al., 2007, 2010) yielded the most comprehensive account of understanding of mental illness, there is no published research which examines COPMI understanding from a Leventhal perspective.

Chapter Four demonstrated that although there are some similarities between non-COPMI and COPMI understanding of mental illness, in some domains understanding is qualitatively different. There is a need for research into COPMI understanding of parental mental illness.

There are two previous studies which have examined COPMI understanding of mental illness which are worth highlighting here. These two studies and the researchers who conducted them, were instrumental in the early stages of the development of this study. Falkov (1995) conducted a study into COPMI (aged eight to 14 years old) and their parents and examined, among other things, COPMI understanding of mental illness. Finney (personal communication, 2006) also conducted a study into COPMI understanding, examining understanding in eight to 12 year olds. Although these studies are unpublished and do not follow a Leventhal approach to examining COPMI understanding, this research, along with discussions with Falkov early in the development of this thesis, shaped the researcher's thinking around this topic.

This study sought to build on the work of both Falkov and Finney in three main ways. Namely to examine the understanding of parental mental illness of a large sample of COPMI, of a wide range of ages, using a Leventhal framework. Aspects of these have been examined within the two studies by Finney and Falkov however they have not been examined within the same study.

The current study explores children's understanding of their parent's mental illness. It builds on the very scant literature in this field. This study will give a much needed insight into what children of parents with mental illness know about their parents' illness, what they'd like to know and how they found out about their parent's illness. It will also contribute to what is already known in the wider field about what children generally know about mental illness.

5.1 Aim

The main aim of this study is to examine children's understanding of their parent's mental illness. Specifically this study aims to explore children's understanding of five domains of mental illness: symptoms, cause of illness, treatment of illness, timeline of illness and consequence of illness. This study also examines children's views about how they found out about their parent's illness and whether they feel that they need further information. The analysis and discussion of how children find out about mental illness are presented in the following chapter, Chapter Six.

5.2 Method

The methodology utilised for the entire thesis is documented within Chapter Two:

Methodology. Although it is documented elsewhere, it is worth briefly revisiting some of the pertinent information here to reorient the reader and assist in understanding the current chapter.

Forty participants were interviewed for the current study. Although parents provided consent for all children to participate in a study examining children's understanding of the parent's mental illness, one child appeared unaware of her mother's illness. As stated in the Methodology Chapter, the interview with this child was discretely concluded and her data has not been included within this chapter.

The Methodology Chapter highlighted that the interview responses from the child participants were analysed in the same way as the parent interviews, using thematic analysis. Interview responses have been broadly analysed under the five Leventhal domains of illness understanding, that is Identity, Cause, Treatment, Timeline and Consequence. The remainder of this chapter has been structured accordingly.

Originally this study was concerned with examining what COPMI knew about parental mental illness. Specifically it was concerned with examining COPMI views of mental illness at different ages. The premise behind this aim was that there would be different responses from younger children and older children. In depth analysis of the data indicated that frequently there was little noticeable difference between the answers of younger children and older children. That is, often the answers given by younger children were similar to older children's answers. Sometimes younger children's responses appeared more comprehensive than older children's responses and rarely were older children's responses noticeably more complex than younger children's responses. With this in mind, the focus of the analysis was redirected and children's responses were analysed as a whole, not in age groups. Where there were age-related differences in responses these have been noted within the appropriate theme below. Where there are no age-related differences noted, there were no age-related differences found within the analysis. For example younger children were equally as likely as older children to use the correct term for their parent's illness, for example calling it schizophrenia or depression. Accordingly there is no age-related difference noted for that theme.

As with the parent chapter, there is an extensive body of data presented within this chapter. Accordingly, the discussion of the analysis of this section has been incorporated into the

analysis to assist with reading this chapter. In addition, the clinical implications of the results are discussed throughout.

5.3 Analysis and discussion

Prior to discussing the themes analysed within this chapter it is worth noting the high use of the initial response “I don’t know” by children within the present study. As highlighted within the analysis, often children responded to questions regarding aspects of their parent’s illness with the response “I don’t know”. Generally, after assuring the child that there were no single correct responses to the questions, children would provide a response. Children were able to provide articulate and thoughtful responses after seemingly not knowing the answer to a question.

The use of “I don’t know” within interaction has been examined within the field of Conversation Analysis. Conversation Analysis is a technique used to examine conversational interaction in depth. Whereas thematic analysis examines themes within people’s talk, conversation analysis examines the interactional actions within conversation. From a conversation analytic perspective, the use of “I don’t know”, instead of being viewed as an indication that the speaker does not actually know the answer to a question, has been recognised as a way to demonstrate uncertainty about what it is the speaker is about to say (Beach and Metzger, 1997). In the current study, the use of “I don’t know” seems to work to warn the interviewer that the response the child is about to provide is not based on factual information and that the child is unsure about whether what they are saying is right.

The clinical implication here may be that when talking to COPMI about parental mental illness their initial response of not knowing about aspects of their parent’s mental illness may not indicate that they do not know anything about their parent’s illness. COPMI may have

well formed and considered ideas about aspects of parental mental illness but may be unsure of the acceptability of these ideas. By assuring COPMI that the interest lies in their ideas about their parent's mental illness and not the "right" or "wrong" answer, this may provide an avenue for COPMI to offer their own theories about aspects of mental illness.

5.3.1 Identity of mental illness

As discussed in the methodology chapter, all child interviews were preceded by a significant amount of time spent building rapport between the interviewer and child participant. During this time we discussed aspects of the child's life such as school, pets and siblings. As reported in the methodology section, a discussion was had with parents regarding the most appropriate way to broach the discussion of mental illness with their children. For example some children knew the word "schizophrenia", others were familiar with the term "mental illness", some parents thought their children may only know that their parent was "sad". This information framed the discussion of the consent form as well as the way the first interview question (regarding what illness their parent had) was asked.

5.3.1.1 What illness does your parent have?

Children were asked what illness their parent had, the terms used when talking about the illness at home or their own terms they used when talking about their parent's illness.

Analysis highlighted that there were four main approaches to talking about the type of mental illness their parent had. The majority of participants (29 of 40) talked about their parent's illness in diagnosis-specific terms. These included words such as "depression", "schizophrenia", "paranoid schizophrenia", "bipolar", "manic depression" and "anxiety". Four children talked about their parent's illness using the general term of "mental illness". One child used her own word, "dizzy dozy", when talking about her parent's mental illness. Seven participants did not have a specific word or specific terminology to talk about their

parent's illness. These children either did not know an illness-specific word to use, rarely talked about the illness and therefore didn't feel the need for a term (for example stating "we don't really talk about it") or did not know about their parent's illness at all. The general term "mental illness" and lack of a term to describe their parent's illness occurred more often in younger participants, however it was not restricted to younger participants. Likewise, the use of diagnosis specific terms occurred more often in older participants but was not restricted to older participants.

Of note was that no child used the term "borderline personality disorder" even though this was one of the more common mental illnesses among their parent's. This was not surprising given that parents themselves had difficulty talking about the diagnosis of borderline personality disorder and given the increased stigma around the diagnosis (Aviram et al, 2006).

5.3.1.1.1 Not sure or incorrect knowledge about illness

Only four children provided responses that fitted into this category. When asked about their parent's illness, these children generally discussed illnesses other than mental illness. For example, when asked why his mother had gone to hospital recently, one child cited physical reasons.

Extract 146

Interviewer (I): What sort of stuff does she go into hospital for?

Child (C):I don't really know (laughs)

I: If you had a guess?

C: I know once she went in.....of um.....cause.....oh.....she kept on coughing during the night

I: And what about the other times?

C: mmm.....I think she just feels really sick

I: Do you know where in her body she is sick?

C:In her stomach....?

(Son of mother with Obsessive Compulsive Disorder and depression, 9 yo)

Another child knew her mother had bipolar disorder but her description of the illness seemed inconsistent with the common symptoms of bipolar disorder.

Extract 147

Yeah...it's not really that big a deal sometimes mum just can't read stuffshe needs me to explain stuff to her that's about it...

(Daughter of mother with bipolar disorder, 16 yo)

One child stated that his father was the one with the illness although his mother had bipolar disorder. Later in the interview the child remembered that his father has diabetes.

Interestingly the child knew that his father could die if he didn't have enough sugar, however he did not know details about bipolar disorder.

Extract 148

I: And which one has it [mental illness] your mum or your dad?

C: I think ...my dad

I: What's wrong with him?

C: He has.....I forgot

(Son of mother with bipolar disorder, 9yo)

5.3.1.1.2 Child knows parent has illness but is unsure of what that means

Some children seemed to have slightly more knowledge about their parent's illness. They knew which parent had the illness but did not seem to be able to provide an explanation of the illness or symptoms.

Extract 149

C: Uh.....she didn't tell me anything she just said mental illness.....well not just that, she said she had problems

I: Do you remember what sort of problems?

C: No

(Son of mother with Borderline personality disorder and schizoaffective disorder, 7yo)

Similarly, there appeared to be confusion with some children about symptoms and whether symptoms are due to mental illness or physical illness.

Extract 150

Oh yeah she sleeps a lot.....she.....(thinking).no no no....thats because she has diabetes.....

(Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 8yo)

Extract 151

...I never know if she's actually just like physically sick or mentally sick ...I would never be able to tell the difference...

(Daughter of mother with depression, 17yo)

5.3.1.2 Symptoms of illness

All children were asked about what symptoms of mental illness their parents had. Some children were initially unable to provide an answer to this question and the concept needed to be explained in more detail. For example, with younger children, if it was clear that the word ‘symptom’ was confusing, then they were asked if their parent’s illness made their parent different to other parents without mental illness. Alternatively participants were asked if there were times when their parent was “good” or “better” and if there were times when their parents were “worse” or when their illness was “bad”. Given the episodic nature of many of the parent’s illnesses, some children were able to articulate the differences in behaviour when their parents were sick compared to when their parents were well. All children were aware of some symptoms of their parent’s illness. Analysis of children’s discussion of this question highlighted that there were a number of symptoms that were recognised by a large number of

children and there were some symptoms recognised by only a few children, as can be seen in *Figure 7* below. Prominent symptoms are discussed below in order of most commonly cited.

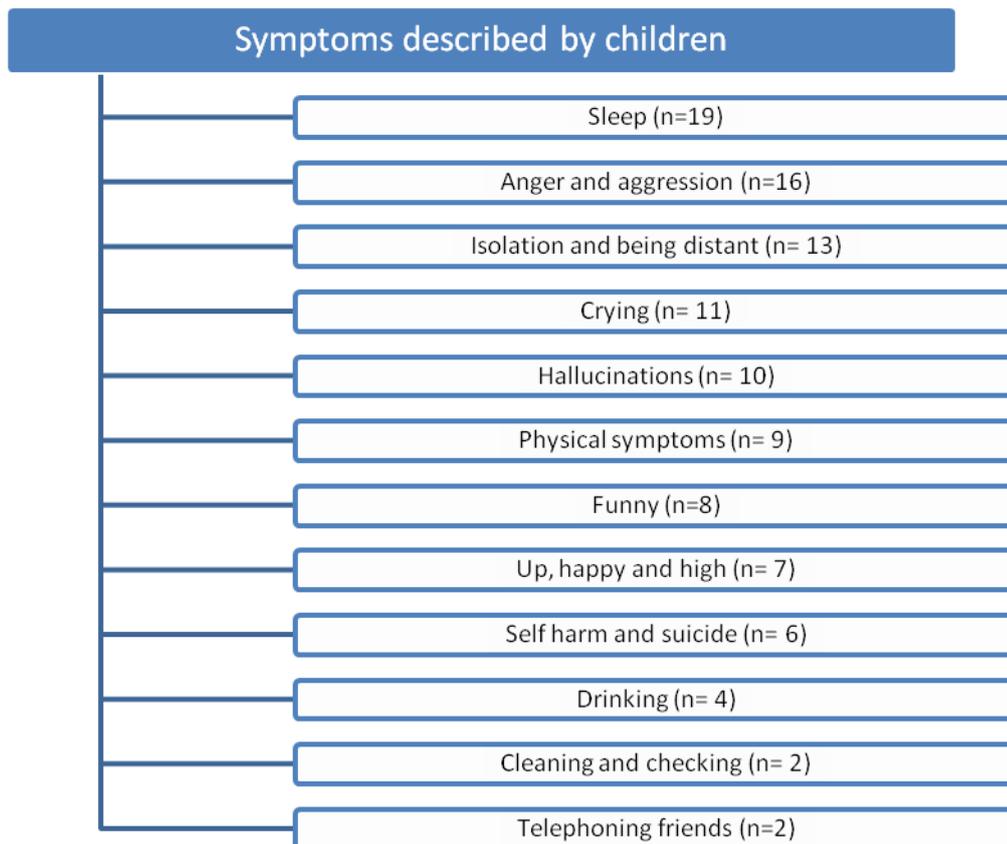


Figure 7. The symptoms described by children in order from most to least endorsed.

5.3.1.2.1 Sleep

When asked about illness symptoms displayed by their parents almost half of the children interviewed (19 of 40) discussed sleep or staying in bed. Only one child mentioned a parent's inability to sleep, all others spoke about an excess of sleep or time spent in bed.

Extract 152

....usually she's just sleeping in a lot because.... Like..because....she's tired from the depression

(Son of mother with depression and post traumatic stress disorder, 10 yo)

Extract 153

Yes....I always remember mum sleeping quite um.....always quite well...and quite longer than usual...

(Son of mother with schizoaffective disorder, 15 yo)

Sleep is rarely cited by non-COPMI as a symptom of mental illness but has been cited in other studies on COPMI as a symptom that their parent experiences (Finney & Falkov, 2009; Valiakalayil et al., 2004).

5.3.1.2.2 Anger and aggression

The second most common symptom cited by children (16 of 40) was anger or aggression. Children discussed their parents being angry or aggressive towards the other parent, other people outside the family and, most commonly, towards the children themselves.

This theme encompassed all levels of aggression. For example lower levels of aggression, such as grumpiness or being ~~a~~ bit mad”, as described in the two quotes below.

Extract 154

she's grumpy at us during the days so we just leave her alone and we know why it is....why it is and everything.....um...

(Daughter of mother with schizophrenia, 17yo)

Extract 155

...if you speak to her and she's a bit mad in her voice

(Son of mother with bipolar disorder, 10 yo)

The majority of children who discussed the theme of anger and aggression, talked about their parent being angry.

Extract 156

..... she used to ring me up from the hospital she used to, sometimes she'd be so mean to me that I'd start crying and.....(step mum) kept telling me it's just her illness talking, don't worry about it and.....((..)).....she used.....like she used to get really uptight about things and angry.... a lot.... for no reason

(Daughter of mother with schizophrenia, 13 yo)

Extract 157

Well ...like when he's really depressed..I can like see it in his anger and that..

(Daughter of father with depression, 10yo)

Extract 158

..he always like targets an individual person which is mostly me and um like I don't know he targets anger out on me or like mum or (older brother)

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Only a few of the children who discussed anger and aggression talked about physical violence.

Extract 159

Um...he just is like a bit more aggro and everything ...(..)..Like usually he's happy and stuffbut um... he, he just was different...like you could tell like.....um.... he just pulled stuff apart and he doesn't usually pull stuff apart (laughs)

(Daughter of father with schizophrenia, 11 yo)

Extract 160

..if she gets depressed while we're there she might start throwing things around... yeah

(Son of mother with bipolar disorder, 12 yo)

Extract 161

I: What sort of things does the illness make him do?

C: Oh it affects him mentally... like his temper...his...attitude...the way he sees life and stuff like that

I: Does it make him do anything else?

C: Oh he gets pretty violent

(Son of father with antisocial personality disorder, 16 yo)

As shown in the review chapter in Chapter 4, in previous literature children cited a range of labels and symptoms associated with mental illness. Non-COPMI participants often used words or terms which implied that people with mental illness were dangerous and unpredictable (Callan et al., 1983; Cogan et al., 2005b ; Poster, 1992; Poster et al.,1986; Sedley, 2002). Children of parents with mental illness within the current study talked about their parent being angry which was generally indicated through an angry tone of voice or choice of words. Approximately 5 participants in the current study perceived their parent to be dangerous.

5.3.1.2.3 Isolation and being distant

When discussing their parent's symptoms a number of children (13 of 40) discussed a range of symptoms which could be grouped under the theme of 'isolation and being distant'. This theme encompasses comments from children in which they had a perception of their parents being socially or physically isolated from other adults and isolated from the children themselves. The theme also encompasses comments from children in which they referred to a perception of parents not doing "stuff" with them or not responding to them. The quotes below include discussion of what the parent is like when not symptomatic as examples of how the parent is different when symptomatic.

Children talked about parents not doing –stuff” with them. –Stuff” included practical things such as being picked up from the bus stop, cooking dinner and doing activities, such as baking.

Extract 162

C: Um...well she’s actually good when she’s not depressed like she might actually like she might get up and cook dinner and stuff yeah... ((..))...pick us up from school....yeah

I: So when she’s not depressed she’ll pick you up from school?

C: Yeah....yeah.....when she picks us up from the bus stop

(Son of mother with bipolar disorder, 12 yo)

Extract 163

She doesn’t do stuff

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

One child talked about the reduction of symptoms when her mother changed medication.

Extract 164

Oh she’s more awake and everything, she’s baking and everything, she’s more awake, she’s like “let’s do something”...we’re like “oh.... ok...”

(Daughter of mother with schizophrenia, 17yo)

Reduction in communication with children was highlighted by some children. This included the child perceiving that their parent wasn’t listening to them and a reduction in their parent talking with them.

Extract 165

..she never listens

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 166

*Yeah she like....her brain goes weird and um it makes them not feel like talking that much
...yeah and they usually like nod or wave and stuff instead of just talking at all*

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Extract 167

....sort of not communicate and shut down a bit

(Daughter of father with depression, 14 yo)

A parent isolating themselves, from both their children and from other people, was also mentioned within the interviews. Children of all ages talked about their parent's isolation or distance, however older children were more able to articulate the concept of isolation. For example older children were more inclined to use the word 'isolation' whereas younger children were more likely to state that their parent went for walks on their own.

Extract 168

He'll isolate himself

(Daughter of father with depression, 14 yo)

Extract 169

a lot of his time is spent upstairs..(..).. we sort of refer to him as "him upstairs" 'cause um... you know a lot of the time he wouldn't come down and it would just be like this snoring from upstairs so you'd just know that there's someone there and you can't see them...

(Daughter of father with bipolar disorder, 16 yo)

Extract 170

...I don't know she just.....oh.....it's really hard to say.....um.....just little things like.....I don't know.....like...(..).....um.....maybe.....I think she's not as sociable as....other people as well...like friendship wise.....she hasn't got as many friends as..... say my friends parents probably do...and stuff like that...yeah....

(Daughter of mother with schizophrenia, 13yo)

A reduction in emotional connectedness was also mentioned within a few of the interviews.

Extract 171

...like when he's relaxed...he's really nice.... and he always gives me cuddles and kisses and stuff

(Daughter of father with depression, 10yo)

Extract 172

C: usually he's like really happy and funny and if I say "I love you" he'll say it in a weird way back to me ...it's funny

I: And if he's sick he won't do that?

C: No

(Daughter of father with schizophrenia, 11 yo)

Extract 173

Um...yeah ...he used to be a bit more playful

(Daughter of father with depression, 14 yo)

Interestingly, one child discussed an increase in physical affection as a marker that her parent was symptomatic. This was in addition to other symptoms such as crying.

Extract 174

....my mum when she's...sort of upset and stuff...she would...like she gives me lots of cuddles and when...she cuddles me and my brother um.....she cries.....

(Daughter of mother with depression, 10 yo)

Older children were more able to articulate the symptom of isolation, many using the word "isolate", although children of all ages talked about behaviour associated with isolation. The

symptom of isolation is not cited by non-COPMI but has been cited by children within other research focussed on COPMI (Garley et al., 1997; Meadus & Johnson, 2000; Riebschleger, 2004; Valiakalayil et al., 2004).

5.3.1.2.4 Crying

Another common symptom that children discussed, was crying or being upset. About a quarter of the children interviewed talked about their parent crying or being upset.

Extract 175

C: she cwies (said in a childish voice)

(Daughter of mother with bipolar disorder, 8 yo)

Extract 176

..... gets upset....abouteither really little things or nothing

(Son of mother with depression and post traumatic stress disorder, 10 yo)

Extract 177

... well she usually starts getting teary...((...))...Well....if she's depressed usually um.. she might be in bed crying

(Son of mother with bipolar disorder, 12 yo)

When talking about parent's symptoms, younger children mentioned crying more often than older children.

5.3.1.2.5 Voices/hallucinations

Hallucinations (both auditory and visual) were mentioned by about a quarter (10 of 40) of the children interviewed. Four of the children had been actively involved in the hallucinations and recounted specific scenarios where they had seen this symptom. Two children did not talk

about this symptom even though their parent had mentioned hearing voices or having other hallucinations within their interview.

Extract 178

C: Um..I worked that out the hard way...um...he um... he like was looking for bugs and everything...like cameras and he kept asking me if my mumhad any cameras or anything.... He ended up breaking his computer

I: Looking for things?

C: Yeah

I: So you know when he's getting sick because he does stuff like that?

C: Yeah

(Daughter of father with schizophrenia, 11 yo)

Extract 179

..... she hears voices all the time and...yeah...worries about our safety and everything as well.. ((...)) ...sometimes she starts talking to herself...and sometimes she's depressed and....yeah.....and like if there's something wrong I'll just say to mum "oh mum how long has it been since you've had your injection...do you need to go and check up on it and stuff"

(Daughter of mother with schizophrenia, 13yo)

Extract 180

I don't know...just went completely nutty, he thought there were aliens in the water tank and started all the showers running and took all his clothes off (laugh/snort)...strange things ...

(Daughter of father with bipolar disorder, 16 yo)

All other discussions about hallucinations were from children who had not been present for the symptom, instead they were aware of it through someone telling them. The question of how children find out information about their parent's illness, such as symptoms, is discussed later in this chapter.

Extract 181

he hears voices sometimes...

(Son of father with schizophrenia, 14 yo)

Extract 182

... uh unnatural ability to hear voices or to see things that are not naturally there or what society defines as not naturally there ...

(Son of mother with schizoaffective disorder, 15 yo)

One child was told on the day of their interview with me that his mother had auditory and visual hallucinations.

Extract 183

C: Well.....she didn't say anything at the time but today she said it causes her to see and hear fings (things) that aren't really happening.

I: Oh ok and what do you reckon she sees and hears do you know?

C: Phwaaar.....I don't really know.

(Son of mother with schizophrenia, 11 yo)

One child discussed their mother having hallucinations even though his mother did not mention hallucinations as a symptom that she was experiencing.

Extract 184

.....just makes them hear stuff in their mind and tells them to do stuff.....like.....that's pretty much it, voices.... in their mind

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

5.3.1.2.6 Physical symptoms

When asked about symptoms of their parent's illness, nine children talked about physical symptoms. These included symptoms such as feeling physically sick and also included symptoms that are visible to others such as shaking, walking "funny" or a difference in the way a parent's eyes look. Eight of the nine participants mentioned the physical symptoms in conjunction with other symptoms.

Feeling sick was mentioned by five children.

Extract 185

I: How do you know when she comes back that she's fine, does she look different?

C: No she doesn't look any different just um... cause sometimes she's um feeling sick and when she comes back she's not feeling sick she's feeling all better

(Daughter of mother with bipolar disorder, 8 yo)

Extract 186

I: Can you tell when mum needs to go into hospital before she tells you?

C: Yeah

I: How?

C: Cause she will stay in bed and say that I don't feel well.....and she feels really bad sometimes.....and when she walks up to put her breakfast there she doesn't feel very well

I: Are there any other signs?

C: Um.....she gets a little bit pale....

(Son of mother with obsessive compulsive disorder and depression, 9 yo)

Extract 187

.....she used to um.... always have a stomach ache and ..always be sick and....kinda talk herself into being sick instead of having a positive attitude and saying I'm going to get better.....

(Daughter of mother with schizophrenia, 13 yo)

Three children stated that shaking, or “the shakes” were a symptom of their parent’s illness.

Extract 188

..... sorta had the shakes and she couldn't really sit still...yeah....

(Daughter of mother with depression, 10 yo)

Extract 189

...I probably wouldn't see it as regularly but I know that her hands would be really shaky....

(Daughter of mother with schizoaffective disorder, 17 yo)

Two children described and demonstrated how their parent's eyes changed depending on whether their parents were symptomatic. The first child described how her mother's eyes changed when she was "dizzy dozy", the second child described how his mother's eyes were different when she wasn't symptomatic.

Extract 190

C: Um.....she...her eyes look kind of white..((...))...Um... she has um like um..a tired kind of eyes...

I: Does she look really sleepy?

C: Um like that (showed eyes half shut)...just relaxed...but a bit dizzy dozy

(Daughter of mother with bipolar disorder, 8 yo)

Extract 191

C: Um...her eyes aren't as ..(eyes slit).....like that as much...like she's never like that any more...her eyes aren't like.....weird

I: What did she used to be like?

C: Um.....she used to have her eyes all down and..... sit and smoke.....

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9yo)

Later in the interview the child talked about his mother's eyes again.

Extract 192

.... like mum's eyes usually all day when she had it were like (slit/droopy) and all the other ones are like (awake)...yeah...

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9yo)

Only one child mentioned that their parent walks differently as a symptom of mental illness

Extract 193

...she walks a bit funny... just a little bit side to side.....

(Daughter of mother with bipolar disorder, 8 yo)

When discussing their parent's mental illness symptoms, younger children were more likely than older children to mention physical symptoms.

5.3.1.2.7 Funny

Eight of the forty one children interviewed mentioned their parent acting in a *'funny'*, *'crazy'* or otherwise unusual way. Each of these terms were used as a description when asked about symptoms of their parent's mental illness.

Four children used terms such as *'strange'*, *'weird'*, *'crazy'*, *'freak'*, *'funny'* and *'silly'* when discussing symptoms of their parent's mental illness.

Extract 194

she goes crazy

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 195

I: And what does it make your mum do?

C: It makes her go all funny..(..).. Like she just acts...weirder...and differently..(..)..

she can't speak properly...she says all this funny stuff

(Son of mother with schizophrenia, 11yo)

Extract 196

like (stepdad's) got a problem like how he's like..um like a compulsive.... freak kind of thing...

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

One child repeatedly talked about his mother's brain or head changing when symptomatic.

Extract 197

....sometimes her head goes all strange...

Extract 198

....her brain goes weird....

Extract 199

....her head went wrong...

Extract 200

....her head problems...

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Another child had constructed her own term to describe her parent's symptoms. This child was unsure what was meant by the words "mental illness" and "bipolar disorder" and instead talked at length about her mother being "dizzy dozy". The word "strange" was also used to describe her mother's symptoms.

Extract 201

I: And can you tell, even if she didn't tell you she was feeling better could you tell?

C: Mm hmmm

I: How would you be able to tell?

C: Because she wouldn't be acting very much dizzy dozy..... at that time

I: So what's the difference between dizzy dozy and not dizzy dozy?

C:um.....when she's acting.... A bit strange....

(Daughter of mother with bipolar disorder, 8 yo)

Derogatory words such as crazy, nuts, dumb and weird were common among non-COPMI participants within the review in Chapter Four. Not surprisingly, the derogatory terminology among participants within this study was less frequent than was found in participants of non-COPMI mental illness research, although it was still present. This supports the research of Cogan and colleagues (2005 b) who compared COPMI and non-COPMI and found that non-COPMI were more likely to use derogatory terminology to describe people with mental illness.

5.3.1.2.8 Up, happy and high

Seven participants mentioned symptoms such as *_ups*‘, being *_too happy*‘, being *_high*‘ and feeling *_so good*‘. Almost all participants talked about these symptoms being associated with symptoms such as being *“too sad”* or being *“down”*.

Extract 202

...like...she’s getting.... Like she’s having..... ups and downs....

(Son of mother with bipolar disorder, 12 yo)

Extract 203

..... it makes her like sometimes too happy at one time and too sad at the other time...((...))... ..um...sometimes when she’s a bit too happy.....I can’t really explain.....uh sometimes she does stuff a bit differently...I can’t really explain it....sometimes she like lets me have a friend over and she like wants to do stuff with me

(Son of mother with bipolar disorder, 10 yo)

Extract 204

Umm...it really depends ...um at times...sometimes she can be really happy then just drop and cry and be angry all that sort of stuff...basically...(inaudible)..((..))....sometimes she just gets really really, really happy ...it’s just....weird... so I guess that’s part of it ...

(Son of mother with bipolar disorder, 15yo)

Extract 205

...sometimes through that time mum may be overly active...um...my family commonly call that the highs and lows....usually when there's quite a big high there's a dramatic low...

(Son of mother with schizoaffective disorder, 15 yo)

Older children were more likely than younger children to talk about a parent experiencing a 'high'.

5.3.1.2.9 Self harm and suicide attempts

When asked about their parent's symptoms five children talked about self harm or suicide attempts. Older children were more likely than younger children to talk about their parent attempting suicide or harming themselves.

One participant acknowledged that although he knew his father attempted suicide, his awareness of the details of the incident is vague.

Extract 206

I: Did he go into hospital at all?

C: Um he did a few times when he.....uh attempted suicide but again it's vague...

(Son of father with antisocial personality disorder, 16 yo)

Two of the children described specific instances of self harm or suicide attempt.

Extract 207

Uh she kept hurting herself...((...))...Um.....she ran out in front of cars sometimes....oh once...and..... she cut her wrist once....yeah....so things like that

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Extract 208

C: Um sometimes he walks out the house and we can't find him and we have to call (friends) up the road and they go search and we go searching and sometimes we can't find him that was the night that he went to (a nearby mountain) and he walked he was really depressed and yeah um I was really worried I was crying in my room

I: Why do you get worried?

C:um...suicide.....

(Daughter of father with depression,10yo)

Later in the interview the participant again talked about suicide.

Extract 209

...he's calming down, he's learning how to calm down more and...he's he hasn't like commit suicide that much at the moment

(Daughter of father with depression,10yo)

And later again in the interview.

Extract 210

..like um...at one stage like...different stages he said that he wanted to um...be suicidal and thatso yeah...

(Daughter of father with depression, 10 yo)

Extract 211

..and like there was a note and it had blood on it and there was a razor blade and I'm like that's really disgusting like I can't believe he did that

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Extract 212

..... and she wanted to.... commit suicide and I was likeOh my god....and she's like get everything sharp out of the house so I just took it all with me...

(Daughter of mother with schizophrenia, 13 yo)

Although only cited by approximately 14% of participants, the symptom of self harm is worth discussing here. Six participants knew about their parent self harming. Children talked about suicide generally and talked specifically about their parent cutting their wrists and running out in front of cars. It is beyond the scope of this thesis to compare all parent interview responses with their child's responses, however it is worth noting that parents had difficulty with disclosing suicide attempts and self harm behaviour to children (as discussed within Chapter Three). What is clear from this finding is that even though parents do not disclose self harm, some children appear to know about it. As Cain (2002) states in his review of theories about telling children about suicide, there is often an assumption that if a parent has not told a child about a sensitive topic then the child does not know. Cain's (2002) review highlights that contrary to this belief, children often know about sensitive topics that their parent has not disclosed. Not all children within this study were aware of their parent's self harm but there were a small percentage who were. Older children were more likely to talk about the symptom of self harm than were younger children.

Children's knowledge of self harm and suicide is rarely addressed within the literature examining both COPMI and non-COPMI perceptions of mental illness. One participant within the study conducted by Meadus and Johnson (2000) discussed their parent's self harm. It is unclear from the literature whether COPMI are unaware of self harm, whether researchers are not exploring this concept with child participants or whether children do not feel comfortable discussing it with researchers. It is clear that children, within this study at least, are aware of self harm. Importantly, there were two children out of the six participants who mentioned self harm, who had not spoken to their parent about the self harm. Knowledge of self harm in a parent, along with an inability to speak to others about such knowledge could place a significant burden on a child. If it is assumed that a child does not know about self harm in a parent then it could be very difficult for a child to raise this topic with their parent

and ask questions. This could lead to a child knowing only limited information about self harm, or knowing about self harm but not being able to clarify information that they are confused about. COPMI knowledge of self harm is an area which requires more research.

5.3.1.2.10 Drinking

Four children mentioned drinking alcohol as a symptom of their parent's illness. It is worth noting that three of the participants were from the same family.

Extract 213

Um...she used to...get drunk a lot

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9yo)

Extract 214

She was like..... "well...I've been really sick and all that because I suffer with depression and I drink..I used to drink to get away from it all but it just made me worse"

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

Extract 215

fine through the day and booze themselves...consume alcohol in the evening um and they fall asleep due to intoxication.....

(Son of mother with schizoaffective disorder, 15 yo)

5.3.1.2.11 Cleaning and checking

Only two participants discussed cleaning or checking behaviour as a symptom of their parent's illness. The two participants were from two different families.

Extract 216

.....she didn't like us to wear shoes in the house and stuff like that.....((...))...She cleans a lot.....and likes everything to be clean.....doesn't like you to bring dirt into the

house...((...))...She didn't like..... dust everywhere.....and thinks that there's germs outside.....and other people may think that but....they wouldn't go as hard as she is
(Daughter of mother with obsessive compulsive disorder and depression, 10 yo)

Extract 217

*C: Um... I don't know what its called.. but it's like umm...I don't know he always has to have... like everything perfect and he always has to double check stuff but um...((...))
.....always has to do everything perfect and yeah...*

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

5.3.1.2.12 Telephoning friends

Two children talked about their parents calling or chatting to friends as a symptom of their illness.

Extract 218

..... call a friend to pick her up and go chat for half an hour or an hour or...

(Son of mother with bipolar disorder, 12 yo)

Extract 219

She talks on the phone...

(Daughter of mother with depression and post traumatic stress disorder, 7yo)

There are clinical implications for the ways in which COPMI view the identity of their parent's mental illness. COPMI use a range of terms to describe their parent's illness, most frequently citing a diagnosis. Parental symptoms of sleeping, anger and isolation appear to be noticed by many COPMI. Some symptoms may be noticed by COPMI even though they have never been discussed within the family. When talking to COPMI about their parent's mental illness it is important to ask them about any possible symptoms they may be aware of.

5.3.2 Cause of mental illness and what can trigger a parent's symptoms

The second section of the interview examined children's views about what initially caused their parent's illness. It also explored children's ideas about what triggers or exacerbates a parent's mental illness symptoms. Analysis of children's responses resulted in a number of themes which are discussed here, in order of most commonly cited.

In comparison to the question about symptoms of a parent's illness, children appeared to have more difficulty answering questions about cause and triggers of a parent's illness. Often children had to be reminded that there was no single right answer to these questions. As discussed below, the most common response was that children didn't know what caused their parent's mental illness. Of the 28 participants who responded with "I don't know", 26 mentioned a possible cause for the illness after prompting. Children's ideas about cause, and the number of children who endorsed each cause, are presented below in *Figure 8*.

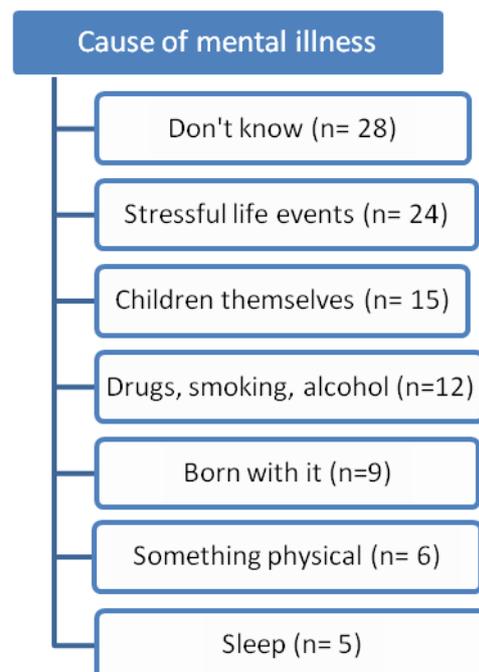


Figure 8. Children's perception of cause of their parent's mental illness

5.3.2.1 Don't know

Twenty eight of the 40 participants replied that they *‘didn't know'* what caused their parent's illness.

Extract 220

How would I know

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 221

Um...(laughs) I don't know...its real hard

(Son of mother with bipolar disorder, 10 yo)

Extract 222

No idea.....no idea.....

(Daughter of mother with schizophrenia, 17yo)

Even after prompting two children still stated that they didn't know what caused their parent's illness. The difficulty children had with answering the question of cause is hardly surprising. Adults too find this a complex question given that the etiology of mental illness is largely unknown (Spitzer & First, 2005).

5.3.2.2 Stressful life events

A stressful life event was the most commonly cited cause of parental mental illness or trigger for mental illness symptoms mentioned by children. Twenty four children mentioned an event or a situation that their parent had experienced which they believed either caused the mental illness initially or caused their parent's symptoms to worsen. The most frequently mentioned stressful events included family issues, work issues and stressful issues which occurred in childhood. Each of these will be explored in turn.

Family issues, as described by children, most commonly related to problems between the parent with a mental illness and the parent without. Divorce and going to court to get a divorce was seen as a possible cause of mental illness or a contributor to exacerbation of symptoms.

Extract 223

....um...when.....she found out that dad married (step mother's name) and that pushed her overboard

(Daughter of mother with schizophrenia and anxiety, 13 yo)

Other family issues included being geographically isolated from extended family, having a child removed from the parent's custody and having a miscarriage.

Extract 224

Uhh I think it was because we were so far away from her family and she didn't know anyone....

(Daughter of mother with schizophrenia, 13yo)

Extract 225

um.....that (youngest brother) has been taken away from her and ...stuff like that

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Extract 226

....but definitely I think it was also um...definitely the miscarriages most definitely...

(Daughter of mother with schizoaffective disorder, 17)

Issues at work were also cited by children as contributing to their parent's mental illness. The issues described by children included too much work, losing a job or general stress at work.

Extract 227

...like if something like they're laying people off at work or something...and he's a bit worried or something

(Daughter of father with depression, 14 yo)

Extract 228

...occasionally like she might do too much work one day and the next day she just breaks down..sort of thing

(Son of mother with bipolar disorder, 15yo)

Stressful issues in childhood were mentioned by a number of children when asked about the original cause of their parent's mental illness or what causes their symptoms to worsen.

Abuse as a child, the way a parent was raised and life in general as a child were all mentioned as contributing factors.

Extract 229

...maybe a bit of childhood...but I'm just guessing because I wasn't even alive then...

(Daughter of father with depression, 10yo)

Extract 230

Um...because sometimes when she was a kid people might have made her feel like too um like mad and sometimes...some people might have made her feel too happy and all of that

(Son of mother with bipolar disorder, 10 yo)

Extract 231

.....I reckon it's because like maybe someone did something to her when she was little or maybe something happened to her that she doesn't want to talk about

(Daughter of mother with bipolar disorder and post natal depression, 12 yo)

Within the review of prior research into children's perceptions of aspects of mental illness, stress and worry were commonly cited as causes of mental illness by both non-COPMI (Bailey, 1999; Callan et al., 1983; Sedley, 2002) and COPMI (Cogan et al., 2005 b; Finney & Falkov, 2009; Riebschleger, 2004; Valiakalayil et al., 2004).

5.3.2.3 Children

After stressful life events, the next most common participant response to the question of what caused a parent's illness or exacerbated their symptoms, was children themselves. Over a quarter of children interviewed cited children as a major contributor to parental mental illness. In rare cases children stated that parents not seeing children contributed to mental illness. For example:

Extract 232

sometimes she just gets worse because sometimes contacts have been cancelled

(Daughter of mother with schizoaffective disorder, 9yo)

In some cases the birth of children was viewed as causing the parent's illness.

Extract 233

Um it started off with....she got...'cause you get it after.... birth? Depressionyeah...I think she got it with (youngest brother) and then it just didn't seem to go away and it just progressed into depression and then they said it was bipolar later...so...

(Son of mother with bipolar disorder, 15yo)

In all other cases children stated that it was the presence of children which either caused the mental illness or triggered mental illness symptoms. In most cases children's behaviour was viewed as being responsible.

Extract 234

yeah she gets angry at us because we're fighting or something like that and then um...((...)).. and then mum would get depressed

(Son of mother with bipolar disorder, 12 yo)

Extract 235

we end up playing and making a big mess and when she wakes up she gets really angry

(Son of mother with depression, 10 yo)

Extract 236

Usually us getting in trouble or something stresses her out....

(Daughter of mother with schizophrenia, 17yo)

In some cases the work involved with raising children was seen to be the cause of mental illness or to exacerbate symptoms.

Extract 237

...well 'cause she's got a panic and anxiety attack and like if I move in with her she'll probably get a relapse because she'll get depressed because I'm there and she has to do everything for me and for her and um.....((...)).. She thinks that it was me who started the illness but then in that same week she told me it was dad's fault

(Daughter of mother with schizophrenia and anxiety, 13 yo)

The finding that children cited themselves as the cause of their parent's mental illness is not surprising given that COPMI commonly blamed themselves for their parent's illness within the studies cited in the review in Chapter 4 (for example, Bourke, 1998; Cogan et al., 2005b; Finney & Falkov, 2009; Riebschleger, 2004). This differs to the research examining non-COPMI understanding of cause of mental illness as non-COPMI obviously do not blame themselves, but nor do they cite the children of people with mental illness as a possible cause

of mental illness. One reason for this could be that non-COPMI do not believe that people with mental illness have children. This is a likely reason given that there are many service providers and researchers who do not believe that people with mental illness have children (AICAFMHA, 2001; Garvin et al., 2002; Risley-Curtiss, Stromwall, Hunt & Teska, 2004; Wang & Goldschmidt, 1996,).

Predominantly, children viewed their behaviour as responsible for mental illness. Fighting with siblings and making a mess were common behaviours thought by children to contribute to mental illness. Children also saw themselves as a burden on their parents, citing the amount of work a parent had to do to raise them as a contributor to mental illness. Self blame is clearly fraught with potential issues. How do children reconcile the belief that they have caused their parent's illness and the possible emotions this gives rise to? As stated within the broad literature review at the start of this thesis, feelings of guilt and low self esteem have been found within COPMI samples (Kelly, 1999; Lancaster, 1999; Taylor & Ingram, 1999). These feelings have been thought to develop as a result of children attributing their parent's illness to something they have done themselves (Lancaster, 1999). It is clear that children within the current study who have beliefs that they caused their parent's illness, for example stating "she'll get depressed because I'm there", could understandably experience feelings of guilt or low self esteem. In addition, research has shown that a child understanding that they are not responsible for their parent's illness is one of the central features of resilient COPMI (Beardslee & Podorefsky, 1988).

5.3.2.4 Drugs, smoking and alcohol

When asked about what they thought contributed to their parent's mental illness, 12 children stated that drug use, drinking alcohol or smoking could be responsible.

Drinking alcohol or smoking was mentioned by four children as a possible cause of mental illness.

Extract 238

I: How did she get the depression in the first place?

C: Um.....drinking and.....((...))...

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Eight children discussed drug use when asked about what caused their parent's mental illness or symptoms. Some children knew of a parent's history of drug use and thought that this contributed to a parent's mental illness.

Extract 239

..um.....I think.....um mum told me that he used to smoke and do drugs and stuff when they were in high schoolyeah...and he smokes as well

(Daughter of father with schizophrenia, 11 yo)

Other children had not been told by a parent about a parent's drug use but had been taught about it from different sources. The topic of how children learn about mental illness will be covered in more detail later in this chapter.

Extract 240

Well, er what I've been taught is that illegal drugs are able to do it and that.

(Son of mother with schizophrenia, 11 yo)

One child discussed how her belief about the cause of mental illness was changed after a discussion with her teacher. The extract below shows how her initial ideas changed and how she is now unsure whether drugs are responsible for her mother's illness.

Extract 241

'cause....I thought.....my teacher....cause we talked about um.... mental illnesses and I said to her...."I think my mum was born with it" and she goes "no you can't be born with it" and I'm like....."oh.....I don't know then" (laughs) I'm like "I don't know then" and she goes "well think about it....there's drugs" and I said "well I don't know what my mum did" like if there's anything....I have no idea what it is

(Daughter of mother with schizophrenia, 13yo)

The theme of drugs, smoking and alcohol was endorsed by almost a third of participants, of all ages, with the majority of those participants stating that drug use (rather than smoking or alcohol) contributed to their parent's illness. A small number of previous studies have also found support from non-COPMI for the idea that drug use (although not smoking or alcohol use) can contribute to mental illness (Cogan et al., 2005b; Fox et al., 2007; Sedley, 2002). The author is aware of only one previous study that reported that COPMI thought that drug use could be associated with their parent's mental illness (Valiakalayil et al., 2004).

Within the current study some parents stated that they did use drugs, or had done in the past, and children were told about this and told that there were risks inherent in using drugs and developing mental illness. Of particular interest are the children who stated that their parent's mental illness was caused by drugs when their parents had not stated that they had ever taken drugs. It is possible that parents did use drugs but did not openly discuss their drug use within the interview, although this seems unlikely. Children who had not been told by a parent about a parent's drug use, instead assuming it was drugs, had been told by teachers and support group workers (such as COPMI focussed support groups) that drug use can cause mental illness. It appears as though there is a message being taught to children about the links between drug use and mental illness. These links are valid as drug use can contribute to increased mental illness (Moore et al., 2007). Perhaps children in this case were taught about

typical causes of mental illness and they extrapolated the cause of their parent's illness from a list of causes including drugs. Alternatively, drug use and its role in mental illness could have been emphasised when talking to COPMI in an effort to dissuade them from taking drugs themselves, given their own heightened risk of developing mental illness.

It appears as though there may be a number of children, at least within the current study, who erroneously think that their parents are using drugs and that this drug use has caused their mental illness or exacerbated their symptoms. This could clearly have ramifications for the parent-child relationship both when the child is young and as they get older.

5.3.2.5 Born with it

As the previous extract shows, some children held the view that their parents were born with mental illness. Nine of the 40 children interviewed either discussed their parents being born with mental illness or discussed the idea that mental illness has a familial link.

Some children gave succinct answers, not elaborating on their ideas about their parent's mental illness being present from birth.

Extract 242

Born with it

(Son of mother with schizophrenia, 11yo)

Extract 243

...his family has a history of that and um...

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Other children discussed their confusion about the relationship between genetics and mental illness.

Extract 244

I thought it could be hereditary but it can't be either.....yeah...but it can't be either...like you can't catch it off your parents...and stuff...so....that's what I always thought when I was.....until this year (when her teacher said that a person couldn't be born with mental illness)yeah and I'm like....um...ok I'll just cross that one off my list (laughs) but yeah I have no.....I'm not sure.....

(Daughter of mother with schizophrenia, 13yo)

Extract 245

Itcould.... be genetic...but I'm not quite sure

(Daughter of mother schizophrenia, 17yo)

A few children showed a more sophisticated understanding of genetics.

Extract 246

I've tried to explain to my sister the statistics behind it...I once read, I think I've got about a 15% chance and (his sister has) got about a 25% chance because she's female, female to female...but I'm still trying to figure out with genetics how those two could come together just as the female whether that be a stronger estrogen strand or something like that...

(Son of mother with schizoaffective disorder, 15 yo)

The eldest participant discussed how her belief in her parent being born with mental illness has shaped the child's own life.

Extract 247

C: it's also genetic as well absolutely because um....my mum's grandpa was an alcoholic and so that could play something maybe and also because it could be a recessive gene um...so...and you know there is genetic counselling out there and...I wanna say clearly that its stopped me from....um...well it's been one of the, at the moment, one of the most

influential reasons....why I don't want to have kids...but I'm not sure about that either...it just depends who I meet.....(laughs)

I: So at this stage it's something that you think about and you think you wouldn't have kids?

C: um but yeah in terms of kids I'm not sure because it just depends who you meet...and genetic counselling is out there so I'd definitely go to a genetic counsellor firstabsolutely and at the moment you know if an unfortunate situation if I became pregnant then I'd definitely have to abort.... I still don't have enough understanding about genetic counselling...and so in a way I still probably wouldn't even have kids...if it was a life or death situation I'd say I'd rather not have kids...id rather adopt...

(Daughter of mother schizoaffective disorder, 17yo)

Older children were more likely to endorse this cause than were younger children, a finding which is consistent with the literature (Finney & Falkov, 2009; Hay, 2004). The notion of being born with mental illness, or heritability of mental illness has been found within numerous other studies examining both non-COPMI (Bailey, 1999; Callan et al., 1983; Fox et al., 2007; Fox et al., 2010; Poster, 1992; Poster et al., 1985; Watson et al., 2004) and COPMI (Cogan et al., 2005b; Finney & Falkov, 2009; Garley et al., 1997; Riebschleger, 2004) views on mental illness. Although a study examining adolescent COPMI experiences of parental mental health found that some of their participants thought they were “immune to developing schizophrenia themselves” (Valiakalayil et al., 2004, p. 531). This was largely because participants in the study by Valiakalayil and colleagues (2004) attributed the cause of mental illness to external factors (such as drugs and stressful situations) rather than attributing the cause to heredity.

It could be assumed that those COPMI who state that their parent's illness has a genetic cause could, at some point, think about their own possible genetic risk. Within the current study there were only two children who discussed their own perceived heightened risk. One talked about making the decision not to have children based on her perceived risk. The concept of

COPMI choosing not to have children based on their COPMI status has been cited in previous research (Foster, 2006; Marsh et al., 1993; Murphy et al., 2011 b; Stevenson, 2002). Foster's (2006) insightful study into ACOPMI experiences illustrates the difficult decision that many ACOPMI have to make about whether or not to have children. As Foster states, some participants within her study were aware of the potential risks and chose to have children, others decided that the risk was too great and chose not to have children. COPMI chose not to have children so as not to pass the illness to future generations and also so that they do not potentially expose their child to the life events that they themselves were exposed to.

Hay (2004) states that questions from COPMI about whether they will develop a mental illness like their parent are particularly difficult to answer. Despite the difficulty with answering such questions, Hay states that it is important for COPMI to know about the actual genetic risk associated with their COPMI status. In the current study, two children cited their potential percentages of risk. Neither had spoken to a genetic counsellor or anyone else regarding their risk; their beliefs were based on what they had read in books and on the internet. One of the participants decided not to have children, at the present time, based on this information.

5.3.2.6 Something physical

When asked what caused their parent's mental illness or what caused their parent's mental illness symptoms to worsen, six children cited physical problems. These included an incident when a parent fainted, general aches and pains, a back injury and encephalitis.

Extract 248

I: What do you think made her get a mental illness in the first place?

C: Hmm.....um.....hm.....probably when um she couldn't move easily she probably had something wrong with her body

I: So you think there's something wrong with her body that makes her have a mental illness?

C: Yeah

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Extract 249

Um I reckon it was when she hurt her back...yeah... because she was a lot better before then, then all of a sudden she started having depression....

(Son of mother with bipolar disorder, 12 yo)

Two children from the same family both cited chicken pox and resulting encephalitis as the cause of their father's mental illness.

Extract 250

Um...well...he got it from um encephalitis and chicken pox.....I think it was about 10 years ago..

(Daughter of father with depression, 10yo)

Extract 251

Yeah he got um... depression through...um.....chicken pox and then got encephalitis....and....then um.....and....cause he was an adult chicken pox was worse for him um.....and....it affected part of his brain and he wasn't able to cope with it and he got depression (Daughter of father with depression, 14 yo)

As mentioned earlier, younger children were more likely to endorse physical symptoms of mental illness. Similarly younger children were also more likely than older children to talk about physical causes of mental illness.

5.3.2.7 Sleep

Sleep and lack of sleep was mentioned by five children when discussing their parent's mental illness. Tiredness was seen as a cause for symptoms getting worse. A parent getting more sleep was also mentioned as a way for parents to reduce their symptoms. This will be discussed in more detail later in this chapter.

Extract 252

Oh.....it's like.....not getting much sleep

(Son of mother with borderline personality disorder and schizoaffective disorder, 12 yo)

COPMII can have a lot of confusion about what caused their parent's illness and this has clinical implications. The causes that they believe may be based largely on their own observations along with pieces of information about mental illness they may have gleaned along the way. It seems that if they are receiving information about the cause of their parent's mental illness it is general information regarding causes of mental illness (such as drug use) instead of information specific to their parent's situation. The cause of mental illness is difficult for adults themselves to comprehend. Clinicians should highlight to children that widely accepted general causes of mental illness are not necessarily the cause of the child's parent's mental illness. In addition the concept of heritability needs to be discussed with COPMI to provide correct information about potential risk and to examine potential fears about passing the illness to their own children.

5.3.3 Treatment for mental illness

In line with Leventhal's illness domains, children were asked if there was anything which could reduce a parent's symptoms or stop the illness altogether. Questions within this section of the interview included questions about whether their parent could do anything to help their illness or symptoms or if there was anything anyone else could do to help. Responses to both questions were grouped together and analysed for themes.

As with other questions within the child interview schedule, some children initially stated that they didn't know if there was anything that could alleviate their parent's illness or symptoms.

Extract 253

I: Is there anything that makes your mums illness better?

C: Um...I don't know

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

When the children stated that they didn't know, the question was revisited later in the interview. Often after the question was reworded, children were able to provide an answer. Children were also more inclined to provide an answer after being assured that there was no wrong answer. All children later provided an answer after initially stating that they didn't know what could alleviate their parent's illness or symptoms.

After removing "I don't know" responses, all other responses to the question about what makes their parent better were grouped together to form seven themes. The seven themes will be presented in order from most frequently endorsed to less frequently endorsed. The seven main themes are presented in *Figure 9* and discussed overleaf.

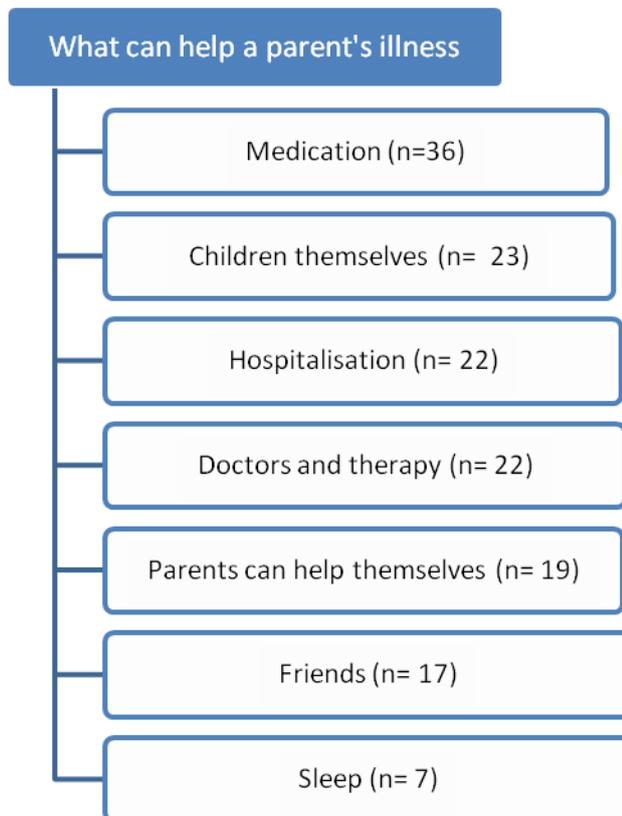


Figure 9. Children's ideas about what could help their parent's illness or symptoms

This aspect of illness perception was not explored by many of the previous COPMI-focused studies. In those that did, medication (Finney & Falkov, 2009; Garley et al., 1997), hospitalisation and treatment from a psychiatrist were seen as treatments for their parents (Garley et al., 1997). Studies examining non-COPMI beliefs about mental illness found a range of suggestions about how to help a person with mental illness, these included suggestions that the person with mental illness be hospitalised (Bailey, 1999; Callan et al., 1983; Fox et al, 2007; Poster, 1992) and that they should see a doctor (Bailey, 1999; Fox et al., 2007; Fox et al., 2010). In the present study, seven types of help were cited by children.

5.3.3.1 Medication

The majority of respondents (36 of 40) discussed the role of medication in helping to alleviate their parent's illness or reduce illness symptoms. It should be noted that although most of the 36 children spontaneously mentioned medication, there were some children who, after having

difficulty answering the question, were asked if their parent took any medication. After being asked this question, often children were able to provide rich detail about their parent's medication. For example the colour and number of tablets and the times of the day tablets were to be taken. Given that participants were prompted, it may be the case that although they are aware of medication, these few participants may not believe that the medication actually helps their parent get better.

Within the theme of medication there were a range of responses, highlighting a continuum between very little knowledge and quite a comprehensive knowledge about medication. The following extract is an example of a child providing only a small amount of detail in response to the question.

Extract 254

I: Is there anything that makes her better?

C: I dunno.....medicine...medication...sometimes....

I: Do you know what medication she's on?

C: No

I: Do you know how often she takes it?

C: No

(Son of mother with schizophrenia, 11yo)

The majority of children provided slightly more detail, for example the colour of tablets, how many their parent took and when their parent took them.

Extract 255

I: What sort of pills does she take?

C: Um.....Little white ones

I: When does she take them?

C: Um...she says she takes about 4 before she goes to sleep

I: And what do they do?

C: Um.....(laughs)...I don't know

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9 yo)

Some children provided simple detail about how the medication helped their parents.

Extract 256

I: Is there anything anyone else can do to help her get better?

C:mm.....give her medicine

I: Is she on medicine at the moment?

C: Um.....before she goes to bed she has to have a few tablets

I: What do they do?

C: Um.....one helps her go to sleep.....mmmmm....and I don't know what the other ones do.....

(Son of mother with obsessive compulsive disorder and depression, 9 yo)

Some children were able to provide theories relating to how the medication worked or were able to name medication.

Extract 257

I: So your mums on medication at the moment?

C: Yep..um like a dozen pills ((laughs))

I: And does she take them in the morning or at night?

C: I think she has to takesome in the afternoon or something and then some at night..like a dozen at night and like...five in the morning or something because she's also got theshe's got the bipolar and the back ones as well for her back pain so she's got like Oxycontin andum...um Lithium andsomething that starts with B which she's only just got

I: And how do the medications work to make her better?

C: Um.....I've been told they just change the brain waves over sort of thing so they try to even it out

(Son of mother with bipolar, 15yo)

Four children discussed Electroconvulsive Therapy (ECT) or “shock treatment” as something which alleviates their parent’s illness or symptoms. All four children provided differing levels

of detail about the procedure. None of the participants were able to give an explanation of how the procedure works to alleviate symptoms.

The extract below is an example of a child who discussed both medication and “shock treatment” when talking about the things which have helped her parent’s illness or symptoms. The participant was able to give brief detail about the procedure and the side effects.

Extract 258

I: And how do you think the medication works?

C:I think.....it's like her mind.... like the medication is going to work and I'll take it and it'll work

I: Like she's almost got a belief that it will work and that's why it's working?

C: Yeah yeah I think so

I: And did she have any other treatment while she was in hospital?

C: Yeah she had shock treatment.

I: Ok and what is shock treatment?

C: Um.....they give you like an electric shock and you have like a two second epileptic fit or something and um.....

I: Did that work?

C: Umm she did it a few times but her memory is like a sieve now..... absolutely...yeah it's taken away pretty much most of her memory like..she'd go in and like I'd visit her and she'd ask me “how was your day?” and I'd tell her about it and then... about 15 mins later “How was your day” and it was like ...”I've told you...”

I: Oh and how do you think that shock treatment works?

C:I don't know

I: If you had a guess

C:.....um.....I

don't.....oh well.....um if I had to take a guess it would probably like go to her brain and kind ofummm kind of um.....

I: Don't know, just goes into her brain and does something?

C: Yeah yeah

(Daughter of mother with schizophrenia and anxiety, 13 yo)

The next extract is an example of a participant who was able to provide quite comprehensive description of the ECT procedure.

Extract 259

C: ECT which is electro convulsive therapy or literally shocking the brain back into action

I: And has your mum had ECT before?

C: Yes she certainly has

I: And how do you understand the way it works?

C:the patient is usually put to sleep..... usually with uh full anaesthetic...they are monitored throughout the procedure as a normal surgical procedure...Electrodes are placed uh...I would most probably guess on what people most commonly call the temples, there are many temples but in this case the ones uh to the right, in other words you can see where I'm pointing now (points to his temples)...um there may also be one placed at the back for sight as in seeing things or just above the ear with listening or hearing things or saying things

I: And do you know how it is effective?

C: How it works? How the procedure is done? I've read particular pamphlets and all that I can rememberis that it's quick and fast...I'm quite sure that the person is restrained but usually...as it could be quite dangerous if the person is in a convulsive state and moving around. And then I'm sure that after the event...so they're left after the effect has taken place ...unhooked from the uh heart monitor and neurological function monitor and then um.....left til awake. And I'd say would most probably get headaches after the event

I: Do you think ECT helps your mum?

C: Um...I think it's a pretty macabre way of dealing with..... the illness...but I think it does help.....obviously...Sorry yes it has shown um substantial evidence and that it helps um particularly for.....Mum is fine again for a day or two and then slowly it works its way back...

(Son of mother with schizoaffective disorder, 15 yo)

Both the previous extract and the following one are from two siblings from the same family.

The following extract is from the older sibling.

Extract 260

C: Um..ECT which is electric shock therapy

I: How often does she have that?

C: Um when she's in hospital often twice a week ..So it might be like a Wednesday and a Monday...It depends on how bad she is...I know it only effects her short term memory but not her long term memory...which is good

I: Do you know how it works?

C: Um...(laughs) yeah I think....is it just when they stick electrodes on you...I'm not sure if they put one in your mouth but um yeah they just basically stick electrodes on her and it's just um.....I'm not sure whether it's to stop her.....I should know I'm embarrassed that I don't know...I'm not sure whether it's to stop her shaking...also probably to calm her down because she's forgotten things that she did yesterday and the day before so it sort of puts you in a state almost like a vacuum...I mean I don't know because I've never had it but I know for a fact that electric shock therapy is treated for people with a lot of depression and that's a major thing that mum gets as well a lot of depression

(Daughter of mother with schizoaffective disorder, 17yo)

Although children of all ages discussed the role of medication in helping a parent's symptoms, generally only older children mentioned ECT.

Children's understanding of medication, and its role in helping their parent's illness, ranged from a basic understanding to a complex understanding. Generally children were able to provide detail about aspects of medication, such as the colour of tablets or what time in the day their parents took them. Four older children spoke about their parent's electroconvulsive therapy (ECT). Within the studies examined for the review in chapter four, no mention was made of COPMI or non-COPMI discussing ECT.

Children discussing ECT within the current study is interesting given that ECT, unlike medication, is conducted within a hospital and out of the sight of family members. ECT has been cited as a highly misunderstood and controversial treatment (Abrams, 1994). Three of

the four children who talked about ECT were not told about it from their parent. It is unclear where their understanding of it came from. Children's sources of information are discussed within the following chapter, Chapter Six.

5.3.3.2 Children themselves

When asked what helps to alleviate a parent's symptoms, the second most common response was children themselves. Similar to children's responses that they were somehow responsible for exacerbating their parent's illness, 23 children stated that they were able to alleviate parent's illness symptoms.

Children tended to talk about emotional help or physical help when discussing how they could help their parent. Emotional help included cuddles, reducing a parent's worry, visiting in hospital and trying to be nice to the parent. The following three extracts are examples of emotional help provided by children.

Extract 261

C: Um.....like us three girls...yeah

I: So you guys help him out?

C: Yeah

I: How do you do that?

C: Like just like um.....make him feel happy about himself and thatand take his mind off ...like mental illness and stress and that

I: How do you make him feel happy?

C: Well just give him heaps of cuddles and kisses (laughs)

(Daughter of father with depression, 10yo)

Extract 262

then we get her out of hospital and try to be nice so she doesn't go back in again... she might stay home for about... probably a month or two and then might go back in again cause she got worse

(Son of mother with bipolar, 12 yo)

Extract 263

Um they usually...when mum was sick at one stage we used to go "oh go away!" and stuff like that to the voices that she thought she heard...so we'd do that and stuff to help her feel better

(Daughter of mother schizophrenia, 17yo)

A common view among children not in the full time care of the parent with the mental illness, was that just being present with their parent could alleviate mental illness symptoms.

Extract 264

...She was never really bad when me or my brothers were there

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Physical help was also discussed by children as a way to reduce their parent's symptoms.

Physical help referred to helping with chores around the house.

Extract 265

she just said stuff like "oh you know how I'm having the ups and downs and that....yeah um...it's...it'd help if you boys would like help out around the house and stuff " so yeah I've been doing it... ever since she's had the depression I've been helping out around the house.... A lot more...than I used to.....

(Son of mother with bipolar, 12 yo)

Similar to the suggestion that children's beliefs about causing parental mental illness could lead to guilt and low self esteem (Kelly, 1999; Lancaster, 1999), it could be surmised that children who feel that they are able to help their parent's illness or symptoms could feel the same. If a child believes that they can help their parent, what does this mean when a parent is unwell despite efforts on the child's part to help? There is no research examining this concept so it is unclear how this belief impacts on children. It is clear, given the research into the

possible links between beliefs about cause and feelings of guilt and self esteem, that there is scope for negative impacts on COPMI.

5.3.3.3 Hospitalisation

Over the course of the interview, 22 children talked about their parents being hospitalised. Similar to the range of responses in the medication theme, some children gave a simple response stating only that their parent had been in hospital, whereas others were able to provide detail and recount a specific time when their parent was hospitalised in order to reduce their mental illness symptoms.

The extract below is an example of children who stated that their parent had gone to hospital but were unsure of the details of what happened in hospital or how the hospital helped their parent get better.

Extract 266

I: And how did they help her in hospital?

C: I don't know

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Some children discussed how hospital helped alleviate their parent's illness or symptoms.

Extract 267

Oh....well if she gets like really bad and that then she'll go into hospital and probably stay for about probably a couple of weeks or something like just to get ... yeahcooled down and stuff and then we get her out of hospital

(Son of mother with bipolar, 12 yo)

Extract 268

C: Well when she had bipolar she was in hospital....((...))...

I: And what did they do in there to make her better again do you know?

C: Um...calm her down...

(Son of mother with schizophrenia, 11 yo)

When talking about the benefits of hospital in alleviating their parent's illness, fourteen participants described a specific event which ultimately led to their parent being admitted to hospital. All fourteen participants provided detail about the symptoms which preceded the hospitalisation and many discussed their experience of the hospitalisation.

Extract 269

.....well the only time I know she went into hospital she was like this (went and laid on the floor) She couldn't get up...and someone had to ring the hospital. And the hospital came and took her to hospital...It was really late in the dark I couldn't go with them....because I had to go to school that day

(Son of mother with schizophrenia, 9yo)

Extract 270

.....my dad was dropping us off...this is last summer I can remember and my dad was dropping me and (sister) off at mums house and we went in and....everything was trashed and...yeah...she was all funny....so we rang the ambulance

(Son of mother with schizophrenia, 11yo)

Extract 271

C: Yeah she...like I had scissors on the table cause I was doing a project and she goes... "get the scissors away from me" and... so I was like... I didn't really want to go to school that day 'cause I didn't want to leave her..(..)...he (mother's boyfriend) stepped in and took her to the hospital. 'Cause the hospital wouldn't take her in cause it was the third time, cause she was in and out in and out. And they said "we can't do anything for you" and then as soon as we said she was suicidal they were like "oh yep we'll take her"

(Daughter of mother with schizophrenia and anxiety, 13 yo)

That participants commonly cited hospitalisation as a treatment for their parent's mental illness is not unique to this study. Most other studies examining both COPMI and non-COPMI ideas about treatment for mental illness have found that participants discuss the role

of hospitalisation, doctors or therapy (Bailey, 1999; Callan et al., 1983; Fox et al., 2007; Fox et al., 2010; Garley et al., 1997; Poster, 1992; Sedley, 2002).

Approximately a third of all participants in the current study were able to describe a specific event which preceded the hospitalisation of their parent. Hospitalisation of a parent has been found to be one of the most stressful aspects of mental illness for both COPMI and their parents (Fudge & Mason, 2004; Maybery et al., 2005; Shachnow, 1987). In addition to the event of hospitalisation, other events can occur within the household at the time of hospitalisation which could contribute to COPMI experiencing stress, for example some may have to move houses to live with the non ill parent, extended family or a foster family for a time (Riebschleger, 2004) and routines may change to compensate for a parent not being there. With this in mind it is not surprising that a number of COPMI within this study were aware of hospitalisation as a treatment for their parent's mental illness.

5.3.3.4 Doctors and therapy

Twenty two children talked about the role of doctors or therapy in helping to reduce their parent's illness symptoms. Some children gave simple responses stating that their parent went to a doctor to help alleviate illness symptoms. Other children provided a more complex response, including details such as the doctor's name, details about appointments, details about whether the doctor was a psychiatrist, psychologist or general practitioner or specific details about how the doctor or therapy worked to help their parent.

The following two extracts demonstrate a simple response.

Extract 272

Um....the doctors take care of her...and um... yeah they take care of her and make her feel better and then she comes back and she's fine

(Daughter of mother with bipolar disorder, 8 yo)

Extract 273

Doctors come and visit her and just..... speak to her and give her stuff

(Son of mother with obsessive compulsive disorder and depression, 9 yo)

Some participants were able to provide more detail in their response. For example in the following two extracts the participants describe what the doctor or therapist does to help their parent. These responses are not comprehensive however they do provide more detail than the previous two extracts. Most responses within the current theme displayed a similar level of detail.

Extract 274

C: Um..sometimes um these people come over and they help, they speak with her....

I: What do the people do when they come over?

C: Um..they're kind of researchers like you. Like ask her questions like... what helps her and um yeah...

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Extract 275

C: Um I think she goes to see him (doctor) about probably..... once a month maybe...yeah

I: And what does he do?

C: Um he just like talks to her and saying "oh well you're going well" and stuff. 'Cause I don't really know I barely go with...But I reckon he probably just goes "yeah you're going well and stuff on your tablets" and then... yeah ...and tries to give her like a booster and stuff so she doesn't get depressed any more

I: Do you reckon he talks to her and gives her a booster?

C: Yeah... talks and stuff like saying "you're going well with them" "probably you can start minus-ing them" because she takes about I think two tablets for her depression or something ...might start saying "oh yeah you might have to take one soon" and stuff...

(Son of mother with bipolar, 12 yo)

It was rare for participants to stipulate what type of doctor their parent went to. For example, most children talked about how their parent went to a ~~doctor~~ or ~~therapist~~. Only three children used terms such as ~~Psychiatrist~~, ~~Psychologist~~ or ~~General Practitioner~~.

Extract 276

I don't think she sees a Psychologist. I'm pretty sure she sees a Psychiatrist and also a GP
(Daughter of mother with schizoaffective disorder, 17yo)

Within the current study COPMI cited doctors or therapists but did not talk more specifically about the types of doctors or therapists, for example only three participants mentioned psychologists, psychiatrists or General Practitioners. None of the participants discussed aspects of therapy such as the type of therapy their parent was involved in (for example Cognitive Behaviour Therapy or Dialectical Behaviour Therapy).

5.3.3.5 What parents can do to help themselves get better

Nineteen participants mentioned a range of responses which are encompassed under the theme of activities or strategies parents can use to help themselves get better. The responses in this theme are varied. A range has been included here as they provide a good example of the variety and depth of responses provided by participants.

Responses which fitted in this category included having a coffee or a cigarette.

Extract 277

Have a coffee....

(Daughter of mother with depression and post traumatic stress disorder, 7yo)

Extract 278

Smoking helps her

(Son of mother with schizoaffective disorder, 15 yo)

Some children discussed physical things their parent could do to try to get better.

Extract 279

Um...mostly when she goes camping she can get better or.....((.....))..... she likes the guitar because it helps her

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Extract 280

Ummm she went to yoga a few times

(Daughter of mother with schizophrenia, 13 yo)

Some children talked about their parent relaxing.

Extract 281

Usually cooking relaxes her too so...

(Daughter of mother with schizophrenia, 17yo)

Extract 282

Um....listen to a relaxation tape or DVD...that's what I do sometimes when I stress...and um....and just lay in bed...just lay on top of the bed if he's really, really tense and depressed and that and just sit there for 5 or even 10 or even 15 if he really needs it. And um...just take 5 or whatever you need breaths and calm down and that

(Daughter of father with depression, 10yo)

A few participants discussed the role of parents' own thoughts and decisions in helping them alleviate their illness.

Extract 283

Try to stay happy all the time

(Son of mother with bipolar disorder, 12yo)

Extract 284

.....she could probably do stuff....um (laughs..at a loss)....I don't know.....((...))... have better decisions and all that...like make better choices

(Daughter of mother with schizophrenia and anxiety, 13yo)

Extract 285

.....um.....*just sit home and try and not think about it*

(Daughter of mother with Obsessive Compulsive disorder and depression, 10 yo)

Three children discussed a change of environment as being beneficial to their parent's mental health.

Extract 286

She tried to look for a job in Darwin

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

Extract 287

like a positive environment

(Daughter of mother with schizophrenia, 13yo)

Extract 288

Ummm..... when she leaves the house

(Son of mother with depression, 14 yo)

Parents being able to help themselves was an interesting finding, one which appears to be unique to this study. Although not further examined within the current study, COPMI placing the onus on a parent to get better could have ramifications for the child, the parent and the child-parent relationship. As discussed, when children blame themselves for the cause of their parent's mental illness there are feelings of guilt and lowered self esteem (Kelly, 1999; Lancaster, 1999). There is potential for emotional responses in COPMI (such as blame and anger) who believe that their parent is able to control their own mental illness but does not.

5.3.3.6 Friends

When asked what could help alleviate their parent's illness, 17 participants discussed the role of parent's friends in the reduction of illness symptoms. Often children talked about the value of their parent talking to friends.

Extract 289

um..yeah like if...I don't know....Like if she has a phone call from a friend she hasn't heard from....Just stuff like that....

(Daughter of mother with schizophrenia, 13yo)

Extract 290

C: Um.....She used to like talk to (friend).....and that's really all that I know

I: And what did she used to talk to (friend) about, how did that help her?

C: Um.....like ways how she can deal with it

(Son of mother with bipolar disorder, 10 yo)

One child mentioned her parent's new relationship as a source of help.

Extract 291

C:Well she met somebody new and that's kind of helped her as well..

I: How do you think that's helped her?

C: 'Cause now she's got somebody in her life other than me and her parents and um.....yeah

(Daughter of mother with schizophrenia, 13 yo)

One child talked about how talking to a friend could possibly help her parent.

Extract 292

C: she could start telling other people like what happened around her.....((..)).....it might help mum a little bit....help her feel better and to know that she can talk to someone

(Daughter of mother with bipolar disorder and post natal depression, 12 yo)

Participants also mentioned how making new friends could alleviate their parent's illness.

Extract 293

Make more friends...that might make her happier.....

(Daughter of mother with schizophrenia, 13yo)

5.3.3.7 Sleep

When asked about what could alleviate their parent's illness or symptoms, seven children mentioned the role of sleep or rest. This theme is similar to the theme within the section —“Cause of mental illness” in which five children mentioned the role of sleep in developing mental illness or worsening a parent's mental illness symptoms.

Extract 294

She sleeps....

(Daughter of mother with depression and post traumatic stress disorder, 7yo)

Extract 295

Have a rest

(Son of mother with obsessive compulsive disorder and depression, 9 yo)

Two children discussed what it was about sleep that helped alleviate their parent's symptoms.

Extract 296

C: Yeah I think it makes her go to sleep

I: And how does that help her?

C:(laughs).....um.....to make her stop thinking about things

I: So it's her thoughts and stuff?

C: Yeah

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

Extract 297

...she has lots to make her sleep..... like sleeping pills because like otherwise she'd be stressed all night and can't sleep...which makes it even worse

(Daughter of mother with obsessive compulsive disorder and depression, 10 yo)

Sleep was more often mentioned by younger children as a way for a parent to get better.

Children are able to articulate a number of possible treatments for their parents. Some COPMI are aware of treatments such as ECT, an aspect of mental illness treatment which has been overlooked within the research examining COPMI perceptions. Clinicians should explore COPMI ideas around treatment. Specifically, the assumptions underpinning the treatment should be addressed. Perceptions that children themselves can help a parent get better, along with perceptions that the parent has control over their illness, have the potential to increase distress in COPMI.

5.3.4 Timeline of mental illness

Participants were asked questions about the timeline of their parent's mental illness.

Generally children were asked the question "how long is your mum/dad going to be sick for" or "how long is your mum/dad going to have schizophrenia for". Similar to other questions, children initially had difficulty answering this question. Rarely did a child respond to this question confident with their answer. Instead their responses were hesitant.

Participant hesitancy when responding to questions regarding the timeline of their parent's illness is not unusual given the nebulous nature of mental illness and the differing opinions within the research about whether mental illness can indeed be cured (Ramon, Healy & Renouf, 2007; Schnittker, 2008). Very few studies within the review in Chapter Four examined children's perceptions of the timeline of mental illness. Those that did generally found that younger children believed that people with mental illness could get "better" over time and older children were more likely than younger children to state that people with mental illness would have the illness for life. The findings appeared to be similar for both

COPMI and non-COPMI (Cogan et al., 2005b; Finney & Falkov, 2009; Fox et al., 2007; Fox et al., 2010 Garley et al., 1997;).

Only two children were unable to provide an answer for this question. The children who did respond provided responses which fitted into one of three main themes (1) a parent's mental illness had been cured, (2) a parent's illness would be cured within a specified period or (3) a parent will have their mental illness for the rest of their life. Children of all ages endorsed each of these responses although older children were more likely to endorse the response that their parent would have mental illness forever. The themes are presented in *Figure 10* below and discussed in order of most frequently endorsed.

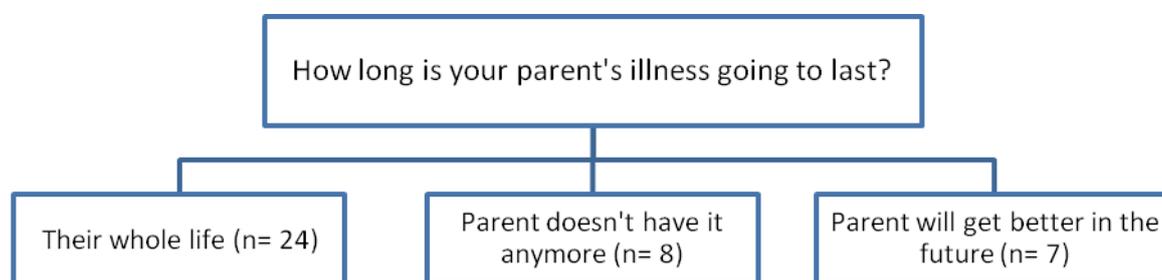


Figure 10. Children's ideas about how long mental illness will last

5.3.4.1 Parent will have mental illness for their whole life

The most common response from participants was that their parent was not going to recover from their mental illness and that they would have it for the remainder of their life. Over half of the children interviewed provided a response which fit this theme.

Extract 298

I: How long do you think your mum will have schizophrenia for?

C:uh.....probably 'til she dies...forever...

(Son of mother with schizophrenia, 11yo)

Extract 299

I: Do you have any idea how long he will be sick for?

C: I don't see it as ending...I don't really think that's likely to happen at all

(Daughter of father with bipolar disorder, 16 yo)

The following extract demonstrates the uncertainty many children displayed when answering this question.

Extract 300

I: How long will her illness last?

C: The rest of her life...It won't go away.....I don't think it can go away...Can it go away?...I don't think it can go away...but I think....I think that if people put in an effort....say people who were taking drugs and got a mental illness from it...if they looked after themselves and like...stopped it...it could become less...it could be like milder if you know what I mean....yeah

(Daughter of mother with schizophrenia and anxiety, 13yo)

Some children discussed the cyclical nature of mental illness. They talked about the notion that although their parents may have periods where they are relatively symptom free, this would be followed by periods of illness. These children acknowledged that their parent would have mental illness for the rest of their life.

Extract 301

I: And do you have any idea how long her illness is going to last?

C:I reckon probably for the rest of her life she'll probably be good then get bad be good then get bad

I: Is that kind of what you've seen so far?

C: Yeah

(Daughter of mother with schizophrenia, 13 yo)

The concept of a parent having mental illness for life raises a number of questions. Given the previous limited research in this area, it could be assumed that COPMI understanding of the timeline of mental illness progresses from a perception that mental illness can be cured towards an appreciation that mental illness may be present for ever. Although not explored within this thesis, COPMI may experience grief in relation to recognising that mental illness will be present in their family long term. There is a growing understanding by professionals and Government that children of people who have a mental illness may experience grief in relation to their parent's illness (AICAFMHA, 2004). Grief in the offspring of people with a mental illness has not been the focus of empirical investigation. Research exploring ACOPMI experience of parental mental illness, although not specifically examining grief, does cite grief as an emotion experienced by participants (Foster, 2006). Research has found evidence for parental experiences of grief when a child has mental illness and sibling and spouse experiences of grief (Godress, Ozgul, Owen, Foley-Evans, 2005; Miller, Dworkin, Ward & Barone, 1990; Solomon & Draine, 1996). The grief experience has been said to be similar to the level of grief experienced when a family member dies (Miller et al., 1990).

In the current study, many children believed that their parent's illness would last forever. Many children appeared to come to this conclusion on their own, it seemed as though they had not discussed this with their parents. No participant stated that their parent had told them the illness would last forever, instead children couched their responses in terms such as "I reckon probably" and "I think it's probably". It appears, in this study at least, that COPMI hold a belief that their parent's mental illness will last forever, yet they have not spoken to their parent about what this means longer term, nor have they discussed the grief that may coexist with that knowledge.

5.3.4.2 Doesn't have it anymore

The information gained within the parent interviews indicated that all parent participants currently had mental illness. Eight of the children interviewed stated that their parent's illness had resolved, that is their parent no longer had mental illness. Responses within this theme came equally from children who permanently resided with their parent with mental illness and from children who lived with their mentally ill parent part of the time. Responses within this theme ranged from uncertain to quite certain that their parent's illness had resolved.

Similar to the uncertainty displayed by participants within the theme of Parents having mental illness forever, some children were unsure how to answer this question but provided a guess.

Extract 302

I: Do you think she will get sick again?

C:that's a hard question.....

I: What would you guess?

C: Well I think she wouldn't....

I: So she's all better now?

C: Yeah...I don't know it's a hard question...I'm just guessing....

(Son of mother with schizophrenia, 9yo)

A few participants appeared quite certain that their parent's illness was no longer present.

Extract 303

I: Do you think OCD is something that last forever or does it go away?

C: Well If you're lucky it can go away like mums did

(Daughter of mother with obsessive compulsive disorder and depression, 10 yo)

Extract 304

I: You said that your mum is better now do you think she'll get depression again?

C: Nup I don't think so

I: So she'll be alright from now on?

C: Yep

I: And that's because of (youngest brother)?

C: Yep....and she got a new job...looking after old people as a carer

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

5.3.4.3 Parent will get better in the future

A number of children stated that their parent was not illness free presently but that they thought they would get better sometime in the future.

Extract 305

I think she might get better in the future

(Son of mother with depression, 14 yo)

Most extracts which fitted into this theme specifically stated a length of time in which the parent would be well by.

Extract 306

It might get better in a few years time

(Son of mother with obsessive compulsive disorder and depression, 9 yo)

Extract 307

I: How long will she have depression for?

C: Hopefully for..... up to three years

(Son of mother with depression, 10 yo)

Extract 308

Um.....About 10 or more years

(Son of mother with bipolar, 10 yo)

This finding appears to be unique to this study. Each of the parents interviewed for the study presented in Chapter Three stated that their child's parent was still living with mental illness. It may be the case that children who endorsed the idea that their parent no longer had mental illness had seen their parent's symptoms diminish recently. Perhaps it was the case that the parents of these children had not been admitted to hospital recently. This belief that parents no

longer have mental illness could have ramifications for the child if a parent becomes symptomatic again.

5.3.4.3.1 Cure for mental illness

When talking to children about how long their parent's illness may last, four of the children mentioned the possibility of a cure. Only one of these four children appeared to hold hope about a potential cure.

Extract 309

I: And how long do you reckon your mums illness is going to last?

C: Well if there's a cure a couple...from 3 months to a couple of years....but if there's no cure.....then... it won't...it won't stop...

I: And do you think there is a cure?

C: No but I hope there is

(Son of mother with schizophrenia, 11 yo)

The three other participants who mentioned a cure stated that although they would like to believe in the possibility of a cure they thought it was very unlikely.

Extract 310

...if medical scientists can hopefully.....create a cure then that would be all well and wonderful...um...my policies on optimism and hope are not very dramatic...I have very little hope((...)).....but no...I think it will go on for the rest of her life

(Son of mother with schizoaffective disorder, 15 yo)

Extract 311

...unless they find a dramatic cure...which I really don't think, because if you think 50 years ago fine DNA was only found 50 years ago ...((...))... I seriously can't see it happening..not even in my lifetime

(Daughter of mother with schizoaffective disorder, 17yo)

There are clinical implications around COPMI beliefs about the timeline of mental illness. COPMI appear to hold one of three beliefs. Each of these are underpinned by assumptions which could benefit from discussion. If a child believes that their parent will have mental

illness forever it is important to explore what this belief means for the child and whether the child is experiencing grief. For children who believe that their parent's mental illness will go away in the future, or who believe that it has gone away already, it could be beneficial to provide further information about the nebulous nature of mental illness.

5.3.5 Consequences of mental illness

Within the interview participants were asked their view about whether their parent's mental illness had affected their life. In an attempt to ensure a balanced range of responses, a number of questions were asked in order to elicit children's ideas about both positive and negative effects on the family. Questions typically asked included "Does your parent's illness make things different in your family?", "Are there good things about your parent's illness?" and "Are there difficult things about your parent's illness?". The range of responses to these questions were analysed, the results of which were used to develop a number of themes. The themes are presented below in *Figure 11* and discussed in order of most frequently endorsed to least frequently endorsed.

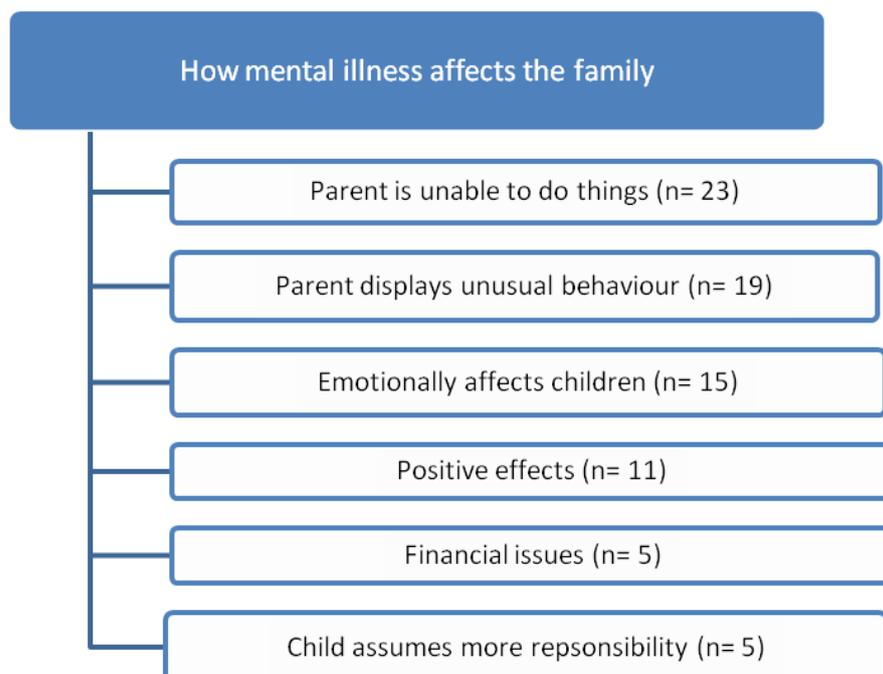


Figure 11. Children's ideas about how mental illness affects the family

As discussed within the review presented in Chapter Four, the domain of ‘consequences’ was often confused with ‘treatment’ by participants in previous studies. Therefore there was no review of literature about COPMI and non-COPMI beliefs about consequences. The Leventhal model views the domain of consequence as beliefs about the expected outcome of the illness. The current study was interested in COPMI beliefs about consequences of mental illness for the whole family, not only the parent with mental illness.

5.3.5.1 Parent is unable to do things or forgets things

When asked how their parent’s mental illness affects their family, 23 children stated that their parent’s inability to do things affected them the most. There were a number of things that children stated that their parent couldn’t do.

For example, some children talked about their parent being unable to do ‘anything’ in a general sense.

Extract 312

Yeah...mum [the parent without the mental illness] sort of has to do everything...um.....and.....yeah mum’s sort of a mum and a dad....

(Daughter of father with depression, 14 yo)

Extract 313

...yeah...um...well.....um.....times when its bad...is like when like.....like um.....she’s sick and she can’t work and she can’t do anything...

(Son of mother with depression, 11 yo)

Some children described specific things that their parent was unable to do when they were sick, such as drying the child’s hair, cleaning and finishing renovations.

Extract 314

C: ‘Cause it’s a bit hard because my dad doesn’t know much about like drying my hair and all of that

I: So does he have to do mummy’s jobs while she’s in hospital?

C: mmm... yeah and he's not much of a cleaning person

(Daughter of mother with bipolar disorder, 8 yo)

Extract 315

'Cause he got sick.....when the house was being built so a lot of things are not completed in our house like...its quite shabby I'd say, it's a nice house but it's not finished.....

(Daughter of father with bipolar disorder, 16 yo)

Although there were a number of children not currently living with the parent with mental illness, only two children mentioned their parent's inability to care for them when talking about the effects of mental illness on their family.

Extract 316

I reckon when I was about two I was pretty much looked after by my Nanna

(Daughter of mother with schizoaffective disorder, 17yo)

Extract 317

Sometimes I'd stay with my Nan and Pop for long, long times, like 3 or 4 months without stopping. Just stay there and they'd walk me to school and take care of me and then I'd go back to mum and dad for a while

(Daughter of mother with bipolar disorder and post natal depression, 12 yo)

Children talked about their parents being unable to get work, unable to work full time or unable to work at all.

Extract 318

Um he's not able to hold down a job and if he is its very part time and never full time

(Son of father with schizophrenia, 14 yo)

Extract 319

...I don't know she just.....oh.....it's really hard to say.....um.....just little things like.....I don't know.....like....like mum said she can't get a full time job

(Daughter of mother with schizophrenia, 13yo)

The most common aspect of mental illness that affected children's lives was a parent's inability to take part in children's activities or physically take them to activities.

Extract 320

Yeah sometimes we have to ...revolve things around her occasionally like if we're going out somewhere ...we might have to stop it because she'll be too upset or...um...And stuff like that...Just her breaking down might stop us from being able to go to footy training or we'll have to organise some other way to get there

(Son of mother with bipolar disorder, 15yo)

Extract 321

Oh....she's never able to reallydo stuff with us.....((...))...Like she can't take us to a park..... because she's sleeping...

(Son of mother with schizophrenia, 11 yo)

Extract 322

..... when it was bad like she stopped me from doing things....Like she couldn't take me to things ...Like she can't drive or anything...Like she couldn't take me to my gymnastics or anything like that

(Daughter of mother with schizophrenia and anxiety, 13 yo)

Two teenage children spoke about their parent's inability to play with them when they were younger.

Extract 323

at first when I was a young kid I used to be jealous...so I would see um...I'd be at the playground and I'd see other mums with their children and I'd be there by myself

(Son of mother with schizoaffective disorder, 15 yo)

Extract 324

... as a child I never really did stuff with him....I never really did like you know.... what you see on TV ...like people playing games and stuff ...so that was never really with him...so there wasn't that initialbonding..maybe...

(Daughter of father with bipolar disorder, 16 yo)

Over half of the participants within the current study stated that the main consequence of mental illness on the family was that their parent was unable to do things. Similar findings have been highlighted in previous literature examining COPMI experience. Previous research has found that COPMI would appreciate domestic help (Fudge & Mason, 2004; Riebschleger, 2004; Valiakalayil et al, 2004) and fun activities to do with the parent (Fudge & Mason, 2004). Meadus and Johnson (2000) found that COPMI within their study felt that their parent was unavailable for both caring for the child and for household duties. COPMI have also stated that they worried about a parent not being able to look after them (Stallard et al., 2004). At the extreme end of a parent being unavailable is neglect of the child, as cited within Cooklin's (2006) research on COPMI.

5.3.5.2 Parent displays unusual behaviour

When asked about whether their parent's illness affected their family, nineteen participants discussed the effect of their parent's behaviour on the family. This included the parent acting "weird" or the parent preventing the child from doing something because they were symptomatic at the time.

Weird things included going on camping trips (to escape the parent's mental illness) and washing school books before bringing them into the house.

Extract 325

C: ...sometimes our family does um.... differenter [sic] things, more weirder things

I: What sort of weird things do you do?

C: Um.....we go camping a lot...and yeah because my like....when we went camping to (place) yeah my mum wanted to go there to calm down... to get away from her mental illness more

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

Extract 326

C:Oh like we'd have to take our shoes off ...have a shower after we got home from school.....and we weren't allowed to go outside...((...))....and my sister had to clean her books

I: Did it make things hard for you as a family?

C: It was probably harder for her but....it sort of was...because we weren't allowed to do a lot of things

(Daughter of mother with obsessive compulsive disorder and depression, 10 yo)

Other things that children weren't allowed to do included not having a friend over and not being able to relax at home.

Extract 327

Yep.....well....if um...like on the weekends, like this weekend I said "oh can my friend (name) come over?" and mum goes "oh... I don't think you are able to because I don't want (stepdad) to have another episode" ...and I'm just like "why do I have to suffer if he has the problem?"...

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Extract 328

We had to walk on eggshells all the time.....basically didn't want to get in his way.....and.....it just made it a lot harder.....it wasn't like as laid back as other families

(Son of father with antisocial personality disorder, 16 yo)

Unusual behaviour has been cited in previous research examining COPMI experience, generally within studies examining COPMI experience of parental schizophrenia. For example, within the study conducted by Valiakalayil and colleagues (2004) COPMI participants cited episodes of parental behaviour which was *'unusual and bizarre'* (p. 532).

5.3.5.3 Emotionally affects children

When asked if mental illness had affected their life, 15 children stated that it had emotionally affected them in some way. Children talked about emotions such as sadness, feeling bad, feeling lonely, embarrassment and worry.

Extract 329

It makes me feel bad sometimes

(Son of mother with depression, 10 yo)

Extract 330

...oh and it makes us feel different...like emotionally.....like....sometimes it upsets us....sometimes it makes us feel different compared to other people.....

(Son of mother with schizophrenia, 11yo)

Extract 331

Um yeah cause it gets me frustrated and everybody else and then we worry for him

(Daughter of father with depression, 14 yo)

Extract 332

like I want to invite my friends over but I can't because if (stepdad) has a go at my mum... Or like he will go off in the car and just won't come back for a couple of hours mum doesn't wantlike she doesn't want like me to feel like..not embarrassed but like.... to deal with that with my friend here...((...))...I'd be so embarrassed that's why they're not allowed.....they can't come over when (stepdad) is in like his episodes

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

The emotions cited by COPMI within the present study are not unusual. Prior research has found similar emotions cited by their COPMI participants: fear, loss, frustration, embarrassment, confusion, worry, sadness and anger (Meadus & Johnson, 2000; Valiakalayil et al., 2004). What is not explored within this study is how children cope with such strong and negative emotions. It could be expected that there would be longer term issues with children experiencing emotions such as these.

5.3.5.4 Positive effect of mental illness on the family

As mentioned at the start of this section, children were asked questions about both the positive and negative effects of their parent's mental illness on their life. The section above shows children's views about the negative effects of mental illness on their life. Almost every child interviewed provided a response about how mental illness had negatively affected their life. Eleven of the children who talked about negative effects of mental illness on the family also stated that there were positives about their parent's mental illness.

Some children talked about positives such as a parent buying children things or being able to stay at a grandparent's house when a parent is symptomatic.

Extract 333

Um.....(laughs) cause like she sometimes.....um...buys us stuff and she gives us pocket money for free ...

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9 yo)

Extract 334

It (his mother's mental illness) makes things good...I get to stay at my grandma and granddad's and my dog's there..(..)...oh there's one more good thing....there's two

good things...she lets me, like when she's so tired, go to friends and um I get to miss out on school

(Son of mother with bipolar disorder, 10 yo)

Some children talked about the positive effect of the illness on their parent and how it is a part of the parent's identity.

Extract 335

She's also very happy because a lot of her time her mental illness is just that, she's incredibly happy and a normal person wouldn't be ..happy in that situation...So that's good and..she's also very imaginative and playful and creative...yeah

(Daughter of mother with schizoaffective disorder, 9yo)

Extract 336

.....makes her who she is...yeah....

(Daughter of mother with schizophrenia, 13yo)

The majority of participants who talked about the positive effects of mental illness, mentioned how mental illness has developed them as a person. Participants talked about developing by gaining knowledge of the illness their parent had and by becoming stronger or more open minded as a result of living with a parent with mental illness.

Extract 337

Um...I suppose that, because when...like my dad always says "when God closes a door he opens a window" so I suppose if she didn't have a mental illness I suppose I wouldn't be able to do the things I can and that is a good thing

(Daughter of mother with schizoaffective disorder, 9yo)

Extract 338

...so when I see mothers and still now I see it occasionally I think I wonder what it's like...but then I think if I hadn't have had the opportunity to live with my (foster parent) I wouldn't be the person I am I wouldn't have this desire to learn more about this illness and how it affects the body and the mental state and also medicine...

(Son of mother with schizoaffective disorder, 15 yo)

Extract 339

Um.....it's kind of opened my mind to kind of things like schizophrenia and things like that...

(Daughter of mother with schizophrenia, 17yo)

5.3.5.5 Financially affects the family

Finances and a lack of money were mentioned by five children when talking about the effect that mental illness had on their lives.

Two children spoke in general terms about a lack of money in their family.

Extract 340

... everybody else at school they're all rich... and everything, and mums all poor.....

(Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 8yo)

Extract 341

It's not very easy.....I'm not one of these rich European people who have all the money in the world and don't do anything.....

(Son of father with schizophrenia, 14 yo)

Other children were more specific about the impact a lack of money had on their life.

Extract 342

C: We can't travel anywhere

I: No, why not?

C: Um...Normally we don't have enough money and that

(Son of mother with bipolar disorder, 9yo)

Extract 343

.... we cant go on as many activities...that's why I went to (support group) so I can go on more activities and see more kids and stuff.....

(Daughter of mother with schizophrenia, 13yo)

One child spoke about a lack of finances specifically due to a parent's spending habits.

Extract 344

it does make things difficult because he spends money quite readily without much consideration...((...)).....It makes it difficult because he spends money and you know both my parents are on pension so it's not like money is ...you know something we can just throw away ... the same as with any family...So it does make things a bit difficult financially ..

(Daughter of father with bipolar disorder, 16 yo)

5.3.5.6 Child assumes more responsibility

Having to assume more responsibility as a result of a parent's mental illness was mentioned by five children. Responsibilities included caring, talking to a parent, checking up on a parent, being the adult and helping out at home.

Extract 345

I: Does your mum's illness make things different in your family compared to other families?

C:yeah it was kind of a bitdifferent because they had a happy life and happy families andwhereas my life was just caring for my mother at times.

(Daughter of mother with schizophrenia, 13 yo)

Extract 346

I have to like talk to her a lot....like a lot more.....if you know what I mean...and talk to her about everything....I don't know, it's really weird...just check up on her...like she's like I don't know...a 10 year old or something

(Daughter of mother with schizophrenia and anxiety, 13yo)

Extract 347

Um....I guess I have to be the adult sometimes and he doesn't

(Son of father with schizophrenia, 14 yo)

Although not commonly cited, the theme of a child assuming more responsibility is worth discussing here due to its low endorsement. Interestingly, only five participants discussed having to assume increased responsibility as a consequence of their parent's illness. It has been found that parents with mental illness often utilise the support of their children for domestic help and emotional support (Aldridge, 2002). Within prior research examining COPMI, increased responsibility has been often cited as a consequence of having a parent with mental illness. Children have spoken about responsibilities within the home (for example cooking meals, paying bills) and responsibility for looking after the parent with mental illness (Garley et al, 1997; Handley et al, 2001; Kelly 1999; Meadus & Johnson, 2000).

It could be the case that the participants within the present study did not assume more responsibility as a result of their parent's illness. Alternatively it could be the case that they did assume more responsibility but did not recognise it, or did not want to state it. As Aldridge (2002) states, support provided by COPMI can be difficult to define, particularly emotional support such as cheering a parent up or making sure a parent is safe from self harm while a child is at school. The interviews with the children within the present study indicated that children were indeed providing support to their parents however this was not raised when asked about the consequences of their parent's illness.

There are clinical implications around COPMI perceptions about the consequences of mental illness. COPMI are able to eloquently describe the effects on the family of having a parent with mental illness. A parent's inability to do housework and other tasks has the potential to lead to COPMI assuming more responsibility within the home. It is important that this is

recognised and that children are identified as young carers and adequate supports put in place. Negative emotions are also an outcome for COPMI and it is important to examine how COPMI cope with high levels of negative emotions.

5.4 Summary

The current study explored COPMI knowledge of pertinent aspects of parental mental illness from the child's perspective. The child participants in this study provided their perceptions of their parent's illness in the areas of identity, cause, treatment, timeline and consequences. The clinical implications of the findings of this study were also addressed.

The current study supported the previous scarce research into COPMI understanding of aspects of mental illness. The findings of the review of COPMI understanding of mental illness, as presented in Chapter Four were supported. There were a number of findings unique to the present study, such as COPMI knowledge of self harm, ideas around parental drug use, the knowledge of the use of ECT as a treatment and the perception of a parent having already overcome their mental illness.

As displayed within the analysis, few participants had a comprehensive understanding of all domains of their parent's illness. However, many participants were able to provide coherent and eloquent account of certain aspects of mental illness. This supports Absler's (1999) assertion that COPMI do notice what is going on around them and are able to understand mental illness. Although there were a few instances where older children appeared better informed about mental illness than younger children this was not always the case.

Importantly, it appears as though children of all ages are able to provide theories about aspects of their parent's illness, particularly if they are given space to provide an answer after an initial response of "I don't know".

The lack of clear evidence to show that older COPMI have a better understanding of parental mental illness than young COPMI suggests that, for this study at least, Piaget's ideas about age related changes in illness understanding are not relevant. Vygotsky's ideas about children's knowledge development being "scaffolded" by the people around the child could be relevant to this sample. It could be the case that those children who appear to have a better understanding about the domains of mental illness could have had their understanding of mental illness enhanced by their peers, siblings, parents or teachers. The concept of where COPMI obtain their knowledge of mental illness will be addressed in the following chapter, Chapter Six.

Misconceptions about mental illness were evident in the current study, supporting numerous other studies of COPMI (Cooklin, 2006; Devlin & O'Brien, 1999; Garley et al., 1997; Stallard et al., 2004). Although COPMI could benefit from further information about all areas of illness understanding, the cause of parental mental illness appeared the most confusing aspect for children within the current study. Interventions for COPMI, focussing on exploring COPMI perceptions of cause of mental illness, have the potential to reduce misperceptions and alleviate fears. There appeared to be confusion within the current sample about whether generally accepted causes of mental illness, such as drug use, were applicable to their parent's situation. It is important, when providing interventions, to be aware that COPMI may take general information regarding mental illness and attempt to understand their parent's illness through that lens.

This was the first study to explore COPMI understanding of each of Leventhal's illness domains. Only one previous study has examined concepts similar to Leventhal's domains with COPMI (Finney & Falkov, 2009). This study builds on the study by Finney and Falkov

by examining illness beliefs in a larger sample of COPMI and with a wider age group. The current study demonstrates that Leventhal's model of illness perception is a useful model for exploring COPMI understanding of parental mental illness. Using Leventhal's model as the basis for asking questions which allowed qualitative responses (rather than using the frequently used quantitative 'Illness Perception Questionnaire' by Petrie et al., 1996) allowed for a wide range of responses. This was important within the current study given its exploratory nature and the lack of prior research in this area. A quantitative measure may not have adequately captured the unexpected findings of this study such as children's knowledge of ECT and children's beliefs that their parent no longer had mental illness.

As shown by the current study, COPMI have varying levels of knowledge about aspects of their parents' mental illness. Thus far, it is unclear where children get their information from about aspects of their parent's illness. Do COPMI believe they have adequate knowledge about their parent's illness? Do they talk to people about their parent's mental illness? The following chapter examines the child's view of the disclosure of mental illness.

Chapter Six: Study Two, Part II – Do children think they have enough information and how is information transmitted?

The previous chapter, Chapter Five, examined children's ideas about aspects of their parent's mental illness. Namely what the symptoms are, what caused it, what alleviated it, how long it would be present for and if it affected the family. Chapter Five provided much needed information about how children of parents with mental illness conceptualise their parent's illness. In order to appreciate children's conceptualisations of mental illness it is important to understand children's sources of information and their views on receiving information.

As highlighted within Chapter Four, a review of children's understanding of mental illness, little is known about how children receive information, who they discuss it with and their views on seeking further information. The following chapter examines children's views on receiving information about mental illness.

6.1 Aim

The main aim of part two of this study is to examine children's views about how they found out about their parent's illness and whether they feel that they need further information.

6.2 Analysis and Discussion

6.2.1 Children's ideas about their understanding of their parent's illness: do children think they need more information?

Within the interview, participants were asked whether they understood their parent's illness as much as they wanted to. As discussed within the literature review, it is a commonly held

assumption that children of parents with mental illness often require more education about mental illness. It is important therefore to better understand children's own desires for information; do they want to know more or would they prefer not to be provided with further information?

Children were asked whether they understood their parent's illness. Accordingly, children generally stated 'yes' or 'no'. Children were then asked if they thought they required more information. Responses to this question again fell into one of two categories; "yes, I need more information" or "no, I don't need more information". Children's responses to these questions were analysed and collated into themes, the results of which are presented in *Figure 12* and discussed below. Please note, due to time constraints or other factors not all children were asked this question.

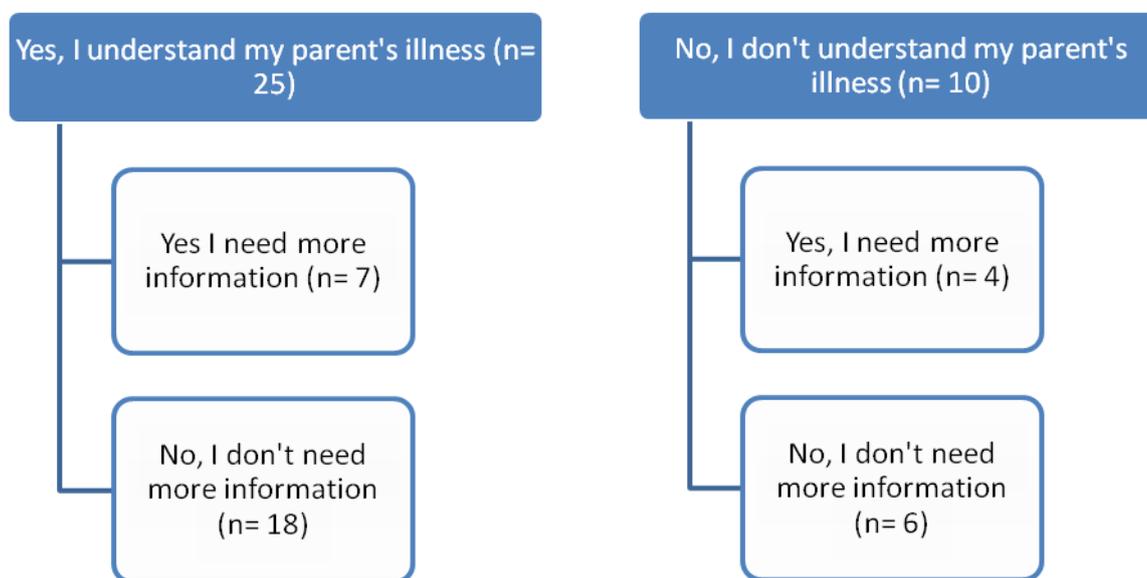


Figure 12. The range of responses to the question of whether children think they understand their parent's illness.

6.2.1.1 Yes, I do understand my parent's illness

When asked if they understood their parent's illness, twenty five children stated that they did.

Responses ranged from having a comprehensive understanding of the illness to being less

sure about their understanding of their parent's illness. Examples of both types of responses are shown below.

Extract 348

Uh very well...yes...

(Son of father with schizophrenia, 14 yo)

Extract 349

Ummm...sort of

(Son of mother with depression, 14 yo)

6.2.1.1.1 Do not want more information

Of the twenty five children who stated that they did understand their parent's illness, eighteen children also stated that they had no need for further information. Both the children who were confident in their knowledge of their parent's illness and those who weren't were as likely to state that further information was unnecessary. The responses within this theme were quite similar. Two have been provided as examples.

Extract 350

I: Do you think you understand your mum's illness well?

C: A little bit

I: Is there more information you think you should know about your mum's illness?

C: I don't really want to know about it

(Son of mother with schizophrenia, 11yo)

Extract 351

I: Do you think you understand his illness well?

C: Yeah

I: Do you think you need more information about it?

C: I sort of know enough so I don't really need to talk about it

(Daughter of father with depression, 14 yo)

6.2.1.1.2 Would like further information

Seven children, who stated that they understood their parent's illness, further stated that they would like more information.

Some children stated that they would like further information but did not provide detail about the sort of information.

Extract 352

I: Do you think you understand your mums illness well?

C: Umm.....slightly.....I understand what... happens and stuff but...not everything

I:...((...))...is there more information that you think you should know about your mums illness?

C:probably.....probably.....its always better to know more stuff about it...

(Daughter of mother with schizophrenia, 13 yo)

Other children provided detail about the type of information they thought they would find useful.

Extract 353

I: Do you think you understand your mums depression well?

C: Yeah

I: Is there any more information you think you should know?

C: Yeah...probably...a bit

I: What sort of stuff would you like to know?

C: Well like....'cause we know how to like stop it from mum getting it a lot like just try and help out and make her happy and that...like what causes it maybe and stuff

(Son of mother with bipolar disorder, 12 yo)

6.2.1.2 No, I don't understand the illness

When asked if they understood their parent's illness, ten children stated that they didn't think they understood it.

Extract 354

I: Do you think you understand your mums bipolar?

C: mmmm...no (laughs)

(Daughter of mother with bipolar disorder, 16 yo)

Extract 355

I: Do you think you understand her depression?

C: ..Um no not really

(Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 13 yo)

6.2.1.2.1 Do not want more information

Of the ten children who stated that they didn't understand their parent's illness, six children further stated that they didn't want to be provided with more information about the illness.

Extract 356

I: Would you like to know more about what your mum has?

C: No

I: So you'd prefer not to know?

C: Yeah

(Son of mother with bipolar disorder, 9yo)

Extract 357

I: Do you think you understand your mums illness well?

C: Um.....not really

I: Is there more information that you want to know?

C: Um.....not really no....

(Son of mother with bipolar disorder, 10 yo)

6.2.1.2.2 Would like further information

Four of the ten children who stated that they didn't understand their parent's illness very well proceeded to say that they would like additional information about their parent's illness.

Children generally did not state specific information that they would like to know.

Extract 358

I: Do you feel that you understand your mum's illness well?

C: Um...no (laughs)

I: Are you happy knowing what you know?

C: No I'd rather know as much as I can because ignorance is not bliss and I'm always forever learning

(Daughter of mother with schizoaffective disorder, 17yo)

Of the 35 participants asked if they understood their parent's illness, 25 stated that they did.

Participants appeared unsure of many of their answers provided regarding their knowledge of specific aspects of their parent's illness (as presented in Chapter Five), so the high percentage of children stating that they understood their parent's illness was an unexpected finding.

Furthermore this finding was unexpected given the prior research which overwhelmingly states that COPMI are confused about parental mental illness, prone to misperception and require more information in order to understand it better (Garley et al., 1997; Handley et al., 2001; Meadus & Johnson, 2000; Pölkki et al., 2005; Stallard et al., 2004).

Of the 35 participants asked if they felt they need further information, 24 stated that they did not. Again, this finding was unexpected given the research highlighting that COPMI often ask for further information (Garley et al., 1997; Handley et al., 2001) and research on ACOPMI

stating that they wish they had been given more information when younger (Dunn, 1993; Knutsson-Medin et al., 2007; Pölkki et al., 2005).

Six of the ten participants who reported that they did not understand their parent's illness stated that they did not want further information. This unusual finding fits with a study conducted by Stallard and colleagues (2004), who found that almost half of their sample of 26 COPMI did not want to know more about their parent's mental illness. It also fits with findings from a study conducted by Maybery and colleagues (2005) which found that some parents perceived that their children did not want to know information about their mental illness. Another study by Reupert and Maybery (2010b) found that a few facilitators of interventions for COPMI also perceived that COPMI did not want information. The facilitators stated "We only provide [education about parental mental illness] if they ask and they rarely do". They also stated that education about mental illness is "not that interesting to many of them [COPMI]" (2010b, p. 635).

The concept of COPMI not wanting to know more about their parent's illness, regardless of whether they already feel that they understand the illness or not, requires further discussion. There are a number of reasons why children may not want to know more about their parent's illness. Clearly, some children feel they have enough information. For those who do not feel they have enough information, but who do not want any further information, perhaps it is that the child feels uncomfortable talking about the topic of mental illness. In previous research, both parents and professionals have stated that they find the topic of mental illness difficult to discuss with children (Cooklin, 2006; Handley et al., 2001; Maybery & Reupert, 2006; Stallard et al., 2004). Perhaps the children in this study have sensed adult discomfort with talking about mental illness. Perhaps it is the case that the children live in a family culture which does not foster questioning. Perhaps COPMI do not want further discussion about

mental illness as they have a fear about what knowing further details will mean. From the previous research examining ACOPMI experience, specifically that ACOPMI state that they would have appreciated information (for example, Dunn, 1993; Knutsson-Medin et al., 2007; Pölkki et al., 2005), it may be the case that those COPMI who do not want information currently may in future, as ACOPMI, wish they had been provided with it.

There is very little literature examining the reasons why children do not want further information about topics which could be seen as important. Previous research has found that within a few studies some children have not wanted further information about other sensitive topics. These include not wanting more than basic information about a child's own cancer (Young, Dixon-Woods, Windridge & Heney, 2003), not wanting further information about sexuality (Kirkman, Rosenthal & Feldman, 2002), not wanting too much information about their own disability (Garth & Aroni, 2003) and not wanting further information about parental suicide (Cain, 2002), although in each case the reasons for not wanting further information were not explored.

Familial communication around mental illness is a complex and interactional process.

Although the current literature espouses the need to talk to children about mental illness, it does not address the role of both parties within the process of discussing mental illness and it fails to take into account situations where children do not want to know. The data from the present study highlighted that within some families the discussion of mental illness was actively avoided by children. Gladstone, Boydell and McKeever (2006) make the insightful point that much of the research into COPMI fails to take into account the fact that children are competent and active agents in their own lives. Within the literature it is often stated that parents or health professionals fail to provide COPMI with information about mental illness. This is based on an assumption that children are passive recipients of information, rather than

active participants in their own lives. Viewing COPMI as active participants in this instance highlights the interactional nature of attempting to provide COPMI with information about mental illness. Parents and health professionals may struggle to provide this information but COPMI may also actively resist it. The concept of COPMI not wanting further information about parental mental illness is an important area which requires further research in order to tease out the reasons for not wanting to know. In addition there is a need to examine the ramifications of not knowing.

Although much of the discussion has focussed on the participants who did not want further information, there were 11 of the 35 (approximately 30%) respondents who stated that they did want more information. This supports much of the previous research into both COPMI and ACOPMI (Dunn, 1993; Garley et al., 1997; Handley et al., 2001; Pölkki et al., 2005; Knutsson-Medin et al., 2007). Although some participants cited wanting vague information, such as knowing ~~more~~ "more stuff about it", other participants were able to articulate specific questions which they would have liked answers for. Where children felt they could find answers to their questions is discussed later in this section.

Although the research is clear that COPMI need to understand their parent's mental illness in order to increase resiliency, talking with COPMI could be met with considerable resistance from COPMI themselves. This needs to be taken into account by both parents and health professionals when raising the issue of parental mental illness with children.

6.2.2 Where does information about mental illness come from?

Within the interview participants were asked about how they found out about their parent's mental illness. The use of interviews as the method of data collection enabled discussion about the ways in which children are provided with information. Being able to facilitate

discussion around this question proved valuable as children’s responses to this question were complex. Listening to children’s responses it became clear that each child generally had a number of answers to this question. The question of “Where does information about mental illness come from?” involves two parts. Firstly, how do children find out about their parent’s mental illness in the first instance and, secondly, how do children continue to gain information as they get older. For example children may state that they were told initially about their parent’s illness from the parent themselves but then go on to state that discussion about mental illness is not encouraged in their house. Or a child could respond that they can’t remember how they initially found out about their parent’s mental illness but that they ask their parent when they have any questions about it. Children’s responses to each of these parts have been collated and analysed together in order to provide a complete representation of where children get information from. Themes are presented in *Figure 13* (below) and are discussed overleaf.

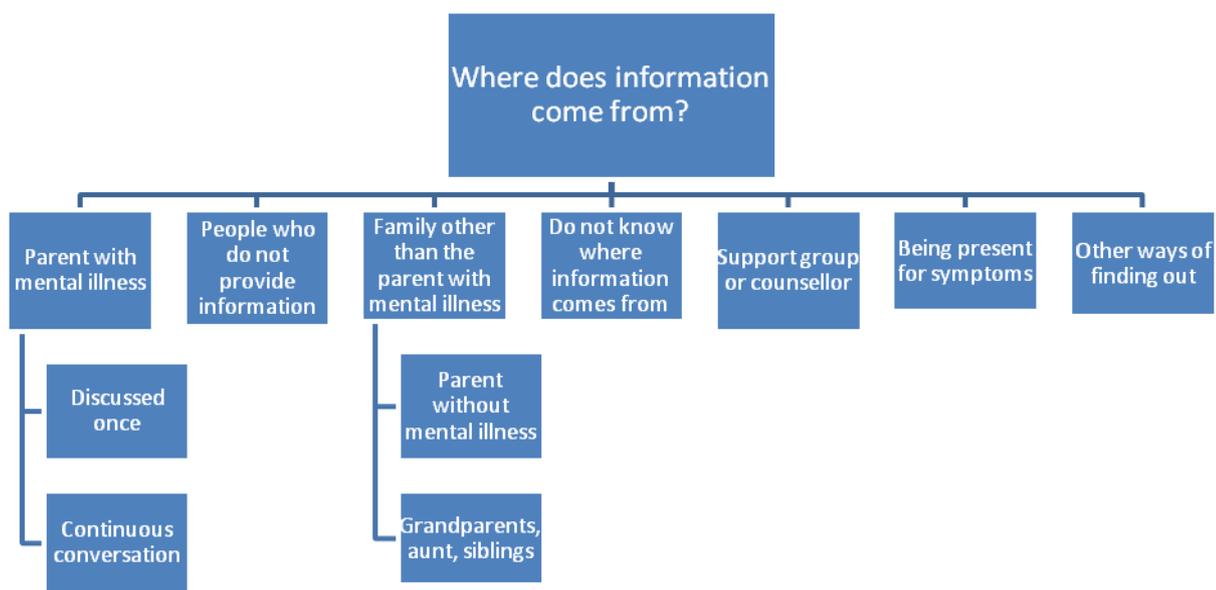


Figure 13. Themes developed in relation to the question “Where does information come from?”

6.2.2.1 Parent with the mental illness

The majority of participants (23 of 40) stated that they had received information about mental illness from the parent with the illness. As mentioned, some children received information initially from their parent, whereas some were not told by their parent initially but have had conversations more recently with their parent. Few children were both provided with information from their parent initially and have had conversations with their parent since then.

The most common response within this theme was that the parent with the mental illness discussed the illness with the child once and has not discussed it again.

Extract 359

I: Who first told you about your mum's depression?

C: My mum

I: And how long ago did she tell you?

C:I can only remember two years ago

I: Can you remember what she told you?

C: No

I: Does anyone else talk to you about it at all?

C: No

I: So just your mum?

C: Yeah

(Son of mother with depression, 10 yo)

The theme of a parent not talking about mental illness with a child frequently is discussed in more detail in the section below; People who don't talk about it.

Very few children stated that they have spoken to their ill parent about the illness since being told about it initially.

Extract 360

I: Who told you about your mums depression?

C: mmm.....sometimes she tells me some things

(Son of mother with post traumatic stress disorder and borderline personality disorder, 9yo)

Extract 361

Um...sometimes mum I ask her because she was a nurse and she's the one who's been through it so um...yeah mostly her ...

(Daughter of mother with schizoaffective disorder, 17yo)

6.2.2.2 People who don't talk about it

When talking to children about where they find out information about their parent's mental illness, over half of the participants mentioned not talking to certain people about their parent's illness.

Most commonly children stated that they do not talk to their ill parent about mental illness. Each child gave an explanation as to why this is the case. In almost all cases children stated that they did not discuss mental illness with their ill parent because they believed their parent did not want to talk about it with them.

Extract 362

I: Has mum ever spoken to you about it?

C: Not really....she doesn't really want to talk about that stuff in front of me....

(Daughter of mother with depression, 10 yo)

Some children stated that they did not talk about mental illness with anyone.

Extract 363

I: Who talks to you about your mummy being sad?

C:

I: Does your mummy tell you about it?

C: No

I: Do you speak to your dad about it?

C: No

I: Do you speak to (brother) about it?

C: No

I: *Do you speak to your mum about it?*

C: No

(Daughter of mother with depression and post traumatic stress disorder, 7yo)

Extract 364

I: *So you don't remember anyone ever speaking to you about it?*

C: *....no not really...no...*

(Daughter of mother with schizophrenia, 13yo)

Extract 365

I: *When your mum goes into hospital do you guys talk about that at home?*

C: *Um.... not really ...usually when mum goes into hospital it's just like get home, have tea, watch TV, go to bed 'cause it's not much time.....get up at like 6.30, 7 o'clock leave for school and then get home at about 6.30, 7 o'clock so...*

I: *So you don't get much time to talk about it?*

C: *Yeah...yeah*

I: *Do you speak to your brothers about it?*

C: *Not really.....no....I'm usually just in my room...like if she's down dad will fix it or she'll be in her room so I'll be in my room trying to escape the family sort of thing*

(Son of mother with bipolar disorder, 15yo)

Extract 366

I: *Has your mum ever explained her illness to you?*

C: *.....no.....not that I can remember its mostly been information I've extracted or I've interpreted (sic) or overheard...I've never actually been explained*

(Son of mother with schizoaffective disorder, 15 yo)

Over half of the participants received information about their parent's mental illness from the parent with the mental illness. Often the parent with mental illness told the child initially and had not spoken to their child about it again. COPMI in the current study stated that they did

not approach their parent to talk about their mental illness as they believed that their parent with mental illness did not want to discuss it with them.

There are two key points within these findings. Firstly, the finding that children perceived that their parent told them about the mental illness initially but had not discussed it with them since then. There are a number of issues with only telling a child about the illness once, these have previously been discussed within Chapter Three but will be briefly addressed again here. A child may be young when first told. The child may need time for the information to absorb before they are able to think of any questions they may have. Parental illness and symptoms may change and the initial explanation may not be adequate. Falkov (2004) suggested that talking to COPMI needs to be a continuous conversation. As Cain (2002) states in his review of disclosure about another sensitive topic, suicide, understanding of a difficult topic is shaped and changed by a child's development and life experiences. New information and explanation is needed over time. As Cain states, disclosure should be viewed as —a process, not as an event” (Cain, 2002, p.135).

The second key point is that COPMI stated that they believed that their parent with mental illness would prefer not to discuss the illness with them. Parents with mental illness have highlighted that discussing their illness with children is difficult (Falkov & Cowling, 2009; Nicholson et al., 1998; Thomas & Kalucy, 2002; Wang & Goldschmidt, 1996). If children have the perception that their parent doesn't want to talk about it, this may have ramifications for children being able to find out information. For example, it could be assumed that COPMI in this situation would be less likely to approach their parent with questions. Given that there were parents within Chapter Three who stated that they would provide information about mental illness to their children only if their children asked them about it, this finding is important. It appears some COPMI are less likely to approach their parent with questions and

some parents are less likely to provide information unless asked, a situation which could easily result in no information being shared.

6.2.2.3 Family other than the ill parent provides the child with information

When answering questions about where they found out information about their parent's illness, eighteen children stated that they had received information from family other than their parent with the mental illness. The parent without the mental illness was mentioned most frequently within this theme.

Extract 367

I: Who did you find out most of the information from?

C: It was dad like..yeah he kept talking about it

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

Extract 368

I: Where did you learn the most about it?

C: My mum telling me about it when I ask questions

(Son of father with schizophrenia, 14 yo)

Other family, such as grandparents, aunts and siblings, were mentioned by a few children.

Extract 369

...yeah I've known about it like from people around me surrounding me and that..

(Daughter of father with depression, 10yo)

Extract 370

C: Uh I think it was my Dad...or like....cause I was really little...I think it was my Dad or my Nan and Pop if I was living with them

I: Do you remember what they said?

C: No

(Daughter of mother with bipolar disorder and postnatal depression, 12 yo)

Approximately 18 children stated that other family provided information, most frequently this was the parent without mental illness. Research suggests that marital disputes, separation and raising their children alone is common for parents with mental illness (Downey & Coyne, 1990; Oyserman et al., 2000; White, Nicholson, Fisher & Geller, 1995). Nicholson and colleagues (1998) found that the family relationships that a person has are complex. Family, such as the partner or parents of the person with mental illness can take over a parent's role without gaining consent from the parent, family can talk in a derogatory way about the parent's illness or the parent themselves, alternatively family can be supportive (Nicholson et al., 1998). In the current study 15 of the 40 participants lived with both of their parents. Although not specifically asked within the interview with parents, a number of parents who were not living with their partner stated that they were estranged from them. This was the case for both the parents with mental illness and the parents without mental illness who were interviewed. Given the mixed research regarding the supportiveness of the family of parents with mental illness, the information provided to COPMI from other family members could be supportive or derogatory towards the parent and their illness.

6.2.2.4 Not sure where the information came from

Throughout the interviews it became clear that there were a number of children who knew about aspects of their parent's illness, such as the name of the illness and the fact that their parent had the illness, but they were unsure how they found out this information. Thirteen participants stated that they had "just always known" about their parent's illness.

Extract 371

I: Do you remember how your dad's illness was explained to you?

C: Nuh... I just remember knowing

(Daughter of father with schizophrenia, 11 yo)

Extract 372

I: Do you remember being told about it at all?

C: No.....i just remember like knowing....it's just happened....it's like with finding out (stepfather) wasn't my father I can't remember that

(Daughter of mother with schizophrenia, 13yo)

Extract 373

I: Who first told you your mum was ill?

C: Um....I'm not really sure..I've just always known

(Son of mother with schizoaffective disorder, 15 yo)

Extract 374

I: And who first told you about his illness?

C: Um.....that was going back a bit....um.....I'm guessing either mum or dad....it's pretty vague I can't really remember

(Son of father with antisocial personality disorder, 16 yo)

COPMI who endorsed this theme gave responses stating that they have “always known”. This is similar to the concept of “awareness” which was discussed within the interviews with parents in Chapter Three. Both COPMI and their parents state that there is an “awareness” or knowledge of mental illness which has developed without input from others. Research has shown that even when children are not explicitly told about other sensitive topics, such as HIV or suicide, they still have some knowledge of it (Cain, 2002; Murphy, 2008).

COPMI having knowledge of their parent’s mental illness without having been told about it fits with the statement made by Finney and Falkov (2009) that if COPMI are not told about

parental mental illness then they will develop theories about the illness themselves. Finney and Falkov (2009) further state that the theories developed by COPMI have the potential to be inaccurate and confusing. The finding in the current study is similar to what has been found previously with studies into ACOPMI experience; that ACOPMI were not told about parental mental illness but that they knew that something was wrong (Foster, 2010).

6.2.2.5 Support group or counsellor

A quarter of the participants mentioned a support group or a counsellor when asked questions about who had provided them with information about their parent's illness. As previously stated, a number of participants were sourced through COPMI-focussed support groups around Australia. A few of these participants credited COPMI-focussed support groups as providing them with information.

Extract 375

I: And who first told you that your mum had bipolar?

C: Umm the tutor that came, (counsellor's name),

I: And who did you find out most of the information about your mums illness from?

C: well ARAFMI

(Son of mother with schizophrenia, 11 yo)

As previously stated, ARAFMI stands for the 'Association of Relatives and Friends of those with a Mental Illness'. There are branches of ARAFMI Australia-wide and they each provide information about mental illness and often provide support groups for adults and children who are relatives or friends of people with mental illness.

Some participants who were not affiliated with COPMI-focussed support groups stated that counsellors had provided them with information about their parent's mental illness. In all

cases the counsellors were a part of a government-provided child and adolescent mental health service.

Extract 376

when I was a little kid I got a lot of counseling...from professionals...who you know who sat down and told me and gave me pamphlets

(Daughter of mother with schizoaffective disorder, 17yo)

Extract 377

I sort of learnt it through counsellors

(Daughter of father with depression, 14 yo)

Extract 378

I: Where did you get most of your information from?

C: From a group....I don't know what it's called

(Daughter of mother with schizophrenia and anxiety, 13yo)

6.2.2.6 Child learned about the illness by being present for symptoms

Throughout the interviews it became apparent that many of the participants had been present for symptoms however only six of the 40 participants explicitly stated that they had found out about the illness as a result of witnessing symptoms. In all but one case children had the illness further explained by the non ill family member shortly after being present for the symptoms.

Extract 379

I: Do you remember when someone first told you about your mum's depression?

C: Um.....well actually no one told us like straight away that she was having depression she started getting like grumpy and upset and stuff and then she went into hospital

(Son of mother with bipolar disorder, 12 yo)

Extract 380

I: Who told you about that?

C:uh...I was there.....we.....my dad was dropping us off...this is last summer, I can remember, and my dad was dropping me and (sister) off at mum's house and we went in and.....everything was trashed and...yeah...she was all funny....so we rang the ambulance
(Son of mother with schizophrenia, 11yo)

Extract 381

I: When did she tell you?

C: Well I knew that um.....she didn't like us to wear shoes in the house and stuff like that.....then she told me..... that last year or something

I: So you kind of knew something was up before she told you?

C: Yeah

(Daughter of mother with Obsessive Compulsive Disorder and depression, 10 yo)

In one case the participant's non ill parent had attempted to explain the illness to her prior to the child witnessing her father's psychotic episode. The child explained that she didn't believe her mum initially.

Extract 382

Um...my mum told me around ...before the time it happened and I didn't really believe her...like I said "yeah I know" but I didn't really believe her.... nanna and...I'm meant to always be with him with someone else there as well and nanna and grandpa both went off and did their thing even though one of them was supposed to stay cause they were fighting over who would look after me so they both went and then dad didn't have his injection and...yeah.....

(Daughter of father with schizophrenia, 11 yo)

6.2.2.7 Other ways children have learned about their parent's illness

A few participants provided responses which were unique to them and did not fit within the themes developed. In order to appreciate the range of ways that children find out information about their parent's illness two of the unique responses are included here.

One child only knew about her mother's mental illness after she overheard her mother telling someone else that she had it. The child has never talked about the illness with her mother or with anyone else.

Extract 383

C: Well... 'cause when I turned 16 I had to go to Centrelink (Government financial support agency) and ...do all that student loan... not student loan but all that stuff...and um she couldn't understand some of the forms and I had to fill them out and she told the lady as well... so that's how I kind of ...I knew she had something but I wasn't sure what it was

I: So that was how you found out?

C: Yep

I: Did you ask her afterwards what it was about?

C: No (laughs)

(Daughter of mother with bipolar disorder, 16 yo)

One participant was particularly proactive in finding out information about his mother's mental illness. Little information had been provided to him so he sought out the information he wanted. The participant's active search for information was uncharacteristic of the participants within this study. In this instance he was discussing using text books to answer his questions. Of particular interest is the effort he put into sourcing textbooks, ordering them from a University even though he was currently in high school.

Extract 384

I: Where do you find the majority of your information?

C: Textbooks.....textbooks.....

I: Did you get these text books from school?

C: Um...a couple I've applied from the University of Adelaide and they'll... I've been told they'll be coming in October um...and I'm looking forward to getting those but they're mostly books I've read at the state library...um...wrote down notes or photocopied pages...or the Barr Smith Library um....and there's other...uh...its mostly just psychology books at home that I've purchased...

(Son of mother with schizoaffective disorder, 15 yo)

As shown in the analysis, sources of information for COPMI about parental mental illness included the parent themselves, the parent without the mental illness, no one, support groups and counsellors, being present for symptoms, and ‘other’ sources of information.

There are clinical implications regarding the sources of information COPMI may have. COPMI have a range of sources that provide them with information about their parent’s illness. It is important for clinicians to understand what these sources are for individual children. It is clear that a child’s understanding of mental illness could be shaped by the source of their information. In some cases COPMI may be told only once about their parent’s illness and may need further conversation about it so that they can ask questions. Depending on the source of information about parental mental illness, it may be that COPMI require a balanced view of their parent’s illness. Importantly, if COPMI have developed their own theories, these need to be explored with the child and any misperceptions addressed.

6.2.3 Do children talk to their teachers, friends or siblings about their parent’s mental illness?

To gain an insight into who children talk with about their parent’s mental illness, participants were asked a number of questions. Specifically children were asked if they had conversations with their siblings, friends or teachers. *Figure 14* displays the proportion of participants who

spoke to siblings, friends or teachers. The majority of children stated that they did not talk to anyone about their parent's illness.

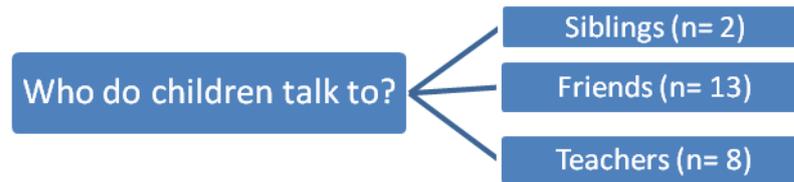


Figure 14. The number of children who talk to siblings, friends or teachers about their parent's illness

6.2.3.1 Talking to siblings

Of the 40 participants within this study, six did not have siblings. The remaining 35 participants were asked if they ever spoke to their siblings about their parent's illness. Only two participants stated that they had spoken to their siblings about it.

One of the participants stated that he spoke to his younger brother about it as a way of helping his younger brother understand their mother's mental illness.

Extract 385

I: Do you talk about it with your brothers?

C: Oh yeah... sometimes....maybe

I: More to the older or younger?

C: Um.....I reckon probably (younger) cause he's younger he might get... he might understand.. like he won't understand that well but he might get something in his head for when he's older and he knows more..... instead of people telling him and stuff.....

(Son of mother with bipolar disorder, 12 yo)

One participant stated that she is able to talk to her older brother about their father's mental illness.

Extract 386

I: Did you ever talk to your brother about it?

C: Oh.....yeah.....well cause obviously he knows about it so I didn't really need to explain it to him because he was older than me...but we have talked about some of the effects like...um how he spends money and that

I: Just the two of you?

C: Yeah...oh and mum as well sometimes..... But uh....we talked about what happens and.....you know...I mean there's not really much we can do about it obviously...but...yeah we just...you know just in passing

I: So you feel like you can talk to him about it?

C: Yeahcause you know I'm used to it now...well it's not like I've ever not been used to it...but it's not like a big.... issue.....oh that's right (laughing)...me and my brother (laughs)...because a lot of his time is spent upstairs that's where his like artist's studio and bed and that is...we sort of refer to him as ""im upstairs"" cause um... you know a lot of the time he wouldn't come down and it would just be like this snoring from upstairs so you'd just know that there's someone there and you can't see them...so we've had a couple of jokes

(Daughter of father with bipolar disorder,16 yo)

The majority of participants didn't speak to their siblings about mental illness. Few participants gave a reason for not speaking to their brothers or sisters. The following extracts are examples of some of the reasons given.

Extract 387

.....no because I hate my brothers

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 388

I: Your brothers?

C: Nah I don't think they'd be really..... caring about it

(Son of mother with post traumatic stress disorder and borderline personality disorder, 13 yo)

Extract 389

C: I think if I ever sat down with the younger boys and went "look...blah..." they just ...they wouldn't understand and then they'd start asking questions to mum ...and it would just....yeah

I: Do you ever speak to (names – older children who still live at home)?

C: ...uh.....No.....I mean we have like spoken about mum getting sick and stuffbut not really her depression no

(Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 17yo)

The question about whether participants in the current study spoke to siblings provided a striking result. Of the 35 participants who did have siblings, only two stated that they had spoken to their siblings about their parent's mental illness. This is striking given that, in previous research, siblings have been found to be a good support for COPMI. The COPMI within Fudge and Mason's (2004) study highlighted the role that siblings had in helping to cope with parental mental illness. Maybery and colleagues (2005) found that both COPMI and their parents identified the sibling relationship as being important at times when the family is experiencing difficulty. Indeed, Maybery and colleagues suggest "sibling support is considered essential for children when a parent has mental illness and opportunities to encourage this needs to be incorporated in future programs" (2005, p.7). From an ACOPMI perspective, Foster (2010) found that sibling relationships were deemed as important when the participants in her study were growing up. Given the importance placed on sibling relationships, especially in times of crisis, as highlighted by Maybery and colleagues (2005) it appears that participants within the current study are lacking a key source of support.

6.2.3.2 Talking to friends

Of the 40 participants, 13 stated that they had talked to their friends about their parent's mental illness.

Some children spoke to their friends about their parents because they felt they needed to, either because of their own behaviour or their parent's symptoms.

Extract 390

Oh yeah....um...basicallyum...I've got to let my friends know ...'cause I mean sometimes I get in a bad mood or stuff like that and they just know just to leave me alone or something like that....yeah so basically I just let them know what's happened and all that

(Son of father with antisocial personality disorder, 16 yo)

Extract 391

C: ...friends....not really it's just... except like if they're over and Mum like has a breakdown and that and then you have to tell them of course 'cause they'd go "oh what's that about?"

I: Have you had that happen before?

C: Oh yeah I had a friend over once and now.... Like I'm like..."oh she just has like ups and downs sometimes" I said to him and he's like "oh yeah my mum has that a couple of times like...not as bad as your mum but sometimes when she gets grumpy"

(Son of mother with bipolar disorder, 12 yo)

Extract 392

C:like I'd have a friend over and then she'd have all these shakes and all and stuff and I would have to like help her out and leave my friend and my friend would be like "...what's wrong with your mother?"

I: What did you used to say to your friends?

C: I just used to go "oh yeah she has her panic and anxiety attacks" and all that kind of stuff.....((...))...

I: Do you speak about with any of your friends here at your new school?

C: Nah

(Daughter of mother with schizophrenia and anxiety, 13 yo)

Other children stated that they talk to their friends about their parent's illness because they wanted to or because their friends were open to talking about it.

Extract 393

I: And do your friends know about it at all?

C: ...yeah some of them...((..))...like my friend (male name) he does...he's pretty cool with it...yeah...he thinks mum's funny...

(Daughter of mother with schizophrenia, 13yo)

Extract 394

I: Do you speak to your friends about it at all?

C: Yeah...my best friend (name)..yeah

I: What sort of stuff do you tell her?

C: I tell her everything...everything....we're totally open with....

(Daughter of father with schizophrenia, 11 yo)

Extract 395

I: Do you talk to your friends about it at all?

C: Yeah um....my friends know that my dad is..got a mood disorder but it's not really a problem...they have sympathy for me obviously... but because I'm not really fussed about it....I don't sit and cry because of it (laughs)

(Daughter of father with bipolar disorder, 16 yo)

Twenty-eight participants stated that they did not talk to their friends about their parent's mental illness. There were a number of reasons provided, the most common are presented below.

A few children had not spoken to their friends because they hadn't thought to tell them or they were too busy at school to talk about it.

Extract 396

I: Do you speak to your friends or teachers about it?

C: Um.....no I never have cause I'm always playing

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 397

I: Do you ever speak to your friends about it?

C: No

I: Why not?

C:because ...um....at lunch or recess...all anyone wants to do is play so.....and I basically forget about it because I've been working hard at school and it's time to play

(Son of mother with depression and post traumatic stress disorder, 10 yo)

Often children cited their peer's potential reaction as a reason not to discuss it with them.

Possible peer reactions included starting rumours, teasing and not understanding the illness.

Extract 398

I: Do you speak to your friends at school?

C: Nup

I: Why not?

C: (Laughs)..... it's embarrassingI'd say so

I: Would you ever tell them about it?

C: (laughs) probably

I: What do you think they would say if you did tell them?

C: Well maybe if we're older they might say "oh I feel sorry for you man" or something like that

I: And at this age they probably wouldn't?

C: Yeah they'd probably tease ya

(Son of mother with posttraumatic stress disorder and borderline personality disorder, 13 yo)

Extract 399

I: Do you speak to your friends about your mum's illness?

C: Hell no.....They don't understand it because they haven't gone through it and because they probably don't know enough about it

(Daughter of mother with schizoaffective disorder, 17yo)

Extract 400

I: Do you speak to your friends about it?

C: No

I: Why not?

C: Because they might pass it on to other people...and then a rumour would start

I: What sort of rumours would start?

C: I don't know

I: So you don't talk to your friends about it?

C: I talk to my friends with other stuff but not about my mum

(Son of mother with bipolar disorder, 10yo)

Extract 401

C: Yeahand and my main friend which I go over his house and he comes over my househe might not want to come over to my house any more..... he might not trust me...

I: So that's why you haven't told any of your other friends either?

C: Yeah

I: Do you think you'll ever tell your friends?

C: Hmmm not really....well I wouldn't tell (certain friend) 'cause when I tell him something he spreads it.

(Son of mother with schizophrenia, 11 yo)

The concept of being able to talk to friends about things other than mental illness was highlighted by other children also. In the following two extracts children state that they share some detail about their parent with their friends but no detail about their parent's mental illness.

Extract 402

I: What about when she goes into hospital do you ever tell your friends she's in hospital?

C:(nods)

I: And what did you say she was in hospital for?

C:....well.....uh....when I didn't know I didn't tell.. but um...like when she was in hospital ...just then.... ah...I said she's in hospital and she has a kidney problem andyeah.....

(Son of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 11 yo)

Extract 403

I: Do you tell your friends about it at all?

C: Oh....my friends.....well I tell my friends stuff like um" oh I have to go to the counsellor today to talk about (stepdad)" and they go " oh yeah like I know what you mean" but um...like they.... like I tell them stuff but I don't tell them...like I didn't tell them about the note with (stepdad) and the blood and stuff because I thought that was... cause um like we've got people at school like an emo and stuff and you know what I mean ...

I: What would happen if you did tell your friends?

C: I think they'd laugh and think it was a joke...

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Maintaining friendships whilst having a parent with a mental illness appeared to involve a delicate balance of sharing some information about home life and withholding information which could jeopardise the friendship. This concept was articulated by one participant as shown in the extract below.

Extract 404

I: Have you ever spoken to your friends about it?

C: No ...see they're so different....its.....its two separate worlds and I tend to keep them very.... like...separated....as much as possible

(Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 17yo)

Two children stated that they didn't tell their friends because they didn't have any friends.

Extract 405

I: Can you speak to any of your friends?

C:um.....all through childhood I didn't like making friends and I was never really good at it and you could say yeah I'm a loner...

(Son of mother with schizoaffective disorder, 15 yo)

Extract 406

I: Do you speak to your friends or your teachers or anyone else about your dad's illness?

C: Um.....definitely really not friends at all...don't really have any.....no....

(Daughter of father with depression, 10yo)

COPMI feeling unable to discuss their illness with friends has been found within much of the previous COPMI research. In one study, parents themselves thought that their child's relationships with friends had changed as a result of their parent's illness (Stallard et al, 2004). Parents within the study conducted by Stallard and colleagues thought that children may be reluctant to have their friends visit their house due to embarrassment about the parent. Other studies have found that COPMI themselves have highlighted an inability to talk to friends about a parent's illness (Cogan et al., 2005a; Garley et al., 1997; Valiakalayil et al., 2004). One study of COPMI also found that COPMI were reluctant to bring friends home (Cogan et al., 2005 b). In contrast, Meadus and Johnson (2000) found that all three of their COPMI participants stated that they could talk to friends about their parent's illness. Maybery and colleagues (2005) also found that friends were important to the COPMI in their study, however the finding was that friends were generally important, not that friends were supportive of a child's COPMI status.

In the current study participants did not talk to their friends even when there was significant disruption to their personal life (for example their parent was hospitalised, or the child or the parent were living elsewhere). Children within the current study appeared to be quite aware of the stigma that surrounds mental illness and they worked hard to keep the two spheres of their life separate.

6.2.3.3 Talking to teachers

Participants were asked if they had ever spoken to their teachers about their parent's mental illness or if their teacher knew about the illness. Similar to the participant responses about talking to siblings and friends, 80% of participants (32 participants) stated that they had not spoken to teachers about their parent's illness. The majority of participants did not provide a reason why they had not spoken to their teachers. Those who did provide a reason stated that they didn't tell their teachers because their teachers were unaware of the mental illness present in their family or they didn't feel comfortable talking to their teachers.

Extract 407

I: Would you speak to a teacher at school at all?

C: Not really

I: Why not?

C: Because my teacher doesn't really..... know about that stuff....

(Daughter of mother with depression, 10 yo)

Extract 408

I: What about teachers?

C: mmmm....I don't really feel comfortable with actual teachers...so....

(Daughter of father with depression, 10yo)

Extract 409

I: Have you ever spoken to your teachers about it?

C: Nup

I: Would you ever speak to them?

C: No (laughs)

I: Why not?

C: I don't really talk much to my teachers (laughs)

(Daughter of mother with post traumatic stress disorder, depression, borderline personality disorder and anxiety, 13 yo)

Extract 410

.....um I wouldn't talk to teachers 'cause that's just lame... no offense but like...umm.. I don't know 'cause I really wouldn't I don't take like um.... my home problems to school because I'm like, schools like the only place where I don't have tothink about (stepdad) being like.....

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Of the 40 participants, eight participants stated that their teacher did know about their parent's illness as shown in the extracts below. For all children who had spoken to their teachers about their parent's mental illness the interaction with their teachers had been a positive one.

Extract 411

I: And would you speak to your teacher about it?

C: um... my year six teacher he knew about it because he gets really close to parentsand he knew about my mum and he tried to convince her not to (move to another area) and then he left the school and then my other teacher did exactly the same thing and she helped me a lot through it as well

I: So you could speak to her about it?

C: Yeah

(Daughter of mother with schizophrenia, 13 yo)

Extract 412

C: I used to speak to my teachers about it....it's just, sometimes it slips out...like um....my Ag (agriculture) science teacher came up to me and she met my aunty and uncle at parent teacher interview night and they just find out because they ask me why I live with them I said "oh because you know I don't live with my dad anymore" and they say "oh where's your mum?" and I'm like "oh what the hell I'll say" and I'm like "she's got schizophrenia and she's really sick" and things like that and I reckon three of my teachers know that because they've had like...just intimate conversation about it

I: Do you feel comfortable speaking to teachers about it?

C: Yeah...because they're just another adult...seriously don't care...they've got an opinion on life that will respect mine...I hope I don't sound like I'm bullshitting too much...

(Daughter of mother schizoaffective disorder, 17yo)

In terms of school support or teachers, only eight of forty participants stated that they had spoken to teachers. Those who had spoken to teachers stated that it was a positive experience. Other participants stated that they did not talk to teachers because they did not feel comfortable about it or because they did not think that their teacher knew about their parent's illness. This is not an unusual finding (Cogan et al., 2005a). Over the course of the interviews participants within this study cited hospitalisations and other parent illness-related crises which occur in their lives. It could be assumed that such upheavals in a child's life could affect school work and performance at school. Children can have difficulty concentrating at school when they are unsure about what is happening at home and when they are unsure about whether their parent is safe (Pretis & Dimova, 2008; Riebschleger, 2004). In addition it has been suggested that COPMI are at risk for leaving school earlier.

Research suggests that COPMI, in comparison to non-COPMI, can have academic difficulties (Downey & Coyne, 1990) and have an increased chance of dropping out of school (Farahati, Marcotte & Wilcox-Gök, 2003). It is unclear why this is the case but it has been speculated that it may be due to the need to look after the ill parent or to undertake household duties that the ill parent is unable to do (Farahati et al., 2003). It may also be due to the child having to

leave home because their living conditions are not acceptable (Lancaster, 1999). Given the findings of the current study, it could be the case that COPMI feel unable to speak to teachers about issues at home. This could mean that teachers do not understand about the source of a child's difficulty with concentration and completing school work on time. A child may eventually leave school because they perceive school and home to be competing for their time. If COPMI felt able to speak to their teachers this could perhaps go some way toward bridging the gap between home and school.

Given that school is a central part of most children's lives, schools appear ideally placed to help to support, and possibly educate COPMI, around parental mental illness (Reupert & Maybery, 2010a). For a few COPMI who have participated in previous research, school is seen as a positive environment where certain teachers and school counsellors effectively support them with their schooling (Reupert & Maybery, 2007b), however it is rare for schools to be involved in larger scale interventions for COPMI (Reupert & Maybery, 2010a). Fudge and Mason (2004) specifically asked COPMI participants how school could support them. Suggestions included having someone at school to talk to (such as a school counsellor or teacher) and practical help such as transport and providing meals if needed. COPMI also wanted schools and teachers to be aware of parental mental illness and to be more flexible and compassionate in times of crisis (Fudge and Mason, 2004). Similar to sibling support, it appears that there is potential for schools to provide support to COPMI within the current study, and indeed all COPMI. Participants within the current study work hard to keep their school and home lives separate, an action which at times of crisis could be difficult.

6.2.3.4 I don't talk to anyone

Sixteen of the 40 participants had discussed their parent's mental illness with either a friend, their sibling or a teacher. Some of them had discussed the illness with more than one group,

for example they had talked about mental illness with friends and a teacher. Twenty five participants had not discussed their illness with a sibling, friend or teacher. Some children appeared not to discuss the illness with anyone, stating that they did not speak to their parents about the illness either.

Extract 413

I: Do you speak to your mum about it at all?

C: (shakes head)

I: What about speaking to your sister?

C: (shakes head)

I: Do you speak to your friends at school about it?

C: No

I: What about other relatives?

C: I hardly see my other relatives

I: What about any teachers at school, do you speak to them about it?

C:nup

(Son of mother with schizophrenia, 11yo)

Extract 414

I: Do you ever speak to teachers or your friends or family about it?

C: No.....

I: Is that because you haven't had the questions or because you don't feel comfortable?

C: Um...I've never really had the questions...but even if I did have questions....sometimes I just let it slip straight through my mind...

I: So if you did have questions would you speak to your mum?

C: Um.....maybe.....

I: The teachers at school?

C: No not really.....no...

I: What about your friends?

C: Um.....not too much

(Daughter of mother with bipolar disorder and post natal depression, 12 yo)

Other children had stated (earlier in the interview) that they had discussed the illness with a counsellor or their parent but that they did not speak to other people about the illness.

Extract 415

I: Have you ever spoken to your teachers about your mum's illness?

C: No

I: And what about your friends at school?

C: No

I: Do they know that your mum has an illness?

C: I don't know.

I: You haven't told them anything about it?

C: No

(Son of mother with schizophrenia, 11 yo)

Responses to the question about who participants talk to about mental illness, specifically friends, siblings or teachers, indicate that there are a large number of COPMI within the current study who do not use these groups as a source of support. Twenty-five of the forty participants indicated that they had not spoken to any of these people about their parent's illness.

There are clinical implications of these surprising findings. Given the role of siblings, school, teachers and friends in most children's lives it seems there is potential to develop at least one of these areas as a support for the child. The area of sibling support in particular, should be examined among COPMI and, if sibling relationships are tenuous, assistance should be provided to help siblings strengthen this relationship. COPMI difficulties with balancing school and home life should not be underestimated as incomplete schooling can have ramifications on further education possibilities and earning potential.

6.2.4 Where would you go to get more information about your parent's mental illness?

Participants were asked about how they would access information about their parent's mental illness if they needed it. Questions were asked regarding finding out information now or in the future. The question about who COPMI feel they can turn to if they do want information about their parent's illness was perhaps one of the most important questions asked of participants, given the apparent lack of communication about mental illness discussed in this chapter.

Responses to this question were analysed and collated together to form four main themes. These themes are presented below in order of most common. Some participants endorsed more than one source. The figure below (*Figure 15*) displays the range of themes developed from this question. The responses within each theme were quite similar so a smaller number of extracts were needed to highlight the range of responses.

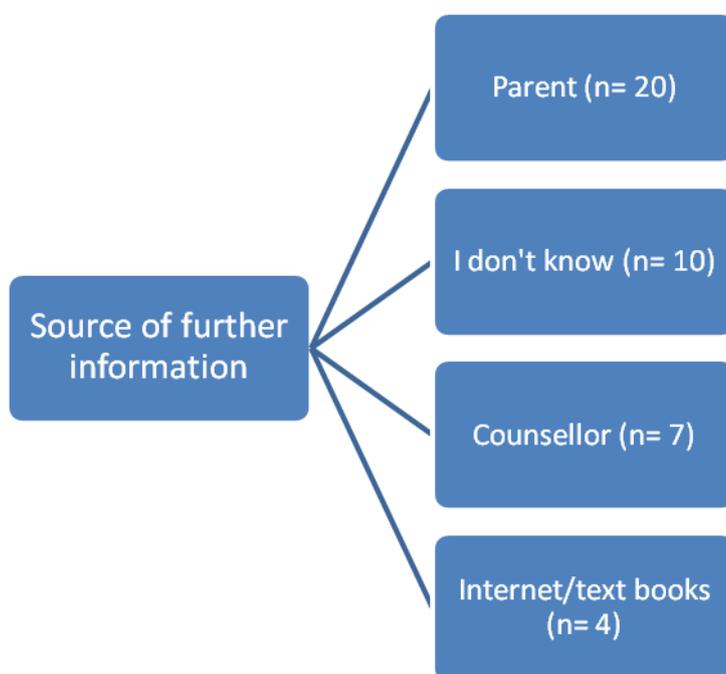


Figure 15. The main themes developed from answers to the question of where children would find further information about mental illness.

6.2.4.1 Parent

When asked about how they would find out further information about mental illness in the future, twenty children stated that they would speak to their parent about it. Parents in this instance included the parent with mental illness, the parent without mental illness and either or both parents. Extracts within this section were very similar so only one from each group has been included.

Extract 416

I: If you did have questions who would you ask?

C: My mum...yep...she knows mostly everything about it

(Daughter of stepfather with depression, anxiety, obsessive compulsive disorder and borderline personality disorder, 15yo)

Extract 417

I: If you did have questions who would you ask?

C: Um probably mum or dad ...

(Son of mother with borderline personality disorder and schizoaffective disorder, 9 yo)

In addition to parents, three children also mentioned other family who they could ask questions about the illness.

Extract 418

I have quite a few people can I name all of them? My Mum, Nanna...possibly my Pa...yep my Pa.....

(Daughter of father with depression, chicken pox, 10yo)

Extract 419

Um...I'd probably ask Nanna

(Daughter of father with schizophrenia, 11 yo)

Extract 420

Um my Nan and Pop, aunty and uncles...everything like that...on my Mum's side of course

(Son of father, with antisocial personality disorder, 16 yo)

It is worth noting that although half of the participants interviewed stated that if they had a question they would ask their parent, very few of these children had actually asked their parent questions about the illness in the past. Although it does not necessarily follow that these participants would not ask questions of their parents in the future, it is important to recognise the lack of questions thus far.

6.2.4.2 I don't know

When asked how they would find out information if they needed it ten children stated that they didn't know how to access further information. This was the second most common response.

Extract 421

I: If you did have questions who would you ask?

C: mm.....um.....I don't know.....I don't know anyone to ask

(Son of mother with borderline personality disorder and schizoaffective disorder, 7yo)

Extract 422

I: If you did have questions who would you ask?

C: Oh.....I don't know

(Son of mother with borderline personality disorder and schizoaffective disorder, 12 yo)

Extract 423

I: Yeah and if you had any questions about your mums illness now who would you ask?

C:I dunno.....

(Daughter of mother with schizophrenia, 13 yo)

This finding that children did not know who to ask for further information was interesting as it suggests that these participants felt that they could not speak to their parents about mental illness if they had a question.

6.2.4.3 Counsellor or support group

Seven participants mentioned child focussed support groups or counsellors when asked how they would find out further information about mental illness. Not surprisingly only children who had been in contact with a counsellor or support group mentioned this as a way to find out further information. Not all children who had access to support groups or counsellors endorsed them as a means of finding out information.

Extract 424

I: And if you had questions about it who would you speak to?

C: ARAFMI

(Son of mother with schizophrenia, 11 yo)

Extract 425

I: If you had questions who would you ask?

C: Um...probably (support worker's name)

(Son of mother with post traumatic stress disorder and borderline personality disorder, 12 yo)

Extract 426

like (support worker's name) or someone 'cause I don't like reading

(Son of mother with bipolar disorder, 15yo)

6.2.4.4 Internet or text books

When discussing where they would go to find out more information about mental illness four participants stated that they would use the internet or text books to look up the information themselves. Older children were more likely than younger children to state that they would get information from the internet or text books.

Extract 427

I: If you wanted more information where would you get it from?

C: Um...internet...or some psychological website maybe

(Daughter of mother with schizophrenia, 17yo)

Extract 428

....um...id probably go to the library and look up mental health in textbooks and things that have been written by professionals so that's where I'd get my information from

(Daughter of mother with schizoaffective disorder, 17)

Although approximately 75% of participants (30 of the 40 participants) in this study cited at least one person who they could talk to or ask questions about their parent's illness, generally participants had not yet spoken to these people. There are clinical implications of this finding. COPMI should be helped to identify at least one person with whom they can talk about their parent's mental illness. In addition COPMI should be provided with information that they can access on their own. Information, books and DVDs about mental illness could provide information to those COPMI who may prefer not to ask questions about parental mental illness.

6.3 Summary

The current study examined COPMI beliefs about their own knowledge about their parent's mental illness. It also explored COPMI views about the process of disclosure of mental illness, specifically where information about mental illness comes from and who they talk to about parental mental illness.

Taken as a whole, the findings of this section of the study indicate that, for many participants, mental illness is a topic which does not get discussed. Children themselves may demonstrate considerable resistance if presented with information about their parent's illness. In addition, some COPMI may hold the belief that their parents would prefer not to talk about it. Potential sources of support within the lives of these COPMI, such as siblings, friends and teachers, are not drawn on by the majority of the participants in this study. Children may see their parent as a potential source of information about mental illness however very few children asked their parents questions.

Thus far this thesis has examined the process of disclosure from both a parent and a child perspective. At present, it is unclear how the discussion of mental illness and the dissemination of information about parental mental illness is conducted within a family context. How do members of the same family view the process of disclosure? Are the views that each family member has about the domains of illness similar or is it possible for family members to hold competing ideas about the same illness? The following chapter, Chapter Seven, examines family communication and understanding of mental illness.

Chapter Seven: Study three – Family communication and understanding of mental illness

The thesis thus far provides an insight into parents' experiences of explaining mental illness to their children. It also provides an insight into children's ideas about mental illness and their experience of receiving information. To obtain a thorough appreciation of children and parents' understanding of mental illness it is important to examine the familial perception of mental illness. Specifically, the way in which children and adults from the same family perceive mental illness and communicate about mental illness.

7.1 Literature examining familial perceptions of illness

Research which simultaneously examines both children's and parent's views of illness in the family is in its infancy. A recent meta-synthesis examined the available literature on parent and child communication about inherited genetic conditions (Metcalf et al., 2008). Among other aspects, the review examined how genetic risk was discussed between parents and children. Although the review did not examine parent and child discussion about mental illness, a main finding was that the studies examining communication do not examine both child and parent perspectives. Instead the current research available which examines communication within the family about genetic risk comes from only one perspective, generally the parent's (Metcalf et al., 2008).

There are only a handful of published papers which explore familial communication about illness from both a parent and child perspective. These include child and parent views about communication of a child's Duchenne Muscular Dystrophy (Plumridge, Metcalfe, Coad & Gill, 2010), HIV status (Kennedy et al., 2010) and parental breast cancer (Forrest et al., 2006),

all of which are within the physical illness area. Findings from these studies suggest that parents can underestimate what their children know about the parent's illness (Forrest et al., 2006), parents can be reluctant to answer children's questions about illness (Plumridge et al., 2010) and that parents and children can view same disclosure process very differently to each another (Kennedy et al., 2010).

7.1.1 Literature examining familial beliefs about mental illness

As already stated within this thesis, there is a dearth of research examining COPMI or parents' perceptions of mental illness. Much of the literature within this field so far focuses on the child's desire or need for more information or the parent's difficulty with knowing how to explain it to their child. Not surprisingly, to date, there is no published data available which has examined what a parent has said to a child and what message their child has taken from the interaction.

The literature regarding familial beliefs about mental illness is also scant. Using Leventhal's illness domains to assess illness beliefs, research has found that congruence in the beliefs that family members have about mental illness is important. Specifically, discrepancy between the illness beliefs of the person with mental illness and their family members (generally parents and siblings, not children) has been linked to higher criticism of the person with mental illness, hostility toward the person with the mental illness and emotional over involvement (Lobban, Barrowclough & Jones, 2006). Other research has found that discrepancy in illness beliefs between people with mental illness and their carers is linked with a range of negative outcomes for both parties (Kuipers et al., 2007). Incongruence in illness beliefs was linked to anxiety and depression in people with mental illness and high distress and depression in their carers. Both the people with mental illness and their carers also had lowered self-esteem when there was discrepancy in illness beliefs (Kuipers et al., 2007).

Exploration of the illness beliefs of both parents with mental illness and their children is needed. Specifically information about the messages parents try to give to their children and the messages that children receive. As Cain (2002) states “there is a difference between being told and knowing” (p. 124). Information is also needed about the perceptions of mental illness held by the parent and the children in the family. Exploration into whether parents and children share views about aspects of mental illness (such as identity, cause, treatment and timeline) could provide useful information about possible ways to communicate to children about mental illness.

This thesis was originally designed to examine child views of mental illness and parent views of explaining mental illness to their children. As the interviews were being conducted, it became apparent that children and parents in some families had quite different views, about both the process of explaining mental illness and their views on mental illness itself. A further study was necessary in order to provide insight into the family experience as a whole.

7.2 The current study

As a part of the interviews conducted with parents (for the study presented in Chapter Three), parents were asked a number of questions about their understanding of their own illness or, as relevant, their partner’s illness. These questions were based around the Leventhal (1984) framework and yielded a substantial amount of information regarding parents’ own ideas about the identity, cause, consequence, timeline and treatment of their illness. It was beyond the scope of this thesis to present the data for all participants. Instead, the data from three parents will be presented as part of the current study.

The current study uses four of Leventhal's components of illness to explore interview responses from members of the same family. It also examines the congruence between parent and child responses to the question of how the child found out about the parent's mental illness. Both parent and child responses to each question are presented together. Presenting the data in this way enables the reader access to a greater level of detail about the nuances of communication and knowledge within families. It also clearly highlights the differences and similarities in perception which are present within the same family.

The data collected for the parent and child studies outlined within this thesis was 'primary data'. Specifically, the data was collected by the primary researcher, with the intent of addressing the research questions highlighted within the parent and child studies. The data within the current study is data from the child and parent studies. It was not collected for the specific purpose of the study within this chapter and is therefore termed 'secondary data' (Boslaugh, 2007). The data were synthesised and subjected to secondary analysis for the purposes of the study within this chapter.

Families were chosen for inclusion in this chapter because they highlight three different types of family groupings based on the children's living arrangements. These family groupings were child living with a parent with mental illness, child living with the parent without mental illness and child living with both the parent with mental illness and a parent without mental illness. There were other family groupings, such as children living in out of home care, however it is beyond the scope of this chapter to include a representation of all possible family grouping types. The three families also highlight a spectrum of different types of communication which were apparent among many of the families within this study.

These particular families were also chosen as their interviews demonstrate some of the main findings from the previous chapter. Although these findings were discussed in the previous chapter, examining them here, in the context of the whole family, enables a multi-dimensional understanding of the way in which families as a whole understand and communicate about mental illness.

The family-linked detail provided in the following section means that more potentially identifying information is inevitably provided. Accordingly, great care has been taken to maintain the anonymity of participants whilst maintaining the integrity of their responses. In some cases less specific identifying demographic details are provided where it is thought that specific detail could identify the participants. Similarly, in some cases certain words have been removed from transcripts if they identified people or places. In all cases care has been taken to maintain the meaning of what participants had said. The participants' own words have been used as much as is possible and where it has been appropriate. Where participants' words have been used they are identified as quotes and written in italicised font. To maintain flow, smaller quotes have been incorporated into the sentence rather than standing alone. Where longer extracts of participants' interviews are presented, the convention used is the same as in each of the previous study chapters.

7.3 Aim

This chapter will examine familial communication and understanding of mental illness.

Specifically it will examine;

1. Child and parent views about how children found out about the parent's mental illness and how the illness was explained
2. Parent and child perceptions of identity, cause, treatment and timeline of mental illness.

7.4 Analysis

7.4.1 Family one

The first family case study involves a large family headed by a single mother with mental illness. Almost a third of families interviewed for this thesis were headed by a single parent with mental illness. The mother, aged in her forties, and five children ranging in age from 8 to 17 were interviewed at their home. In addition to contacting the researcher to indicate interest in the interview, the mother also offered to ask her friends if they would be willing to participate. She identified as being actively involved in helping others with mental illness and involved in talking to other children about mental illness. Both the 8 year old and 11 year old children appeared to enjoy the interview process. They willingly provided details and spent time telling the interviewer stories about their life. The 13 year old girl provided minimal detail and appeared unsure of many of her responses. Both the 15 year old boy and 17 year old girl provided detail within their responses.

This set of interviews provided a unique insight into the differences and similarities in knowledge that can be present between siblings. The interviews also provided information about how the act of talking to children about mental illness can be overlooked by the parent.

7.4.1.1 The process of explaining mental illness

Mother

The mother made the important point that whilst she explained mental illness to some of her children a number of years ago, some of them were too young at the time (one was a newborn):

...sort of somehow things were explained at that stage but then you kind of don't really...say and they grow up and they grow and you don't realise..you know...that um...'cause it kind of needs to really be ongoing sort of thing cause as they're at different

stages cause quite often they say "oh nobody told me" you know and I thought that I'd told them all...

It was not until one of the children returned from a COPMI-specific camp, and questioned her about who in the family had mental illness, that this mother was prompted to sit her children down and tell them about her mental illness.

When asked if she remembers how mental illness was disclosed to her children at that point, the mother stated that she herself had explained the illness, she explained to her children that it was an *"illness in the brain"* and also stating *"Mum's got a mental illness, lots of people have mental illness"*. She also further explained to them that *"sometimes it makes me tired"*. The mother would have preferred help with explaining the illness, for example from a GP, rather than explaining it on her own. She stated: *"I would've preferred help with it, I would've preferred to know how to do it properly"*.

The mother stated that she doesn't regularly talk about her illness to her kids: *"I have done yeah...I don't do it a lot... but I have done"*. She also stated that her numerous physical illnesses have caused confusion for her children, especially her younger children:

...I think the little ones sometimes get a little bit confused..(..)... like I get migraine headaches so I think like (youngest child) often thought that migraine's mental illness...um.... because it's to do with the brain (laughs)...

8 year old son

When asked how he knew his mother had a mental illness the 8 year old participant stated that he only knew because his mother has *"got a sticker thing in her room and it says something about mental illness"*. When further questioned he stated that his mother had explained it to

him but that *“I’ve got no idea what she said..... it was too long ago for me to remember”*. He stated that his mother hadn’t spoken to him about it since then: *“that was the last time I heard from her about it”*. When asked if he thought he understood his mother’s illness he stated that *“maybe”* he did and stated: *“I’d like her to tell me....like she told me when I was little so she could tell me now and I probably would be able to understand a bit more than last time”*.

11 year old son

When asked how he found out about his mother’s mental illness the 11 year old participant stated that he thought that his mother had told him but that it was *“ages ago”* and he can’t remember what she said at the time. He stated that he didn’t think he understood his mother’s illness very well and that there was more that he’d like to know about it, in particular: *“why she has to go to hospital every time”*. When asked if he would ask his mother questions about her illness he stated that he wouldn’t.

13 year old daughter

The 13 year old participant stated that her mother told her about depression ~~–~~*ages ago”*. She stated that she would ask her mother questions if she had any but at this stage she didn’t want any more information about it.

15 year old son

The 15 year old son also stated that he had learnt about his mother’s mental illness: *“ages ago...before I can remember”*. He stated that he hadn’t spoken to her about it recently but did not feel the need to. The 15 year old son stated that he felt he understood his mother’s illness as much as he needed to and that he would *“probably speak to her”* if he had any questions about it.

17 year old daughter

The 17 year old participant stated that although she had been to COMPI-specific support groups when she was younger, she did not understand that she was there because her mother had mental illness: *“they used to just say “oh yeah your parent has a mental illness” but I never really understood it”*. She discussed similar experiences:

..like um...I can recall... I think it was when I was in about year 9 or year 10 this lady came around and me and (younger brother) filled in a survey and it was talking about all types of mental illness and we knew mum had diabetes and we thought it was that..

The 17 year old participant stated that no one had ever discussed her mother’s illness with her and that there was more that she would like to know about it. She stated that they did not talk about it at home, stating: *“and I think that’s maybe cause she (her mother) prefers it that way”*. When asked who she would ask if she wanted further information about her mother’s illness the 17 year old participant stated that she didn’t know. She stated that asking her mother questions about it *“would be a bit weird”* further stating:

...mum’slike quite happy not making it a big issue and I’m just gonna like respect that that’s what she wants...and if she ever did wanna actually sit down and talk to us then I’d actually sit down and listen...

7.4.1.2 Identity

Mother

The mother identified as having Depression currently and as having Post Traumatic Stress Disorder, Anxiety and Borderline Personality Disorder in the past. She also stated that she had previously experienced psychotic episodes. The mother stated that her symptoms included difficulty sleeping, or sleeping too much: *“one extreme or the other”* and crying a lot. The

participant also stated that she had a sleep disorder which meant that she thought it was often hard for her children to differentiate between sleep symptoms due to mental illness and sleep symptoms due to the sleep disorder.

8 year old son

The youngest child stated that his mother had “*mental illness*”, he didn’t elaborate or provide detail about the specific illness(es) his parent had. The only symptom he identified was that his mother slept a lot, citing one story in particular when his mother didn’t pick he and his siblings up from school:

C: Yes.....she...uh once we..we had to stay at school for a very, very long time because she was ...sleeping.....and.....she didn’t get up and then the phone rang and she went...and it was the people at (school name) and she was like “oh the kids!”

I: So sometimes it can make her sleep so much that she forgets to pick you up?

C: Mmm

I: What makes her sleep a lot?

C: Probably about the mental illness I’m pretty sure....

Given that the mother had stated that she cried a lot and that she thought this symptom was visible to her children, the youngest son was asked about whether his mum cried at all. He stated that she didn’t.

11 year old son

When asked about what illness his mother has, the 11 year old stated: —... *she’s got mental illness and I know she’s got sleep apnoea ..and....that’s all that I really know*”. He did not provide a specific label for the type of mental illness his mother had. When asked about his mother’s symptoms, the participant stated that she was often sick, she experiences migraines and ~~she~~ *can’t really do sort of stuff*”.

13 year old daughter

The 13 year old daughter stated that her mother had “*depression*” and when asked about the symptoms of her mother’s illness stated that her mother: *—..stays in bed a lot...I don’t know (laughs)”*.

15 year old son

When asked what illness his mother had, the 15 year old son stated that she had “*depression*”. He appeared unsure about symptoms of her illness but stated: *—don’t know ...think she cries... ”*.

17 year old daughter

The 17 year old daughter also stated that her mother had depression. She provided detail about the symptoms that her mother has:

Um..she cries...she’ll sleep.....she.....and like.....she..she sometimes will get quite angry likeI don’t know....but I mean...’cos like...this is like...that many kids living in the house with just her...the house is always a mess and you know...

The participant also stated that her mother wouldn’t show her symptoms in front of the children: “*she never really would let it show in front of the kids... especially not the younger ones”*.

7.4.1.3 Cause

Mother

When asked about the cause of her mental illness, the mother drew on a number of causes. Citing the depression of 3 older generation relatives (her mother and her maternal and

paternal grandmothers) the participant drew on the idea of genetic cause. The participant also cited a *“depressed environment”* and *“a lot of traumatic experiences also throughout my childhood”* as early contributions to her mental illness. Later contributions included pregnancy and motherhood which contributed to both post natal depression and post partum psychosis. The participant also believed that marriage breakdown and domestic violence contributed to the development and maintenance of her mental illness.

8 year old son

When the 8 year old son was asked about his views on what caused his mother’s illness he stated that it was to do with a fainting incident that he witnessed a couple of years prior. He also mentioned that it could be to do with her smoking. His response indicates that he has a vivid memory of the incident and that he is convinced that it caused the illness, although he is unsure of the exact mechanism:

C:..pretty sure that...something happened about her fainting.....((..)).....It could be because of the smokingshe just had a smoke and she walked out and she just faintedand I was only four.....

I: And did you see it?

C: Yes.....and then I brought out my pillow and I was lying down like what mum was doing and the ambulance came in and there was.....people from the hospital....

I: So that caused the mental illness do you think?

C: I’m pretty sure...

The 8 year old talked about smoking contributing to his mother’s mental illness and stated that his mother denies having seen the anti-smoking advertisements on television:

It’s because um.....that.....mum also smokes....and I reckon that’s it as well and we always say “do you watch the smoke ads” and she says “I never seen them” and sometimes she watches them and she still says no.....that’s the bad thing about it...

It is clear that the child believes smoking is dangerous and has seen advertisements highlighting this. It is unclear whether the child believes that if his mother stopped smoking the mental illness would go away.

11 year old son

When asked about cause of mental illness the 11 year old participant provided a seemingly circular response:

I: What caused your mums illness?

C: Uh.....I really don't know that.....uh....yeah I don't really know

I: What would be your guess?

C: I always...I always thought depression....

I: So depression caused it?

C: Yeah

I: And do you know what caused the depression?

C:no.....

In an effort to fully explore the child's understanding, the interviewer then asked further questions around the cause of mental illness. Instead of asking what the initial cause of mental illness was, questions were asked about whether there was anything that made his mother's depression worse at times. He stated that there were times when his mother's depression was worse: *—times when its bad...is like when like.....like um.....she's sick and she can't work and she can't do anything*". The participant stated that the cause of this was "stress".

13 year old daughter

When asked about the cause of her mother's illness, the 13 year old participant was hesitant in providing an answer, instead stating: *—I don't know*". When questioned further she stated:

“Um.....(laughs)....her life as a kid or something. This differed from her younger brothers’ responses in that it indicated that the cause of mental illness was rooted in the distant past.

15 yr old son

The 15 year old participant stated that he thought his mother’s mental illness was caused by a “.....stressful life”. This issue of stress was explored and the participant stated: *“I think she had a stressful childhood but...even more so like her life now....”*. When asked what it was about his mother’s life now the participant explained that the cycle of his mother working because she has “so many kids” and having to do “stuff” for the children contributed to his mother’s mental illness.

17 year old daughter

The 17 year old daughter was the only child to mention the possible genetic contribution to mental illness, naming other family members who may have had it; *“I think...it was through the family or something like that I think her mum has it or her grandmother has it or...some genetic...”*. This participant was also able to describe a number of other current issues which she thought contributed to her mother’s illness:

...um...dad...(laughs)..he has a huge influence on her...yeah....and he...like I just overhear some of their arguments sometimes. He’ll constantly come over here and tell her that she’s selfish and blame her and it’s really not her fault...((...)).. and... then on top of her mental illness her having to work so much to keep like....us...like living..and it’s really hard for her...

Arguing with the other parent and working a lot in order to support a large family seemed to be the most salient issues for this participant.

7.4.1.4 Treatment

Mother

The mother identified a range of treatments she was receiving for mental illness. She named three specific medications and also stated that she regularly saw a psychiatrist and a psychologist. The participant stated that she had been hospitalised frequently, although not at all in the previous two years.

8 year old son

When asked if there was anything which helped make his mother's symptoms better the 8 year old participant stated:

C:probably...she has heaps of tablets cause in her room she has like this massive things of tablets and then I only have two sets of tablets to fix my nose

I: So your mum takes medicine to help her?

C: Um....no she just takes tablets

He stated that he wasn't sure about how the tablets worked to help his mother. He also stated that his mother *—always has needles*". When asked what they were for he stated: "*...uh to fix mental illness.....like the other stuff like the tablets...*".

11 year old son

The response given by the 11 year old participant suggested a developing realisation that his mother's hospital visits may have been due to mental illness. He had previously been unsure as to whether her symptoms were due to physical or mental illness and a similar confusion was apparent within his answer to the question about treatment. He stated:

C: well she's been in the hospital a lot of times...the last time she went into hospital was about...I don't know..I think about 2 months ago for her kidney...but there's been a lot of time she's been in hospital but I don't know why

I: So you think it might be because of that (mental illness)?

C: Yeah

The mother did not mention a recent mental illness-related hospitalisation so it would appear that her most recent hospitalisation was for a physical illness.

The 11 year old participant stated that he didn't know what happened within hospital to make his mother's symptoms better, stating :*-because they usually just....tell us to go out if they're doing something to her*". He also mentioned that when his mother is sick at home his father gives her a needle. The participant was aware of other medications too: *"Yeah she takes a lot of medicine....she's got like this big medicine box with all tablets in it...there's like this tablet tray that she's got"*. When asked what the medicine does he stated *"um.....it.....makes her happy....."*.

Other possible things that could help reduce his mother's symptoms were: *"relax I guess...and not get stressed...."*.

13 year old daughter

The response given by the 13 year old daughter also highlighted the confusion between physical and mental illness:

C: Oh I know she's been put in hospital for heaps of stuff but I don't necessarily know...

I: If it's the depression?

C: Yeah...(...)... Um I know she takes a lot of medicine (laughs).. I'm not quite sure what it's for...

The participant also mentioned that her mother could “*Um...talk to her friends...*” in an effort to reduce her symptoms as well as the children helping out at home.

15 year old son

When asked about the type of treatment his mother had received for her illness, the 15 year old participant discussed hospitalisation and, like his siblings, displayed uncertainty about the exact reason for hospitalisation. This participant thought that his mother had been hospitalised for other health reasons and not for symptoms of mental illness; *—Ummm.....she has gone to hospital quite a few times but I think it’s been things other than her depression so....yeah...*. The participant was unsure whether his mother took medication.

This participant also talked about his mother’s symptoms reducing when she was able to reduce how much she was doing for the children at home. When asked about what caused the illness, both this participant and his older sister mentioned the role of their mother’s responsibilities at home. This participant mentioned that both “*us kids*” and their father could “*take some of the pressure off her*”.

17 year old daughter

The 17 year old responded that her mother’s symptoms reduced *—when I help her out... ..like helping her out around the house*”. This was similar to her younger brother’s response however this participant singled herself out as the one who could help. Similar to her siblings responses this participant also knew her mother took medication but, like her siblings, was unsure what it was for:

...like she does have her little Sunday, Monday, Tuesday, Wednesday, weekly thing...Like I said she’s got lots of physical illness as well as her mental illness...I’m assuming she does, I know she takes lithium...

The 17 year old participant also talked about her family receiving a support service which included help with cleaning and help with the children:

..um....there was a lady and she used to come over and help mum out with cleaning and they'd be really, they'd talk and she would really be a good help. And there was a lady she'd come over like every Tuesday and help the kids do their homework or she'd take us out somewhere on the weekend but they stopped coming...

This participant was the only child within the family to talk about the support service.

7.4.1.5 Timeline

Mother

When asked about how long she thought she would have mental illness, or whether her illness would be cured, the mother replied: *—I think forever..I'm quite accepted that it'll...that it's a part of me now and that um...yeah that I just....I live with mental illness”.*

8 year old son

The 8 year old participant responded similarly to his mother:

C: um...for.....probably...I'd say for the rest of her life maybe (spoken very quietly)

I: How long? [I restated the question as the response had been inaudible in person, but was clear on the recording]

C:the rest of her life maybe (laughs) ...she could like...be an old woman and still have a mental illness...”

The participant's use of the words “*maybe*” and “*could be*” indicated that he was possibly unsure of his response.

Later in the interview, in response to another question, the 8 year old participant spoke about mental illness being “*dangerous*”. When asked why it was dangerous he responded:

C: *'cause it could kill them*

I: *The mental illness could kill them?*

C: *.....I'm pretty sure...*

11 year old son

The 11 year old participant also stated that his mother's mental illness would last for “*ever*”. Again the participant appeared unsure of his response, posing the word “*ever*” as a question rather than a statement.

13 year old daughter

When asked how long her mother's illness would last the 13 year old participant stated that she thought it would last for the rest of her mother's life, adding “*I guess*” to the statement. This was similar to her mother and younger brother's responses.

15 year old son

Given the responses of his mother and his younger siblings the response given by the 15 year old participant was interesting. This participant stated: “*...it will definitely I reckon last until all us kids are a lot older (laughs)*”. When asked more about this, the participant explained that the mental illness may go away when all the children are grown and have moved out of the house.

17 year old daughter

The 17 year old participant was unsure initially how long her mother's mental illness would last, stating that she didn't know. When she was asked if she could make a guess, her

response fitted with the response that she had previously given regarding cause of mental illness:

.....I think.....like um...maybe like.....I mean...as the kids get older when they move out of home and stuff she'll...I don't know she'll have more like free time on her hands. But I think it's like just something that might just always be there cause like...as I said I'm not 100 % sure but I'm pretty sure like our grandma has it and I mean she still..she still has problemsat the age she is now so....I'm pretty sure it's something that will be with her...because there'll always be things that will go wrong in this family (laughs), on top of like the things that don't go wrong...

This response was interesting as it was the only one which stated reasons for why her mother's illness was permanent. The response showed that she thought that the symptoms may reduce over time but would never disappear. This response was also unique in that it provided a reason as to why she thought that her mother's illness was permanent, namely that her grandma still has "*problems*".

7.4.2 Family two

The second family case study involves a small, one-parent family headed by a single father whose ex-partner has mental illness. Twenty percent of families within the larger study were headed by a single parent without mental illness. The father, aged in his thirties, and his nine year old daughter were interviewed at a library near their home. This set of interviews provided a unique insight into one family's understanding of mental illness in a family member who they do not live with. The child's mother has mental illness and is largely estranged from the family. The interviews also provided information about the difficulties that can be faced by the non-mentally ill parent when trying to explain mental illness to a child.

Both the father and the daughter were actively involved in educating others about mental illness. They both appeared to enjoy the interview process and willingly gave plenty of detail

within their answers. The nine year old daughter is the father's only child and they live together full time. The father rarely sees the child's mother and has not seen her much over the past 3 years. The daughter has contact with her mother fortnightly.

7.4.2.1 The process of explaining mental illness

Father

According to the father, the child's mother didn't want him to explain the illness to the child. The father stated that he overrode the child's mother's wishes as he thought it was better to tell the child. He stated that he got most of his information about the child's mother's illness through court records which contained the mother's medical records. He stated that he and his daughter have been able to "*talk freely*" about her mother's mental illness since his daughter was 4 years old. The father's sister had told him "*you've got to tell her*" about her mother's mental illness. The father stated that he was "*very frank*" and told his daughter "*mum's got a mental illness*" and drew the analogy between a "*broken arm or a cold*". He believed that at the age of 4, his daughter needed only basic information such as "*mum loves you, she's got a mental illness, sometimes she might do some strange things, it's not a reflection on you*".

The father talked about the difficulty he faced in trying to obtain information about the child's mother's illness. He explained how he had been viewed as giving inappropriate information to his daughter. The acronym DOCS in the following extract stands for Department of Community Services.

...Um.....well I actually didn't say things that I didn't know about...I went and got the help that I needed....like places like ARAFMI ...But I found a lot of people....(child's mother's name) was against me...DOCS...A particular case worker at the time was a bit more sympathetic to a mother who has lost her child and so was not real keen on me talking to (child's name) about it. And I said "well sorry, I'm just doing what I think is best" I basically had to say "I don't care what you think, I'm doing it" because (child's

mother's name) would complain. I wouldn't even ask people for permission but (child's mother's name) would complain to DOCS that I've talked to (child's name) about this or that...

The father utilised COPMI-specific support groups to provide information to his daughter, as well as the internet and books. He is also involved in mental illness-focussed organisations and received some of his information from there. As his daughter got older she wanted to know “*more in depth stuff*” and she now “*knows the research*” as they discuss research into lithium. The father stated that he emphasises that mental illness is common and that there are ways to live with it which are different to the way her mother is living with it. With regard to talking about mental illness regularly the father said “*sometimes we have long talks about it um...and often we go over ground we've covered before but that's what (child) needs to do*” and then stated “*we talk about it openly always..whenever she feels a need to*”.

9 year old daughter

When asked about whether she could remember initially being told about her mother's mental illness, the 9 year old participant said that she couldn't remember exactly and that she has “*known it for ages*”. She said that she thought that it was probably her dad who told her, “*because he's like a person who would tell me if I wanted to know, he just takes my best interests into heart*”. When asked about whether she felt she understood her mother's illness, the 9 year old girl said that she thought that she did and stated: “*dad's always giving me lots of information and ARAFMI's given me lots of information*”.

The 9 year old participant stated that she doesn't speak to her mother about mental illness. When asked why she stated: “*she doesn't like people knowing about her mental illness so I don't think it would turn out very well if...um...if I started talking about it*”. When asked why she thinks that her mother is reluctant for people to know about her mental illness she stated:

“I think she just wants people to think that she’s normal because you know no one would like people staring at her or thinking that she’s strange because she has a mental illness”.

Although she stated that she was content with her level of understanding currently, the participant stated that if she had a question about mental illness she would ask her father, *“cause he always basically tells me”*, or she would ask ARAFMI *“because they’re professionals and they probably know the most information”*.

7.4.2.2 Identity

Father

The father stated that the child’s mother has schizoaffective disorder which he stated was a *–ombination of schizophrenia and manic-uh bipolar”*. He stated that the child’s mother is rarely *“depressed”*, instead she is either *“flat or manic”*. The father stated that the child’s mother also *“sees things and hears things that aren’t there”* and specified a number of things that the child’s mother had seen in the past. He stated that she could have:

...an appearance of normality but she’s saying absolutely crazy things or she’s glowing, she looks like a winner and she knows it and she’s just there doing it and everything she does turns to gold and nothing can stop her...

He stated that the times when the child’s mother is experiencing these symptoms is when the 9 year old child *“has been put at most risk”* stating that the child’s mother has *“done some crazy stuff”*. The father also stated that the child’s mother was *“verbally aggressive and violent towards others”* this included her daughter and strangers accosted in public.

9 year old daughter

When asked what illness her mother had, the 9 year old daughter stated that her mother has “*schizophrenia and bipolar*”. When asked about what specific symptoms her mother had, the daughter stated:

...well.....other parents they..sometimes they do get a little bit annoyed and stuff but mum when she gets annoyed she gets really angry, sometimes she feels she’s so.....she’s so powerful and she goes around doing these things where ...um...like you’re not allowed to do but she thinks that no one...it won’t matter because she’s so.. she feels so good...

When asked what her mother does that she’s “*not allowed to do*”, the 9 year old stated: “*she speaks to the person..this person in a way or rude way or like...or like assaults them or something*”. She stated that her mother “*has hallucinations and stuff*” and “*yells at the TV*”. The 9 year old child also stated that her mother “*sometimes gets really depressed..um.. she just doesn’t do anything*”.

7.4.2.3 Cause

Father

When asked what he thought caused the child’s mother’s illness the father cited a long history of drug taking within the family. He was careful to state that he tries:

...not to base it on my own theories but just from what’s come out, from what her mother has told me herself and what I’ve watched over 10 years of the family...

The father then stated:

...it’s also exactly what I’ve always said to (child) (child) knows all about sex and drugs and things because she’s at that stage now and we talk freely about drugs as well and

amphetamines and all the drugs that are around and the new ones and the old ones. But she knows that mum has been a victim and this is not mum, she is not a nasty person...um...yeah I mean...the one thing I want her to know is that you can destroy your life with drugs I mean sure there might be a reason but your life is still destroyed..and you don't want to cheapen your life so much that you just throw it awayfor drugs...

9 year old daughter

When asked what caused her mother's illness the 9 year old participant first stated: *Oh well um...I don't...well....um...dad says....like dad wasn't trying to poison me or anything against my mum he thinks it's important for me to see her*". She then went on to say that her father had told her the family history of drug taking and that drugs caused her mother's illness; *"Nan was involved in drugs and once when they went to a party, Nan gave her daughter drugs and then mum kept taking them and then that caused her illness...."* The 9 year old participant then stated *"but dad didn't just tell me that just because he wanted me to hate mum, he just told me because I asked him"*. When asked what she thought caused her mother's illness she said she thought it was drugs.

Both the father and daughter qualified their responses to this question, the father stating that he wasn't putting forth his own theories and the daughter stating that her dad was not trying to *"poison"* her by telling her things about her mother's illness. It is unclear exactly why the qualifier is needed. Perhaps it is because both the father and the child are aware of the stigma attached to mental illness, it could be assumed that there are children who are *"poisoned"* by theories about their parent with mental illness. Both father and daughter could be aware of stigma against drug taking.

7.4.2.4 Treatment

Father

The father stated that the child's mother takes medication and that the type of medication she is on changes regularly. He stated that he doesn't "*see it as something she is going to get better from*". He stated that although he knows that there are "*resources out there*" he doesn't "*believe she's the kind of person who'd go and get some therapy or do some group therapy or things like that*".

9 year old daughter

The 9 year old daughter stated that her mother takes medication. She was unsure of the type of medication. The daughter didn't think that her mother had any other treatment for mental illness.

7.4.2.5 Timeline

Father

The father stated that he does not think that the child's mother will recover from mental illness. He stated that he had read psychiatrist reports which described his child's mother's illness as "*chronic*". The father stated that the child's mother in a "*manic state*" had talked about recovering from mental illness.

9 year old daughter

The 9 year old child's response displayed a balance between a desire for her mother to be mental illness-free and a belief that there are "*no actual cures*". She stated "*I think she's probably gonna have it for the rest of her life but um ...but her medication helps her manage it*".

7.4.3 Family three

The third family case study involves a small two-parent, one child family in which the father has mental illness. Approximately 50% of the families interviewed for this thesis were comprised of two parents and their children. In the current family, both parents, aged in their 30s, and their 14 year old son were interviewed. This set of interviews provided a unique insight into the communication of information about mental illness through a two parent family.

7.4.3.1 The process of explaining mental illness

Father

When asked about how his illness was first communicated to his son the father replied that he thought that his wife told his son initially, or that it may have been a *“health professional”* and that he wasn't sure. He stated that his wife probably told his son *“because she tells everyone I've got schizophrenia....she tells the dog next door that I've got schizophrenia”*. He stated that he thinks that his son has known from *“quite a young age”*. The father said that communication about mental illness would have occurred when the father was *“very sick”* and when he *“wasn't in an aware stage”*.

The father stated that although he doesn't think that anyone understands his illness well, he thinks his son understands that he hears voices and that this changes the father's behaviour.

Mother

The mother recalled a specific incident which prompted her to explain mental illness to her son. Although the mother stated that the son was aware of some symptoms when he was *“about 3 or 4”*, such as hiding under the table because his father thought that people were *“spying on us”*, it wasn't until the child was 6 that he received an explanation. The child

“told a friend we had aliens in our garden” which resulted in intervention from a child-focussed government department. The mother stated:

...so at that point um....we had to explain to him that sometimes dad sees things....but as he's got older um...he learnt along the way I 'spose and his understanding got better...

She then stated that *“by 9 (years old) he sort of had a good understanding of what it was”*.

The mother cogently stated that her son learning about his father's mental illness has been *“evolutional”*, she stated that they often had *“health professionals”* in their house and he has learnt a lot from them over time. She stated *“he'd always known his dad had schizophrenia...so it's... never been hidden from him you know what I mean”*.

When asked whether she thinks her child has a good understanding of his father's illness the mother replied that he did. She stated that he questions his dad about his symptoms, for example if his father is shouting he will ask *“what's upsetting you dad, are the voices worse?”*, or if his father is agitated he will say *“dad you're pacing, why are you pacing, what's going on?”*. She stated that her son has *“actually taken on that carer role”* and *“he'll ask me the minute he walks through the door “has dad had a good day?”*.

14 year old son

When asked when he was first told about his father's illness the 14 year old participant stated *“I don't think I was really told I just....had learned that he was different in some way and then once I'd asked questions about it I was told about it, probably”*. He stated that he was about *“5 or 6”* when he started asking questions about the illness. When asked where he got the majority of his information from he stated he got information from his dad, from doctors and from his mum telling him when he asked her questions. He stated that he asked his father

questions about his illness, stating *“you get the answers off the source. I ask dad....how he....how it affects him”*.

When asked if he thought he understood his father’s illness well the 14 year old participant stated *“uh very well...yes”*. The only extra information he thought he might like to know is *“information of what he’s doing to maybe trigger it...yeah that might help so then you could take those triggers away”*.

7.4.3.2 Identity

Father

The father identified as having *“drug resistant chronic schizophrenia”*. He stated that he has a number of symptoms. He has *“flashbacks”* from a *“bad trip”* he took years prior. He also hears voices, hears the TV talking to him and feels as though people are watching him through the TV. The father stated that he struggles with concentration and staying focussed and motivated. He also stated that he sleeps a lot and does not shower often enough.

Mother

When asked what illness her husband has, the mother stated that he has *“drug resistant paranoid schizophrenia”*. She said that he *“has positive symptoms all of the time, so his voices are there all the time”*. The mother also said that he experiences *“paranoia and delusions”* which are intermittent and they *“might not see them for a few months and then they come back for a good week”*. She stated that her husband also experiences agitation and he shouts a lot, *“not necessarily that he’s being angry it’s just that he’s trying to drown them out”*. He also has *“negative symptoms”* such as *“lack of motivation...social isolation...the sleeping all the time”*. She stated *“when he’s not real well, like you notice things like that”*.

14 year old son

The 14 year old participant stated that his father had “*paranoid drug resistant schizophrenia*”. When discussing his father’s symptoms he stated that “*sometimes he can act like a child maybe like a two year old..sometimes he can be really angry and agitated and start yelling*”. He also stated that his father paces and “*hears voices sometimes...I can’t really know that for sure*”. The 14 year old also stated that his father can “*be really silly and if you react to it he’ll then act like an adult and punish you for it....it’s just his mental thoughts are all up and down*”.

7.4.3.3 Cause

Father

When asked about the cause of his illness, the father stated that he thinks that LSD (Lysergic acid diethylamide) usage caused it, specifically “*a bad trip, combined with marijuana and depression*”. He gave details about the first time he used marijuana and how it affected him and stated “*I think I was prone to the disease by smoking marijuana*”. He stated that dusk can make his symptoms worse; “*coming on dusk if I’m outside when the sun falls and it gets dark I get a little bit trippy I get flashbacks from the LSD and that sort of stuff*”. The father also stated that in terms of making symptoms worse “*stress has a big impact on it as well*”.

Mother

When asked what caused her husband’s illness, the mother replied “*we think it’s genetic*”. She stated that although he is the first person in the family to have it he “*doesn’t have the right shaped brain.....his brains actually a different shape....they can’t tell us why*”.

Further in the interview the mother stated that other people had “*always mentioned the stress of having him (their child) could have brang (sic) the illness out*”. She stated that she thought that her husband had the illness prior to having their child and that she was “*always very, very conscious that no one ever said...that (child) caused this*”.

The mother stated that the child may have a different idea about what caused his father’s illness, stating:

...we tell (their child) that he’s not allowed to smoke ganja (marijuana) and things like that because his chances of getting schizophrenia are 3 % but if he does drugs or drinks and carries on like that his chances actually go up higher...

She thought that her son may state drugs when asked in his interview about what caused his father’s mental illness. She stated that “*from very little I just instilled it in him, if you do this shit you’re gonna mess your brain*”. The mother said that she instilled the link between drugs and mental illness in her child because she is “*not going to take any chances*”.

14 year old son

The 14 year old participant stated that he was not born when his father developed his illness and that “*they suspect that it was a mixture of something that was already in his head and drugs...yeah so um..either LSD....marijuana ...whatever else he was taking then*”. He stated that there are times when his dad’s symptoms are worse and that he doesn’t “*really know what triggers it, it just happens sometimes*” then stating “*sometimes I suspect that he might be doing drugs again because that’s how it seems*”.

7.4.3.4 Treatment

Father

The father stated that he was on four types of medication, namely antidepressants and antipsychotics. He stated that he is “*permanently*” on medication and that he is “*always compliant with medication*”. He stated that the “*drug resistant*” aspect of his schizophrenia means that he needs “*higher dosages and sometimes the medications just don’t work*”. The father stated that he sees a therapist and he also sees a doctor every few months who “*assesses me to see if I’m suicidalor.....um.... going to kill anyone uh....(laughs)*”.

The father stated that he has “*a lot of safety mechanisms built in*”, namely if he starts to hear voices he can “*rational [sic] them out in my head to stop them continuing*”. When this occurs he tells himself “*well that’s not real*”. When asked if there are things other people do to help with his symptoms the father stated “*there could be a lot of things but there’s not a huge amount of trust and love in every relationship.... that I...that a schizophrenic has*” stating that this is because “*I don’t realise the things I do hurt people and that pushes them away*”.

Mother

When asked what treatment her husband is on, the mother stated: “*he’s on three antipsychotics, an antidepressant and anti anxiety and sleeping pills...that’s why they call it drug resistant*”. She stated that the medication that he is on helps him to be “*functional*” but that “*he’s never been symptom free*”. The mother also stated that although her husband had been admitted to hospital a number of times in the past, there have been no hospital admissions over the last 10 years.

14 year old son

When asked if there was anything that helped his father's symptoms, the 14 year old participant stated "*not any more*". He stated that given that his father's illness is "*drug resistant*" the illness "*keeps adapting to those certain pills*". When asked how he thought the medication worked he stated "*um they affect the chemicals in your brain so.... if you had an... imbalance of chemicals that cause you depression you'd have anti depressants that put it back into line*".

The 14 year old participant stated that there were things his father could do to help himself but that he lacked the motivation to do them "*let's just say he can motivate himself to do things and get his mind off certain things but he doesn't have the motivation to keep doing it and keep himself well*".

7.4.3.5 Timeline

Father

When asked how long he thinks he will have mental illness the father stated that he thinks it is "*coming to an end*". He clarified this by stating that he thinks that he is "*in control of it now*".

Mother

The mother stated that she thinks that her husband will have mental illness for "*the rest of his life*". She stated that she has heard people talk about cures but that she "*honestly can't see a cure for schizophrenia...not in my lifetime*".

14 year old son

When asked how long he thought his father's illness would last the 14 year old participant stated "*probably the rest of my life and his*".

7.5 Discussion

The current study explored family communication about mental illness, specifically how parents have explained mental illness to their children and what their children understand about mental illness. This study also explored family beliefs about mental illness. Family beliefs around four of Leventhal's illness domains were examined: identity, cause, treatment and timeline. The following section will examine each set of family responses and highlight particular points of congruence or incongruence within family accounts. The clinical implications of the findings of this study will also be discussed.

7.5.1 Family one

The first family included in this chapter was unique in that five children from within the same family were willing to be interviewed. As shown in the case study, each of the five children had different ideas about their mother's mental illness and often these ideas were different to their mother's ideas about her illness. Of particular note was the family view on the process of finding out about mental illness initially. The mother stated that although she thought she had told her children previously, she realised that some of them hadn't been told. She then sat her children down recently (within the last two years) and told them about her mental illness.

Parental confusion about which of their children had been told has already been discussed in this thesis. Although this point was discussed in the parent chapter, the family context was missing so it was unclear what the children of the family thought about whether they had already had mental illness explained to them. The present case study showed that the eldest

child believed that she had never spoken to her mother about her mother's illness. Each of the other children said that their mother told them about her illness a long time ago and that they couldn't remember what she had said about it. Of interest is that three of the five children stated that they would like to know more about their mother's illness. The 17 year old participant thought that the mother preferred not to talk about her illness and, as such, did not ask her mother questions about it. Believing that a parent did not want to talk about mental illness was a theme discussed within the previous chapter, Chapter Six. None of the children within this family had asked their mother about her illness. This is perhaps a contributor to the incongruence between the mother's perception of her own illness and her children's perception.

The notion of asking questions about a parent's illness, both in the current family and within other families in this study, raises an interesting question of causality. There were a number of children who stated that they wouldn't ask their parent questions about mental illness or that they felt that their parent was not open to discussing it. Likewise there were a number of parents who stated that they did not think that their children wanted to know about mental illness or that they would tell children about it when the children asked questions. It is unclear, from the data within this study alone, whether the inability to ask questions or to provide information stems from the parent, from the child or from a mix of the two. Data from this study indicate that questions around mental illness are a systemic issue, that there are communication styles within families which make discussion about mental illness more or less likely.

The term "mutual pretense" has been coined by researchers within the childhood illness field (Chesler, Paris and Barbarin, 1986). It refers to the situation which can occur when a parent avoids talking about a child's illness with the child because they are trying to shield the child

from details about the illness which may frighten them. The child is aware of the parent's desire not to talk about the illness and subsequently avoids conversation about the illness in an effort to "protect" the parent. Although it usually refers to the dynamic between a parent and a sick child, the term "mutual pretense" could apply in the current context also. All five of the children interviewed from family one displayed reluctance about talking to their mother about her illness. It could be surmised that this reluctance was born through a developing awareness that their mother preferred not to share illness details with them perhaps combined with the children's own uneasiness about how much they wanted to know.

With regard to illness identity, the children within this family talked about "mental illness" and "depression". The mother stated that she had spoken to her children about "mental illness" and it could be assumed from this that she did not go into detail about the specific mental illnesses she identified as having. No mention was made by the children about the other mental illnesses that their mother had. Children's ability to identify depression more readily than other mental illnesses could be due to the prevalence of depression in Australia. Within Australia, depression is one of the most common mental illness experienced by the population (Knox, Harrison, Britt & Henderson, 2008). In addition, the children's ability to identify depression could be due to the recent disclosure about mental illness from high profile public figures. In 2001 an Australian cricketer, Michael Slater, resigned from cricket and publicly stated that he had depression. In addition, in 2006, Geoff Gallop, the then Premier of Western Australia, resigned from his position of Premier, citing publicly that depression was the reason for the resignation. As previously discussed within the parent chapter, their apparent unawareness of their mother's other illnesses, such as Borderline Personality Disorder, could be due to the reluctance of the parent to talk about illnesses which carry more stigma.

Each child saw the symptoms of their mother's illness slightly differently than did their siblings. Although the mother thought that her symptom of crying was visible, only the older two children mentioned it. Increased sleep was mentioned by four of the children. The eldest daughter insightfully stated that her mother hid her symptoms from the children. Hiding symptoms, failing to disclose mental illness and having a range of physical illnesses, all appear to have contributed to the children within the family knowing only part of their mother's mental health history. These factors also appear to have contributed to the children's confusion around the range of treatment's their mother has for mental illness. Hospitalisation and tablets were mentioned by all children but in all cases, regardless of age, the children were unsure as to whether these were treatments for physical or mental illness.

Although few definitive age related trends were apparent within the data for the child study in Chapter Six, possible age related differences can be seen in this family within the responses regarding cause of illness. As the children's age increased, their responses appeared to increase in depth and complexity, in line with Piaget's ideas about the sequential development of children's ideas about illness (Bibace & Walsh, 1980; Eiser & Kopel, 1998). The youngest child endorsed smoking as a cause of his mother's illness. The second youngest endorsed a circular response whereby depression caused mental illness. When discussing cause, the older children within the family endorsed the idea that the cause of their mother's illness was rooted in the past, although only one child, the eldest, mentioned genetics. Interestingly, having "*so many kids*" and having a "*stressful*" life were endorsed by most of the children even though these causes were not mentioned by the mother.

The children's answers about the timeline or possible cure for their mother's illness were very similar. Four of the five children believed that their mother would not recover from her mental illness. The second eldest child believed that the mother's mental illness would go

away once the children had grown and left home. Given the lack of communication within this family, the children's belief that the mother would not recover from her illness is likely to be based on their own theories. Other researchers have suggested that children do indeed develop their own theories if not provided with information about the illness (Bibou-Nakou, 2003; Shachnow, 1987). In addition it has been suggested that COPMI "can deal better with reality than with their fantasies" (Bibou-Nakou, 2003, p.250). Lack of communication and questions which are unasked can contribute to COPMI experiencing self blame (Cogan et al., 2005 a; Duncan & Reder, 2006). In the current family the youngest child had a belief that his parent's mental illness could "kill" her. This was based on his own theory rather than something he had learned from his mother. In the current case it appears that for the youngest child at least, the reality of his mother's illness may well be better than his fantasy.

7.5.2 Family two

The second family included within this chapter comprised of a single father, who identified as not having mental illness, and his daughter whose mother has mental illness. In contrast to Family One, comparison of the father and daughter's ideas about mental illness showed high congruence in their perceptions.

The father stated that he thought it was important to talk to his daughter about her mother's mental illness. He stated that he and his daughter have been talking "freely" about mental illness since his daughter was 4 years old. The father also stated that he had spoken to his daughter about other potentially sensitive topics such as sex and drug use. Interestingly, although the daughter stated that her father had first told her "years ago" about her mother's illness, she stated that she currently had ample information and that she felt that she understood aspects of her mother's illness well. It appears that, like the children in the previous family, she initially found out about her mother's illness a long time ago. Her

circumstance was also similar to some of the children in the previous family in that she felt unable to talk to her parent with mental illness about the illness.

Unlike the children within the previous family, the daughter in this family was content with the level of information she had regarding mental illness. There are a number of probable reasons for this. Firstly, although the daughter could not talk to her mother about the illness, she was able to speak to her other parent about it. None of the children in the previous family mentioned their other parent as a source of support or as a source of information. Secondly, the parent within family two viewed communication about mental illness as a continuous conversation rather than a one off event. Finally, the daughter was well connected to other resources and sources of information outside of her family. The connections outside the family were sought out and established by the well parent.

With regard to illness identity, both the father and daughter within family two gave very similar responses. They both used the words "*schizophrenia*" and "*bipolar*" to describe the daughter's mother's illness. They both also talked about "*mania*", being "*powerful*" and aggression as symptoms of the illness. The only point of difference was that the daughter spoke about the mother experiencing depression whereas the father stated that the mother was "*rarely*" depressed.

Both father and daughter gave similar responses to the questions regarding cause, treatment and timeline of mental illness. Both stated that drugs were the main cause of the mother's mental illness and both stated that the main treatment the mother was receiving was medication. The father and his daughter also believed that the mental illness would remain with the mother for her lifetime. Interestingly the father stated that the mother believed that she may be mental illness free sometime in the future. Ideally all three members of the family

should have been interviewed for this study in order to get a fuller picture of the family's perception of mental illness. Unfortunately this was not possible at the time.

The daughter's responses demonstrated an insight into mental illness, something that seemed to be lacking with the children from family one. From an age perspective, many of her responses seemed to show a greater understanding than even the eldest daughter within family one. She was aware of a range of symptoms, such as hallucinations and aggression, and appeared confident that the behaviours were related to her mother's mental illness and not another illness. It is worth noting that, given that the mother was not interviewed for this study, it is unclear whether the symptoms cited are actual symptoms experienced by her mother.

The father's responses also demonstrated insight into mental illness. His situation was different to a number of parents within the study as he did not identify as having mental illness himself. His insight into his former partner's mental illness appeared to come from both living with her previously and from actively sourcing information himself. It would be interesting to find out whether other non-mentally ill parents are willing or able to actively seek out information about their estranged partner's illness. The participants within the parent study for this thesis provided mixed responses. Some parents had sought out information about their estranged partner's illness whereas other parents had experienced great difficulty in accessing any information. The father in Family Two had acquired information from court records and medical records, something which had proved difficult for other parents interviewed for this thesis. He also became actively involved within mental health advocacy organisations and sourced information from these.

Both the child from Family Two and the child from Family Three had a well developed understanding of their parent's illness. According to Piaget's ideas about illness development, as explored by Bibace and Walsh (1980) the depth of understanding displayed by both children should not be present until children are at least 11 years old. Given the extensive discussion about mental illness within each family, the two children's understanding about their parents' illness could be due to Vygotsky's notion of "scaffolding". The parents in the two families could have built on the child's limited knowledge by providing extra information which could have led to the child's current well developed understanding. Independently these children may not have been able to develop such a comprehensive understanding, but with parental guidance their potential for understanding is much greater (Borzekowski, 2009; Rushforth, 1999).

The father had provided his daughter with information about mental illness against the mother's stated wishes. A number of parents within the previous parent study stated that their estranged partner had provided their children with information about their illness that they themselves disagreed with. It is useful to have data which highlights both experiences within the same study. It is clear that there can be disagreement between parents as to whether children need to know about mental illness in the family and, if so, the extent of information they need to know. Disagreement between parents about disclosure appears to be unique to mental illness. Although other research examining disclosure has found that mothers are more likely to disclose HIV than fathers, disagreement about disclosure is not discussed (DeMatteo et al., 2002).

There are ramifications when the parent without mental illness takes the lead in educating the child about the other parent's mental illness. There are clear benefits; the child is provided with information which may help to reduce confusion about a parent's behaviour or

hospitalisation, the child may feel as though they are able to ask the disclosing parent questions about the other parent's mental illness, education about mental illness is linked to better outcomes in COPMI (Beardslee & Podorefsky, 1988; Garley et al., 1997; Goodman et al., 2011; Secunda, 1997).

As well as the possible benefits, there are clear ethical issues inherent in disclosing to a child about mental illness without the other parent's permission. Parents with mental illness are a largely disenfranchised group of people (Hinshaw, 2005). They have a higher rate of custody loss of their children compared with parents without mental illness (Joseph et al., 1999; Leschied et al., 2005; Mowbray et al., 1995 b; Nicholson et al., 2001) and their parenting role is largely denied within research and practice (Nicholson et al, 2001; Nicholson & Deveney, 2009). Given the losses and disempowerment they may have already experienced, disclosing their illness to their children without their permission is an action which requires consideration. Depending on the information provided to the child at the time, disclosure could lead to the child viewing the parent differently and the relationship between the child and the parent with mental illness may change. The right of the child to know about mental illness in the family is important, however the parent's right to have an input into the disclosure of their own illness is also important. Examining disclosure from a number of perspectives highlights the complexity of the disclosure process.

The mother in Family One stated that she would have liked help discussing mental illness with her children, whereas the father from Family Two appeared content with the quality of the discussions with his daughter. The quality and amount of information apparently conveyed by the father to the daughter within Family Two is higher than the information apparently conveyed by the mother within family one. This may be due to the father's active search for information and support groups for children of parents with mental illness.

However, given that the mother within family one was involved in the support and education of other people with mental illness it could be assumed that she too had access to information and support groups. Alternatively, the higher level of information provided could be because the father is not talking about his own mental illness and is instead talking about someone else's. Perhaps it is easier to provide details about aspects of mental illness when you are not talking about your own illness. Although the non-mentally ill parent does not have first-hand knowledge of the illness they also do not experience the self-stigma (Corrigan, Watson & Barr, 2006) that can be present for people with mental illness.

7.5.3 Family Three

The third family within this chapter provided a unique insight into how the disclosure of mental illness may occur in a two parent family. The initial disclosure occurred when the father was symptomatic. In contrast to Family Two, this family appeared to navigate the disclosure of mental illness in a way which was acceptable for both the parent without mental illness and the parent with mental illness. In contrast to Family One, the child within this family appeared to have a solid understanding of his father's mental illness and, in contrast to the children in both Family One and Two, he stated that he knew he could talk to his father if he had questions about the illness.

Similar to Family Two, the mother within Family Three stated that it was important that the disclosure is a process rather than an event. The belief about the importance of openness appeared central in this family and could explain the congruence in each of the family members accounts of the domains of mental illness. The illness beliefs each family had about identity, treatment and timeline were largely consistent with each other. Previous research examining the attachment between parents and children has found that secure attachment is linked to open communication within the family (Poehlmann, 2005). Difficulties in

attachment can form when information is not provided to children and when important details are hidden (Poehlman, 2005). Research examining COPMI has found that attachment is linked to education about mental illness (Walsh et al., 2009). Although not examined here, it could be surmised that the level of open communication within each of these three families could have impacted on the attachment between the children and their parents.

The only point of incongruence of illness beliefs within Family Three was the domain of the cause of mental illness. Within this two parent family, all three family members had quite different ideas about the cause of the father's mental illness. The father believed that LSD and marijuana caused the illness initially and that dusk and stress maintain the illness. The mother believed that the cause of her husband's illness was genetic and that he had a different shaped brain. The son within this family stated that the cause of his father's mental illness was "*a mixture of something that was already in his head and drugs*". Importantly, the child then stated that he thinks his father may be doing drugs again as his symptoms appear to worsen and then get better.

Carers and relatives beliefs about the cause of mental illness in someone in the family has been examined extensively (Hinrichsen & Lieberman, 1999; Kuipers et al., 2007; Kuipers, Onwumere & Bebbington, 2010; Smith & Greenberg, 2008). Importantly, relatives beliefs about cause have been linked to how the relative responds to the patient, how much distress a relative experiences and the way a relative copes with the mental illness in the family (Lobban, Barrowclough & Jones, 2003; Lobban, Barrowclough & Jones, 2006). Research has consistently shown that if a relative believes that the family member with mental illness is responsible for the illness, and that they can do more to reduce their symptoms, this can lead to negative emotions in the relative (Lobban et al., 2003). In terms of the beliefs held by the relatives in Family Three, the son's belief that the father's illness may be due to drug use,

which could be perceived as being within his father's control, could be linked to feelings of criticism, hostility, disappointment and rejection of his father (Barrowclough & Hooley, 2003; Hinrichsen & Lieberman, 1999; Smith & Greenberg, 2008). It is worth noting however, that the research on beliefs about cause of mental illness in a relative most often examines the beliefs of the parents or siblings of the person with mental illness, not their children.

The mother's belief that the father's brain shape is the cause of his illness could mean that she experiences lower levels of illness-related distress than the son. Research suggests that beliefs that the person with mental illness is not to blame for their illness is linked to less distress, lower criticism and lower hostility toward the person with mental illness (Kuipers et al., 2010). The mother also stated that the cause of her husband's illness could be genetic. Research examining people's beliefs about the cause of mental illness has found that although genetic attributions for mental illness can reduce stigma, they can also be linked with pessimism about the possibility of recovery (Austin & Honer, 2007).

A somewhat surprising finding within the interview of Family Three was the mother's statement that although she believed that the father's mental illness was caused by genetics or a different shaped brain, she had instilled in her son a belief that drugs had caused his father's illness. Given the son's interview response which indicated that he believed his father may still be taking drugs, the mother's message to her son appears to have been effective. Her reasoning was that she did not want her own son to take drugs as his chances of mental illness would increase. The mother's caution regarding her son's genetic risk of schizophrenia, and the role that drugs could play in the development of mental illness, is understandable given the lack of definitive research available which explores the interplay of such risks (Austin & Honer, 2007). Although it is accepted that there are links between genetics and the development of mental illness (Beardslee et al., 1996; Beardslee et al., 1998; Biederman et al,

2001; Cowling et al., 2004; Goodman & Gotlib, 1999; Leschied et al., 2005) it remains unclear how and why these genes are expressed (Austin & Honer, 2007).

It has been suggested that genetic counselling has a place in counselling people with mental illness and their relatives (Austin & Honer, 2007; Phelan, Yang & Cruz-Rojas, 2006).

Although it is not generally offered to families with mental illness, researchers suggest that the beliefs that families can hold about mental illness, and their subsequent emotional experience of the illness, could be assisted by genetic counselling (Austin & Honer, 2007).

Using the example of the current family, genetic counselling could alleviate the possible negative emotions the son is experiencing and could facilitate an honest discussion about the cause of mental illness between father, mother and son. Genetic counselling could provide the son with a realistic perception of risk, remove his doubt about his father's possible drug use and could enhance the family relationship.

7.5.4 Overall discussion

The use of the Leventhal model as the basis for the current study proved valuable for the current study and has possible applications outside the research setting. Using the Leventhal model enabled a qualitative exploration of the illness beliefs of numerous members of the same family. The model also highlighted the differences and similarities of beliefs which can exist within one family. In addition the Leventhal model allowed a comprehensive exploration of a range of domains of mental illness. Any tool which is able to be used to access the illness beliefs of both parents and their children across a wide range of domains of mental illness could prove useful in clinical practice. This concept will be discussed further in the following chapter, Chapter Eight.

The findings of this small-sample study support the scarce previous research into parent and child communication about sensitive topics. One parent within this study was reluctant to answer her children's questions about mental illness as has been found in research examining familial communication about Duchenne Muscular Dystrophy (Plumridge, Metcalfe, Coad, Gill, 2010). In addition it seems as though one parent within the current study may have underestimated what her children knew about her illness as per previous studies (Forrest et al., 2006; Nicholson et al., 1998), although the other two parents appeared to have a good understanding of their children's knowledge. Parents and children can view the same disclosure process very differently to each another (Kennedy et al., 2010).

In depth exploration of the two families within this chapter has provided rich detail about the level of congruence between parent and children's ideas about mental illness and ideas about talking about mental illness. The difference in the level of congruence within each family appears to be due to a number of factors. Firstly, the approach that the parent has towards discussing sensitive topics with their child. Being open to talking about the illness with the child and answering questions, as well as actively talking about the illness frequently, both appear to contribute to higher congruence between parent and child mental illness beliefs.

The second factor which appears to contribute to the level of congruence within a family is the child's desire and ability to ask questions. This is a complex concept and one that requires further research in order to tease out the cycle of asking and answering questions about sensitive topics. It is unclear whether a child's ability to ask questions about mental illness is reliant on their perception of their parent's desire to talk about mental illness or if a child's preference not to talk about mental illness stems from another factor such as fear about what the answer may be, the cognitive level of the child or other factors. What is clear is that those

children who are open to asking questions about the illness generally appear better informed about their parent's illness.

A third factor which appears to contribute to the congruence between family accounts of mental illness is the level of information and support perceived as available to the parent. A parent may have a range of resources available to them to help them explain mental illness but may be unsure of how to use these resources to meet their needs. It may be the case that resources and supports need to actively approach parents to ask them if they would like help with disclosure of mental illness.

There are a range of clinical implications which arise from the findings of this study. The clinical implications are largely similar to those which have been discussed in previous chapters however there are some implications which are related specifically to the relational aspect of disclosure of mental illness which are discussed forthwith. Clinicians need to be aware of the possibility that children within the same family may hold very different theories relating to their parent's mental illness. This can be due to age but is likely to be due to timing of disclosure. In situations where the illness has not been disclosed in full, children may still hold theories about the illness. Each child's understanding of mental illness should be assessed separately in order to explore the meaning mental illness has to them.

Finally, the rights of the parent need to be taken into account in the disclosure of their illness. The research strongly suggests that COPMI should be told about a parent's illness as it has been suggested that it can enhance resiliency and ameliorate some of the negative effects of having a parent with mental illness. The initial findings of this study indicate that children could benefit from being told about parental mental illness, however the findings are ambiguous and would benefit from further research into this area. Ideally when discussing

mental illness with COPMI, the views of both parents regarding disclosure should be taken into account.

Overall, the results of this study indicate that it is important for clinicians to explore the meaning of mental illness for each member of the family. Clearly members of the same family can perceive aspects of mental illness quite differently, or similarly, depending on the family. Although age-specific information could be useful for some children, in other cases age is not the most appropriate indicator of a child's need for information. Instead, factors such as the child's willingness to talk about the illness, a child's erroneous beliefs about mental illness and the family perspective on disclosure of mental illness are examples of factors which could indicate a child's need for further information. The results of this study, along with the results of the two previous studies within this thesis, provide insights into the experience of the disclosure of mental illness which have rarely been documented previously. The findings of this thesis will be summarised in the following chapter, Chapter Eight.

Chapter Eight: Summary and conclusions

This concluding chapter begins by reorienting the reader to the foundational literature which was the basis for the explorations within this thesis. Each of the study chapters are summarised in turn and the four key findings of the thesis are presented. The four key clinical implications are also highlighted. The methodological strengths and limitations of the current thesis are presented and the possibilities for future research are explored.

8.1 Reorientation to the rationale behind the current research

There has been a strong call for COPMI to be educated about their parents' mental illness (AICAFMHA, 2001; Owen, 2008). Education about mental illness is thought to promote resilience and ameliorate some of the detrimental effects of being a COPMI (Beardslee & Podorefsky, 1988; Cogan et al., 2005; Garber & Martin, 2002; Garley et al., 1997; Goodman et al., 2011; Kinsella & Anderson, 1996). Despite the benefits of understanding a parent's mental illness, research suggests that often children are not told about a parent's mental illness (Dunn, 1993; Foster, 2010; Garley et al., 1997; Handley et al., 2001; Knuttson-Medin et al., 2007; Meadus & Johnson, 2000; Pölkki et al., 2005; Stallard et al., 2004). Parents have stated that they struggle to explain their mental illness to their children (Falkov & Cowling, 2009; Nicholson et al., 1998; Thomas & Kalucy, 2002; Wang & Goldschmidt, 1996) although the parent's view of the disclosure process has not been explored in previous research. COPMI knowledge about specific aspects of mental illness is largely unknown, as are their views about the process of disclosure.

Accordingly, the major objectives of this thesis were to firstly explore, from the parent's view, the process of disclosure about mental illness. In addition, COPMI ideas about specific

aspects of mental illness were sought as well as their views on how they obtain information about mental illness. Beliefs about mental illness were also examined from a family perspective, along with familial ideas about the disclosure process.

8.2 Summary of current research

8.2.1 Study one: Parents' ideas about disclosing their illness to their children

The first study examined the process of disclosure of mental illness to children from the parent's perspective. Parents in this study included parents with mental illness (n=17) and parents without mental illness (n= 9), the aim of the study was to explore the experience of disclosure for all parents who have a child with a parent with mental illness. The results of this study suggested that it is not unusual for children to find out about mental illness through someone other than the parent and that often this could be a negative experience for the parent. Parents cited a range of factors which made disclosure difficult. These factors fitted generally into child focussed factors, such as a child not wanting to know, and parent focussed factors, such as finding mental illness too difficult to discuss. Parents had difficulty explaining self harm and suicidal behaviour and this symptom had not been disclosed to many children. A few parents highlighted the need for the disclosure of mental illness to be a continuous conversation rather than a one off event. In general, parents lacked resources to help with disclosure and would have appreciated help with disclosure had it been available.

The findings of this study provide a much needed insight into the disclosure experience from the parent's point of view. It is the first study to explore parents' ideas about the disclosure of mental illness; how they disclose, the difficulties they face with disclosing and resources which may help the process.

8.2.2 Study Two, Part I: Children's ideas about their parent's illness; symptoms, cause, treatment, timeline and consequences for the family

The second study examined the beliefs about parental mental illness held by 40 participants between the ages of seven and 17. Each child interviewed for this study had a parent with mental illness. Participants beliefs about mental illness were examined in accordance with Leventhal's (1980) illness domains; identity, cause, treatment, timeline and consequences of mental illness. The results of this study suggest that children of all ages are able to provide cogent ideas about all aspects of their parent's mental illness. The most common symptoms identified by the participants within this study were sleep, anger and isolation. The identification of self harm, although only identified by a minority of participants, was an interesting finding given parents' inability to disclose this symptom. The most common causes identified by children were stressful life events, children themselves and drugs and alcohol. Medication, children themselves and doctors or hospitals were the most cited treatment options provided by participants. Just over half of the participants believed that their parent would have mental illness for life, with the remainder believing that the mental illness would dissipate in time or believing that their parent was already mental illness free. Participants in the current study were most affected by their parent's inability to do things, their parent's unusual behaviour and the emotional effect the illness had on the child themselves.

The findings of this study provide an insight into the beliefs of a larger sample of COPMI about specific domains of their parents' mental illness. The results of this study supported the scarce research currently available in this area. The current study also provided results which are unique to this study: such as COPMI knowledge of self harm, ideas around parental drug use, the knowledge of the use of ECT as a treatment and the perception of a parent having already overcome their mental illness.

8.2.3 Study Two, Part II: Do children think they have enough information and how is information transmitted?

Part two of the second study was an extension of the study outlined above. The participants within the study examining children's beliefs about domains of mental illness were also asked about their views of their level of knowledge about mental illness. In addition participants were asked about the disclosure process and the people who they speak to about their parent's mental illness. The results of this study suggest that the participants generally believe that they understand their parents' illness. Of those who stated that they did not understand their parent's illness, the majority stated that despite not understanding the illness, they did not want further information about it. COPMI in the current study initially learnt about their parent's illness from the parent themselves, from other family members or they were unsure about how they were provided with the information. It was rare for COPMI to speak to their siblings, friends or teachers about their parent's mental illness. Half of the participants in the current study identified their parent as someone they could ask if they had a question about mental illness. Importantly, a quarter of participants stated that they did not know who to ask for further information.

The process of the disclosure of mental illness from the child's point of view has not previously been explored. As such, the findings of this exploratory study provide important early information about the child's potential role in disclosure.

8.2.4 Study Three: Family communication and understanding of mental illness

While analysing the data for both the parent interviews and the child interviews it became apparent that family communication is a reciprocal arrangement. Study three was developed to highlight the congruence and incongruence of beliefs about mental illness which can occur in families. Study three was also designed to examine the process of disclosure from multiple

members of the same family. The three families included in the third study highlighted a spectrum of congruence and incongruence of beliefs. The members of one family had incongruent ideas about both illness beliefs and the process of disclosure. The two other families had reasonably congruent ideas. It was hypothesised that congruence within families was a result of the parent's explanatory style, the child's ability to ask questions and the resources available to the parent to help with disclosure.

Taken together these studies offer a valuable contribution to the scant literature available in the field of parents with mental illness and their children. The four key findings of this thesis will be discussed in turn below.

8.3 Key findings of the current body of work

1. Parents have difficulty with disclosure

This thesis demonstrated that parents in general find it difficult to disclose and talk about mental illness with their children, regardless of whether they are the parent with mental illness or not. Many parents felt that their child did not want to know about the mental illness of their parent. Parents may wait until the child asks questions before disclosing the illness or before providing further detail to the child. Importantly, there were children within the study in this thesis, who stated that they would not ask their parents' about mental illness. Taken together these findings indicate that in terms of communication about mental illness, parents and their children could be at an impasse.

Some parents also believe that a parent's symptoms may not be visible and that this may negate the need to disclose to their children. Conversely parents have also stated that they have been too symptomatic to disclose to their children. It could be surmised that there are some parents who feel that their symptoms are not visible initially, who then become too

symptomatic to disclose to their children, effectively missing an opportunity to disclose. As a consequence, parents stated that their children had been told without their permission or input. This is further discussed later in this chapter.

2. Illness understanding was not determined by age of the child

Given the call for 'age-appropriate information', one of the initial aims of this thesis was to examine the age related differences in children's understanding of mental illness. There were very few distinctive age related differences in the data presented within this thesis. This thesis demonstrated that COPMI of all ages were able to theorise about their parent's illness and that, in many cases, age was not the determinant of a comprehensive response. The ability to generalise these findings to all COPMI is discussed within the methodological limitations section below.

3. The differing requests for information of COPMI and ACOPMI

For many participants in the current study, mental illness is a topic which does not often get discussed. As highlighted, this was in part due to a reluctance of parents to disclose to their children. Importantly, there were a number of children within the current study (24 of the 35 children asked the question) who did not want further information about parental mental illness regardless of their current level of perceived knowledge. This finding did not fit with the majority of previous research which has found that COPMI do desire further information about parental mental illness (Garley et al., 1997; Handley et al., 2001; Meadus & Johnson, 2000; Pölkki et al., 2005; Stallard et al., 2004). The lack of desire for further information also contradicts the ACOPMI research which states that ACOPMI would have liked to have had more information about their parent's illness when they were younger (Dunn, 1993; Knutsson-Medin et al., 2007; Pölkki et al., 2005). Is it the case that the COPMI in the current study may, as ACOPMI, retrospectively wish that they had been given further information?

Although COPMI may prefer not to know about their parents' mental illness, this does not mean that they do not require the information. Regardless of their desire to be told, the provision of information could be linked to better outcomes for COPMI. The finding that COPMI do not desire further information is interesting and is a finding which is worthy of further examination, as discussed as a possibility for future research.

4. Members of the same family can hold different beliefs about mental illness

The study examining family beliefs about mental illness showed that members of the same family could perceive mental illness quite differently to one another. There were differences in beliefs between siblings, between children and parents and between parents themselves. Although differences in siblings' beliefs could conceivably be age related, within the current thesis, the difference in beliefs did not appear to be due to age. This concept was not fully explored but there is some evidence within the current thesis to suggest that the timing of disclosure could have an impact. For example in some families, older children were disclosed to and younger children were not. The congruence and incongruence of illness beliefs within families requires further exploration to unpack the ramifications of differing illness beliefs on the functioning of the family. This is discussed further in this chapter.

8.4 Summary of key clinical implications

There were a number of clinical implications highlighted throughout the thesis. The key clinical implications are outlined below.

1. The need for parents to have a plan for disclosure

As stated previously, in some cases the process of disclosure has been taken out of the parent's hands. Parents have not disclosed when they were well enough to do so and then possibly became too symptomatic to disclose. In these cases disclosure was conducted by

someone else, without parent input, and was largely seen as a negative experience for the parent. There is a need for parents, who do not wish to disclose whilst they believe the illness is not visible, to develop a plan for the disclosure of mental illness to their children. Such a plan would ideally include both parents' perspectives, although given the rate of estrangement this may not be possible. The plan could contain information about the amount of information the parent wants their child to know, who should provide the information and what should be said about the parent's current hospitalisation or symptoms. This would enable the provision of a well thought out explanation for the child and one which the parent or parents were comfortable with. Although not foolproof, such a plan could go some way to reducing, for others, the largely negative experience which has occurred for the participants in the current thesis.

2. Parents need help with disclosing

Contrary to the parents who do not want to disclose until absolutely necessary, there were other parents who do want to disclose but have trouble doing so. For instance, some parents in the current study had disclosed many aspects of mental illness to their children but were unsure of how to disclose self harm or personality disorders. These parents indicated that they needed help with disclosure and would willingly accept help if offered. Help could conceivably be provided by adult mental health workers given that they were the most constant and most suitable person in many parents' lives, although the difficulties faced by adult mental health workers in advising parents on this topic have been discussed within this thesis.

Ideally help with disclosing, provided by adult mental health workers (for example), would assist parents in talking through their fears about disclosure, help with understanding the types of questions their children may ask and help with providing answers to children's questions.

Parents may also need specific help with communicating to children who may resist disclosure.

Although only mentioned by a minority of participants, approaching disclosure of mental illness as a process rather than an event appeared to lead to parents finding it easier to explain mental illness and children having a more detailed knowledge of the illness. In many cases it seems as though early conversations with children about aspects of mental illness may pave the way for the child being open to in depth discussions as the child gets older. Parents should be supported to provide their children with information about their parent's mental illness from an early age. This is further discussed as a future research recommendation below.

3. Confusion about the cause of illness

Although COPMI of all ages were confused about a number of aspects of mental illness, the domain which appeared to cause most confusion for COPMI was that of the cause of mental illness. This was understandable given the confusion within the general population about the etiology of mental illness (Spitzer & First, 2005). Research on adult beliefs about the cause of a family member's illness has shown that beliefs about cause can be linked to distress (Lobban et al., 2003). In the current thesis there were a number of causes put forward by COPMI which could be linked to increased distress. Some COPMI erroneously believed that drug use caused their illness regardless of whether their parent had a history of drug use. COPMI also believed that they themselves were responsible for their parent's illness. There is a need for the exploration of individual COPMI illness beliefs to determine whether they hold erroneous beliefs which could be increasing their distress.

4. COPMI appear to be largely without support

Findings of this study indicate that COPMI, at least within the current sample, do not discuss their parent's illness. The relationships that many children may rely on for support may not be a source of support for some COPMI, at least in terms of support with their COPMI status. Siblings, friends and teachers were not often spoken to about the participant's parent's illness. The COPMI in the current study were often managing living with parent's symptoms and hospitalisation while their friends and teachers were unaware of what was happening at home. As discussed this could have ramifications for children's ability to perform at school. Also discussed was the lack of sibling support, which was an interesting finding given the previous research on the value of sibling relationships for COPMI.

The role of school-based interventions have been highlighted by Reupert and Maybery (2010a) and it appears that, for this sample, there is scope for the school to provide more support. Increased support could be particularly useful during times of crisis such as hospitalisation of a parent or a change in living circumstances. Given the value other COPMI have found in sibling support, there is scope to develop and foster sibling relationships for COPMI who may not have considered their sibling a potential source of support.

8.5 Strengths and limitations of the current study

The strengths of this thesis include the sample size included in both the parent and child focussed studies. Historically it has been difficult to recruit large numbers of participants for interview based COPMI studies. Conducting interviews Australia-wide provided access to a larger number of participants which in turn provided a number of different voices to be included in the research. A further strength is that participants were sourced through a number of avenues, not only through mental health services.

The inclusion of both parent and child views provided a perspective which is not often seen in research in this field. Both perspectives are important when examining parenting with mental illness and being the child of a parent with mental illness. The two perspectives provided rich data and highlighted the complexity of disclosure, something which would not have been achieved with either voice alone.

The use of the Leventhal model to underpin much of the current thesis proved valuable for the exploration of parent and child beliefs. The Leventhal model allowed a comprehensive exploration of a range of domains of mental illness. It enabled the current research to build on the previous research into children's illness beliefs which is largely focussed solely on the domain of the cause of illness. The model enabled a qualitative exploration of the illness beliefs of numerous members of the same family. Leventhal's model also highlighted the differences and similarities of beliefs which can exist within one family.

When examining the findings of this thesis and the clinical implications suggested, the limitations of the studies within this thesis need to be considered. Firstly, the views of the participants in this study may not be representative of the view of all parents with mental illness. The nature of the recruitment for this study meant that participants for this study self-selected. Participants were not randomly selected parents, rather they were parents who found out about the study and actively requested to participate. Accordingly parents in this study could differ from parents who did not request to participate.

In addition, parents who took part in this study knew that I was also interviewing children. Although it was not requisite that both parent and child were interviewed from the same family, the majority of parents who participated also consented for their child to participate. Generally this meant that parents had already discussed mental illness with their children to

some extent. It could be surmised that there are parents within the community who chose not to participate in the study because they had chosen not to talk to their children about their illness. The findings of this study could be enhanced by further research examining the views of more parents who have actively chosen not to disclose any aspect of mental illness to their children.

Similarly, there were parents in the current study who did not give permission for all of their children to participate in the study. It could be assumed that the children who were given permission to participate may have been different to the children who did not participate. Children who participated may have been thought of by their parent(s) as more suitable for the study, parents may have perceived them as having a better understanding of mental illness. It is unclear if this is the case and ideally all children in each family should have been interviewed. In addition, a further limitation was that children were not asked if they themselves identified as having mental illness. An ethical decision was made not to ask children about their own mental illness status as it was peripheral to the main premise of this thesis and would have added unnecessary ethical considerations.

The sample size of both the parent and the child participants, whilst large in terms of qualitative research, was too small to be able to generalise findings to the population as a whole. The purpose of qualitative research is not to make broad statements, but rather to explore, in depth a phenomena of interest. This was achieved with the current sample but general assumptions about the population as a whole (for example, stating that illness knowledge differences do not exist for COPMI) are limited.

Further methodological limitations included the inability to analyse the qualitative data whilst it was being collected. Many qualitative approaches state that qualitative data needs to be

iterative. That is, as data is being collected it should be analysed concurrently. Within the current thesis, questions about the data were raised after all interviews had been conducted. If the data was analysed simultaneously, these questions could have been asked of subsequent participants. The data collection within the current thesis was constrained by limited interstate travel and very limited funding. This meant that interviews needed to be conducted within a very short time frame. These constraints could have impacted on the quality of the findings of this thesis.

The combination of the interviews of all parents within the analysis is another methodological limitation. The parent focussed study within this thesis was concerned with how parents (both with mental illness and without) disclose mental illness to children who have a parent with mental illness. Parents both with mental illness and without mental illness were included and their data was analysed as one set. It could be hypothesised that there could be important variation in the accounts of disclosure between the groups of parents. Future studies might explore the differences and similarities of the experiences of disclosure of parents with mental illness and parents without.

As is common within research examining parents with mental illness, there were very few fathers voices included in this thesis. All parents who expressed an interest in participating were included in the study so it may have been the case that the recruitment methods did not attract fathers. The fathers who were involved in the thesis provided a unique insight into the disclosure process. Further research in this domain should actively attempt to attract fathers to participate. Only then will the familial experience of disclosure be properly understood.

8.6 Recommendations for future research

The current thesis was exploratory in nature and has provided a useful foundation for further research. Specifically this thesis has provided preliminary information about the disclosure process from the parents' perspective and the child's perspective. This thesis has also explored COPMI beliefs about mental illness. This initial exploration has illuminated a number of areas which would benefit from further research.

1. The use of Leventhal's model for further research

The Leventhal model is a useful tool to understand both parent and COPMI conceptualisation of mental illness. There is scope to use it as a quantitative measure (as it is used with many other populations; Weinman et al., 1996) after further exploration with a larger sample. There is a call to talk to COPMI in 'developmentally appropriate ways', although the current study did not provide evidence for any developmental differences in understanding. A quantitative study, using Leventhal's model could be a useful way to determine, on a larger scale what children know about parental mental illness and whether there are significant differences according to age with a larger sample size.

The current thesis did not analyse COPMI illness perceptions as a whole. COPMI beliefs about identity were grouped together, as were COPMI beliefs about cause and so forth. There is scope for the examination of illness perceptions as a whole to see whether COPMI ideas about domains are linked. For example, one child within the current study stated that smoking caused his mother's illness but he did not mention that quitting smoking could be a possible treatment. Using Leventhal's model to examine perceptions as a whole could provide a clearer picture of how COPMI conceptualise their parent's illness.

As discussed within this thesis, Leventhal's model has been used in other populations to examine the link between illness perception and level of distress (Lobban et al., 2003). Once COPMI perceptions as a whole are examined there is scope for further research to examine whether certain perceptions about mental illness are linked with resilience in COPMI or whether there are certain perceptions which are linked with negative outcomes.

Similarly, there is scope to examine the parent's own understanding of mental illness and how this impacts on the child's understanding. Do parents with mental illness and their children hold similar beliefs about all domains of illness? If not does this affect the parent-child relationship? Does it affect parent and child attachment if there are differences in beliefs about mental illness? There are a number of questions which could be answered by examining both parent and child beliefs simultaneously.

Likewise, there would be value in finding out whether there are key elements of illness perception (such as cause of illness) which are linked to better outcomes for COPMI. If it were the case that a comprehensive understanding of certain domains of illness was linked to better outcomes, then education of COPMI could focus specifically on these domains.

2. Exploration of COPMI need for information over time

Many of the children interviewed for the current thesis did not want further information about their parent's mental illness. Retrospectively ACOPMI have stated that they would have liked to have been provided with more information about their parent's mental illness when they were younger. Is it the case that the COPMI participants in the present thesis will retrospectively have wanted information by the time they reach adulthood? Are there certain ages where COPMI do desire information about a parent's illness? Importantly, is there a

crucial period in a child's life where they are most amenable to receiving information about sensitive topics?

3. The development and evaluation of a disclosure intervention

The difficulties the parents in the current study faced regarding disclosure of mental illness are not unusual. Disclosure of parental HIV status appears fraught with similar difficulties (Murphy, Armistead, Marelich, Payne & Herbeck, 2011 a). Recently Murphy and colleagues (2011 a) have developed and run a disclosure intervention for parents with HIV and their children. The disclosure intervention focuses on providing parents with information such as the benefits and potential negative impact of disclosure; improving family communication to help build a foundation for disclosure; providing advice from other mothers about disclosure (including information about how their own child responded) and behavioural practice of the disclosure process (Murphy et al., 2011 a, p. 206).

There is scope for the development of a disclosure intervention, similar to the one developed by Murphy and colleagues (2011 a), which is specifically tailored to the unique situation of parents with mental illness and their children. A disclosure intervention which addresses parents' specific concerns about disclosure and provides advice from other parents who have disclosed could benefit both parents with mental illness and COPMI. In addition, if appropriate, the disclosure intervention could focus on the disclosure needs of both parents within the child's life. Further research could focus on the development of an appropriate intervention and the evaluation of the intervention from a range of relevant view points. Longitudinal research could examine whether there are long term benefits of such an intervention for both parents and their children.

8.7 Conclusion

The current thesis provided a unique insight into both parent and children's experiences regarding disclosure. Parents provided candid accounts of their experiences in an effort to assist with research which they believed was important. Children answered questions regarding a topic which, in many cases, was seldom discussed at home. Parents and their children, understandably, can have competing wishes regarding the disclosure of mental illness and it is clear that, at times, the balance between the rights of the child and the rights of the parent is tenuous. The findings of this study provide a valuable springboard from which to further explore both the experience of disclosure and the beliefs that families hold about mental illness.

References

- Abrams R. (1994). The treatment that will not die. *Psychiatric Clinics of North America*, 17, 525-530.
- Absler, D. (1999). Talking with children about their parents' mental illness or health problems. In V. Cowling (Ed.), *Children of Parents with Mental Illness*. Melbourne, Vic: Australian Council for Educational Research.
- Aldridge, J. (2002). Children caring for parents with severe and enduring mental illness. *Centre for Child and Family Research Evidence Paper* (Issue 5). Leicestershire, UK: Loughborough University. Retrieved from <https://dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/2927/5/Evidence5.pdf>
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders: DSM-IV* (4th ed.). Washington, DC : Author.
- Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: Are mothers telling their children? *Journal of Pediatric Psychology*, 26, 11–20.
- Armstrong, D., Gosling, A., Weinman, J., & Marteau, T. (1997). The place of inter-rater reliability in qualitative research: An empirical study. *Sociology*, 31: 597
- Austin, J. C., & Honer, W. G. (2007). The genomic era and serious mental illness: A potential application for psychiatric genetic counseling. *Psychiatric Services*, 58, 254-261.
- Australian Infant Child Adolescent and Family Mental Health Association. (2001). *Children of parents affected by a mental illness – Scoping Project Report*. Stepney, SA: Australian Infant Child Adolescent and Family Mental Health Association Ltd.
- Australian Infant Child Adolescent and Family Mental Health Association. (2004). *Principles and Actions for Services and People Working with Children of Parents with a Mental Illness*. Stepney, SA: Australian Infant Child Adolescent and Family Mental Health Association Ltd.
- Aviram, R. B., Brodsky, B. S., & Stanley, B. (2006). Borderline Personality Disorder, Stigma, and Treatment Implications. *Harvard Review of Psychiatry*, 14, 249-256.
- Babooram, M., Mullan, B. A., & Sharpe, L. (2011). Children's perceptions of obesity as explained by the Common Sense Model of Illness Representation. *British Food Journal*, 113, 234-247.
- Bailey, S. (1999). Young people, mental illness and stigmatisation. *The Psychiatrist*, 23, 107-110.
- Barnes, J., Kroll, L., Burke, O., Lee, J., Jones, A., & Stein, A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. *British Medical Journal*, 321, 479-482.

- Barrowclough, C., & Hooley, J. M. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review, 23*, 849-880.
- Barrowclough, C., Lobban, F., Hatton, C., & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology, 40*, 371-385.
- Beach, W. A., & Metzger, T. R. (1997). Claiming Insufficient Knowledge. *Human Communication Research, 23*(4), 562-588.
- Beardslee, W. R., Hoke, M., Wheelcock, I., Rothberg, P. C., van de Velde, P., & Swatling, S. (1992). Initial findings on preventive intervention for families with parental affective disorders. *American Journal of Psychiatry, 149*, 1335-1340.
- Beardslee, W. R., Keller, M. B., Lavori, P. W., Podorefsky, D., Seifer, R., Shera, D., & Staley, J. (1996). Prediction of adolescent affective disorder: Effects of prior parental affective disorders and child psychopathology. *Journal of the American Academy of Child & Adolescent Psychiatry, 35*(3), 279-288.
- Beardslee, W. R., & Podorefsky, D. (1988). Resilient adolescents whose parents have serious affective and other psychiatric disorders: Importance of self-understanding and relationships. *American Journal of Psychiatry, 145*(1), 63-69.
- Beardslee, W. R., Versage, E. M., & Gladstone, T. R. G. (1998). Children of affectively ill parents: A review of the past 10 years. *Journal of the American Academy of Child & Adolescent Psychiatry, 37*, 1134-1141.
- Beatson, J., & Taryan, S. (2003). Predisposition to depression: The role of attachment. *Australian and New Zealand Journal of Psychiatry, 37*, 219-225.
- Berry, K., Barrowclough, C., & Wearden, A. (2007). A review of the role of adult attachment style in psychosis: Unexplored issues and questions for further research. *Clinical Psychology Review, 27*, 458-475.
- Bibace, R. & Walsh, M. E. (1980). Development of children's conceptions of illness. *Pediatrics, 66*, 912-917.
- Bibou-Nakou, I. (2003). "Troubles Talk" among professionals working with families facing parental mental illness. *Journal of Family Studies, 9*, 248-266.
- Biederman, J., Faraone, S. V., Hirshfield-Becker, D. R., Friedman, D., Robin, J. A. & Rosenbaum J. F. (2001). Patterns of psychopathology and dysfunction in high-risk children of parents with panic disorder and major depression. *American Journal of Psychiatry, 158*(1), 49-57.
- Bool, M., van der Zanden, A. P., & Smit, F. (2007). Children of parents with psychiatric problems, Factsheet Prevention. *Trimbos-instituut: Utrecht, Netherlands*.
- Borzekowski, D. L.G. (2009). Considering children and health literacy: A theoretical approach. *Pediatrics, 124*, S282-S288.

- Boslaugh, S. (2007). *Secondary data sources for public health: a practical guide*. UK: Cambridge University Press.
- Bourke, A. B. (1998). *Children's attributions of their severely mentally ill parent's symptomatic behaviour: A retrospective study (Doctoral dissertation, University of Massachusetts Amherst, Massachusetts, USA)*. Retrieved from ProQuest Dissertations & Theses.(AAT 9841843)
- Bowlby, J. A. (1969). *Attachment and loss* (Vol. 1). New York, NY: Basic Books.
- Boyatzis, R. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa
- Britten, N. (1995). Qualitative interviews in medical research. *British Medical Journal, 311*, 251-253.
- Busch, A., & Redlich, A. D. (2007). Patients' perception of possible child custody or visitation loss for nonadherence to psychiatric treatment. *Psychiatric Services, 58*(7), 999-1002.
- Cain, A. C., (2002). Children of suicide: The telling and the knowing. *Psychiatry, 65*(2), 124-136.
- Callan, V.J., Wilks, J., & Forsyth, S. (1983). Cultural perceptions of the mentally ill: Australian and Papua New Guninean high school youth. *Australian and New Zealand Journal of Psychiatry, 17*, 280-285.
- Carbonell, D.M., Reinherz, H.Z., Giaconia, R.M., Stashwick, C.K., Paradis, B.A., & Beardslee, W. R. (2002). Adolescent protective factors promoting resilience in young adults at risk for depression. *Child and Adolescent Social Work Journal, 19* (5), 393-412
- Cerel, J., & Roberts, T. A. (2005). Suicidal behavior in the family and adolescent risk behavior. *Journal of Adolescent Health, 36*, 352-352.
- Chester, M. A., Paris, J., & Barbarin, O. A. (1986). "Telling" the Child with Cancer: Parental Choices to Share Information with 111 Children. *Journal of Pediatric Psychology, 11*(4), 497-516.
- Cicchetti, D., Rogosch, F. A., & Toth, S. L. (1998). Maternal depressive disorder and contextual risk: Contributions to the development of attachment insecurity and behavior problems in toddlerhood. *Development and Psychopathology, 10*, 283-300.
- Clark, L.A., Watson, D., & Reynolds, S. (1995). Diagnosis and classification of psychopathology: Challenges to the current system and future directions. *Annual Review of Psychology, 46*, 121-153. doi: 10.1146/annurev.ps.46.020195.001005
- Cogan, N., Riddell, S., & Mayes, G. (2005a). Children living with an affectively ill parent: How do they cope? *Educational & Child Psychology, 22*(4), 16-28.

- Cogan, N., Riddell, S., & Mayes, G. (2005b). The understanding and experiences of children affected by parental mental health problems: A qualitative study. *Qualitative Research in Psychology*, 2, 47-66.
- Cohler, B., Stott, F., & Musick, J. (1996). Distressed parents and their young children: Interventions for families at risk. In M. Gopfert, J. Webster & M. Seeman (Eds.), *Parental Psychiatric Disorder: Distressed Parents and their Families* (pp. 107-134). Cambridge: University Press.
- Cooklin, A. (2006). Children of parents with a mental illness. In L. Combrinck-Graham (Ed.), *Children in Family Contexts, Second edition: Perspectives on Treatment* (pp. 265-291). New York, NY: The Guilford Press.
- Cooklin, A. (2010). 'Living upside down': being a young carer of a parent with mental illness. *Advances in Psychiatric Treatment*, 16, 141-146.
- Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, 13(6), 537-548.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9, 35-53.
- Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social & Clinical Psychology*, 25(9), 875-884.
- Cowling, V. (1996). Meeting the support needs of families with dependent children where the parent has a mental illness. *Family Matters*, 45, 22-25.
- Cowling, V. (1999). Finding answers, making changes: Research and community project approaches. In V. Cowling (Ed.), *Children of parents with a mental illness* (pp. 37-59). Melbourne, Vic: Australian Council Educational Research Press.
- Cummings, E. M., & Davies, P. T. (1994). Maternal depression and child development. *Journal of Child Psychology and Psychiatry*, 35, 73-112.
- Cowling, V., Luk, E. S., Mileshekin, C., & Birlison, P. (2004). Children of adults with severe mental illness: Mental health, help seeking and service use. *Psychiatric Bulletin*, 28(2), 43-46.
- Davies, P., & Windle, M. (1997). Gender-specific pathways between maternal depressive symptoms, family discord, & adolescent adjustment. *Developmental Psychology*, 33(4), 657-668.
- Dematteo, D., Harrison, C., Arneson, C., & Salter Goldie, R., Lefebvre, A., Read, S. E., & King, S. M. (2002). Disclosing HIV/AIDS to children: The paths families take to truth-telling. *Psychology, Health & Medicine*, 7(3), 339-356.

- Devlin, J., & O'Brien, L. (1999). Children of parents with mental illness. I: An overview from a nursing perspective. *Australian and New Zealand Journal of Mental Health Nursing*, 8(1), 19-29.
- DiCicco-Bloom, B., & Crabtree, B. (2006). The qualitative research interview. *Medical Education*, 40, 314-321.
- Downey, G., & Coyne, J. C. (1990). Children of depressed parents: An integrative review. *Psychological Bulletin*, 108(1), 50-76.
- Downey, G., & Coyne, J. C. (1990). Children of depressed parents: An integrative review. *Psychological Bulletin*, 108(1), 50-76.
- Duncan, S and Reder, P. (2003) How do mental health problems affect parenting? In P. Reder., S. Duncan & C. Lucey. (Eds) *Studies in the Assessment of Parenting* Bruner-Routledge: New York.
- Dunn, B. (1993). Growing up with a psychotic mother: A retrospective study. *American Journal of Orthopsychiatry*, 63(2), 177-189.
- Eiser, C. (1989). Children's concepts of illness: Towards an alternative to the stage approach. *Psychology and Health*, 3, 93-101,
- Eiser, C., & Kopel, S. J. (1998). Children's perceptions of health and illness. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness* (pp. 47-76). London: Harwood Academic Publishers.
- Falkov, A. (1995). *Troubled Lives - Psychiatric morbidity in children living with psychotic parents*. Unpublished manuscript.
- Falkov, A. (1997). Adult psychiatry—a missing link in the child protection network: A response to Reder and Duncan. *Child Abuse Review*, 6, 41-45.
- Falkov, A. (2004). Talking with children whose parents experience mental illness. In V. Cowling (Ed.), *Children of parents with mental illness: Personal and clinical perspectives* (Vol. 2, pp. 41–56). Melbourne, Vic.: Australian Council of Education Research.
- Falkov, A & Cowling, V. (2009). Talking with parents – concerns & dilemmas. In A. Falkov, S. Heriot, V. Cowling, P. Hazell, & K. Nunn (Eds.), *The Clinician (Volume 4) – Vulnerable Families: Children of Parents with Mental Illness* (pp. 31-37). Westmead, NSW: WHO Presentations.
- Finney, D. & Falkov, A. (2009). Children's understanding of severe parental mental illness. In A. Falkov, S. Heriot, V. Cowling, P. Hazell, & K. Nunn (Eds.), *The Clinician (Volume 4) – Vulnerable Families: Children of Parents with Mental Illness* (pp. 21-30). Westmead, NSW: WHO Presentations.
- Focht-Birkerts, L., & Beardslee, W. R. (2000). A child's experience of parental depression: Encouraging relational resilience in families with affective illness. *Family Process*, 39(4), 417-434.

- Folkman, S., & Lazarus, R. (1988). Coping as a mediator of emotion. *Journal of Personality and Social Psychology*, *54*, 466-475.
- Forrest, G., Plumb, C., Ziebland, S., & Stein, A. (2006). Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: Qualitative study. *British Medical Journal*, *332*, 998-1003. doi:10.1136/bmj.38793.567801.AE
- Foster, K. (2006). *A Narrative Inquiry into the Experiences of Adult Children of Parents with Serious Mental Illness*. (Doctoral dissertation, Griffith University, Qld). Retrieved from <http://www4.gu.edu.au:8080/adt-root/uploads/approved/adt-QGU20070228.170846/public/01Front.pdf>
- Foster, K. (2010). 'You'd think this roller coaster was never going to stop': Experiences of adult children of parents with serious mental illness. *Journal of Clinical Nursing*, *19*, 3143-3151. doi: 10.1111/j.1365-2702.2010.03293.x
- Foster, K., O'Brien, L., & McAllister, M. (2004). Addressing the needs of children of parents with a mental illness: Current approaches. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, *18*(1-2), 67-80.
- Foster, N. E., Bishop, A., Thomas, E., Main, C., Horne, R., Weinman, J., & Hay E. (2008). Illness perceptions of low back pain patients in primary care: What are they, do they change and are they associated with outcome? *Pain*, *136*, 177-187.
- Fox, C., Buchanan-Barrow, E. & Barrett, M. (2007). Children's understanding of mental illness: An exploratory study. *Child: Care, Health and Development*, *34*, 10-18. doi: 10.1111/j.1365-2214.2007.00783.x.
- Fudge, E., Falkov, A., Kowalenko, N., & Robinson, P. (2004). Parenting is a mental health issue. *Australasian Psychiatry*, *12*(2), 166-171.
- Fudge, E., & Mason, P. (2004). Consulting with young people about service guidelines relating to parental mental illness. *Australian e-Journal for the Advancement of Mental Health*, *3*(2), 1-9.
- Garber, J., & Martin, N. C. (2002). Negative cognitions in offspring of depressed parents: Mechanisms of risk. In S. H. Goodman & I. H. Gotlib (Eds.), *Children of depressed parents: Mechanisms of risk and implications for treatment* (pp. 121-154). Washington, DC: American Psychological Association.
- Garley, D., Gallop, R., Johnston, N., & Pipitone, J. (1997). Children of the mentally ill: A qualitative focus group approach. *Journal of Psychiatric and Mental Health Nursing*, *4*(2), 97-103. doi:10.1046/j.1365-2850.1997.00036.x
- Garth, B., & Aroni, R. (2003). 'I value what you have to say'. Seeking the perspective of children with a disability, not just their parents. *Disability & Society*, *18*(5), 561-576.
- Garvin, S., McAllister, S., & Phillip, R. (2002). Children of parents with a mental illness: A national initiative. *Youth Studies Australia*, *21*(2), 17-27.

- Gladstone, B. M., Boydell, K. M., & McKeever, P. (2006). Recasting research into children's experiences of parental mental illness: Beyond risk and resilience. *Social Science & Medicine*, 62(10), 2540-2550.
- Godress, J., OZgul, S., Owen, C., & Foley-Evans, L. (2005). Grief experiences of parents whose children suffer from mental illness. *Australian and New Zealand Journal of Psychiatry*, 39, 88-94
- Goldman, S., Whitney-Saltiel, G., & Rodin, J. (1991). Children's representations of "everyday" aspects of health and illness. *Journal of Pediatric Psychology*, 16(6), 747-766.
- Golombok, S., MacCallum, F., Goodman, E., & Rutter, M. (2002). Families with children conceived by donor insemination: A follow-up at age 12. *Child Development*, 73, 952-968.
- Goodman, S., & Gotlib, I. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review*, 106(3), 458-490.
- Goodman, S.H., & Gotlib, I. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review*, 106(3), 458-490.
- Goodman, S. H., Adamson, L.B., Riniti, J., & Cole, S. (1994). Mothers' expressed attitudes: Association with maternal depression and children's self-esteem and psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry*, 33(9), 1265-1274.
- Göpfert, M., Webster, J., & Seeman, M. V. (1996). *Parental psychiatric disorder: Distressed parents and their families*. New York, NY: Cambridge University Press.
- Green, M (1994). Diagnosis, management , and implications of maternal depression for children and pediatricians. *Current Opinion Pediatrics*, 6, 525-529.
- Greenberg, J. S., Kim, H.W., & Greenley, J. R. (1997). Factors associated with subjective burden in siblings of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67, 231-241.
- Gross, D. (1995). Children of mentally ill. In B. S. Johnson (Ed.) *Child, Adolescent and family psychiatric nursing*. New York, NY: Lippincott.
- Grunebaum, H., & Cohler, B. J. (1983). Children of parents hospitalized for mental illness: 1. Attentional and interactional studies. *Journal of Children in Contemporary Society*, 15(1), 43-55.
- Hall, W., Lynskey, M., & Teesson, M. (2001). What is comorbidity and why does it matter? In M. Teesson & L. Burns (Eds.), *National comorbidity project* (pp. 11-17). Canberra: Commonwealth Department of Health and Aged Care.

- Halligan, S.L., Murray, L., Martins, C., & Cooper, P.J. (2007). Maternal depression and psychiatric outcomes in adolescent offspring: a 13-year longitudinal study. *Journal of Affective Disorders*, 97(1-3), 145-154.
- Handley, C., Farrell, G. A., Josephs, A., Hanke, A., & Hazelton, M. (2001). The Tasmanian children's project: The needs of children with a parent/carer with a mental illness. *Australian & New Zealand Journal of Mental Health Nursing*, 10(4), 221-228.
- Hatfield, A. B., & Lefley, H. P. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal*, 41(3), 327-338.
- Hay, D. A. (2004). Understanding and explaining the genetics of mental illness. In V. Cowling (Ed.), *Children of parents with mental illness: Personal and clinical perspectives* (Vol. 2, pp. 5–14). Melbourne, Vic.: Australian Council of Education Research.
- Hay, D. (2009). Are children of parents with mental illness (COPMI) still ‘hidden’? In A. Falkov, S. Heriot, V. Cowling, P. Hazell, & K. Nunn (Eds.), *The Clinician (Volume 4) – Vulnerable Families: Children of Parents with Mental Illness* (pp. 4-6). Westmead, NSW: WHO Presentations.
- Hay, D. F., Pawlby, S., Angold, A., Harold, G. T., & Sharp, D., (2003). Pathways to violence in the children of mothers who are depressed postpartum, *Developmental Psychology*, 39, 1083-1094.
- Hennessy, E., Swords, L. & Heary, C. (2007). Children’s understanding of psychological problems displayed by their peers: A review of the literature. *Child: Care, Health and Development*, 34, 4-9. doi:10.1111/j.1365-2214.2007.00772.x
- Herring, M., & Kaslow, N. J. (2002). Depression and attachment in families: A child-focused perspective. *Family Process*, 41, (3), 494-518.
- Hinrichsen, G. A., & Lieberman, J. A. (1999). Family attributions and coping in the prediction of emotional adjustment in family members of patients with first-episode schizophrenia. *Acta Psychiatrica Scandinavica*, 100, 359-366.
- Hinshaw, S. P. (2005). The stigmatization of mental illness in children and parents: Developmental issues, family concerns and research needs. *Journal of Child Psychology & Psychiatry*, 46(7), 714-734.
- Holahan, C. J., Moos, R. H., & Schaefer, J. A. (1996). Coping, stress resistance, and growth: Conceptualizing adaptive functioning. In Zeidner, M., & Endler, N. S. (Eds.), *Handbook of coping: Theory, research, applications* (pp. 24-43). Oxford, England: John Wiley & Sons.
- Holliday, J., Wall, E., Treasure, J., & Weinman, J. (2005). Perceptions of illness in individuals with anorexia nervosa: A comparison with lay men and women. *International Journal of Eating Disorders*, 37(1), 50–56.
- Hops H. (1995). Age- and gender-specific effects of parental depression: A commentary. *Developmental Psychology*, 31(3), 428-431.

- Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology & Health, 17*(1), 17 – 32.
- Horwitz, A. V. (1993). Siblings as caregivers for the seriously mentally ill. *Milbank Quarterly, 71*(2), 323-339.
- Horwitz, A.V., Tessler, R.C., Fisher, G.A., & Gamache, G. M. (1992). The role of adult siblings in providing social support to the severely mentally ill. *Journal of Marriage and the Family, 54*, 233-241.
- Hosman, C., van Doesum, K., & van Santvoort, F. (2009). Prevention of emotional problems and psychiatric risks in children of parents with mental illness in the Netherlands: I. The scientific basis to a comprehensive approach. *Australian e-Journal for the Advancement of Mental Health, 8* (3), 250-263.
- Hung, N. C. & Rabin, L. A.(2009). Comprehending childhood bereavement by parental suicide: A critical review of research on outcomes, grief processes, and interventions. *Death Studies, 33*(9), 781-814.
- Hunter, M. S., Salter-Ling, N., & Glover, L. (2000). Donor insemination: Telling children about their origins. *Child Psychology & Psychiatry Review, 5*(4), 157-163.
- Jacobsen, T., & Miller, L. J. (1998). Mentally ill mothers who have killed: Three cases addressing the issue of future parenting capability. *Psychiatric Services, 49*(5), 650-657.
- Joseph, J. G., Joshi, S. V., Lewin, A. B., & Abrams, M. (1999). Characteristics and perceived needs of mothers with serious mental illness. *Psychiatric Services, 50*(10), 1357-1359.
- Karasz, A. (2005). Cultural differences in conceptual models of depression. *Social Science & Medicine, 60*(7), 1625–1635.
- Kauffman, C., Grunebaum, H., Cohler, B., & Gamer, E. (1979). Superkids: Competent children of psychotic mothers. *American Journal of Psychiatry, 136*(11), 1398-1402.
- Kelly, M. (1999). Approaching the last resort: A parent's view. In V. Cowling (Ed.), *Children of parents with mental illness* (1st ed., pp. 60-76). Melbourne: ACER Press.
- Kennedy, D. P., Cowgill, B. O., Bogart, L. M., Corona, R., Ryan, G. W., Murphy, D. A., ... Schuster, M. A. (2010). Parents' disclosure of their HIV infection to their children in the context of the family. *AIDS Behavior 14*, 1095-1105.
- Kinsella, K., & Anderson, R. (1996). Coping skills, strengths and needs as perceived by adult offspring and siblings of people with mental illness: A retrospective study. *Psychiatric Rehabilitation Journal, 20*(2), 24-33.
- Kirkman, M., Rosenthal, D. A., & Feldman, S. S. (2002). Talking to a tiger: Fathers reveal their difficulties in communicating about sexuality with adolescents. *New Directions for Child & Adolescent Development, 97*, 57-74.

- Knox, S. A., Harrison, C. M., Britt, H. C., & Henderson, J. V. (2008). Estimating prevalence of common chronic morbidities in Australia. *Medical Journal of Australia*, *189*(2), 66-70.
- Knutsson-Medin, L., Edlund, B., & Ramklint, M. (2007). Experiences in a group of grown-up children of mentally ill parents. *Journal of Psychiatric & Mental Health Nursing*, *14*(8), 744-752.
- Kodish, E., Eder, M., Noll, R. B., Ruccione, K., Lange, B., Angiolillo, A., ... Drotar, D. (2004). Communication of randomization in childhood leukemia trials. *Journal of the American Medical Association*, *291*(4), 470-475.
- Kroll, L., Barnes, J., Jones, A. L., & Stein, A. (1998). Cancer in parents: Telling children. *British Medical Journal*, *316*, 880-880.
- Kuipers, E., Onwumere, J., & Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *British Journal of Psychiatry*, *196*, 259-265.
- Kuipers, E., Watson, P., Onwumere, J., Bebbington, P., Dunn, G., Weinman, J., ... Garety, P. (2007). Discrepant illness perceptions, affect and expressed emotion in people with psychosis and their carers. *Social Psychiatry & Psychiatric Epidemiology*, *42*, 277-283.
- Lancaster, S. (1999). Being there: How parental mental illness can affect children. In V. Cowling (Ed.), *Children of parents with mental illness* (1st ed., pp. 14-33). Melbourne: ACER Press.
- Lane, A., Byrne, M., Mulvaney, F., Larkin, C., Waddington, J. L., Walsh, D., & O'Callaghan, E. (1992). Evidence for increased fertility in married male schizophrenics. *Schizophrenia Research*, *6*(2), 94.
- Lee, M. B., & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *AIDS*, *16*, 2201-2207
- Leschied, A. W., Chiodo, D., Whitehead, P. C., & Hurley, D. (2005). The relationship between maternal depression and child outcomes in a child welfare sample: Implications for treatment and policy. *Child & Family Social Work*, *10*(4), 281-291.
- Leventhal, H., Benjamin, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations; theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness* (pp. 19-45). London: Harwood Academic Publishers.
- Leventhal, H., & Cameron, L. (1987). Behavioural theories and the problem of compliance. *Patient Education and Counselling*, *10*, 117-138
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Medical psychology* (Vol. 2, pp. 7-30). New York, NY: Pergamon Press.

- Leventhal, H., Nerenz, D. R., & Steele, D. F. (1984). Illness representations and coping with health threats. In A. Baum & J. Singer (Eds.), *A handbook of psychology and health* (pp 219–252). Hillsdale, NJ: Erlbaum.
- Lobban, F., & Barrowclough, C. (2005). Common sense representations of schizophrenia. *Clinical Psychology & Psychotherapy*, *12*, 134-141.
- Lobban, F., Barrowclough, C., & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical Psychology Review*, *23*, 171-196.
- Lobban, F., Barrowclough, C., & Jones, S. (2005). Assessing cognitive representations of mental health problems. II. The illness perception questionnaire for schizophrenia: Relatives' version. *British Journal of Clinical Psychology*, *44*, 163–180
- Lobban, F., Barrowclough, C., & Jones, S. (2006). Does Expressed Emotion need to be understood within a more systemic framework? An examination of discrepancies in appraisals between patients diagnosed with schizophrenia and their relatives. *Social Psychiatry & Psychiatric Epidemiology*, *41*, 50-55.
- Luntz, J. (1995). The invisible dimension in mental health — children whose parents suffer from a serious mental illness. *Australian Social Work*, *48*, 19–27.
- Luthar, S. S., & Ziegler, E. (1991). Vulnerability and competence: A review of research on resilience in childhood. *American Journal of Orthopsychiatry*, *61*(1), 6-22.
- Lycett, E., Daniels, K., Curson, R., & Golombok, S. (2004). Offspring created as a result of donor insemination (DI): A study of family relationships, child adjustment, and disclosure. *Fertility & Sterility*, *82*, 172-179.
- Mac Dougall, K., Becker, G., Scheib, J. E., & Nachtigall, R. D. (2007). Strategies for disclosure: How parents approach telling their children that they were conceived with donor gametes *Fertility & Sterility*, *87*(3), 524-533.
- Mack, J. W., & Grier, H. E. (2004). The day one talk. *Journal of Clinical Oncology*, *22*(3), 563-566.
- Magliano, L., Fiorillo, A., De Rosa, C., & Maj, M. (2006). Family burden and social network in schizophrenia vs. physical diseases: Preliminary results from an Italian national study. *Acta Psychiatrica Scandinavica*, *113*(Suppl 429), 60-63.
- Malpas, P. J. (2006). Why tell asymptomatic children of the risk of an adult-onset disease in the family but not test them for it? *Journal of Medical Ethics*, *32*, 639- 642.
- Marsh, D. T., Dickens, R.M., Koeske, R.D., Yackovich, N.S., Wilson, J.M., Leichliter, J.S., & McQuillis, V. (1993). Troubled journey: siblings and children of people with mental illness. *Innovations and research in clinical services, community support and rehabilitation*, *2*(2), 17-28.
- Mason, P., & Goad, N. (2000). *Supporting Our Family: A Child's Care Plan*. Retrieved from <http://www.howstat.com/comic/ChildCarePlan.asp>

- Maas, E., Maracek, J., & Travers, J. R. (1978). Children's conceptions of disordered behaviour. *Child Development*, *49*(1), 146-154.
- Maybery, D., Ling, L., Szakacs, E., & Reupert, A. (2005). Children of a parent with a mental illness: Perspectives on need. *Australian e-Journal for the Advancement of Mental Health*, *4*(2), 1-11.
- Maybery, D., & Reupert, A. (2006). Workforce capacity to respond to children whose parents have a mental illness. *Australian & New Zealand Journal of Psychiatry*, *40*(8), 657-664.
- Maybery, D., Reupert, A., Patrick, K., Goodyera, M., & Crase, L. (2009). Prevalence of children whose parents have a mental illness. *Psychiatric Bulletin*, *33*, 22-26.
- McLellan, J. D. & Ganguli, R. (1999). Family planning and parenthood needs of women with severe mental illness: Clinicians' perspective. *Community Mental Health Journal*, *35*(4), 369-380.
- Meadus, R. J., & Johnson, B. (2000). The experience of being an adolescent child of a parent who has a mood disorder. *Journal of Psychiatric and Mental Health Nursing*, *7*(5), 383-390. doi: 10.1046/j.1365-2850.2000.00319.x
- Metcalfé, A., Coad, J., Plumridge, G. M., Gill, P., & Farndon, P. (2008). Family communication between children and their parents about inherited genetic conditions: A meta-synthesis of the research. *European Journal of Human Genetics*, *16*, 1193-1200.
- Miller, F., Dworkin, J., Ward, M., & Barone, D. (1990). A preliminary study of unresolved grief in families of seriously mentally ill patients. *Hospital and Community Psychiatry*, *41*, 1321-1325.
- Miller, L. J., & Finnerty, M. (1996). Sexuality, pregnancy, and childrearing among women with schizophrenia-spectrum disorders. *Psychiatric Services*, *47*(5), 502-506.
- Moore, T. H. M., Zammit, S., Lingford-Hughes, A., Barnes, T. R. E., Jones, P. B., Burke, M., & Lewis, G. (2007). Cannabis use and risk of psychotic or affective mental health outcomes: A systematic review. *The Lancet*, *370*, 319-328
- Mordoch, E., & Hall, W. A. (2002). Children living with a parent who has a mental illness: A critical analysis of the literature and research implications. *Archives of Psychiatric Nursing*, *16*(5), 208-216.
- Mordoch, E., & Hall, W. A. (2008). Children's perceptions of living with a parent with a mental illness: Finding the rhythm and maintaining the frame. *Qualitative Health Research*, *18*, 1127-1144.
- Mowbray, C., Schwartz, S., Bybee, D., Spang, J., Rueda-Riedle, A., & Oyserman, D. (2000). Mothers with a mental illness: Stressors and resources for parenting and living. *Families in Society – The Journal of Contemporary Human Services*, *81*(2), 118-129.

- Mowbray, C. T., & Mowbray, O. P. (2006). Psychosocial outcomes of adult children of mothers with depression and bipolar disorder. *Journal of Emotional & Behavioral Disorders, 14*(3), 130-142.
- Mowbray, C. T., & Oyserman, D. (2003). Substance abuse in children of parents with mental illness: Risks, resiliency, and best prevention practices. *Journal of Primary Prevention, 23*(4), 451-482.
- Mowbray, C. T., Oyserman, D., & Ross, S. (1995). Parenting and the significance of children for mothers with a serious mental illness: Research on pregnancy, childbirth and the postpartum. *American Journal of Orthopsychiatry, 65*(1), 21-38.
- Mowbray, C. T., Oyserman, D., Zemencuk, J. K., & Ross, S. R. (1995). Motherhood for women with serious mental illness: Pregnancy, childbirth, and the postpartum period. *American Journal of Orthopsychiatry, 65*(1), 21-38.
- Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: A review. *Clinical Child Psychology & Psychiatry, 13*(1), 105-122. doi: 10.1177/1359104507087464
- Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: The TRACK Program. *Journal of Consulting & Clinical Psychology, 79*(2), 203-214.
- Murphy, G., Peters, K., Jackson, D. & Wilkes, L. (2011). A qualitative meta-synthesis of adult children of parents with a mental illness. *Journal of Clinical Nursing*. doi: 10.1111/j.1365-2702.2010.03651.x
- Nachtigall, R. D., Becker, G., Quiroga, S. S., & Tschann, J. M. (1998). The disclosure decision: Concerns and issues of parents of children conceived through donor insemination. *American Journal of Obstetrics & Gynecology, 178*(6), 1165-1170.
- New South Wales Commission for Children and Young People, & Social Justice and Social Change Research Centre. (2005). *Participation: Count me in! Involving children and young people in research*. Sydney, NSW: NSW Government & University of Western Sydney.
- Nicholson, J., Biebel, K., Hinden, B., Henry, A., & Stier, L. (2001). Critical issues for parents with mental illness and their families. Retrieved from <http://www.nmha.org/download.cfm?DownloadFile=A04D60B2-1372-4D20-C8DFC0CBF51ACF9C>.
- Nicholson, J., Biebel, K., Katz-Leavy, J., & Williams, V. (2002). The Prevalence of Parenthood in Adults with Mental Illness: Implications for State and Federal Policymakers, Programs, and Providers. *Psychiatry Publications and Presentation*, Paper 153.
- Nicholson, J., & Deveney, W. (2009). Why Not Support(ed) Parenting? *Psychiatric Rehabilitation Journal, 33*(2), 79-82. doi: 10.2975/33.2.2009.79.82
- Nicholson, J., Geller, J. L., & Fisher, W. H. (1996). 'Sylvia Frumkin has a baby': A case study for policy makers. *Psychiatric Services, 47*, 497-501.

- Nicholson, J., Geller, J. L., Fisher, W. H., & Dion, G. L. (1993). State policies and programs that address the needs of mentally ill mothers in the public sector. *Hospital & Community Psychiatry, 44*(5), 484-489.
- Nicholson, J., Nason, M. W., Calabresi, A. O., & Yando, R. (1999). Fathers with severe mental illness: Characteristics and comparisons. *American Journal of Orthopsychiatry, 69*(1), 134-141.
- Nicholson, J., Sweeney, E. M., & Geller, J. L. (1998). Focus on women: Mothers with mental illness: I. The competing demands of parenting and living with mental illness. *Psychiatric Services, 49*(5), 635-642.
- Nobes, G. & Smith, M. (1997) Physical punishment of children in two parent families. *Clinical Child Psychology and Psychiatry, 2*, 271–281.
- Olsen, B., Berg, C. A., & Wiebe, D. J. (2008). Mother-child similarity in illness representations and adjustment to type 1 diabetes. *Psychology and Health, 23*, 113-129.
- Outridge, D. (2009). A GP perspective on the care of children of parents with mental illness. In A. Falkov, S. Heriot, V. Cowling, P. Hazell, & K. Nunn (Eds.), *The Clinician (Volume 4) – Vulnerable Families: Children of Parents with Mental Illness* (pp. 120-124). Westmead, NSW: WHO Presentations.
- Owen, S. (2008). *Children of Parents with a Mental Illness: Systems Change in Australia*. Available from http://www.copmi.net.au/evaluation/evaluation_reports.html.
- Oyserman, D., Mowbray, C. T., Meares, P. A., & Firminger, K. B. (2000). Parenting among mothers with a serious mental illness. *American Journal of Orthopsychiatry, 70*(3), 296–315.
- Perrin, E. C., & Gerrity, P. S. (1981). There's a demon in your belly: Children's understanding of illness. *Pediatrics, 67*(6), 841-849.
- Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Predicting return to work and functioning following myocardial infarction: The role of the patients' view of their illness. *British Medical Journal, 312*, 1191-1194.
- Pawlby, S., Sharp, D., Hay, D., & O'Keane, V. (2008). Postnatal depression and child outcome at 11 years: The importance of accurate diagnosis. *Journal of Affective Disorders, 107*, 241-245.
- Phelan, J. C., Yang, L. H., & Cruz-Rojas, R. (2006). Effects of attributing serious mental illnesses to genetic causes on orientations to treatment. *Psychiatric Services, 57*, 382-387.
- Pilowsky, D. J., Wissow, L., & Hutton, N. (2000). Children affected by HIV: Clinical experience and research findings. *Child & Adolescent Psychiatric Clinics of North America, 9*(2), 451-464.

- Plumridge, G., Metcalfe, A., Coad, J., & Gill, P. (2010). Family communication about genetic risk information: Particular issues for Duchenne muscular dystrophy. *American Journal of Medical Genetics, 152A*, 1225-1232.
- Poehlmann, J. (2005). Representations of attachment relationships in children of incarcerated mothers. *Child Development, 76*(3), 679-696.
- Pölkki, P., Ervast, S., & Huupponen, M. (2005). Coping and resilience of children of a mentally ill parent. *Social Work in Health Care, 39*(1), 151-163. doi: 10.1300/J010v39n01_10
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: Analysing qualitative data. *British Medical Journal, 320*, 114-116.
- Poster, E. C. (1992) Children's concepts of the mentally ill. *Journal of Child and Adolescent Psychiatric and Mental Health Nursing, 5*(2), 28-36.
- Poster, E. C., Betz, C., McKenna, A., & Mossar, M. (1986). Children's attitude toward the mentally ill as reflected in human figure drawings and stories. *Journal of the American Academy of Child Psychiatry, 25*(5), 680-686.
- Pound, A. (1996). Parental affective disorder and childhood disturbance. In M. Gopfert, J. Webster & M. Seeman (Eds.), *Parental psychiatric disorder: Distressed parents and their families* (pp. 201-218). Cambridge: University Press.
- Pretis, M., & Dimova, A. (2008). Vulnerable children of mentally ill parents: towards evidence-based support for improving resilience. *British Journal of Learning Support, 23*(3), 152-159.
- Ramon, S., Healy, B., Renouf, N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal Social Psychiatry, 53*(2), **108-122**.
- Reupert, A., & Maybery, D. (2007a). Families affected by parental mental illness: A multiperspective account of issues and interventions. *American Journal of Orthopsychiatry, 77*(3), 362-369.
- Reupert, A. & Maybery, D. (2007b). Strategies and issues in supporting children whose parents have a mental illness within the school system. *School Psychology International, 28*(2) 195-205.
- Reupert, A., & Maybery, D. (2009a). A "snapshot" of Australian programs to support children and adolescents whose parents have a mental illness. *Psychiatric Rehabilitation Journal, 33*(2), 125-132.
- Reupert, A., & Maybery, D. (2009b). Fathers experience of parenting with a mental illness. *Families in Society: The Journal of Contemporary Social Sciences, 90*(1), 61-68.
- Reupert, A. & Maybery, D. (2010b). Families affected by parental mental illness: Australian programs, strategies and issues. The (missing) role of schools. *International Journal for School-Based Family Counseling, Volume II*. Retrieved from

<http://www.schoolbasedfamilycounseling.com/docs/IJSBFC%20-%20Volume%20II%20-%20Reupert%20and%20Maybery.pdf>

- Reupert, A. E., & Maybery, D. (2010 a). "Knowledge is power": Educating children about their parent's mental illness. *Social Work in Health Care*, 49(7), 630-646. doi: 10.1080/00981380903364791
- Riebschleger, J. (2004). Good days and bad days: The experiences of children of a parent with a psychiatric disability. *Psychiatric Rehabilitation Journal*, 28(1), 25-31.
- Risley-Curtiss, C., Stromwall, L., Hunt, D., & Teska, J. (2004). Identifying and reducing barriers to reunification for seriously mentally ill parents involved in child welfare cases. *Families in Society*, 85(1), 107-118.
- Rushforth, H. (1999). Practitioner review: Communicating with hospitalised children: Review and application of research pertaining to children's understanding of health and illness. *Journal of Child Psychology and Psychiatry*, 40, 683-691.
- Rutter, M. (1985). Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry*, 147, 598-611. doi:10.1192/bjp.147.6.598
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57(3), 316-331.
- Rutter, M. (2004). Pathways of genetic influences on psychopathology. *European Review*, 12(1), 19-33.
- Rutter, M. (2006). Implications of resilience concepts for scientific understanding. *Annals New York Academy of Sciences*, 1094, 1-12.
- Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). "What if they ask how I got it?" Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy and Planning*, 23, 36-42. doi:10.1093/heapol/czm040
- Savvidou, I., Bozikas, V. P., Hatzigeleki, S., & Karavatos, A. (2003). Narratives about their children by mothers hospitalized on a psychiatric unit. *Family Process*, 42(3), 391-402. doi:10.1111/j.1545-5300.2003.00391.x
- Scherer, D. G., Melloh, T., Buyuck, D., Anderson, C. & Foster, A. (1996). Relation between children's perceptions of maternal mental illness and children's psychological adjustment. *Journal of Clinical Child Psychology*, 25(2), 156-169.
- Schnittker, J. (2008). An uncertain revolution: Why the rise of a genetic model of mental illness has not increased tolerance. *Social Science & Medicine*, 67(9), 1370-1381.
- Schulze, B., & Angermeyer, M. C. (2005). What is schizophrenia? Secondary school students' associations with the word and sources of information about the illness. *American Journal of Orthopsychiatry*, 75(2), 316-323.
- Secker, J., Armstrong, C., & Hill, M. (1999). Young people's understanding of mental illness. *Health Education Research: Theory and Practice*, 14(6), 729-739.

- Secunda, V. (1997). *When Madness Comes Home: Help and Hope for the Children, Siblings, and Partners of the Mentally Ill*. New York, NY: Hyperion Books.
- Sedley, B. P. (2002). *His brain has just gone haywire: The development of children and young people's concepts of mental illness* (Doctoral dissertation, Victoria University of Wellington, New Zealand). Retrieved from <http://researcharchive.vuw.ac.nz/bitstream/handle/10063/509/thesis.pdf?sequence=1>
- Siegler, R. S., Deloache, J. S., & Eisenberg, N. (2005). *How children develop*. USA: Arizona State University.
- Senn, T. E., & Carey, M. P. (2008). HIV, STD, and Sexual Risk Reduction for Individuals with a Severe Mental Illness: Review of the Intervention Literature. *Current Psychiatry Reviews*, 4(2), 87-100.
- Shachnow, J. (1987). Preventative intervention with children of hospitalized psychiatric patients. *American Journal of Orthopsychiatry*, 57(1), 66-77.
- Sharp, D., Hay, D. F., Pawlby, S., Schmücker, G., Allen, H., & Kumar, R. (1995). The impact of postnatal depression on boys' intellectual development. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 36(8), 1315-1336.
- Siegel, N., & Peterson, C. C. (1999). Becoming mindful of biology and health: An introduction. In N. Siegal & C. C. Peterson (Eds.), *Children's Understanding of Biology and Health* (pp. 1-19). New York, NY: Cambridge University Press.
- Smith, M. (2004). Parental mental health: Disruptions to parenting and outcomes for children. *Child and Family Social Work*, 9, 3-11.
- Smith, M. J. & Greenberg, J. S. (2008). Factors contributing to the quality of sibling relationships for adults with schizophrenia. *Psychiatric Services*, 59, 57-62.
- Solomon, P., & Draine, J. (1996). Examination of grief among family members of individuals with serious and persistent mental illness. *Psychiatric Quarterly*, 67(3), 221-234.
- Solomon, G. E. A., Johnson, S. C., Zaitchik, D., & Carey, S. (1996). Like father, like son: Young children's understanding of how and why offspring resemble their parents. *Child Development*, 67(1), 151-171.
- Spitzer, R. L., & First, M. B. (2005). Classification of psychiatric disorders. *Journal of the American Medical Association*, 294(15), 1898-1899.
- Stallard, P., Norman, P., Huline-Dickens, S., Salter, E., & Cribb, J. (2004). The effects of parental mental illness upon children: A descriptive study of the views of parents and children. *Clinical Child Psychology & Psychiatry*, 9(1), 39-52.
- Stevenson, T. (2002). *The adult experience of growing up with a seriously mentally ill parent(s)*. Unpublished Masters dissertation. Curtin University of Technology, Perth, Australia.

- Styron, T. H., Pruetz, M. K., McMahon, T. J., & Davidson, L. (2002). Fathers with serious mental illnesses: A neglected group. *Psychiatric Rehabilitation Journal*, 25(3), 215-222.
- Taylor, L., & Ingram, R. (1999). Cognitive reactivity and depressotypic information processing in children of depressed mothers. *Journal of Abnormal Psychology*, 108(2), 202-210.
- Taylor, S. E., & Stanton, A. (2007). Coping resources, coping processes, and mental health. *Annual Review of Clinical Psychology*, 3, 129-153
- Thastum, M., Johansen, M. B., Gubba, L., Olesen, L. B. & Romer, G. (2008). Coping, social relations, and communication: A qualitative exploratory study of children of parents with cancer. *Clinical Child Psychology and Psychiatry*, 13(1), 123-138. doi: 10.1177/1359104507086345
- Thomas, L. J., & Kalucy, R. S. (2002). Parents with mental illness: A qualitative study of the effects on their families. *Journal of Family Studies*, 8(1), 38-52.
- Thomas, L., & Kalucy, R. (2003). Parents with mental illness: Lacking motivation to parent. *International Journal of Mental Health Nursing*, 12(2), 153-157.
- Valiakalayil, A., Paulson L. A., & Tibbo, P. (2004). Burden in adolescent children of parents with schizophrenia: The Edmonton High Risk Project. *Social Psychiatry & Psychiatric Epidemiology*, 39, 528–535. doi: 10.1007/s00127-004-0778-9
- Veldtman, G. R., Matley, S. L., Kendall, L., Quirk, J., Gibbs, J. L., Parsons, J. M., & Hewison, J. (2000). Illness understanding in children and adolescents with heart disease. *Heart*, 84, 395–397.
- Australian Infant Child Adolescent and Family Mental Health Association. (2004). *Principles and Actions for Services and People Working with Children of Parents with a Mental Illness*. Stepney, SA: Australian Infant Child Adolescent and Family Mental Health Association Ltd.
- Department of Health. (2007) *Families where a parent has a mental illness: A service development strategy*, Melbourne, Victoria: Victorian Government, Department of Human Services
- Wahl, O.F. (2002). Children's views of mental illness: A review of the literature. *American Journal of Psychiatric Rehabilitation*, 6, 134-158. doi:10.1080/10973430208408430
- Walsh, J. (2009). Children's understanding of mental ill health: Implications for risk and resilience in relationships. *Child & Family Social Work*, 14, 115-122.
- Walsh, J., Schofield, G., Harris, G., Vostanis, P., Oyeboode, F., & Coulthard, H. (2009). Attachment and coping strategies in middle childhood children whose mothers have a mental health problem: Implications for social work practice. *British Journal of Social Work*, 39, 81-98. doi:10.1093/bjsw/bcm090

- Wang, A. R., & Goldschmidt, V. V. (1996). Interviews with psychiatric inpatients about professional intervention in regard to their children. *Acta Psychiatrica Scandinavia*, *90*, 459-465.
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new method for assessing the cognitive representation of illness. *Psychology and Health*, *11*, 431-445.
- White, C. L., Nicholson, J., Fisher, W. H., & Geller, J. L. (1995). Mothers with severe mental illness caring for children. *Journal of Nervous and Mental Disease*, *183*(6), 398-403.
- Young, B., Dixon-Woods, M., Windridge, K. C., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *British Medical Journal*, *326*, 305-310.

Appendices

Appendix A: Advertisement wording for ARAFMI and MIFSA newsletters

Appendix B: Information sheet for parent as participant

Appendix C: Information sheet for parent about their child as a participant

Appendix D: Information sheet for child as participant

Appendix E: Consent form for parent as participant

Appendix F: Consent form for parental consent for child participation

Appendix G: Consent form for older child as participant

Appendix H: Consent form for younger child as participant

Appendix I: Broad interview schedule and prompts

Appendix J: Further detail regarding Piaget and Vygotsky's theories

Appendix K. Table showing the non-COPMI studies included in the review within Chapter Four

Appendix L. Table showing the COPMI studies included in the review within Chapter Four

Appendix A: Advertisement wording for ARAFMI and MIFSA newsletters

Research Study - Participants wanted

Are you a parent and do you also have a mental illness?

Parents living with a mental illness and their children are sought for a University of Adelaide study into how parents and children understand parental mental illness.

The purpose of this research is to examine the different ways in which children and their parents understand mental illness. Research such as this is needed to give insight into how children might be better educated about mental illness. This research is also important as it will explore parents own views about educating their children.

To participate in this study you will need to be a parent (with at least one child in your care) and have a mental illness (such as anxiety, depression, bipolar disorder, schizophrenia or a personality disorder). Children over the age of 7 years are also invited to participate.

The study involves taking part in a short interview. There are no right or wrong answers and each participant will be paid \$20 for their time and effort. All responses will be anonymous.

Interviews are being conducted in South Australia, New South Wales and Western Australia.

If you would like to take part in the study, or if you have any questions, please contact Brooke Ferguson on (08) ##### or brooke.ferguson@adelaide.edu.au

Appendix B: Information Sheet for parent as participant



Information about participating in a study about parent and child mental illness beliefs

My name is Brooke Ferguson and I am a PhD student at the University of Adelaide. I am doing a research project about the ways in which parents and their children understand parental mental illness.

What will be involved?

This project will involve a short interview/discussion (approximately 30 minutes) with yourself about your thoughts on aspects of your illness. The interview will be tape recorded. The interview can take place at a time and place that best suits you.

Who can take part in this study?

If you are a parent and also have a mental illness you can take part in this study. You must have at least one child in your care in order to participate. You have to agree to take part in order for the interview to be conducted. Even if you decide to take part you have the right to withdraw from the project at any time.

Will I be identified as a research participant?

No, you cannot be identified through the research. No report from this project will identify you. When the interviews are written up any identifying information about you, such as your first name or surname, will be removed.

How will the information be used?

The information you share during the interview will be written up and included in a PhD thesis. The information may be published in journals however the information will be a mix of all participants' responses. The interview tapes will be kept in a locked filing cabinet at the University of Adelaide and will only be accessed by the researchers. It is hoped that research such as this will help in developing programs to better educate children about illness.

Who should I contact if I have any questions or if I wish to withdraw from the study at a later date?

If you have any questions or concerns regarding this study or if you wish to withdraw from the study at any time please contact either of the two researchers listed below:

Brooke Ferguson (PhD candidate)
Email: brooke.ferguson@adelaide.edu.au
Telephone: #####

Dr Lisa Kettler (Supervisor)
Telephone: (08) #####

If you have any concerns regarding this study please refer to the complaints procedure form included with this information sheet.

Appendix C: Information Sheet for parent about their child as a participant



Information for parents about their child participating in a study about mental illness beliefs

My name is Brooke Ferguson and I am a PhD student at the University of Adelaide. I am doing a research project about the ways in which children understand illness. I am asking you and your child if it is ok for your child to take part in this research.

What will be involved?

This project will involve a short interview/discussion (approximately 20 minutes) with your child about their thoughts on mental illness. The interview can take place at a time and a place that suits you and your child.

Does my child have to take part?

No, your child does not have to take part. Both you and your child have to agree to take part in order for the interview to be conducted. Even if you and your child decide for your child to take part you both have the right to withdraw from the project at any time.

Will my child be identified as a research participant?

No, your child cannot be identified through the research. No report from this project will identify your child. When the interviews are written up any identifying information about your child, such as their first name or surname, will be removed.

How will the information be used?

The information your child shares during the interview will be written up and included in a PhD thesis. The information may be published in journals however the information will be a mix of all participants' responses. The interview tapes will be kept in a locked filing cabinet at the University of Adelaide and will only be accessed by the researchers. It is hoped that research such as this will help in developing programs to better educate children about illness.

Who should I contact if I have any questions or if I wish to withdraw from the study at a later date?

If you have any questions or concerns regarding this study or if you wish to withdraw from the study at any time please contact either of the two researchers listed below:

Brooke Ferguson (PhD candidate)
Email: brooke.ferguson@adelaide.edu.au
Telephone: #####

Dr Lisa Kettler (Supervisor)
Telephone: (08) #####

If you have any concerns regarding this study please refer to the complaints procedure form included with this information sheet.

Appendix D: Information Sheet for child as participant



Information to help you decide about taking part in the research project: Children's understanding of illness

My name is Brooke Ferguson and I am a PhD student at the University of Adelaide. I am doing a research project about the ways in which children understand their parent's illness. I am asking you and your parent if it is ok for you to take part in this research.

What is the project about?

We are trying to find out about how children think about their parent's illness. Finding out information about this could help us to make programs which will help other children understand illness.

What will I have to do if I take part?

I will visit you for an interview at a place where you feel comfortable. You will be asked some questions about illness. The interview will take about 20 minutes. The interview will be taped on a tape recorder so that I don't have to write down the things that you say. Everyone who does this study will be given \$20 to thank them for their time.

Do I have to take part in the research?

No, you don't. If you don't want to take part, that's ok. It's up to you. Even if you take part at the beginning, you can change your mind and choose not to take part later on. All you need to do is tell the researcher that you don't want to take part in the research any more. You can also decide not to answer any questions you don't want to. That is ok as well.

Will anyone know that I am taking part or hear about what I tell you?

No, no-one will know what information you gave the researcher. You can tell them whatever you want and no one will know it came from you. When I listen to the tape of your interview later and write down the things you said I will make sure your name isn't written down so no-one will know it was you.

What will happen to the information I tell you?

The information you tell us will only be used by the researcher. No-one else will be allowed to use the information. The information will be used with information from other young people in reports and papers about the research. No one will be able to tell that it is you who has given me the information. The interview tapes will be kept in a locked filing cabinet at the University of Adelaide and will only be listened to by Brooke Ferguson.

What do I need to do?

If you agree to take part in this project, please let your Mum, Dad or the person who cares for you know so they can fill in a consent form to let you take part. If you have any questions you can ring the researchers or email them on the details below.

Brooke Ferguson (PhD candidate)
Email: brooke.ferguson@adelaide.edu.au
Telephone: (08) #####

Dr Lisa Kettler (Supervisor)
Telephone: (08) #####

Appendix E: Consent from for parent as participant

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE
STANDARD CONSENT FORM
FOR PEOPLE WHO ARE PARTICIPANTS IN A RESEARCH PROJECT

1. I, *(please print name)*

consent to take part in the research project entitled:

Child and parental understanding of parental mental illness

2. I acknowledge that I have read the attached Information Sheet entitled:

Information about participating in a study about parent and child mental illness beliefs

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....

(signature) *(date)*

WITNESS

I have described to *(name of participant)*

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: PhD student

Name: Brooke Ferguson

.....

(signature) *(date)*

Appendix F: Consent Form for parental consent for child participation

Consent form for your child to participate in a research project

1. I,(please print your name)

consent to allow(please print your child's name)

to take part in the research project entitled:

Child and parental understanding of parental mental illness

2. I acknowledge that I have read the attached Information Sheet entitled:

Information for parents about their child participating in a study about mental illness beliefs

and have had the project, as far as it affects(your child's name)
fully explained to me by the research worker. My consent is given freely.

IN ADDITION, I ACKNOWLEDGE THE FOLLOWING ON BEHALF OF

.....(your child's name)

3. Although I understand that the purpose of this research project is to give insight into how children understand illness, it has been explained to me that involvement may not be of any benefit to him/her.

4. I have been given the opportunity to have a member of his/her family or friend present while the project was explained to me.

5. I have been informed that the information he/she provides will be kept confidential.

6. I understand that he/she is free to withdraw from the project at any time and that this will not affect his/her involvement with any support programs offered to him/her.

7. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....Parent/Guardian
(signature and please indicate relationship)

.....
(date)

WITNESS

I have described to (name of parent/guardian)

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: PhD student

Name: Brooke Ferguson

.....
(signature)

.....
(date)

Appendix G: Consent Form for older child as participant

Consent form to take part in a study about the way children think about mental illness

I (please write your name)

- ★ agree to take part in a study about the way children think about illness. My parent/person who cares for me has agreed for me to take part in the research. I understand that the research is trying to find out about how children think about mental illness.
- ★ I have read the information sheet called '**Information to help you decide about taking part in the research project: Children's understanding of mental illness**'
- ★ I can choose not to take part in the research at any time, including at the end of the research. If I change my mind I will let the researcher know. I understand that I don't have to answer the questions that are asked if I don't want to. I won't get into trouble if I choose not to answer a question or if I stop taking part in the research.
- ★ I understand that by taking part in the research I will be interviewed and asked some questions about illness. I understand that the interview will be taped.
- ★ If anything I talk about during the research makes me feel upset I will let the researcher know and the research will be stopped. My parents/person who cares for me will be told and I will be given the names of people I can talk to about what is making me upset, if that is what I want to do.
- ★ I understand that my answers are confidential. Nothing that can identify me, like my name or address, will be used in the research. That means that no-one will know where the information came from and no-one will be able to connect it to me.
- ★ I understand the information I provide will be written up as a report and the tapes of the interview will be kept in a locked filing cabinet at the University of Adelaide.
- ★ I will be given a copy of this consent form to keep.

Name of participant:

Signature of participant:

Date:

I have described to (name of child)

the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in project: PhD student

Name: Brooke Ferguson

.....

(signature)

(date)

Appendix H: Consent form for younger child as participant

Consent form to participate in the study about the way children think about mental illness.

I (please write your name) agree to take part in a project about how children think about their parent's mental illness. My parent or carer has agreed for me to take part in the project as well.

I know that:

Tick if you agree

★ It is ok for me to stop being a part of the project whenever I want to.	
★ A researcher will talk to me about what I think about mental illness.	
★ While we are talking our voices will be tape recorded so the researcher can remember what we have said.	
★ If anything we talk about makes me feel upset, the project will be stopped. The researcher will tell my parent/carer. We will be given the names of people I can talk to about what is making me upset if that is what I want to do.	
★ What I say during the project is special and belongs to me. The researcher won't tell anyone else that I took part.	

I will be given a copy of this form to keep. If I have any questions about the project I can contact either:

Brooke Ferguson
Phone: #####

or

Dr Lisa Kettler
Phone: #####

If I have a complaint about the project I can contact the telephone number on the next page.

Name of participant:

Signature of participant:

Indicate if verbal consent []

Name of researcher: Brooke Ferguson

Signature of researcher:

Date:

Appendix I: Broad interview questions and prompts

Parent questions

Age:

Illness:

How many children do you have?

How long have you been ill for/has the other parent been ill for?

Questions relating to how parents understand their illness/illness of the other parent

Identity

What do you call it?

What is the first sign that you are getting sick/first sign the other parent is getting sick?

How do you know that you're getting sick/other parent is getting sick?

What does it make you do, how does it make you different/how does it make the other parent different?

Cause

How do you think you got sick in the first place/other parent got sick in the first place?

Timeline

How long do you think you'll be sick for/other parent will be sick for?

Consequences

Does your illness make it difficult to do anything/difficult for other parent to do anything?

Controllability

Do you have control over your illness at all/other parent have control over their illness?

Does anyone else have control over your illness/over the other parent's illness?

What sort of treatment do you have for your illness/ other parent's illness? Does it help?

Knowledge of illness

Do you feel that you understand your illness enough/understand other parent's illness enough?

Where did you learn the most about your illness/other parent's illness?

Parent views on how their children understand their illness

Do your children know about your illness/ other parent's illness?

(if 'yes' then)

Who told your children about your illness/ other parent's illness?

What did they tell them?

How was it explained to them?

Why did they tell them?

When did they tell them (child's age, stage of illness)?

What was their reaction when they were told?

What do you think they understand about your illness/ other parent's illness?

Did your children have any questions about the illness?

When do you believe that the illness should be explained?

(if 'no' then)

Why haven't you told them?

Who do you think should be responsible for explaining the illness to them?

How would you like it explained to them?

Would you like your child to be told about your illness/ other parent's illness?

When should the illness be explained?

Child questions

Age:

Sibling order:

Identity

What is your parent's illness? What does it make her/him do, how do you know that she/he's got it?

What do you call it?

What is the first sign that your parent is getting sick? How do you know she/he is sick?

How is she/he different?

Cause

How did your parent get the illness in the first place? Why do you think your parent got sick?

What makes your parent sick? Why do you think your parent keeps getting sick?

Timeline

How long is your parent's illness going to last?

When will it go away?

Do you think the illness will go away sometime in the future?

What do you think will make it go away?

What makes your parent's illness better and what makes it worse?

Consequences

In what ways does your Mum/Dad's illness make things different in your family compared to other families?

In what ways does your Mum/Dad's illness make things hard for them and/or for you?

What are the best things about your Mum/Dad's illness?

What are the worst things about your Mum/Dad's illness?

Controllability

Is there anything your parent can do that makes them get better?

Does your parent have any treatment or take medicine to help with her/his illness? If yes, what does it do?

Is there anything anyone else can do that helps your parent get better?

Knowledge of illness

Do you think that you understand your parent's illness well?

Where did you find out most of the information about your parent's illness?

Do you speak to anyone (teacher, friend, relative) about your parent's illness?

Did you know anything about (the illness) before your parent had it?

How did you find out your parent was sick? Who told you? When?

Is there more information you think you should know about your parent's illness or are you happy knowing what you know?

Appendix J: Further detail regarding Piaget and Vygotsky's theories

Further information regarding the theories of Piaget and Vygotsky

Piaget's theory of child development is generally labelled as a constructivist theory. This refers to the idea that a child actively constructs their knowledge independently and from their own experience (Siegler, Deloache & Eisenberg, 2003). As outlined within Siegler, Deloache and Eisenberg's (2003) comprehensive text on development, Piaget's theory posits four stages of child development: Sensorimotor (from birth to the age of 2 years), Preoperational (from ages 2 to 7 years), Concrete Operational (from ages 7 to 12 years) and Formal Operational (from 12 years and older). Briefly, the Sensorimotor stage encompasses the sensory and motor skills displayed by infants. Their cognitive abilities are based in the here and now. The Preoperational stage for children involves children experiencing language and mental imagery. Piaget posited that within this stage children are unable to think in consistent or logical ways. Within the Concrete Operational stage children develop the ability to think logically and consistently although they are unable to think in an abstract manner. The final stage, the Formal Operational stage encompasses skills such as the ability to think abstractly and hypothetically.

Piaget's stage theory of child development has been criticised for focusing on cognitive deficit and the limitations of what children are able to know at each stage, rather than what they do know (Rushforth, 1999). There is the assumption, within Piaget's theory, that children at younger ages are only capable of limited understanding of illness due to cognitive immaturity. As a result, it is suggested that children's understanding of illness can only develop into a complete understanding as a result of increased chronological age (Rushforth, 1999).

The child development theories of Vygotsky have often been viewed as the alternative to the Piagetian view. Vygotsky's theory comes from a sociocultural approach (Siegler, Deloache & Eisenberg, 2003). Of primacy in sociocultural theories of cognitive development is the idea that

children are social beings, embedded in a social world, continuously influenced by culture and their own context.

Like Piaget, Vygotsky also recognised that knowledge and understanding in children can be limited. Vygotsky stated that this limitation was not limited by chronological age, rather children can be assisted by those around them (within their sociocultural context) to develop their knowledge further. Vygotsky's theories posit that children's cognitive development does not develop within the bounds of concrete stages. Instead of cognitive development being universally experienced as specific stages which are stable across cultures, Vygotsky suggested that the unique attributes of a culture influence the children within that sociocultural environment (Siegler, Deloache & Eisenberg, 2003).

Sociocultural theorists, such as Vygotsky posit that there are three main principles that work to assist cognitive development in children (Siegler, Deloache & Eisenberg, 2003). Briefly, *Intersubjectivity* refers to the effect of two people focussing on, or communicating about, the same topic and the mutual understanding which results from this. *Social Scaffolding* refers to the assistance more knowledgeable people can provide to children to think at a level higher than they could achieve alone. Scaffolding by an adult is generally better quality than scaffolding provided by other children. The *Zone of Proximal Development*, as mentioned within this thesis, is concerned with the child's ability to perform a task, or understand a concept independently. In addition, the zone is concerned with the child's highest level of ability achievable when receiving targeted support and guidance (Siegler, Deloache & Eisenberg, 2003). Each of these three concepts work to support and develop children's understanding. They suggest that, contrary to Piaget's stage view, children's understanding can be considerably enhanced with the right supports in place (Rushforth, 1999)

Appendix K. Table showing the non-COPMI studies included in the review within Chapter Four

Author (year)	Data collection	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Sample origin	Country	Disorder
Maas, Maracek and Travers (1978)	Vignettes, interview, rating scale	Both	Not stated	7-11	60	School	USA	Range of mental illness symptoms
Callan, Wilks & Forsyth (1983)	Questionnaire	Both	Not stated	16-17	277	School	Papua New Guinea, Australia	Mental illness
Poster, Betz, McKenna and Mossar (1985)	Human figure drawings and stories	Both	Content analysis	8-11	168	School	USA	Mental illness
Poster (1992)	Questionnaire/vignette	Qualitative	Content analysis	8-11	168	School	USA	Depression, anxiety, schizophrenia
Secker, Armstrong & Hill (1999)	Focus group, individual semi-structured interviews	Qualitative	Thematic analysis	12-14	120	School	Scotland	Mental illness
Bailey (1999)	Questionnaire	Both	Not stated	11-17	106	Lecture	UK	Mental illness
Sedley (2002) Unpublished thesis	Focus groups	Qualitative	Thematic analysis	6-18	99	School	New Zealand	Mental illness
Watson et al (2004)	Questionnaire	Quantitative	Frequencies, means, t-tests	6,7,8th grade	1566	School	USA	Depression, mental illness
Schulze & Angermeyer (2005)	Survey, open ended questions	Both	Not stated	16	293	School	Germany	Schizophrenia
Fox, Buchanan-Barrow, Barrett (2007)	Semi structured interview, card selection task	Quantitative	Hi-log linear analysis	5-11	89	School	UK	Depression, schizophrenia, anorexia
Fox, Buchanan-Barrow, Barrett (2010)	Semi structured interview, card selection task	Quantitative	Hi-log linear analysis	6-11	240	School	UK	Depression & anorexia

Appendix L. Table showing the COPMI studies included in the review within Chapter Four

Author (year)	Data collection	Qualitative or quantitative	Data analysis	Age group (approx)	Sample size	Sample origin	Country	Disorder
Garley, Gallop, Johnston & Pipitone (1997)	Interview (COPMI)	Qualitative	Not stated	11-15	6	Outpatient clinic	USA	Mood Disorder
Bourke (1998) Unpublished thesis	Questionnaire /open ended question (ACOPMI)	Both	Not stated	Retrospective	30	Advert	USA	Range of mental illnesses
Handley, Farrell, Josephs, Hanke & Hazelton (2001)	Interview or focus group (COPMI)	Qualitative	Thematic analysis	11-15	4	Mental health services	Australia	Major affective disorder
Riebschleger (2004)	Secondary analysis of interview data (COPMI)	Qualitative	Thematic Analysis	5-17	22	Mental health services	USA	Mood disorders, schizophrenia PTSD
Valiakalayil, Paulson & Tibbo (2004)	Interview (COPMI)	Both	Not stated	13-18	13	Inpatient unit	USA	Schizophrenia
Cogan, Riddell & Mayes (2005b)	Individual semi-structured interview (COPMI, Non-COPMI)	Qualitative	Thematic analysis	12-17	40	Mental health services and groups	UK	Affective illness
Finney & Falkov (2009)	Interview (COPMI)	Qualitative	Not stated	8-12	Not stated	Hospital/health service	Australia	Range of parental illnesses