



MONASH University

THE BIDIRECTIONAL IMPACT OF CO-EXISTING MENTAL ILLNESS IN FAMILIES

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This thesis includes four original papers published in peer reviewed journals and no submitted publications. The core theme of the thesis is the bidirectional impact of mental illness in families. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the School of Rural Health under the supervision of Professor Darryl Maybery.

(The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.)

In the case of *chapter 4 section 4.1.2 and section 4.2.2 2, and chapter 6 section 6.1.2 and section 6.2.2* my contribution to the work involved the following:

Thesis chapter	Publication title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) Nature and % of co-author's contribution*	Co-author(s), Monash student Y/N*
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I have renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

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I hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

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Bidirectional Impacts, Child, Child and Adolescent Mental Health Service, Children, Community Mental Health Service, Cross-sectional Study, Family, Mental Illness, Mother, Outcome Measures, Parent, Perspectives, Prevalence.

Abstract

A great deal is now known about the impact of parental mental illness on children and similarly extensive research has outlined the impact on parents of having a child with a disability or developmental disorder. However, few studies have considered the bidirectional impacts of the interaction between a child and parent's mental health.

This thesis has sought to examine the previously un-researched interplay of mental illness in families. The thesis has incorporated four papers focusing on the key research questions: prevalence of mental illness in parents of children attending a regional mental health service; impacts of parental mental illness on children's recovery trajectory; how parents with a mental illness experience life in a family where a child has a mental illness; and how children with a mental illness experience life in a family with a parent with a mental illness.

The four studies were conducted using a mixed methods design outlined in chapters 3 and 5. To achieve an optimal outcome the research used a concurrent triangulation design approach in its methodology to assist with corroborating the findings. The first two papers utilised quantitative data from a regional child mental health service. The second two papers utilised qualitative data from 37 families attending a child mental health service covering 42,000 square kilometres of rural and semirural Australia. In each family a parent and a child presented with a validated mental illness. The first two papers sought to establish prevalence and impact through routinely gathered data in mental health services. The second two papers sought to gather personal narratives of parents and children in families where there was co-existing mental illness.

As limited research was available on the extent (prevalence) of parental mental illness where a child attended a regional child and adolescent mental health service (CAMHS), the first study (chapter 4.1.2) used a cross-sectional study design involving a case record review and clinician-completed questionnaire. It was found that over three quarters of these children were living with a parent with a mental illness. The study also identified a number of other factors impacting these families with social isolation of greatest significance. Having established that children attending mental health services were likely to live with a parent with a mental illness, the second study (chapter 4.2.2) examined whether living with a parent with a mental illness impacted on the symptomology of a child who attended a CAMHS. This study collected data from routine, CAMHS clinician-recorded, outcome measures of all CAMHS clients over a six-month period. Paired samples t-tests compared improvement in the children's outcome measure scores for those children living with a parent with a

mental illness and those children living with a parent with no mental illness. Trend findings suggested parental mental illness impacted on overall child outcomes, and this influence remained irrespective of clinical intervention.

With prevalence and impact established, the subsequent papers sought to examine the lived experiences of parents and children from the same families. The third study (chapter 6.1.2) utilised an interpretative phenomenological approach to examine the understandings of parents with a mental illness living with a child with a mental illness. Individual narrative interviews followed by thematic analysis revealed some themes as consistent with previous research along with several new and innovative ideas specific to the family type. The final study (section 6.2.2) explored the perspectives of life for a child with a mental illness living with a parent with a mental illness. These children's themes centred on the additional burden of living in an environment with co-existing mental illness. They also highlighted their experiences of interventions in isolation to their mentally ill parent who, when they were well, they frequently provided care for. In common with their parents, issues of school and stigma were stressed. From the perspective of children in these families the issues raised were frequently amplified because both the child and parent struggled with mental illness. The third and fourth studies are then discussed including new ideas for family interventions, where there is co-existing mental illness along with suggestions for service improvement, and development, to better support this family type.

This thesis adds new knowledge to the mental health literature, and to child services in particular, by providing empirical evidence as to the extent of parental mental illness where children attend a regional CAMHS. The findings also show that there is a likely association between a parent's mental illness and the symptomology of their child. Unlike any other research this study has, through individual narratives, made an essential link between the bidirectional influences of mental illness experienced by both parents and children. Through the discourse significant gaps in the intervention and integration of service delivery for these families has been identified. Bidirectional impacts of mental illness are a rare consideration in policy and clinical intervention with involvement taking a mainly unidirectional approach. The findings highlight the importance in service delivery of addressing the micro level of the interaction between children and parents in order to effectively improve the whole family system. What is more such a focus on bidirectional influences would be a major first step in breaking the cycle of intergenerational mental illness.

The findings from this research have critical implications for clinical practice and policy in terms of interventions, focus and collaboration between those providing services for families.

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List of abbreviations

ADHD – Attention deficit hyperactivity disorder

ASD – Autism spectrum disorder

CAMHS – Child and adolescent mental health service

CGAS – Children’s Global Assessment Scale

CMH – Community mental health

CMI – Client Management Interface

COPMI – Children of Parents with a Mental Illness

Disability – Physical or mental

FaPMI – Families where a parent has a mental illness

HoNOSCA – Health of the Nation Outcome Scales Child and Adolescent

ICD10 – International Statistical Classification of Diseases and Related Health Problems

PDD – Pervasive developmental disorder

PPD – Post-partum depression

SDQ – Strengths and Difficulties Questionnaire

Statement of original authorship declaration

This thesis is an original work of my research and contains no material that has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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To my sons Jack and Brodie, your understanding through this journey has itself been an inspiration to me – thank you. To my partner Jonine for being so patient and for being there, encouraging and always keenly supporting a very special thank you - I owe you.

TO THESE VERY SPECIAL FAMILIES AND THE MANY OTHERS IN OUR COMMUNITIES WHERE CO-EXISTING MENTAL ILLNESS EXISTS, I PROMISE TO CONTINUE MY COMMITMENT TO CHALLENGING YOUR PREDICAMENT.

Signature: _____

Date: _____

Terminology

In this thesis:

CAMHS is defined as those services specifically assessing and/or treating children aged 0-18 years experiencing mental health difficulties.

The term *child* is defined as children and youth aged less than 18 years.

Child mental illness relates to a diagnosed mental illness as determined by a child and adolescent psychiatrist.

The term *mental illness* is used as an overarching term to cover the range of mental illnesses presented by children and parents and as classified through ICD10¹ (anxiety, depression, personality disorders, schizophrenic disorders, psychotic disorders and developmental disorders).

The term *parent* in this thesis is defined as a biological parent providing primary care for the child and may include one or more.

Parental mental illness relates to a diagnosed mental illness as determined by a psychiatrist, GP or clinical psychologist.

¹ ICD10 is the diagnostic tool used by the Australian Government for reporting purposes

Chapter 1: Introduction

It is estimated that between 15% and 23% of children worldwide live with a parent who has a mental illness (Maybery, Reupert, Patrick, Goodyear, & Crase, 2005; Leijdesdorff, van Doesum, Popma, Klaassen, & van Amelsvoort, 2017). The number of mental health patients who are parents has been estimated at between 12% (Jessop & De Bondt, 2012) and 45% (Gatsou et al., 2016). Similar rates were found in the census conducted by Howe, Batchelor, and Bochynska, (2009). A great deal is known about the impact of parental mental illness on children, with multiple studies having looked specifically at the many factors a child may experience because of their parents' mental illness (Beardslee, Versage, & Gladstone, 1998; Hanington, Heron, Stein, & Ramchandani, 2012; Nicholson, Biebel, Williams, & Katz-Leavy, 2004; Reupert & Maybery, 2009; Reupert, Maybery, & Kowalenko, 2012; Shen et al., 2016). Compared to their peers, children living with a parent with a mental illness are at risk of behavioural and developmental difficulties as well as an increased chance of experiencing psychological problems (Reupert, Maybery, & Nicholson, 2015). In Australia Lawrence et al. (2015) found almost 14% of children in the 4 to 7-year age bracket have emotional or behavioural challenges. Longitudinal studies have shown that children of parents with a mental illness have a 41 to 77% risk of developing a mental illness or a serious socioemotional disorder (Van Doesum, Hosman, & Riksen-Walraven, 2005). A number of studies have also considered the impact of childhood developmental issues on parents (Diez Roux, 2007; Ludlow, Skelly, & Rohleder, 2012; Resch, Elliott, & Benz, 2012; Garbarski & Witt, 2013). Current research has focused on children with problems such as autism or those with developmental disorders without looking specifically at any comorbid mental health problems. The literature does highlight the emotional strain experienced by these parents (Bonis, 2016) and the likelihood of increased depression scores (Dykens, Fisher, & Taylor, 2014). It is through the research in the area of autism and developmental disorders that the discourse in relation to examining bidirectional impacts between children and parents begins.

It is extraordinary that there is no research on the bidirectional influences between parents and children where both the parent and child have a mental illness such as depression, anxiety or attention deficit hyperactivity disorder (ADHD). Indicators of these bidirectional influences are evident in the literature. For example, where adult children of parents with a mental illness have reported on their experiences, they report emotional abandonment and parentification issues as of primary concern (Murphy, Peters, Jackson, & Wilkes, 2011; Aldridge, 2006). Also, a number of studies have highlighted how maternal depression is linked to insecure attachment in children and a mother's poor

parenting skills (Hipwell, Goossens, Melhuish, & Kumar, 2000; Oyserman, Bybee, Mowbray, & Hart-Johnson, 2005; Badovinac et al., 2018).

Little is known about the mental health status of both a parent and their child when one or both are attending community mental health (CMH) services in Australia (Gatsou et al., 2016). Importantly a systematic audit using both clinician reports, verified and augmented through a case file audit, had never been conducted in Australia before. Furthermore, the experiences of parents with a mental illness and children with a mental illness in the same family have never been considered.

1.1 A PERSONAL DIVERSION

While my work has provided a rationale for this study my life growing up with a parent and a brother both with a mental illness has posed a number of unique challenges. I can relate firsthand to the struggles of family life. As the oldest of four children I took on a role that required me to remain strong when what I now know as bidirectional influences were occurring. As my mother's mental illness deteriorated my father withdrew more and more until at my mother's fourth bout of postpartum depression and psychosis he 'disappeared'. My father's absence initially through work left me with the responsibility of caring for my mother and my brothers; no easy task with one brother struggling with childhood schizophrenia. Each day I could see how my mother and brother would set each other off and each day in the home we existed in a complete state of high anxiety. Despite all that was happening behind closed doors the problems were a family secret. My grandfather helped a lot but we never spoke about it outside the home. Back then I was the principal liaison with the schools – not bad at 13 years. It was just accepted that things were different, and the older brother would 'deal with things'.

With responsibility came loss – loss of childhood and loss of friendships. There was also an inner loss of attachment and fear. When my mother disappeared for 3 months things at home were more settled. My brother's illness appeared to be more controlled and the tension at home was reduced. I continued to clean the house and help Grandad with the chores. My grandfather asked me the day before my mother returned home to do something special. So, at 15 years I made a special roast dinner. My mother appeared oblivious to the event as she walked through the door with her new friend who she met in hospital. I could never say for sure but the new friend seemed to be as unwell as my mother and this made my brother even worse with increased delusions and a significant deterioration in his speech.

My grandfather moved out with my two youngest brothers and left me to look after my mother and brother. Although I tried my best the underlying anxiety, stress and other emotional challenges became too much to bear and I ran away. So started my journey in the caring professions.

As I listened to the children and parents in this research, I knew I needed to keep an open mind and put aside any potential bias.

1.2 BACKGROUND

People will often joke about the ‘crazy’ family they grew up in (Dunn, 1993) but for many of those children who attend mental health services this is a daily reality. Initially working with child and adolescent mental health services (CAMHS) in the UK, moving to CAMHS in New Zealand and then working for CAMHS in Australia I was hearing the same story over and over. For a large number of children attending CAMHS they lived with a parent with a mental health problem. For a small minority a parent might receive psychiatric support from a CAMHS psychiatrist but these incidences were rare. Furthermore, working with children and families in the mental health arena it became apparent that the children frequently felt unheard within the family. A problem reported by many of these children was of feeling ‘a sense of disconnect’ between their mental illness and the mental illness of their parent. It was evident in discussions with children that they considered interventions to be individually focused with mostly little account being taken of wider family factors. Importantly there appeared to be a link between mental illness presenting in children and mental illness of parents, which went unrecognised or at least unmanaged in mental health services. From observations and anecdotal reports from families there appeared to be an ongoing interaction between a parent’s and a child’s mental illness. This idea had been reinforced by the commonly held belief in the community that one person’s mood can affect other people. Joiner and Katz (1999) described this as the contagion effect which was particularly pronounced with depression. In discussion with child and adult mental health clinicians it also became evident that many were unaware, or unfamiliar, with the extent and possible influences of co-existing mental illness in families. Beyond clinical issues this family cohort indicated they also struggled socially, describing more negativity from other people and organisations. Such negativity appeared to have further effects by limiting the families’ ability to seek and receive appropriate support and treatment. The question raised was how reliable and candid these assertions were. If this was in fact a reality for a lot of families attending CAMHS how many families would likely be having these types of experiences? Were just a few families affected or could there be many with a large number not being effectively supported? What were the actual experiences and were these common across families?

1.3 CONTEXT

A great deal is now known about the impact of parental mental illness on children with multiple studies having looked at these influences (Howe et al., 2009; Gunlicks & Weisman, 2008; Royal College of Psychiatrists, 2011; Göpfert, Webster, & Seeman, 2004; Maybery & Reupert, 2009; Meltzer, Gatward, & Ford, 2003; Gladstone, Boydell, Seeman, & McKeever, 2011; Barker, Copeland, Maughan, Jaffee, & Uher, 2012; Baker & Lees, 2014). Other studies have considered the impact of childhood developmental issues on parents focusing on children with problems such as autism and developmental disorders (Weiss, 2002; Morton, 2004; Diez Roux, 2007; Neely-Barnes & Dia, 2008; Meadan, Halle, & Ebata, 2010; Garbarski & Witt, 2013; Resch et al., 2012). There are no studies considering the impact of children's mental illness on parents. Bidirectional influences of mental illness are considered in the literature when examining developmental disorders but not when considering families where both a parent and child have a mental illness (Deater-Deckard, 1998; Lazarus & Folkman, 1985; Abbeduto et al., 2004; Garbarski & Witt, 2013; Hayes & Watson, 2013; Al-Gamal & Long, 2012; Kuusikko-Gauffin et al., 2013). This research has started to fill a very significant gap.

Both biology and environment play a role in the impact of parental mental illness on children. Research from a biological perspective has investigated genome imprinting. Halmoy et al. (2010) and Crespi and Badcock (2008) point to the expression between parental genes determining mental health as a key factor in the development of mental illness for children and adolescents (children). Bellingham-Young and Adamson-Macedo (2003) found that the fetal environment influences the life of children, particularly in relation to hormone and neuro-transmitter secretions that may affect later psychological health. It is clear that children of parents with a mental illness are at 'high-risk' for developing psychopathology (Wesseldijk et al., 2018; Middeldorp et al., 2016). While genetic vulnerabilities dominate the discussion, Walker and Diforio (1997) highlight a number of prenatal environmental and stress factors that might also influence fetal development. Feldman, Stiffman, and Jung (1987) found that where a parent had a serious mental illness the family would likely experience isolation, disruption in a child's schooling, poverty, housing problems and disorganisation. Van Doesum and Hosman (2009) identified the need for a better understanding of wider social and environmental factors versus the genetic factors impacting on mental health trajectories of children. However, risk factors are usually highly inter-correlated making the identification of determinants complicated (Abbott, Gumusoglu, Bittle, Beversdorf, & Stevens, 2018; Walker, 2002).

Ever since the young carer's projects², a feature of research has been the search for the voice and experience of children living with a parent with a mental illness. Cass, Smyth, Hill, Blaxland, and Hamilton (2010) looked specifically at the nature of parental illness and the impact of the caring role on the young person. In the longitudinal study of Australian children 40% of 14 to 15-year-olds had a caring role in their family (Longitudinal Study of Australian Children, 2017). Dearden and Becker (2004) estimate a third of young carers in the UK care for someone – usually a parent – with a mental illness. The views of children have been considered by a variety of writers with notable work done by Becker (2004) and McDonald (2008). Children who take on the role of carer are seen as being parentified assuming an adult role before they are emotionally ready (Jurkovic, 1997; Chase, 1999). What if more children in this role are seen to have forfeited their own needs?

Maybery, Ling, Szakacs, and Reupert (2005) highlighted that 'being a child of a parent who has a mental illness involves considerable risk to the child's secure attachment and long-term mental health. Parental mental illness places children at significantly greater risk of lower social, psychological and physical health as compared with children in families not affected by mental illness'. (p. 2). Compas, Langrock, Keller, Merchant, & Copeland, (2002) noted that depression is associated with substantial interpersonal demands and challenges for those living with people who have mental health conditions. Edhborg, Lundh, Seimyr, and Widström (2003) and Hosman, van Doesum, and van Santvoort (2009) found that children of depressed mothers have lower resilience, lower peer confidence and less persistence in play than the children of non-depressed mothers. Trimbos-Instituut (2007) talks of the harmful impact of stress, anxiety and substance use on the developing cognitive and emotional regulation of children leading to possible mental illness. With children taking on a caring role it would seem quite possible that their responsibilities and experiences would likely impact their mental health.

In the UK the focus of research has been on the subject of young carers – those children and adolescents³ living with a parent with mental illness. This gained momentum with funding from the Department of Health and Ageing to set up Young Carers Projects (YCP) in the 1980s. These projects were established to provide counselling, information and advocacy services for children (Dearden & Becker, 1995).

Following on from YCP there was the development of the children of parents with mental illness (COPMI) initiative (Cowling, 1999; Department of Health and Ageing, 2004). The initiative

² The purpose of the Young Carers Research Project was to research the number, characteristics and needs of young primary carers in relation to facilitating their social and economic participation in the community.

³ Both children and adolescents are now referred to as children to facilitate a clearer reading process

was started initially as a resource for workers before expanding to include material for parents and children. COPMI has expanded over the years now providing a number of eLearning resources and courses (COPMI, 2016). More recently information has been provided to a range of services supporting parents with a mental illness as well as providing information for parents and families. A challenge for many COPMI, particularly in Europe, had been the limited reach to children and the parental barriers that restricted children from accessing the resources.

Coupled with problems reaching children through parents Houlihan, Sharek, and Higgins (2012) determined that mental health nurses also have relatively low levels of education, knowledge and confidence in supporting practice that encompasses the children of parents who have mental illness. In a study of an adolescent inpatient unit by LeFrancois (2007) it was noted that ideas of youth participation were related to ideas of adult agendas and control issues rather than to issues of children's participation. Komulainen (2007) went further saying that the voice of children is infrequently taken into account when determinations are made by those choosing service delivery. In Australia, Maybery et al., (2005) were some of the few who had looked at the views of children living with a parent who had a mental illness.

Almost 14% of children and youth between the ages of four and 17 years have emotional or behavioural problems (Lawrence et al., 2015), and approximately nine% of Australian children aged 0-14 years are thought to have long-term mental health problems (Australian Institute of Health and Welfare [AIHW], 2010). Kessler, Chiu, Demler, & Walters, (2005) reports that 50% of mental health disorders start before the age of 14 years and 25% of those children will have a higher 'burden of disease' associated with their disorder.

For adults in Australia it is reported that 45% will experience a mental health problem in their lifetime (AIHW, 2012). As such, based on Australian population estimates, 23.3% of children will have a parent with a mental illness (Maybery et al., 2005). As noted earlier the impact of parental mental illness on children has been well documented (Beardslee et al., 1998; Nicholson & Henry, 2003; Hanington, Heron, & Ramchandani, 2012 Reupert et al., 2012; Reupert & Maybery, 2009). Both Maybery, Reupert, Goodyear, Ritchie, and Brann (2009) and Meltzer, Gatward, and Ford (2003) report that there is a two to three times greater chance of a child developing a mental illness if their parent has a mental illness. Rasic, Hajek, Alda, and Uher (2014, p. 28) highlighted that children of parents with mental illness have a 32% risk of 'developing mental illness themselves', increasing 1.6-fold in parents with schizophrenia. Furthermore, Maybery et al., (2009) found that such children generally have more difficulty in all aspects of their lives. The impact on children who have (a) parent(s) with a mental illness can be pervasive and influence a multitude of factors including: peer

relationships, school performance, social interaction and day-to-day living (Feldman, Stiffman, & Jung, 1983; Maybery, Reupert, Patrick, Goodyear, & Crase, 2005; Reupert & Maybery, 2007). It is also important to be aware that these children are at an increased risk of developing a mental illness (Cowling, 1999; Rutter, Silberg, O'Connor, & Simonoff, 1999). While the risks exist, it is necessary to remain cognisant that not all children of parents with a mental illness will develop mental health problems themselves (Anthony, 1986; Rasic et al., 2014) and children are socially competent so able to cope and adjust (Hutchby & Moran-Ellis, 1998).

Parenting can be difficult at the best of times, and it is undoubtedly more demanding for parents with a mental illness. Stress from the parenting role may affect parental mental health and conversely the parent's mental illness could influence their capacity to parent (Royal College of Psychiatrists, 2011). Mental illness can negatively affect both the parent and their children/families' well-being on a temporary or ongoing basis (Göpfert et al., 2004; Reupert & Maybery, 2009). Where there are improvements in a parent's symptoms of mental illness there can also be an improvement in their child's mental health (Swartz et al., 2008). It has also been found that where a child has a significant other adult in their life this can also reduce the impact of parental mental illness (Maybery et al., 2005).

Given the strong link between child and parent mental illness, it is surprising there is a paucity of research on the connection between a parent's mental illness and their child's mental illness. What has become apparent has been the focus of available studies on a one-directional view looking in the main at impacts of parental mental illness. It is equally unexpected that there is this scarcity of research about the family status of children attending mental health services and particularly in relation to the diagnostic status of parents (Orel, Groves, & Shannon, 2003; Hetherington, Baistow, Johanson, & Mesie, 2000). This international issue is also found in Australia where data are not routinely collected on the incidence of CAMHS patients living with a parent with mental illness. Despite the Victorian Government's initiative (Department of Health and Human Services, 2015a) for mental health services to recognise and respond to the needs of children and parents with mental illness the systematic collection of data remains elusive. In fact, many adult mental health services do not, or rarely, inquire about and record whether their adult clients have children. CAMHS mostly record parental mental illness as part of routine assessment but this statistical information is not utilised at a state level beyond that juncture. Statistical information in relation to the mental health status of others in a mental health client's home is not a key indicator. Without such information there may likely be an impact on the effectiveness of service delivery and on the success of treatment planning.

In a search of the literature studies have been conducted in relation to the parental status of adult service clients. For example, Howe et al., (2009) utilised a census approach of an adult mental health service and found that a third of adult mental health patients were parents of children under 18 years and 60% of children were living with a parent with mental illness. An audit of UK adult and child mental health services and disability services (Gatsou et al., 2016) found that 59% of children had at least one parent with a mental illness and 40% of adult services had parents with dependent children. In examining children's services specifically, data is more sporadic; for example, it was found in Canada that 71% of children lived in a family where a parent had a mental illness or mental health concern (Baker & Lees, 2014). In the Netherlands a CAMHS study by Van Veen, Batelaan, Wesseldijk, Rozeboom, & Middeldorp (2016) determined that of the 230 parents attending the specialised service, 62% of mothers and 46% of fathers indicated they had a mental illness. Outside the literature the most comprehensive and inclusive study comparable to the regional context of Australia had been the unpublished Canadian audit by N. Mercer and D. Knapton (personal communication, January 31, 2014). In the Canadian regional child and adolescent mental health service, 262 open mental health files were reviewed, and they found 68% of families had parents with a mental illness or a mental health concern, with 70% of these being mothers. The principal diagnosis of the parents was depression (67%) and anxiety (39%).

1.4 FOCUS ON FAMILIES

The purpose of this thesis has been to explore the extent of mental illness in parents and children of those families seeking treatment in a regional mental health service. Additionally, the thesis has sought to determine, from individual narrative, the positive and negative influences on mental health of another family member's mental illness. The suggestion is that the mental illness in one person may add to the mental illness of the other with the alternative proposition that positive mental health is also transferable between people.

Guided by the Family Model (Falkov, 2012), this thesis has sought to investigate the lived experience of children and parents who currently live in families where there is co-existing mental illness. The Family Model has provided a framework to learn from the stories of families living with co-existing mental illness. To examine the perspectives and experiences of children and parents a narrative phenomenological approach was used. This approach offered the most effective way to obtain an insight into how parents and children made sense of the bidirectional influences of mental illness in their particular family context. This methodology was relevant for understanding how family members interpreted their experience and how these particular parents and children conceptualised those understandings. The methodology had at its core the need to better recognise

any bidirectional influences between a parent and their child. Importantly this research was the first of its kind. With a number of questions raised this study had sought to examine four areas with three of these previously un-researched and one with a paucity of research: prevalence in a regional CAMHS; impact on outcome measures; parents' perspectives when living in a home with a child with a mental illness; and children's perspectives when living in a home with a parent with a mental illness. In examining their stories, a further intention was to better understand possible precursors to children's mental illness as a result of any influences related to their parent's mental illness (Kowalenko, Barnett, Fowler, & Matthey, 2000; O'Donovan, 1993; Rutter & Quinton, 1984).

Based on population estimates from data provided by the Australian Bureau of Statistics (ABS), 23.3% of all children in Australia have a parent with a mental illness and furthermore 20.4% of mental health service users have dependent children (Reupert, Maybery, & Kowalenko, 2012). While parental mental illness features highly in the statistics so too does childhood mental illness. There are approximately 4.1 million children between the ages of 0 and 14yrs in Australia and approximately 9% of these have 'a long-term mental health problem' (AIHW, 2012). Kessler, Chiu, Demler and Walters (2005) reported that 50% of mental health disorder starts before the age of 14 years and that 25% of those children have a higher burden of disease and physical health problems. While the magnitude of mental illness in families is clearly extensive current research is very limited as to the scope of the problem for CAMHS children. Research in the area of prevalence has been expanded following this thesis being articulated at a number of conferences.

For prevention and intervention to be effective it is clear that services need to have an understanding of the extent of any problem and then be able to address potential problems as they relate to the specific family type. Family life is no doubt stressful for many families as pressures on finances, work, relationships and community impact on daily living. Stress on becoming a parent is well documented with Deater-Deckard (1998) highlighting how adults try to adapt to being a parent. A parent's mental illness can potentially influence their capacity to parent (Royal College of Psychiatrists, 2011). As such, mental illness can negatively affect both the parent and their child's well-being on a temporary or ongoing basis (Göpfert et al., 2004; Reupert & Maybery, 2009; Siegenthaler, Munder, & Egger, 2012). The risk is present across a range of mental illnesses including personality disorders (Barnow, Schuckit, Smith, Spitzer, & Freyberger, 2006), anxiety disorders (Santvoort et al., 2015) and depression (Kowalenko et al., 2012). Importantly improvements in the parent's symptoms can lead to an improvement in their child's mental health (Swartz et al., 2008). Being responsible for the care of a newborn child can be difficult for most new parents but how then is that stress further affected by the presence of a chronic mental illness? Is there a difference in the

way parenting occurs or does it produce greater resilience in the child? Only those with lived experience can answer this question. Furthermore, only those living with the stressed parent can answer how they understand and respond to parental stress and mental illness. As noted by Danese and McEwen (2012) adverse childhood experiences alter the child's allostatic system of homeostasis, with Ellis and Del Giudice (2014) highlighting long-term stress as a key factor in psychological and other risks for children. Some mental illness such as depression has been shown to have an impact on parenting behaviours and even on economic influences in families (Lyons, Henly, & Schuerman, 2005). Borderline personality disorder (BPD) in a parent can impact a child in different ways through self-esteem and emotional dysregulation (Kluczniok et al., 2018). Focusing on a specific mental illness rather than the entire family may have some benefits (Hosman, van Doesum, & van Santvoort, 2009) but the focus in this thesis has been the universal affects between a parent and a child.

Two key models that summarise the research in this area are the logic model for intervention (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006) and the Family Model (Falkov, 1998) that examine the key domains impacting on parents and children in families. There are a number of factors that play a part in the key interactions between parents and children and some of these key contributors are now considered.

1.4.1 Developmental factors

Before birth fetal development is being programmed with the purpose of preparing the child for the environment into which they will be born (Glover, O'Connor, & O'Donnell, 2010; Gluckman, Hanson, & Clarke, 2005). It is at this time that a child is most susceptible to a mother's stress (Weinstock, 2008) and where later childhood behaviours may be imprinted. Leis and Mendelson (2010) found that parental depression had a strong association with subsequent child mental health. Plant, Barker, Waters Pawlby, and Pariante (2013) found that mothers who had experienced childhood maltreatment themselves were highly likely to suffer maternal antenatal depression which in turn would lead to their child suffering later mental health problems.

Deater-Deckard (1998) describes the difficulties of parenting stress and how this might impact parental mental health. This concept is nicely represented in the Stress Process Model (Pearlin, 1989) which links to the Crossing Bridges Family Model. From a sociological perspective being a parent adds additional responsibilities that increase stress and impact mental health. Balancing parental responsibilities with general social duties adds to parental strain. Couple this stress with a chronic or emerging mental illness and problems are likely to be exacerbated. Problems are not confined to the early years with impacts of parent-adolescent relationships adding a different dynamic (Nomaguchi, 2012).

Another important element of development is attachment. Writers in this area believe that it is early attachment that can have a profound effect on emotional and cognitive development of children leading to insecure attachment (Harder et al., 2015; Hipwell et al., 2000; Kowalenko et al., 2012). With the intergenerational transmission of parenting styles a key factor in attachment parents with problems, particularly permissive parents, are likely to have poor social skills and maturity (Tavassolie, Dudding, Madigan, Thorvardardarson, & Winsler, 2016), which may impact attachment with their child. Attachment security has been related to psychosocial functioning and may be adversely impacted by a parent's mental health (Goldberg, 2000; Cunningham, Harris, Vostanis, Oyeboode, & Blissett, 2004). The impact of depression likely has an impact on affect and motivation which in turn may also alter the way a person parents (Psychogiou & Parry, 2014). Parental mental illness can impact on the child and parent interactions and impact on the quality of the care a parent provides (van Doesum & Hosman, 2009; Morawska, Winter, & Sanders, 2009).

When things go wrong, parents – primarily the mother – are seen as responsible for failing to adequately socialise or engage with their child. Where the mother has a mental illness, such views are likely reinforced. Thorne (1987) notes that: 'women are closely and unreflectively tied with children' (p. 96). It is also important to note that, as Gunlicks and Weissman (2008) and Weissman et al. (2014) found, children's levels of mental health difficulty improved correspondingly with improvements made in the treatment of their parents' depression.

1.4.2 Transgenerational factors

In the study by Patrick, Reupert and McLean (2019a) it was found that adult children of parents with a mental illness may require additional support in developing their parenting skills because they have not learned certain steps of parenting. While the genetic transmission of susceptibility has been well researched the intergenerational transmission of psychiatric risk is less clear. It is apparent that family environment and parenting as well as maternal stress are just as important as any other factors (Beardslee et al., 1998; Benjet, Azar, & Kuersten-Hogan, 2003; Danchin et al., 2011). The transmission of vulnerability is not fully understood and may be a combination of both genetics and environment factors (Gröger et al., 2016). Other factors that are linked with the effects of adverse experiences include low self-esteem and reduced interpersonal effectiveness. These factors together may impact on family relationships and functioning adding to maladaptive responses, by both parents and children, to the consequences of mental illness. The theory underpinning this thesis is that of the social construction of childhood which is based on the way in which childhood is negotiated in everyday life through interactions and discourses (James & James, 2008). Different sets of reality occur when people interact with each other and their environment and thus relations are socially

constructed. The focus on children is on the future and not on the here and now of their experiences; like other areas mental health sees children as being at risk and vulnerable. These ideas may lead to an emphasis on rescuing rather than empowering children. This situation may be compounded where mental illness is a significant factor. Huntsman (2008) highlights the potential impact of parental mental illness on areas such as attachment, behaviour and parenting. This study has sought to ask what, if anything, might ameliorate some of the social constructions in families where parents and children have mental illness.

1.4.3 Sociological factors

From a sociological point of view a range of factors impacting on parents can lead to mental health problems and negative life events (Pearlin, 1989; Criss, Pettit, Bates, Dodge, & Lapp, 2002). What is more the stress and potential mental health challenges of parenting can have implications for a child's well-being. As noted above the quality of the parent-child interaction can itself play a part in a parent's mental well-being (Nomaguchi, 2012; Thomeer, Umberson, & Williams, 2013). Other factors that may play a part in the mental health of parents include financial difficulties (Pollmann-Schult, 2014) and employment opportunities (Nomaguchi, & Johnson, 2016). On top of this are educational issues which may in turn be linked to the mental health struggles a parent might have experienced as a child. Seabury et al. (2019) highlights the importance of improved education outcomes for children with serious mental illness. Without addressing issues of education there is likely to be an overall effect on life outcomes, including health and employment opportunities, for these children. Leach and Butterworth (2012) in their Australian study of national survey data noted that childhood mental illness is associated with early school cessation. Such impacts on the child with mental illness in turn may impact on their future parenting capacity and level of life stress.

Taking a social constructivist standpoint to help explore the impact on families where both a parent and child have a mental illness is a useful locus. Importantly in this theory, as first postulated by Vygotsky (1978), the focus is on human development through social interaction. Core to the theory is the process by which subjective meaning becomes a social occurrence. From this viewpoint learning occurs because of the interactions that occur between a person and those with whom they interact. The shift in this theory from a traditional social-learning perspective is to place interaction as the primary determinant in relationships. Within constructivism are the ideas of Cottone (2004) who describes community (and by extension a family) as absolute while for those outside that community reality is subject to other 'truths'. This idea suggests possible implications for family interactions when one person is unwell with even wider ramifications where two people are unwell.

Developmental psychology has provided the dominant discourse in child development over the past hundred years (Cairns, & Cairns 2007). The theoretical principle places children as growing to adulthood through certain stages and is dominant within many aspects of modern life, from theory and practice through to politics and policy. This view is one where the collective child proceeds along a line of development reaching a set of preordained stages, which mark another step on the road to maturity. This Anglocentric view takes little account of the sociocultural context and disadvantages of those who do not fit the dominant view of the universal child. Social constructivism moves from this individualistic, invisible child viewpoint (Smart, Neale, & Wade, 2001) to one that places a child very much in a social and family context.

1.4.4 Sociology of childhood and sociocultural factors

The sociology of childhood is another important conceptual lens when considering mental illness in families and has helped inform this thesis. Children are not passive recipients in their world but they are social actors who are active in their own construction of their environment and are able to influence the world in which they live (James & Prout, 1990; Smart et al., 2001; Smith, Taylor, & Gollop, 2001). Smith contends:

Children gradually come to know and understand the world through their own activities in communication with others. A continual process of learning generates development. The greater the richness of the activities and the interactions that children participate in, the greater will be their understanding and knowledge. (Smith, 2002, p. 77)

Childhood is not a natural classification or universal occurrence but is a construct developed and controlled by adults (Freeman, 1998). The adult perspective with its cultural values, aims, and norms determines childhood (Mayall, 1999). Childhood is an inevitable part of social class, gender and ethnicity all contributing to a particular construct of childhood. Within different cultures the capacity of children to undertake different tasks varies. For example, Lansdown (1994) highlights a wide range of views across cultures on the ability of children to take up employment or to be left alone. If this is the case how might parental mental illness and a child's mental illness play a part in the construction of childhood? Within this viewpoint children are disempowered by adults to ensure they are maintained as subservient to adults who hold power and control. Such ideas as 'the dangerous child' and 'the vandal' help adults maintain a moral panic over a perceived threat to the social order by a group labelled as children. Such labels coupled with the presence of mental illness helps maintain children in the home and keeps them invisible.

For families where a parent and a child have a mental illness, children are likely to be as diverse a group as any other and the way they shape and construct their own lives may be influenced by their

experiences within that family environment. These like any other children have a purpose and, as well as being influenced, they also influence and construct relationships and experiences (Mathews, 2007; Mayall, 1999; Frankel, Twum-Danso Imoh, Thomas, Spyrou, & Curtis, 2017). Studies of children's interactions have shown that there is not an acceptance of adult definitions but a highly developed culture of their own which creatively uses information from the adult world to manage peer worries (Adler & Adler, 1998; Corsaro, 2003; Corsaro & Fingerson, 2003). Despite this these children may have fewer friends and positive relationships (Criss et al., 2002).

Sociocultural theory offers a more contextualised view and situates development within a frame of sharing in activities that occur within social interactions and relationships in families. Smith (2002) describes the sociocultural approach as children slowly but surely becoming acquainted with and comprehending their environment. This occurs through what they do for themselves in interactions with others and within the cultural context that is the family in which they live. Sociocultural theory challenges the traditional views of child development more than developmental psychology and places importance on social processes. Vygotsky (1978) believed that children grow into the intellectual life around them. To be competent a child needs to be challenged and extended with help. As help is withdrawn, so the child is able to do more on its own. Vygotsky argued that child development couldn't be understood by looking at individuals.

Vygotsky (1986) introduced the idea of internalisation of interpersonal process. Cultural development is from a process of dual exposure. Firstly, there is exposure between people: where parents view children from the context of their own family. Secondly there is exposure, which is internal, and at an individual level: children seek guidance from within their family context. Thus, in understanding childhood it is necessary to examine the context of the culture within which a child lives. Child development is about acquiring skills that are seen as important in the culture around the child. Vygotsky (1986) was able to show that children are better able to perform skills when they receive guidance or support rather than when they are alone.

Another key concept introduced by Vygotsky (1986) is the zone of proximal development. This concept places development as occurring within relationships with others. In this process there is a pattern of developmental change where a segment of adult support or guidance, scaffolding, is followed by a segment of child achievement. Within this wheel of development new child behaviour is followed by an adult reaction and interpretation that defines the behaviour as a social act. The child in this situation is in effect instigating communication. As the experiences are internalised, they become a part of the independent development of the child and fine-tuning of the scaffolding allows for greater control of the activity by the child. The zone of proximal development is the difference

between what can be done alone and what is done in partnership that is ‘When adults or peers are engaged in joint attention with children, this has the effect of working within their zones of proximal development and promoting the extension of their skills and capabilities’ (Smith, 2002, p. 78)

Development is in part incumbent on two key factors: participation in increasingly complex reciprocal activity with a significant person (Bronfenbrenner, 2005); and the expectations and opportunities offered by family and the support received to reach competence (Smith & Taylor, 2000). Smith (1998) highlights that when experience is scaffolded and participation is encouraged, children are better able to actively participate. The question here is whether such scaffolding can occur in an environment of mental illness.

1.4.5 Genetics

It is important to mention the emerging field of epigenetics and how this might also play a part in the family experience. Studies in the area of epigenetics indicate that epigenetic marks are vulnerable to alteration early in life triggered by stress related events such as PTSD, anxiety or depression (Lee & Alisch, 2012). Other writers in the field suggest that there are key periods of vulnerability to genetic heritability of psychiatric disorder (Guintivano & Kaminsky, 2016). These key periods include gestation, the early postnatal period and periods of major hormonal rearrangement. Maccari et al. (2017) describe how any deficiency in affection between the mother and newborn can result in non-conscious affectivity which they call ‘anaffettivita’. This they go on to describe is ‘a critical postnatal pathogenic factor that can determine...later mental illness (p. 243). Importantly these writers suggest that stress related events in the early years of development can impact on later mental health outcomes and are not pre-conditioned.

1.5 SIGNIFICANCE

Research has shown that children who have a parent with mental illness are at risk for similar problems, irrespective of the mental illness their parent has (Reupert, Maybery, Cox, & Scott Stokes, 2015; Reupert, Maybery, & Nicholson, 2015; Hosman et al., 2009). With this knowledge and recognising the gap in current research it was important to focus attention on the extent of the problem, if one existed at all. Having then established if children attending CAMHS lived with a parent with a mental illness it was important to identify any possible influences of parental mental illness on clinical outcomes for these children. This again was an area never before considered in the literature.

It is presumed that all children experience comparable concerns about their mentally ill parent (Reupert et al., 2012). This being said the discourse in current research has assumed a parent has a

mental illness but not the child or conversely the child had a mental illness and not the parent. Current research also considered retrospective views of adult children, which adds an additional limitation to any findings. In this thesis it was important to understand how parental mental illness influenced problems in children and how the mental illness of children influenced problems in parents. Furthermore, in establishing these experiences it was important to examine the different understanding within an established family context.

As can be seen from the above the occurrence of mental illness in a parent is an indicator of vulnerability for a child developing a mental illness as well as impacting a child's consequent likelihood of recovery. As a critical determinant of mental well-being in childhood the status of parental mental health is a crucial consideration when planning therapeutic interventions and supporting recovery for children experiencing mental illness. Unaddressed parental mental illnesses may compromise children's capacity to engage with services and respond to treatment. This thesis seeks to improve preventive interventions for children by improving mental health and other service provider's knowledge about the extent of the problem and raising the profile of these particular family needs as highlighted through their personal narrative.

1.6 THESIS OUTLINE AND RESEARCH QUESTIONS

Chapter 2 describes the current literature in relation to the thesis research questions looking at the literature around parental mental illness and child disability. Chapter 3 presents the overview of the quantitative research design and discusses the methodology for the first part of the study into the extent of co-existing mental illness in families where children attend CAMHS. This chapter also covers the process for examining any parental mental illness impacts on children's clinical symptomology. Chapter 4 considers the theoretical perspectives underpinning the quantitative research and presents the first two research papers.

Chapter 5 presents the qualitative methodology. The third and fourth papers are presented in chapter 6 examining the narratives of parents and children both with mental illness living in the same family. Finally, the results of the preceding chapters are brought together and discussed in chapter 7. This final chapter also addresses the implications for service delivery and provides suggestions for continuing research.

1.7 AIM

The overarching aim has been to examine, through a mixed method approach, the bidirectional impact of first-degree intergenerational mental illness within families. The four aspects comprising

this thesis focus on four different original and innovative facets of the overarching aim of the study.

In meeting this aim, the objectives have been to:

1. Carry out an investigative audit, to determine the extent of mental illness co-existing in families attending a child-focused mental health service
2. Carry out an audit of routine outcome measures to investigate any impacts of parental mental illness on child symptomology
3. Undertake a narrative discourse with parents, to determine the influence of mental illness in the family and, from a parental perspective, establish what would be helpful in reducing those influences
4. Undertake a narrative dialogue with children, to ascertain the impact of mental illness within the family and seek their ideas on what would moderate those influences

Chapter 2: Literature Review

Examining literature specifically focused on the bidirectional impacts of mental illness in families had been difficult as very little specific material existed. To provide some contextual clarity this chapter considers the literature that looks at mental illness in what is best described as a unidirectional manner. Divided into three main sections this chapter considers the literature in relation to how parental mental illness affects children (section 2.2). It then considers the literature looking at the effect children with a learning difficulty or developmental disorder might have on their parent (section 2.4). The final part (section 2.5) looks at literature related to the impact of a child's mental illness on their parent. Each section is subdivided into the key areas of relationship issues; care issues; anger and behaviour issues; economic issues; abuse issues; and stress and mental illness. With the absence of direct literature on bidirectional impacts the next section considers theoretical models examining the bidirectional impact of child and parent mental illness (section 2.7). The final section, 2.8, provides a brief summary illustrating the dearth of evidence in respect to this topic area. The chapter highlights the need for research into families where both a child and a parent have a mental illness to both understand the issue and explore solutions to any problems.

2.1 BACKGROUND

This literature review has considered the literature that describes the impact of parental mental illness on their children. This is an extensively researched area which is thoroughly covered and critically examined in the literature. In comparison when considering the literature looking at the impact of child mental illness on (a) parent(s), material has proven very sparse. In order to better understand how a child's presentation might impact a parent it was appropriate to examine the literature pertaining to child disability as this contained more extensive material that offered some similarities between parent-child interactions. This literature focused predominantly on the impact of childhood disability and pervasive developmental disorders on a parent's own well-being. It seemed appropriate that with research in the area of disability considering bidirectional aspects of relationships this might be instructive and informative in this study discourse as to how child mental illness might impact on their parent.

The review followed standard procedures for an integrative literature evaluation and was conducted across six academic journal databases (CINHAL+, Embase, Medline(R) +Epub, PsycINFO, Scopus, Web of Science). This was completed at the start of the study and reviewed on a

regular basis. The search-term structure used was as comprehensive as possible with seven key search areas (Parent, Child, Mental Illness, Disability, Service, and Bidirectional). Search terms were adapted as required by the relevant databases. A further manual search of citations within eligible studies provided additional potential studies suitable for further investigation. Results were firstly organised in Endnote and matching records were removed. Articles that had not been peer reviewed (e.g. book chapters, grey literature), that included only secondary data, or that were otherwise opinion pieces, were excluded from the literature review. The Falkov (2012) Family Model book was instrumental in informing aspects of the literature review as was the unpublished study by Mercer and Knapton (2014). The final data was collated into a standard spreadsheet organised by category (parent impact on child, child impact on parent, bidirectional impacts) and the data was then evaluated for key themes within each category.

Varying interpretations of themes occurred as the different categories were examined. Thus, relationship issues might include attachment with significant others or extend to interactions with peers (Maybery et al., 2005) while it might have described relationships through the broader contexts of family functioning (Zubrick et al., 1995). Considerable variation existed on the theme of stress and mental illness, deviating between diagnosable conditions and psychological disorders to low mood and worry (Aldridge & Becker, 2003; Fernbacher, Goodyear, & Farhall, 2009). Another term identified as having a wide definition was caregiver; for some of the authors it related to specific care giving skills while for other writers it referred to the presence or absence of a caregiver. For ease of the reader the categorisations were generalised into the premise aligning with the study's intent. The broad groupings in this process are now considered for the three areas under discussion.

2.2 IMPACT OF PARENTAL MENTAL ILLNESS ON CHILDREN

Up to 50% of adult mental health service users may be parents (Howe et al., 2009). While parental mental illness is a major public health concern there has been little analysis of this in terms of the impact on children within the home (Gunlicks & Weisman, 2008). A parent's mental illness may adversely affect their parenting capacity and stress from the parenting role can jeopardise their mental health (Royal College of Psychiatrists, 2011). McLaughlin et al. (2010) found childhood adversity was strongly linked to parental mental illness. In assessing parents with BPD, Infurna et al. (2016) found parenting attachment linked to parental mental illness had an adverse effect on children. A link was also found between parental mental illness and younger children's presentation of oppositional defiant disorder (ODD) (Antúnez, La Osa, Granero, & Ezpeleta, 2018). It is widely recognised children growing up with a parent with a mental illness may be at risk in a number of areas (Beardslee, Gladstone, & O'Connor, 2011; Barker et al., 2012; Singh, Evans, Sireling, & Stuart,

2005); it is also important to note though that not all children of such parents are affected (Falkov, 2012). Parental mental illness may also be compounded by other factors affecting the child, such as genetic vulnerability, environment and dysfunctional relationships (VanDeMark et al., 2005). Difficulties in parenting tend to occur at times of relapse and during the acute phase of the parent's mental illness and can adversely affect both the parent and their children's/families' well-being on a temporary and on an ongoing basis (Göpfert et al., 2004; Maybery & Reupert, 2009). Meltzer et al. (2003) found in a large epidemiological study that where parents screened positive for mental illness on the General Health Questionnaire-12 (GHQ) the children of these parents were three times more likely to have a mental illness; the proportion of childhood mental illness was highly correlated with the parental score. Additionally, these families were more likely to exhibit problematic functioning. Significant correlation was found between maternal mental health and risk factors for these children with increased risk for internalising or externalising disorders (Barker et al., 2012).

Despite parental mental illnesses being identified as a major public health concern there had been little analysis of how improvements in parental mental health could impact on children. In Gunlicks and Weisman's (2008) systematic review of 10 studies it was found that there was a relationship between improvements in adult mental health with improvement in issues for children. The areas of renewal they noted were in terms of attachment, temperament and cognitive development. In the 10 studies looked at, none specifically examined how improvements in parental mental health might lead to improvements in the mental health of children. Gunlicks and Weisman (2008) say that having a depressed parent 'can be stressful for youth' and go on to say 'symptom reduction of the depressed parent is, of course, not the full story for helping the offspring' (p. 388); they suggest further examination of the precise relation between adult and child symptoms is required.

Although not solely exclusive six key themes were identified in the literature relating to the impact of parental mental illness on children. The themes were: mental health/stress; relationship issues; anger and behaviour issues; care issues; economic issues; and abuse issues. These areas are now outlined in the following sections.

2.2.1 Relationship issues

In their report the Royal College of Psychiatrists (2003) talk of the integrated ecological model of influences on relationships and mental health. Primarily it is reported that where there is mental illness adults within the family argue more and this leads to relationship issues. It is in this context that there may be domestic violence between carers as well as towards children (Caton, Cournos, Felix, & Wyatt, 1998; Herbert, Manjula, & Phillip, 2013; Ranning, Laursen, Thorup, Hjorthøj, & Nordentoft, 2016; Australian Institute of Health and Welfare, 2019a). In families where there is

mental illness there is increased risk of social isolation with few extended family supports and poor relationships with extended family (Maybery et al., 2005). Van Loon, Van de Ven, Van Doesum, Witteman, and Hosman (2014) found that interactions between children and parents, where a parent had a mental illness, were substantially worse than interactions for other children. They also noted the caring relationship children carried out and the negative environment in which children of parents with mental illness lived. In the context of mental illness, it was reported that some care givers separate, and where they did stay together the relationships could be fractured. In addition, relationships between the parent and the child were also found to be fractured in other ways with examples of the mentally ill parent being distant or conversely being overly involved in the child's life. Aspects of attachment between the parent and child where there is mental illness were found to vary from ambivalent to anxious or avoidant (Grossman, 2005). The literature begins here to intimate that parental behaviour might impact on their child and vice versa. Relationships were found to be broadly linked into parenting styles, with some parents with mental illness adopting a style of relationship dependent on the contexts of their mental health at the time (Rogosch et al., 2004; Mowbray, Oyserman, Bybee, & MacFarlane, 2002). Abraham and Stein (2010) in their study of 94 children found that children felt an obligation towards their parent, and this had an impact on the child's psychological adjustment. Certainly, a closer bond between parent and child has been related to improved well-being (Boutelle, Eisenberg, Gregory, & Neumark-Sztainer, 2009; van Wel, ter Bogt, & Raaijmakers, 2002).

2.2.2 Care issues

Not dissimilar to the relationship theme care refers to the type of care given by a parent to a child and was almost as often referred to by the authors as being related to relationship issues (Aldridge & Becker, 2003; Aldridge, 2006). The care in this context referred to the amount or level of care a child received because of the parent's mental illness. For example, maternal depression was linked to a lack of engagement with children who were left to their own devices and to fend for themselves. Even where there was engagement this was reported as dysfunctional and avoidant (Becker, 2004). More significantly the literature identified how children themselves take on the care giving role becoming responsible and caring for their parent (Aldridge, 2006; Becker, 2007; Falkov, 2012). Even young children have been found to take on care responsibilities in the home (Becker, 2004).

2.2.3 Anger / behaviour issues

This theme was a little more mixed with authors referring to the behaviour of parents towards their child and the resultant behaviour of children in response (Maybery et al., 2012; Fernbacher et

al., 2009). From the literature anger appears to be a common behavioural response to a parent's mental illness. This emotion was seen to be bidirectional because it was found to be occurring from both parents and children. There is a consistency within the research that shows higher levels of behavioural and emotional problems for children of parents with a mental illness which can often be seen as anger issues (Beardslee et al., 1998; Van De Mark et al., 2005; Skärsäter, 2006).

2.2.4 Economic issues

The economic impact on children because of their parent's mental illness was frequently mentioned with financial issues causing whole family stress. Economic impacts overall were quite broad and included loss of work or work opportunities, poor social environment, lack of resources and poor housing (Gladstone, Boydell, Seeman, & McKeever, 2011; Maybery et al., 2002, 2005; Fernbacher et al., 2009). From this the impact on the child was often more likely to be of a practical and financial nature where the child had limited resources and opportunities because of the family's economic status. Not insignificantly, economic issues are also reported as having an impact on diet and health with the resultant impact on children's overall physical and emotional well-being (Zubrick, 2005).

2.2.5 Abuse issues

This premise also had a strong crossover with a number of authors describing how parent's mental illness could lead to increased abuse (Falkov, 2012; Fernbacher, Goodyear, & Farhall, 2009). The ideas around this theme in the literature link across all the categories, for example: relationship problems that were due to mental health problems leading to domestic violence. Also highlighted were reactions to anxiety disorders in a parent leading to avoidant behaviours. These avoidant behaviours in turn impacting on family economic functioning leading to negative behaviours by either parents or children. Relationship problems were similarly linked to behavioural issues which might in turn result in inappropriate parenting or even abuse. Such abuse is variably described as varying from direct physical abuse to more subtle neglect or emotional abuse, whether intentional or not (Oyserman & Mowbray, 2000). An additional dynamic is that of gender where boys are exposed to more stress, frustration and anger from parents than girls.

2.2.6 Stress and mental illness

As noted above stress and mental illness is an idea in the literature that has a wide scope and comes with some ambiguity. While some authors are quite clear about the mental illness referred to, such as anxiety or depression, other authors tended to use the blanket and unspecified term of stress. A straightforward definition of stress from a medical definition is 'physical, mental or emotional

factor that causes bodily or mental tension' (Shiel, 2018, Para 1). Reupert and Maybery (2007) describe children as living with expressions of mental illness. Hammen, Burge, and Stansbury (1990) found a pernicious course of mental illness in families and found a link between parenting and behavioural patterns being learned by children living with a depressed mother. Stress in itself is a condition that was identified as being very closely related to depression and could be mistaken for such a condition. A broader definition of parental stress was described by Webster-Stratton (1990) who described stress as anything from depression through to marital discord. Children who experience stress must deal with the multiplicative effect within their own family as well as from the compounded stressors from interactions with people outside the family.

2.3 SUMMARY

While a number of factors impact on children when they live with a parent with a mental illness, the literature clearly shows that parental mental illness is a major influence on children. While definitions may vary and there may be some crossover, it is significant that all the authors argue parental mental illness has a fundamental effect on children and that the effects are pervasive across a number of key components of a child's life; living with a parent with mental illness is not easy. Beyond mental health impacts there are influences on relationships within the family system and further into the wider family and social networks. The relationship impact is pervasive from the earliest years of the child's life thus parental mental illness can immediately and significantly affect the attachment between a parent and child and have long-term consequences (Grossman & Grossman, 2005). Other influences include behavioural ramifications and economic effects on the family unit as well as the overall influence on a parent's caring capacity.

From the literature it was quite clear how parental mental illness might impact a child. Despite this, within the parent related literature, there was found to be sparse material on the impact of a child's mental illness on their parent(s). While much is written on brain development and the impact on children's development of their early experiences, the lack of material establishing links back to parents seemed to be a deficiency. With some of the literature highlighting the influence of genetic factors in the development of mental illness (Bagot & Meaney, 2010) and others considering intergenerational transmission (McLaughlin et al., 2010) it seemed that likely bidirectional influences would be inevitable for some families. Some of the literature talks of the general vulnerability of children because of parental mental illness (Bornovalova et al., 2010) but are these vulnerabilities entirely caused by parents or are they an effect from the child? Classic studies certainly indicate that children exposed to altruistic behaviours are more likely to imitate those behaviours. If a parent is unwell such altruism may not be evident (Rushton, 1976; Yarrow et al., 1976). These ideas fit nicely

with social-learning theory which is not examined in this thesis but does provide a clue as to how children identify and internalise the experiences that are provided to them by their well or unwell parents.

To further the understanding of a child's mental illness on parents the child disability literature was examined. By far, the most wide-reaching research has been conducted in relation to the impact of a child's disability or developmental disorder on parent(s). The next section looks at this literature.

2.4 IMPACT OF CHILDREN'S DISABILITY OR DEVELOPMENTAL DISORDER ON A PARENT'S MENTAL HEALTH

From a selection of the expansive literature that considers how child disability directly impacts parents, key categories were found that aligned closely to those areas identified in relation to the impact of parental mental illness on children. Within this field of the literature a wide range of studies considered the impact on parents of caring for a child with an autism spectrum disorder (ASD). While ASD is defined as a neurodevelopmental syndrome (American Psychiatric Association, 2013) it is also recognised that 70% of those with ASD have comorbid mental illness (Simonoff et al., 2008). The ideas coming out of the disability literature were again not exclusive with frequent crossovers as was seen previously in the case of parental mental illness. As before, an important caveat in the discussion is the vagaries in which some of the terms are used. For example, stress had been couched in terms of general anxiety or low mood but also considered in relation to overall levels of parental stress. In contrast relationships appeared to be more clearly defined when looking at a family where a child had a disability.

Many people with a range of disabilities may have behaviour and emotional issues such as: limited verbal communication and pragmatic language disorder; poor social skills; problems with social relationships; aggression; and stress (Deater-Deckard, 1998, Lazarus & Folkman, 1985). All or just a few of these may impact on members of the family both immediate and extended.

In this section disability encompasses both physical problems such as cancer and long-term health problems as well as developmental disorders (e.g. autism [ASD] and pervasive developmental disorder [PDD]). An important consideration in the literature is the difference between responses of parents to a child with a physical disability and one with a developmental disability. This is not mentioned as a theme but requires further remark because of its importance for this particular family group. In families where a child has a physical disability, studies highlight greater understanding of the challenge's parents face. There is also a general view of these parents having a significant emotional attachment to their child. In contrast the family where a child has a developmental disorder

or learning difficulty, including autism, the indications are of there being a poor emotional attachment between the parent and child. The reason for this is best described by Bouma and Schweitzer (1990) who concluded that the key element impacting on parents of a child with a learning difficulty is the effect on the parent of the emotive response. Whilst emotive responses are clear and evident in many children with a physical disability this is not so apparent in children with PDD or ASD.

To maintain consistency the themes considered here follow the same categories as discussed earlier in section 2.2.

2.4.1 Relationship issues

The research shows that where a child has a physical disability or a developmental issue there are a number of relationship issues that occur within the family. Norlin and Broberg (2013) found that mothers of children with an intellectual difficulty had low overall well-being compared to that of other parents. Studies relating specifically to ASD reported finding parents as having a higher level of stress and mood disorders (Bouma & Schweitzer 1990; Bolton, Pickles, Murphy, & Rutter, 1998; Piven, Palmer, Jacobi, Childress, & Arndt, 1997; Abbeduto et al., 2004; Hu et al., 2018; Kuusikko-Gauffin et al., 2013; Totsika et al., 2011; Uljarević et al., 2014). Boström, Broberg, and Bodin (2011) emphasise how the behaviour and temperament of a child with a disability can impact on relationships in the family. All the authors point to a child's disability or developmental problem as impacting on various aspects of the family system. As with the situation with parents with a mental illness this primarily is reported in the context that adults within the family argue more and there are relationship issues between adults in the family which in this setting can include domestic violence between carers as well as towards children (Morton, 2004; Garbarski & Witt, 2013).

While this is an important factor in developmental disorders, the literature indicates that for some families this is less significant noting where there is a physical disability parents come together more (Taylor & Stanton, 2007). These families were identified as experiencing social isolation which impacted on parental relationships outside the family (Samadi & Mahmoodizadeh, 2013). From a more practical viewpoint it was found that physical disability was more likely to restrict parents to the family home just because of the care needs of their child.

Relationships between a parent and child were found to be fractured and distorted with examples of the parents being over involved in their child's life. As with mental illness the relationship was broadly linked into parenting style with some parents adopting a more controlling parenting relationship. Al-Gamal and Long (2012) suggest there is 'less cohesion' in these families. Garbarski and Witt (2013) linked relationship issues to child limitations and went on to say there is

likely to be a bidirectional effect. There is a consequential impact in these families of social isolation which in turn affects other family members, particularly siblings (Rivers & Stoneman, 2003). Social isolation was identified as being related to increased social anxiety with studies such as Kuusikko-Gauffin et al. (2013) showing increased social anxiety in mothers compared to fathers in families where a child had PDD. This increase in anxiety was higher where there was PDD than for all other disability types.

2.4.2 Care issues

Caring for a child with a disability presents with a number of challenges with the role of caring itself affecting the mental health of parents (Cadman, Rosenbaum, Boyle, & Offord, 1991; Hastings & Beck 2004; Patton, Ware, McPherson, Emerson, & Lennox, 2018; Dykens, Fisher, & Taylor, 2014). The impact of caring for children with a disability results in a number of effects including general psychological factors such as fatigue and stress as well as physical health problems such as increased risk of ulcers and heart attacks. In interviews with parents Ludlow, Skelly, and Rohleder (2012) noted the key impacts for parents as not only managing difficult behaviours but also experiencing stigma and emotional distress. Sawyer et al. (2010) in their study of 216 mothers of children with autism found the pressure of caregiving was related to a mother's overall mental health. In the later study by Sawyer et al. (2011) of parents caring for children with cerebral palsy there was again found to be a clear association between the caring role and maternal depression.

Morton (2004) described the difficulties in the caring relationship between the child with a developmental disorder and the parent as a process of cause and effect stating, 'There is no single cause of anything' (p. 53). It is significant that where a child has a disability it has been found that mothers spent more time caring for their disabled child than in any other activity (Crowe & Florez, 2006).

2.4.3 Anger / behaviour issues

Anger as expressed by a child was the most common behavioural issue in the context of physical or developmental disorders (Garbarski & Witt, 2013; Meadan, Halle, & Ebata, 2010; Ludlow et al., 2012). Less commonly the literature referred to anger and aggression occurring in both directions, as in parent to child and child to parent (Falkov, 2012; Ludlow et al., 2012; Altieri & von Kluge, 2009). This is a subject often referred to in the literature and is the one that most frequently crosses boundaries. Behaviours in the area of disability range from a child's anger towards others through to self-harm and even school refusal. School refusal was found to be the most commonly reported

behaviour in children with developmental disorders. In addition, these children experienced bullying at a mainstream school which then became an issue at home (Meadan et al., 2010; Jones et al., 2012).

It is in this particular part of the literature that the closest direct links are made between bidirectional influences between parents and children. For example, Ricci et al. (2017) found a link between parental stress and behaviour problems in their child. Rodas, Zeedyk, and Baker (2016) found a significant link between a child's internalising behaviour problems and parental depression.

2.4.4 Economic issues

Financial issues were reported as another significant factor for families where there was a child with a disability. The focus in this area was on a lowered quality of life for parents and families in general because of the direct impact of having to care for a young person with a disability which in turn prevented parents from engaging fully in the workforce (Powers, 2001). Additionally, the increased demands for resources to be able to effectively care for a disabled child placed families in considerable economic difficulty (Emerson, 2003). Stabile and Allin (2012) describe families as facing direct, indirect and long-term economic costs as a result of having a child with a disability. In these families it had been found that there was an increased economic burden as parents needed to adjust their work hours to meet the particular demands required to be able to care for a child with a disability. In the literature it was noted that where a child had a disability parents had more calls to attend school or respite carers to provide support to their child or to remove their child because the school or respite carer were unable to manage the child (Bourke-Taylor, Howie, & Law, 2010).

2.4.5 Abuse issues

Parental anger, resulting in physical abuse of a child with a disability was a significant element of the literature (Morton, 2004; Garbarski & Witt, 2013; Ludlow et al., 2012). Parental anger tended to be related, most commonly, as a general response by the parent to a child's behaviour. It was particularly striking that compared to children with other disabilities children with autism were found to be more frequently physically restrained by their parent because of the child's behaviour (Allen, Hawkins, & Cooper, 2006). Jones et al. (2012) described violence from parents towards a child with a disability as more extensive than family violence reports indicate and point to the impact of domestic violence on the family system and family secrecy. Meadan et al., (2010) highlighted how a child with a disability might have behaviours requiring a parent to physically restrain their child to ensure the safety of other family members. Overall the literature points to children with a disability as being at increased risk of physical abuse (Svensson, Bornehag, & Janson, 2011). Additionally, such physical abuse is just as likely to be bidirectional (Jones et al., 2012).

2.4.6 Stress and mental illness

Increased stress and lower levels of mental well-being were found for parents with a child with ASD with this disorder having a significantly higher impact on parents than for any other childhood disabilities (Abbeduto et al., 2004; Hayes & Watson, 2013). In parents living with a child with a disability stress was found to be a precursor to depression, increased anger, anxiety, and even relationship difficulties. Manuel, Naughton, Balkrishnan, Paterson, and Koman (2003) and Bourke-Taylor, Howie, and Law (2010) found that mothers caring for a child with a disability were more at risk of depression. Glasberg, Martins, and Harris (2006) found that mothers of children with PDD experienced significantly more stress than those of children with Down's syndrome. Parental mental illness, in conjunction with a child's disability was frequently linked to an overall 'strain' within the family system with roles such as parenting, marriage, work and caring often skewed (Garbarski & Witt, 2013). Kuusikko-Gauffin et al. (2013) found higher levels of anxiety in parents who cared for a child with a disability with specifically higher levels of social anxiety, which in turn had an associated impact on relationships and economic factors.

In studies looking at children with cerebral palsy it was found that parental stress predominated with poor social support as an additional major factor for parents. Instead of services moving to support families under stress it was found that the more stress parents were under the less likely they were to be supported (Al-Gamal & Long, 2012). For other writers it was found that stress in general was higher in families where a child had a disability and this stress was a key factor for parents (Quine & Pahl, 1991; Emerson, 2003).

Skok et al. (2006) looked at Australian families and found that the severity of any disability was not a factor in relation to parental stress while Solnit and Leckman (1984) found that the more disabled a child was the less accepting of the child a parent was. Masulani-Mwale, Mathanga, Silungwe, Kauye, and Gladstone (2016) found that the burden of caring for a child with a disability impacted overall levels of stress and the mental health of a parent.

2.5 SUMMARY

The literature in relation to disability has indicated that there were more practical and pragmatic elements involved where a child had a physical disability and a more emotional aspect when the issue was a PDD. The categories in this case are very closely aligned and external factors are seen as essential in reducing the burden on parents. It is noteworthy that it is in the area of disability where issues of bidirectional influences between parents and children are first considered. As has been seen

the categories of concerns for disability were not dissimilar to those in the literature relating to children living with a parent with mental illness.

The question remained what happens in families when a child has a mental illness? Does the level of parental stress increase with a resultant impact of emotional dysregulation and abuse or does something different happen? With no known literature specifically examining the impact of a child's mental health on a parent the final section to this chapter examined the theoretical discourse in relation to likely influences on families. As previously, the areas of relationships, care issues, anger and behavioural issues, economic, abuse and stress/mental illness issues are considered. As will become clear later in this thesis all these factors are neatly located within the Falkov (2012) Family Model.

2.6 IMPACT OF A CHILD'S MENTAL ILLNESS ON THEIR PARENT

As Hetherington, Baistow, Johanson, and Mesie (2000) have highlighted there is little research into the impact of a child's mental illness on a parent. A number of authors have hypothesised as to the likely impacts. For example, Gladstone, Boydell, Seeman, and McKeever (2011) in reviewing the impact of parental mental illness on children hypothesised that there was likely to be a reverse influence on parents whereas others such as Maybery et al., (2005), when discussing their child focus group findings, suggested likely effects on children of parental mental illness. To fully understand the relationship between parental mental illness and child mental illness Gladstone et al. (2011) conducted a review of the literature examining the experiences of children who lived with a parent who had a mental illness. In the review, of the 19 studies, it was identified that 10 focused exclusively on children's narrative of their experience. The review importantly highlighted that limited studies included the children's voice, and in those that did they usually collected perspective or retrospective data from adults. These findings had reinforced the view, as highlighted in the literature from the sociology of childhood, that historically research has adopted the dominant social view. That is the general understanding that the parent's voice is the important voice. One study, Haug Fjone, Ytterhus and Almvik (2009), provided some brief narrative descriptors of young children's experiences. For example, they outlined how children felt left out because of their parent being different, of the shame they had experienced, of the many processes they felt they have to go through to try not to be different and how they wanted to talk to others about their experiences. Although wide ranging the study did not ask about any impacts on the child's mental health or how the child may have affected the parent.

Both Gunlicks and Weisman (2008) and Gladstone et al. (2011) examined literature linking the prevalence of psychiatric problems in children of parents with a mental illness. In the review by Gladstone et al. (2011) they considered studies that focused on children's narratives of their

experience and found only 10 that were suitable. She identified three key areas where parental mental illness influenced a child: impact on daily life; how children cope; and how children understand mental health problems. She sought to show that children are more (or less) than victims of their parent's mental illness rather they are active participants in the construction and experience of family life where there is mental illness. Gladstone et al. (2011) noted that '...there has been little research on how children's actual daily lives are affected by a parent's mental illness' (p. 272). Smith and Taylor (2000) highlighted how the voice of children has frequently been ignored or muzzled in research and how these voices are the 'missing piece of the puzzle in understanding childhood'. Furthermore, it has been argued that children's experiences of exclusion and stigmatisation, because of their status in society, make them a difficult group to access (Warren, 2007; Olsen, 2000).

In considering children's experiences a limitation noted in the literature has been in relation to the influence placed on children of parents and caregivers who might appear to prejudice children's responses (Gladstone et al., 2011). While some of the studies (Haug Fjone, Ytterhus, & Almvik, 2009; Aldridge & Becker, 2003) were, in the main, independent of parental influence most of the others had complicit parental influence. A large proportion of the studies sought retrospective narratives (Haug Fjone et al., 2009; Pölkki, Ervast, & Huupponen, 2005). It was evident from the literature that it was much easier to seek retrospective views, with all the subsequent biases of retrospection, from adults rather than seek children's voices.

Gudmundsson and Tomasson (2002) and Barry and Busch (2007) found that caring for a child with a mental illness affected the caring and psychological health of carers more than any other condition. A number of studies have established that around 33% of parents with mental illness have a child with a mental illness (Lauritzen & Reedtz, 2016; Howe et al., 2009; Maybery et al., 2005). These studies have also noted higher parental stress and less parental involvement with children where parents and children had mental illness. Hughes, Sciberras, and Goldfeld (2016) noted lower attainment in communication, literacy and social development of children with parents who have a mental illness while Radke-Yarrow and Klimes-Dougan (2002) simply said 'there is a high relation between parental mental illness and child mental illness'. Where there is domestic violence in a family Lang and Stover (2008) found a 25% incidence of emotional and psychological distress of clinical significance in children.

2.6.1 Relationship issues

The general discussion in the literature relates to a more fractured relationship between parents and children where the latter has a mental illness (Falkov, 2012; Maybery et al., 2005). The lack of emotional attachment and behavioural problems are significant aspects in this theme. Family

functioning may have a bidirectional impact on the mental health of those within a family system (Wilkinson, Harris, Kelvin, Dubicka, & Goodyer, 2013). These authors note that while there have been no studies to date on ‘mental health in one party...causing deterioration in other family members’ (p. 4), they postulate that a link does exist and that family relationships play a significant part in the association. Certainly, a number of authors have suggested that parental conflict may interfere in the treatment a child receives for their mental health (Anant & Raguram 2005; Dadds, 1992; Reyno & McGrath 2006). While parental discord has been linked to increased internalising and externalising issues in children the question remains as to whether the precipitating factors behind any parental discord could be due to the child’s mental illness and behaviours or might be related to issues of parental mental health.

2.6.2 Care issues

The issue of care is a less significant category with the main focus being the difficulties parents might face when managing a child with a mental illness (Falkov, 2012; Maybery et al., 2005; Biederman et al., 2006). There is no discussion found in this review of the literature that talks about any bidirectional effect in the caring relationship. Despite this in the study by Nagl-Cupal, Daniel, Koller, and Mayer (2014) it was found that child caregivers showed higher ‘worry’ than their peers. Certainly, caring for a mentally ill parent increases the risk of a child developing a mental illness (Department of Health, 1999; Grant, Repper, & Nolan, 2008).

2.6.3 Anger/behaviour issues

Parental psychopathology had been found to be associated with behaviour issues in children and Wilkinson et al. (2013), in their study, suggested there may be a bidirectional effect. Holmes (2013) described how poor maternal mental health was found to be related to behavioural problems in children. Research does indicate that children who show disruptive and aggressive behaviour are more likely to have difficulties with dyadic relationships (Rubin, Bukowski, & Parker, 2006).

2.6.4 Economic issues

The primary difficulty raised in relation to economic issues were the financial strain placed on parents of getting their child to appointments and having to take time off work to care for their child (Harden, 2005). The impact of caring for a child with a mental illness and being restricted because of their own mental illness was, as suggested by Wilkinson et al. (2013), highly likely.

2.6.5 Abuse issues

The risk of parent-child aggression is increased particularly in relation to any negative child attributes (Azar, Okado, Stevenson, & Robinson, 2013; Montes, de Paúl, & Milner, 2001) and it could

be posited that such a scenario is more probable where a child has a mental illness (Wolfe, 2011). In the research by Pajer et al. (2014) and Stith et al. (2009) links were found between abuse issues and mental health factors. Falkov (2012) highlighted how the response of a child can cause a parent to be abusive to the child rather than the abuse occurring the other way around. This does not consider the specific issues of oppositional defiant disorder or conduct disorders which are both beyond the scope of this thesis.

2.6.6 Stress and mental illness

As with parental mental illness childhood mental illness may impact on a parent by way of anxiety and depression and as noted previously other authors have tended to use the blanket and unspecified term of stress. Weismann et al. (2006) found ‘some’ causal effect between maternal depression and child depression. Wilkinson et al. (2013) found there were somatic symptoms, depression and anxiety in both children and their parent (s). The STAR*D study by Weismann et al. (2006), like the study by Wilkinson et al (2013), found that when mothers were treated for depression and this improved so too did the chance of improvement in their child’s depression. In a comparison study Batten et al. (2012) found that the severity of a mother’s depression was predictive of child behavioural problems. These findings would seem to indicate a bidirectional link between child mental health and parent mental health. A number of writers report that there is likely a link between parental and child stress levels (Serido, Almeida, & Wethington, 2004; Wexler, DiFluvio, & Burke, 2009). In the study by Harden (2005) it was found that a stress contributor for parents was a feeling of guilt that their own mental illness led to or impacted on their child’s mental health.

Hammen, Burge, and Stansbury (1990) found that children of unipolar women also experienced significant rates of disorder and these were commonly comorbid disorders. Vidair et al. (2011) evaluated 848 children of depressed or anxious parents and found they were at increased risk of developing a mental disorder. More recently Wesseldijk et al. (2018) found that children of parents with a mental illness were at 30% higher risk of developing and maintaining psychiatric symptoms in the long term. What is more, childhood mental illness had been found to be related to long-term negative effects on psychosocial functioning (Finsaas et al., 2018).

2.7 THEORETICAL MODELS OF THE BIDIRECTIONAL INFLUENCES WHERE THERE IS CO-EXISTING MENTAL ILLNESS

The influences within individuals may be genetic, social or environmental. Research looking at the impact of any improvement in maternal mental health on the child’s mental health has indicated a link. There has been no specific research looking at the area of the bidirectional impact of child

mental illness and parental mental illness but as has been seen from the literature the indicators are that there is a bidirectional link in the key areas of mental health or stress and relationships within the family system. While this makes sense there appears to be a significant vacuum in current research.

To fully consider this issue it is important to consider what might be happening where there are reciprocal mental health issues (where the parent has a mental illness and the child has a mental illness). Figure 1 below depicts these possible linkages and highlights how these interactions can link to emotional dysregulation within the whole family system. Emotional regulation is a possible key in the whole dynamic of the parent-child interaction as it is central to the functioning of children and adolescents. Emotional regulation is a good place to help us understand what might be happening within the family system. Gross (1998) describes emotional regulation as critically related to behaviour and is a mechanism to help children manage what is happening around them. Many writers (Salovey, 2006; Blair, 2003; Shapiro, 2000) describe emotional regulation as the key to happiness, competence and success. Most practitioners in the field believe that emotional regulation can be taught but how realistic is such training when living in an environment of ongoing emotional dysregulation? How too does the parent in this family cope with the environmental triggers and intensity of emotion they might experience because of their own mental illness?

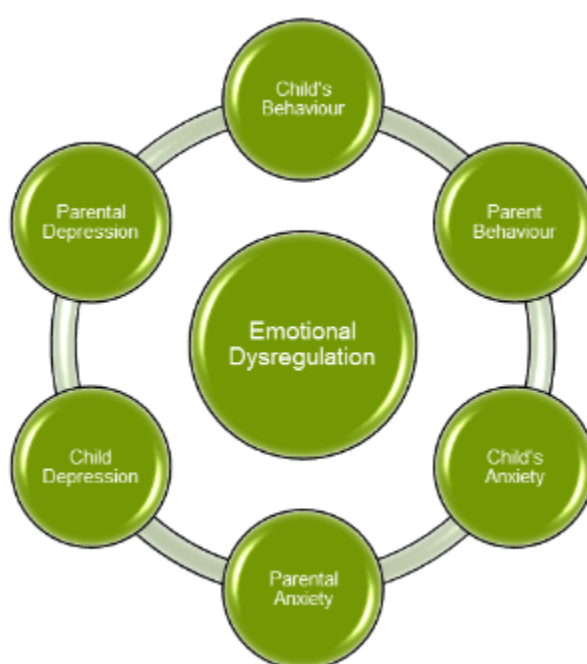


Fig 2.1: Prospective linkages between child and parent mental illness.

The Crossing Bridges Family Model (figure 2.2) developed by Dr Adrian Falkov (1998) and further expanded (2012), is a model that integrates mental health, social and family domains in a way that exemplifies the interactions between the various components of the family system. The model

can be usefully to help us understand, in an easily followed form, the issues families experience when a parent suffers mental illness and how this might impact on a child's mental health. It also helps to elucidate the impact on the family system of some other key factors: family resilience and risk and parent-child-professional interactions (Falkov in Göpfert et al., 2004). The Family Model uses eight key areas, or domains, in an attempt to show how interactions between a child, a parent, parenting issues and adult mental health issues interrelate in many directions and with great complexity. Falkov's model importantly points to how both risk and protective factors impact on what happens in a family and therefore need to be considered in any discussion and intervention with parents and children.

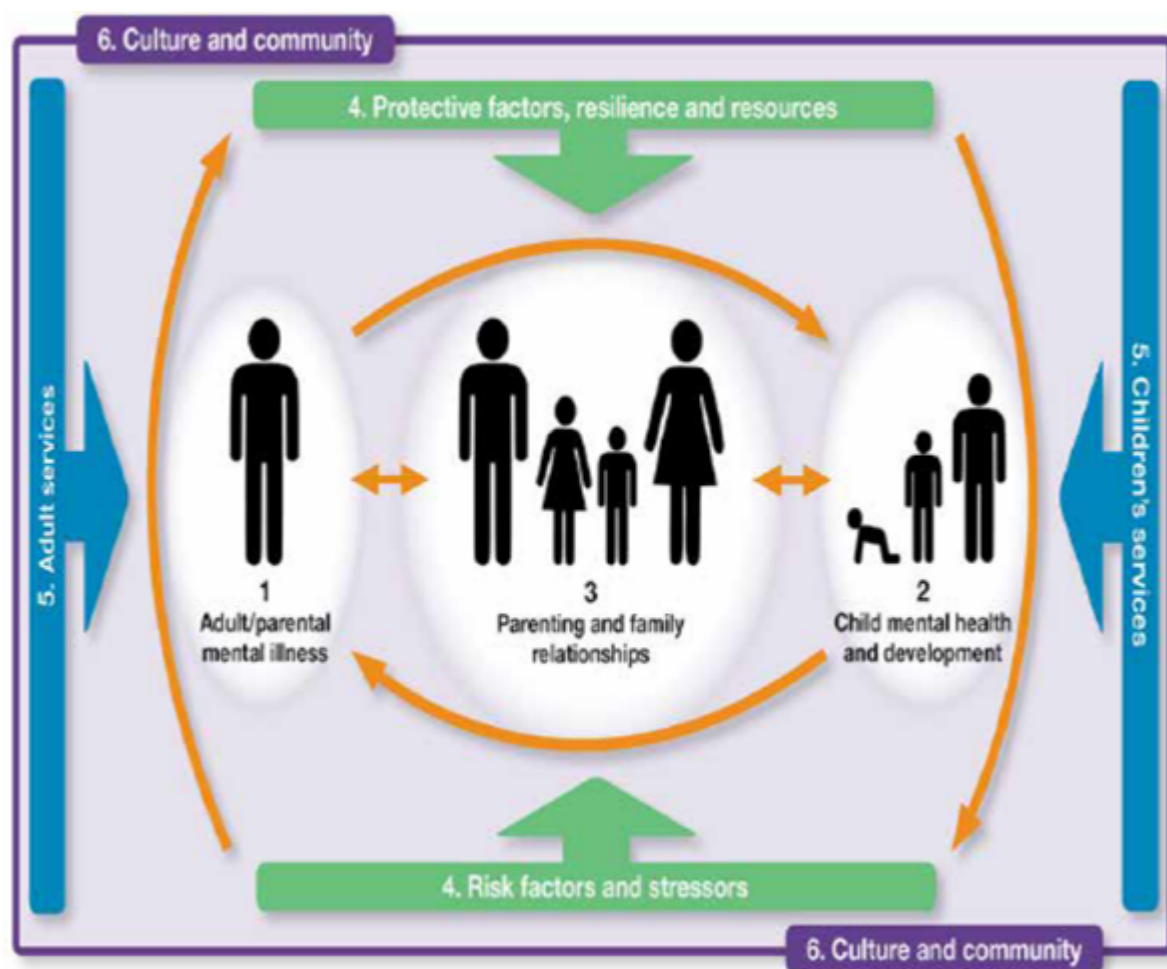


Fig 2.2: The Crossing Bridges Family Model.

While the Falkov model is a comprehensive look at the eight domains influencing the family system, and particularly parental mental illness, the focal interest of this study is on the interplay between the parent and child where both have a mental illness. The focus of the thesis has been in examining the microenvironment within the Family Model of the interaction between a parent and child. Falkov highlights a 'substantial' relationship between parental and maternal psychopathology

and mental health outcomes for children. Falkov provides us with a comprehensive view of the linkages between parental mental illness, parental symptoms and the effects on parent-child relationships. He highlights how parental mental illness impacts on cognitive and language development as well as educational achievement of children as well as on social and emotional development. Falkov talks of the interplay between a child's response to their parent's mental illness and the subsequent effects this might have for both the child and parent. Not a unidirectional but a bidirectional consideration. The Family Model goes on to point to the multitude of impacts on the child such as attachment issues, developmental issues and health issues. Falkov points to the compelling evidence that parental mental illness is a significant high-risk factor for children and adolescents and highlights a key statement from a Harvard working paper:

Serious depression in parents and caregivers can affect far more than the adults who are ill. It also influences the well-being of the children in their care... When children grow up in an environment of mental illness, the development of their brains may be affected, with implications for their ability to learn as well as for their own later physical and mental health.

(National Forum on Early Childhood Policy Programs, p.1, 2008)

Difficulties are more likely when the parent/child relationship is characterised as being more extreme or there are inappropriate patterns of interaction. Where a parent has a mental illness there are likely to be a number of parent-child relationship difficulties (Falkov, 2012). Within this the risk exists that the child might be drawn into their parent's symptoms. Another consideration in the parent-child interaction has been seen in the lack of emotional support from the parent that can lead to a child becoming depressed (Forbes & Cohn, 2003).

The gaps evident in current research can be found in the linkage and co-relationship challenges that occur between a parent and child. Consideration of successes and challenges where both have a mental illness need further examination which is what this thesis begins to do.

It is evident that the interactions between various components in the Family Model are not simple or unidirectional. A circulatory micro process likely occurs in the interactions that those with mental illness experience. The way mental illness impacts on a parent may affect their parenting style, which in turn may influence a child's behaviour and emotional response. This circulatory micro process in turn feeds back into how a parent might parent. Similarly, the child's presentation (intelligence, behaviour, and personality) may affect the parent's style of interaction or parenting; the effectiveness or otherwise of this may in turn impact on the amount of stress the parent experiences and thus this may in turn further influence a parent's mental health (Falkov, 2012; Van Loon et al., 2014; Murphy, Peters, Wilkes, & Jackson, 2014). It is important to note that it has been found that

the particular mental illness of a parent does not result in different effects on children (Friedmann et al., 1997; Biederman et al., 2001), a process called transgenerational equifinality (Cicchetti & Toth, 2009).

Children's outcomes can be improved through the greater dissemination of knowledge about mental illness and by providing this at a younger age. This review of the literature indicated that it is imperative children's help-seeking behaviours are supported in order to avoid the transmission of psychiatric disorders and to reduce a wide range of risk factors and negative outcomes (Goodman & Gotlib, 1999; Ramchandani & Psychogiou, 2009; Nicholson & Henry, 2003). As mentioned previously, there is large area of research in child and adolescent development in relation to resilience and protective factors, which contributes to the framing of how children seek help. It is through help seeking that children may ameliorate the impacts of bidirectional mental illness, though the literature does not directly provide an evidence base on how programs or interventions increase children's help-seeking behaviour (World Health Organization, 2007). This study has sought to add further to the literature in this area through the lived experience of children.

2.8 SUMMARY AND IMPLICATIONS

The literature review identified a lack of research into how a child's mental illness might impact on a parent. It was also found that limited research existed in relation to the prevalence rates of parental mental illness where a child attended a tertiary mental health service. Generally, the literature takes a unidirectional viewpoint which hinders the capacity to understand any bidirectional influences between parents and children. To address these gaps in the literature this thesis has sought to tackle the following questions:

1. To determine the extent of mental illness co-existing in families attending a child-focused mental health service
2. To investigate any impacts of parental mental illness on child symptomology
3. To determine the influence of mental illness in the family and, from a parental perspective, establish what would be helpful in reducing those influences
4. To determine the influence of mental illness in the family from a child's perspective and establish what would be helpful in reducing those influences

In seeking to address the research questions the thesis has used a mixed methods approach that consisted of two parts: data collection using clinician questionnaires and file audit; and interviews with parents and children analysed through interpretative phenomenological processes. The mixed

method approach has ensured the research questions have been answered from different perspectives, adding to the overall research validity (Cresswell, 2003). To achieve an optimal outcome for the approach the study has used a concurrent triangulation design model methodology. Chapter 3 outlines the quantitative methodology employed for this study and then describes the procedures used to implement the quantitative part of the research in line with the first two research questions. The purpose at this point of the study had been to establish whether anecdotal ideas that many children presenting to CAMHS lived with parents with a mental illness were in fact true. In the event such a situation existed, would the data show that co-existing mental illness impacted on mental health service outcomes? It should also be noted that the research methodology is shown in the specified papers of this thesis.

In light of the limited data in relation to child and parent experiences of co-existing mental illness in families the quantitative part of this study sought to examine the extent of mental illness in families of children attending an Australian regional CAMHS (section 4.1). Use of routine outcome measures are frequently used to ascertain improvement in children's symptomology and the second part of the study (section 4.2) has examined whether living with a parent with a mental illness produces any impact on routine clinical outcome measures.

This literature review has purposefully not been exhaustive as the aim had been to highlight the unidirectional approaches that dominate the current discourse. As previously pointed out, there is extensive literature considering parents with a mental illness and children with a disability. There is little direct literature specifically examining bidirectional impacts of mental illness in families where there is both parental mental illness and child mental illness.

Chapter 3: Research Design - Quantitative

Section 3.1 discusses the methodology used in the study, the stages by which the methodology was implemented, and the research design (section 3.1.1); section 3.2 details the participants in the study; section 3.3 briefly describes the procedure and time line; section 3.4 outlines the analysis; and the final section of this chapter, section 3.5 discusses the ethical considerations of the research and problems and limitations.

3.1 QUANTITATIVE METHODOLOGY AND RESEARCH DESIGN

All behavioural research is made up of a combination of quantitative and qualitative elements (Newman & Ridenour, 1998). This thesis is no different with the premise that without knowing if there is a problem there is no point in considering the phenomena of those who live in the family where there is co-existing mental illness. The lack of research in the area indicates that there is likely not an issue worth considering but this assertion does not fit with anecdotal reports from those who attend and work in child and adolescent mental health services. In this part of the thesis the research design has been guided by Creswell and Plano Clark (2007) and is two-fold. Firstly, through a descriptive design to determine the current status of mental illness in the cohort of regional CAMHS families. Secondly by the examination of outcome measures, using a correlational design and exploring the relationship between clinical scores for children compared to the status of parental mental health.

3.1.1 Research design

Following a presentation to community mental health service managers, explaining the research purpose and rationale a follow up letter was sent to the managers with a simple questionnaire that could be completed in hard or soft form. The audit approach examined all the active cases of the regional mental health service for both child and adult clients. The initial audit approach was through a case manager completed questionnaire [Appendix A] for all open cases at the time of the study. The questionnaire was constructed based on audits that had previously been developed in previous studies by Mercer (unpublished), Howe et al., (2009), Baker and Lees (2014), and Fernbacher et al., (2009). To standardise the multitude of possible diagnosis ICD10-AM (2015) classifications were used and split into the most significant presenting mental illnesses: mood disorders, anxiety disorders, behavioural/emotional disorders and pervasive developmental disorders (PDD), with the remainder classified as a mix of other disorders. The questionnaire consisted of three parts: general

demographics; parental mental illness details; and child mental illness details. The final questionnaire design was reviewed for consistency and appropriateness by a selection of clinicians and consumer advocates from different external mental health services to the one being considered.

3.2 PARTICIPANTS

Participants were active clients of the mental health service which covered a regional area of Australia. Client demographics were varied with a large number on benefits (welfare) but also some in employment or looking for employment. Poverty and low educational achievement were a consistent part of the client profile, though not exclusively a feature of the cohort of people presenting to the mental health service. The majority of people attending the service were white Australian with only 2% of Aboriginal descent.

3.3 PROCEDURE AND TIMELINE

The majority of clinicians completed the questionnaire electronically with the data stored on a CMH restricted file only accessible by an administrator and the researcher. Each questionnaire was given a unique code. The clinicians were asked to complete the questionnaire over a one-month period to coincide with the service reporting cycle. For the purpose of this thesis only the data in relation to CAMHS clients was analysed.

The first visual examination of the CAMHS data showed a significant amount of incomplete data with a large number of questionnaire fields left blank. An amended ethics application was made to allow data to be collected through paper files and the Department of Health, Client Management Interface (CMI) data base. This data was collected by a team of health students and independent clinicians and entered onto the questionnaire data base. Although able to enter the data the team were unable to read any existing data as these fields were locked. The information was compared electronically and incomplete fields updated with completed fields verified. Discrepancies were cross checked with the data files and in discussion with clinicians. At this point data was coded and de-identified.

In the second part of the audit all the information (routine outcome measures) were extracted directly from the CMI database and were taken at commencement of intervention and at each of the following two statutory outcome measure reviews.

3.4 ANALYSIS

Analysis of the primary data was conducted using frequency and tabular examinations utilising IBM SPSS software for more in-depth analysis. To provide consistency with the Department of

Health (2015b) reporting, the mental illness diagnosis of both the children and the parents was classified according to (ICD10-clinical modification) the health department categorisation. The grouping of diagnoses was applied to all data, which were combined into the five key presenting diagnoses: mood, anxiety, behavioural/emotional, and pervasive developmental disorders, with all remaining disorders placed in an ‘other’ category. Children’s diagnoses were then linked to any parental diagnosis. The final stage was to apply the recorded demographic data to all the children and link this additional information to parental diagnosis using a simple tabular form.

The second research question of this thesis sought to use outcome measure data, routinely collected by CAMHS, to determine change over time. The measures examined consisted of Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) and Children’s Global Assessment Scale (CGAS) (Department of Health and Human Services [DHHS], 2018). The original intention was to assess the HoNOSCA, CGAS and Strengths and Difficulties Questionnaire (SDQ) scores. However, the SDQ completion rate was meagre. Of the total possible SDQs for the initial and 6-month periods (n=268) the numbers completed were: parent (n=19, 7.1%) and child (n=15, 5.6%). In light of the low completion rate, it was decided to exclude SDQ data from the investigation. Clinicians provided raw scores for each child, and these were matched using a de-identified code to parent status. Using Excel and SPSS, the data was analysed using means and averages to assess for any trends and differences. Following an initial general review of both the HoNOSCA and CGAS scores in Excel for Mac (version 14.7.7) all subsequent data analyses were performed using IBM SPSS statistics for Mac version 24.0 (2017). Preliminary checks were conducted to ensure that there was no violation of the assumptions. This was followed by paired samples t-tests to compare improvement in the children’s HoNOSCA and CGAS scores between children living with a parent with a mental illness and those living with a parent without a mental illness.

3.5 ETHICS AND LIMITATIONS

Ethics approval for the study was obtained from both the regional hospital (HREC: 2014000988) and Monash University (MUHREC: CF14/1973) Human Research Ethics Committees. Consumer consent was not required as data used in the study were routinely collected within CAMHS. All the outcome measures were completed during routine service delivery by clinicians and were lodged with the Department of Health and Human Services (DHHS) independent of the research. The collection of the data was covered by local statute (DHHS, 2018) and CAMHS policy.

The initial limitations of clinician apathy in the first part of the data collection process were overcome by finalising the audit through data matching and comparing all the data produced. In the

second part of the data collection electronic data was limited through DHHS provision that gave clinicians an option to omit two (SDQ parent and SDQ Child) of the four collected outcome measures.

Chapter 4: Quantitative Papers

4.1 BRIEF INTRODUCTION

The need to establish if an issue existed was examined in this first paper.

Objective 1 - Carry out an investigative audit, to determine the extent of mental illness co-existing in families attending a child-focused mental health service.

Given the strong link between a child and parent mental illness, it was unexpected to find a paucity of research concerning the mental health status of parents of children attending mental health services. With the limited research in this area only a few early isolated studies from the UK were found. One found 36% of the 253 children attending a CAMHS had a caregiver (either biological or not) with a concurrent psychiatric disorder (Dover, Leahy, & Foreman, 1993). Another was a retrospective case study which found 9% of the 322 children had a parent with a mental illness (Robson & Gingell, 2012). Although not looking specifically at CAMHS, Maybery, Reupert, Goodyear, Ritchie, and Brann (2009) found that children living with a parent with a mental illness were twice as likely to develop a mental illness themselves compared to their peers.

In the earlier national survey of mental health in Australia (Birleson, Sawyer, & Storm, 2000) there was found to be a high prevalence rate of children with a significant mental health problem. These findings were consistent with those of Costello (1989) who found prevalence rates of between 17% and 22%. With an average of 60% of children with at least one parent with a mental illness, and 40% of adult mental health services patients found to be parents (Nicholson et al., 2004; RCP, 2011) the question raised was to what extent is there co-existing mental illness in families attending mental health services. Importantly, parental mental illness is not an area that is specifically addressed by the services children access for their mental illness (Gatsou et al., 2016). In examining children's services in Canada, Baker and Lees (2014) found that almost three quarters of patients had a parent with a mental health concern or diagnosed mental illness. Of these, the primary diagnoses were depression (38%) and anxiety (26%). Of the 28 parents who later took part in a telephone interview, three quarters highlighted that they felt they needed additional support services involved with their family. Fernbacher et al., (2009) audited a group of services for families where a parent has a mental illness (FaPMI). That study utilised direct structured interviews with clinicians to augment their audit data and found that 40.4% of FaPMI clients were mothers living with their child. The principal diagnosis for the parents in that study was schizophrenia, psychosis, or depression.

The few published international studies indicate that, where children are receiving treatment, a majority of their parents also have a mental illness. While current studies examine specialist and targeted services, none have looked at a regional CAMHS using a cross-sectional study design. Essential for this investigation was the novel use of both a clinician questionnaire and case file audit to ensure triangulation of the data collection. The question being considered for this thesis, and in answer to the first research question, was to what extent does mental illness co-exist in families of children attending a regional child mental health service?

While Dover et al. (1994) had examined a CAMHS the cohort of carers was mixed biological and foster caregivers. Also, the study itself noted a key limitation as being ‘there were no diagnostic criteria for the presence of caretaker psychiatric illness’ (p. 140). In another study by Vidair et al. (2011) Hispanic children who were referred solely by a paediatrician were considered looking at parents’ self-reports rather than at clinically determined diagnoses. The closest study to this thesis was the unpublished examination of a regional CAMHS by Mercer and Knapton (2014) referred to earlier. This study pondered the problem of there not being a systematic approach for screening parents whose child attended a CAMHS, an issue raised by Nicholson, Geller, Fisher, and Dion (1993) over 20 years before this current discourse. Furthermore, there seemed to be a paradox existing whereby comparable studies of general CAMHS appear to have been neglected for some considerable time. Recent studies have focused their approach on a specific mental illness which fit with the ideas that consider a possible association between a specific child and parent mental illness (Bornovalova, Hicks, Iacono, & McGue, 2010). This is in contrast to the viewpoint that there is no link between outcomes for children and a specific diagnosis for a parent (Hosman, van Doesum, & van Santvoort, 2009).

4.1.1 Theoretical underpinnings

The theoretical approach of the Falkov (2012) Crossing Bridges Family Model describes the ‘interplay between any child’s response to parental symptoms and the consequent effects (emotional and behavioural adaptations) on parents, siblings and others in the family’ (p.118). The model outlines the importance of the child-parent dyad in disturbing, even escalating, child and parent mental health issues. Accepting the premise that an interplay exists in the interaction between children and parents, this thesis expands the literature by examining the bidirectional impacts of mental illness. As highlighted by Reupert, Maybery, Cox, and Scott Stokes (2015), in their narrative thematic analysis of 31 eligible papers, there is ‘little systematic examination of the specific place of family roles and relationships in the recovery process and how different family members might facilitate and/or hinder recovery’ (p. 497). Two key points from this are significant for this study: firstly, negative family

interactions which might be directly related to psychiatric difficulties (Topor et al., 2006); and different family roles. As Markowitz (2001) suggested the severity of mental illness can impact relationships and when mental health improves so to do relationships.

Theories in relation to transgenerational influences of behaviour, communication and emotional responses also play a part and might impact the next generation (Paul & Byfield, 1975). The quality of relationships in families influences subsequent relationships and functioning of children, with patterns of behaviour transmitted from generation to generation. Family secrecy around emotions, in turn, shape children's emotional experiences. Benoit and Parker (1994) found a strong link between grandparent's emotional attachment and their grandchild. Studies have shown an active link between adult attachment security and infant security (Crittenden & Landini, 2011; Dozier, Stovall, Albus, & Bates, 2001; Shah, Fonagy, & Strathearn, 2010). In earlier work, Crittenden (2008) suggests that the continuity of attachment across generations is stronger where there is a secure attachment. The Bailey, Tarabulsky, Moran, Pederson, and Bento (2017) study of 184 mother-infant dyads concluded that 'intergenerational configurations of attachment might be linked to the elaboration of disorganisation' (p. 444). The first step in any examination is to determine the extent of the problem. With the Crossing Bridges Family Model in mind, the goal was to ascertain if a problem existed in a regional CAMHS in Australia.

4.1.2 Paper 1 - Prevalence of mental illness within families in a regional child-focused mental health service




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ORIGINAL ARTICLE

Prevalence of mental illness within families in a regional child-focussed mental health service

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ABSTRACT: Nearly 50% of all mental illnesses begin in childhood before the age of 14 years, and over 20% of parents have a mental illness. Few studies have examined the co-occurrence of mental illnesses in parents and children. In the present study, we examined the extent of mental illness within families of 152 clients attending an Australian regional child and adolescent mental health service (CAMHS). A cross-sectional study design was employed involving a case record review and clinician-completed questionnaire of the children and youth attending a CAMHS. It was found that 79% of these children were living with a parent with mental illness. The predominant diagnosis of both child and parent was an anxiety or mood disorder, and many families had co-occurring risk factors of domestic violence and limited social supports. The findings in this Australian cohort are similar to those of other international research. While novel in nature, the present study has highlighted the extent of both mental illness and scarce supports for both children and parents in the same family. The findings indicate the need for a coordinated multiservice delivery of appropriate and consistent family-focussed interventions, responding to both mental illness and social supports for children and parents. Further research should examine specific components of family need and support, as seen through the eyes of the child and their parent.

KEY WORDS: child, community mental health service, cross-sectional study, mother, prevalence.

INTRODUCTION

A nationwide study by Lawrence *et al.* (2015) found that almost 14% of Australian young people between the ages of 4 and 17 years have emotional or behavioural problems, with many of these having long-term mental health conditions (Australian Institute of Health and Welfare, Australia's Health, 2016). Kessler *et al.* (2005) reported that half of all mental illnesses start before the age of 14 years, and one-quarter of those

young people will have a higher 'burden of disease' associated with their illness.

With almost half the Australian adult population experiencing a mental health problem in their lifetime (Australian Institute of Health and Welfare, 2016), it has been estimated that almost one-quarter of Australian children have a parent with a mental illness (Maybery *et al.* 2005). The impact of parental mental illness on children has been well documented (Beardslee *et al.* 1998; Hanington *et al.* 2011; Nicholson *et al.* 2004; Reupert & Maybery 2009; Reupert *et al.* 2012; & Shen *et al.* 2016). Both Maybery *et al.* (2009a,b) and Meltzer *et al.* (2003) further reported that there is a two-to-three times greater chance of children developing a mental illness themselves if they have a parent with a mental illness. Rasic *et al.* (2014) also highlighted that children of parents with mental illness have a 33% risk of developing a mental illness themselves, with an overall increased risk in parents with

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schizophrenia, bipolar disorder, and major depressive disorder. Furthermore, children of parents with a mental illness generally have more difficulty in all aspects of their lives, with influences on their peer relationships, school performance, social interaction and day-to-day living (Maybery *et al.* 2005; Reupert & Maybery 2007). While not all children of parents with a mental illness develop mental health problems (Gladstone *et al.* 2006), there is an increased risk that they might do so (Cowling 1999; Rutter *et al.* 1999).

Parenting can be difficult at the best of times, and it is undoubtedly more demanding for parents with a mental illness. Stress from the parenting role can negatively affect parental mental health, and conversely, the parent's mental illness can potentially influence their capacity to parent (Royal College of Psychiatrists 2011). As such, mental illness can negatively affect both the parent and their children's/family's well-being on a temporary or ongoing basis (Göpfert *et al.* 2004; Reupert & Maybery 2009). Improvements in the parent's symptoms can lead to an improvement in their child's mental health (Swartz *et al.* 2005).

There is a paucity of research on the connection between a parent's mental illness and their child's mental illness, with the focus of available studies being one directional, looking specifically on the impact of the parent's mental illness on their children. The Australian study undertaken by Howe *et al.* (2009) utilized a census approach of an adult mental health service, and found that one-third of adult mental health patients were parents of children under 18 years, and over half of these children were living with a parent with mental illness. The principal diagnosis of parents was found to be mood or psychotic illness. The authors, however, reported limitations due to a reliance on clinician-reporting accuracy.

In a further Australian study, Fernbacher *et al.* (2009) audited a group of services for families where a parent has a mental illness (FaPMI), highlighting differences in recording protocols across those services. That study utilized direct structured interviews with clinicians to augment their audit data, and found that 40.4% of FaPMI clients, the majority being mothers, lived with their child. The principal diagnosis for the parents in this study was schizophrenia, psychosis, or depression, with 22 clients noted as having an unconfirmed diagnosis.

Given the strong link between child and parent mental illness, it is surprising that there is a scarcity of research in the area of children attending mental health services in relation to the mental health status

of their parents. In a literature search, only four relevant studies were found. An audit of UK adult and child mental health services and disability services found that 59% of young people had at least one parent with a mental illness, and 40% of adult services had parents with dependent children (Gatsou *et al.* 2016). Furthermore, it was found that parental mental illness was not addressed by services the children accessed for their own mental illness, with only three families having multiagency supports in place. In examining children's services in Canada, Baker and Lees (2014) found that almost three-quarters of patients had a parent with a mental health concern or mental illness. Of these, the primary diagnoses were depression (38%) and anxiety (26%). Of the 28 parents who later took part in a telephone interview, three-quarters highlighted that they felt they needed additional support services involved.

A family-focussed study in a Netherlands child and adolescent psychiatry outpatient clinic (Van Veen *et al.* 2016) focussed on screening parents for mental illnesses. Of the 230 parents, approximately two-thirds of mothers and almost half of fathers indicated they had a mental illness.

The most comprehensive study with direct parallels to the current study is the unpublished audit by Mercer and Knapton (pers. comm., 2014). In their Canadian regional child and adolescent mental health service (CAMHS), they reviewed 262 open mental health files and found that 68% of the families had parents with a mental illness or a mental health concern, with 70% being mothers. Similar to the Canadian study, the principal diagnosis of the parents was depression (67%) and anxiety (39%), with almost one-third of families using substances, and over three-quarters of families lacking additional family support.

While approximately one-quarter of all Australian children have a parent with a mental illness, and one-fifth of Australian adult mental health service consumers are parents, little is known about the mental health status of parents of children attending CAMHS in Australia. The few published international studies indicate that, where children are receiving treatment, a majority of their parents also have a mental illness. In the most comparable studies, the primary diagnosis of these parents is either mood or anxiety disorders, with more than three-quarters reporting they have few or no additional family supports.

A cross-sectional study design was used for the present study, involving a case record review and clinician-completed questionnaire exploring the incidence

of parental mental illness in a population of children attending an Australian CAMHS. The study employed a data-collection procedure based on previous protocols (e.g. N. Mercer & D. Knapton, pers. comm., 2014), along with a case file audit to ensure triangulation of the data collection. The aims of this cross-sectional study were to: (i) evaluate through a questionnaire with mental health clinicians the extent of mental illness and other concerns for families of regional CAMHS clients; (ii) consolidate information from clinicians through a file and government electronic data system review; and (iii) describe the characteristics and key demographics of the cases at the time of the study.

METHODS

Participants and setting

The study region comprised a large rural and regional area of Australia, with the hospital providing CAMHS across the district. Seven area offices provide general and specialist child and adolescent psychiatric services. There are 22 full- or part-time clinicians in CAMHS, both in nursing and other disciplines, working with children and adolescents from the age of 0–18 years referred because of a possible moderate-to-severe mental illness. In line with other CAMHS, interventions vary from individual through to family work (Department of Health 2015), with each clinician carrying a caseload of between 16 and 26 young people, depending on the seniority of the clinician and complexity of the case. At the start of each CAMHS episode of care, the CAMHS clinician would commence a comprehensive biopsychosocial assessment with the young person, their parent(s), caregiver(s), and close support people. There were 152 young people aged between 5 and 18 years attending CAMHS during the study period (August 2014). Of the 152 children, 59% were male ($n = 90$) and 41% were female ($n = 62$).

Procedure

A three-pronged procedure was used in the study: clinician-completed questionnaire, case record review, and a review of the Government Electronic Client Management Interface system (Department of Health 2017). The initial study approach sought to ascertain the extent of mental illness within families through the clinician-completed questionnaire (Appendix S1). The questionnaire was informed by audits developed by Mercer and Knapton (pers. comm., 2014), Howe *et al.*

(2009), Baker and Lees (2014), and Fernbacher *et al.* (2009). All these studies used the approach of obtaining the information from the clinician, either through an audit questionnaire or by interviewing the clinicians. A focus group of academics and key mental health stakeholders from the health sector reviewed the audit formats from the earlier studies, and made adaptations to better meet the target group of the regional service. Five clinicians from a mix of disciplines and services then examined the draft questionnaire tool, with minor amendments being made before distribution to the wider community mental health service.

From the World Health Organization [WHO], 2010 the International Classification of Diseases 10th revision (ICD10-clinical modification) sets out internationally-agreed diagnostic criteria; the standard required by the Department of Health and Human Services for all health bodies (Department of Health 2015), and was used in the present study. A consultant child and adolescent psychiatrist had diagnosed all the young people with a mental illness. The main diagnosis of these children fell into four main categories as related to ICD10: mood disorders, anxiety disorders, behavioural/emotional disorders, and pervasive developmental delay, with the remainder a mix of other disorders. All the parents who disclosed a validated mental illness reported this, as diagnosed by a general practitioner or psychologist.

Prior to the study commencing, a presentation was given to the mental health service managers explaining the reasoning and rationale for the study. This was then followed by presentations to each of the community mental health area teams. Clinicians were advised about confidentiality, and were reassured that once the data-collection process was completed, all information would be de-identified.

Clinicians completed the data collection form for each of their clients in the service. The study gathered individual and family demographic data, including sex, age, and key risk factors. In order to triangulate data, this information was then compared to files and the Victoria Health Department (2015) Client Management Interface system. All study data were inputted onto a secure electronic database within the hospital computer system, only accessible by the researchers once the cross-sectional study period had finished.

The initial analysis of the data showed inconsistencies and missing data in 43 (28%) questionnaires. An electronic file review of all 152 CAMHS files was then undertaken by two independent clinicians to check the accuracy of the information received from the other

clinicians and to input omitted data. The independent clinicians logged the information separately, as recorded on the electronic records. These were matched for any inconsistencies to rule out any potential bias.

While the study focussed on a period of 1 month, the clinician-completed questionnaires were filled in over 2 months to reduce the burden on clinicians, with clinicians being sent regular reminders to improve completion rates. The research was approved by the university and hospital ethics committees.

The data obtained from the case records and clinician-completed questionnaire were examined using frequency and tabular examination of children's ages according to diagnosis, along with examining mother and child diagnoses; χ^2 -test analyses were undertaken to examine differences in key variables (e.g. domestic violence) that might be found according to parental mental health status.

RESULTS

The data collected consisted of demographic information about the child, parent, and family circumstances, including mental illness diagnosis, substance use in the family, domestic violence in the home, and the level of social support received by the family. To provide consistency with Victoria Health Department (2015) reporting, the mental illness diagnosis of both the children and the parents was re-classified to (ICD10-clinical modification) categorization. The grouping of diagnoses was applied to all data, which were combined into the five key presenting diagnoses: mood, anxiety, behavioural/emotional, and pervasive developmental disorders, with all remaining disorders placed in an 'other' category. The majority of children in this study lived in households with their mothers as the sole caregiver ($n = 91$, 60%); 14 children (9%) lived solely with their fathers; 27 (18%) were cared for by both parents; and 20 (13%) lived in alternative

arrangements, including eight (5%) living in foster care.

The mental illness diagnoses of the 152 children attending CAMHS over the cross-sectional study period was split into three age ranges: (i) younger primary school-aged children; (ii) older primary and young secondary school-aged children; and (iii) older secondary school-aged children (Table 1).

As shown in Table 1, 32% of children had a primary diagnosis of anxiety disorder, followed by 23% with a mood (affective) diagnosis, and over one-quarter with behavioural/emotional disorders. When considering diagnosis by age group, the younger children presented with behavioural/emotional issues, middle-year children most commonly had anxiety disorders, and the older children experienced high levels of mood (affective) disorders and anxiety disorders. In addition to their primary diagnosis, 63% of the children had a recorded secondary diagnosis, with these broken down into anxiety disorders (26%), behavioural/emotional disorders (16%), and mood disorders (12%).

The diagnoses of the children with that of their mothers are aligned in Table 2. As mothers represent 78% ($n = 118$) of the primary caregivers reported in the study, they are the only parent reported on in Table 2. Of the 14 fathers who were nominated as the primary caregiver, five were reported to have a mental illness ($n = 4$ anxiety, $n = 1$ mood disorder). When validated and non-validated diagnoses were combined, the most common parental (mothers and fathers) diagnosis was a mood disorder ($n = 64$, 54%).

As seen in Table 2, the results show that, on average, just under half of the mothers had a mood disorder diagnosis, and nearly half of the mothers reported a non-validated mental health issue. Thirty-four percent of the mothers with a mood disorder, and almost half those with an anxiety disorder, lived with a child who also had an anxiety disorder. Clinicians reported that a general practitioner or private psychologist diagnosed 83% of the parents with a mental illness.

TABLE 1: *Children's age stages according to diagnosis*

Child's diagnosis	Age (years)			Total
	5–10	11–14	15–18	
Mood (affective) disorders	1 (0.5%)	7 (4.5%)	27 (18%)	35 (23%)
Anxiety disorders	9 (6%)	20 (13%)	20 (13%)	49 (32%)
Pervasive developmental disorders	4 (3%)	5 (3%)	11 (7%)	20 (13%)
Behaviour/emotional disorders	15 (10%)	15 (10%)	10 (6.5%)	40 (26.5%)
Other disorders	0 (0%)	2 (1.5%)	6 (4%)	8 (5.5%)
Total	29 (19.5%)	49 (32%)	74 (48.5%)	152 (100%)

TABLE 2: *Mother's diagnosis in relation to child's diagnostic category*

	Mother's diagnosis					
	Mood disorder (<i>n</i> = 53)	Anxiety disorder (<i>n</i> = 24)	Other disorders (<i>n</i> = 5)	Non-validated (<i>n</i> = 18)	No diagnosis <i>n</i> = 18)	Mother total (<i>n</i> = 118)
Child's diagnosis						
Mood disorder (<i>n</i> = 25)	14 (26%)	1 (4%)	1 (20%)	11 (61%)	0 (0%)	27 (23%)
Anxiety disorder (<i>n</i> = 39)	18 (34%)	11 (46%)	0 (0%)	3 (17%)	0 (0%)	32 (27%)
Behaviour/emotional disorder (<i>n</i> = 33)	9 (17%)	7 (29%)	3 (60%)	0 (0%)	0 (0%)	19 (16%)
Pervasive developmental disorders (<i>n</i> = 16)	8 (15%)	3 (12.5%)	1 (20%)	2 (11%)	2 (11%)	16 (14%)
Other (<i>n</i> = 5)	4 (8%)	2 (8.5%)	0 (0%)	2 (11%)	16 (89%)	24 (20%)
Children total (<i>n</i> = 118)	53 (100%)	24 (100%)	5 (100%)	18 (100%)	18 (100%)	118 (100%)

TABLE 3: *Demographic data and risk factors for children*

Child diagnosis	Domestic violence		Substance abuse		Level of social support		
	Yes	No	Yes	No	Poor	Minimal	Good
Mood disorder (<i>n</i> = 35)	9 (26%)	26 (74%)	11 (31%)	24 (69%)	15 (43%)	19 (54%)	1 (3%)
Anxiety disorder (<i>n</i> = 49)	24 (49%)	25 (51%)	12 (24.5%)	37 (77.5%)	20 (41%)	26 (53%)	3 (6%)
Behaviour/emotional disorder (<i>n</i> = 40)	23 (57.5%)	17 (42.5%)	6 (15%)	34 (85%)	11 (28%)	23 (57%)	6 (15%)
Pervasive developmental delay (<i>n</i> = 20)	6 (30%)	14 (70%)	3 (15%)	17 (85%)	7 (35%)	13 (65%)	0 (0%)
Other diagnosis (<i>n</i> = 8)	0 (0%)	8 (100%)	2 (25%)	6 (75%)	2 (25%)	6 (75%)	0 (%)
Total children (<i>n</i> = 152)	62 (41%)	90 (59%)	34 (22%)	118 (78%)	55 (36%)	87 (57%)	10 (7%)

The demographic data of key risk factors for the children highlight that 41% of families had a history of domestic violence (Table 3). Where historical domestic violence had been reported, the children most commonly had a behavioural/emotional or anxiety disorder.

Substance abuse by a parent occurred in just over one-fifth of the families, and was most prevalent in families where the child had a mood disorder. Almost all of the families attending CAMHS reported poor or minimal support, and the levels of support rates were similar in families where the children had either anxiety or mood disorders. However, the level of family support was better for children who had a behavioural/emotional disorder diagnosis, albeit in a small sample.

A series of χ^2 -test analyses were undertaken to determine differences between mothers with a mental illness compared to mothers without a mental illness in the areas of substance use, domestic violence, and level of social support. The χ^2 -test for independence (with Yates's continuity correction) indicated no significant association between mothers with a mental illness and those without for the three variables: substance use,

domestic violence, and level of social support. The findings were: χ^2 (1, *n* = 118) = 0.09, *P* = 0.76, ϕ = 0.054; χ^2 (1, *n* = 118) = 2.39, *P* = 0.122, ϕ = 0.166; and χ^2 (1, *n* = 118) = 0.379, *P* = 0.538, ϕ = 0.107, respectively.

Notably, there was a trend for mothers with a mental illness to be slightly more likely to have experienced domestic violence compared to those who had not; however, this was not a significant difference.

DISCUSSION

The present study is the first in Australia to examine mental illness for both a child and their parent in the same household where the child was attending a CAMHS. At the time of the study, there were 152 young people under the age of 18 years registered with the service. Anxiety disorders (32%), behavioural/emotional disorders (26.5%), and mood disorders (23%) were the predominant child diagnoses, with 87% of children living with one or both parents on a permanent basis. Of these parents, 79% were diagnosed with, or reported to have had, a mental illness. This is slightly higher than that found in the studies

of Gatsou *et al.* (2016), Baker and Lees (2014), Van Veen *et al.* (2016), and Mercer and Knapton (pers. comm., 2014). In addition, mothers were generally the primary caregivers of the children (78%). In contrast, fathers were the primary caregivers in just 9% of families, with the remaining 13% of children living in other care arrangements.

Confirming the high level of parental illness in the CAMHS is an important finding, as it strengthens the understanding that a large proportion of young people attending CAMHS are raised in a family with a parent who has a mental illness. It is well known that children from families with a parental mental illness are at higher risk and have greater needs, and it is very important that services respond. This provides further evidence of the need for family-inclusive approaches, as recommended by Falkov (2012) in his family model. One of the key recommendations from the current study is for CAMHS teams to ensure that they have robust assessment processes that explore the degree of risk factors and support needs within families. The present study has highlighted the strong link between child and parental mental illness, as well as the need for service improvement, to tailor family-focussed approaches to the specific requirements of families where both parent(s) and child(ren) have a mental illness.

The primary mental health concern for parents was mood or anxiety disorders, with depression occurring in 53% of parents. This finding is slightly lower than that found by Mercer and Knapton (pers. comm., 2014) (67%), and higher than that of Baker and Lees (2014) (38%). In terms of social support, 93% reported poor or minimal support. This is lower support compared to the other studies reviewed. None of the other studies compared the parental diagnosis with the child diagnosis, and none reported the incidence of domestic violence in the families, which in the present study was found to be twice as prevalent as substance use. The study by Swartz *et al.* (2005) found that 61% of the 222 mothers with children receiving intervention self-reported a mental health concern. However, in this Australian study, more parents presented with a validated than non-validated diagnosis, which could indicate a greater presence of previous help-seeking behaviours. Unlike the studies by Baker and Lees (2014) and Gatsou *et al.* (2016), the number of children in the present study living with a mother with a mental illness was high at 85%. For these parents of CAMHS clients, 40% of parents had depression and 18% had an anxiety disorder diagnosis, which is similar

to that found by Mercer and Knapton (pers. comm., 2014).

The entry criteria for the four studies reviewed was somewhat different and might explain the differences across the studies. A variance in service focus will likely have impacted on the types of children and youth seen, the issues for parents, and the types of family supports required within the family. For example, in the Netherlands (Van Veen *et al.* 2016), the service focus is specifically on children with attention deficit hyperactivity disorder and conduct disorder. Mercer and Knapton's (pers. comm., 2014) study was most closely aligned to this study.

In the current study, there was a high level of anxiety-, behavioural/emotional-, and mood-related disorders in children presenting to the CAMHS, and the diagnoses varied considerably across the different age groups, from behavioural/emotional disorders in younger children to anxiety and mood disorders in older children. The principal diagnosis of the 104 parents with a mental illness included mood (affective) disorders ($n = 54$, 52%) and anxiety disorders ($n = 28$, 27%), and this was across all the children's diagnoses. When comparing like for like, one-quarter of the mothers with a mood disorder lived with a child with a mood disorder, and many mothers were recorded as stating they suffered with mood-related issues. Similar numbers were seen where children presented with an anxiety disorder; one-quarter of the mothers also presented with an anxiety disorder.

What is not clear from the data is the timing of the mother's diagnosis, prior to or post the child's diagnosis. Future studies should examine this more fully. It remains to be determined what influence genetics and the environment play in the development of mental illness across family generations. In terms of parental diagnosis, a key limitation has been the efficacy of the diagnosis reported by parents. Very few parents had seen a psychiatrist, and most relied on a diagnosis from a general practitioner or private psychologist. Although these latter professionals can provide sound diagnoses, this is in contrast to their children who accessed CAMHS and were overseen by a specialist consultant child and adolescent psychiatrist. Another limitation of the present study was that information about the mental illness status of family members living away from the home was not consistently recorded.

It was notable that, in children who have behavioural/emotional and anxiety disorders, the extent of historical domestic violence in the family was high at 57.5% and 49%, respectively. In families where

substance use is a key issue, children's mood disorders and anxiety disorders were represented in 31% and 24.5%, respectively. Social support represents a key risk factor for children, with 97% of children with a mood disorder and 94% of children with an anxiety disorder having poor or minimal family support. All the children with a pervasive developmental disorder diagnosis were also recorded as having poor or minimal social support. Whether the level of domestic violence and substance use is predetermined by the child's mental illness, or is the other way around, is not known. In addition, the extent of substance misuse and domestic violence within the families might also be underreported, due to the reluctance of families to report such issues during initial appointments. Equally, Croton (2007) indicated that clinicians might be reluctant to ask questions about substance use and domestic violence when interviewing women. Such gender disparities are highlighted in the Gender and Women's Health factsheet (World Health Organization 2016) around gender stereotypes. CAMHS clinicians themselves allude to difficulties in gathering information on domestic violence and substance use, often quoting the threat to the therapeutic alliance as a reason.

The data analysis suggests there is an association between a child presenting with a mood or anxiety disorder and a mother presenting with the same disorder (over one-quarter of mothers had a mood or anxiety disorder). Although children presenting with a pervasive developmental disorder represented only 10% of all the children's diagnoses, 70% of mothers caring for these children presented with mood or anxiety disorders. As highlighted by Falkov (2012, p. 7), mental illness has 'a critical and enduring influence on family life'.

While factors such as domestic violence, substance use, and low levels of social support were found in a large number of these families, the analysis showed no significant associations according to the mothers' illness. The lack of difference could be a function of the small sample size and the complex degree of difficulties facing all families of children with mental illness presenting to CAMHS, and is an area requiring further investigation. Alternatively, while there were no differences in parents with and without mental illness, the high levels of domestic violence and lower supports are important issues generally for CAMHS. Van Dorn *et al.* (2016) noted the compounding effect of domestic violence leading to other issues, including psychological problems. It is also potentially possible that domestic violence and substance use were underreported in the

present study, because the focus of the initial mental health assessment for both family and clinician was the individual child. Further research is recommended to understand the complex interplay of social factors and comorbid issues.

STUDY LIMITATIONS

In the present study, we sought to gather data through clinician reports by a questionnaire and then by review of recorded assessments. Both techniques rely on the assessment skills of the clinician, with the former being reliant on the extent of the knowledge held by the clinician about particular families. A further limitation is the reliance on the accuracy of the history provided to, and interpreted by, clinicians.

Two points were raised by this data analysis. First, the discrepancy between clinician-reported data and the mental health file review. A number of possibilities might explain this difference, such as the clinician who provided the clinician-completed questionnaire not necessarily being the clinician who completed the original assessment. This would likely mean that the information gained was not in the mind of the treating clinician. Alternatively, there might have been an issue of the clinician remembering all the information because of the focus on the child. Another explanation could be that CAMHS clinicians were not sure about the study or were busy and filled out the questionnaire quickly without too much thought. For Hansen *et al.* (2002), such discrepancies relate to the paternalism of clinicians, while Skinner *et al.* (2007) noted 'that patient and professional recall frequently do not concord with one another' (p. 560). Tavakol *et al.* (2008) found that organizational culture and support are critical for active involvement in research. It could be argued that because information is gathered from families over time, these gaps indicate the electronic assessment tool was not being used as 'a living document' as intended. The present study, however, utilized both clinician reporting and independent verification to enhance the accuracy of the findings. The initial questionnaire completed by CAMHS clinicians relied heavily on the clinician's capacity and inclination to complete the form while managing competing demands. The case review of the electronic mental health database (Client Management Interface system) by the independent clinicians provided a robust balance and check on the information provided by clinicians. The cross-sectional study process used overall in the present study was a valuable tool to define the

prevalence of mental illness within the families of case-managed CAMHS clients. While the incidence of parental psychopathology among CAMHS attenders can be widely known anecdotally by CAMHS practitioners, actual numbers, diagnoses, and complicating factors remain an underresearched and underreported area. Similarly, adult mental health services might or might not know the incidences of consumers with children who also have a mental illness. If services do not have shared knowledge, then inter-service coordinated and intergenerational care can be fractured and ineffective.

Future research is required to determine the bidirectional impact of mental illness within families to understand the support needs for these families. Qualitative methodologies could explore in greater depth the interplay between child and parent mental illness, including the way families manage, and to ascertain any gaps in service provision. Further investigation needs to consider the voice of young people and their families on what they want from agencies, such as CAMHS. Consideration also needs to be given to whether families think a stronger family-centred and integrated care approach, as espoused by Falkov (2012), should be adopted by all those working with children and families.

CONCLUSION

In the present study, we found that a large number of children with a mental illness, who had accessed CAMHS, had a mother with mood or anxiety disorders. The results showed a strong relationship between the mother's diagnosis and the child's; this was particularly evident where both mother and child had an anxiety disorder. The study results also found that a high percentage of families experienced domestic violence, and a substantial number reported as having inadequate social supports. From this, it has been determined that there is a pressing requirement for early intervention and coordinated and extensive family-focussed care within child and youth mental health services. Importantly, there is a great need for inter-service coordination and wrap-around care collaboration for this population who are at increased risk of the additional impact of domestic violence and drug and alcohol misuse, with the additional disadvantage of minimal supports.

RELEVANCE FOR CLINICAL PRACTICE

Although mental health services provided by mental health nurses and other professionals are divided into

age-specific teams (child and youth, adult, and aged), the present study highlights the need for teams to think beyond the age-determined scope of their team when care planning with mental health consumers. The push for individualized care packages in mental health (Department of Health, 2015) runs the risk of clinicians focussing on the first key areas of self-care, self-management, daily living skills, physical health, and housing, rather than on the ninth point of parenting and caregiving. The significantly high number of young people accessing mental health services, who have mothers with their own mental health issues, supports inter-service and inter-team care coordination. Current individualized approaches mean that, while a child might receive excellent individual attention, parental issues might not be addressed or are left for parents to manage themselves. In coordinated care planning between the different teams, a family systems approach could ensure complementary care that assists both young people and their family.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article at the publisher's website:

Appendix S1. Mental illness within families review.

4.2 CONCLUSION

While novel in nature for a regional CAMHS in Australia, the present study has highlighted the magnitude of co-existing mental illness in families where children attend CAMHS. The study has also highlighted the extent of a number of demographic factors that impact on these families. With the findings indicating the widespread nature of co-existing mental illness in families it is important that greater emphasis is placed within current clinical practice on this central area of family intervention to achieve more effective outcomes and improved recovery. The finding aligns with current anecdotal thinking of clinicians in CAMHS and for some in adult mental health services that postulate co-existing parent-child mental illness is a major factor in families presenting to a CAMHS.

4.3 BRIEF INTRODUCTION

The second paper of this study had sought to establish if parental mental illness had any influence on child symptomology as measured through standard outcome measures.

Objective 2 - Carry out an audit of routine outcome measures to investigate any impacts of parental mental illness on child symptomology.

In addition to the data indicating the prevalence of parental mental illness for CAMHS children there was additional data provided through the same data set. This additional information related to the outcomes for children in CAMHS. The Department of Health and Human Services (2018) emphasised utilising quality and outcome measurement tools to determine a clinical change for mental health clients. Self-rated and clinician-rated consumer outcome measure data are routinely collected through the National Outcomes and Casemix Collection system. The data that is provided by clinicians and families gives a coherent picture across Australia of mental health service effectiveness. The use of routine outcome measures has formed a fundamental part of service delivery and monitoring. These outcome measures are also used to advise on service involvement and to target therapeutic intervention (Department of Human Services, 2008). The aims of the routine outcome measures are to provide an evaluation of both clinical effectiveness and in determining progress in securing improvement in symptomology. The influence on children of living with a parent with a mental illness and how this might impact on outcome measures appears to be absent, or is regarded as less significant than other issues, from the general discourse. It is noteworthy that in a recent study evaluating factors relevant to clinical decision making it was highlighted that a broad area of parental health issues needed to be determined among a suite of complex factors for child mental health (Martin et al., 2017). However, Patalay and Martin (2017) in their extensive study of 16,754 clinical records noted a focus on child characteristics without mention of any parental influencing factors.

A paucity of research existed on the link between a parent's mental illness and their child's mental illness; the focus in available studies had been one directional looking most commonly at how a parent's mental illness might impact on a child. The main aim of CAMHS treatment is to reduce symptoms and show improvement in domains of well-being (as measured by the HoNOSCA). Considering the strong link between child mental well-being and parental mental illness, the scarcity of research concerning the mental health status of parents whose children attend mental health services had been unexpected. The question from this, and in seeking to answer the second research question was, does parental mental illness impact on overall symptomology as reflected in mental health outcomes?

4.3.1 Theoretical underpinnings

In Australia mental illness and substance use disorders account for 12% of the total burden of disease with mental health problems the key disease burden for the 15–44 age group (Australian Institute of Health and Welfare, 2019b). Current research repeatedly signifies that a parent's mental illness can have a major impact on children. These impacts include emotional school and behavioural problems (Gladstone, Boydell, Seeman, & McKeever, 2011; Maybery et al., 2005). Estimates of the prevalence of parental mental illness have varied with studies reporting rates of 21–23% (Maybery & Reupert, 2009), 32% (Rasic, Hajek, & Uher, 2014) and 50% (Leijdesdorff et al., 2017). A recent review of the prevalence of parents attending adult psychiatric services estimated between 12 to 45% of service users to be parents (Maybery & Reupert, 2018). Four studies had rates between 36% and 38% (Benders-Hadi, Barber, & Alexander, 2012; Gatsou et al., 2016; Hearle, Plant, Jenner, Barkla, & McGrath, 1999; Östmann & Kjellin, 2002). Figures indicate approximately one third of adult psychiatry service users are likely to be parents. These figures signify increased risk for children living with a parent with a mental illness of developing a mental illness themselves. Parental mental illness can impact on the well-being of both parents and children (Göpfert et al., 2004; Maybery & Reupert, 2009), with Bournsnel (2014) suggesting parental mental illness impacts on parenting capability. Nevertheless, not all children of parents with mental illness acquire mental health problems (Gladstone, Boydell, & McKeever, 2006) though they may have more difficulties in other aspects of their life (Reupert & Maybery, 2007).

It is evident in the literature that mental illness can affect a person's ability to relate to others and manage day-to-day tasks. What is more, unwell people can have a reduced capability to cope with the ordinary demands of family life. With the World Health Organization reporting depression as the leading cause of disability worldwide and highlighting how interventions for children can reduce parental depressive symptoms (WHO, 2018) it was surprising greater account of parental mental illness in families where a child has a mental illness is not made.

Paper 2 has taken the theoretical relationships espoused in the Crossing Bridges Family Model a step further and sought to discover if a parent's mental illness would impact upon a child's treatment for their own mental illness. Importantly the second paper has also sought to establish any parental mental illness effects on children's symptomology. Within this examination it is recognised that there is a lack of data on the experience of carers and none on co-existing mental illness in families (Mental Health Drug and Alcohol Principal Committee [MHDAPC], 2015).

4.3.2 Paper 2 - Impact of parental mental illness on children's HoNOSCA results in a regional child and adolescent mental health service



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ORIGINAL ARTICLE

Impact of parental mental illness on children's HoNOSCA results in a regional child and adolescent mental health service

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ABSTRACT: Use of routine outcome measures are frequently used to ascertain improvement in children's symptomology, this study examined whether living with a parent with a mental illness impacted outcome measures. The study examined 134 children attending a Child and Adolescent Mental Health Service (CAMHS). The majority lived with a parent reporting mental illness. Routine HoNOSCA and CGAS outcome measures were collected over a 6-month period. Children of parents with a mental illness scored higher on most outcome measures. All children improved on most variables over the 6 months of CAMHS intervention with children of parents with mental illness showing greater improvement compared to other children on behaviour but less improvement on all other variables. They did not, however, improve as much on education-related factors and showed lower improvement in overall functioning. Younger children with a parent with a mental illness improved least in the area of behaviour. This study highlighted the need for greater use and integration of measures where children live with a parent who has a mental illness. Findings suggest parental mental illness impacted on overall child outcomes, and this influence remained irrespective of clinical intervention. The common occurrence of parental mental illness, where children also have a mental illness, indicates focusing on a wider set of outcome measures for more effective intervention. Analysis of a larger cohort sample is warranted.

KEY WORDS: child and adolescent mental health service, children, parent, mental illness, outcome measures.

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Declaration of conflict of interest: We confirm that there are no 'Competing interests'.

We confirm that the data are available through the Department of Health Clinical Management Interface (CMI). SPSS data analysis is available through Monash University. All authors are in agreement with the manuscript.

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OVERVIEW

Wolpert *et al.* (2017) concluded that one in 10 children worldwide experience 'mental health difficulties that substantially affect their lives' (p. 1). Factors that contribute to this phenomenon continue to be identified and discussed. One such factor is the possible impact of parental mental illness on children (Leijdesdorff *et al.* 2017), a circumstance estimated to affect 50% of children. Furthermore, Maybery and Reupert (2018) suggest that 20.4 to 38.5% of adult consumers of public mental health services are parents.

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Estimates of the impact of parental mental health problems include a 2–3 times greater chance of developing a mental illness compared to children of parents without a mental illness (Dean *et al.* 2010; van Santvoort *et al.* 2015). For children of parents with a serious mental illness, about a third will also develop a serious mental illness by adulthood (Rasic *et al.* 2014). Furthermore, children of parents with a mental illness are more likely to experience difficulties in other aspects of their lives, for instance peer relationships, school performance, social interaction, and day-to-day living (Singleton 2007). The occurrence of mental illness in children has been linked to a number of risk factors both genetic (Riley *et al.* 2003; Weissman *et al.* 2005) and psychosocial (Gladstone *et al.* 2011; O'Connell 2008). Risk factors such as financial issues, parenting style, contextual stressors, adverse life events, and attachment relationships have been highlighted by Fudge *et al.* (2004). The combination of mental illness and parenting approaches likely has a negative affect on the well-being of both parents and their children either on a temporary or ongoing basis (Göpfert *et al.* 2004; Reupert & Maybery 2009). Parental influences can also present through the interaction of these psychosocial, genetics, and neurobiological risk factors (Hosman *et al.* 2009).

Göpfert *et al.* (2004) and Reupert and Maybery (2009) explain how a parent's mental illness can both positively and negatively affect a child's well-being. A randomized double-blind study of 76 mothers and their children, conducted by Weissman *et al.* (2014), found that remission in mother's symptoms of depression had a positive impact on their child. In the study of 47 mothers, Swartz *et al.* (2008) determined that improvements in maternal psychiatric symptoms could have a positive impact on their child's mental health, suggesting alterations in the mother might facilitate better child outcomes. A child may show characteristics such as imitating a parent's behaviour or they may display maladaptive coping styles. In contrast, a parent may influence their child, for example where a parent has major depression or panic disorder, in such a circumstance a child will likely struggle with comorbid separation anxiety disorder and generalized anxiety disorder (Biederman *et al.* 2001). However, it also has to be noted that not all children of parents with a mental illness will develop mental health problems (Gladstone *et al.* 2006; Kuhn & Laird 2014).

There is a paucity of research exploring the bidirectional impact of mental illness within two generations living in the same household; the focus in available

studies has been one-directional looking specifically at how a parent's mental illness impacts on a child. An Australian study undertook a census of an adult mental health service that identified a third of adult mental health patients were parents of children under 18 years and over half the children were living with a parent with mental illness (Howe *et al.* 2009). Most of the parents were diagnosed with a mood disorder or a psychotic illness. A more recent study found 79% of children engaged with a regional CAMHS were living with a parent with a mental illness (Naughton *et al.* 2017). However, the majority of parents in this study had a diagnosis of anxiety or depression. In another Australian study, Fernbacher *et al.* (2009) found, from direct structured interviews with clinicians, that 40.4% of Families where a Parent had a Mental Illness (FaPMI) there was one or more children living in the family.

An aim of child mental health treatment is to reduce symptoms and show improvement in well-being as measured by a suite of outcome measures that look at a child's overall functioning, physical symptoms, and social context. Research indicates the potential significant impact of parental mental illness on children. This study hypothesized that children of parents with a mental illness, receiving CAMHS intervention, would experience inferior outcomes compared to those whose parents did not have a mental illness. It was further hypothesized that CAMHS recipients living with a parent with mental illness would record higher morbidity scores across all commonly utilized outcome measures. The study sought to answer three questions: (i) do children in the CAMHS improve over time; (ii) do children living with a parent with mental illness score differently to those living with a parent without a mental illness; and (iii) do outcomes differ by age?

METHOD

Participants

The cohort included those children aged 0–17 years who were registered with CAMHS as an open 'Episode of Care' during a 4-week period. Children who reached 18 years of age or were discharged from CAMHS during the study period and those accepted for intervention by CAMHS after the start of the study period were excluded. Of the initial sample of 152 children registered with CAMHS, 12% ($n = 18$) were ineligible for inclusion due to their reaching 18 years of age over the study period. Girls constituted 39.5% of the sample

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($n = 134$). The mean age of the sample was 13 years ($SD = 3.484$). By age grouping, as used by Chung (2018) in describing the eight stages of psychosocial protective development, 36% of the sample were pre-school and primary school-aged children (4–12 years) and 64% secondary school-aged children (13–17 years).

Instruments

To determine change over time, this study sought to use outcome measure data routinely collected by Child and Adolescent Mental Health Services including (i) Children's Global Assessment Scale (CGAS); (ii) Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA); and (iii) Strengths and Difficulties Questionnaires (SDQ). The child and parent-rated SDQ were subsequently excluded from this study due to poor completion rates. Consequently, only data from clinician completed measures, namely the HoNOSCA and CGAS, were used.

The CGAS summarizes a child's overall severity of disturbance and level of functioning through a clinician-rated score of between 1 and 100 with lower scores indicating more difficulties (Department of Health & Ageing 2003). A CGAS score below 70 is recognized as clinically significant, while scores from 71 to 80 are accepted as indicating minor impairment and scores 81 to 100 classified as good to superior functioning.

The HoNOSCA is a rated measure developed by the Royal Australian and New Zealand College of Psychiatrists (2010) and first described by Gowers *et al.* 1999. The tool is used to guide day-to-day clinical practice and to measure social and health outcomes. Whilst it is general in nature, it does provide a guide for clinical practice. Importantly, the HoNOSCA is considered as a tool in a suite of tools with some, such as the SDQ, offering a clearer picture of other influencing variables.

HoNOSCA scores are considered useful indicators of change and progress in children who attend CAMHS and are utilized to inform the direction of intervention. The inter-rater reliability of the HoNOSCA tool has been well researched (Eggleston & Watkins 2008; Lamers *et al.* 2015). Within CAMHS, there has been a general confidence in the HoNOSCA tool with its use providing an indication of recovery when working with children.

HoNOSCA consists of two sections. Part A has a clinical focus, while Part B explores service recipients' understanding of their problems and knowledge of services. As illustrated in Table 1, Part A is composed of

four domains (Gowers *et al.* 2013). Part B was excluded from the analysis as our focus was on examining children's clinical change. The 13 clinical items (see Table 1) form part of four overall domains and are each scored on a 5-point Likert scale of 0 (no problems) through to 4 (severe problems), (Department of Health & Ageing 2003). The AMHOCN review of recovery measures (AMHOCN 2005) suggests that item scores around 2 are clinically significant.

Data collection, management, and analysis

Children's Global Assessment Scale and HoNOSCA scores collected for analysis included those routinely completed by clinicians at the initial first review following engagement with CAMHS and the subsequent 91-day reviews. Only the initial and 6-month (second 91-day review) rating scores are reported in this study.

Following an initial general review of both HoNOSCA and CGAS scores in Excel for Mac (version 14.7.7), all subsequent data analyses were performed using IBM SPSS statistics for Mac version 24.0 (2017). Preliminary checks were conducted to ensure that there was no violation of the assumptions. Whilst paired samples *t*-tests were carried out to compare improvement in the children's HoNOSCA and CGAS scores, these results were unremarkable so are not reported here. Analysis of mean scores at initial and 6-month points was then conducted with further analysis of mean scores by the two age cohorts, primary and secondary aged children. Change over time was also

TABLE 1: HoNOSCA scoring table

	Item score	Domain score
Domain a. Behavioural problems		
1. Aggressive/antisocial	0–4	0–16
2. Overactivity, attention	0–4	
3. Self-harm	0–4	
4. Substance misuse	0–4	
Domain b. Impairment		
5. Scholastic/language skills	0–4	0–8
6. Physical disability	0–4	
Domain c. Symptomatic problems		
7. Hallucinations and delusions	0–4	0–12
8. Nonorganic somatic symptoms	0–4	
9. Emotional and related symptoms	0–4	
Domain d. Social problems		
10. Peer relationships	0–4	0–16
11. Self-care and independence	0–4	
12. Family life and relationships	0–4	
13. Poor school attendance	0–4	
Total (sum of scores 1–13)		0–52

calculated. For ease of interpretation, any improvement in symptoms (i.e. lowering in HoNOSCA score) is reported as a positive value and deterioration (i.e. increase in HoNOSCA score) is reported as a negative value.

Ethical approval

Ethics approval for the study was obtained from both the regional hospital (HREC: 2014000988) and Monash University (MUHREC: CF14/1973) Human Research Ethics Committees. Consumer consent was not required as data used in this study were routinely collected within CAMHS. All the outcome measures were completed during routine service delivery by clinicians independent of the researchers. The collection of this data was covered by local statute (Department of Health & Ageing 2003) and the CAMHS policy, ‘...information may also be used for research and planning, which will help us provide better health care overall. In this situation, your personal details are removed so that you cannot be identified’ (Latrobe Regional Hospital 2018).

RESULTS

Children’s Global Assessment Scale as a measure of overall impairment shows improvement by an increase in the clinician rating over the 6 months. As seen in Table 2, CGAS scores started higher (59.64), better functioning, for children living with a parent with no mental illness. At 6 months, they had improved at a

similar but slightly higher level (66.55) compared to children living with a parent with a mental illness, whose mean ratings changed from 58.79 to 65.7.

It can also be seen in Table 2, Time 1 HoNOSCA scores for children living with a parent with a mental illness are higher in the symptomology domain compared to those living with a parent with no mental illness. This differential in HoNOSCA scores persisted across the period of CAMHS intervention. Table 2 also indicates that children with a parent with mental illness showed greater improvement compared to other children on behaviour but had less improvement on all other domains.

Examination of the 13 HoNOSCA items (see Table 3) found that children living with a parent with a mental illness had higher scores in 11 of the 13 items at Time 1 compared to those living with a parent with no mental illness. Interestingly, children whose parent did not have a mental illness scored higher on the nonorganic somatic symptom items at base line and on the hallucination and delusions item at both measurement points. It is also important to note that school attendance and scholastic achievement did not comparatively improve over time for children living with a parent with a mental illness compared to the other children.

There was a similar trend in improvement of scores over the intervention period for children living with a parent with a mental illness as those living with a parent without a mental illness across all HoNOSCA domains and items. Larger differences were evident for both the impairment and social domains compared to the other domains (see Table 2).

TABLE 2: CGAS and HoNOSCA domains – spread mean and variance statistics

Scale/domain	Time 1 (initial)					Time 2 (6 months)				
	Min	Max	Mean	Std. dev.	Total variance	Min	Max	Mean	Std. dev.	Total variance
No parental mental illness (<i>n</i> = 22)										
CGAS (level of impairment)	31	90	59.64	12.97	168.14	31	90	66.55	12.36	152.79
HoNOSCA domains										
Behaviour	0	8	3.55	2.50	2.35	0	8	3.18	2.26	1.78
Impairment	0	7	1.55	2.04	0.98	0	4	1.05	1.46	1.03
Symptom	0	11	4.09	2.51	0.44	0	5	2.82	1.33	0.96
Social	2	14	6.05	3.36	0.22	0	8	4.14	2.25	0.23
Parental mental illness (<i>n</i> = 112)										
CGAS (level of impairment)	38	90	58.79	10.78	116.09	40	90	65.71	11.30	127.69
HoNOSCA domains										
Behaviour	0	11	4.41	2.73	1.71	0	11	3.44	2.50	2.16
Impairment	0	8	1.89	1.73	1.11	0	6	1.84	1.52	0.75
Symptom	0	12	3.91	1.95	0.84	0	7	3.07	1.51	0.66
Social	1	15	7.13	3.22	0.34	0	15	5.98	3.42	0.44

TABLE 3: HoNOSCA items – spread mean and variance statistics

Item	Time 1 (initial)					Time 2 (6 months)				
	Min	Max	Mean	Std. dev.	Total variance	Min	Max	Mean	Std. dev.	Total variance
No parental mental illness (<i>n</i> = 22)										
Aggressive/antisocial	0	4	1.45	1.34	1.79	0	3	1.18	1.07	1.149
Overactivity/attention	0	4	1.36	1.33	1.78	0	3	1.09	1.00	0.99
Self-harm	0	3	0.50	0.89	0.80	0	3	0.45	0.84	0.70
Substance misuse	0	3	0.23	0.67	0.45	0	3	0.45	0.78	0.61
Scholastic/language skill	0	3	1.23	1.35	1.81	0	3	0.77	1.04	1.09
Physical disability	0	4	0.32	1.02	1.04	0	2	0.27	0.62	0.38
Hallucinations and delusions	0	4	0.73	1.18	1.380	0	3	0.41	0.78	0.61
Nonorganic somatic symptoms	0	4	0.95	1.40	1.950	0	3	0.55	0.84	0.70
Emotional and related symptoms	0	4	2.41	1.30	1.70	0	4	1.86	0.97	0.94
Peer relationships	0	4	2.05	1.07	1.13	0	3	1.36	0.88	0.78
Self-care and independence	0	4	0.59	1.03	1.06	0	3	0.45	0.84	0.70
Family life and relationships	0	4	2.36	1.19	1.41	0	4	2.00	0.95	0.91
Poor school attendance	0	4	1.05	1.30	1.68	0	1	0.32	0.47	0.22
Parental mental illness (<i>n</i> = 112)										
Aggressive/antisocial	0	4	1.67	1.35	1.81	0	4	1.23	1.12	1.25
Overactivity/attention	0	4	1.63	1.20	1.45	0	3	1.22	1.02	1.05
Self-harm	0	4	0.82	1.06	1.13	0	4	0.61	0.99	0.97
Substance misuse	0	3	0.29	0.72	0.51	0	4	0.38	0.89	0.79
Scholastic/language skill	0	4	1.44	1.27	1.62	0	4	1.32	1.19	1.42
Physical disability	0	4	0.46	0.91	0.82	0	4	0.52	0.97	0.95
Hallucinations and delusions	0	4	0.54	0.95	0.91	0	4	0.31	0.68	0.47
Nonorganic somatic symptoms	0	4	0.56	1.03	1.05	0	3	0.58	0.84	0.71
Emotional and related symptoms	0	4	2.80	0.91	0.82	0	4	2.18	0.92	0.84
Peer relationships	0	4	2.15	1.13	1.27	0	4	1.65	1.13	1.28
Self-care and independence	0	4	0.92	1.05	1.10	0	4	0.91	1.06	1.12
Family life and relationships	0	4	2.53	1.01	1.02	0	4	2.14	1.07	1.14
Poor school attendance	0	4	1.54	1.50	2.25	0	4	1.28	1.39	1.93

To further refine the results, the change in the mean score for all HoNOSCA items from baseline to the final rating was calculated (see Fig. 1). This indicates that children living with a parent who had a mental illness showed most improvement in four areas: attention; self-harm; emotional, and other relations compared to the children living with parents without a mental illness. In contrast, children living with a parent with a mental illness showed the least improvement in five areas: aggression; scholastic/language skill; somatic symptoms; self-care; and school attendance. However, an increase in substance misuse was recorded for both groups; interestingly, a greater change was rated for children of parents without mental illness. Children of parents with mental illness were also reported to have had a decline in their physical well-being.

Figure 2 illustrates change in mean HoNOSCA domain and item scores by school age (primary and secondary). Improvement in the overall behaviour domain was least for younger children living with a parent with a mental illness. With respect to the other

three domains, both age groups of children living with a parent with mental illness showed greater improvement over the 6 months than children living with a parent without a mental illness. Nonetheless, both age groups of children living with a parent with mental illness continued to experience greater levels of acuity compared to children of parents without mental illness.

Figure 3 illustrates that CGAS ratings reported less improvement in the overall level of functioning for younger children living with a parent with a mental illness. However, there was a deterioration over the 6 months in both groups of younger children. In comparison, improvement in overall functioning for the older group of children was greatest for those living with a parent with a mental illness. Despite the greater improvement, children living with a parent with a mental illness consistently scored lower than children living with a parent without a mental illness.

In general, the children living with parents with a mental illness scored higher on most HoNOSCA domains and items on entry to the service and at 6-

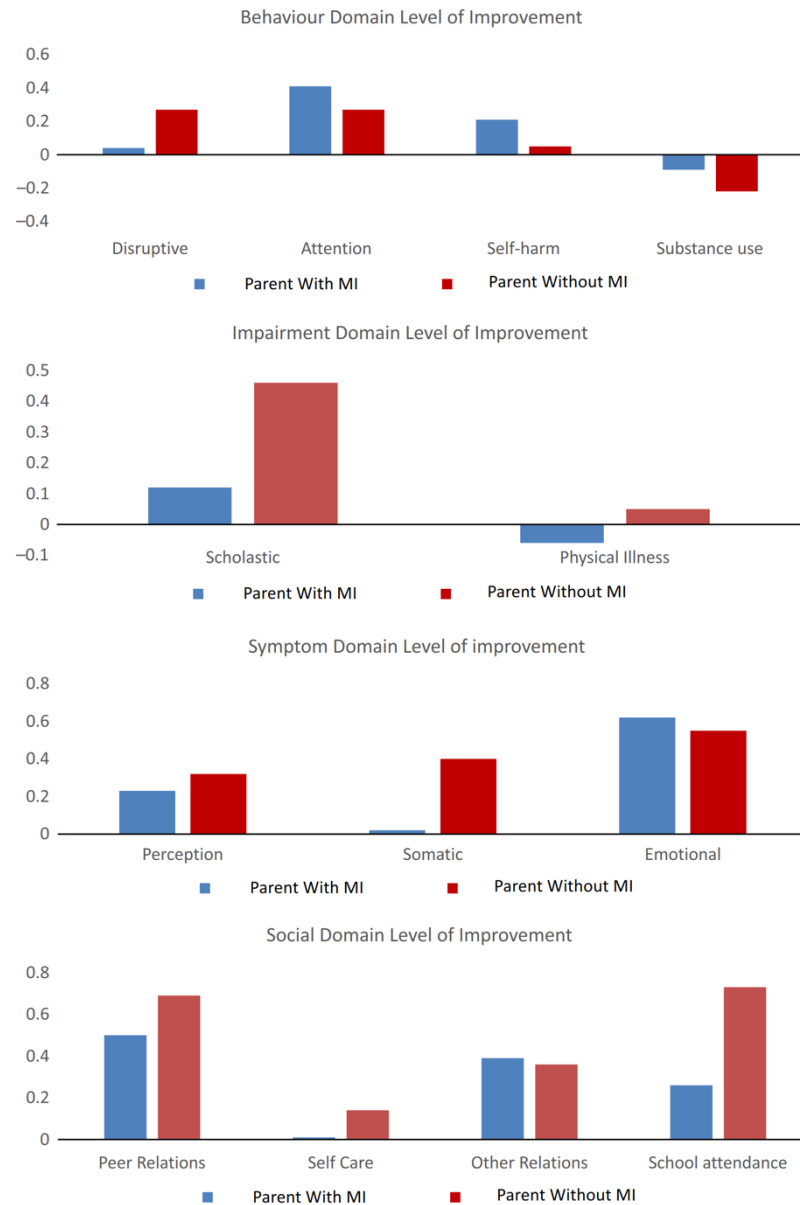


FIG. 1: Domain subscales level of improvement over intervention period.

month follow-up. All children improved on most variables over the 6-month period. On some of the variables, children of parents with mental illness improved

more than their counterparts. Though the trend in improvement was small, it was greatest for the behaviour and social domains. However, children with a

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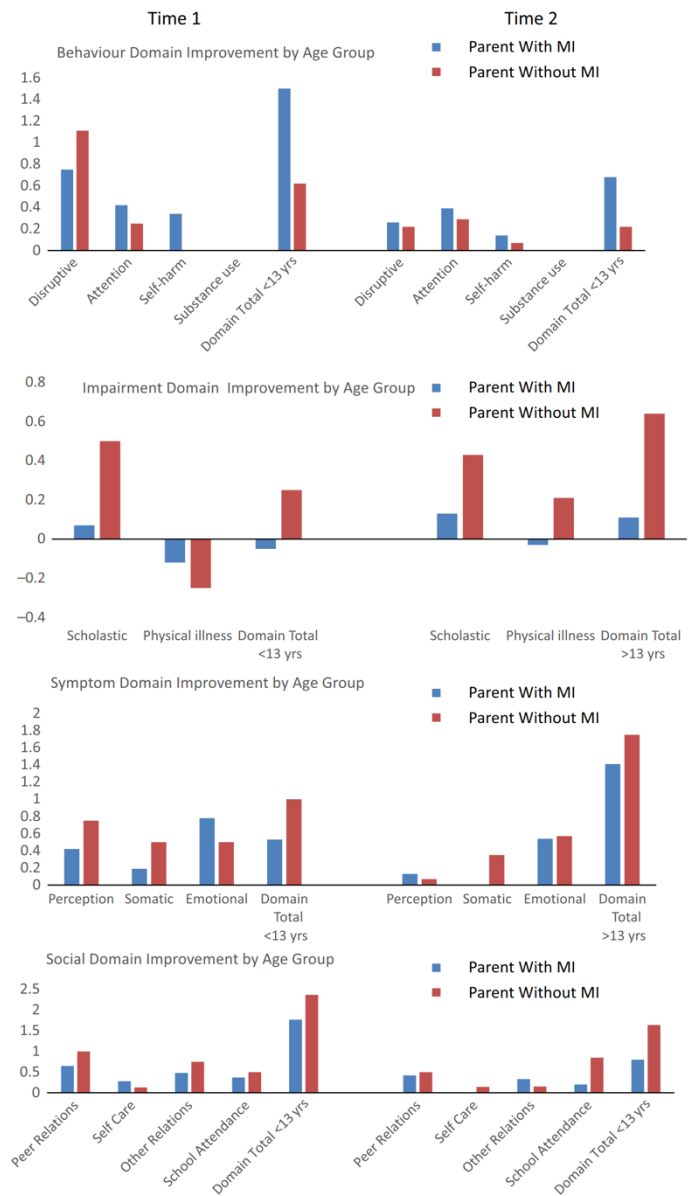


FIG. 2: Domain improvement by age group.

parent with a mental illness did not appear to improve as much on education-related factors as the other group and showed lower improvement in the overall

level of functioning. Younger children living with a parent with a mental illness improved least in the behaviour domain.

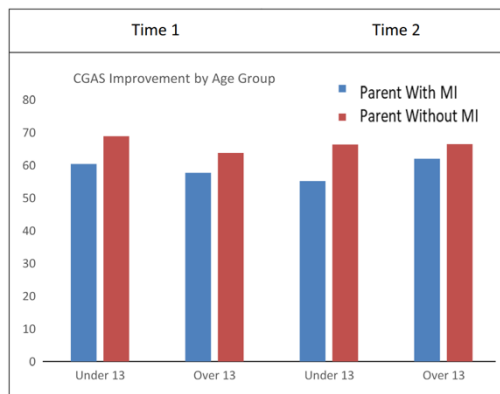


FIG. 3: Children's Global Assessment Scale improvement by age group.

DISCUSSION

This study sought to determine any difference between CAMHS client outcome measures for children living with a parent with a mental illness compared to children living with a parent without a mental illness. Routinely collected HoNOSCA and CGAS rating scores of children receiving care from a regional CAMHS were analysed. This is the first study to explore whether parental mental illness status was related to differences between clinician-rated HoNOSCA and CGAS scores.

Clinical improvement was found across thirteen HoNOSCA item scores and the CGAS score with respect to both children living with a parent with a mental illness and those living with a parent with no mental illness. These findings are in contrast to studies reported by Lambert (2013) and Warren *et al.* (2010) that reported children attending a CAMHS had an overall 24% deterioration rate over the time of CAMHS intervention. The improvement in scores was consistent with the findings of the inpatient study conducted by Harnett *et al.* (2005).

A question needing further examination is why HoNOSCA scores between the two groups of children remain consistently higher for those children living with a parent with mental illness. It can be argued that such improvement in a community CAMHS is more a reflection of a result-based discourse than one of client recovery. Some have suggested that accountability through measures might be considered as spin and is liable to clinician complacency (Drury 2014). Happell (2008) goes further suggesting the HoNOS, the basis

of the HoNOSCA, increases the possibility of clinicians focusing on symptoms. As highlighted by Moran-Ellis (2010), interventions are '...directed towards establishing the standards of provision of mental health services for children and adolescents which health and social care/welfare providers have to meet' (p. 200). Cuellar (2015) goes further and describes interventions for children as '...fragmented and disordered' and recommends a '... focus less on relieving symptoms and more on educational achievement and overall functioning' (p. 111). The continued focus on individual symptomatology potentially undermines consideration of broader psychosocial influences, such as parental mental illness.

The results show improvement across most HoNOSCA items for children, whether living with a parent with a mental illness or not. Concordant with our hypothesis, children living with a parent with a mental illness had higher outcome measure scores in most areas at both time points. While children with a parent with a mental illness improved over time, they continued to have higher scores on all variables after 6 months. In the study of 833 children by Maybery *et al.* (2009) investigating SDQ scores, it was found that children living with a parent with mental illness both had a higher child and parent-rated SDQ scores (thus more life difficulties) than children not living with a parent with a mental illness. This study also found that children living with a parent with a mental illness had the highest level of improvement over time in terms of behaviour but improved to a lesser degree on the remaining three HoNOSCA domains. These results suggest that the recovery trajectories differ for children of parents with a mental illness compared to those with parents with no mental illness.

Parents with a mental illness have more struggles in the parenting role particularly with depressed parents being less emotionally available, compared to parents without a mental illness (Oyserman *et al.* 1994). Autobiographical accounts have shown that adults, recalling their childhood where they were living with a parent with a mental illness, describe generally being unsettled and their day-to-day life being disrupted (Stjernswärd & Östman 2009). Maybery *et al.* (2005) reported that being a child of a parent with mental illness poses a severe risk to a child's long-term mental health and secure attachment. In the study by Bergman *et al.* (2010), it was found that good parent-child relationships have an ameliorating effect on biological markers for children's potential for mental illness. Bush *et al.* (2017) report maternal prenatal stress as

'uniquely' predicting offspring stress and psychopathology. The wide-ranging study of 18 827 children from the British Millennium cohort study (Fitzsimons *et al.* 2017) found that a parent's mental illness corresponds to their child's mental illness. We therefore contend that greater consideration of parental mental illness is an essential and critical factor in the clinical determination of outcomes in children accessing mental health services.

Concepts from the sociology of childhood suggest parenting affects children through teaching habits and behaviours. From this perspective, children are not passive rather they are active participants in interactions. Parent mental illness and parent-child interactions are therefore also significant factors in child mental illness. The intricate interplay between children and others has often been broken down to simple interactions between children and parents (Rose & Abi-Rached 2013). Debate on the impact of parent-child interaction has shifted away from the ideas of the sociology of childhood which have focused on the intricate relationships between society, children, and adults. The contemporary discourse now focuses on child-parent interactions and parent failings, with a subsequent impact on parental anxiety (Macvarish *et al.* 2014). Such a demeaning approach likely has a compounding impact where a parent already struggles with a mental illness.

Children with a parent with a mental illness did not improve as much as the other children on education-related factors. Whilst the other children improved on school-related factors, there were minimal changes for those with a parent with a mental illness. This included scholastic/language and particularly school attendance. Other research supports this finding with Bell *et al.* (2018) recently highlighting the poor school readiness of children starting primary school when their parents had been hospitalized for a psychiatric condition, compared to their age-typical peers. A Swedish study by Hjerm *et al.* (2017) revealed that double the number of children whose parents had been hospitalized for a mental illness showed lower results at school and were unable to commence secondary education, compared to children without parental mental illness. This suggests an important area for future intervention, as previously raised by Reupert and Maybery (2016). Support of children who have a parent with a mental illness should be targeted to include family-focused interventions that are designed and planned to address the impact of parental mental illness. Siegenthaler *et al.* (2012) suggest interventions need to be put in place to

prevent mental illnesses in children of parents with a mental illness.

Limitations

The HoNOSCA scores for children living with a parent with a mental illness trended higher across 10 of the 13 HoNOSCA items. Despite greater improvement for these children, their overall scores continued to be higher than children living with a parent without a mental illness. Although the results indicate a pattern, further validation will be required. Consideration needs to be made of several factors including: reliability of clinician-rated outcome measures in determining the impact of parental mental illness; any differentiation made by clinicians, if at all, between children living with a parent with a mental illness and those who do not; and the use of any additional collaborating data such as the SDQ.

Although parental mental illness was examined here other variables such as poverty, family conflict or parenting style may also impact upon outcomes for CAMHS children and should be considered in future research as predictor or covariables.

A further limitation of this study has been the sample size difference. The numbers of children living with a parent with a mental illness in this analysis were four times higher than those children living with a parent without a mental illness. In future studies, an equal comparison with larger sample sizes may yield more definitive data and allow for statistical analysis of significant differences.

The reported change over the 6 months of CAMHS intervention solely utilized clinician-reported data and therefore does not reflect parent or child perceptions of change. Several authors have outlined potential problems with such an approach (Gowers *et al.* 2013; Johnson 2009; Lambert 2013; Yates *et al.* 1999). Future research should examine parent and child perspectives.

CONCLUSION

With a large number of children attending a CAMHS living with a parent who has a mental illness, we sought to examine whether there was a corollary effect on children's outcomes and thus treatment interventions. Although a significant difference was not found between all the scales used in the HoNOSCA, the trend was for higher scores across the domains for children living with a parent with a mental illness. Further assessment of a broader cohort sample of children is

planned to better assess any difference between the two groups. Childhood mental health problems have been strongly linked to problems in the family (Houtrow & Okumura 2011; Wilkinson *et al.* 2013). Within CAMHSs, the presentation of children can often be considered an indication of the relational problems within the family. The data from this study have shown consistently higher scores for children living with a parent with a mental illness compared to those living with a parent not reporting mental illness. These findings suggest that family background does impact upon children attending CAMHSs and indicates the need to train CAMHS clinicians in evidence-based interventions that are family-focused and specifically address the bidirectional impact of mental illness in families.

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4.4 CONCLUSION

From this study it has been highlighted that there is a need for greater use and integration of clinician and child/parent measures where children live with a parent who has a mental illness. The findings from the data on HoNOSCA results suggest parental mental illness impacted on overall child outcomes and that this influence remained irrespective of clinical intervention. While the results were not significant there was a consistent trend for higher child outcome scores at commencement and also after 6 months of intervention, where children were living with a parent with a mental illness. This trend of children's psychopathology being higher when they live with a parent with a mental illness was also found in the similar study, using self-reported outcomes, rather than clinician measures, conducted by Wesseldijk et al. (2018). The tendency for parental mental illness, where children also have a mental illness, indicated the need to focus on a broader set of outcome measures for more effective intervention. Such a change would require mandatory child/parent recording at all stages of intervention. Analysis of a larger cohort sample from different child mental health services to further examine any impacts of parental mental illness is warranted.

Chapter 5: Research Design - Qualitative

Section 5.1 discusses the methodology used in the qualitative aspect of the study, the stages by which the methodology was implemented, and the research design (5.1.1); section 5.2 details the participants in the study; section 5.3 briefly describes the procedure and time line; section 5.4 outlines the analysis; and the final section of this chapter, section 5.5, discusses the ethical considerations of the research and its problems and limitations.

5.1 QUALITATIVE METHODOLOGY AND RESEARCH DESIGN

It had been seen that prevalence was an area identified as of significance in this study but the existence of prevalence on its own does not establish impact. Analysis of routine outcome measures indicated a trend for greater impact on children living with a parent with a mental illness but the results from the small sample were not definitive. How then to answer the third research question relating to parent's connectedness with the phenomenon of their family and their mental illness. As argued by Green and Thorogood (2004) qualitative research can better reach the parts that quantitative research cannot. Qualitative research is an inductive approach that strives to further understand and develop in-depth meaning of the experiences of people both as individuals and in their relationships and interactions (National Institutes of Health [NIH], 2018; Creswell & Plano Clark, 2017). Importantly this research methodology can help in the development of practice through the in-depth and interpreted understanding of the world in which people live through exploring the experiences and meanings of individuals in their natural context (Moriarty, 2011). The focus in this second part of the thesis was qualitative research examining the interpretation of the subjective meaning and description provided by parents and children about their context and their understanding of the circumstances that form the setting in which they live. In determining the significance or not of the trend in outcome measures the use of a qualitative approach offered the only practicable solution. A further advantage in using the qualitative approach in this part of the study was in its consideration as an interpretivist perspective. What has been important has been the interpretations of the parent and child lived experience of their reality. When reflecting on clinician's evaluations of the outcome measures, as seen in paper 2, the appraisals of a child's current mental health state was an application given by clinicians to children. The determinations made by clinicians were likely based on a certain clinical reality not on the children's or the parent's interpretations. Qualitative methodology offered the most suitable approach to challenge the dominant clinical ideology and to really understand what children and parents understood as facts and events they experienced on a day-to-day basis.

Comparatively little attention has been given to the situational characteristics or on identifying patterns of adjustment and modification that impinge on the child and parent relationship.

5.1.1 Research design

Studying families is not easy even more so when both a child and a parent have a mental illness. Despite this the enquiry was needed to discover and explain a set of phenomena never previously considered and then to go further link these phenomena to a range of behaviours and experiences for two very different and yet similar groups, children and parents. Initially the research design had been structured around a semi-structured interview approach that was to be analysed using an interpretative phenomenological approach (Smith & Osborn, 2007). This thesis has sought to examine the world of the child and parent as well as to explore their experiences and perceptions. The rationale behind use of this semi-structured interview question design was the high interrater reliability of the semi-structured modality (Cresswell, 2003). Additionally, the application of this approach in the mental health field was likely to be less threatening to children and parents. After only three interviews it became apparent this assertion was incorrect and the approach was not going to be appropriate for parents and children struggling with a multitude of mental health and social issues. As one person so eloquently explained, ‘Can I just tell you my story?’ Norgaard and Parnas (2012) highlighted that interviewing people with a mental illness should be guided by phenomenological distinctions which come from the ‘flow of the patient’s subjective life’. With this in mind a broadly free flow narrative approach was adopted for the remaining 34 families. Utilising this more empathic approach was now clearly a crucial approach for interviewing families and individuals who were at various stages of their mental illness. Applying an interpretive approach allowed for the examination of each individual’s personal discourse in a way that would highlight things perhaps not intended or issues the person may not have even been consciously aware of. Using this approach provided for a richer analysis and helped in the determination of the meanings constructed by the parent and child. To understand the inner world of parents and children it was necessary to understand their experience of their world and be able to form an interpretation of the ‘actual’ emotional and mental state presented. Importantly the in-depth qualitative analysis helped in the formulation of meaning while also helping make sense of the experiences of the children and parents in these families and understanding to a certain degree what they have been through. A key rationale for using an open inductive approach (Bowman, Mackay, Masrani, & McKiernan, 2013) allowed for a broadly free flow narrative interview to engender greater dialogue between the researcher and the parents and children. This in turn would allow for greater exploration of interesting and diverse areas of discourse as they occurred.

5.2 PARTICIPANTS

Families were recruited from the cohort of children attending the regional CAMHS. Initially a general letter was sent out (Appendix B) to all the parents of these children explaining the research and inviting parents who might be interested to discuss the study further with the clinician working with their family. Clinicians were given a brief about the interview stage of the research and had copies of the information sheet (Appendix C) to allow them to better explain the process to families. Recruitment was originally slow but following clinicians identifying potential families, reminders were provided to those parents who had expressed an interest and further clarification was offered. From this over half the families who initially expressed an interest (n=61) agreed to participate in the study (n=37). A number of problems resulted in the process of interviewing the eligible families: issues of time in synchronising interviews; distance needing to be covered (420km between some families); deterioration in mental health of parent and or child; and missed or cancelled appointments. In total 37 parents and 38 children were interviewed after one child had withdrawn consent.

5.3 PROCEDURES AND TIMELINE

Interviews were recorded on a Dictaphone with only one parent wanting the interview recorded in writing. On completion of the interviews, and after the first 10 interviews were transcribed, the remaining electronic recordings (n=65) were sent to a professional University employed transcriber. All the transcriptions were only identified by a number and a letter (e.g. 1a parent, 1b child; 2a parent 2b, child etc.). On completion of the transcribing the typed transcripts were analysed in NVivo. From this process key themes were established with only slight variations in interpretation needing to be discussed between the researcher and the thesis supervisors.

5.4 ANALYSIS

Transcribed interviews were read and reread several times to assist in capturing any patterns and to help in developing a sense of the phenomenon of parent's and children's experiences. All transcripts were read and coded by the writer and the thesis supervisors. Each independently read and thematically analysed the transcripts with the adult interviews reviewed (Maybery) and child interviews reviewed separately (Goodyear). The original audiotapes were reassessed again to help in re-affirming an empathic connection with each parent's experiences and each child's experiences. Responses were sorted into key common content areas.

At the second stage of the analysis an inductive thematic analysis was conducted in NVivo while ensuring the elements that described the parent's experience were maintained. It was important

in this process to preserve the meaning behind the parent's and child's understandings. Themes were deduced from the number of instances words and phrases occurred with ideas subsequently merged and catalogued. Finally, responses were coded, and codes were combined into common concepts that were agreed by the researcher and the thesis supervisors. With a range of phenomenological characteristics from the stories provided by the parents and children, it was inevitable that many of the codes were not mutually exclusive. The valuable data provided by these parents and children offered both collective and individual themes. Although examined separately the same process was used for both the child and parent interviews.

5.5 ETHICS AND LIMITATIONS

Ethics approval for the study was obtained from both the regional hospital (HREC: 2014000988) and Monash University (MUHREC: CF14/1973) Human Research Ethics Committees. Parents provided consent to take part and provided initial consent for their child to also take part. Interviews were mostly conducted in people's homes with only a few taking place at the various mental health buildings. In addition, children also consented to take part separately from their parent. Parents were seen separately to avoid any bias or influence by either party. Despite children's parents providing initial consent all but one was quite open and free in their discourse though age of the children did appear at times to limit the depth of the interview.

Chapter 6: Qualitative Papers

6.1 BRIEF INTRODUCTION

The third paper investigated, from a phenomenological perspective, the reality and social construct of parents with a mental illness living with a child with a mental illness.

Objective 3 - Undertake a narrative discourse with parents, to determine the influence of mental illness in the family and, from a parental perspective, establish what would be helpful in reducing those influences.

While the prevalence of the problem is important it has been examined in a variety of slightly different forms. Current research into mental illness in families is invariably retrospective in nature, asking adults about their childhood. In this research the novel approach has been to examine the perspectives of both parents and children in the same family. Importantly this research has heard the voice of children under 18 years explaining their lived experiences rather than hearing retrospective views of adult children. These discourses can be described as fresh and of the moment.

Gladstone et al. (2011) hypothesised about impacts on parents of childhood mental illness while Maybery, Szakacs, and Reupert (2005) reported on the influence of parental mental illness on children. The Falkov (2012) Family Model proposes an intricate interplay between risk and resilience in families where there is mental illness. This perspective offers a useful overview of the link between bio-genetic inheritance and psychosocial adversity in families where there is a co-existing mental illness. Taking the ideas of this interplay a step further the third research objective sought to address the question, what are the lived experiences of parents who have a mental illness and live with a child with a mental illness? To achieve this, the investigation moved in a qualitative direction to investigate, through in-depth interviews of a narrative design, the interplay of factors for parents as they perceived them. Many studies consider the unidirectional impact of mental illness with a lot known about the role of endogenous and exogenous risk factors in the development of mental illness (Leijdesdorff et al., 2017). This knowledge stems from research that indicates children are at 'high-risk' for developing psychopathology (Gottesman, 1991) particularly with a genesis in the family. Walker and Diforio (1997) highlight prenatal environmental factors as influencing fetal development. Halmoy et al. (2010) and Crespi and Badcock (2008) suggest parental genes are determining factors for the development of children's mental illness. The genetic component cannot be considered in isolation and plays a part in the much larger picture of environmental and social influences in families.

Falkov (2012) emphasises a connection between biological and psychosocial factors in the development of children's mental health. Vondrova et al. (2017), in their study of 87 children, found exogenous determinants significantly affecting children's mental health. Importantly a unidirectional view of mental illness appears to provide a constricted interpretation of what happens in families where a parent and child have a mental illness. Gudmundsson and Tomasson (2002) and Busch and Barry (2007) found caring for a child with mental illness affects caring and psychological health of caregivers more than any other condition. Mensah and Kiernan (2010) established many deficits in children whose parent had a mental illness while Radke-Yarrow and Klimes-Dougan (2002) comment on the importance of the relationship between parent and child mental illness. Gladstone et al. (2011) hypothesised about impacts on parents of childhood mental illness while most reports relate to the influences on children of parental mental illness. This study has considered the important dynamic of the bidirectional impact of mental illness in families

6.1.1 Theoretical underpinnings

A unidirectional view of mental illness provides a constricted view of what happens in families where a parent and child have a mental illness. As reported above researchers have found that caring for a child with mental illness affects the caring and psychological health of caregivers more than any other condition. Other researchers have established children whose parent has a mental illness present with a number of problems. If warmth, nurturance and the provision of developmentally appropriate supervision are the hallmarks of good parenting, through childhood, what is the effect on the developing child if this is not available? While many parents who have a mental illness are capable parents, mental health problems can affect parent-child interactions in a number of ways. The capacity of parents to care for themselves when unwell, let alone a dependent child would seem to be at best challenging. The potential struggles for parents and children had indicated a need to understand the experiences and meaning for parents with a mental illness of what it was like being a parent of a child with a mental illness. Also, it was important to be able to grasp an understanding of how parents understood their day-to-day experiences and challenges. These ideas are particularly important considering a number of mothers are described in the literature as experiencing mental illness pre or post childbirth, with risk of onset remaining elevated during their years of parenting (Oyserman & Mowbray, 2000; Badovinac et al., 2018). If the challenges and focal issues of parenting are associated with a child's developmental phase, the sociocultural context within which parenting is rooted, and a parent's mental health, this phenomenon clearly needed further examination. There certainly appeared to be an important, though unexplained, relationship between parental and child mental illness.

If mood is considered as an emotional dynamic causing influences between people and is something that has been found to exist in the general community, and parental mental illness impacts on children, the question to be postulated is why such transference from children to parents and vice versa has never before been investigated. Adult centric views, identified in the sociology of childhood, provide the current basis for the discourse which would appear to limit any true understanding of the micro interactions between parents and children. Certainly, the relationship dynamic between parents and children and the ideas of attachment theory are pertinent and relevant in any analysis of mental illness in families and would seem to be an important element for the future in this current discourse. While not a vital component of this thesis attachment does play a role in the way parents and children interact with one another. Importantly, parental attachment has been found to be a significant influence on children's mental health (Wilkinson & Marmot, 2003). In considering attachment as the relationship between people it is entirely feasible that the influences of mental illness might fracture relationships in families. For example, a useful model for understanding the relationship between people experiencing anxiety is suggested by Mikulincer, Shaver, and Berant (2013). In their model, it is proposed that when people experience anxiety, they try to reduce the experience of anxiety by seeking closeness with others. However, in seeking closeness they may be accepted or rejected in their request. In a process described as hyperactivation, there is an increase in insecurity and anxiety because of this rejection. The hyperactivation and attachment avoidance strategies people adopt lead to further negative thoughts and less resourcefulness in handling problems and stressful situations. In considering this idea, it might be expected that hyperactivation is a key factor featuring in the interaction between children and parents where both have a mental illness.

The second consideration in relation to the theoretical underpinnings can be found in the philosophy and approach of phenomenology. This is important because at the core of phenomenology is the lived experience of those being investigated – the parents in the first part of this stage of the study. In considering the essence of these parents' experiences, the aim has been to develop a deeper level of awareness of their understanding of life in a family with co-existing mental illness. While considering the idea that there is no single reality and what is important is how people make sense of experiences (Scotland, 2012), this philosophical approach has allowed a focus on the phenomenological stresses that only parents with a mental illness, living with a child with a mental illness, are capable of espousing.

Initially, 20 questions relating to the parent's experience were proffered in a semi-structured interview. The first three parents interviewed reported feeling stifled and stressed by the interview

format. A review by the reference group led to a more open approach using the following general and non-leading prompts: (1) Please try and describe your experiences when you are unwell and when your child is unwell; (2) How, if at all, have you been supported as a family; and (3) Based on your experience how might other families be best supported? The revised open inductive approach provided parents with the opportunity to express their views and for this study to hear those events as parents experienced them. The open inductive approach also allowed for a bottom-up understanding of each parent's situation.

ORIGINAL ARTICLE

A parent’s perspective of the bidirectional impact of mental illness in families

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ABSTRACT

Objective: Recent research has found over 70% of children attending a mental health service also have a parent with a mental illness. Research on the impact of mental illness in families focuses primarily on how parental mental illness impacts on children. What is not understood is the experience of parents and children where both have a mental illness. The aim of this study was to investigate the experiences of parents where both a child and a parent have a mental illness.

Methods: Thirty-seven parents were interviewed using a narrative design to determine their personal and family experiences. Interviews were analyzed using interpretative phenomenological analysis with a number of themes highlighted.

Results: Themes particular to this family type were: impact of parental mental illness; specific strategies; bidirectional impacts of mental illness; and intergenerational factors. Also raised were supports parents would have liked. From the narrative of these parents the challenges of families, where both a parent and a child have a mental illness, are highlighted.

Conclusions: It is from these interviews, that awareness of clinicians can be raised, and more effective, well-thought-out interventions put in place. Interventions that take account of the bidirectional influences of mental illness will be more successful in meeting the needs of all members of a family. People do not operate in isolation and providing a family focused approach is an essential first step in helping people manage where mental illness is a prevalent factor for different family members.

Key Words: Family, Parent, Child, Mental illness, Bidirectional impact

1. INTRODUCTION

Many studies consider the unidirectional impact of mental illness with a lot known about the role of endogenous and exogenous risk factors in the development of mental illness.^[1] This knowledge stems from research that indicates children are at “high-risk” for developing psychopathology,^[2] particularly with a genesis in the family. Walker and Diforio^[3] highlight prenatal environmental factors as influencing fetal development. Halmoy et al.^[4] and Badcock and Crespi^[5] suggest parental genes are determining factors for the development of children’s mental illness. The genetic component

though, is a part of a much larger picture of environmental and social influences.

The number of children of parents with a mental illness developing mental illness themselves cannot be underestimated. The van Santvoort et al.^[6] systematic review of 76 papers found a strong relationship between parental disorders and various childhood disorders. A recent review of nine studies of adult psychiatric services found parent numbers amongst service users ranging from 12.2 to 45.0 percent.^[7] Leijdesdorff et al.^[1] proposed children of parents with a mental illness have a 50 percent chance of developing mental illness

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themselves. Göpfert, et al.^[8] and Maybery and Reupert^[9] found parental mental illness could adversely affect parent and child well-being. These children may not develop mental illness,^[10] but there is an increased risk^[11,12] with some authors suggesting children of parents with a mental illness are more likely to have greater difficulties in all aspects of their life.^[13,14]

Where parental mental health improves the literature indicates improvements in children's attachment, temperament and cognition.^[15] Falkov^[16] emphasizes a connection between biological and psychosocial factors in the development of children's mental health. Vondrova et al.^[17] in their study of 87 children, found exogenous determinants significantly affecting children's mental health.

Childhood disability and developmental disorders impact on family systems. Effects on parenting, marriage, work and caring are well known^[18] with Hayes and Watson^[19] finding childhood Autism causing more stress than any other disability. Kuusikko-Gauffin et al.^[20] found high anxiety in parents of children with a disability. Manuel, et al.^[21] found that mothers of children with a physical disability were at increased risk of depression. In contrast literature on the impact of children's mental illness on parent's is limited.

A unidirectional view of mental illness provides a constricted view of what happens in families where a parent and child have a mental illness. Gudmundsson and Tomasson^[22] and Busch and Barry^[23] found caring for a child with a mental illness affects caring and psychological health of care givers more than any other condition. Mensah and Kiernan^[24] found a number of deficits in children whose parent had a mental illness whilst Radke-Yarrow and Klimes-Dougan^[25] comment on the importance of the relation between parental and child mental illness.

Jessop and De Bondt^[26] determined 29.6% of parents whose children attended a child mental health service identified as having a mental illness. Similarly Gatsou et al.^[27] found 59 percent and in a Netherlands child and youth service an estimated 42.1 percent of mothers and 21.8 percent of fathers had a mental illness.^[28] The two highest CAMHS appraisals of co-existing parental mental illness have been Naughton et al.^[29] with 79 percent and Baker and Lees^[30] with 70 percent. This data indicates dual parent-child disorders as being a very important public health issue.

Gladstone^[31] hypothesized about impacts on parents of childhood mental illness whilst Maybery et al.^[13] report an influence on children of parental mental illness. The Falkov^[16] Family Model of the interplay between risk and resilience offers a useful overview of the link between bio-genetic inheritance and psychosocial adversity in families where there

is co-existing mental illness. His model shows the variety of connections existing in families and how these impact across generations. Taking the ideas of this interplay a step further this study aimed to investigate, through in-depth interviews, the interplay of factors for parents and children where both have a mental illness.

2. METHODS

Community mental health clinicians were asked to identify potential families for the study. The criterion for inclusion was a parent and a child from the same family both with a mental illness, with children needing to be over the age of 12 years. Clinicians spoke to eligible parents about the study and provided information sheets. Subsequently, clinicians offered consent forms and the opportunity to discuss the research further with the research team. Parents contacted the researchers to participate in the study at which time they were asked to verify their and their child's diagnosis and further consent to involvement. The study was approved by the research ethics committees of the community mental health service and Monash University.

2.1 Participants

There were 37 parents interviewed including 29 women and eight men with 59.5% (n = 22) living in regional towns, the remainder living in semi-rural areas. While 24.3% (n = 9) were employed, 45.9% (n = 17) were on a disability pension because of their mental illness. Parents were aged between 30 and 55 years with almost half between 36 to 45 years of age. Parents had a mix of diagnosis as did their children (see Table 1); most had comorbid anxiety and depression. All parents were, or had been, previous clients of adult mental health services. All children were active clients of CAMHS. Only 13.5% (n = 5) of the parents indicated that they felt well supported within the community. All but one family reported extended family mental illness with many experiencing some level of domestic violence. From the original sample of 41 families, four parents withdrew from the study because of a deterioration in their mental health.

2.2 Interviews

Parents chose the venue for the discussion with the majority preferring to be interviewed in their own home. The lead author has over 20 years of extensive clinical experience working with children and families. Additional support and supervision were provided by a team of clinically skilled child psychologists. Development of the semi-structured interview questions was through a reference group of consumer advocates, child and adolescent clinicians and adult mental health clinicians.

Table 1. Mental health & G.P. recorded diagnosis of parent and child illnesses

Mental Illness	Parent		Child	
	Number	Percentage	Number	Percentage
ADHD and Anxiety	0	0	3	8.1
Anxiety	3	8.1	2	5.4
Anxiety and Depression	25	67.6	13	35.1
Autism Spectrum Disorder	0	0	2	5.4
Depression	5	13.5	4	10.8
Early Psychosis	0	0	2	5.4
Other*	0	0	11	29.7
Personality Disorder	3	8.1	0	0
Schizophrenia	1	2.7	0	0
Total	37	100	37	100

Note. * Classified ICD10 – F98.9 (Unspecified behavioural and emotional disorders)/DSM 5 - Disruptive Mood Dysregulation Disorder

With the aims and objectives explained, and a written copy of the information sheet offered, parents consented to their family participation (interview information not included here). It was emphasised at the start and end that consent could be withdrawn at any time until the point transcripts were de-identified. Use of a Dictaphone voice recorder with subsequent transcription of the material was explained, one parent selected the use of written notes only. Interviews started and finished with a general conversation to help with the rapport building process. Connection was more easily established in the home setting and ensured an idiographic focus. Parents were offered several opportunities for clarification and to ask questions. Interview lengths varied with the most extended 90 minutes and the shortest 35 minutes. Some of the additional material was provided once the Dictaphone had been switched off.

The phenomenological approach used in the study sought to obtain an insight into how parents made sense of the bidirectional influences of mental illness in their family context. The principal aim being to explore in detail how these parents understood and conceptualised their experiences in terms of any bidirectional impacts between themselves and their child. To achieve this, a phenomenological approach was employed to help get close to the parent's experience of living with mental illness and also having a child with a mental illness. As described by Conrad^[32] we wanted to get an "insider's perspective". Initially 20 questions relating to the parent's experience were proffered in semi-structured interviews. The first three parents interviewed reported feeling stifled and stressed by the interview format and a review by the reference group led to a more open approach using the following general and non-leading prompts: (1) Please try and describe your experiences when you are unwell and when your child is unwell; (2) How, if at all, have you been supported as a

family; and (3) Based on your experience how might other families be best supported?

This revised open inductive approach provided parents the opportunity to express their views and the researchers to hear those experiences. The open inductive approach also allowed for a bottom up understanding of each parent's situation.^[33] The thematic analysis applied full criteria of credibility, consistency, applicability and confirmability.^[34]

2.3 Data analysis

Interviews were professionally transcribed, and text returned to the research team for thematic analysis. Utilising NVivo (for Mac, version 11.4.3) the transcribed material was re-read several times to assist in capturing any patterns and to help the team get a sense of the phenomenon of the parent's experiences. Audio tapes were also reviewed to help with the empathic connections we sought in the parent's experiences. In the first part of the analysis responses were sorted into key common content areas. Secondly, an inductive thematic analysis was conducted in NVivo while ensuring we maintained the elements that described the parent's experience. It was important in this process to not lose the meaning behind the parent's understandings. Themes were deduced from the number of instances words and phrases occurred with ideas subsequently merged and catalogued. Finally, each of the team members coded responses independently, and codes were combined into common concepts. Uncertainties were resolved through discussion and agreement. With a range of phenomenological characteristics from the stories provided by the parents it was inevitable that many of the codes were not mutually exclusive. The precious data from parents provided both collective and individual themes as reported below in the results. Parents perspectives were taken as true and correct individual perceptions.

3. RESULTS

From analysis of the transcripts seven overarching themes emerged and these are presented below.

3.1 Bidirectional impact of child-parent mental illness

In this study all parents reporting an association between parent and child mental illnesses. Central to this theme was how a child's mental health impacted parents, irrespective of the classification of the parent's mental illness.

"Very difficult, it (anxiety) upsets the whole household, it goes from one child to the other, it is unsettling for everyone."

Mother depression: four daughters anxiety/depression.

The bidirectional impact was also illustrated by extreme child behaviour and the struggle of not letting their child's mental illness affect them.

"I sat up with him for three nights; I was tired I didn't know what to do because I didn't want to leave him in case he killed himself. But he was yelling and he got violent and angry – it's very scary because you don't know what to do... my anxiety went through the roof."

Mother anxiety/depression: son psychosis.

One parent described how she could not afford to fall apart for fear that everyone else (in the family) would do the same. Within this theme parents reported concern about their child's mental illness, worry about their own health, and anxiety for the future. The concept of "holding it together" was important for parents who sought to suppress their own mental illness to help them manage their child's mental illness. In addition to bidirectional influences of anxiety, mood and frustration, parents reported anger as they sought to redirect their emotions when their child was unwell. Redirection and staying calm and relaxed was more difficult when they too were unwell. Parents struggled with fear of being "tipped over the edge" by their child's mental illness. Observing mental illness in their child added to parental stress: as did the reported feelings of not being believed when they first voiced concerns about their child. Parents disclosed frustration and confusion before their child was diagnosed believing this was because of their own mental illness. They described this period of uncertainty as causing an aggravation of their mental illness.

3.2 Socio-economic issues for families

Family violence, finances, work, transport and accommodation were all issues for some of the families in this study. Family violence from ex-partners and family violence between parents and children were reported by a large minority of families and were major contributors to both parent and

child mental illness.

"She was really scared of her father and was making herself sick in order to be picked up from school and not go to her dad's and all sorts of things and then that just made me even more anxious."

Mother personality disorder: three daughters anxiety/depression.

Finances were a major concern with one mother reporting:

"Finances can be such a burden, you know when you are unwell like my anxiety when I couldn't get out of the house and then I just got more anxious worrying how he would get food and stuff."

Mother agoraphobia: daughter anxiety.

For most parents going to work was an impossibility, even when mentally well. Needing "to deal" with their child was a significant barrier to being able to work. Difficulties getting to appointments was raised by half these parents. Predominantly getting to CAMHS appointments was a challenge though for some attending adult mental health services was as much a challenge. Catching multiple buses and juggling pickup of other children was a major barrier to obtaining intervention. Accommodation impacts included: houses too small, being isolated, community problems, and landlords blaming mental illness for housing issues. While a problem for some, others saw home as a sanctuary – a safe place, to escape pressures in society and the stigma they perceived they had experienced because of mental illness.

3.3 School issues

School was highlighted as a major difficulty for most of the parents with the greatest concerns about bullying experienced by their child and how this resulted in a knock-on impact on their mental health. For most of the parents it was a struggle persuading their children to attend school and commonly this resulted from their child wanting to care for them. Additional stress for parents was the tendency of schools to call when children presented with even minor emotional difficulties.

"It is stressful when the school has trouble dealing... when they struggle, the first person they would call is me, which is hard for me."

Father anxiety/depression: daughter depression.

Schools frequently calling parents added to parental anxiety. These calls resulted in lowered parental mood because of uncertainty and insecurity on how they might manage their child's mental illness. The issue of lack of training for teachers and limited welfare support in schools was a major concern for parents. However, one parent highlighted

good school support as occurring in a few schools though she noted this support could easily be disrupted.

"School was my support that was giving me time through the day, but ... at the same time, you never knew when they were going to ring you up and say 'Look come and get him'".

Mother anxiety/depression: autistic son with anxiety.

3.4 Parenting with a mental illness

Most parents reported "triggering" others in the family and how their own mental illness changed their parenting behaviour and their responses as a parent. Feelings of being an inadequate parent when unwell was described by a majority of the parents.

"That's been really upsetting for him and really triggering his anxiety so ... it's hard for any parent to deal with but if you already had anxiety yourself, and then your kid's anxiety flares up, it's really very difficult."

Father anxiety: two children anxiety.

They described their mental illness impacting on what they could or could not do and how inadequate they sometimes felt as a parent. Many parents described behaving irrationally when mentally unwell, but they recognized their children just accepted this as "the way things are".

Hospitalization, or being "taken away" by mental health services, was a major issue for over half of the parents, particularly not knowing what happened to children. Lack of reassurance or information was described as adding to increasing dysregulation which in turn prevented them from successfully expressing their concerns. For some they felt this made them seem more unwell.

"I'm scared for him, you know because I, like many years ago I was scared for myself, I was crying out for help but I was overdosing and I was crying out for help myself."

Mother personality disorder: child depression.

Socialization issues were described as exacerbated by parent-child mental illness, as was guilt over mental illness "consuming" both parents and children.

All the fathers reported feeling "out of control" when unwell and struggling with frustration and anger issues which they felt unable to control. These fathers described inner guilt over their response to their child's mental illness. Associated to anger all parents reported the issue of stigma, in relation to mental illness, as a substantial burden for them. Parents described stigma as widely occurring in different contexts: in interactions with others; in relation to support services in the community; family; and schools. A mother with a

terminal illness felt well supported for her physical issues but stigmatized because of her mental illness.

"I just feel like, why do they make me feel so bad – I already feel shame, why do you keep rubbing it in with stigma, you know what I mean?"

Mother with cancer, anxiety/depression: son anxiety.

Parents highlighted the major challenges of managing their own mental illness and supporting their child with mental illness. They often blamed themselves for a number of issues including: their child's mental illness; child behaviour difficulties; failing to prevent bidirectional influence; and feeling powerless to provide "mental stability" to prevent their child becoming unwell. All found parenting a child with a mental illness stressful and highlighted how this had a considerable impact on their own mental health. The consequence was an effect on parental self-esteem and confidence in their parenting abilities.

"... my kids can be a big stress on me that often sets me off so no matter how hard I try the kids often cop it."

Father depression/psychosis: two children anxiety/depression.

3.5 Useful family strategies

Parents identified strategies specific to the challenges of bidirectional parent-child mental illness. These included the following child, parent and family focused strategies.

3.5.1 Child

Parents described reducing the bidirectional influence of mental illness through walking away, usually with children or parents going to their room.

"They sort of go off and stay by them self in their rooms."

Mother depression/anxiety: four children anxiety.

Half of the parents found this useful whilst the other half found it frustrating wanting to talk things over. All parents recognized this strategy as an effective way to de-escalate situations between family members.

3.5.2 Parent

One strategy used by parents was utilizing the home as a safe sanctuary and a place to keep stigma, and the outside world, at bay.

"... making an effort to give him more attention and the fact he was in our room... making a deliberate effort too, because I realised it was an issue."

Mother anxiety/obsessive-compulsive disorder (OCD): daughter anxiety.

These parents described routine as the way to manage mental illness in the family. Staying attuned to their child's mental health and trying to suppress their own mental illness was also important. For most parents, when first having a child, there was an initial anxiety over anticipated child mental illness. As children became older a determination developed that provided them a level of aptitude to inhibit their mental illness to support their child. Importantly all these parents sought, often inadequately, to try and protect their child from distress about parental mental illness. Whilst infrequently successful they felt reassured they had made the effort. Despite mental illness parents described being available for children was an important aspect for protecting them.

A common strategy used by parents was distance or using distraction. Giving time to get their mental health "back on track" was a frequent approach. Pets were identified by many as a great calmer for both themselves and their child. Other parents used the internet to learn parenting strategies though, most preferred strategies from family and friends.

3.5.3 Family strategies

Focusing on agencies, particularly schools, helped redirect stress giving a sense of control. Half appreciated that their actions were seen by others as reflections of their mental illness. Sharing problems was important for 73% (n = 27) of parents.

"... our family just talk about problems: it's a problem session but it really makes my son happy to know he's not the only one going through this emotional roller coaster. Family time is very special which I actually fit in every day."

Mother anxiety/depression: son anxiety/depression.

However, only a small number of parents had whole family strategies involving family time and conversation where everyone would talk about their emotions and feelings.

3.6 Sources of support

This was the second area to generate the greatest response from parents. Difficulties with schools, mentioned above, and family doctors were often reported as a problem. The majority of parents believed their mental illness clouded responses from professionals when they raised concerns about their children. Other key support issues included: the brevity of interventions; substantial gaps between appointments; referrals being made to specialists some distance away, in the city; prohibitively costly supports, such as psychiatric input; and being advised to use the internet which added to confusion and anxiety for parents.

All but two highlighted the need for external family support suggesting support should start as early as possible with

agencies needing to recognize that parenting with a mental illness has unique challenges.

"I think that it's really important that doctors and people that are in those sorts of jobs listen more and understand more and consider mental health more in kids because I feel like that was not even considered for my daughter."

Mother OCD: daughter anxiety.

All the parents reported difficulty in finding services that were understanding of the bidirectional impact of mental illness. Providing understandable and accessible information to parents, to improve parenting knowledge and skills, was thought vital for helping these parents. Parents also highlighted the importance of raising awareness of mental illness, including within schools. Overwhelmingly parents felt organizations and agencies being cognizant of the nature of bidirectional mental illness in families was fundamental. Some of the parents would have liked respite opportunities as well as groups for children focusing on the bidirectional impacts of mental illness.

3.7 Intergenerational mental illness

Parents spoke of transgenerational mental illness best described by one parent:

"I have this child, and I give her anxiety through this, you know, whole transgenerational thing, I can see from my father's own mother, you know, very difficult. ... So, it was like I could see that (mental illness) coming... Mental illness is toxic, weighs you down, using so much energy suppressing. And then when you do behave strangely, you're not quite sure why you're behaving strangely, and it's because of those split-off thoughts. It's just you being dysregulated, you're making your child dysregulated and you got it from your parents."

Mother OCD: daughter OCD/anxiety.

All but one family reported other family members, such as a grandmother or grandfather, with a mental illness.

4. DISCUSSION

This article contributes to the literature on mental illness in families in two significant ways. Firstly, some themes generated by parents reiterate findings from current published research. However, these established themes are from a very unidirectional rather than bidirectional viewpoint. Earlier studies have primarily considered viewpoints of children living with a parent with a mental illness. This study expands the thinking as it looks at bidirectional and intergenerational impacts of mental illness. Secondly, in examining themes where both a parent and a child have a mental illness, we

have opened a new and previously neglected discourse. From the voices of these parents' the very specific challenges faced in families where both a parent and a child have a mental illness have been emphasized.

Parent interviews reaffirmed previously well-documented difficulties relating to school, stigma, community and supports. Social difficulties, highlighted earlier, are in line with Platt et al.^[35] who found events, such as school problems, may increase parental stress and child anxiety. Bibou-Nakou^[36] and Reupert and Maybery^[14] have suggested school staff may not have training or knowledge on what to do in relation to mental illness, an issue identified here. Strategies for families might usefully focus on providing schools psycho-education on matters relating to bidirectional impacts of mental illness. Supporting teachers in developing positive relationships and improving perceptions of families would also reduce stress. Consistent with Corrigan et al.^[37] the issue of stigma impacting parents was an enduring problem. In the study by Hasson-Ohayona et al.^[38] stigma was found to produce a sense of shame in extended family members because of negative views about mental illness. These negative views were equally discovered in the wider community. For some of the parents' in this study social isolation was preferable to experiencing the stigma they felt in relation to their and their child's mental illness.

In this study historical family violence and an emotional intensity between parents and children was a common experience. We found other socioeconomic issues including finances, poor or inadequate accommodation, and transport issues were predominant concerns for parents. Factors such as these are well documented in the literature.^[39-42] In this research however, parents perceived having two people with mental illness in the family compounded socioeconomic and other issues.

Importantly this research adds to current literature with the following new themes emerging from parent interviews: general bidirectional impacts between parent and child mental illness; elite impacts of bidirectional influences; and specific strategies related to bidirectional effects. As interviewees were parents, where they and their child both had mental health problems, predictably the bidirectional impact of mental illness emanated as a key theme. Irrespective of diagnosis, all parents described a psychosocial association between parent and child mental illness. Critically parents described how child mental health problems impacted their own mental illness. They also explained that the mix of their own and their child's mental illness had a profound effect on how they parented. Parents reported how the sometimes-extreme behavior of children would upset and unsettle everyone in the

family. An ongoing struggle existed for parents in trying not to let the child's illness affect their illness which in itself had an influence on overall levels of family stress. This dilemma was typified by one parent suggesting:

"If my anxiety or depression is playing up I surely react differently to the way she is behaving, that is a huge part, my mental health, the way I feel about myself, affects greatly how I parent."

Father Anxiety/medical issue: daughter anxiety/depression.

In this interplay the parents indicated the importance of subduing their own mental health concerns for the benefit of their parenting and children. This finding extends the previous work in this area (e.g.^[43-46]) including that related to the impact on parenting.^[47,48] This research supports the theoretical approach of the Falkov^[16] Crossing Bridges Family Model. The findings put 'flesh on the bones' of the Falkov model which describes the "... interplay between any child's response to parental symptoms and the consequent effects (emotional and behavioral adaptations) on parents, siblings and others in the family" (Falkov, p.118).^[16] He argues for the importance of the parent child dyad in affecting, even intensifying, a deterioration in mental health. His family model emphasizes "how risk and resilience may be transmitted through generations." (Falkov, p.40).^[16] The interplay between the mental illness of parents and children was a significant aspect of this study. Intergenerational transmission of mental illness was an important feature evident in this study with almost all participants indicating transgenerational mental health problems within their families.

Parents keenly described, in-depth, the interplay between their mental illness and family functioning. This was important as they disclosed struggling with guilt and worry over any influences they might have on their child's mental illness. Universally, deterioration in parental mental health triggered emotional responses in other family members. These emotional responses were displayed through worsening mental health and increased negative behaviors. Parents described "blocking out" their own behavior's when unwell. These reports by parents reinforced our proposition of a bidirectional impact of mental illness.

The research revealed that parents being hospitalized impacted in two discreet ways; firstly, by removing parenting influences in the family, and secondly impacting on family socialization through increased stigma. From both the children and parent's perspectives, parental hospitalization had a major impact on families.^[13] In the Swedish study by Östmann and Kjellin^[49] relatives of patients in a psychiatric unit reported patients' mental illness impacted on relation-

ships and their relatives mental health. In this study parents' descriptions of children being overlooked, with what they felt was little regard by professionals of any emotional impacts, highlights potential gaps in service delivery. Inevitably a stressful situation was doubtless compounded where the child also had a mental illness.

Parents outlined fundamental strength-based strategies for the management of parent-child mental illness (e.g. getting away; building a home sanctuary). Being attuned to each other and establishing and maintaining strong routines was also important. These ideas invite similarities to trauma-informed models of care recognizing stability, routines and trust as helping individuals.^[50] Whilst not new such ideas suggest formal inclusion of these interventions in discussions with families where there is parent-child mental illness.

Parents described two areas they felt were neglected by mental health services. They felt unsupported in adjusting to living with a child with mental illness and they felt their treatment was managed in isolation with poor, or non-existent, family approaches. Parents described inadequate help managing the "grief" of having a child with a mental illness. None received reassurance or guidance in relation to their fears of bidirectional influences. Corrigan and Miller^[51] highlight parents as frequently stigmatized for their child's mental illness. Whilst Saunders,^[52] in the study of 37 parents, found stress common for all family members. Importantly parents did not feel specialist child mental health services took any account of parental mental illness when supporting children. It is unclear why such gaps exist, but two possibilities need consideration. Firstly, a great deal is written about the impact of parental mental illness on children only a few references^[15,53,54] relate to the impact of children's mental illness on parents. Secondly a focus on person centered care and individual recovery appears to reinforce the individual over the communal family. As expounded by Gask and Coventry^[55] there needs to be a move from "patient-centeredness" (p.142) to family and community. Focusing on the parent as an individual, rather than as a parent in a family, further impacts on their mental health. Such an emphasis reinforces a sense of uncertainty insecurity and feelings of inadequacy as a parent. Effectively supporting family units, going beyond the "patient", is indicated as an approach for improving parent's mental health and aiding whole family recovery. Kaplan and Racussen^[56] determined intervention should support service users to take ownership and control of managing their recovery. For these parents that ownership and control is around being heard, with services mutually embracing support for both the parent and the child. Falkov^[16] describes how services need to be connected with, and responsive to, people with mental illness to enable effective intervention. Six years

on from Falkov the parents in this study reported little change to the individual approach.

Study limitations and strengths

Families were recruited through clinician referral, a methodology reliant on clinician interest and potentially a predisposed type of family. Similarly, the parent's interest in taking part may have impacted on the rationale for involvement. The level of parental acuity and state of mental health may have been an additional dimension which might have influenced responses.

It was notable while interviews were conducted in a very informal friendly manner, to support parent engagement, this approach resulted in a brutally honest and open discourse. The difficulty for these parents of acknowledging the challenges of being a parent with a mental illness cannot be underestimated. Honesty born out of frustration with services and elements of their own mental illness might be considered a limitation but can also be considered a strength. Equally, despite being initially guarded a parent with paranoid schizophrenia was determined to have her voice heard despite at times feeling mentally overwhelmed. This desire to have their voice heard was evident with all the parents. Two parents, who have subsequently died because of their physical health problems, viewed the study as a lasting legacy in raising awareness of bidirectional influences of mental illness.

Despite mostly negative experiences the parent's narrative contained a number of positive characteristics. Concepts of love of their child and everyone doing their best to help each other, as well as families pulling together, all important aspects which might also be considered as limiting factors.

5. CONCLUSIONS

People with a mental illness have a difficult journey when they become parents. In addition to managing their mental illness they have challenges of stigma and denunciation. There is little if any information given on influences of parental mental illness on children. Bidirectional impacts of mental illness are typically not considered by mental health services.

With limited support and imperfect intervention these parents have developed personal strategies to manage. They highlight a critical need to address how parents with mental illness are supported when they have children of their own. Our investigation has revealed gaps in provision for these families with clinicians needing to take account of bidirectional influences. Reassurance for parents in relation to their child can help alleviate stress. There needs to be greater emphasis on training clinicians in the understanding

of bidirectional impacts of mental illness. As highlighted by Falkov^[16] clinicians being able to support parents in managing emotional impacts of mental illness is fundamental. Challenging stigma, engagement, and early intervention are important to these parents. Providing skills in understanding early years attachment and working with children's emotions are key skills parents need. More research is needed into

the bidirectional impact of mental illness looking at both positive and negative factors. With limited research focusing on Parents of Children with Mental Illness (PoCMI) this is an area needing further investigation.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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6.2 CONCLUSION

Co-existing mental illness in families is more than a theoretical paradigm. Parents living with mental illness experience a multitude of stressors which they report as compounded by having a child with a mental illness. Parents in this study confirmed a number of issues raised by other researchers but they also added a new dimension never fully considered before.

The important issue for these parents had been the compounding effect of having a child with a mental illness, the extra demands they felt were placed on them and the burden of exaggerated and overstated stigma. Parents were quite clear in describing the difficulties they had in trying to cope from what many described as a disadvantaged starting point. Certainly, the problems of the reported individualistic service stance had added to their difficulties. These issues are further examined and discussed in greater depth in chapter 7.

6.3 BRIEF INTRODUCTION

The fourth paper, again utilising a phenomenological perspective, had explored the reality and social construct of children with a mental illness living with a parent with a mental illness.

Objective 4 - Undertake a narrative dialogue with children, to ascertain the impact of mental illness within the family and seek their ideas on what would moderate those influences.

Jessop and De Bondt (2012) estimated that 29.6% of child and youth mental health services clients had a parent with mental illness. Van Veen et al. (2016) found 42.1% of mothers and 21.8% of fathers, of clinic attendees in the Netherlands, had sub-clinical mental health scores. Amiri, Ghoreishizadeh, Alavizadeh, and Saedi (2014) illustrated that 25% of mothers and 33% of fathers met criteria for mental illness (using SCID-4). Other writers have found as many as 70% of children attending a CAMHS had at least one parent potentially with a mental illness (Baker & Lees, 2014). In this study that number reached 79% of children had a parent with a validated mental illness (Naughton, Maybery, & Goodyear, 2017).

With the high level of parental mental illness evident in CAMHS clients, it is important to take account of transgenerational influences of behaviour, communication and emotional responses that are passed down from generation to generation (Albert, 2017). Such transgenerational influences may have had an influence on the quality and content of the discourse of these children. The quality of relationships in any family will impact on subsequent relationships and the functioning of children. With patterns of behaviour likely to be transmitted from generation to generation what part, if any, might mental illness play in a child's life and interactions? These influences in families may be further

affected by family mystery around feelings that affect how a parent and child express their emotional and behavioural experiences.

The problems of insecure mother-infant attachment have been well researched with the emotional availability model suggesting mothers are less emotionally available where there is increased stress (Cassibba, van Ijzendoorn, & Coppola, 2012). In a more recent study Cassibba, Coppola, Sette, Curci, and Costantini (2017) found intergenerational continuity of attachment styles persisted along the intergenerational maternal line going further to say mothers have ‘the strongest influence in the development of children’s mental representations’ (p. 401).

Maintaining the focus of the previous parent paper in-depth interviews, what might best be described as conversational narratives were utilised to determine any interplay between a parent and child with mental illness, as seen from children’s perspectives. Use of this more relaxed and open narrative approach empowered children to engage and be open in their discourse. It is in the fourth paper that the last research question has been explored: what are the lived experiences of children who have a mental illness and live with a parent with a mental illness?

Stress and additional mental health problems were reported by parents where their child had a mental illness. There is anecdotal evidence at the practice level of the interplay between parental mental illness and childhood mental illness, often couched as stress. Some writers report that there is a link between parental and child stress levels (Roberts et al., 2013; Serido et al., 2004). Some causal effects have been found between maternal depression and child depression (Weissman et al., 2006; Walker, Davis, Al-Sahab, & Tamim, 2013). In their STAR*D study, it was established that improvements in a mother’s symptoms of depression resulted in a consequent improvement in their child’s depression. In the recent study by Naughton, Maybery, and Goodyear (2019a) parents reported child mental illness as adding to their own stress and exacerbating their symptoms. This indicated an interplay between child mental health and parental mental health. Harden (2005) found parents experienced guilt over impacts of their mental illness on their child’s mental health which may be an added stressor. Falkov (2012) provided a useful theoretical model to explain the broad interplay of interactions in families. In contrast, the socio-emotive trait mediation model helps explain the interplay between emotions and coping in families (Carlo et al., 2012). Falkov (2012) describes how parental mental health can impact early on in a child’s life and is an important factor for children’s health and social outcomes, going on to emphasise how the burden of mental illness can alter the proficiency and success of the parenting role. Within this model, it is evident that there is a linkage between parental and child mental illness with, as Falkov defines, children ‘drawn into their (parent’s) symptoms’ (p. 163). Carlo et al. (2012) on the other hand, suggests that emotional instability is

managed by children using emotion-focused coping, a skill learned through socialisation learned from parents.

6.3.1 Theoretical underpinnings

In line with the parent's interviews, an interpretative phenomenological approach was adopted and followed the interpretations grounded in the children's accounts. Importantly in embracing a hermeneutic stance with the children, it was essential to utilise the lens of the sociology of childhood. The sociology of childhood derives from youth sociology as well as ethnography, focusing on day-to-day life and the ways children position themselves in the family and the society in which they live. This paradigm is about the cultural performances and the social worlds children construct and take part in. Children are seen as active participants and members of the world that forms their personal cultural and social reality from the start of their life. From this perspective children and adolescents are not outsiders or lesser beings but are seen as 'emergent' members of society. The sociology of childhood highlights the differentials in interaction ranging from the amount of time spent with children to how much parents invest in their children's futures. Parents are seen to bring biases into the relationship with their children and parents' actions influence attachment, behaviour and mental health.

Sociocultural theory offers a contextualised view and situates development within a frame of sharing in activities that occur within social interactions and relationships in families. Smith (2002) describes the sociocultural approach as children slowly but surely becoming acquainted with and comprehending their environment. This understanding occurs through what children do for themselves in interactions with others and within the cultural context that is the family in which they live. Sociocultural theory challenges the traditional views of child development more than developmental psychology and places importance on social processes. Vygotsky (1978) believed that children grow into the intellectual life around them. To be competent, a child needs to be challenged and extended with help from those around them. As help is withdrawn, so the child needs to do more on their own. Vygotsky argued that child development could not be understood by looking at individuals. When a child with a mental illness lives with a parent with mental illness how might these interactions and developmental processes change and if they do change how might both the child and parent be affected?

6.3.2 Paper 4 - A child's perspective of bidirectional impacts of mental illness in families: "It's like a cold it goes from one of us to the next"

ORIGINAL ARTICLE

A child's perspective of bidirectional impacts of mental illness in families: "It's like a cold it goes from one of us to the next"

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ABSTRACT

Objective: Investigations into the influence of mental illness in families concentrates on how a parent's mental illness has an effect on their child, but we now know over two thirds of children with a mental health issue also have a parent with a mental illness. This study examines experiences of these children.

Methods: Thirty-eight children were interviewed, including two sibling groups. Interview transcripts were analysed using interpretative phenomenological analysis with a number of themes identified.

Results: It was clear from children's accounts that family life presents some unique challenges because of co-existing mental illness. These included social challenges; school issues; and family interactions. Children also postulated ideas on the support that they considered helpful for comparable children and families. The latter included coping strategies, experiences of professionals and support that they would have liked.

Conclusions: The voices of these children indicate that interventions should not be considered in isolation and that it is important to focus on bidirectional influences of mental illness. Understanding the perceptions and interpreted realities of children in these families will facilitate more successful outcomes for the whole family. Providing a family-focused, bidirectional approach, is an important initial phase in helping children manage where mental illness is a ubiquitous feature for multiple family members.

Key Words: Children, Mental illness, Bidirectional impacts, Perspectives, Family

1. INTRODUCTION

Estimates of the prevalence of parental mental illness have varied with studies reporting rates of 21%-23%,^[1] 32%^[2] and 50%.^[3] A recent review of the prevalence of parents attending adult psychiatric services estimated between 12% to 45% of service users to be parents^[4] with four studies showing rates between 36% to 38%.^[5-8] These figures indicate approximately one-third of adult psychiatry service users are likely to be parents. These data suggest where a

parent has a mental illness children are at increased risk of developing mental illness themselves.

In recent years there has been an intensification in research attempting to understand the prevalence of mental illness of parents of children presenting to mental health services. Studies have estimated varying degrees of parental mental illness of Child and Youth Mental Health clients with numbers ranging between 30% and 42%.^[9-11] However, in regional Canada, Baker and Lees^[12] found 70% of children attending

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a Child and Adolescent Mental Health Service (CAMHS) had a parent with a possible mental health concern. The current study extends an earlier investigation of CAMHS families that determined almost 80% of these children were living with a parent with mental illness.^[13]

A systematic review by van Santvoort et al.^[14] found a connection in the research between parental and child disorders impacting on the well-being of both parents and children.^[1,15] Boursnell^[16] suggests parental mental illness impacts on parenting capability and Hautamäki^[17] noted maternal unresponsiveness and low parental sensitivity where there is mental illness. The interaction, and resulting effects of mental illness in families, is usefully explained in the Crossing Bridges Family Model.^[18] The model outlines the consequence of the child-parent dyad in disturbing, even intensifying, child and parent mental health issues.

Transgenerational influences of behaviour, communication and emotional responses have been found to impact on the next generation.^[19] The quality of relationships in families influence subsequent relationships and functioning of children, with patterns of behaviour transmitted from generation to generation. Family secrecy around emotions, in turn, shape children's emotional experiences with strong links found between grandparent's emotional attachment and their grandchild.^[20] Studies have also shown an active link between adult attachment security and infant security.^[21-23] The Bailey et al.'s study of 184 mother-infant dyads concluded that "intergenerational configurations of attachment might be linked to the elaboration of disorganisation".^[24] (p. 444).

Considering co-existing family mental illness through the lens of the sociology of childhood adds to the discourse. Children are recognised as active participants in their own environment interacting and creating a culture they share with others. As social actors' children are active in their construction of the world and can influence that world.^[25-27] With children seeking to be effective family members and wanting to understand social rules and relationships the influence of parental mental illness cannot be underestimated. Children as young as two are capable of asserting themselves and causing parental conflict and emotional dysregulation.^[28] A situation possibly made worse through the lens of mental illness. Children actively contribute to their world construction as social actors able to evaluate and reflect on things happening around them.^[29,30] Importantly, relationships between adults and young people are distinguished by a disparity in power. Children have a dependency relationship with adults whether they want it or not and a child's socialisation is often constructed to fit into a particular social role.^[31,32] From this

perspective, it might be argued that a child living in a world consumed by parental mental illness is likely to adapt to that environment in very particular ways.

Whether children's risk of mental illness is a consequence of parental attachment issues, is shaped by transgenerational factors, or is mitigated by a child's constructions and biological factors is a matter for further consideration. This study takes a child-centric approach in examining the experiences of children with a mental illness living with a parent with a mental illness.

2. METHODOLOGY

Community mental health clinicians from a regional mental health service were engaged to identify children from their caseload, over the age of 12 years, who also had a parent with a mental illness. The identified families were invited to participate in a qualitative interview study.

2.1 Participants

From 37 volunteer families, there were 38 children interviewed that included two siblings (see Table 1). One child withdrew consent at the member checking stage. Of these families, 59.5% (n = 22) lived in regional settings, with the remainder from rural areas. Notably, 24.3% (n = 9) of the parents were employed, 45.9% (n = 17) on a disability support pension due to a mental health condition and 8% (n = 3) were seeking employment, the remainder were on other types of benefit. Parents ranged between 30 and 55 years of age with nearly half within the 36 to 45 age bracket. There were 32 mothers and 5 fathers. Children ranged in age from 12 to 23 years: 45% (n = 17) aged between 12 and 14 years; 42% (n = 16) aged between 15 and 17 years; 13% (n = 5) were aged over 18 years. Parents had either current or past involvement with adult mental health services with all children engaged with CAMHS. The primary diagnosis of the children was depression (40%, n = 15) and depression and anxiety (34%, n = 13). Of the total 11% (n = 4) had anxiety alone with 11% (n = 4) with co-morbid ADHD and anxiety. Only 3% (n = 1) had a diagnosis of psychosis with one other child diagnosed with high functioning autism.

Children were interviewed without the parent present in the room, though parents remained in close vicinity. Monash University and community mental health service ethics committees approved the research.

2.2 Interviews

The children chose when and where they wanted the interview to occur with most interviewed in their own home. The principal interviewer was an experienced child and family clinician with over 20 years' experience. During the in-

terview process support and supervision was provided for the principal researcher from a team of clinical child psychologists. Support for parents and children remained with the treating mental health team. Prompting questions were developed through a focus group of consumer advocates and mental health clinicians. Three open-ended facilitating prompts were used to encourage the descriptive discourse

of the children and followed the format of the preceding parent interviews. The prompts used were: (1) Please try and describe your experiences when you feel (mentally) unwell and when your mum or dad is (mentally) poorly; (2) Please describe any supports you and your family have had; and (3) Based on any support you have had what, if anything, do you think could be done better?

Table 1. Demographic information of children, parents, grandparents and communities

Child Mental Illness	Child Gender	Child Age	Child School	Grandparent MI	Parent Work	Parent Mental Illness	Parent Gender	Community	Isolation From
Depression	Female	12-14	Main	Yes	Employed	Schizophrenia	Female	Rural	Community
Depression	Female	15-17	Main	Yes	Employed	Schizophrenia	Female	Rural	Community
Depression	Female (1)	15-17	Alternate	Yes	Employed	Anxiety & Depression	Female	Town	Community
Depression	Female (1)	15-17	Main	Yes	Employed	Anxiety & Depression	Female	Town	Community
Depression	Female (2)	18-20	Alternate	Yes	Employed	Anxiety & Depression	Female	Rural	Family & Community
Depression	Female	18-20	Main	Yes	Employed	Anxiety & Depression	Female	Town	Family & Community
Anxiety	Female	12-14	Main	Yes	Employed	Anxiety & Depression	Male	Rural	Community
Anxiety	Male	12-14	Main	Yes	Employed	OCD	Female	Rural	Community
Anxiety & Depression	Male	12-14	Main	Yes	Employed	Depression	Female	Rural	Community
Anxiety & Depression	Male	12-14	Main	Yes	Employed	Anxiety & Depression	Male	Town	Community
Anxiety & Depression	Female	12-14	Alternate	Yes	Employed	BPD	Female	Rural	Community
Anxiety & Depression	Male (2)	12-14	Main	Yes	Employed	Schizophrenia	Female	Rural	Family & Community
ADHD & Anxiety	Male	12-14	Main	Yes	Employed	Anxiety & Depression	Female	Rural	Community
ADHD & Anxiety	Male	15-17	Main	Yes	Employed	Anxiety & Depression	Female	Town	Community
Psychosis	Male	15-17	Main	Yes	Employed	Anxiety & Depression	Female	Town	Family
ASD	Female	12-14	Main	Yes	Employed	Anxiety & Depression	Female	Rural	Community
Depression	Female	12-14	Main	Yes	Pension	Anxiety	Female	Rural	Family & Community
Depression	Female	12-14	Alternate	Yes	Pension	Anxiety & Depression	Female	Rural	Family & Community
Depression	Female	12-14	Main	Yes	Pension	Anxiety & Depression	Female	Rural	Family
Depression	Male	15-17	Main	Yes	Pension	Anxiety	Male	Town	Community
Depression	Female	15-17	Main	Yes	Pension	Anxiety & Depression	Female	Rural	Community
Depression	Female	15-17	Main	Yes	Pension	Anxiety & Depression	Female	Town	Community
Depression	Female	18-20	Alternate	Yes	Pension	BPD	Female	Rural	Community
Anxiety	Female	15-17	Alternate	Yes	Pension	Anxiety	Female	Town	Good Support
Anxiety & Behaviour	Male	15-17	Alternate	Yes	Pension	Anxiety & Depression	Female	Town	Community
Anxiety & Depression	Female	12-14	Main	Yes	Pension	Anxiety & Depression	Male	Rural	Community
Anxiety & Depression	Female	12-14	Main	Yes	Pension	Anxiety	Female	Rural	Family
Anxiety & Depression	Female	15-17	Main	No	Pension	Anxiety & Depression	Female	Rural	Family
Anxiety & Depression	Female	18-20	Home School	Yes	Pension	Anxiety & Depression	Female	Rural	Good Support
Anxiety & Depression	Female	21-23	Main	Yes	Pension	Depression	Female	Town	Good Support
ADHD & Anxiety	Female	12-14	Main	Yes	Pension	Anxiety & Depression	Female	Rural	Family & Community
Psychosis	Male	15-17	Main	Yes	Pension	Anxiety & Depression	Female	Town	Community
Depression	Male	15-17	Main	Yes	Home Keeper	Anxiety & Depression	Female	Town	Community
Depression	Female	12-14	Main	Yes	Home Keeper	Anxiety & Depression	Female	Rural	Community
ADHD & Anxiety	Male	15-17	Main	Yes	Home Keeper	Anxiety	Female	Rural	Family & Community
Anxiety	Female	15.17	Main	Yes	Home Keeper	Anxiety & Depression	Male	Rural	Community
Anxiety & Depression	Female	12-14	Main	Yes	Home Keeper	Anxiety & Depression	Female	Town	Community
Anxiety & Depression	Female	15-17	Alternate	Yes	Home Keeper	Anxiety & Depression	Female	Town	Family

Note. (1) & (2) - Two Sibling groups

The purpose of the research was explained with the Information Sheet offered. Both parents and children consented to being involved. It was emphasised on a number of occasions that they could withdraw from the research at any time prior to transcripts being de-identified. The procedure for voice recording was explained with children provided opportunities for clarification and to ask questions. Dialogue length was wide ranging varying between the shortest at 20 minutes and the most extensive at 90 minutes.

Based on prior experience with their parents, the interviews with children were carried out using an approach allowing the children to build their own story around the three prompts. The researchers sought to understand, through an interpretive approach, how these children's active involvement in the family formed part of the creation of their family experience. It was also important to understand how these children added to the construction of their own childhood. Our approach was based on the humanistic ideas of Rogers^[33] supporting greater openness and ensuring experiences could be effectively understood. We adapted our methodology to best meet the emotional exigency of the children (see Figure 1) ensuring we were therapeutic and non-threatening.^[34]

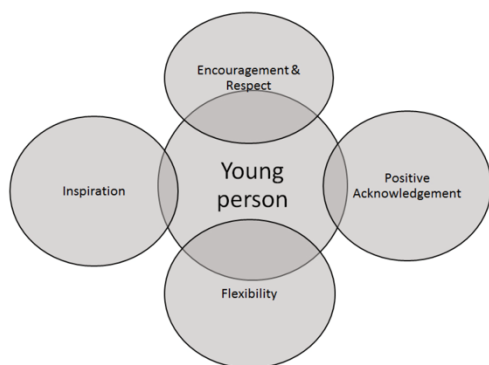


Figure 1. Approach to support the engagement of children with mental illness

Member checking was conducted with the children sent a copy of their original transcripts. Seven of the children, all from the 15-17 years group, asked for a follow-up interview to discuss the transcripts. While transcripts were not amended, children provided further clarifying ideas that were added to the original data.

2.3 Data analysis

Voice recordings were transcribed professionally with the text returned to the research team for thematic analysis. The first step was to integrate responses into single narratives

within each prompting area before completing an inductive thematic analysis.^[35] Individually research team members coded the responses before then being collated into a context for inclusion or exclusion. Utilising NVivo for Mac (Version 11.4.3) the transcriptions were again coded to establish similarities and crossovers. By the very nature of the phenomenological descriptions provided by the children codes were not mutually exclusive and there were a number of instances where codes were matched to multiple themes. Word mapping in NVivo was used to further refine the coding process and a matrix was used to provide illustrative extracts for each theme. To assist in capturing any patterns transcripts were read several times. This was important to ensure meaning was not lost and children's interpretations and experiences of reality were effectively encapsulated. Ideas were determined from the frequency in which words and phrases occurred. Concepts were then amalgamated and classified independently by two of the authors who together agreed upon the core themes. Any word and theme uncertainties were discussed, and consensus reached.

3. RESULTS

Just over half the children stated it was mid-way through primary school when they first realised their family was different. Several recalled recognising there was family mental illness at about age 7 years with only a few not realising until they were teenagers. The following outlines themes from the interviews.

3.1 Children's experience of their own mental illness

Children described the manner in which mental illness impacted on daily life and interactions. They described feelings of frustration and anger even resentment at being burdened with mental illness.

"... when I'm anxious I find it really difficult to remember anything..."

Children defined mental illness as overwhelming and despite this, they would try to hide their mental illness from others. Overpowering and consuming, mental illness caused anger at not being able to be "normal" with guilt and anger towards parents. Feeling sad and alone were also commonly reported.

"I more like hide in my room... ignore reality and just sit in bed, just not doing anything."

For over three-quarters of the children there was an unease about how their parent understood them. They also believed it took some time before parents realised they had a mental health problem. One child described this as:

"Before I figured out what was wrong with me I felt like my mum didn't love me ... she had to put me as low priority"

because she had to look after my stepdad and my sisters first. We didn't know what was going on with ourselves."

3.2 Children's experiences of their parent's mental illness

Feeling rejected and abandoned by their parent, when their parent was unwell, was commonly reported. A third of the children had experienced their parent being assessed at an emergency department where the children felt "lost" and "unsure". A particular concern was not being told what was happening. A similar scenario occurred when mental health clinicians visited homes. Having clinicians visit was reported as increasing stress and as having a negative impact on parents. Children recognised ambulance services or police were worried about them but due to the acuity of their parent's presentation the focus of intervention was concentrated on the parent. Some found themselves suddenly being cared for by other family members or family friends, and this increased their anxiety and sense of insecurity. Uncertainty and anxiety also occurred when considering the need to get outside help for their parent.

"... she wasn't accepting outside help, and it was hard ... where do you make that point of saying 'okay you're coming (to hospital) now'. And so it got quiet, she got, like she ... deteriorated before we actually took her to the hospital."

Children reported parents becoming wrapped up in themselves when unwell, often not caring for anyone. All the children described in great depth having to "modify" their behaviour to avoid their parent becoming upset and unwell. A common comment being:

"... you have to do it right, and if you don't do it right then he gets really stressed and upset and yells at you, and so he did that a lot, obviously I wanted to do things to keep the peace."

Children described a sense of rejection when their parent was unwell, and this was particularly felt in primary school years. Feeling a sense of duty to protect their parent was common as they understood parental actions were not within the parent's control.

"she didn't want to be aggressive ... so when she'd suddenly get emotional and stuff she'd lash out and whack us with a wooden spoon or something, there were a couple of times where it got a bit heavy-handed ... she was just freaking out cos she was feeling [mentally] unwell, and it's like she didn't know what to do."

It was also suggested that hospital admissions amplify children's sense of rejection:

"... my brother had just been born, and my mother went into [psychiatric] hospital for a stay – it seemed like forever. No

one ever talked about it or bothered to explain things. I knew it wasn't good for her and that stressed me out even more."

Even when these children sought to appease their unwell parent, they felt consumed by guilt over what they should do: they spoke of an underlying fear about how they should respond.

"I guess that's the problem with having a parent with a mental illness – you have several parents in one body – you have your unwell one, and you're depressed one; you're manic one, and you're always treasure hunting for that little bit of the parent that you know loves you."

Commonly the girls, and some boys, described having to take over the parenting role when their parent was unwell. Responsibilities included easing sibling stress, paying bills, making meals and trying to keep a family routine. Once parents calmed, and the mental illness had become more manageable, girls spoke of turning to self-injurious behaviours to manage their own distress and dysregulation. Boys described anger and using bad behaviour as a response to parental mental illness.

The bidirectional impact of mental illness

Children commonly described the "family infection of mental illness". They explained how their parent's mood caused their mood to change and how anxiety followed this "infectious" pathway. Several children spoke of stress in the parent causing stress in themselves. They recognised when they were unwell that might cause their parent to become unwell. Sometimes increased anxiety and lowered mood were described as concern for the parent's well-being.

"I start to feel sad, and I start to feel desperate to try and make her feel better ... When everyone is grumpy I get very grumpy, I just get mad. It's like pretty contagious ... I would just worry and worry and that made me really sad."

Universally anxiety was described as worse than their parents. Despite adapting and being better able to manage with increasing age they described hyper-sensitivity to parental mental illness.

"When she was unwell I didn't have her to protect me because if she's scared then obviously the thing that's making her scared is some huge thing that I am useless against if she's useless against it. I didn't feel protected or safe when she was anxious. She will say things that are coming from her anxiety not from logic and then I just get more anxious myself."

They described being attuned to their parent but struggling with the parent's lack of understanding and empathy when trying to discuss mental illness. Family life was explained as

a particular way of living.

"... my stress would come out when I went to bed because I would not be able to go to sleep ... or when I went to sleep when I woke up that morning I had wet the bed."

A further bidirectional influence was the sense of living like separate people in the same house. Importantly children behaved in ways to reduce stress and anxiety, and to avoid any deterioration in their parent's mental health which had consequences for their own mental health. Frequently they described taking these emotions to school showing anger or withdrawing.

3.3 Children's experiences of support

A core area of feedback from interviews focused upon what could broadly be termed Experiences of Support. This could be broken into four key areas of school, coping, experience of professionals and support that they would have liked. These are outlined in subsections below.

3.3.1 School experiences

School was seen as both a saviour and/or an aggravator. For most, it was a negative factor. Children felt stigmatised because of their mental illness and additionally stigmatised as a result of parental mental illness. The experiences they portrayed were of being ostracised or labelled as "weird" and "different". Stigma was exacerbated by a lack of understanding or awareness of the many issues they confronted because of parental and personal mental illness. Children became horrified when their parent came to the school because they reported an increase in negative talk about them from both teachers and peers. The issue of stigma made school a horrible experience that impacted on their ability to focus on school work and affected their own or their parent's mental illness. If they were unwell, they reported being unable to think about school work and for some even to hear the teacher. When they sought space to settle their thinking, they described usually being declined. When well the children spoke of worrying about their parent, would they be well when they got home or how would their parent cope without their support? For most children the bidirectional influence had a dual effect.

"... when I was at school I was actually at my worst point in my life. I was at the point where I was wanting to commit suicide and I had no friends and I was being bullied all the time. I talked my mum into putting me on this home-schooling program because I was able to help her with her stuff [- mental illness]."

Another noted:

"They don't understand me at school. And yeah, there's not

much help I can get from school, because I feel like just none of them care. My teacher will notice but he won't do anything. Or like, I'll be crying, or I'll come out of the toilets teary-eyed or something like that, from having a panic attack, and no one will notice or help."

Peer relations were difficult with several describing being isolated from their peers. Half thought it was their parent's mental illness causing peers to avoid them, others thought it was because of their own mental illness.

"Friends would just disappear. One minute they're there and then the next minute they're not. And they just, they don't care."

For a few, school was a positive experience providing escape from parental mental illness and a place where they would get help. Having specific mental health support in the school reduced some of the negativity they experienced and ensured their family was understood. Connecting with likeminded peers helped children feel better understood. A third of children had at least one friend they could confide in and who was understanding of their personal and family challenges. Particularly useful were friends who accepted children's specific experiences and family situation.

"So that was always something my sister and I both had real phobias about being seen as being anything other than completely normal..."

3.3.2 Children's strategies for coping

A variety of strategies were reported with giving space a common approach, usually going off to a private area. Music was also an important strategy either listening, playing or singing. Video games provided release from both their own and their parent's mental illness with over two-thirds believing this escape was leading to a problem.

Parentification was both a necessity and obligation that they reported as adding to stress and impacting negatively on their mental health. The burden of being a surrogate parent becoming a contentious and often conflicting issue. Getting away from a parent frequently magnified children's negative self-talk and feelings of being out of control. Even children who didn't describe themselves as taking on parenting roles took on responsibilities for caring for their unwell parent.

"... I felt really capable because maybe I felt like I could see things more clearly than my mum could and that made me feel- sort of in control."

Responsibility was reported as affecting personality, with girls in particular describing having lost a part of their childhood. Older boys maintained distance from their parent by isolating themselves. Responsibility was both emotionally

negative and positive with children feeling positive about being a support but also feeling guilt for a perceived undermining of their parent.

“... there was a knot that I pushed through and it looked out over the paddock and I used to sit and look through that knot and dream about worlds beyond my shitty little backyard.”

3.3.3 Children's experiences of professionals

Children reported not being listened to or included in decisions professionals made about their parent's mental illness.

“... they didn't tell me anything that they didn't think I needed to know... they never asked me how I was doing.”

For the majority, children described being on the periphery of their parent's intervention or at the centre themselves without professionals considering what was going on for their parent.

“... she was actually, a counsellor for my mum, now I think that's bad because she wasn't very understanding of my issues, she was more for my mum. ... yeah it was just for her though not us kids.”

Three-quarters were frustrated and angry child protection services had been involved because of issues around parental mental illness. Despite involvement, they felt little action was taken to support them or their parent; instead, a punitive approach was taken by child protection and this in turn added to the stress and deterioration in mental health for everyone in the family.

“... child protection was involved quite frequently. I lost count of how many times which is pretty sad and nothing ever really actually happened. I felt blamed by them for my mum being mad.”

Despite a predominantly negative view of support, a few positives did emerge. Key was a support person who was able to listen and take a broader view of children's circumstances. Someone who realised the issues were not just individual, but family based. Where parents saw professionals, who were aware of bidirectional influences, the children reported feeling more supported and understood.

“... they know what's been going on with me and my mum so they understand and they could easily help when me or my mum have a mental breakdown.”

Good support people were those children could trust and who would stick by them. These were frequently a peer who was available, understanding and non-judgemental. Often online friends, who were removed from their reality, were most accepting of the strains they faced in having a parent with mental health problems. Boys particularly described on-line friends as helping reduce emotional distress.

“... my online friends... are angels... they just understand what's going on for me and dad.”

3.3.4 Children's deliberations on support they would have liked

Consideration of support for other families was a problematic area for the children to conceptualise. However, the most important concepts they illustrated were family time, help with family dynamics, and receiving more information about mental illness. The idea of help early, even in kindergarten, was perceived as necessary. Children also suggested different approaches in schools focusing on helping them understand mental illness in families and addressing the issue of stigma.

“... counselling and help with more complex issues like family dynamic and stuff... you need help to understand and manage your emotions and stuff.”

4. DISCUSSION

Four groups of influencing factors can best describe key findings from the interpretative phenomenological analysis. Firstly, children felt parental mental illness was a factor in their feeling rejected and abandoned from a very young age. They reported parents as displaying a lack of attachment or having an angry approach to parenting. Worry about what parents might do next or blaming themselves for any deterioration of their parent's mental health was common. Living in a constant state of uncertainty around parental mood was frequently reported. The current literature indicates child psychological difficulties result from exposure to parental mental illness.^[36] Uncertainty increases children's anxiety and impacts on their own mental illness, invariably exacerbating their mood or other symptoms. Confusion over parents' symptoms and presentation adds to children's anxiety. Children in our study described parental mental illness as exacerbating their mental illness though also noting a strong emotional assimilation with their parents.

Secondly, children recognised how their mental illness impacted on relationships inside and outside the family unit. Older children took on parenting roles, and lived in what they described as a state of uncertainty and insecurity. Children sought to control their own mental illness, particularly when a parent was mentally unwell. Such approaches were rarely long term and might reflect two factors: emotional immaturity; and lack of scaffolding from their parent. Lareau^[37] suggests children living in poor families have less structure and poorer interactions with less parental engagement. Suggestions from these children indicate a similar process when there is co-existing mental illness in families. Confusion over their own and their parent's mental illness led to resentment and anger which in turn compounded difficulties in the

child-parent relationship.

Thirdly support was an issue for the children with all the children describing parental support as changeable and inconsistent. Outside of home children sought solace, usually from peers, finding one like-minded peer to share experiences and strategies with. Most found school and professional support a hindrance because of stigma and a lack of understanding of the complexity of their situation. The scarcity of suitable counselling and mental health education was a major barrier for children.

Finally, children described bidirectional factors which were equivalent to a cold or infection transmitted between family members. They recognised how personal mental health issues could push their parent to also become unwell. As parents became unwell so the level of anger and anxiety increased in the children. Anxiety was presented as a key bidirectional influence: each family member uncertain about what to expect from the other, thus intensifying the anxiety. Depression was also presented as significant in families, where the mood of one person had a domino effect, affecting the mood of others in the family. Bidirectional influences did not show solely at the emotional level but also at the behavioural level with children reporting they would invariably find themselves (when mentally unwell) behaving just like their parent.

The strategies children utilised included time away from others. In those families where family time was used, this approach was felt to be essential for reducing bidirectional influences of mental illness (see Figure 2). Where this approach was established, children felt they were understood and listened to by their parent. Use of family time helped reduced the overall stress in the family.

Whilst little research exists on how children understand their own mental illness, the children in this study described their mental illness as a reflection of their parents. This important clue for intervention appears to be absent in current clinical discussions. Often CAMHS clinicians are drawn into parents' own concerns rather than those of the children. Children may have limited understanding of mental illness and with parents' present their responses might be inhibited.^[38] How much more might the influence of parental mental illness have on children's responses?

Children's accounts reiterate widely known difficulties relating to school, community and supports. Social and school problems may increase a child's anxiety.^[39] Children in this study felt school staff did not know how to manage the issues of child and parent mental illness likely due to a lack of training.^[40,41] It has been found that 61.5% of children suffer bullying because of their mental illness.^[42] From these

children's accounts such bullying is amplified by parents also having a mental illness.

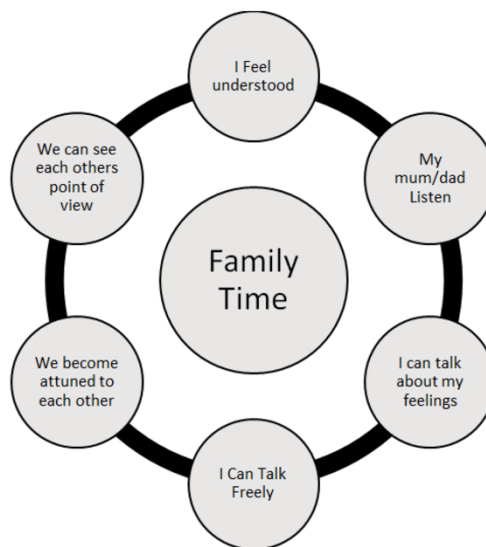


Figure 2. Family time as a process to reduce bidirectional impacts of mental illness

Stigma for children with mental illness, although levels are significant, is not well conceptualised and may occur for even very young children.^[43] Indeed, children in this study noted stigma as problematic both in school and with peers. Furthermore, they reported the stigma relating to their parent's mental illness also impacted on peer friendships. It would appear from the accounts of these children, that addressing stigma requires a multimodal approach incorporating early intervention aimed at younger children. For some of these children social isolation and avoiding school was preferable to experiencing mental illness stigma. Children described school avoidance as a key coping strategy which met two goals: avoiding bullying; and allowing them to support their parent at home. Undoubtedly a novel approach is needed to address this problem. Schools frequently describe their environment as for "learning" and suggest social and emotional issues are a family responsibility. It would seem that this argument lacks strength in the mainstream discourse when considering children living in a family with co-existing mental illness. In this study, the children highlighted lack of school support as an issue, which has been emphasised by other research in this area.^[44-46]

Where a high level of support existed children felt positive about school and the attitudes of the school staff to mental ill-

ness. Children in this study suggested schools' access more mental health assistance and support for children, families and staff. Universal school programmes on mental health problems can have a positive impact on how children cope and on their level of anxiety.^[47] A focal point for intervention might be on providing psycho-education to school staff on issues relating to the bidirectional effects of mental illness. It would seem important for teachers, particularly senior school staff, to gain an awareness of the complexities and demands faced by children where there is coexisting mental illness. Also important is for teachers to understand how to support a reduction in children's anxiety.

Where parents needed to go into hospital, children reported being overlooked and not informed of what was happening, adding to their distress. This perception of children, that their emotions were not considered when a parent was admitted to hospital emphasises a significant gap in service delivery. Not feeling listened to was repeatedly highlighted, with children feeling that they were considered as individuals, not as individuals within a family. Children felt this individualistic view failed to recognise the bidirectional influences of mental illness in the family. Two-thirds of the children felt professionals wanted to direct rather than engage with them. Such approaches suggest some gaps may exist in how mental health clinicians understand children who lives in families with intergenerational mental illness. Notably parental mental illness was either not considered or was given little weight by children's clinicians. The lack of psychoeducation appears to be a significant gap hindering children's resilience. The importance for these children of wanting their or their parent's clinician to take a broader view cannot be underestimated, and their descriptions suggest an important gap in the way professionals think about co-existing mental illness in families. For the children we interviewed they did not feel empowered in their recovery journey. Part of the problem may be rooted in the dearth of literature in this area. Supporting family units, and seeing further than just the child or parent, is signified as important for enhancing children's mental health and supporting family recovery. Important for this discussion is the notion of "linked collaborative services".^[18] (p. 55) Services connected with and alert to all people in families with mental health problems to enable intervention to be effective.

5. STUDY LIMITATIONS

Families were recruited through clinician recommendation, a methodology dependent on clinicians' selection of families for this study. Whilst recognising the children tended to follow the initial prompts it was clear in the narrative they were open and expansive in their interpretations and consciousness.

Such was this, insider perspective, it was possible to obtain a rich and valuable insight into what is normally a very private and protected family world. Although limited in size this regional and rural sample of children provided a valuable and informative description, an account delivered with a passion founded on these children's wide-ranging experiences.

6. THE BIDIRECTIONAL IMPACTS

The children in this study highlight two key points: The need for bidirectional influences to be considered, and the need for specific strategies to help families address bidirectional effects. As co-existing mental illness was a criteria for this research it was foreseeable that bidirectional impacts of mental illness might arise as a key theme. Regardless of their diagnosis children reported a bipartite connection between their own and their parent's mental illness. Children felt strongly impacted by their parent when the latter became unwell, and they recognised how a deterioration in their mental illness influenced their parent. Anxiety and mood issues dominated as important bidirectional influences with all the children describing a corollary effect. Despite having significant mental illnesses, themselves children described having experienced bidirectional transference as more significant when they were younger. Whilst unclear from these interviews why this might be the case it is possible that older children are better able to adapt to the situation they find themselves in and are better able to articulate for support from peers and others.

Two important aspects were revealed in the interplay between children and parents. Firstly, children felt parentified to keep the home environment functioning. For some they took on caring roles. Secondly when parents became unwell children would try to subdue their own mental health concerns to try and ease parental distress and to protect siblings. Children described such strategies as rarely working with invariably children's mental health deteriorating in line with their parents.

7. CONCLUSIONS

Children born into families where there is mental illness may have an arduous journey from the day they are born. Attachment issues can be significant with bidirectional influences of mental illness contriving to change the experiences of childhood. In addition to managing their mental illness, children experience stigma and denunciation for their and their parent's mental illness. There is little if any information given to these children and supports emphasise individual rather than family systems. From these children's accounts, bidirectional impacts of mental illness are not usually contemplated by mental health services. With inadequate sup-

port and incomplete intervention, children adapt to be able to manage. Tackling how families with concurrent mental illness are supported and how interventions address bidirectional influences need to be primary in future consideration for helping families. This research has exposed significant gaps in provision for families where there is co-existing mental illness and highlights the need for greater attention to bidirectional influences. Education of children about their parent's mental illness can occur at an early age and so empower children and lessen stress and mental health problems. There needs to be greater emphasis on training clinicians in the understanding of bidirectional impacts of mental ill-

ness. Children and parents do not operate in isolation but are part of a system that has consequence affects. Challenging stigma, providing prompt education, full family engagement and early involvement by mental health services are essential for these children. A stronger emphasis on family-based approaches and integrated service provision, with attention to bidirectional impacts, may help minimise mental health problems for children living with a parent who has a mental illness. With limited investigations into bidirectional impacts of mental illness, this is an area needing further exploration.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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6.4 CONCLUSION

The ideas of bidirectional influences between parents and children are not new and were espoused over 70 years ago (Sears, 1951). Yet despite this the dominant unidirectional view remains even where there is co-existing mental illness. In this study it has been found that, not dissimilar to their parents, children identified some common themes that had previously been raised in the extensive COPMI research arena on children living with parents with a mental illness (Yamamoto & Keogh, 2018; Dam & Hall, 2016; Mordoch & Hall, 2008). For these children the techniques through which they coped were influenced by their own mental illness. Similarly, they experienced the compounding effect of having a parent with a mental illness in the same way their parent experienced the compounding effect of having a child with a mental illness. For children this multiplying effect was identified as being most significant in the home as well as in the school setting. This is considered further in the next chapter. The discourse of the children has provided a basic knowledge and conceptualisation about the phenomena that is the basis of their day-to-day experience. It is through this study that a basis for family behaviours and interactions across the mental health continuum can be further assessed.

Chapter 7: Discussion

This thesis has been structured into two parts. In the first part, the aim was to determine the extent of co-existing mental illness in families and whether the mental health status of a parent had an impact on treatment outcomes for their child. In the second part of the thesis the aim was to better understand the challenges of the lived experiences of children and parents living in a family where there is co-existing parent and child mental illness. Importantly the research has sought to understand the very particular challenges of bidirectional mental illness in families.

A number of themes emerged from the parent and child interviews that have offered insight into the challenges faced by these families. Particularly the compounding of issues around stigma, social challenges, school issues, and family interactions as well as problems in accessing appropriate holistic support. The themes also offered a unique insight into the needs of families and pointed to the requirement for a prerequisite of a family-focused, bidirectional approach by mental health services. Such a step was found as being essential in helping children and parents manage their mental illness. Findings from the interviews also offered an important understanding of barriers to effective interventions for these families with community stigma and mental health clinician predisposition to individualising intervention key hurdles. The perspectives of children and parents, both with mental illness and living in the same household, have not been previously sought. The findings are discussed below in relation to the literature.

The research questions posed by this thesis were two-fold. Firstly, to determine the extent of co-existing mental illness in families and secondly to document the lived experiences of children and parents in those families. Importantly the research sought to understand the very particular challenges of bidirectional mental illness in families. In the first part of the research the hidden extent of the issue was uncovered. Furthermore, the data indicated these families were more likely to live in a less than positive social context with very little community or professional support. Additionally, the routinely collected data at the CAMHS indicated the symptomology of children in these families was consistently higher than that of children in families where there was no co-existing mental illness.

A number of themes emerged from the parent and child interviews that have offered insight into the challenges faced by this particular family type—particularly the compounding of issues around stigma, social challenges, school issues, and family interactions as well as problems in accessing appropriate holistic support. The themes also offered a unique insight into the needs of

families and pointed to the requirement for the prerequisite of a family-focused, bidirectional approach by mental health services. Such a step was found as being essential in helping children and parents manage their mental illness. Findings from the interviews also offered an important understanding of barriers to effective interventions for these families with community stigma and mental health clinician predisposition to individualising intervention key hurdles. The perspectives of children and parents, both with mental illness and living in the same household, have not been previously sought. The findings are discussed below in relation to the literature.

7.1 RECOGNISING THE PROBLEM

7.1.1 Summary of study 1

In the first part of the research the hidden extent of the issue was uncovered. While it had been well established that over 20% of parents have a mental illness this seminal research found that where a child who was attending CAMHS had a mental illness 79% also lived with a parent with a validated mental illness (118 mothers and two fathers). Furthermore, the data indicated these families were more likely to live in a less than positive social context with very little community or professional support. Additionally, the routinely collected data at the CAMHS indicated the symptomology of children in these families was consistently higher than that of children in families where there was no co-existing mental illness. While all children improved over time the children living with a parent with a mental illness maintained higher symptomology.

While diagnosis was not the primary determinant in the study the primary CAMHS diagnoses of the children was anxiety disorder, which was highly correlated to the mother's anxiety diagnosis. There was also a correlation with mood disorder where child and parent diagnoses closely associated. This close linking of diagnosis between a parent and child suggests an area for further investigation particularly when considering the aspects of bidirectional impacts and intergenerational transmission of mental illness. A number of general demographic factors in relation to children's diagnosis were significant in the overall findings. Children presenting with behavioural and emotional disorder had come from an environment where there was domestic violence and those with mood disorder had lived in families where there was substance abuse. While not necessarily key determinants of a child's mental illness the data suggests an additional aspect to the dynamic of children's experiences. What was not known in this study was whether the absent parent had a mental health problem linked to their negative behaviour. The most significant demographic factor impacting these children and their family was the level of social support, either community or extended family. The data suggests a link with diagnoses and is closely associated with the experiences espoused by families interviewed for

this study. It is important to note the CAMHS population is just 0.25% of the total 0–17-year-old population of the regional area (ABS, 2016) and represents a much smaller proportion of all children with a mental health disorder. In the Australian national household survey 14% of children in this age bracket were assessed as having a mental health disorder (Lawrence et al., 2015). There are likely a number of influencing factors on these numbers including access to services and previous negative experiences, both difficulties raised by families in this study. Importantly the rate for domestic violence was highest across the state for the region examined (CSA, 2018) and this may have been a further variable influencing children's diagnoses. The findings from this study stress the importance of paying attention to wider social, and particularly parental mental health, issues when treating children attending a service for mental health intervention.

It is widely acknowledged that children of parents with a mental illness are at high risk of harmful mental health outcomes (Campbell et al., 2012; Beardslee et al., 2011; Göpfert et al., 2004). This study found that there exists a hidden problem of co-existing mental illness in families where one person is receiving help from mental health services and another family member also has a mental illness. The degree of mental illness in other family members is infrequently considered by mental health clinicians and when it is identified it rarely receives appropriate or adequate attention. Prior to this research only one other study, conducted by Mercer and Knapton (2014), had produced a similar investigation on the extent of co-existing mental illness in families of children attending a regional children's mental health service.

A number of studies have looked at aspects of co-existing mental illness and these are best seen as either diagnostic specific investigations, genetic or parent specific investigations (Wesseldijk et al., 2018; Baker & Lees, 2014). In the study of disruptive mood dysregulation disorder (DMDD) in children (Axelson et al., 2012) a short paragraph notes parental psychiatric history for a number of parental diagnoses. These varied from 67% for depression to 30% for ADHD and 14% for psychotic disorder. Importantly the study did not find a link between parental mental illness or substance use disorder and DMDD. A study into depressed adolescents with BPD (Guile et al., 2016) noted high levels of family problems which included parental psychopathology. Specifically, in relation to mood the study found 30% of mothers and 7% of fathers had depression. In a further study Guilé, Boissel and Alaux-Cantin (2018) noted the interaction effect of a bidirectional relationship between adolescents and the family. Further they found that family influences can contribute to the progression of mental illness. Attention deficit hyperactivity disorder (ADHD) is one of the most common psychiatric disorders in children (Faraone et al., 2005; Currie & Stabile, 2006; Perou et al., 2013) and has been the focus of a number of prevalence studies of parental mental health problems. It has been

reported by Okan et al. (2019) that women with ADHD have a strong probability of having a child with ADHD and symptoms of ADHD can persist into adulthood in up to 70% of cases (Kessler et al., 2005; Lara et al., 2009). In the extensive study of 757 children Middeldorp et al. (2016) found a prevalence rate of 30% of parents with indicators of a mental illness and a strong link between maternal ADHD problems and childhood ADHD. Importantly Middeldorp et al. (2016) based problem scores on parental self-rating rather than on clinical diagnosis. With the difficulties associated with adult ADHD, such as problems in organising and developing routines and particularly problems in responding to children's emotions and behaviours, a number of studies have sought to determine the extent of co-existing ADHD in families (Dentz, Romo, Konofal, & Parent, 2016; Agha, Zammit, Thapar, & Langley, 2013; Takeda et al., 2010; Sundarlall, Van Der Westhuizen, & Fletcher, 2016). All the studies emphasised that children with ADHD are likely to have a parent with adult ADHD and also highlighted the predominance of family problems.

Parent investigations take a number of forms, usually looking at children accessing outpatient services and the investigation questioning clinicians or families. Through this approach comorbid mental illness in families has been found to range between 71% (Baker & Lees, 2014) and 34% (Wesseldijk et al., 2018). In both of these studies parental depression was the predominant diagnosis. Other studies have pointed to the strong link between parental mental illness and risks to children's well-being as well as problematic psychosocial circumstances (Khasakhala, Ndeti, Mathai, & Harder, 2013; Golhar & Srinath, 2013; Ranning et al., 2016; Maybery & Reupert, 2018). In the extensive study of 66,045 children from Australian population data Green et al. (2018) determined that the greatest risk to children of developmental vulnerability and mental disorder at age 5 years was through exposure to maternal mental illness.

Current research indicates that 60% of children live with a parent with a mental illness (Gatsou et al., 2016). With such high figures for parental mental illness it was surprising to find a lack of research in the area of children and families. This study has become a steppingstone for others to conduct a broader analysis and discussion of the possibility of co-existing mental illness in families. While such discourse has become more common in research its integration into mental health practice remains elusive.

There are a number of reasons associated with the difficulties in recognition of co-existing mental illness within mental health services that have come out of the research. Firstly, the research found that recording of co-existing mental illness was not a priority area and did not form part of key reporting criteria. Secondly, the fluidity of staff, lack of training and resource issues appeared to impose attention on the individual rather than the family unit. These ideas were supported by initial

clinician questionnaires being poorly formulated and clinicians self-reporting on questionnaires. Finally, sociocultural issues, although recognised, are selectively considered in mental health services with little inter-service collaboration. File reviews showed recording of sociocultural problems was common but action in relation to those problems was poor. While the data points to these challenges the dialogue of parents and children offer a much clearer insight and are considered later.

The inconsistency between the lived and the recorded data was indicative of a general malaise within mental health services in the area of co-existing mental illness. Importantly the data indicated that a large proportion of parents with a mental illness had issues of depression and anxiety: both mental illnesses that might be related to bidirectional impacts of mental illness within the family. Current recording did not indicate when parental mental illness commenced and what, if any, genetic factors may have played a part. Such a gap being filled would likely impact on treatment and intervention outcomes.

Overall, all the research in this area highlights the need for mental health services to take account of parental mental health when working with children and that adult mental health services need to take more account of parenting functioning when working with adults. Baker and Lees (2014) and Gatsou et al. (2016) have suggested that clinicians should be taught to recognise the interplay between a parent's mental illness and a child's mental illness. Baker and Lees (2014) stress the importance of clinicians taking a more holistic view of the family as part of their practice and supporting families through family-oriented recommendations. Dentz et al. (2016) and Sundarlall et al. (2016) recommend that interventions focus on supporting parents' capabilities to carry out their parental role which, as seen earlier, would likely impact on their child's mental well-being.

With current research in the area of prevalence so diverse in terms of what and how information is collected there needs to be a consistent approach taken both within and for services to consolidate data and so help inform future decision making.

This study found that there exists a hidden problem of co-existing mental illness in families where one person is receiving help from mental health services and another family member also has a mental illness. The extent of mental illness in other family members is rarely considered and where it is it infrequently receives the attention families would want or expect. With only the Mercer and Knapton (2014) investigation conducting a similar enquiry into the extent of co-existing mental illness in CAMHS families the gap in research in this area is concerning.

7.1.2 Summary of study 2

Routine outcome measures form the basis for informing the direction of intervention in mental health services. In CAMHS a mix of tools – HoNOSCA, CGAS and SDQ – are used. This study sought to establish any links between a child's outcome measures and parental mental illness. When looking at the 13 subscales of the HoNOSCA on most items children living with a parent with a mental illness trended higher and showed least progress in five of the subscales, though these results were not significant. These trends are represented in the results of paper 2. When examining the data by age group younger children improved least on the behaviour domain with both age groups living with a parent with a mental illness showing greater acuity over the six-month time period.

CGAS results were unremarkable with only younger children living with a parent with a mental illness showing less improvement. The overall trend was for children living with a parent with a mental illness to score higher in the outcome measures. Despite some improvement for both groups the children living with a parent with a mental illness continued to trend higher at the end of the time period.

The unanswered question is why children living with a parent with a mental illness consistently scored higher even after intervention. In the similar study by Wesseldijk et al. (2018) that analysed a suite of self-rated measures they also found a trend for higher symptom scores where a child lived with a parent with a mental illness. When considering one of the purposes of outcome measures has been to improve processes for the treatment of individuals and to improve responsiveness to the needs of carers (DoH, 2005), it is surprising that almost 15 years on a comparison between children living with a parent with a mental illness and those living with a parent with no mental illness is not a standard process. It is noteworthy that in the recent study of Barbalt, Bergh and Kossakowski (2019) it was found that the connectivity between symptoms, as seen on an adult HoNOS, increased over time. Although this study highlights the value of clinician-rated outcome measures in measuring symptom reduction it does not answer the question of wider factors impacting on the mental health patient and how these may influence results. Of concern in any clinician-only outcome measure is the possibility that change might be related to service requirements rather than patient need (Stedman et al., 2000).

Consequently, the need for a family-centred approach to improve outcomes should start with effective outcome measures considering all aspects of a child's and parent's life is needed. Such an approach is best described by Viscardis (1998):

Begins with the child's and family's strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services

and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers. (p. 44)

There remains a gap in the literature in relation to the analysis of outcome measures in CAMHS considering the mental health of a parent. The current study was relatively small and from one geographical area. In future a broader study looking at a more wide-ranging cohort of both groups of children would help identify any important issues for these children and families.

Routine outcome measure data provided the information for this analysis but immediately produced some challenges. Not all outcome measures are compulsory and, in this sample, a large number of clinicians did not use non-mandatory measures: child and parent-based measures. The second problem was the large disparity between children living with a parent with a mental illness and those living with a parent with no mental illness. Despite these challenges the clinician-rated measure with its 13 subscales produced a consistent difference between the two groups in 10 of the subscales. Importantly, compared to the non-parental mental illness group, children living with a parent with a mental illness scored higher for symptomology at the start of intervention. Following 6 months of CAMHS intervention clinicians scored a slight improvement for both groups but improvement was smaller for children living with a parent with a mental illness. Importantly the differential in the scores remained across most of the subscales.

These results suggested that recovery trajectories are different for children of parents with a mental illness compared to those children living with (a) parent(s) with no mental illness.

7.2 THE INTERPLAY OF PARENT AND CHILD MENTAL ILLNESS

7.2.1 Summary of study 3

The third study (described in chapter 6) looked at parents' perspectives of living with a mental illness and with a child with a mental illness in the same household. Thirty-seven parents were interviewed mostly in their own homes.

The study used a phenomenological approach to obtain an insight into these parents' understanding and perceptions of their experience of co-existing mental illness. There were seven key parent themes each with sub-themes within them which are shown in table 7.1 below.

While a number of themes are reflections of many previous studies (Maybery, Szakacs, Baker, & Ling, 2002; Maybery & Reupert, 2009; Mowbray, Bybee, Oyserman, Bybee, & MacFarlane, 2006; Reupert, Maybery, & Kowalenko, 2012; Queensland Health, 2010) there are some additional themes that relate specifically to co-existing child and parent mental illness. As previously highlighted the

problem of a parent becoming unwell and this leading to a deterioration in the child or vice versa was a major aspect of the concerns for parents. Also reported was the dual impact of mental illness being used as a reason for family violence or the breakdown in relationships with the mentally well partner. Schools were a significant problem but for these parents, school punished them twice for their child's mental illness and for parental mental illness. Most parents felt unsupported by the school system and felt schools reinforced the stigma the parents experienced. While issues of being a parent with a mental illness are reflected elsewhere importantly these parents described a strong sense of being forgotten as parents.

They felt that aspects of their life were not important to professionals because mental illness alone was the priority. All but one parent spoke of intergenerational mental illness and how it caused great stress because they felt unable to break the cycle. Problems of accessing services and services not understanding the issues of co-existing mental illness was another key feature.

Despite the downsides these parents were determined to do their best and to seek out positive support wherever they could. For many adopting family approaches to manage the challenges was the best they could do.

Research to date has focused in a unidirectional way looking at the impact of parental mental health on children or a child's mental health on a parent. In this study, which is the first of its kind, the researcher has sought to explore those personal experiences and interpretations from a bidirectional viewpoint.

Table 7.1: Parent interview themes and sub-themes

THEME	SUB-THEME	KEY ISSUES
1. Bidirectional impact of mental illness	a. Negative b. Positive	-How the influence of mental illness 'infects' family members* -How it forces redirection of thinking
2. Socio economic	a. Accommodation/housing b. Financial c. Relationships	-Mental illness affecting housing opportunities -Financial hardship -Domestic violence from partners blamed on mental illness*
3. Schools	a. Negative attitudes b. Expectations c. Lack of support d. Positive attitudes	-Stigma from schools -Double bind of co-existing mental illness* -Poor support and expecting parents to manage when child unwell -Finding one understanding welfare worker in school
4. Parenting with a mental illness	a. Impact on self b. Impact on child	-Feeling inadequate -Not being able to stop triggering child* -Feeling out of control and in grief when unwell*

	c. Impact on mental health d. Mental health services	-CMH forgetting parents are parents*
5. Intergenerational mental illness	a. Recognising b. Worrying about	-Knowing mental illness was in grandparent -Not knowing and worrying about how to break the cycle*
6. Useful family strategies	a. In relation to child b. Own strategies c. Whole family	-Walking away -Staying attuned -Sharing and talking*
7. Sources of support	a. Positive b. Negative	-Child's mental illness -Extended family -Lack of agency understanding of co-existing mental illness* -Brevity of interventions and difficulty accessing

7.2.2 Summary of study 4

In contrast to study 3 here the perspective of the children in the same families were considered. Not only did this study look at a parent and child view it has examined this from within the same household.

There were seven key child themes with some sub-themes within them which are shown in table 7.2 below.

Table 7.2. Child interview themes and sub-themes

THEME	SUB-THEME	KEY ISSUES
1. Impact of own mental illness	a. Feelings b. Relationships	-Emotional roller coaster* -Impact on daily life -Increased anxiety*
2. Parent's mental illness	a. Rejection and abandonment b. Professionals c. Parental self-focus when unwell	-Feeling lost and grieving -Not being informed what was happening -No acceptance of being a carer -Wanting to protect parents and be the parent
3. Schools	a. Stigma b. Attitudes c. Unrealistic expectations d. Lack of support	-Stigma from school* -Poor support and being expected to go to school when parents unwell -Fear of what would happen at home -Escape from parental mental illness
4. Experience of professionals	a. Negative b. Positive	-Not listened to either for self or for parent -Left on the periphery* -Involvement of Child Protective Services* -Professionals who were aware*

5. Intergenerational mental illness	a. Recognising b. Worrying about	-Knowing mental illness was in grandparent -Worrying about never getting better*
6. Child strategies	a. Personal b. Parent	-Taking off / listening to music / video games -Feeling out of control and this affecting own mental health* -Losing childhood -Mutual understanding with parent*
7. Support would have liked	a. Family Time b. Information c. Early help	-Wanting strategies to do more things as a family -Wanting to have a better understanding of mental illness -Needing to know more about mental illness sooner: kindergarten

Children have a particular world view and have ideas about what parental mental illness means for them (Simpson-Adkins & Daiches, 2018). The children manage their experiences and interactions within their own conceptualisations of their family situation. From a sociology of childhood perspective, they are active in their own construction of their environment. Themes again introduced some specific concepts related to families where there is co-existing mental illness. The issue of the emotional roller coaster and feeling infected by parental mental illness cannot be underestimated. This was a dominant theme which reinforced the idea that when one person in the family was unwell so the mental health of others would deteriorate. A father with a low mood would soon induce a low mood in their child. A mother's anxiety would soon lead to more obsessive types of behaviour in a child. Even escaping to isolation increased anxiety (Weissman et al., 2006) and particularly for boys resulted in addictive distractions such as video games.

Children in this study felt ill-informed about their parent's mental illness and felt an obligation to protect their parent but then felt guilty if their own mental illness prevented them from filling their self-imposed role. They described a sense of guilt about their parent's behaviour which was compounded at times by their own behaviour. For Dam and Hall (2016) this relates to the process of shame children experience.

Wanting to protect their parent was a strong emotion but they still felt embarrassed when a parent arrived at the school. All the children felt judged for both their own and their parent's mental illness. School was both a place to escape to but also a place they felt judged. For the few who had understanding peers, school was less of a burden. School support being limited and professionals not understanding their family situation was a common theme. School supports were seen as just focused on them and not taking any account of their parent. These ideas have been reinforced by teachers

from the state in which this study was conducted. Teachers themselves see the mental health of students as a key problem area in the classroom.

More than this in a recent study less than half the teachers surveyed (n=3500) felt they had access to suitable mental health services. The same study found mental illness affected academic performance of children and 90.2% of the teachers reported family and parenting issues as of significant concern (Carey, 2019). Where Child Protective Services were involved these children felt disengaged and in a state of grief. Most had a mutual caring relationship with their parent that had been upset. Now the children felt more anxious and more out of control than they had ever done before. Interestingly only two children had felt CAMHS clinicians understood the difficulties of living in a family where a parent has a mental illness.

Worrying about not getting better and feeling out of control because of their own mental illness was significant for these children. Despite this they felt a mutual understanding of their parent and their own mental illness which was a positive. As found in other studies they wanted to know more about their parent's mental illness and be part of the treatment in much the same way as their parents were part of their treatment (Drost, van der Krieke, Sytema, & Schippers, 2016). A further worry highlighted by all the children related to future support and interventions. The issue of not getting help beyond CAMHS and feeling they might not be 'unwell enough' played on children's minds. These ideas were consistent with the findings of Sukhera, Fisman, and Davidson (2015) who found a lack of capability to successfully transition children into adult services. For these children, having seen what happened to their parent, they feared adult services would not be able to support them. They had ideas that information for children about mental illness should start very early, in kindergarten or primary school. They also felt strongly that parents needed better support on being a parent with a mental illness and on how to break the cycle of intergenerational mental illness. These ideas of educating parents on being a parent fit in with the findings of Patrick, Reupert, and McLean, (2019b) who in their study of adult children of parents with a mental illness noted the absence of a parent reference point.

Without research looking specifically at co-existing mental illness in families the issue of bidirectional impacts and family-focused approaches are at risk of remaining subsumed by the dominant discourse of the medical model.

7.3 OVERVIEW OF THE MAIN FINDINGS

While the prevalence and service trajectory findings from this research showed important information about the local CAMHS perhaps the most important and innovative aspect of this

research has been the perspectives of children and parents. Undertaking a novel enquiry and glimpsing into the life and challenges of these particular families was as important as recognising the hidden extent of co-existing mental illness in families. A number of authors have previously suggested a theoretical link between parent and child well-being (Falkov, 2012; Gladstone, Boydell, & McKeever, 2006); this research has provided tangible real-life narratives of those links.

Families living with a parent and child with a mental illness are substantially more common than might have been expected. Current research has started to expand in this area following the researcher's initial discussions of the idea at the CoPMI Conference in Italy (2015). With only limited research in the area, and what research there is using a variety of different approaches, it was useful to find that the results of prevalence were consistent with the only other study of its kind. The results also reinforced the long-held view by many clinicians and agencies, from non-governmental organisations to child protection, that the issue of co-existing mental illness is more significant than is currently recognised. The families in this CAMHS were found to struggle with additional challenges which were compounded by having a child with a mental illness. This study found that social isolation was greater for families where there was co-existing mental illness and that adult relationship issues were principal factors in family life.

While analysis of the impact of parental mental illness on child outcomes was inconclusive the results indicated a trend for poorer outcomes for children living with a parent with a mental illness. In the one other similar study in this area the trend was also present. In areas where symptomology played a major part outcomes differences were less significant between the groups of children. In contrast the differences in outcome measure results were greater in the behaviour and social areas for children living with a parent with a mental illness.

Parents with a mental illness living with a child with a mental illness experienced mental health difficulties in a number of ways and had similar experiences of services and supports to other parents. Where these parents struggled most was in trying to manage mental illness in an environment that frequently acted as a trigger. Children's mental illness itself caused parental deterioration as did the additional burden of guilt and self-blame. For parents with a mental illness living with a child with a mental illness they experienced compounded stigma and felt overly judged and blamed by others. Furthermore, these parents felt out of control, unable to stop the inevitable pathway to further intergenerational mental illness. It is important in considering these influences on parents to take account of the emphasis parents made in research interviews with them. For parents who struggle with a mental illness the primary and only catalyst to family problems starts with the interaction between themselves and their child. Every parent emphasised how they quickly 'picked up' on their

child's mood or anxiety or even psychosis. This in turn impacted the parent whose own mental health was subsequently affected. It could be argued that the picture presented by these parents emphasises the need to get the individual and family interaction and well-being right before any other factors can be considered. As spoken many times by parents, individual support will not work if they return home to the bidirectional influences of mental illness.

Children in families with co-existing mental illness presented with many of the worries and concerns of their counterparts with as many externalising and internalising responses to their parent's mental illness. Where these children differed was in their recognition of how their mental illness could deteriorate in line with a deterioration of their parent's mental illness. They also were quite aware from an early age that in conjunction with their parent's mental illness they were treated differently by schools and their peers. The compounding effect impacted them as much as their parent. Although not blamed for their parent's mental illness they often felt responsible for any deterioration or not being emotionally available to their parent. A significant anxiety for all these children was evident in their concern about not being able to break from the cycle of mental illness.

The key influences on these children can be seen as both internal and external. But all the children were clear in their concerns about how parental mental illness is 'like a virus it spreads from one of us to the next'. It was the way parental mental illness led to a deterioration in their own mental health that was a primary determinant for these children. As highlighted before, without a family inclusive approach an individual focus on children will be less than effective as children return to an environment markedly influenced by the moods and anxieties of the mentally ill parent.

A considerable gap and a major finding of this research has been the ongoing focus on individual interventions by clinicians and a number of support services. The issues of co-existing mental illness appear to go unrecognised with treatment and support being implemented in a unidirectional rather than family and multidirectional fashion.

7.4 THE LIVED EXPERIENCE: RELATIONSHIP WITH THE FAMILY MODEL

While the prevalence and service trajectory findings from this research showed important information about the local CAMHS perhaps the most important and innovative aspect of this research has been the perspectives of children and parents. Undertaking this enquiry and glimpsing into the life and challenges they have faced has provided an insight into the challenges encountered by these families. A number of authors have previously suggested a theoretical link between parent and child well-being (Falkov, 2012; Gladstone et al., 2006); this research has provided tangible real-life narratives of those links. Table 7.3 below provides an overview of the themes raised by parents

(Naughton, Maybery, & Goodyear, 2019a) and children (Naughton, Maybery, & Goodyear, 2019b) while making links from within the discourse with the Family Model.

Adrian Falkov's Family Model is pivotal to understanding the relationships within families where there is mental illness. The model is formative in current thinking and practice with a principal aim of achieving 'greater family-focused care'. Importantly the model highlights a need to focus on individuals in a family while considering wider impacting factors. The important element in the whole family picture is the interactions between different family members (Patterson, Dishion, & Bank, 1984).

Some of the themes were consistent for both parents and children. Importantly it can be seen from the experiences of children and parents how important the relationship dynamic is between them where there is co-existing mental illness, and this has been the key focus of this thesis. Importantly these ideas derived from interviews related directly to the Family Model and are now discussed in more detail.

Table 7.3: Link between parent and child themes and the Family Model

Key Issues for children and parents:			
Key issue	Parent ⁴	Child ⁵	Family model domains
Stigma	√	√	1-2-3-4-5-6
School system	√	√	1-2-4-6
Stress, worry	√	√	1-2-3-4
Family	√	√	3 & 4
Mental health services	√	√	1-2-3-4-5-6
Social	√	√	4 & 6
Relationships	√	√	3 – 4 – 6
Community support	√		4 & 6
Money	√		1 – 4 – 6
Peers		√	2 & 6
Uncertainty	√	√	1 – 2 – 3 – 4 – 6
Bidirectional	√	√	1 – 2 – 3

The above table highlights the themes that are now considered. It is important to note that personal narratives of children and parents pointed to a greater crossover of themes, which highlights the dangers that might occur because of compartmentalisation by professionals.

7.4.1 Parental mental illness

Domain one in the Family Model looks at parental mental illness and highlights how children are affected from their cognitive development through to social, emotional and behavioural development. The model goes on to describe disordered attachments and parents being less responsive, more withdrawn and even fussy because of their mental illness.

From the interviews conducted for this research parents took a more personal view recognising how their mental illness impacted their capacity to parent and feeling out of control because of their mental illness. Importantly from their perspective mental illness was pervasive in all aspects of their lives and they felt powerless to better support the family because of their mental illness. Significantly missing from the model, and raised consistently by parents, was the sense of guilt both in terms of what their child saw but also how their mental illness was a transgenerational issue.

⁴ For ease of the reader themes have been simplified here to better fit with the discussion around the Family Model.

Original Parent Themes were: 1) Bidirectional impact of child-parent relationship; 2) Socio-economic issues; 3) School issues; 4) Parenting with a mental illness; 5) Useful family strategies; 6) Sources of support; 7) Intergenerational mental illness.

⁵ Original child themes: 1) Experience of own mental illness; 2) Experience of parent's mental illness; 3) Experience of support; 4) Support children would have liked.

7.4.2 Child mental illness

The Family Model (Falkov, 2012) recognises the ‘interplay between parental symptoms and the consequent effects (emotional and behavioural adaptations)’ (p. 118). The model focuses on impacts of parental mental illness on development and general vulnerabilities. Falkov (2012) goes on to point out there is no direct relationship between a parent’s mental illness and a child’s problems, though pointing to the greater risk to children of mental illness among a myriad of other problems for example: attachments; low self-esteem; neglect; and abuse. The link between a parent’s mental illness and a child’s brain development is important in this domain.

Having seen earlier that the extent of parental mental illness in children attending CAMHS can be very high it could be argued the issue is more significant than is suggested. This is particularly so when the children in this research highlighted how their own mental illness impacted on interactions and relationships within the family. These children felt consumed by their mental illness and like their parents felt guilt about how they might cause a deterioration or other response in their parent. While it is generally believed that the onset of mental illness in children occurs in late adolescence and early adulthood (McGorry et al., 2008; Murray & Lopez, 1996) the children in this research indicated they were aware of becoming unwell at about seven years of age. If this is taken in the context of transgenerational transmission of mental illness and the effect of parental mental illness on brain development a more robust early intervention approach would be appropriate. This aspect is further considered next.

7.4.3 Parenting and family relationships

The Family Model highlights the importance of an excellent parent-child relationship and how such a relationship is linked to positive outcomes for children. The important issue of the toxic stress response is raised as is the importance of the relationship between parents and children. The model also points to the important issue of the different stages of development and the lifespan perspective of relationships.

It could be argued this is in fact the key area for helping and engaging with families where there is co-existing mental illness. Rather than focusing on the impact of a parent on the relationship it is the important bidirectional influences within the parent-child relationship that set the scene for all other parts of the model. If a parent or child is mentally unwell and affecting the other certainly this is the key to addressing any problems. When a parent’s mental illness leads to challenges for the child or a child’s mental illness or related behaviours exacerbates parental mental illness this is where interventions need to be focused. If parents and children fight an internal battle to control mental

illness for the fear of upsetting others how can they address their mental illness? If mental illness in families really is like an infection it must be treated at the source by addressing both parent and child mental illness in a coordinated and collaborative way.

7.4.4 Risk and protective factors

Within this domain of the Family Model it is briefly mentioned that the stress of mental illness in a parent and child as well as other factors in combination increase the overall risk to either the parent or child. So too are attachment issues related to parental mental illness considered as key risk factors. The emphasis in relation to this domain is on the interplay between risk and protective factors with no real discussion of bidirectional impacts.

Interestingly in the narratives for this research both parents and children were quite open about the risks imposed by their individual and joint mental illness. Families have described ongoing loss of potential because of the intrusion of mental illness and the effect of parent-child interaction (Van Loon et al., 2014). In this case the primary concern for both parents and children was the risk and influence of mental illness causing internalising and externalising difficulties. As discussed in relation to the previous domain this suggests risks and protective factors need to be viewed at the micro level between parent and child as the primary issue to be addressed before considering other intrinsic factors. It could be argued that from the interviews it was clear how mental illness in either a parent or a child was the principal catalyst for further risk and stress within the family that then frequently extended into the wider community. This study also argues that if at the outset a child is experiencing negative attachment experiences because of the difficulties a parent is having with mental illness the long-term and ongoing risks are likely to be significant. Research shows that parent-child interactions early in life can affect an infant's sensitivity and responses (Braungart-Rieker et al., 2014; Haltigan, Leerkes, Supple, & Calkins, 2014). Recent work in relation to attachment has moved from an individual psychological base to a relationship base and this fits with the argument in this thesis of the need to focus, as a priority, on the parent-child interaction and experiences in families where there is co-existing mental illness (Sroufe, 2017).

7.4.5 Services for children and adults

The Family Model describes the need for a much broader analysis by mental health services and makes recommendations in terms of practice. Mental health assessment should make consideration of parenting and the capacity of parents to meet their child's needs. Implications for practice in the model focus on risks a parent's mental illness places on a child.

With responses provided by children and parents, as well as from personal experience, the issues go beyond the simple assessment and intervention at the clinic. Many of these rural families couldn't get to appointments in the first place. A number reported needing to catch three or more buses to get to a mental health service often requiring the whole day to do so. One mother with four children described the impossibility of that day trip with prams. Some were referred to prohibitively expensive private providers and all reported when they did attend mental health services there was a failure of mental health services to recognise and address the unique challenges of parenting. A clear gap exists in providing specific support for families with co-existing mental illness and children were particularly scathing of the paternalistic approach of clinicians. The comments of the children reinforced the view that within mental health services children are seen not heard; this despite even young children taking on certain caring duties in the home. It was very clear from the interviews that the move towards clinic base services and the adoption of adult mental health service ideologies in CAMHS has led to children receiving limited if any services. In those cases where children were seen at school the outcomes were considerably different and suggest a different intervention model.

7.4.6 Culture and community

In this domain of the model it can be seen how stigma and discrimination can be considered in terms of cultural and community supports. Importantly here are a range of experiences for children and supports for families. Also important is the need for cultural awareness by clinicians and 'understanding of their experiences can help when trying to explain the prescribed treatment' (Falkov, 2012. p. 149).

Families do need their culture to be recognised starting at the micro level of the cultural dynamic between parents and children. Going beyond this service providers need to extend into the wider community rather than hiding in the protective walls of clinics. As a number of children said it was so much better being helped in their own home. Parents too felt clinicians had a better understanding when they could see the environment. Support needs to go further and be extended to schools and community agencies. Rarely do services outside mental health know how to respond to co-existing mental health and invariably they struggle to get advice and support from what appears to be a fragmented mental health service whose ideology appears adult western centric.

7.4.7 The Family Model: Importance of the micro-perspective

While not diminishing the importance of models that focus on the family system, it could be argued that this research points to the principal importance of the very particular dyadic interactions that occur between a parent and a child. Dyadic psychotherapy describes disorders in attachments and

relationships between children and carers as in part due to separation (Hughes, 2003). This research has highlighted the interplay of the parent-child relationship with the particular nuances peculiar to having a mental illness. As suggested within the sociology of childhood, children learn strategies to adapt but when the ‘infection’ of mental illness occurs even the most resilient child falls foul to their parent’s emotions and mental illness. The same ‘infection’ also occurs from the mentally ill child to their parent. As seen in the discussion of parent and child themes there are some key areas that are consistent for both parent and children. This is graphically shown in figure 7.1 below which highlights the importance of the relationship dynamic between the parent’s and child’s mental health and has been developed from the child and parent themes.

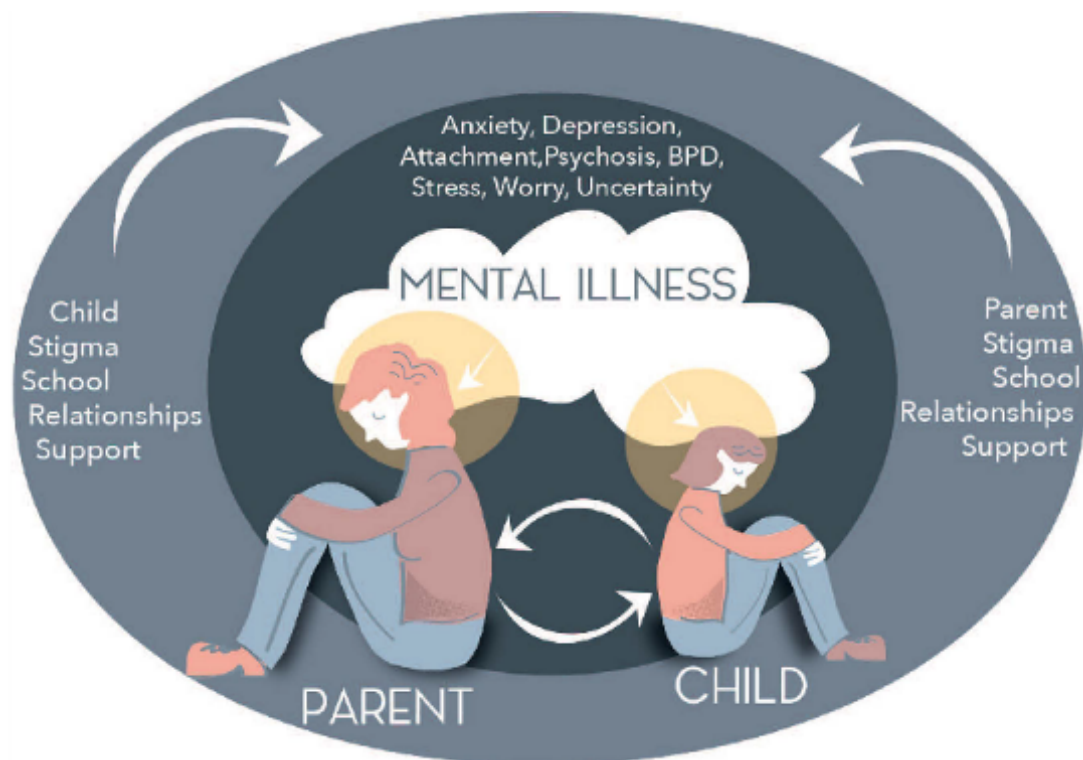


Fig 7.1. Focused model of the ongoing relationship dynamic between a parent and child

The model proposed in this thesis is one that looks within the Family Model at the microenvironment of the parent-child interaction. Like any system the family system can only function effectively if all its component parts are functioning adequately. The interviews of these parents and children has shown just how important the issue of bidirectional impacts really is. Working with parents before children are born and then focusing on the challenges of parenthood that are likely to be exacerbated by mental illness is very important. By building resilience and strength in the dyadic relationship of the parent and child and confronting the bidirectional influences of mental illness this research suggests the cycle of transgenerational mental illness can be broken.

7.5 IMPLICATIONS

A number of implications arise from this research that are important determinants of future practice in mental health service delivery. The discourse from this thesis indicates a more focused approach is needed to the way children and parents are supported and recognised by mental health services. It is through understanding the links between parent and child mental illness approaches that interventions can be improved. If the presence of co-existing mental illness is unknown or clinicians choose to ignore it, it could be argued the problems within families will never be effectively resolved. Seven years on from Adrian Falkov's Family Model and processes to ensure there is a family focus within mental health services appear to be a distant future.

Becoming a parent is difficult at the best of times. Becoming a parent when struggling with a mental illness has a whole new set of challenges. With little information or support parents are left to fend for themselves and society then bemoans their inadequate skills. With a large proportion of new parents who have a mental illness having their own parent/s with a mental illness, what strategies have been passed on that might lead to further challenges? Services mainly focus on the mental illness and not on the new child. Interventions to support new parents with a mental illness are poorly coordinated and frequently fall short of meeting parents' needs. Mental health clinicians lack training in the area of bidirectional impacts of mental illness and provide often excellent individual interventions but fail to consider the broader factors. Significantly parents with a mental illness are not supported and educated on the important issues of attachment and emotional dysregulation. With little research into the area of parents of children with mental illness perhaps a new acronym is needed (PoCMI) to encompass this as an area needing much wider investigation?

Children born to a parent/s with a mental illness may struggle with attachment issues and the influences of bidirectional mental illness. Children customarily exist as part of a family system and it is within that system, they function guided by their parent whether mentally unwell or not. Despite the children living within a family system, mental health services tend to focus on individuals rather than the whole family. This research indicates the need for a change in focus considering all aspects of a child's family experiences. Children need reassurance and support beyond their own mental illness, and they need to understand what is happening for their parent. Support for children with a mental illness should be support for families with particular account taken of concurrent mental illness. With bidirectional influences significant for children with a mental illness a significant review of current mental health provision is urgently needed. From the broader perspective a greater emphasis is needed to challenge stigma and educate those with whom children interact.

7.5.1 Implications for clinical practice

It has long been recognised that child-parent psychotherapy is crucial in preventing future problems for children (Osofsky & Lieberman, 2011; Tronick & Beeghly, 2011). This is particularly important throughout intervention where a child and a parent have a mental illness. While most of the material in this area is trauma related its applicability to families where there is co-existing mental illness cannot be underestimated.

In considering this research through the lens of the Family Model it has been possible to link the important aspects of this research to a grounded intervention approach. While the Family Model provides important and essential elements for clinicians working with families the need for a targeted therapeutic and educational approach looking at the micro interactions between parents and children is paramount. It is only through work at that micro level that changes will occur in the broader family system. A number of key implications are highlighted for clinical practice.

The key issues that fell out of this research for clinical practice were:

1. Providing information around intergenerational mental illness
2. Being culturally sensitive to the needs of families where there is co-existing mental illness
3. Better education and support for children: Groups that address stigma and co-existing mental illness with interventions to break the cycle of intergenerational mental illness

7.5.1.1 Clinical focus

Paternalism in medicine is a well-established phenomenon originating from the Hippocratic Oath. In contrast, for mental health, the relationship between clinician and patient is fundamental for psychotherapeutic treatment. However, clinician paternalism can be influential in key areas impacting on patients including patient freedom; power imbalances; and service delivery choices. Clinicians can use their knowledge to force people to receive treatment and can use that same knowledge to direct or decide on interventions. The explanation for paternalism in mental health is frequently based on the belief that the person with a mental illness lacks rationality and competence. The problem here is the hidden dynamic within decision making, that is the clinician's subjective and personal values, particularly when considering families (Riebschleger, 2002). More recently Bladon (2019) has highlighted how paternalism in mental health continues as an indefinable and subtle presence. With clinicians reflecting dominant, often medical, models of mental illness the people they work with become disempowered in the process of intervention (Thomas & Cahill, 2004). The dilemma for clinicians is in striking the right balance between autonomy and intervention. Giving people choice in treatment impacts on engagement (Wisdom, Clarke, & Green, 2006; Gilbert, Rose, & Slade, 2008)

and empowers families thus becoming an influential factor in outcomes for recovery within the whole family system. Such ideas suggest the need for an innovative and empowering clinical focus when working with families.

Clinical focus on attachment and developmental issues at a very early stage is extremely important in breaking the cycle of mental illness in families. Current moves for early intervention and proactive support are a step in the right direction. Clinical intervention needs changes in practice that encompass a greater emphasis on training and staff development in this area.

Clinicians also need training and general awareness on the implications of bidirectional impacts of mental illness in families. Equally clinicians, whether inpatient or outpatient, need to account for the experiences and knowledge of other family members and they need to engage with the carer even if that carer is a child.

7.4.1.2 Family focus

Working with the whole family is a clear message that comes out of this research (Ward, Reupert, McCormick, Waller, & Kidd, 2017; Foster et al., 2016; Watkins et al., 2011). Clinicians need to move away from the individualistic unidirectional approach to a more holistic family inclusive practice as seen in the family partnership model and the Family Model (Day, 2013; Falkov, 2012).

Working with families and supporting the parent-child relationship allows the opportunity for clinicians and other practitioners to build on the strengths and experiences people bring to their interactions. There needs to be a tailored approach to supporting and ensuring families are referred to the right services (Skogay et al., 2018).

7.4.1.3 Education

Parents and children need education on all aspects of mental illness from early impacts to bidirectional influences. Agencies and services need to address the issue of stigma. School education needs to be more effective to confront stereotypes and challenge belief systems. Adopting an approach similar to those used in drug education in schools (VET, 2019; Evans & Tseloni, 2019) may be more useful than current one-off suicide prevention education. An approach that engages teachers, parents and students is a model likely to be more effective in helping break the barrier of mental health stigma and the compounding effects for these families.

7.5.2 Implications for policy

The clear messages coming out of this research indicate the need for greater effort in analysing the data in relation to co-existing mental illness in families. Policy areas also needing further development include greater integration of services and a focus on early intervention. Greater effort, through government initiatives and system changes, is needed to support interventions that will break the intergenerational transmission of mental illness. Part of this process would include the need for mandatory assessment for co-existing mental illness in families. Policies that recognise the importance of early intervention and ensures processes are put in place to target young children and new families, particularly where a new parent has a mental illness.

7.5.2.1 Data analysis

Although clinicians may know if there is a family with co-existing mental illness there is currently no systematic approach to evaluating this family information. This research has highlighted the gaps in outcome measures. While policy allows the exclusion of key outcome data the effectiveness of results is limited. Improved data analysis would help inform critical clinical decision making.

7.4.2.2 Early intervention

As has already been highlighted early intervention and education is critical at the practice level, though such intervention needs to be embedded in policy. The current focus in mental health appears to be on adult services with a medical model leading intervention approaches. With government statistics indicating 64% of mental illness has already commenced by age 21 years (DoH, 2007) and most mental disorders occurring in the first few decades of life (De Girolamo, Dagani, Purcell, Cocchi, & McGorry, 2012) the question needs to be asked why wait until the horse has bolted?

7.4.2.3 Integration of approaches to a bidirectional focus

While current approaches in mental health service delivery usually have a very specific focus, and children and parents might receive excellent individual attention, issues of others in a family are rarely addressed and left to individuals to manage themselves. In CAMHS it is the child, in CMH adult services it is the adult. Even in programs focusing on families the emphasis is on reducing dysfunction (Reupert et al., 2012). Such programs focus on parents rather than on dealing with a child's symptomology specifically. They may reduce depression or anxiety at one level and programs targeting children are useful in increasing knowledge and helping with the development of coping skills. It could be argued that services working together and addressing the way mental illness has a bidirectional impact needs to be an added element across all programs. With a significantly high

number of young people accessing mental health services and who likely have a parent with a mental illness, there is clear need for inter-service and inter-team coordination. From this research it is clear that CMH, as the primary tertiary intervention service for mental illness, needs to adopt a more collaborative and integrated approach between adult and child services. Such an approach would ensure that children moving to adult services receive the support they need (Sukhera et al., 2015) and CMH as a whole would better meet the need of families. Overall CMH has to embrace a more family-centred focus that is consistent across the different elements of its operations with policies in place to ensure there is coordinated care planning between the different teams. Policies in place that support a family systems approach could ensure complementary care that assists both young people and their family and ensures local adaptations are not allowed to divert intervention focus from where it is needed.

7.5.3 Implications for research

There are a number of implications that fall out of this study for future research. Future mental health research should consider more in-depth analysis of the areas considered in this thesis. Research that is consistent and focused in its approach will lead to more reliable data on the key areas.

7.4.3.1 Prevalence

Future research is essential to determine the bidirectional impact of mental illness within families to understand the support needs for these families. The starting point for this will be a consistent analysis of CAMHS state-wide using a systematic approach to analysing the extent of co-existing mental illness in families. Anecdotally the evidence exists now that all services need to be reviewed as without understanding prevalence fully interventions will continue to maintain a unidirectional focus. As a follow on from this study this is an area currently being investigated.

7.4.3.2 Outcome measures

With childhood mental illness strongly linked to parent psychopathology and family environmental factors it is surprising that research understanding outcomes from mental health interventions is not more closely scrutinised. Routine outcome measures are a tool routinely collected and it could be argued, from this study's findings, rarely used to influence policy in ways that are useful in supporting families. In-depth and extensive service analysis of HoNOSCA and other outcome measures need to be considered a priority. This research has indicated a trend but further research needs to examine if a trend is in fact a statistical difference.

7.4.3.3 Ideas of children and parents

As has been apparent in this study the ideas of children and parents are only now beginning to be considered. With the strong influence of bidirectional impacts indicated by these families a wider analysis is needed of different cohorts of families. Further to this current research a more in-depth analysis of the similarities and divergent ideas of children and their parents is being conducted. The question from this area of the research is the consideration of specific factors playing a part in the interactions occurring between family members. Such an analysis will help in further informing interventions in family-focused approaches.

7.5.4 Limitations

As with any study this research has a number of limitations. In examining only one CAMHS the data and population profile may have been imbalanced. The strong regional focus has a particular bias that only a wider analysis could correct. Having said this the results were comparable with the unpublished research carried out at a similar regional CAMHS in Canada.

The problems with the outcome data were previously mentioned but it is worth highlighting here the small sample size and over representation of parents with a mental illness made effective statistical analysis and comparison difficult. With no comparable studies in this area it was also not possible to have any base line comparison.

The final limitations relate to the families interviewed. While recruiting people with a mental illness is usually considered difficult, in this cohort of CAMHS families people were very open to take part in the research indicating a particular interest in the research area. Some of the parents and children saw the research as a way to ‘change the system’. Although possibly a biased group the stories and insights were very open and unreserved in the discourse. Other limitations in this section of the research included the possibility of researcher bias. Despite the personal history discussed in chapter 1, many years working in the mental health field ensured a non-judgemental inclusive approach. As defined by Kvale (1983) the focus was on gathering a description of the parent and child’s world. Dialogue was intentionally one directional with only empathic responses in attempt to avoid intonation, body language and other social cues (Opdenakker, 2006). Using the Dictaphone in itself had disadvantages. While an accurate representation of the spoken work it did not provide context which was written, usually in the car, after the interview. A final limitation that presented a problem was the venue. With most interviews in people’s homes they felt relaxed and it most likely allowed them to be more open to providing a richness to their narrative. Unfortunately the background noise on a small number of the tapes made transcribing certain parts quite difficult and required

several reviews of the audio tapes. Importantly the interviews highlighted the depth of the experience for these parents and children. All those who took part, despite some mental health challenges, were willing to share in a very deep and meaningful way that illuminated their experiences.

7.5.5 In summary

The micro level of the interaction between children and parents is a critical element for any interventions to effectively bring about change and improve the whole family system. This crucial aspect of family intervention is of particular importance when considering families where there is both parent and child mental illness. Confronting bidirectional influences in families is the first step in breaking the cycle of intergenerational mental illness.

Despite the limitations of the research reported earlier, the results have critical implications for clinical practice and policy in terms of interventions, focus and collaboration between those providing services for families.

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Appendices

Appendix A

Mental Health Within Families: Clinician Questionnaire:

MENTAL HEALTH WITHIN FAMILIES REVIEW



CLIENT DETAILS

CLIENT UR NUMBER

GENDER		EMPLOYMENT		DOMESTIC VIOLENCE ISSUES		PRIMARY DIAGNOSIS		MENTAL ILLNESS NOT LIVING IN THE HOME									
MALE		Full Time		Yes		List below		Yes									
FEMALE		Part Time		No				No									
		Casual															
MARITAL STATUS		Unemployed		SUBSTANCE USE ISSUES		SECONDARY DIAGNOSIS		Relative 1				Relative 2					
Single				Yes		List below		RELATIONSHIP									
Married				No				FAMILY TYPE									
Defacto		STUDENT						PRIMARY DIAGNOSIS									
Separated		Primary School		SUBSTANCE TYPE		NON VALIDATED DIAGNOSIS		SECONDARY DIAGNOSIS									
Divorced		High School		List below		List below		NON VALIDATED DIAGNOSIS									
Widowed		TAFE															
Same Sex		University															
Other		Not attending any															
				CURRENT USE		DATE OF FIRST INVOLVED WITH CMHS		Relative 3				Relative 4					
				Yes		Year. List below		RELATIONSHIP									
				No				PRIMARY DIAGNOSIS									
RESIDENCE TYPE		LANGUAGE SPOKEN						SECONDARY DIAGNOSIS									
House		ENGLISH						NON VALIDATED DIAGNOSIS									
Flat		Well		PAST USE													
Other		Not Well		Yes		LEVEL OF INVOLVEMENT		INCLUDING OTHER									
		Not at all.		No		First Presentation											
						One Episode per Year		EXTENDED FAMILY SUBSTANCE ABUSE									
SOCIAL SUPPORTS		OTHER LANGUAGE				2-3 Episodes per Year		Yes									
None		List below				Ongoing Intervention		No									
Minimal				ALCOHOL USE ISSUES													
Good				Yes													
		ABORIGINAL/TS ISLANDER		No		KNOWLEDGE OF MENTAL ILLNESS											
		Yes				Good		MENTAL ILLNESS HAS BEEN A BARRIER TO INTERVENTION									
		No				Poor		Little									
						None		Not at all									
								A Lot									

N(S) IN THE HOME WITH A MENTAL ILLNESS

	Relative A		Relative B		Relative C		Relative D		Relative E	
RELATIONSHIP										
AGE										
GENDER										
DIAGNOSIS										
ANXIETY										
DEPRESSION										
SCHIZOPHRENIA										
BPD										
OTHER										
NV DIAGNOSIS										
	YES		YES		YES		YES		YES	
	NO		NO		NO		NO		NO	
HAS BEEN IN FOSTER CARE										
	YES		YES		YES		YES		YES	
	NO		NO		NO		NO		NO	
RECEIVING TREATMENT FROM:										

Family Suitable and Willing to be Contacted Further about the Study			
Yes Suitable			
Not Suitable			
Is Aware & Willing			
Not possibly willing.			
CONTACT DETAILS if willing:			
SURNAME			
FIRST NAME			
PHONE NUMBER			

perception of parent's & child's

CHILD / CARE GIVER

RANGE 0 - 5

0=No Awareness

5=Extensive Knowledge

at makes you believe this?

Please specify below

CLINICIAN'S perception of the CHILD / CARE GIVER

RANGE 0 - 5

0=No Awareness

5=Extensive Knowledge

at makes you believe this?

Please specify below

Appendix B

Letter for Families

Date

Dear

Monash University, is embarking on a research project which is the first of its kind in Australia. In this project parents who live with a child who has a mental illness are invited to be involved in an informal one on one discussion about their experiences. Those who participate may also like to write a personal story of their experience.

The purpose of this project is to gather individual stories on people's experiences of living with another person with a mental illness, particularly where they themselves may be struggling with stress or some other mental health problem. From such experiences it is hoped to improve supports for families.

This letter is written to ask, if you think you meet the criteria, if you would be interested in yourself and your child taking part in this ground-breaking research?

If you are interested the information sheet and consent form, with a return envelope, is attached for you to complete. Alternatively, you may wish to discuss the research further with your child's clinician.

Thank you for your time in considering this request and I sincerely hope you will consider taking part in the research.

Yours sincerely

Michael Naughton

Appendix C

Information Sheet

MONASH University



Explanatory Information Sheet for parents

“A discussion of what it’s like in families where parents and children have mental health struggles”

This information sheet is for you to keep.

My name is Michael Naughton and I am conducting an evaluation project with Dr. Darryl Maybery (Associate Professor) and Dr. Mel Goodyear towards a PhD at Monash University. This means that we will be writing papers for publication in a number of journals.

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding if you wish to participate.

The aim of this study is to look at what it is like living in a family where a parent and a child or young person has a mental health problem. We are keen to learn from those of you who live and experience on a day-to-day basis what the challenges and difficulties might be. We believe that by looking at things that are happening in families we can ensure that supports are better focused.

To be involved in this study you must:

- Be a mother or a father or someone looking after a child
- Have at least one child aged 12-18 with a diagnosed Mental Illness
- Experience anxiety, depression or some other mental health problem that has been diagnosed at some time
- Be receiving or have recently completed treatment for your mental health issue (for example, from your GP, or a psychologist)
- Have access to a support worker (such as your GP or psychologist)

As the parent it is up to you whether you agree to your child being involved or not. Having said this it is really important that we get ideas from children too. Importantly because the study is anonymous if you give permission and you talk to us we will not be able to link what is said by you, or your child. It is really important that we find out from both parents and children how they feel and what supports they would like to be available.

If you are prepared to be involved in this project, complete the consent form and email/send to us. We will then contact you to set up a time at your convenience to meet.

Being in this project involves the following steps:

- You would complete a demographic questionnaire.

- You would be involved in a chat about what its like to live with another person who has a mental health issue, this is not compulsory.
- You will be asked to review the copy of what was discussed at the interview and you can make changes if I get something wrong.
- You will be invited to attend a further interview in six months to chat about any other things that you might have thought about, but this is entirely up to you. This part is also not compulsory.

The whole conversation process will be at a time and place of your convenience. Altogether the whole process will take approximately 30 to 60 minutes depending on what you think it is important to talk about.

As I have said if you wish, you can be provided with a copy of your responses to the interview. If you are interested in receiving this, you need to let us know and provide us with your personalised code, so we can locate your specific questionnaire responses.

It is important to remember that it is up to you whether you participate in the interview. You can withdraw at any time up until the time the interview is de-identified.

Importantly we are also asking for feedback from a child (ren) in your family. If you provide consent, we would then talk to your child about the study and invite him or her to participate. They would be invited to attend a short interview in a suitable relaxed environment where they will have the opportunity to provide anonymous statements about their experiences and what would be useful for them. As well as your consent we will also need the consent of your child.

Your involvement, and the involvement of your children, in this study is voluntary and you are under no obligation to participate. Your involvement or non-involvement will not impact on any clinical services you or your child (ren) receive.

If you no longer wish to participate, you (and/or your child) may withdraw from the interview aspect at any time. You (or your child) can withdraw from the interview part of the study only prior to your approval of and the de-identification of the written record of the interview.

All information reported will be de-identified and at no times will names or identifying information be reported. If you do take part in the interviews we will not report your name at any time. As highlighted earlier, you can be provided with the individual results of your interview if you wish. Just let us know and we will arrange this for you. You will also have the opportunity to view a copy of the interview and invited to change/delete any information you believe is incorrect and/or potentially identifies you or your family.

We expect that some aspects of this process might be confronting to some parents and/or their family. Please bear this factor in mind when deciding whether you will take part in the research and it is critical that you consider carefully prior to making a decision for your child (ren) to participate. If you do decide to be involved and at any point things become distressing there is a list of organisations and helplines that you can access, the organisations listed here might help you. We would also encourage you to talk to your usual health care provider. However we will make the whole research process as relaxing and easy going as we can and we believe that there is minimal or no risk in being involved in this study.

Organisations that might support you if you do experience distress are:

Relationships Australia 1300 364 277
<http://www.relationships.org.au/>
 Lifeline 13 11 14
 Beyond Blue Info line 1300 22 4636
 Kids Helpline 1800551800 or <http://www.kidshelp.com.au/>

Your participation will aid in the development of mental health support for families, and you may find the process of talking about interrelations a useful place to think about all sorts of things.

Storage of the data collected will adhere to university regulations and be kept for five years. Only the researchers will have access to the data.

You will not be named or identified in any reports or publications arising from this research. If you would like to be informed of the results of the study, please contact Darryl Maybery by sending an email to darryl.maybery@monash.edu

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research is being conducted, please contact:
Dr. Darryl Maybery, Associate Professor MUDRI Moe Monash University, Vic 3800 Telephone: 03 9902 4587 Fax: 03 9905 5127 Darryl.maybery@monash.edu	Executive Officer, Human Research Ethics Committee Latrobe Regional Hospital Tel: +61 3 5173 8000

Thank you for considering taking part.

Michael Naughton

Appendix D

Letter to Expert Panel



MONASH University



Michael Naughton
20 Washington Street
Traralgon
Vic 3844
Tel 03 5128 - 0100
Fax 03 5128-0099
Email MNaughton@lrh.com.au

Re: Research Study into the bidirectional impact of mental illness where a parent and a child have a diagnosed or suspected mental illness.

Dear Sir / Madam,

I am writing to request your assistance in developing purposeful questions for parents and young people aged between the age of 12yrs and 18yrs. This is part of a PhD research project looking into the bidirectional impact of mental illness within families.

Current research evidence is mixed as to children's knowledge, and understanding, of mental illnesses and how best to deploy resources to help them acquire optimal information (Gladstone et al. 2011). Additionally, children's desire to be recognized as important to their parents' well-being can frequently conflict with adults' perceptions that children should be protected from too much responsibility (Gladstone et al 2011). Maybery et al (2005) looked at the views of children living with a parent who had a mental health problem. Other research has investigated genome imprinting, which points to parental mental illness as a determining key factor in the development of mental illness for children and adolescents Johansson (2010) and Crespi (2008).

In investigating the current literature on mental illness in families, very little research has been conducted into exploring ideas of young people who have a mental illness and who live with a parent with a mental illness and vice versa. Many researchers speculate on possible factors and call for further enquiry. There is only one study worldwide (unpublished) that briefly examines what parents and children experience when they, or the other person, are unwell. The ideas of social imprinting as espoused by Bowlby and later Ainsworth and others have been considered but such work does not take account of the views of young people and their care givers in the understanding of their own mental health issues within the dichotomy of family mental illness. Additionally, young people and carers views of any correlation and interrelationship between their own mental health and the mental health of the person they live with have not been investigated. This PhD research seeks to investigate the interplay of these factors through semi-structured interviews and focus groups with young people and parents.

The first part of the research will seek to determine the extent of mental illness in parents and young people in the same family. An LRH audit⁶ of case managed clients is due to commence in the next 6 weeks with potential participants approached by an independent recruiter.

The survey study has received approval from Monash University and Latrobe Regional Hospital Human Research Ethics Committees.

Through this research it is hoped to develop an effective, sustainable model of family inclusive practice for advanced care planning for mental health treatment/care that is customized for the Australian context. A better understanding of the impact of mental health issues on family members may help improve mental health interventions in a number of areas including: medication compliance and the working association between patients and clinicians,ⁱ increase the uptake of psycho-education,ⁱⁱ and may reduce involuntary admissions,ⁱⁱⁱ service use, and overall care costs.^{iv} In order to develop a model that seeks to determine the views and ideas of all family members we need to gain an in-depth understanding regarding the possible extent of the issue, whether formally diagnosed or based on family or clinicians' opinions. The clinicians' experience and understanding of the families with whom they work is crucial in these early stages of this study.

⁶ The audit will follow the format of the unpublished Canadian study conducted by Mercer & Knapton to allow for comparison.

To help inform the research and guide the question format, an expert reference committee overseeing this work is needed and I would like to invite you to take part in that group either directly or by submitting ideas. There will be an initial meeting in the Mental Health Director's Office next Friday at 10:30am. I look forward to your valued input to this part of the research.

If you have any queries, or require further information, please do not hesitate to contact me.

Yours sincerely

Michael Naughton

ⁱ Gladstone,B.M., et al. (2011). Early Intervention *Psychiatry*, 5 (4): 271 -289.

ⁱⁱ Maybery, D., et al. (2005). *Advances in Mental Health*, ; 4 (2) 78 - 88.

ⁱⁱⁱ Johannson,C.F. (2010) *British Journal of Psychiatry*; 196: 334-335.

^{iv} Crespi, B. (2008) *Biological Reviews*; 83 (4) : 441-493

Appendix E

Initial Interview Questions

Interview Preamble: Consent form signed.

The aim of this discussion is to identify what some of the challenges are in living with another person with a mental illness. By discovering your needs and any challenges as a family this research will help inform future support and intervention in families where more than one person has a mental illness.

It is important to understand that responses will not impact in any way on your participation in future programs or supports available in this area.

Did you want another copy of the explanatory letter?

Even though you have provided written consent for our talk and to having this discussion taped, please can you repeat for the audiotape?

A copy of this audio tape will be sent to a transcriber at Monash University but without your name. Please also remember not to use anyone's name during our chat.

Do you have any questions or issue about the study before we begin?

A. What is it like to live with a parent/child (or other family member) with a mental illness when they are unwell?

1. Please describe how you feel when your, child/mum/dad/etc., becomes unwell.
2. Please describe what you do when your, child/mum/dad/etc., becomes unwell.
3. Please describe what sorts of things you are thinking about when your, child/mum/dad/etc., becomes unwell.
 - a. How does mental illness impact upon the family as a whole?
 - b. How does mental illness impact upon others in the family?
 - c. Are others helpful when child/mum/dad/etc., becomes unwell?
 - d. Are others unhelpful when child/mum/dad/etc., becomes unwell?

B. How does it affect you?

4. Does it impact on your mental health when child/mum/dad becomes unwell?
5. If yes how does it affect your own mental health when your, child/mum/dad/etc., becomes unwell?
6. If mum/dad/child is unwell please describe how this affects your own mood or anxiety.
7. When your, child/mum/dad/etc., is unwell please describe how this influences your thinking regarding their illness.
8. When your, child/mum/dad/etc., is unwell please describe your experience of them as a person.

C. How do you affect them?

9. Please explain what happens, when you are feeling unwell, things that effects others in the family.
10. When you and your mum/son/dad/daughter are both unwell – does the unwellness impact on the other person and your relationship – if so how?

D. What help support changes do you want???

11. What do you think could be done to help you with your illness?
12. What do you think could be done to help your mum/dad etc?

-
13. Is there something that could be done by others outside of the family?
14. What help do you get at the moment?

E. What should the treating agency be doing?

Thinking about the service that you attend – and thinking about the 2 of you having a mental health problem –

15. Does the service assist you or other family members in any way?
16. Do they acknowledge that you have other/stress/emotional/mental health problem as well?
17. Does the parent/child service assist you?
18. What have they done to help you both (other than individual treatment)?
19. How and what could they do to help you and your family?

F. Other

Thinking of the two of you both having a problem.

20. Overall what is the most important problem/difficulty?
21. What is the thing that would help you the most?
22. What is the thing that would help the other person the most?

G. What advice would you give another family in the same situation?

Any other comments or things you would like to add/not already talked about?